



# THE BLUEPRINT OF CARE

for teenagers and young  
adults with cancer

**Second edition**

Edited by: Sam Smith, Suzanne Mooney, Maria Cable, Rachel M Taylor

# BIOGRAPHIES

## **Sam Smith**

(MSc, BSc, RN Child, Specialist Practitioner)  
*Head of Nursing and Clinical Services, Teenage Cancer Trust*

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Sam is a qualified paediatric nurse and specialist practitioner who has over twenty years of clinical experience and was previously a Nurse Consultant for teenagers and young adults with cancer in the health service before moving into the charitable sector to lead the development of nursing. Sam works across the whole of the UK and advises both nationally and internationally on teenage and young adult cancer. Sam's particular interests are development of specialist nursing in teenage and young adult care and leadership and led the development of the national teenage and young adult nurse competency and career framework endorsed through the Royal College of Nursing. Sam was awarded the European Oncology Nursing Society "Lifetime Achievement Award" 2015 for her contribution to nursing in this field.

## **Maria Cable**

(RN, RNT, BSc (Hons) Cancer Nursing, PGC E, MA Teaching and Learning in Higher Education)  
*Course Director- Teenage Cancer Care and Cancer Care programmes, Coventry University*

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Maria is an Oncology Nurse with more than 10 years clinical practice experience in Haematology as a Clinical Nurse Specialist and Unit Manager in Berkshire. Since 2000, she has been at Coventry University as an educator focussing specifically since 2005 on delivering accredited and non-accredited programmes for an inter-professional student body on Teenage/Young Adult Cancer Care. Maria is also involved in research and workforce development. She sits on the Education Committees of both TYAC and the European Oncology Nursing Society. A big emphasis of her work is in using technology to deliver educational programmes and has been bestowed a Teaching Excellence Award for this work.

## **Suzanne Mooney**

(MSc, MRes, MA, DipSW)  
*Lecturer in Social Work and Systemic Practice and Family Therapy Programmes Director, Queen's University Belfast*

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Suzanne is a social worker and systemic family psychotherapist with over twenty years' clinical practice experience with children, young people and their families in a range of cross-sector contexts including physical health and disability, mental health, and children's services. Following ten years in the voluntary sector, Suzanne moved to hospital social work with teenagers and young adults with cancer where she contributed to developing TYA services in N. Ireland. In 2009, she was awarded a Research and Development Fellowship by the N. Ireland Research and Development Office, Public Health Agency to undertake a doctoral study exploring the wellbeing of teenagers and young adults with cancer and optimal hospital care, sponsored by the Belfast Health and Social Care Trust. Suzanne has published and presented at national and international conferences.

## **Rachel Taylor**

(PhD, MSc, DipRes, RSCN, RGN)  
*Senior Research Manager, BRIGHTLIGHT, University College London Hospitals NHS Foundation Trust*

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Rachel is a children and adult trained nurse with over 20 years of experience working in research with young people. Rachel is currently co-ordinating the national evaluation of teenage and young adult specialist cancer services across England. She has published in numerous journals and has presented at both national and international conferences. Rachel is a member of the National Cancer Research Institutes (NCRI) Psycho-oncology and Survivorship Clinical Studies Group (CSG), Understanding and Measuring the Consequence of Cancer and its treatment subgroup and Health Services Research subgroup of the NCRI TYA CSG. She is a Steering Committee member of the Royal College of Nursing (RCN) Research Society and on the Scientific Committee of the RCN International Research Society annual conference. Rachel is funded through an NIHR Programme Grant for Applied research (RP-PG-1209-10013). The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health.



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*Uniting professionals. Improving practice*

Endorsed by TYAC

# CONTENTS

<table border="0"> <tr> <td style="background-color: #808080; color: white; padding: 5px;"><b>6</b></td> <td style="background-color: #808080; color: white; padding: 5px;"><b>ACKNOWLEDGEMENTS</b></td> </tr> <tr> <td style="background-color: #808080; color: white; padding: 5px;"><b>7</b></td> <td style="background-color: #808080; color: white; padding: 5px;"><b>FOREWORD</b></td> </tr> <tr> <td style="padding: 5px;">8</td> <td style="padding: 5px;">LIST OF CONTRIBUTORS</td> </tr> <tr> <td style="padding: 5px;">9</td> <td style="padding: 5px;">LIST OF ABBREVIATIONS</td> </tr> <tr> <td style="background-color: #0056b3; color: white; padding: 5px;"><b>10</b></td> <td style="background-color: #0056b3; color: white; padding: 5px;"><b>EXECUTIVE SUMMARY</b></td> </tr> <tr> <td style="padding: 5px;">10</td> <td style="padding: 5px;">SCOPE</td> </tr> <tr> <td style="padding: 5px;">10</td> <td style="padding: 5px;">APPROACH</td> </tr> <tr> <td style="padding: 5px;">11</td> <td style="padding: 5px;">CONSULTATION</td> </tr> <tr> <td style="padding: 5px;">11</td> <td style="padding: 5px;">KEY MESSAGES</td> </tr> </table> <table border="0"> <tr> <td style="background-color: #4682b4; 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color: white; padding: 5px;"><b>27</b></td> <td style="background-color: #8bc34a; color: white; padding: 5px;"><b>CHAPTER 3: MULTI-DISCIPLINARY TEAM WORKING, MODELS OF CARE AND PATIENT PATHWAYS</b></td> </tr> <tr> <td style="padding: 5px;">27</td> <td style="padding: 5px;">TEENAGE AND YOUNG ADULT CANCER SERVICES</td> </tr> <tr> <td style="padding: 5px;">29</td> <td style="padding: 5px;">NHS STRUCTURE</td> </tr> <tr> <td style="padding: 5px;">29</td> <td style="padding: 5px;">TYA PRINCIPAL TREATMENT CENTRES AND DESIGNATED HOSPITALS</td> </tr> <tr> <td style="padding: 5px;">30</td> <td style="padding: 5px;">TYA KEYWORKER</td> </tr> <tr> <td style="padding: 5px;">30</td> <td style="padding: 5px;">CARE PATHWAYS, MODELS OF CARE AND CHOICE</td> </tr> <tr> <td style="padding: 5px;">33</td> <td style="padding: 5px;">TYA MULTI-DISCIPLINARY TEAM</td> </tr> <tr> <td style="padding: 5px;">36</td> <td style="padding: 5px;">TYA MDT AND TRANSITION PATHWAYS</td> </tr> </table> <table border="0"> <tr> <td style="background-color: #ff9800; 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color: white; padding: 5px;"><b>53</b></td> <td style="background-color: #ff9800; color: white; padding: 5px;"><b>CHAPTER 5: STAFFING CONSIDERATIONS</b></td> </tr> <tr> <td style="padding: 5px;">53</td> <td style="padding: 5px;">WORKFORCE NEEDS</td> </tr> <tr> <td style="padding: 5px;">53</td> <td style="padding: 5px;">Continuous Professional Development</td> </tr> <tr> <td style="padding: 5px;">54</td> <td style="padding: 5px;">LEARNING OPPORTUNITIES</td> </tr> <tr> <td style="padding: 5px;">55</td> <td style="padding: 5px;">Spending time with young people</td> </tr> <tr> <td style="padding: 5px;">55</td> <td style="padding: 5px;">COMMUNICATION AND THERAPEUTIC RELATIONSHIPS</td> </tr> <tr> <td style="padding: 5px;">56</td> <td style="padding: 5px;">Confidentiality and its limitations</td> </tr> <tr> <td style="padding: 5px;">57</td> <td style="padding: 5px;">Using technology as a communication tool</td> </tr> <tr> <td style="padding: 5px;">58</td> <td style="padding: 5px;">PROFESSIONAL BOUNDARIES</td> </tr> <tr> <td style="padding: 5px;">58</td> <td style="padding: 5px;">Getting too personal</td> </tr> <tr> <td style="padding: 5px;">59</td> <td style="padding: 5px;">Warning signs for crossing of professional boundaries</td> </tr> <tr> <td style="padding: 5px;">59</td> <td style="padding: 5px;">STAFF SUPPORT</td> </tr> <tr> <td style="padding: 5px;">60</td> <td style="padding: 5px;">SAFEGUARDING VULNERABLE TEENAGERS AND YOUNG ADULTS</td> </tr> <tr> <td style="padding: 5px;">61</td> <td style="padding: 5px;">YOUNG PARENTS IN THE HOSPITAL SETTING</td> </tr> </table> <table border="0"> <tr> <td style="background-color: #00bcd4; color: white; padding: 5px;"><b>63</b></td> <td style="background-color: #00bcd4; color: white; padding: 5px;"><b>CHAPTER 6: HOLISTIC NEEDS AND SUPPORTIVE CARE</b></td> </tr> <tr> <td style="padding: 5px;">63</td> <td style="padding: 5px;">INTRODUCTION</td> </tr> <tr> <td style="padding: 5px;">63</td> <td style="padding: 5px;">HOLISTIC NEEDS ASSESSMENT - WORKING IN PARTNERSHIP WITH THE YOUNG PERSON AND THEIR FAMILY</td> </tr> <tr> <td style="padding: 5px;">64</td> <td style="padding: 5px;">Assessment tools</td> </tr> <tr> <td style="padding: 5px;">64</td> <td style="padding: 5px;">Some examples of assessment tools:</td> </tr> <tr> <td style="padding: 5px;">66</td> <td style="padding: 5px;">HOLISTIC NEEDS - AREAS OF CONSIDERATION BASED ON THE IAM</td> </tr> <tr> <td style="padding: 5px;">66</td> <td style="padding: 5px;">Physical well-being</td> </tr> <tr> <td style="padding: 5px;">67</td> <td style="padding: 5px;">Family, friends and relationships</td> </tr> <tr> <td style="padding: 5px;">69</td> <td style="padding: 5px;">Education and Work</td> </tr> <tr> <td style="padding: 5px;">70</td> <td style="padding: 5px;">Housing, transport and finance</td> </tr> <tr> <td style="padding: 5px;">71</td> <td style="padding: 5px;">Interests, social life and peer support</td> </tr> <tr> <td style="padding: 5px;">72</td> <td style="padding: 5px;">Lifestyle</td> </tr> <tr> <td style="padding: 5px;">73</td> <td style="padding: 5px;">Sex, sexuality and fertility</td> </tr> <tr> <td style="padding: 5px;">74</td> <td style="padding: 5px;">Thoughts and feelings</td> </tr> <tr> <td style="padding: 5px;">74</td> <td style="padding: 5px;">Faith, spirituality and culture</td> </tr> </table>	<b>53</b>	<b>CHAPTER 5: STAFFING CONSIDERATIONS</b>	53	WORKFORCE NEEDS	53	Continuous Professional Development	54	LEARNING OPPORTUNITIES	55	Spending time with young people	55	COMMUNICATION AND THERAPEUTIC RELATIONSHIPS	56	Confidentiality and its limitations	57	Using technology as a communication tool	58	PROFESSIONAL BOUNDARIES	58	Getting too personal	59	Warning signs for crossing of professional boundaries	59	STAFF SUPPORT	60	SAFEGUARDING VULNERABLE TEENAGERS AND YOUNG ADULTS	61	YOUNG PARENTS IN THE HOSPITAL SETTING	<b>63</b>	<b>CHAPTER 6: HOLISTIC NEEDS AND SUPPORTIVE CARE</b>	63	INTRODUCTION	63	HOLISTIC NEEDS ASSESSMENT - WORKING IN PARTNERSHIP WITH THE YOUNG PERSON AND THEIR FAMILY	64	Assessment tools	64	Some examples of assessment tools:	66	HOLISTIC NEEDS - AREAS OF CONSIDERATION BASED ON THE IAM	66	Physical well-being	67	Family, friends and relationships	69	Education and Work	70	Housing, transport and finance	71	Interests, social life and peer support	72	Lifestyle	73	Sex, sexuality and fertility	74	Thoughts and feelings	74	Faith, spirituality and culture
<b>6</b>	<b>ACKNOWLEDGEMENTS</b>																																																																																																																																																															
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72	Lifestyle																																																																																																																																																															
73	Sex, sexuality and fertility																																																																																																																																																															
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74	Faith, spirituality and culture																																																																																																																																																															

<b>77</b>	<b>CHAPTER 7: PROMOTING WELL-BEING AND RESILIENCE</b>	<b>95</b>	PROFESSIONAL WELL-BEING	<b>109</b>	Immediate family and support network
<b>77</b>	THE IMPORTANCE OF WELLBEING AND RESILIENCE FOR YOUNG PEOPLE WITH CANCER	<b>95</b>	The importance of self-care	<b>109</b>	Supporting cancer peers when a death occurs
<b>77</b>	TYA vulnerability	<b>95</b>	Self-care in endings	<b>109</b>	Supporting staff when a young person dies
<b>77</b>	Good outcomes are more than survival	<b>97</b>	<b>CHAPTER 8: LIVING WITH AND BEYOND CANCER</b>	<b>111</b>	Attending funerals
<b>77</b>	Current and future well-being: developing resilience	<b>97</b>	INTRODUCTION	<b>113</b>	<b>CHAPTER 10: YOUNG PEOPLE AND RESEARCH</b>
<b>78</b>	POSITIVE HEALTH CONCEPTS: FROM RISK TO RESOURCE	<b>97</b>	PREPARING FOR LIFE AFTER TREATMENT	<b>113</b>	RESEARCH IN THE NHS
<b>78</b>	Well-being	<b>98</b>	LIFE AFTER TREATMENT	<b>113</b>	Research governance
<b>78</b>	Resilience	<b>98</b>	Treatment Summary	<b>115</b>	RESEARCH ACROSS THE TEENAGER AND YOUNG ADULT AGE RANGE
<b>78</b>	PROMOTING WELL-BEING AND RESILIENCE IN YOUNG PEOPLE WITH CANCER	<b>100</b>	Holistic Needs Assessment	<b>116</b>	Research evidence in TYA
<b>78</b>	The role of allied health and psychosocial professionals	<b>100</b>	Cancer care review	<b>116</b>	Age as a barrier to taking part in research
<b>79</b>	PSYCHOLOGICAL WELL-BEING	<b>100</b>	Health and Well-being Clinics	<b>117</b>	HEALTHCARE PROFESSIONALS AS A BARRIER TO TAKING PART IN RESEARCH
<b>79</b>	Clinical Psychology: working with mental health disorders and promoting TYA resilience	<b>100</b>	LATE-EFFECTS	<b>117</b>	THE ROLE OF PROFESSIONALS IN EVIDENCE BASED PRACTICE
<b>79</b>	Psychological distress	<b>100</b>	Physical late-effects	<b>117</b>	THE ROLE OF PROFESSIONALS IN FACILITATING RESEARCH
<b>81</b>	Anxiety	<b>101</b>	Psychosocial impact of TYA cancer survivorship	<b>118</b>	THE ROLE OF RESEARCHERS WORKING WITH YOUNG PEOPLE
<b>85</b>	Other important mental health problems	<b>103</b>	LONG-TERM FOLLOW-UP	<b>119</b>	Maximising recruitment to research studies
<b>87</b>	PHYSICAL WELL-BEING	<b>105</b>	<b>CHAPTER 9: PALLIATIVE AND END OF LIFE CARE</b>	<b>123</b>	<b>CHAPTER 11: INTERNATIONAL PERSPECTIVES</b>
<b>87</b>	Compromised well-being: The physical side-effects of cancer and treatment	<b>105</b>	WHAT IS PALLIATIVE CARE?	<b>123</b>	INTRODUCTION
<b>87</b>	Physiotherapy: promoting well-being throughout the illness trajectory	<b>105</b>	WHAT IS DIFFERENT ABOUT PALLIATIVE CARE FOR YOUNG PEOPLE?	<b>123</b>	INTERNATIONAL DEVELOPMENTS: EUROPEAN NETWORK FOR TEENAGERS AND YOUNG ADULTS WITH CANCER
<b>88</b>	Physical activity and exercise	<b>105</b>	TALKING ABOUT DYING AND DEATH	<b>124</b>	INTERNATIONAL DEVELOPMENTS: USA PROGRESS IN ADOLESCENT AND YOUNG ADULT ONCOLOGY
<b>90</b>	Fatigue	<b>106</b>	FOCUS OF CARE	<b>125</b>	THE AUSTRALIAN YOUTH CANCER SERVICES
<b>91</b>	PSYCHOSOCIAL WELL-BEING	<b>106</b>	PALLIATIVE CARE AND SYMPTOM MANAGEMENT	<b>127</b>	INTERNATIONAL DEVELOPMENTS: DEVELOPING COUNTRIES
<b>91</b>	The pursuit of 'normal'	<b>107</b>	Psychological and spiritual care	<b>129</b>	<b>REFERENCES</b>
<b>91</b>	Promoting participation in life	<b>107</b>	Financial and Social Issues		
<b>91</b>	Occupational Therapy: adjusting to life with and beyond cancer	<b>107</b>	Families and carers		
<b>91</b>	Providing equipment	<b>107</b>	Co-ordinating Care		
<b>92</b>	SOCIAL WELL-BEING	<b>108</b>	END OF LIFE CARE		
<b>92</b>	Family support	<b>108</b>	Planning for end of life		
<b>93</b>	Peer support	<b>108</b>	Place of death		
		<b>109</b>	End of life care		
		<b>109</b>	BEREAVEMENT SUPPORT		

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We cannot forget to acknowledge thanks to those who wrote and designed the initial Blue Print of Care, whose efforts provided the foundation on which the second edition was based:

Sam Smith, Lorraine Case, Kerrie Waterhouse, Nicky Pettitt, Lorraine Beddard, Janet Oldham, Diane Hubber, Shona Simon, Jan Siddall and James Robertson.

Most importantly, we must never forget how young people with cancer and their families teach and inspire us every day.

We are grateful to Teenage Cancer Trust who are wholly supportive of this work and fund the publication of this document. This ensures that many more people can learn from our experience and insights whilst this specialism continues to evolve.

# FOREWORD

This document is a much awaited and welcomed second edition of the Blueprint of Care and will make a significant contribution to further describing the specific elements, complexities, and “tried and tested” approaches to providing the best care for young people with cancer. The speciality of teenage and young adult (TYA) cancer care and the numbers of specialist staff working in this field have grown significantly since the implementation of the Improving Outcome Guidance<sup>1</sup>. This is reflected by the contribution to this edition from a wide range of expert health professionals across many disciplines representing all four United Kingdom (UK) nations. The contributors to this document are from diverse backgrounds and reflect the truly multi-professional nature and approach that is delivered so well in TYA cancer care in the UK.

The Blueprint will act as a practical guide to help shape services and approaches to care to ensure we continue to strive to provide excellent standards of support to all young people with cancer and their families. The contributors have shared years of day-to-day “hands on” experience as practitioners as well as those with expertise from the research, education and academic sectors. This publication is unique in that it captures, on paper, the expertise and experience that has been developed over time that is so often lost due to the day-to-day demands of providing healthcare. The Blueprint of Care 2nd Edition builds on the guidance set out in the original publication and will provide users working within TYA services or those who aspire to develop new services with a practical tool to help shape and deliver age appropriate care.

Evidence, education and research has grown significantly, but there is much more to do to sustain the speciality and grow the next generation of professionals who will lead TYA cancer services in the future. There is always more to learn through education, service development, research and particular consideration should be given to investment in workforce and professional development.

Significant progress has been made in starting to develop a strong evidence-base through the growth and publication of medical, nursing and social science research. The Blueprint of Care was the first publication to capture and describe the practical and complex elements of age appropriate care and it is exciting to see other books and publications follow that further define TYA cancer care. Readers are encouraged to explore this publication, use the contents to signpost and make use of the resource information. The Top Tips are particularly helpful and should provide practitioners and professionals with “tried and tested” tips and successful approaches to delivering care. The Blueprint should be used as a reference guide for all those working with teenage and young adult cancer patients in order that we strive to continue to deliver and develop the best care possible to young people with cancer and their families.

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# LIST OF ABBREVIATIONS

<b>AHP</b>	Allied Health Professional	<b>LMIC</b>	Low/Middle Income Countries
<b>AYA</b>	Adolescent and Young Adult	<b>MDT</b>	Multi-disciplinary Team
<b>CAB</b>	Citizens Advice Bureau	<b>NCCCN</b>	National Comprehensive Cancer Center Network
<b>CNS</b>	Clinical Nurse Specialist	<b>NCRI TYA CSG</b>	National Cancer Research Institute Teenager and Young Adult Clinical Studies Group
<b>COG</b>	Children's Oncology Group	<b>NHS</b>	National Health Service
<b>COSD</b>	Cancer Outcome and Service Delivery	<b>NICE</b>	National Institute for Health and Care Excellence
<b>CPD</b>	Continuing Professional Development	<b>NPS</b>	New Psychoactive Substances
<b>CV</b>	Curriculum Vitae	<b>NWKIT</b>	North West Knowledge and Intelligence Team
<b>CYPIOG</b>	Children and Young People's Improving Outcomes Guidance	<b>OT</b>	Occupational Therapy(ist)
<b>DGH</b>	District General Hospital	<b>PIP</b>	Personal Independence Payment
<b>DH</b>	Designated Hospital	<b>PTC</b>	Principal Treatment Centre
<b>EHCP</b>	Emergency Health Care Plan	<b>R&amp;D</b>	Research and Development
<b>ENTYAC</b>	European Multi-disciplinary Network for Teenage and Young Adults with Cancer	<b>RCN</b>	Royal College of Nursing
<b>ESA</b>	Employment Support Allowance	<b>REC</b>	Research Ethics Committee
<b>FSC</b>	Faith, Spirituality & Culture	<b>SAYAO</b>	Society for Adolescent and Young Adult Oncology
<b>FYSOT</b>	Find Your Sense of Tumour	<b>SPARC</b>	Sheffield Profile for Assessment and Referral to Care
<b>GCP</b>	Good Clinical Practice	<b>SS</b>	Site Specific
<b>GP</b>	General Practitioner	<b>STI</b>	Sexually Transmitted Infection
<b>IAM</b>	Integrated Assessment Map	<b>TYA</b>	Teenagers and young adults
<b>IRAS</b>	Integrated Research Application System	<b>TYAC</b>	Teenagers and Young Adults with Cancer
<b>HIC</b>	High Income Countries	<b>UK</b>	United Kingdom
<b>HRA</b>	Health Research Authority	<b>WHO</b>	World Health Organisation
<b>IPE</b>	Inter-professional Education	<b>YSC</b>	Youth Support Coordinator
<b>IT</b>	Information Technology		
<b>IVF</b>	In Vitro Fertilisation		
<b>LGBT</b>	Lesbian, Gay, Bisexual and Transgender		

## EXECUTIVE SUMMARY

There is growing recognition, both in the United Kingdom (UK) and overseas, that teenagers and young adults (TYA) with cancer have specialist needs that differ to those of both children and older adults. The National Institute for Health and Care Excellence (NICE) published its 'Improving Outcomes Guidance for Children and Young People with Cancer' (CYPIOG) in 2005<sup>1</sup>. These practice recommendations have been partially implemented within England and Wales and act as an important benchmark for TYA services in Scotland and N. Ireland.

The focus of this Blueprint of Care builds on the first edition and further defines and describes the complex elements and characteristics of age-appropriate care. By exploring the specific issues that arise in TYA cancer care and addressing a number of key themes, it offers recommendations regarding TYA practice principles, models of care, practice guidance, and practical tips for those caring for this group of patients throughout the UK and beyond.

TYA cancer care cross cuts numerous disciplines including oncology, haematology, other relevant medical and surgical specialties, psychology, psychiatry, palliative care, social work, youth work, education and wider support from allied health professionals. This document recommends that care should be multidisciplinary, incorporating both disease-specific and age-specific expertise.

### SCOPE

The information presented in this document relates to young people diagnosed with cancer between the ages of 16 and 24 years treated within Principal Treatment Centres (PTC), TYA Designated Hospitals (DH) or District General Hospitals (DGH) across the UK. For some younger teenagers (aged 13-15 years) parts of this Blueprint of Care will also have relevance and healthcare professionals should use their judgement following individual patient assessment on the application of the practice principles and guidance to younger patients. The Blueprint will also have relevance and scope internationally. Whilst service configuration may be very different in other countries the essence and principles of TYA cancer care and practice will be applicable. This Blueprint of Care is not intended to apply to patients treated for cancer during childhood who have now reached the TYA age range.

The Blueprint can be used as a learning resource for staff, providing information to multi-disciplinary teams caring for young people with cancer, irrespective of their care setting. It is recognised that treatment settings and services for young people will vary according to geographical location, level of care (i.e. PTC, TYA designation arrangements, adult cancer centres or DGHs) and, in part, may be limited through local resource availability. However, these recommendations set out best practice for the care of young people that can be applied irrespective of regional variations in service configuration and resources.

This document is intended for use by healthcare professionals as a guide to good practice and to share expertise with other professionals who are in the position of initiating TYA service development. It includes useful guidance for many of the practical day-to-day issues that arise in this field.

The term TYA is used frequently throughout the document and, unless otherwise stated, should be read to mean 'teenage and young adult.' Teenagers and young adults are also referred to collectively as 'young people.'

### APPROACH

This document brings together the expertise and accumulated knowledge of TYA healthcare professionals who have been leading in TYA cancer care over the past twenty-five years in the UK from both the National Health Service (NHS) and independent sectors. The recommendations are also based on feedback from young people, together with consultation with other leading bodies and professionals in the field of TYA cancer in the UK and internationally.

#### The development of the document was informed by:

- Existing literature and research
- Expert input from academia and researchers
- Knowledge and experience of the Teenage Cancer Trust National Senior Nurses Forum
- Knowledge and experience of a growing body of TYA Lead Nurses, Youth Support Co-ordinators, TYA Clinical Nurse Specialists (CNSs), TYA Social Workers and TYA Allied Health Professionals (AHPs), medical professionals and those working in the research or academic sectors.

- A peer review and ratification process through the TYAC Executive Board (The professional membership organisation Teenage and Young Adult Cancer)

It is likely that as TYA cancer care and expertise gathers momentum we will see a rapid growth of books, publications and research that will collectively drive practice and professional development in this field. This second edition will be re-evaluated in three years' time and the Editors will review whether a third edition is warranted in the future.

## CONSULTATION

Health and social care professionals, AHPs, voluntary organisations and national professional groups have participated in the writing of this document. Each chapter has undergone robust review through an Editorial team. Authors have been invited to make additions and amendments during the process and the final draft has been shared for consultation, peer review and ratification.

## KEY MESSAGES

- **Staff caring for young people with cancer should have specific knowledge and understanding of life stage development including social, emotional, psychological and physical development and assess individual needs according to developmental stage.**  
.....
- **Understanding and getting to know each young person as an individual person, taking into account their interests, past experiences, important relationships, future aspirations and coping strategies will enable teams to develop a tailored care package to support each young person and their primary support people effectively through the cancer pathway.**  
.....
- **Staff should pay particular attention to the importance of young people's support networks, including family, peers and other significant relationships. Contact with their support networks should be encouraged and facilitated at all times, and relevant support provided.**  
.....
- **It is important that all staff are consistent in their approach to care, treatment and provision of information.**  
.....
- **Staff should set clear and well-defined behaviour boundaries balanced with encouraging negotiation and flexibility in routine and care approaches.**  
.....
- **Staff across all settings should be encouraged to develop knowledge, expertise and competence in caring for this unique age group.**  
.....
- **Every effort should be made to ensure the experience of TYA cancer and early interface with healthcare services, while challenging, is well utilised to support young people's resilience and on-going development, achieving optimal quality of life throughout treatment and beyond.**

These key messages and core principles are further detailed and reinforced throughout the publication.



# CHAPTER ONE: INTRODUCTION

Authors: Lorna Fern, Sarah Lea

Cancers in young people are rare, accounting for less than 1% (1 in 100 new cases) of all newly diagnosed cancers in the United Kingdom (UK)<sup>2</sup>. There are approximately 2,214 new cases of cancer diagnosed every year in young people aged 15-24 years<sup>3</sup>. Despite its rarity, cancer is the leading medical cause of death in young people, accounting for approximately 11% of deaths per year and preceded only by accidental death, which includes suicide<sup>3</sup>.

The seminal work of Professor Jillian Birch and colleagues first identified that the pattern of cancer types appearing in young people differs from both children and older adults<sup>4</sup>. Our understanding of the unique spectrum of diseases occurring in young people has significantly advanced our ability to plan services and provide care. Young people experience late onset paediatric cancers, 'true adolescent cancers' (i.e., cancers which are most common in this age group) and also early onset adult cancers. The true adolescent cancers are Hodgkin's lymphoma, germ cell tumours of the testis, ovary and brain, and bone and soft tissue sarcomas including osteosarcoma and Ewing's Sarcoma<sup>4</sup>. The most common type of cancer across this age group is lymphoma, which accounts for around 21% of all cases (approximately 422 new cases per year) and these are mainly Hodgkin's lymphoma. Carcinomas are the second most common cancer in this age group and account for 20% of new cases (n=393) and it is this which really differentiates young people from older adults in terms of the types of cancers they experience<sup>3</sup>. The distribution of cancer types varies with increasing age, and also by gender. The majority of cancers occurring in older adults are carcinomas, around 80% compared to 20% for teenagers and young adults (TYA), and for older females the most common cancer is breast cancer and for older males, prostate cancer. You can read more about the changes in cancer types by age and gender hereon the Cancer Research UK website<sup>5</sup>.

In 2013, approximately, 352,197 new cases of cancer were diagnosed in the UK, and over and half of these were carcinomas of the breast, colon, prostate and lung<sup>6</sup>. These are typically referred to as 'The big four'. In contrast, only 20% of cancers in young people are carcinomas and they exhibit a much more heterogeneous pattern of carcinomas, predominately carcinomas of the cervix, thyroid, head and neck, and early onset breast and colon<sup>4</sup>. Lung cancers and prostate cancers in young people are extremely rare but have been reported. **Table 1.1** shows distribution of cancer types in young people.

**Table 1.1:** Distribution of newly diagnosed cancers in young people aged, 15-24

Cancer type	Incidence cases
Lymphomas	422 (21%)
Carcinomas	393 (20%)
Germ cell	311 (15%)
Brain and CNS tumours	275 (14%)
Melanoma	226 (11%)
Leukaemia's	178 (9%)
Bone Sarcomas	103 (5%)
Soft Tissue Sarcomas	80 (4%)
Unspecified	26 (1%)

CNS: central nervous system; Adapted from Cancer Research UK<sup>3</sup>

Cancer is typically a disease of older age, over half of all new cancers occur in older people over 70 years old<sup>6</sup>, and a consequence of an accumulation of genetic changes over time. Why young people develop cancers is not fully understood and the evidence is not conclusive, although genetics, environmental factors, viruses and hormonal changes during puberty have all been implicated. Large scale genetic and biological studies are required to fully elucidate the mechanisms of disease development and progression in this age group.

## SURVIVAL RATES FOR YOUNG PEOPLE IN THE UK

Overall survival rates for young people with cancer are good, with five-year survival (the number of young people who are alive five years after diagnosis) are high, in excess of 80%, and mortality rates for young people have more than halved since the 1970s. Survival rates for females are slightly higher than for males (84% versus 81%)<sup>3</sup>. However, we must be cautious when citing these figures as it masks the marked variation in survival by cancer type. For example, cancers of the testis and thyroid have five years in survival in excess of 95%, compared to bone and soft tissue sarcomas which have five-year survival in the region of 50% and for which survival improvements over the past two decades have been limited<sup>3</sup>.

Survival for some cancers is less in young people compared to children and older adults with the same cancers; these include soft tissue sarcoma and bone sarcomas<sup>7</sup>. The reasons for this are not fully understood but may be related to differences in cancer biology, host biology, differences in treatment regimens and the intensity of therapy.

While survival rates for common TYA cancers such as Hodgkin's lymphoma and testis cancers are impressive there is a need for newer less toxic therapies. Survival rates are a measure of the numbers of young people still alive but gives no indication of how young people are living, quality of life and the impact of long-term and late treatment and disease effects, which for many are significant and in some instances debilitating.

This is a brief overview of cancer epidemiology in young people and readers are encouraged to visit references 2-5 for further reading. These have been selected as they are all open access articles and are available free of charge to everyone.

## TYA CANCER CARE IN THE UK

The Platt Report<sup>8</sup> first highlighted the specific needs of the adolescent patient in 1959. However the particular issues faced by adolescent cancer patients were not acknowledged until many years later in the Calman Hine Report in 1995<sup>9</sup>. A growing number of publications, research studies and initiatives stemmed from this and the concept that these patients are a sub-speciality in their own right is gradually

being accepted, resulting in increased provision of specialist centres and services<sup>10</sup>.

Teenage Cancer Trust opened their first unit in London over 25 years ago<sup>11</sup> and has encouraged and facilitated a gradual increase in recognition of the speciality, acting as an advocate for this patient group. There are now 28 specialist Teenage Cancer Trust units across the UK, staffed by expert teams of professionals who understand the medical and psychosocial needs of young cancer patients. It is suggested that teenagers and young adults benefit from being in a dedicated unit surrounded by peers of a similar age, separate from younger children and adults<sup>12</sup>.

The original *Children and Young Peoples Improving Outcome Guidance* (CYPIOG) was published in 2005 by the National Institute of Health and Care Excellence (NICE)<sup>1</sup>, the purpose being to provide recommendations on cancer services for children and young people with cancer based on the best available evidence. The guidance covered all cancers in children and young people from birth to twenty-four. It recommended that patients aged 16-18 should be treated in Principal Treatment Centres (PTC) and those aged 19-24 should be offered a choice regarding their place of care. Regardless of place of care, all young people should be offered expert medical care and have access to age-appropriate care, services and support<sup>1</sup>. While the aim is for all young people with cancer to receive treatment and support tailored specifically to their needs, data shows we still have progress to make<sup>13</sup>. A report showed 48% of young people aged 15-24



years diagnosed with cancer are not being notified to PTCs and therefore do not have access to the expertise of specialist TYA centres and health professionals<sup>3</sup>, a requirement of both the CYPIOG and peer review.

It is suggested that young cancer patients benefit from specialist teenage and young adult services<sup>14</sup>. However there is a need for increased evidence for specialist teenage cancer services and how to meet young people's needs effectively<sup>15,16</sup>. Following a review of the CYPIOG by a team of stakeholders in 2014, no evidence was identified that would change the 2005 guidance recommendations<sup>17</sup>. It was reported that on-going studies, such as BRIGHTLIGHT, may impact on TYA service guidance in the future and the guideline should therefore be reviewed again when more evidence emerges<sup>17</sup>.

Services in the UK are constantly evolving to ensure every young person is identified and offered the level of support they require. This includes being creative in how services are provided. For example, a new nursing outreach model has recently been piloted in the North West of England as a way of reaching young people who live too remotely or do not have easy access to a specialist unit<sup>11</sup>. The model ensures specialist care reaches young people being treated in their local hospitals; with independent Teenage Cancer Trust nurses collaborating with the medical and nursing teams at the local treating hospital to support young people and their families from the point of diagnosis, providing age-specific advice and expertise<sup>11,18</sup>. The success of this pilot ignites a discussion for those developing and commissioning future TYA services. Creative and innovative roles and infrastructure will enable success in reaching the key aim of TYA services: to provide 'age-appropriate, safe and effective services as locally as possible, not local services as safely as possible'



# CHAPTER TWO: DEVELOPMENT AND THE IMPACT OF CANCER

**Authors:** Alison Finch, Beth McCann, Bethan Ingram, Joanna Poole Caroline Knott, Caroline Newton, Maria Cable

## YOUNG PEOPLE IN SOCIETY

The transition to adulthood for young people today is at a time of global change. We exist in an era of transformation that is witnessing huge technological advancements, cultural change, economic crisis and demographic change<sup>19</sup>. During this life stage young people are in the unique and challenging position where they are not only attempting to make sense of personal, interpersonal and physical changes, but also society around them.

Young people today live in an aging society. Resource distribution has shifted to support the aging population and young people are under pressure to work to provide<sup>19</sup>. Coupled with this, young people have been hit with the implications of the financial recession of 2008-2009<sup>20</sup>. Within Europe the countries most affected by the financial crisis also have the highest level of youth unemployment, demonstrating how young people have been more severely affected by the recession than other workers<sup>21</sup>. Long-term periods of youth unemployment have a detrimental effect on the individual and society as a whole, including reduced life time earnings and a higher risk of future unemployment. In turn, this results in poorer health and well-being for generations to come<sup>20</sup>. Young people are under pressure to provide but with limited resources to do so. A cancer diagnosis impairs this further, as the young person's ability to work or continue their studies may be diminished by the constraints of treatment and the diagnosis itself.

Young people are often misrepresented in the media. Every day we are faced with negative images of youth in society<sup>22</sup>. The media regularly report rising levels of youth crime, often depicting the troublesome 'hoodie' figure<sup>23</sup>. Gang culture is generally reported by the media as threatening. This is a very negative representation of what may be normal youth subcultures which focus around peer activities and music<sup>22</sup>. This depiction can leave young people feeling misunderstood, and unduly influence the services designed to support them.

Young people today also represent a new generation within society. The 'millennial' generation has been brought up to have an opinion and not to unquestioningly believe what someone else is telling them. This needs to be taken into account by healthcare professionals when discussing all aspects of care. Advancements in social media have reinforced this cultural shift, allowing people to voice their opinion easily as witnessed through the rise of blogging<sup>24</sup>.

## YOUNG PEOPLE IN SOCIETY AND CONNECTIVITY

Rapid advancements in both social media and the internet have created a 'connected' generation who never need be alone<sup>22</sup>. These changing forms of communication have been well utilised by cancer services and individuals through the creation of online forums, Facebook groups and Twitter feeds, creating virtual peer support networks for cancer patients.

In contrast, the younger Generation Z (generally considered those under the age of 20 years) are more risk averse and more hesitant about sharing online, having learnt from the mistakes of the generation before them<sup>25</sup>. They are more money-orientated and entrepreneurial than the generation before them. Mark Zuckerberg earned his first billion at the age of 23 years<sup>26</sup>. This younger generation is considered to be not so easily influenced; wanting to express their own sense of style rather than mimic others<sup>27</sup>. These and many other social influences shape and challenge young people as they move into adult life.

Online technologies and social media play a crucial role in the lives of young people, and although specific technologies change, they collectively provide a space to inform, educate and also 'hang out and connect with friends'<sup>28</sup>.

**“The impact of digital technologies can have both positive and negative aspects, which should be taken account of by healthcare professionals.”**

Going online is now completely embedded in young people's lives, with 9 to 16 year olds spending on average 88 minutes per day online. Social networking sites enable young people to communicate. In fact, many young people report finding it easier to be themselves on the internet than in 'real life'<sup>29</sup>

Healthcare professionals should be aware that alongside the rise of social media is a concern that social media has the potential to increase bullying, often referred to as 'cyberbullying'<sup>30</sup>.

Boyd<sup>28</sup> suggests social media has not “radically altered the dynamics of bullying, but it has made these dynamics more visible to more people”. As young people hang out with peers on social media they may find themselves caught up in interpersonal conflicts over reputation, status and popularity<sup>28</sup>. Similarly, it is very easy for disagreements amongst ‘real life’ friends to extend online. Cyberbullying can undermine young people’s confidence and sense of security, which in turn may affect their attendance and performance at school, college or in work and it can isolate them from accessing support<sup>30</sup>.

Encouraging young people to make use of safety and privacy settings can help safeguard and protect them from unwanted exposure. Assumptions should not be made, however, that young people who are social media savvy, also have the digital skills to manage privacy and personal disclosure (for example blocking messages or contacts). They may not have an appreciation that they leave a digital footprint or trail on the internet that can be traced.

Use of the internet, social media and online searches may also leave young people vulnerable to inappropriate information. When searching the internet for information about their health and well-being, young people may find both reputable and poor sources of information. Healthcare has been slow to adapt to the increasing impact of social media on young people’s lives although some attempts are being made to reach out to patients through social media or to canvas their views and experiences of care through online surveys. Using our understanding of patients’ ‘online’ lives and shaping care accordingly should be a priority consideration in TYA cancer care. Where possible, professionals should create opportunities for young people to communicate using technology whilst being cognisant of the issues and risks it may present.

## NEUROLOGICAL, COGNITIVE AND PSYCHOLOGICAL CHANGES

The adolescent brain undergoes significant developmental changes from the onset of puberty right up until the late twenties or early thirties<sup>31</sup>. The specific area of the brain where most of this development takes place is called the frontal lobe. MRI scans of adolescent brains have revealed unexpectedly late changes in the volume of grey matter, which forms the thin, folding outer layer or cortex of the brain which is largely responsible for our ability to control our emotions and impulses. It is said that the teenage brain is in a state of physical change, probably greater than at any time since two years old. During this time the brain undergoes pruning, myelination, and the remodelling. This means it begins to rewire itself to become more efficient as excessive neural connections made in early childhood are whittled down, making room for further synaptic connections to strengthen

## TOP TIPS

### for using social media and the Internet

- Provide access to the internet during hospitalisation to encourage young people’s usual day to day connectivity using social media.
- Guide young people to reputable and approved sources of online cancer information
- Help educate and support young people to gain the digital literacy and safety skills to manage privacy and personal disclosure online.
- Healthcare professionals should be mindful of their own online behaviour so that professional boundaries with young people are maintained.
- Encourage young people to talk about their online experiences as part of normal everyday conversation with parents and carers. This will encourage early discussion of anything they encounter that upsets them.

*There is further information for health care professionals on using social media as a tool for communication with young people with cancer (see chapter 5).*

the brain and its function. Adolescence is a time when another important change occurs which involves the increased production of the sleep-inducing hormone melatonin. This results in different sleep behaviour patterns being observed in young people. Most adults start to produce melatonin at about 22:00 whereas teenagers tend to begin to produce the hormone at 01:00<sup>32</sup>.

Several internal and external reasons for this have been proffered<sup>33</sup>. Behavioural consequences, such as when young people stay up late, playing computer games or watching television may be one reason. This stimulates the brain and exposes teenagers to bright lights which could cause the later release of melatonin. Conversely, the hormonal upheaval of puberty itself could be causing a later release of melatonin, in which case teenagers are being kept awake by their biological mechanisms.

Sochat *et al.*<sup>34</sup> indicated that inadequate sleep is associated with negative outcomes in several areas of health and functioning, including somatic and psychosocial health, school performance and risk-taking behaviour. When a young person

is faced with cancer and its treatment it is important to be mindful of this issue and, where possible, promote good sleep hygiene and facilitate changes to clinical routines to promote quality sleep, healing and general well-being during this time of sleep-debt.

Environmental and social factors also have an important influence during neurological and cognitive changes and development. As young people begin to establish their own identities in the adult world, they begin to question their beliefs and those of others. They develop the cognitive ability to consider abstract concepts and conceptualise their own mortality<sup>35</sup>. Although the cognitive and psychological changes that take place throughout adolescence are less visible than the physical changes that occur during this time<sup>31</sup>, they can, however, be observed in stereotypical behaviours often associated with teenagers, such as:

- **Rebelling against rules and pushing boundaries as the young person attempts to find where they fit into society: this may present as non-adherence with cancer treatments or hospital protocols.**
- **Inconsistent, yet often very strong beliefs as the young person “tries on” new identities.**
- **Egocentricity or difficulty in seeing things from the perspectives of others and reading others’ behaviour: this may result in the young person feeling very self-conscious.**
- **Reduced levels of emotional control and reasoning: this may be observed through young people experiencing mood swings, impulsive behaviour, appearing to frequently change their mind, or by fluctuating between mature and childlike behaviours.**
- **A shift from reliance on parents to an emphasis on peer relationships as the young person moves towards independence, resulting in responding to peer pressure and a desire to ‘fit in’.**
- **Risk-taking and experimentation without consideration of the consequences.**

As young people experience these cognitive changes their bodies are also undergoing rapid physical development, driven by sex hormones, oestrogen or testosterone. The young person may experience inner conflict as they test out and become more comfortable with their new appearance, thoughts and emotions<sup>36</sup>. At this time young people are also faced with important choices about education, careers and developing personal values. These decisions shape the development of their unique identity, the emergence of an independent adult and influence future life chances. Teenagers may look forward

to adulthood at the same time as experiencing anxiety and a sense of loss for their childhood. This process requires major psychological adjustment with adaptation spread over several years when typically the young person resolves one issue at a time<sup>37</sup>. A traumatic experience such as a cancer diagnosis however, is likely to disrupt this process<sup>38</sup>.

At this life stage young people are also beginning to think beyond their own perspectives and consider those of other people. It is this development that gives rise to “adolescent egocentricity”<sup>31</sup>. Young people may struggle to differentiate between other people’s thoughts and their own. Therefore, if they are preoccupied by a thought or problem, e.g. the way they look, they will assume that others are also focused on this thought. This stage of psychological development means that appearance changes may be even more traumatic for the adolescent cancer patient than for any other age group.

## TOP TIPS

### for supporting developmental changes

- Young people may not have enough life experience to furnish them with adequate positive coping strategies.
- Always try to provide information and support appropriate for the young person’s developmental stage.
- Provide age-appropriate written information to reinforce verbal information. This may be particularly important in areas where the young person may be reluctant to ask questions e.g. sexual health.
- Young people’s behaviour patterns may fluctuate when going through cancer treatment, with regression sometimes observed. This can be normal and often dissipates as time goes on.
- Promote health sleep hygiene routines for the young person.
- Where possible facilitate changes to ward routines to enable later wake up times.

## ADOLESCENCE AND ILLNESS

***“The psychosocial complexities facing a teenager or young adult with cancer are monumental, presenting unique developmental challenges for both the individual and the family. The superimposition of a potentially life-threatening diagnosis onto the normative developmental tasks of teenage and young adulthood can have a particular impact on adaptation and coping”***<sup>39</sup>

The normal challenges facing all adolescents and emerging adults still have to be faced by a young person with cancer. Such is the significance of the interplay between adolescent development and chronic illness, the World Health Organisation has described how some of the biological, practical and emotional tasks can affect a young person (Table 2.1).

Table 2.1: Chronic illness or disability and adolescent development <sup>40</sup>	
Potential effects of illness or disability on development	Effects of developmental issues on illness or disability
<b>Biological</b> <ul style="list-style-type: none"> <li>● Delayed puberty</li> <li>● Short stature</li> <li>● Reduced bone mass accretion</li> </ul>	<b>Biological</b> <ul style="list-style-type: none"> <li>● Increased calorie requirement for growth may negatively impact on disease parameters</li> <li>● Pubertal hormones may impact upon disease parameters</li> </ul>
<b>Psychological</b> <ul style="list-style-type: none"> <li>● Regressive behaviour</li> <li>● Adoption of sick role as personal identifier</li> <li>● Egocentricity (persists into late adolescence)</li> <li>● Impaired development of sense of sexual or attractive self</li> </ul>	<b>Poor adherence and disease control due to:</b> <ul style="list-style-type: none"> <li>● Poorly developed abstract thinking and planning (reduced ability to plan and prepare using abstract concepts)</li> <li>● Difficulty in imagining the future; self-concept as being ‘bullet-proof’</li> <li>● Exploratory (risk-taking) behaviours</li> </ul>
<b>Social</b> <ul style="list-style-type: none"> <li>● Reduced capacity for independence at a time when independence is normally developing</li> <li>● Difficulties in peer relationships</li> <li>● Restricted opportunities to form intimate (couple) relationships</li> <li>● Social isolation</li> <li>● Interruption of educational and vocational attainment impeding the development of independent living</li> </ul>	<b>Associated health risk behaviours</b> <ul style="list-style-type: none"> <li>● Poor eating habits may result in poor nutrition</li> <li>● Smoking, alcohol and drug use often in excess of normal population rates</li> <li>● Sexual risk-taking, possibly in view of realisation of limited life span</li> </ul>

Adolescence is marked by a rapid developmental phase which includes physical, cognitive, psychological and social changes<sup>36,41</sup>. Many young people may feel added pressures or stresses during this time as they experience and are faced with negotiating a multitude of challenges in their daily lives. For a young person with a cancer diagnosis, the ‘normal’ challenges of adolescence are juxtaposed with the complex challenges associated with disease and its treatment. The challenge for healthcare professionals is to support this normal developmental process throughout a complex cancer journey. As such, working with teenagers and young adults requires a detailed understanding of adolescent and young adult development in order to extend support in the most appropriate way.

Adolescent development does not always follow a linear trajectory with physical, psychological, cognitive and social changes varying significantly between individuals and fluctuating over time<sup>42</sup>. As age is rarely an accurate reflection of a person’s level of maturity, each young person should be individually assessed at diagnosis to help inform how best to offer support. Irrespective of age or maturity, most young people will not have had exposure to life experiences that furnish them with the capacity to cope adequately with a cancer diagnosis.

A cancer diagnosis and treatment during adolescence and young adulthood present the ill young person with multiple challenges relating to:

Body image	Self-identity	Self-esteem
Life perspectives	Future prospects	Distress levels
Peer relationships	Family dynamics	Communication needs
Educational attainment	Loss of control	

Care provided during this time must be based on an individualised approach with consideration given to each young person’s personality, presenting level of maturity, family circumstances, cultural heritage, beliefs and ethnic identity. Time should be taken to explore what is important to the young person themselves, beyond the outward values or beliefs articulated or displayed by the family. Care offered should feel safe for the young person, yet responsive, flexible and consistent. It will need to adapt as the young person becomes more used to life with a cancer diagnosis, and as they mature developmentally. Most importantly, care should extend beyond direct treatment to actively assist the young person to achieve their full potential<sup>43</sup>.

The aim of the teenage and young adult (TYA) cancer team should be to promote each young person’s self-agency to negotiate their everyday life, enhance resilience and maintain

a sense of identity beyond illness so that they are able to achieve their life potential both in the short term and beyond treatment. When communicating and interacting with young people it is essential to respond to individual needs and situations. Issues of confidentiality need to be carefully considered and negotiated, particularly when there is family conflict or safeguarding concerns. It is important for staff to build trusting relationships whilst maintaining professional boundaries to avoid young people confusing professional support with friendship.

While it is appropriate to communicate with young people as you would an adult by listening to their needs and evaluating their responses, it is useful to recognise that interactions with young people can change rapidly as they fluctuate between adult and child-like understanding and behaviour. Healthcare professionals' adaptability and understanding of the young person's emotional development is therefore key to successful interaction<sup>44</sup>. Being cared for by professionals who have an understanding of the likely impact of cancer on teenagers and young adults is essential.

## PHYSICAL CHANGES AND BODY IMAGE

Teenage years are characterised by the onset of puberty when vast physical, emotional and sexual changes take place marking the transition from child to adult. At this time it is common for a young person to become acutely aware of their changing physical self, which at times can make them feel self-conscious<sup>45</sup> and negatively impact self-esteem. The physical changes experienced in the teenage years can be confusing and destabilising for the young person, as they are intrinsically linked to the development of their identity and sense of self<sup>46</sup>. Some young people describe feeling at odds with their changing body, or find the phase awkward or embarrassing<sup>47</sup>.

'Body image' is a multi-dimensional construct that encompasses the body, self, attitudes, thoughts and personal beliefs. How the young person views their physical appearance often becomes central to their world, impacting on their self-esteem<sup>48</sup>. TYA cancers and cancer treatment can affect physical appearance and development in a variety of ways, which, in turn have an impact on the young person's psychological and psychosocial coping. Examples of treatment and treatment side-effects which have physical implications include:

- Radiotherapy and/or surgery for central nervous system tumours can halt or interrupt physical development, affecting height, weight and sexual development.
- Hair loss and skin changes as a result of chemotherapy
- Scarring from surgery

- Amputation
- Needing to use physical aids to support mobility and participation in activities of daily living
- Central venous catheters
- Weight changes (loss and gain)
- Loss of muscle tone and fatigue

A cancer diagnosis alters many elements of the young person's normal life and routine. Even with specialist TYA cancer services frequent visits to hospital, invasive medical procedures, changes in the young person's physical appearance and having to face uncertainty about the future cannot be avoided. If a person already has insecurities with regard to their body image, these could be further compounded by cancer treatment. Young people may perceive their physical appearance as ugly, abnormal, weak, useless or unattractive<sup>49</sup>.

Specific side-effects of medications can feel devastating for many young people. They may cause significant weight gain, acne, stretch marks and hair loss which can be traumatic for young people trying to retain some normalcy. For those who have had surgery there could also be other body changes impacting on their body image, e.g., severe scarring and limb amputation. Amputation or indeed any asymmetry of



## TOP TIPS

### physical changes and behaviour issues

- Bear in mind that the young person's physical and psychosocial development continues as they experience cancer. Most importantly their adolescent development will be impacted by the cancer experience in many ways.
- The young person may experience a range of emotions as regards their changing bodies and often are confused by these changes. This may be compounded by cancer and its treatment.
- The significance of peers to help navigate adolescent development is not to be underestimated and where possible it is helpful to facilitate this in clinical settings.
- How a young person looks is a key feature of adolescent development so how cancer and its treatment changes this requires attention, therefore referrals to experts/organisations who can provide emotional and practical help is encouraged.
- Where body appearance is likely to be affected, (e.g., amputation, hair loss, central venous catheter placement), engage the young person in the discussion as early as is possible so pre-emptive measures to minimise the impact can be taken, such as making a referral for wig, discussing the position of the central venous catheter.

the body, particularly the breasts (or testicles) can have a devastating effect on a young person's sexual self-image<sup>50</sup>. These all serve as signs that the young person is essentially different from their peers<sup>51</sup> which can exacerbate feelings of abnormality and unattractiveness<sup>52</sup>.

The vast emotional and physical changes that young people experience when growing up is often normalised within a person's peer group. It has long been recognised that body image is not simply the perception of the teenager themselves, but is also constructed by a reflection of attitudes and interactions with others<sup>53</sup>. This highlights the important role of family and in particular of peers in helping young people adjust.

The complexity of the impact of their illness on their sense of self, however, can mean that many young people distance themselves from their own body to help them deal with the physical changes they encounter. They may feel a level

of envy towards their friends who have healthy bodies and whom they perceive as 'normal'. The young person may make unfavourable comparisons between their physical appearance now and how they felt about themselves before their treatment began, and may at times find it too upsetting to be in the company of their peers.

## THE PSYCHOSOCIAL IMPACT OF CANCER

Adolescence is already a challenging time as the young person undergoes rapid physical, cognitive, psychological and social changes. Add to this the experience of cancer, which can be highly disruptive to young people's development, potentially resulting in extreme psychological distress. Although under-researched, it is well recognised that detrimental psychological impact can last into adulthood if unaddressed<sup>58</sup>. TYA healthcare professionals need to prioritise psychological and psychosocial care alongside meeting the young person's physical and clinical health needs, facilitating successful emergence into adulthood.

### PEER RELATIONSHIPS

Peer relationships are likely to be severely disrupted by cancer as the young person is absent from school, college/university or work, too unwell or fatigued to take part in social activities, or embarrassed by changes in their physical appearance<sup>58</sup>. Alongside this loss of their normal peer contexts, young people with cancer may find themselves spending much more time at home with parents or adult family members than prior to their illness onset<sup>54</sup>. Some young people describe maturing through their illness and find they have more in common with other patients who understand and share some of their own cancer experiences than their friends at 'home'<sup>55</sup>. Other young people may choose to spend long periods of time on their own, sleeping, playing computer games or browsing the internet.

Healthcare professionals should be mindful of too much solitary behaviour and encourage some peer interaction extending support to patients' friends as well as their families as a core component of their care. Feelings of being physically and emotionally different from one's peers can exacerbate this sense of aloneness<sup>56</sup>. Encouraging the young person when possible to attend or stay connected with school, college or their place of work, creating a ward environment that is friendly and open for friends to visit and investing in WI-FI access to allow young people to stay in touch whilst away from home can help young people feel a sense of connection with their home life and build resilience<sup>56</sup>.

### INTIMATE RELATIONSHIPS

Sexual development is a central component of adolescence and young adulthood. Throughout the adolescent years a considerable amount of self-esteem is derived from sexual identity<sup>49,57</sup>. First sexual encounters and romantic

relationships (heterosexual or same sex) as well as experimentation and risk-taking behaviours form part of this consolidation process. Amongst young people, establishing romantic relationships and a positive sexual identity can be even more challenging following a cancer diagnosis<sup>58,59</sup>.

Young people may be diagnosed at a time when they are beginning to establish an important personal or sexual relationship. A cancer diagnosis is challenging to even strong relationships, testing commitment and care. Partners will require support during this time. Additional tension may occur as partner and parents establish who the young person's primary carer is. Young partners may either feel isolated as families resume care of the sick young person or conversely, feel overburdened by their caring responsibility.

Extended periods of hospitalisation can mean that young people may become isolated from peers and social groups who may continue to meet and evolve without them. Peers may feel sorry for the young person and increasingly view them as a 'sick' person; perceptions that can reduce the likelihood of developing romantic or sexual relationships<sup>60</sup>. Isolation from peers can equally hinder the development of social skills and confidence necessary in starting relationships.

The issue of when to disclose a cancer history to potential partners is particularly salient in the TYA population<sup>61,62</sup>. This disclosure may mean risking alienation and rejection further compounding negative perceptions of the body and emerging sexuality<sup>56</sup>. What is experienced as rejection by potential partners may be due to a fear of inability to procreate, even if having children is not necessarily on their horizon, or there may be concerns around becoming close to a young person who may subsequently die. Both partners may feel anxious or worried thinking about the future.

### **FAMILY AND SIBLING RELATIONSHIPS**

Every young person develops at a different rate and has unique social circumstances. For some, their move towards independence will be interrupted by their cancer diagnosis and they may revert to being more dependent on parents. Young people may be embarrassed by parental attempts to care for them or revert to child-like behaviours. Parents may also become protective and seek to withhold information from the young person about their illness<sup>63</sup>. TYAs with cancer may have to surrender a growing independence. They may have to move back home after periods of living independently and become dependent on parents or a partner in a way they never considered or anticipated.

Within the family tension or conflict may arise as the young person prioritises peer acceptance. This is more likely if the family disapprove of certain peer groups or a choice of partner. Parents may complain that their young person is communicative with friends but withdrawn and moody within the family. Parents also need to adapt and may struggle with letting their 'child' go<sup>54,64,65</sup>.

The emotional needs of siblings also require careful consideration. Depending on their age, siblings may experience feelings of fear, guilt, sadness, anger and jealousy of the extra attention their unwell sibling receives<sup>66</sup>. This can result in additional tension within a family that may be already struggling to maintain a sense of 'family' amidst the demands of treatment and hospital life.

### **PATIENTS WHO ARE YOUNG PARENTS**

While some young people may be reliant on their families, others may already have become parents themselves. When faced with the worry and upset of cancer, young parents may find themselves having to rely more on family and friends to help maintain daily life and usual routines for their child or children at home. Young parents may need support in telling their child they have cancer, or discussing their illness

## **TOP TIPS**

### **for providing psychosocial support**

- Recognise that there may be conflicting views between parents and young people. In such circumstances, staff should help resolve conflicts as soon as possible whilst maintaining a sensitive and caring approach to both.
- Treating teams should take into account the needs of the wider family and dependants, offering support or referral to appropriate services where necessary
- Peer and social acceptance plays a central role in normal adolescent development and must not be underestimated. Peer support is invaluable in helping young people cope with their diagnosis and treatment.
- Support young people to maintain social contact with their usual peer group to help avoid social isolation.
- Provide opportunities for young people to meet and spend time with other young patients. This can enhance coping with cancer and its treatment.
- Facilitating young people to maintain a sense of 'normality' is vital to effective coping.
- Where possible, encourage and support continuing education and/or work. If patients are treated locally, the TYA team at the Principal Treatment Centre should be able to help with education/employment issues.

with their child. Many charities, including Macmillan Cancer Support now provide information and advice on this. Cancer can be costly. If unable to work, the young person may also be worried about financially supporting their family in spite of certain child benefits or tax credits to help. Young parents report that they feel upset that they can't 'parent' as they would like and worry about the impact this may have on their relationship with their child. Indeed, childcare (whether paid or offered by family) is a significant issue for young parents who need to attend hospital frequently or have lengthy inpatient stays. It can have huge implications for extended family in both practical and emotional terms.

Socially, young people are tasked with developing independence and societal integration. Social challenges include developing sexuality, intimacy, personal relationships and separation from parents<sup>67</sup>. Interaction with peers is pivotal to this development. This accounts for the emphasis young people place on friendships and the relatively common occurrence of bullying in this age group. Young people may struggle to fit into a peer group, compete for a position or acceptance and may frequently change their alliances as they explore their social selves<sup>55,65,68</sup>.

## **SPIRITUALITY, FAITH AND RELIGION**

Young people with a cancer diagnosis may ask "why me?" or "why now?" This kind of questioning is just as common amongst young people who do not consider themselves

religious as well as those who describe having a faith or religious belief system. Developmentally, as a young person matures through adolescence, questions about their identity, purpose in life and existence become more focal<sup>69</sup>, alongside a growing capacity for abstract and reflective thought<sup>70</sup>. This can evoke a multitude of emotions as the young person tries to make meaning and sense of their life.

Spirituality means different things to different people but describes a conscious connection between oneself and the wider world<sup>59</sup>. To be spiritual does not require a belief in God or membership of a religion; rather it is concerned with a sense of connectedness with others and how many people find meaning in their lives. Young people may express this sense of spirituality without describing themselves as religious. Equally, some people may consider themselves to have faith without identifying with any particular religious group.

Spirituality and religion can be important to the well-being of someone with cancer and may help some individuals (and their families) make sense or find meaning in their experiences<sup>71</sup>. Young people may question treatment efficacy and may wish to explore loss of hope or fear of dying. If professionals take time to explore the young person's existential questions and beliefs this may not only offer comfort, but may help them find a sense of meaning and well-being.

In today's secular society assumptions should not be made about a family's beliefs based on how they describe their religious affiliation e.g. Muslim, Jehovah's Witness. Some



## TOP TIPS

### for supporting spirituality

- Make time to ask about a young person's spiritual beliefs.
- Explore the young person's beliefs beyond the family's religious affiliation.
- Be mindful of the impact that the young person or indeed their family's religious beliefs may have on their decision-making process. Sensitive discussion may be needed to explore specific issues, for example, the decision to bank sperm, consent for treatment or discuss aspects of palliative care.
- See chapter 6 for further questions to consider when assessing a young person's needs in this area.

families may practice the customs associated with their religion without having deep religious beliefs or conviction. Care should also be taken to explore the young person's personal beliefs aside from the family's stated religion. This is of particular importance when planning palliative care which has a clear spiritual component<sup>71</sup>. Some young people describe feeling alone despite having supportive family and friends. Many teenagers and young adults may welcome having the opportunity to talk alone with someone from the chaplaincy or palliative care service irrespective of their beliefs. **(See Chapter 6 for further information)**

### Resources

[www.youngpeopleshealth.org.uk](http://www.youngpeopleshealth.org.uk)

[www.jtvcancersupport.com](http://www.jtvcancersupport.com)

[www.nice.org.uk](http://www.nice.org.uk)

[www.livestrong.org](http://www.livestrong.org)

<https://www.minded.org.uk/> (MindEd is a free educational resource on children and young people's mental health for all adults)

<https://www.minded.org.uk/totara/program/index.php?categoryid=13>

[www.macmillan.org.uk](http://www.macmillan.org.uk)

[www.clicsargent.org.uk](http://www.clicsargent.org.uk)

[www.teenagecancertrust.org](http://www.teenagecancertrust.org)

### Further reading

EU Kids Online, debunks the top 10 myths of children and young people's online risks offering a series of evidence based recommendations

Livingstone S., Haddon L., Görzig A., Ólafsson K. (2011) *EU kids online: final report*. EU Kids Online, London School of Economics & Political Science, London, UK.

Available at: <http://eprints.lse.ac.uk/39351/>

Livingstone, S., Mascheroni, G. and Staksrud, E. (2015) *Developing a framework for researching children's online risks and opportunities in Europe*. EU Kids Online, London, UK.

Available at: <http://eprints.lse.ac.uk/64470/>



# CHAPTER THREE: MULTI-DISCIPLINARY TEAM WORKING, MODELS OF CARE AND PATIENT PATHWAYS

Authors: Nicky Pettitt, David Wright, Charlene Jones, Sasha Daly

## TEENAGE AND YOUNG ADULT CANCER SERVICES

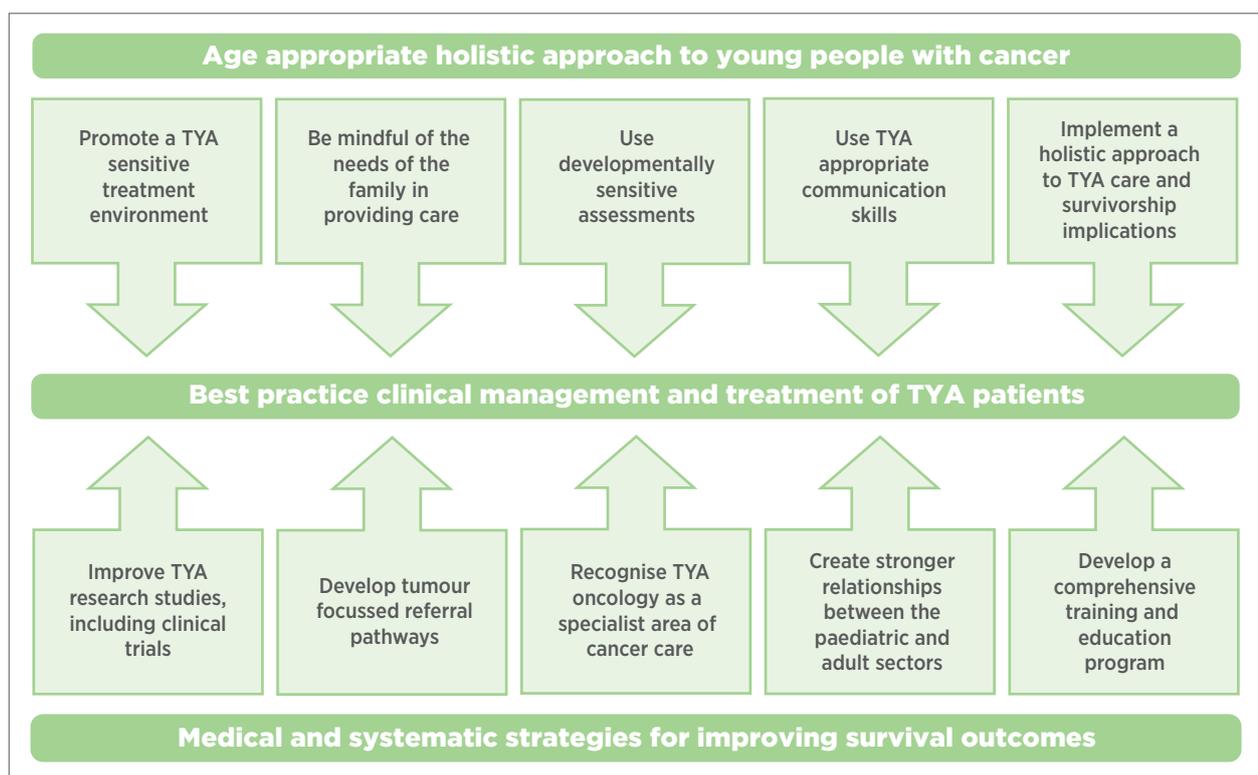
The unique needs of teenagers and young adults (TYA) have been well documented over the last four decades<sup>72</sup>. They have in the past been perceived as an isolated and overlooked group<sup>73</sup>, who as a cohort of patients are 'neglected'<sup>74</sup>. TYA cancer care is less about a discipline incorporating a specific set of illnesses occurring to a particular age group, and more about the way services provide care<sup>75</sup>. TYA cancer care as a distinct specialty began in the UK but is a service that is rapidly becoming embedded into healthcare services internationally<sup>76,77</sup>.

**Figure 3.1** illustrates how best practice can be achieved through the combination of an age-appropriate holistic approach to care together with medical strategies for improving clinical outcomes. Care provision and 'best'

medical management for TYA is multi-faceted. Providing holistic care to a developmentally, psychosocially diverse age range is complicated by the spectrum of diseases and range of treatments, as well as care crossing both adult and paediatric services, and oncology and haematology specialties. Furthermore, the nature of treatment varies markedly between tumour types. For example, a patient with a Hodgkin lymphoma will require mainly outpatient treatment, whereas a patient with an osteosarcoma will face lengthy inpatient stays. The care pathway may well incorporate several medical consultants and their teams, across different hospital sites, potentially even different hospitals and NHS Trusts, in order to best meet the medical needs of the patient.

The healthcare team must provide holistic care in the context of the young person's unique circumstances including ethnicity, culture, race, spirituality and religion, and family

**Figure 3.1:** Factors contributing to best clinical management<sup>78</sup>



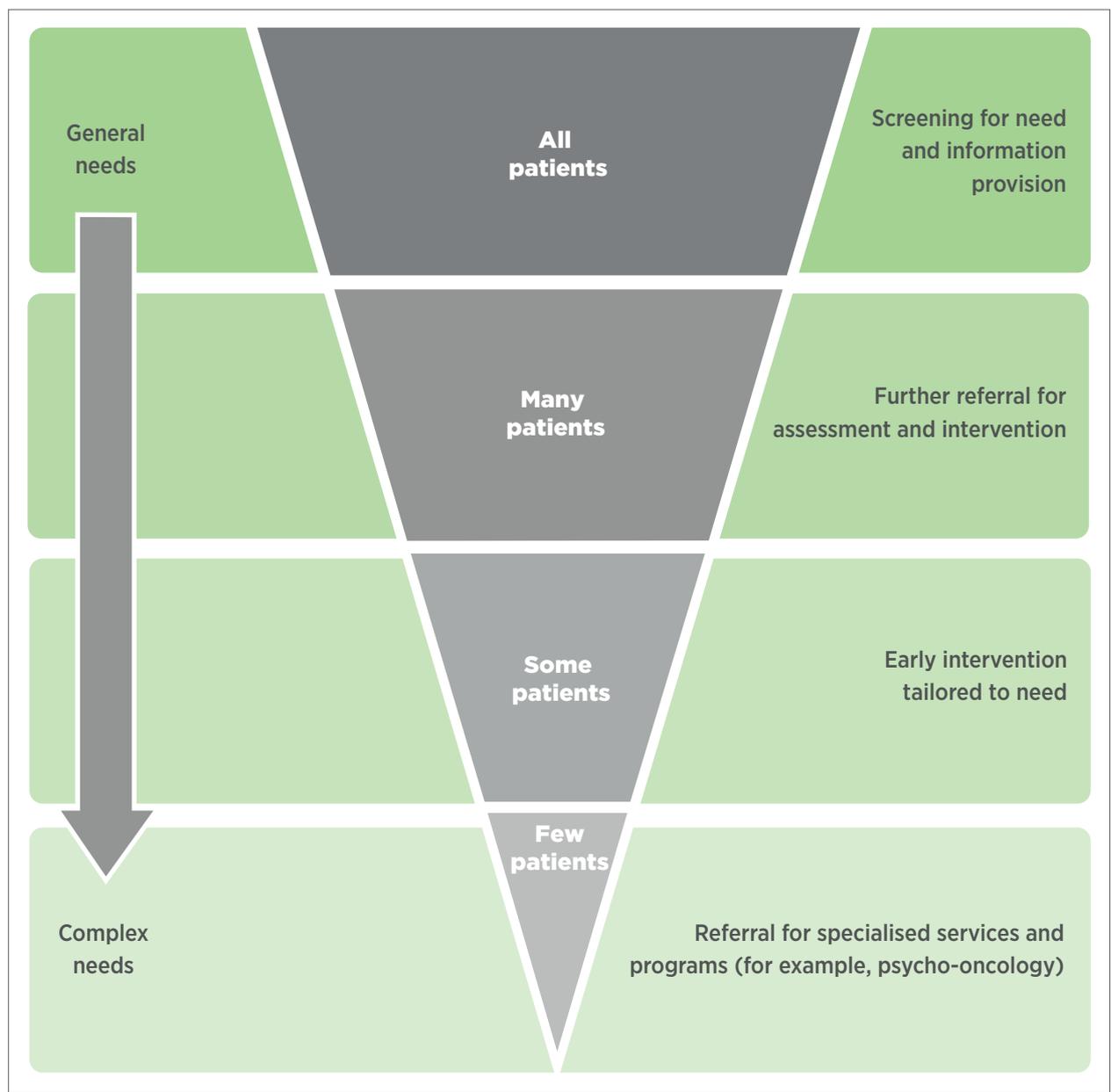
relationships while attending to their developmental needs as they transition from adolescence to adulthood.

It is essential that any care provided to the patient is multi-dimensional and incorporates the needs of their family. Familial issues, such as difficulties with work, increased costs due to travel, living away from home, increased family stress, caring for other siblings, care for their own children and anxiety and depression in other family members, must be addressed.”<sup>1</sup>

Priority of needs will inevitably change as the young person progresses through treatment. Levels of intervention and

support may vary dramatically between patients over the course of their treatment trajectory. While all young people and their loved ones will require regular support and information from members of the TYA multi-disciplinary team (MDT), levels of support required will differ in each individual case. As with any patient group, the level of support required or the impact of diagnosis and treatment cannot be accurately predicted or allocated by a predetermined plan of care. Every patient presents with a unique set of needs which evolve throughout the treatment trajectory as new challenges emerge (**Figure 3.2**).

**Figure 3.2:** Model of Supportive Care Provision<sup>79</sup>



## TOP TIPS

### for providing age-appropriate services

- Best practice is delivered through a combination of expert medical management and expert age appropriate psychosocial support. Treating teams should access services/support offered by TYA Principal Treatment Centres.
- Screen all patients using a psychosocial assessment tool and refer on to hospital-based support or community services as appropriate (e.g. psychology, counselling, occupational therapy).
- Ensure psychosocial assessment and screening is continued throughout treatment, recognising that individual circumstances and needs will change during the care pathway.
- Ensure robust referral pathways for psychology, psychiatric services and counselling are in place to refer patients when necessary.
- Ensure a portfolio of support services and local resources are available for wider family members and carers.

## NHS STRUCTURE

Across the United Kingdom (UK), TYA cancer services are delivered within the National Health Service (NHS). Health is a devolved area of Government responsibility, meaning that the NHS in England, Wales, Scotland and Northern Ireland all operate differently and regional health systems are now more diverse than ever before<sup>80</sup>. The fact that TYA cancer services are all reflected in policy and guidance for practice across all of the UK countries is indicative of the advocacy of champions, changing public awareness and focus that the specialism has generated.

### Resources

#### Links to policy:

**England.** <https://www.england.nhs.uk/commissioning/spec-services/npc-crg/group-b/b17/>

**Wales.** [http://www.wales.nhs.uk/sites3/Documents/322/Teenagers\\_and\\_Young\\_Adults\\_Cancer\\_Standards\\_-\\_Final\\_-\\_English.pdf](http://www.wales.nhs.uk/sites3/Documents/322/Teenagers_and_Young_Adults_Cancer_Standards_-_Final_-_English.pdf)

**Scotland.** <https://www.youngcancer.scot.nhs.uk/admin/js/libs/tinyMCE/plugins/moxiemanager/data/files/Cancer%20Plan%202012-15%20published.pdf>

**Northern Ireland.** <https://www.dhsspsni.gov.uk/publications/cancer-prevention-treatment-and-care-service-framework-documents>

## TYA PRINCIPAL TREATMENT CENTRES AND DESIGNATED HOSPITALS

The 2014 TYA Peer Review Measures<sup>81</sup> states that there should

be an identified Principal Treatment Centre (PTC) for young people based within cities that have a PTC for children. The PTC is a specialised centre for TYA cancer treatment and **all** young people aged 16-18 should be treated within such a centre. TYA PTCs have certain requirements they must meet, as set out by the Peer Review Measures. These requirements include specific environmental standards and staffing measures. The TYA PTC, however, is also a place of treatment for 19-24 year olds but, unlike 16-18 year olds, they can choose (if it is appropriate treatment-wise) to have their treatment at other hospitals closer to home. These are called TYA designated hospitals (DH) and require nationally agreed TYA Peer Review.

TYA DHs are hospitals that provide care to young people and would like to be recognised as a place of treatment option for 19-24 year olds. In proposing to be TYA DH, each hospital agrees to meet the standards set out in the Peer Review measures. There is a critical relationship between the DH and the PTC to ensure that young people are identified and discussed by the TYA MDT at appropriate times in the treatment pathway to ensure optimal coordinated healthcare. The DH-PTC relationship is also important in helping to ensure that all young people are offered the very best treatments through dissemination of trial information.

In summary, 16-18 year olds should all receive treatment at a PTC, while 19-24 year olds should be offered 'unhindered' choice of receiving treatment at a PTC or a DH, as long as the treatment is comparable. TYA Services across the UK have evolved within this guidance to create a number of different service models, which are explored later in this chapter.

## TYA KEYWORKER

Traditionally young people treated at the PTC are allocated a key worker, often a TYA CNS, who becomes a key point of contact and support throughout treatment, survivorship or end of life care. The TYA Clinical Nurse Specialist (CNS) is based in the hospital but may also provide support to young people through home visits and community care<sup>82</sup>. However, it is important to acknowledge that there may be more than one key worker depending on support requirements. For example, a key worker could be a social worker, youth support co-ordinator and site specific (SS) CNS.

Young people aged 19-24 who choose to be treated locally at the DH do not generally have access to the same level of age-appropriate expertise and are often treated in isolation from peers. A nursing and support model piloted by Teenage Cancer Trust developed a new type of nursing model to support young people treated at a DH<sup>83</sup>.

The model aimed to bridge the gap in service provision by placing a TYA CNS to work alongside SS treatment teams in the DH and provide age-appropriate enhanced support to young people and their families. In line with Department of Health guidance<sup>84</sup>, which support the integrated coordination of care across hospitals and community settings, the CNS liaises with community, primary care, secondary care and the PTC to ensure individually tailored support is provided, close to where the young person with cancer is being treated as an inpatient, outpatient or through home visits. This approach is now undergoing national roll out as a means of supporting all young people with cancer, irrespective of place of care<sup>85</sup>.

## CARE PATHWAYS, MODELS OF CARE AND CHOICE

When considering TYA cancer models of care it is crucial to acknowledge the complexity of patient pathways and the variety of time-points at which individual patients can present. Young people are not always guaranteed to present and follow existing care pathways already in place for specific disease sites due to delays in diagnosis<sup>86</sup>.

Young people's transient lifestyles due to education, family and social factors means that they may present with symptoms in a number of different settings across different geographical locations. This is not just the case for newly diagnosed patients but also for those on long-term follow-up and those who present with recurrence. This has significant implications for optimal treatment and care.

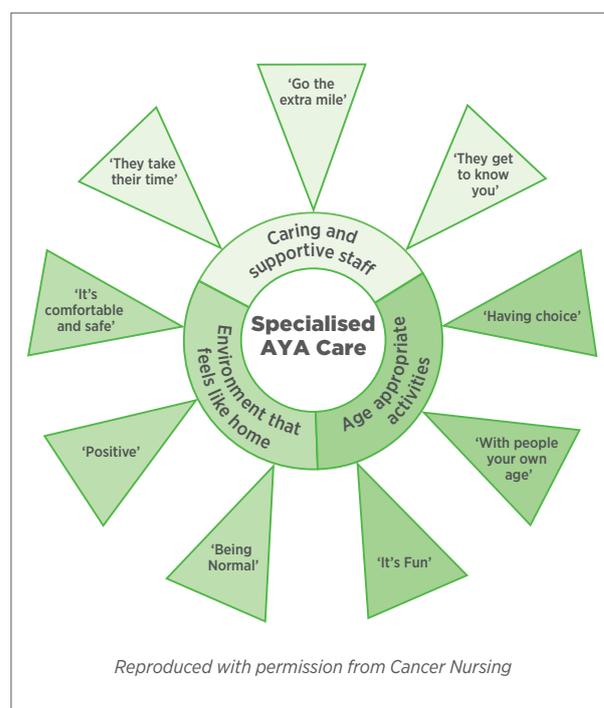
Equal access to expert TYA cancer services and the ability to offer choice is inherent to delivering high quality care to young people, irrespective of location. It is also what young people tell us they want from their services, as access to appropriate services and the option to have treatment closer to home were key issues in the Teenage Cancer Trust 'Young Voices' report<sup>87</sup>.

TYA services need to be multi-faceted to respond to the needs of the patient group and regional services have evolved and grown to meet the needs of the local patient population. Differences in models of care are often dependent on capacity, resource availability, site specific disease group and local speciality.

It is interesting to note that despite the wide array of plans, guidelines, standards and service frameworks, at no point has the term 'age appropriate' been defined. There are currently multiple models of TYA service provision throughout the UK. By identifying key areas of care locally that the TYA Service teams can focus on with the knowledge, skills and relationships at its disposal, these models evolve to reflect current policy and practice to the best of its ability. It is crucial to recognise that a 'one size fits all model' is unachievable due to the regional variations.

Vindrola-Padros *et al*<sup>77</sup> describe a mapping study that aimed to identify the main components of TYA care in England. Through semi-structured interviews with young people, family members and healthcare professionals the range of approaches to service delivery were explored and components of care identified (**Figure 3.3**).

**Figure 3.3:** Main components of adolescent and young adult cancer care <sup>77</sup>

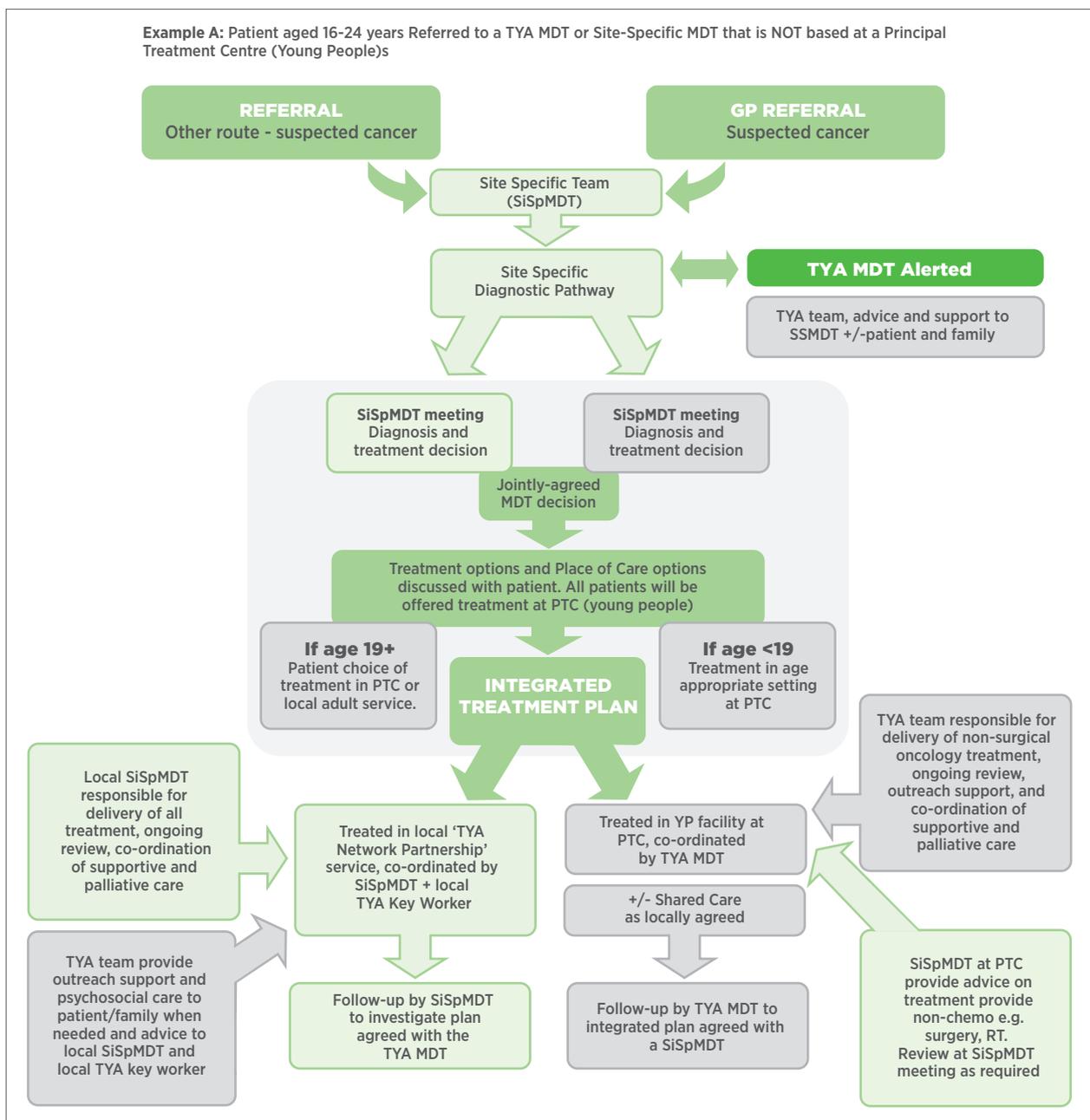


The Children and Young People's Improving Outcome Guidance (CYPIOG) Advisory Group produced illustrative pathways for young people newly diagnosed with cancer and showed the vital link between TYA and SS MDTs. All pathways are underpinned by the principle of 'informed patient choice'

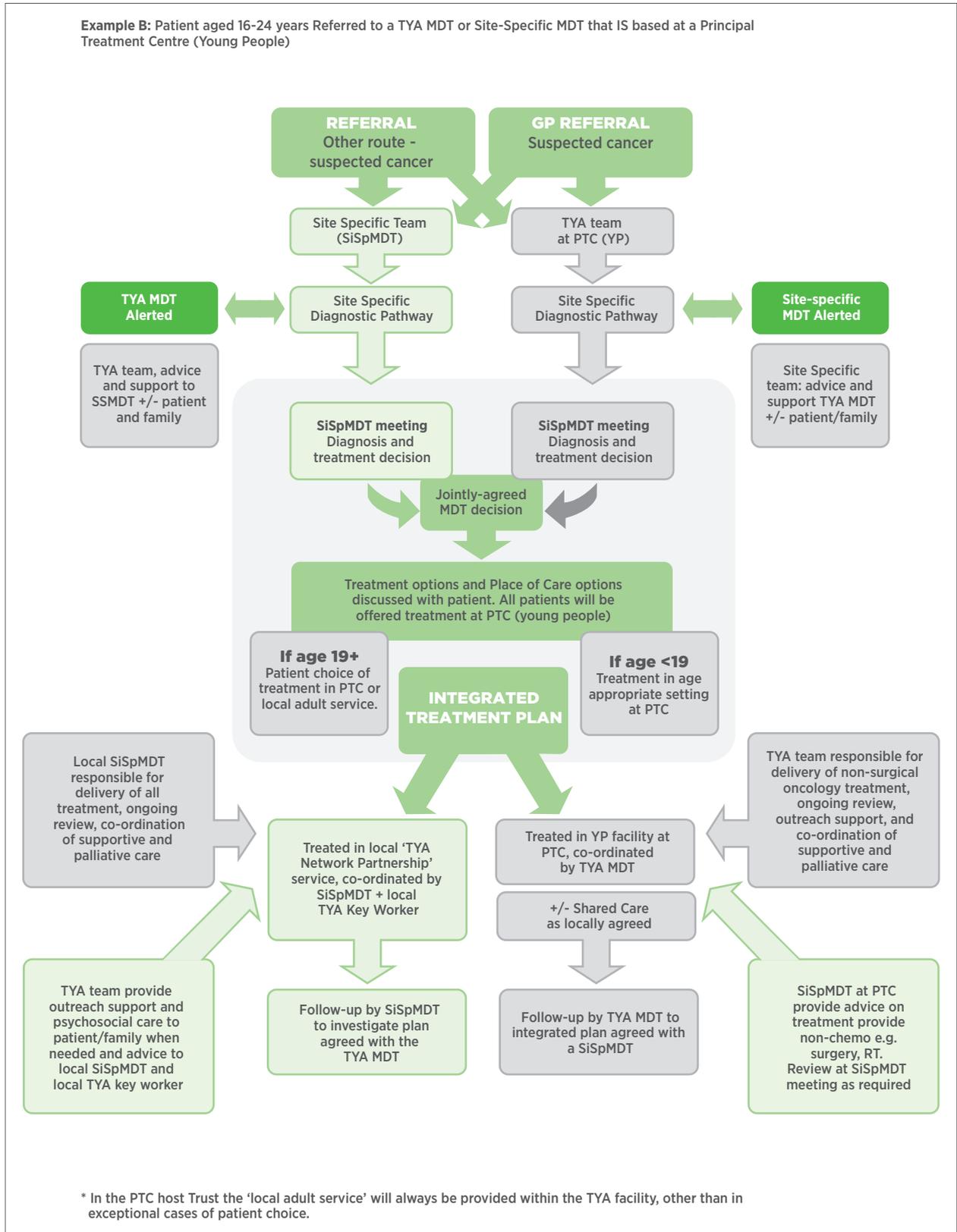
(Figures 3.4a & 3.4b). Choice regarding place of care must be unbiased, informed and delivered in a timely manner. The NHS Choices website<sup>88</sup> is now available and provides clear, appropriate and comprehensive information to support young people to make an informed choice at the beginning of treatment. This site may also provide useful guidance to none-TYA healthcare professionals who are guiding and supporting young people through their choices. Some TYA services provide PTC specific information leaflets to help support young people's decision-making.

The whole patient pathway is covered by the CYPIOG, from diagnosis and treatment, through to rehabilitation, survivorship and long-term follow-up or palliative care and bereavement. Issues relating to research, clinical trials and data management are also included. This broad scope is in contrast to existing Improving Outcome Guidance (IOG) documents for adult cancer services, which tend to focus solely on SS diagnosis and treatment<sup>89</sup>. In this sense, all young people's care provision is guided by at least two IOG documents and, potentially, a third if palliation is required. It

**Figure 3.4a:** Principles of informed choice



**Figure 3.4b:** Principles of informed choice



is now widely recognised that best practice in TYA care can only be achieved through collaborative working between site specific and TYA teams.

## TYA MULTI-DISCIPLINARY TEAM

The characteristics of an effective MDT were first identified in 2010 by the National Cancer Action Team<sup>90</sup>. Cancer care is now defined and delivered by teams of professionals, with wide ranging professional backgrounds, coming together to form an MDT. The consideration of each individual patient by an MDT with specialist knowledge and skills in the relevant area of cancer care ensures that diagnosis, staging and treatment plan for each young person is of high quality, with the patient at the heart of every decision.

The TYA MDT is different to that of the SS MDT as it has both disease specific input and psychosocial focus and provides additional value to the diagnostic and treatment planning functions of the traditional SS MDT. The TYA MDT also considers the best place of care and relevant clinical trials for the young person.

The complex breadth of services that young people will need to access transcends both organisational and institutional boundaries. It is recommended that the best approach to medical and psychosocial support for young people is a partnership between the TYA MDT and the SS MDT. The CYPIOG outlines the core members, whose expertise and skills are required to form an optimal TYA MDT<sup>1</sup> (**Table 3.1**).

Core members	Extended membership
Lead Clinician Consultants with clinical practice in the following: <ul style="list-style-type: none"> <li>● Leukaemia</li> <li>● Lymphoma</li> <li>● Germ Cell Malignancy</li> <li>● Bone and/or soft tissue sarcoma</li> <li>● Brain and CNS Malignancy</li> </ul> Paediatric Oncologist Lead Nurse of the PTC Specialist Nurse Young Peoples Social Worker Youth Worker/Activity Co-ordinator MDT Co-ordinator and Secretary	Member of Palliative Care Team Physiotherapist Occupational Therapist Dietician

MDT may choose additional members for both extended and core roles as they see fit. For more information, please refer to the TYA Measures 11-7D-201 and 11-7D-202

Weekly TYA MDT meetings bringing together the expertise of a wide-ranging group of professionals ensure that:

- Young people are considered from a range of viewpoints and expertise to ensure medical and psychosocial needs are appropriately addressed.
- Promotion of shared learning amongst professionals.
- There is increased probability of timely, appropriate treatment and continuity of care.
- There is regular professional discussion, which is likely to lead to improved clinical outcomes, promote more effective care delivery and increase participation in audit and research

There are challenges as well as benefits of TYA MDTs, especially the time needed for significant changes in attitude in order to create new ways of collaboration to overcome barriers to joint working<sup>91</sup>. More recently, strengthened TYA services, research and practice across the UK has led to changes, with the TYA MDT increasingly embedded as part of good practice. The determined efforts of TYA service champions have been strengthened by the TYA MDT having dedicated measures within the peer review processes for cancer services. However, this comes with the caveat that TYA teams across the regions are still evolving as models of TYA care and relationships between TYA PTCs and DHs wax and wane against the backdrop of an ever challenged NHS system.

While the challenges of developing a TYA MDT have been identified<sup>91</sup>, these can be overcome by a variety of strategies (**Table 3.2**).



**Table 3.2:** Strategies to overcome the challenges of developing a TYA MDT

Challenge	Strategy
<b>Time constraints</b>	Finding a suitable time and day to suit all members of the team is unrealistic. Rotating the time and day may allow more professionals to attend. The use of technology can also be useful, utilising conference calls or video conferencing. There are also local projects currently exploring the efficacy of secure virtual platform meetings that may influence the future of MDT functioning.
<b>Perceived duplication</b>	Justifying the necessity for young people to be discussed at both SS and TYA MDT meetings requires good communication skills and can be assisted by raising the profile of TYA specialist services. Cultural change is required and others may need to see the enhancement that the TYA MDT can bring to the diagnostic/treatment MDT and conversely the benefit to SS team members attending the TYA MDT. It is important to clarify that the TYA MDT discussion and agreement of treatment plans would not delay delivery of treatment.
<b>Demonstrating outcomes</b>	Perceptions and the value placed on psychosocial care are variable amongst healthcare professionals. Many consider that it is not required when making treatment decisions. Key points and action plans need to be captured and show the benefits of the additional knowledge. For example, the challenge of non-adherence may be more effectively addressed within the TYA MDT than SS MDT. Communication of outcomes to professionals outside of the PTC is vital to foster collaborative relationships. The importance of this is on-going throughout the patient pathway, especially if there is an expectation for shared care for some elements of treatment.
<b>Feedback</b>	Communication to referral sources must also show actions and outcomes to demonstrate clear benefit to the referrers for patients being discussed. This should enable holistic TYA care provision. Data can then be reviewed and audited regularly alongside referrals to demonstrate the benefits of MDT discussion.
<b>Resources</b>	Large numbers of professionals and the time consuming nature of administration before and after a MDT meeting cannot be avoided. Realistic bids for funding and time must be made and commitments obtained from management and resource providers. Job plans must accurately reflect the workload generated. The MDT will not be successful if there is no MDT co-ordinator to complete the administration created by a meeting with such complex inputs and outputs.
<b>Improvements in outcome</b>	Specialists in TYA care must collaborate to evaluate the benefits of the service. While survival is a key metric consideration, other outcomes, such as quality of life, may be as important to young people.
<b>Increased clinical trial recruitment</b>	It is well-documented that young people experience poor clinical trial entry <sup>92</sup> . TYA MDT meetings are noted as a means to address this important gap.

Challenge	Strategy
<b>Multi-agency working</b>	Lack of knowledge of other professionals' roles in patient care can cause individuals to feel threatened, especially if responsibilities overlap. Regular meetings improve communication, familiarity and thus patient and family experience.
<b>Education and shared learning</b>	The opportunity to communicate and share practice should be welcomed by all professionals in the TYA MDT. The varied backgrounds and specialties of those involved can bring great educational benefits to the group. Some TYA MDT have regular educational slots timetabled around the MDT for specific teaching or information sharing, for example feeding back to colleagues after attendance at a conference or study day. There is also the element of TYA expert professionals supporting and informally supervising others who may not encounter TYA patients on a frequent basis and therefore be challenged within their normal practice
<b>Improved transition</b>	The TYA MDT meeting creates a perfect forum for the development of transition links between paediatric and adult services. The TYA MDT meeting must establish its role in transition. This is discussed in more detail later in the chapter.
<b>More equitable services</b>	Young people may have previously been cared for in isolation, never meeting another young person going through a similar experience. They may also have been cared for in environments more suited to either younger children or older adults and by professionals with little or no experience of caring for teenagers and young adults. It may be that the young person was not even aware that they had a choice about their place of care. Once the TYA MDT is aware of a patient, a sensitive approach can be made via the SS team or directly to the patient in negotiation with the treating team. This requires good communication between the TYA team, the SS professional and young person.
<b>Overcoming professional boundaries</b>	In an ideal world adult and paediatric services would work in harmony. The setting up of a TYA MDT is a step towards this ideal. Enhanced communication between adult and paediatric colleagues will lessen any perceived threat and promote collaborative working
<b>TYAC registration</b>	Data collection of all 15-24 year olds who are newly diagnosed with cancer commenced in January 2009 across the UK. This was introduced by TYAC (Teenage and Young Adult Cancer), the UK TYA professional organisation, in partnership with the North West Knowledge and Intelligence Team (NWKIT), with the aim of gathering data on TYA cancers, monitoring the implementation of the CYPIOG <sup>1</sup> and evaluating the effectiveness of services. At the time the TYAC registration form was the only data source on a number of important outcomes, such as clinical trial information. NWKIT stopped collecting data at the end of March 2014. Data now comes from the Cancer Outcomes and Services Dataset (COSD), providing data for patients in England only. NWKIT TYAC data from 2009-2013 can be accessed from the National Cancer Intelligence Network website <sup>93</sup> .

## TOP TIPS

### for setting up a TYA MDT

- A local TYA MDT operational policy should be in place outlining formal notification procedures. All TYA, irrespective of place of care, should be formally notified to a TYA MDT for discussion, treatment and care planning, and the opportunity to access age-appropriate services and support from a TYA team.
- A TYA MDT should meet once a week or as guided by patient numbers.
- A TYA MDT co-ordinator is essential to successful functioning, co-ordination of meetings.
- Good open, honest communication acknowledging all contributions by all levels of professionals is vital to effective MDT functioning.
- Technology can be harnessed to good advantage, facilitating regular and timely discussion i.e. video conferencing, internet use to facilitate discussions with SS MDT.
- A TYA MDT provides a forum for holistic consideration of each patient, which includes both medical and psychosocial care and assignment of a keyworker
- A separate psychosocial TYA MDT, in addition to the treatment planning MDT, should be considered.
- Ensure good communication channels are developed between hospital teams, key workers and community teams/services.
- All young people should be referred to the TYA MDT for the purpose of notification and to assist with age-appropriate assessment, management and care.



## TYA MDT AND TRANSITION PATHWAYS

Transition within healthcare is defined as: ***'A purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with chronic physical and medical conditions as they move from child-centred to adult-oriented health care systems'***<sup>94</sup>.

The complexities of transition for all young people with medical conditions and for TYA specifically have been well documented<sup>94-97</sup>. Equally, the pathways and principles of good transition have also been well documented<sup>98</sup>. Complexities include a wide range of service-based challenges as well as issues that lie with individual young people, families and professionals.

At a service level the importance of transition is not always recognised. Paediatric and adult services do not always perceive that they have the facilities or capability to initiate transition, services may not communicate with each other to discuss cases for transition and services may not believe they have the professionals or facilities to support young people and families through an effective transition process.

The TYA MDT can play a key role in helping overcome some of these service challenges by providing an essential forum for discussion and planning. Members of the core team will represent expertise in both paediatric and adult fields, facilitating discussion around the best place of care for each young person. The transition of a teenager from paediatrics into TYA or adult care should be facilitated by the paediatric team who will already have a holistic understanding of the young person. Likewise, the transition of a young person from TYA care to adult services should be facilitated by the TYA team.

The transition process can also be impacted by young people and their families. How the move from one service to another is perceived by those involved can weigh heavily upon how they engage with the move and how they engage with the professionals within the new service. Some young people and their families will have been a part of a service for many years and will have developed strong relationships with the professional team within that service which they may be fearful of losing. They may fear that the new team will not know them, or that different clinical practices may take place in the new service. They may also have heard stories from other patients about what happens in the new service.

It is difficult to completely put young people's fears at ease but generally it is regarded to be best practice to start the process of transition as early as possible to generate collaboration and integration between the current and new services. This allows relationships to be developed, new environments to become familiar and for different clinical practices to be discussed. Further top tips are listed as part of this chapter.

## TOP TIPS

### transition

- Transition should be a gradual process facilitated by healthcare professionals and preferably coordinated by an identified key worker in partnership with the young person.
- Allow for flexibility within the policy and practice of transition to ensure it is at an appropriate and safe point in the patient's cancer pathway. For example, consider the maturity of the patient, the stage of treatment, any palliative needs, history or likelihood of relapse.
- Do not transition a patient between services/place of care at times of relapse or in palliative care unless absolutely necessary. Engage the young person and their family consistently through the transition process in order to empower and increase confidence in the new care arrangements.
- Check out any concerns the young person and their family may have or what they have heard about the new service in order to address any underlying fears that may constrain successful transition and relationship-building with the new service.
- Offer visits/introductions to new clinical settings (with key worker/ youth support worker/young person's social worker) prior to actual transition.
- Ensure agreed protocols and policies are developed to delegate roles and responsibilities across the MDT and both service providers.
- Invest time to build professional relationships and knowledge between different service settings.
- The potential for transition should be highlighted in patient literature that is produced by the TYA ward/service.

It is important for professionals to recognise that transition can occur at different ages and under different and sometimes difficult circumstances. Young people fall into distinct groups within transition. These consist of those who are on the cusp of children and TYA services (aged 15-18 years) at presentation and who will require transition into TYA service or adult services. There are those at the

upper end of the TYA age range (23 – 24 years) who will require transition to adult services. There are those who have previously completed treatment but relapse at an age that means they require treatment within a new service.

There is also a group of young people who will require transition to a new service to receive palliative treatment or palliative care. This practice is generally not recommended but is sometimes necessary. When this is the case and an acute transition is required then professionals should use the top tips wherever possible. Communication is the key to successful transition: communication between professionals and communication with the young person and their family. For example, providing the young person and family with clear instructions of how to get to the new service and providing them with the name of a person within the new service that is expecting them can minimise stress and anxiety. The new service can ensure that the named person is there to greet the family and can show them around the new environment and give clear information as to what is going to happen. These are simple ideas that can make a huge difference.

In some professional contexts transition systems operate independently and as discreet services. For example, transition nurse roles exist across numerous disciplines e.g. cystic fibrosis and congenital heart disease. Staff caring for TYA and children should develop local transition policies and pathways in order to support young people moving beyond paediatric and TYA services.



To download the Transition Best Practice Statement, please go to the TYAC website: [www.tyac.org.uk](http://www.tyac.org.uk)





## CHAPTER FOUR: AGE APPROPRIATE CARE

Authors: Sue Morgan, Sam Smith, Suzanne Mooney, Beth McCann

### TREATMENT ENVIRONMENT

Following the implementation of the Children and Young People's Improving Outcomes Guidance (CYPIOG)<sup>1</sup> much work has been undertaken across the UK in developing services for young people with cancer. Teenage Cancer Trust has been pivotal in many of these changes that now see young people being treated in a variety of settings. We know that being cared for in an age appropriate environment such as a Teenage/Young Adult (TYA) cancer Unit has many advantages and benefits<sup>14</sup>. However, this is just one aspect of TYA cancer care, which together with an age-appropriate ethos and model of care can make a positive difference to young people's treatment and care experience. Wherever young people are treated, every step should be taken to ensure that their environment is conducive to experiencing the best care alongside maximising treatment benefit.

Young people should be treated in an environment that promotes age-appropriate care, with as much access to age-appropriate facilities as possible. The development of specialist teenage and young adult cancer units across the UK has made access to such environments easier to achieve. These, alongside expert care and treatment, aim to provide optimum care for young people and their families. The young person may choose, however, to be treated in a hospital that is nearer their home (Designated Hospital [DH]). In such cases, working collaboratively with Principal Treatment Centres (PTC) can be beneficial in helping to ensure that TYA expertise is available alongside expert adult care in the DH. Teams working together and collaboratively in this way can ensure each young person with cancer receives quality age-appropriate care wherever they are treated<sup>85</sup>.

“Teenage Cancer Trust facilities have been incredible since I was diagnosed with leukaemia. Everyone has made my stay much more comfortable and reassuring.”

Reena, 16, Leukaemia

DHs without dedicated facilities should, where possible, encourage the creation of an environment that promotes a sense of familiarity and age appropriateness for the young

patient<sup>99</sup>. This may involve encouraging the young person to bring personal items into the hospital such as pillows, duvets, photographs, games, and laptops, whilst adhering to local infection control policies and restrictions. This can help to promote a sense of normality and helps to keep the young person in touch with their world outside of the hospital<sup>14</sup>.

“Being able to use all these things is great for keeping in touch with family and friends and even better for getting to know other patients.”

Kim, 21, Ewing's Sarcoma

Prior to coming into hospital for the first time it is helpful to provide young people and families with information suggesting examples of items to bring for periods of inpatient care. Consider having fittings in rooms and bays, such as notice boards for cards, mementos and photographs which will help create a more personal space.

The ward should be as flexible as possible in accommodating individual patient and family routines. For example, many specialist units provide space and facilities for patients and their carers to prepare and cook food, encouraging young people to continue to eat and maintain good nutrition whilst in hospital. Where possible this should be encouraged as young people don't always want to eat hospital food, or at the times when it is routinely delivered. Young people like

“Open visiting and having friends or parents there is really important. My mum didn't leave my side as I wanted her there 24/7. I was scared and felt reassured having someone there to comfort me. When I eventually told my friends it was a nice break to have them there and in a way, it relaxed me and gave me a sense of getting back to what I would usually do.”

Nicole, 17, Medulloblastoma

to have access to drinks and snacks at any time, so a ‘snack drawer’ is always a popular commodity. Flexible mealtimes, ward routine and visiting hours also contribute to a more age-appropriate environment<sup>16</sup>.

Many young people gain support from having someone staying with them at particular times<sup>16</sup>. This is common practice in paediatric and teenage and young adult units but not necessarily in adult treatment centres. However, it is recommended that this opportunity be offered to all young people, although some negotiation may be required to facilitate this in some settings. Many young people may not require this form of support but knowing the option is there can be reassuring in itself. If it is not possible for a relative to stay on the ward due to space considerations, other relatives’ accommodation on the hospital site should be sought.

**“I need my parents with me, a bit unsure without them but staff help a lot.”**  
DS, 19, Leukaemia

It is helpful if young people have access to appropriate recreational equipment. This might include music, electronic games, books, television, pool and table tennis tables, computer and internet access, and magazines. It is also important, where possible, for young people and their families to have access to a dedicated space for relaxing away from their bed, where social interaction can take place. A day room in a bespoke Teenage Cancer Trust Unit is often the hub for social interaction and a place where young people can experience some normality away from the medicalisation of their treatment.

**“The best most comfortable ward I have ever stayed on. Prolonged stays are barely an issue due to the relationships that develop with the staff. The environment is not uniform and clinical.”**  
Anon, 20

## RECREATIONAL ACTIVITIES

All Teenage Cancer Trust Units are fortunate to be able to employ Youth Support Co-ordinators. These posts are pivotal in helping the young people maintain some normality, encouraging peer group support and distracting them from the difficult scenarios that they may face day to day on the ward. Where possible, activities should also be organised

away from the hospital setting and an outreach service to those who do not come to the PTC should be developed.

Such recreational activities should be viewed not as secondary to multi-disciplinary treatment but as part of the holistic care for young people (see Chapter 7 for some examples of group activities). These activities have many positive by-products which can promote a young person’s psychological and social well-being through treatment<sup>100</sup>:

- **Promotion of normality**
- **Reduce the sense of being in a hospital setting**
- **Provide enjoyment and distraction**
- **Assist with apathy and depression**
- **Promote social interaction with their peers – therefore enhancing support**
- **Provide a conduit for discussion with family and friends**
- **May encourage visitors thus reducing social isolation**

It is also advisable to review the layout of waiting areas in outpatient departments. The ideal is to have a TYA-specific outpatient department/setting or a specific TYA outpatient session. If this is not possible, then some thought needs to be given to developing the waiting area so that young people are not waiting with young children or with much older people. Where feasible, appropriate entertainment and recreation facilities should be available for young patients and their siblings in the waiting areas.

Young people benefit from having access to the internet. It allows them to stay in touch with friends, which helps to avoid social isolation and loss of contact with this significant support network. However, many considerations need to be given to providing this service. Strict rules should be applied to internet access regarding inappropriate use of certain types of website, e.g. pornography and gambling. Software packages (anti-virus and spy software) should be utilised so that inappropriate websites can be blocked. Information

**“Email/Facebook and Mobile Phones are important for coping. The social aspect allows you to forget about hospital for a bit and maintain friendships.”**  
Josh, 18

technology (IT) departments should be able to assist with these measures. **(For further information on social media and the Internet see Chapter 2)**

It is recognised that the creation of specific environments for teenage and young adult patients in all cancer centres is not always practical or possible. There will be many pressures on hospital beds that limit flexibility in admission planning. However, in planning admissions for care, consideration should be given to the distress and isolation experienced by young people when placed in wards with older patients, whose outlook both clinically and psychosocially is very different. However, we should also be mindful that many young people will be perfectly happy being cared for in an adult setting. It is good practice to ascertain whether the young person is happy to be cared for in a bay alongside older adults, otherwise where possible, providing a side room is advised.

## PRIVACY AND DIGNITY AND SAME SEX ACCOMMODATION

The provision of same-sex accommodation is an important target in the NHS in order to meet the privacy and dignity needs of patients and improve the quality of care. However, delivery can be challenging and may be particularly complex in some specialist areas. It may not always be possible to provide same-sex accommodation on a TYA Unit. The Department of Health have issued the following practice guidance:

***“Teenage and Young Adult Units are required to segregate male and female patients in line with the national drive to deliver same-sex accommodation in hospital. However, in the event that young people cannot be accommodated in a same-sex age-appropriate facility, patients should be offered choice regarding their place of care and may choose between a mixed sex bay in the TYA Unit or same-sex accommodation on an alternative adult ward.”***<sup>101</sup>

## REDUCING TIME IN HOSPITAL

All treating hospitals should actively work to minimise the distress associated with extended inpatient stays. Long hospital stays for young people with cancer are commonplace due to the nature of disease types and treatment regimes in this age group. Prolonged time in hospital can be extremely disruptive to many aspects of life for both the young people and their carers but unfortunately are often unavoidable. Many young people wish to continue

**“I think it is important to get patients out of hospital as soon as possible even if only on day leave, but I think health and common sense come first.”**

Josh, 18

## TOP TIPS

### Same-sex accommodation for young people with cancer

- Decisions should be based on the needs of each individual, not the constraints of the environment.
- Patient preference and consent should be sought, recorded and respected.
- Reasons for mixing gender and steps being taken to revert back to same-sex environments should be explained to patients and families.
- Mixed gender bays should be the exception and not the norm.
- Where mixing of gender is unavoidable, reconfiguration of bed allocation should occur as soon as possible to revert to same-sex accommodation, providing clinical care and individual patient needs are not compromised.
- All teenage and young adult patients within a mixed sex facility must provide consent. This includes the patient being admitted and the existing in-patients.

to attend school or university or just have time at home to socialise ‘normally’ with their peers<sup>14</sup>.

Ways to help reduce the length of time young people spend in hospital include:

- Suggest that the young person rings the ward on the day of their admission to determine the best time to present to the ward and reduce unnecessary waiting times after arrival.

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- Sending texts about treatment times or appointments is helpful, particularly in outpatient areas, so that the young person does not feel they have to sit around waiting.

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- Some young people may wish to negotiate treatment times to fit around school or work or important social occasions. Flexible treatment planning is crucial to support this.

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- Enable the young person to get bloods taken the day before admission to reduce waiting times or unnecessary trips to the hospital when blood counts are low. These can be organised at general practitioner (GP) surgeries or at local hospitals. Results can then be sent to treatment centres to allow treatment to be made and ready for the day the patient attends.

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- Ensure chemotherapy regimens are prescribed and ready prior to admission.

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- Try to organise tests and investigations to occur on the same day to avoid repeated hospital visits over a number of days.

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- Ensure any medication that needs to be taken home on discharge is ordered and ready the day before.

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- It may be that some patients may want to go home in the middle of the night if hydration/treatments are completed at that time. Try and facilitate this where appropriate.

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- Developing shared care arrangements with Designated Hospitals can reduce the impact treatment has on a young person’s life by providing some tests and treatments closer to home.

## SETTING BOUNDARIES

Young people respond well to consistent boundaries - they provide a sense of safety and promote trust. However, for young people this stage of life is all about pushing boundaries

## TOP TIPS

### Treatment Environments

- Provide a ‘home from home’ environment for young people. This can be done by personalisation of the environment affording young people some ‘ownership’ of the space. Allow young people to bring in personal items such as pillows, throws and photographs to individualise their bed area (must be compliant with local infection control and health and safety policy).
- TYA patients should be able to use a mobile phone and laptop whilst in hospital. These are often ‘lifelines’ to peers and family.
- Given the heightened significance of peer and family relationships during adolescence, flexible visiting times should be allowed to enable peer and family visiting, including overnight stays where possible.
- Recognise individual age-related routines and consider adapting usual ward routines making allowances for individual patients e.g. going to bed later, waking later, eating at different times of the day, etc.
- Provide age-appropriate recreational activities e.g. internet access (with appropriate regulations and restrictions), games consoles, pool table.
- Where a dedicated TYA area is not available in an adult or paediatric unit, consider side room accommodation or placing young people with patients of a similar age range.

and this is where much of the challenge in working with the age group emanates from. It is very important that the young person is aware of what is and is not acceptable with regard to behaviour when inside the hospital.

It is useful to establish ‘ground rules’ for your unit, ward or service when caring for young people and their families. Ground rules should be made in partnership with the young people, and should be clear, precise and visible; promoting behavioural boundaries that are appropriate to the hospital or treatment setting. These may be incorporated into local behavioural or operational policies and outline acceptable and unacceptable behaviour, consequences of breaching local policies and address issues such as drug/alcohol use, bullying, theft, vandalism and behaviour towards staff and other patients.

## PROVIDING AGE-APPROPRIATE INFORMATION

All patients should be given written information to support verbal discussions regarding their disease and treatment. In addition, age-appropriate literature should be provided regarding local TYA services, national support networks, treatment and supportive information and services. This

### Box 4.1: Age-appropriate information and resources

#### Main websites for information:

- Teenage Cancer Trust  
support4you@teenagecancertrust.org  
information@teenagecancertrust.org.
- Cancer Research UK
- CLIC Sargent
- Macmillan cancer support
- Marie Curie Cancer Care
- National Institute for Health and Care Excellence (NICE)
- NHS Choices
- Cancer Fund for Children
- Cancer information and support for young people (13-24)
- Brain Tumour Charity
- CCLG - Children's Cancer and Leukaemia Group
- ChildLine
- Child Exploitation and Online Protection (CEOP)
- Citizens Advice Bureau (CAB)
- Climbing Out
- Cruise Bereavement Care (Hope Again, previously RD4U)
- Cyclists Fighting Cancer
- Dreams come True
- Drinkaware
- Ellen MacArthur Cancer Trust
- Government Website (student info and financial info/help)
- Hair4U
- Harley Staples
- Headsmart
- JTV Cancer Support
- Little Princess Trust – provide real hair wigs for teenagers and young adults
- Look Good Feel Better
- Maggie's
- Mummy's Star
- On Target - TYA Help
- Paul's Place
- Rays of Sunshine
- Samaritans
- Smokefree
- Teens Unite
- Trekstock for helping recover fitness post-cancer treatment
- Willow
- Winston's Wish
- Youth Cancer Trust

literature can be given in whatever way is best for the young person i.e. electronic web links/leaflets.

Young people are IT literate and they are likely to attempt to find further information about their disease on the internet (see Chapter 2). Certain information sources can be highly distressing and can be inaccurate. It is therefore important to support them in finding appropriate information, by providing them with websites that are safe, authoritative and appropriate to their age. There are a range of established and recognised age-appropriate resources that have been produced by national charities, the NHS and independent organisations. These should be highlighted to every young person and their carers (Box 4.1).

“Everybody was really helpful offering clear and to the point information.”

Josh, 18

## NON-COMPLIANCE AND ADHERENCE

Non-compliance with treatment plans is often observed in young people<sup>102</sup>. This extends to their attendance at hospital for treatment or clinic appointments. It is not easy to convince a young person of the benefits of adherence to treatment or clinic attendance. It can be hard for them to fit medications into their life and side effects can be disturbing and difficult to manage. Treatment may be resisted for many reasons, including feeling out of control of the situation, not having a full understanding of what is happening, or they may be frightened. Establishing contact via text can be a useful way of encouraging appointment attendance.

## UNDERSTANDING RISK-TAKING AND SUPPORTING DECISION-MAKING

Adolescence and young adulthood is widely recognised as a transitional period in the life-course which involves risk-taking<sup>103</sup>. It is a time of exploration and experimentation, when young people begin the process of disembedding from their family of origin to form their own unique identity and worldviews<sup>104</sup>. Adolescent sexual awareness and physical development quite naturally coincide with sexual exploration as young people discover their sexual identity, often expressed through intimate peer relationships. As they move away from close parental authority and supervision, young people push previously acceptable behaviour boundaries, engaging in activities previously prohibited such as smoking or drinking alcohol, learning through trial and

## TOP TIPS

### Non adherence

- Be knowledgeable about the law and best practice with regard to consent and confidentiality
- Respect the young person's decisions about treatment and self-care. Explain safety issues, give them time to reflect on their decision, reassure, listen and discuss but remember they have a right to self-determination.
- Advocate on the young person's behalf where necessary.
- Be flexible – don't make young people do things just because it is usually done that way e.g. ward routines; allow them control wherever possible, over issues such as when to get up, go to bed and have treatment.
- Take time to explain the benefits of adhering to treatment i.e. related to outcome etc.
- Ensure treatment, where possible, fits around other important aspects of the young person's life.
- Keep the young person informed at all times and ensure they understand the information provided. Helping them to be actively involved in decisions will give them a sense of control over their lives which is important when ill.
- Ensure they have positive relationships with the health professionals involved with their care.
- Encourage young people to express their concerns and foster open communication.
- Promote communication via text for hospital appointments etc.
- Promote follow-up communication with key members of the team should they not attend important appointments

error to moderate new behaviours, including substance use. While some will take only marginal risks for others at this time in their lives, risk-taking becomes part of their behavioural repertoire, with frequent episodes of high-risk behaviour such as binge drinking, illegal drug use, dangerous driving and unprotected sex. At this life stage young people tend to consider themselves 'invincible', often embarking on courses of action with little thought for the personal consequences, unconsciously and naively testing their mortality<sup>105</sup>.

These exploratory behaviours, however, do not take place in a vacuum but rather are considered rites of passage through which young people assert their social status measured by peer acceptance<sup>106</sup>. Episodes of alcohol consumption, for example, are rarely simply events to get intoxicated but, rather, are engaged in as part of accepted social norms and ways of having peer relationships, known to be critical for the young person's emerging identity<sup>104,106</sup>.

### YOUNG PEOPLE WITH CANCER AND RISK TAKING: INCREASED VULNERABILITY

While risk-taking is normal at this life stage when a young person has cancer there are heightened consequences. For example, use of drugs and/or alcohol while undergoing treatment can bring danger and complexity impacting patient safety<sup>107</sup>. Research also indicates that childhood cancer survivors who engage in high-risk behaviours such as smoking and drinking experience life-threatening health outcomes at increased rates compared to healthy peers<sup>108,109</sup>. Lifestyle factors are also known to influence survivors' risk of disease and may further increase the likelihood of adverse late-effects<sup>110,111</sup>.

### CANCER DIAGNOSIS AS OPPORTUNITY FOR HEALTH EDUCATION

Morgan *et al.*<sup>107</sup> use the maxim of 'sex, drugs and rock 'n' roll' as a means to consider normal adolescent developmental risk-taking behaviours in the context of TYA cancer and the challenges they raise for optimal age-appropriate care. Given that a young person's development is not postponed in the event of cancer diagnosis, they argue that TYA practitioners need age-specific expertise to understand these behaviours in the context of adolescence and successfully engage young people to consider their behaviour and make informed decisions. Rather than aiming to curtail young people's risk-taking behaviour, they propose that contact with cancer services should be positively embraced as an opportunity for health education on a range of issues. In this way healthcare professionals can facilitate young people's emerging adulthood, supporting the development of knowledge and skills to allow young people to assert control and agency in their lives, enabling consideration of the cancer experience as a period of growth and development, rather than diminishment<sup>112</sup>.

### RISK-TAKING BEHAVIOUR AND AGE-APPROPRIATE CARE

In order to achieve these ultimate goals, Morgan *et al.*<sup>107</sup> propose a number of key practice principles, including the establishment of open and frank communication with the young person about risk-taking behaviours; professional awareness of their own values and beliefs in relation to these issues; and the importance of ascertaining the young person's priorities.

#### Open and frank communication

Talking about risk-taking behaviours may not be easy for the young person or the professional. These are sensitive

issues the young person may not previously have discussed with anyone and may initially not quite understand their relevance to their cancer diagnosis and treatment. Using validated holistic needs assessment tools (see Chapter 6) can help ensure these important issues are not overlooked but addressed in a sensitive, non-judgemental manner. To discuss risk-taking behaviours it is necessary to create a context of openness where a two-way patient-professional information exchange can take place. To achieve this healthcare professionals need to directly address the issue of confidentiality and its limitations<sup>113</sup>, assuring young people understand why these issues are important for their well-being during and after treatment. They should also clarify where the information they share will be stored and how it will be used. Trusting professional relationships develop over time as key professionals establish and clarify important boundaries early in their contact with young people, working towards open and frank communication from the outset. It is vital to recognise that discussing and providing psycho-education about risk behaviours to young people involves paying close attention to issues of age-appropriate information and safeguarding.

### Professional attitudes and competence

Before conferring about risk-taking behaviours with young people it is essential that practitioners are confident and aware of their own values and beliefs on risk behaviours. Young people sense when a practitioner is hesitant or judgemental and it will inevitably restrict the information exchange. Care should also be taken to avoid assumptions about young people's lives, adopting an attitude of sensitive curiosity towards young people's behaviours, views, hopes and fears. Practitioners do not need to be expert on all aspects of sexual health or substance use but they do need to have the knowledge, confidence and skills to discuss these important areas with young people, access appropriate resources and refer on for specialist advice and services when necessary.

### Young people's priorities

When developing a relationship with young patients to provide optimal care it is essential to understand what is important to each young person, as this will vary. Paying attention to important milestone life events such as 16th, 18th and 21st birthdays, family/friend weddings, exam results, graduation, school formal dances etc. is an important way for professionals to show the young person they are interested in them as a unique individual, not just as a cancer patient. It is known that flexibility in treatment regimens to permit attendance at such important events promotes treatment adherence<sup>107</sup>. Awareness of such key events also provides the opportunity to discuss risk-taking behaviours, such as alcohol consumption, that often accompany milestone events. Although it may be unrealistic for the young person to abstain, facilitating discussion allows for improved understanding of safety issues and informed decision-making which will promote the young person's self-agency, enhance family support as well as consolidate the patient-

professional relationship. Overly controlling or paternalistic relationships with treating teams and parents has been shown to negatively impact treatment adherence<sup>114</sup>.

### SEXUAL BEHAVIOUR AND INFORMATION NEEDS

Sexual development is a central theme of adolescence<sup>115</sup>. During the adolescent years young people consolidate the influences of biological sex, gender identity, sexual attraction, sexual orientation into behaviours and relationships expressed in the context of relationships through complex, fluid and highly nuanced developmental processes. Cancer and its treatment at this stage in the life-course often interrupts and complicates these processes<sup>116</sup> and can lead to psychosexual concerns for the young patient and unmet psychosexual needs<sup>117,118</sup>. These are thought to be more pronounced when diagnosis occurs at a young age<sup>118</sup>, as it may impede TYA identity formation and health related quality of life<sup>119</sup>. These issues are distinct to fertility concerns discussed later in this chapter.

TYA cancer patients may experience physical sexual difficulties such as decreased sexual arousal and satisfaction, influenced by pain, vaginal atrophy and erectile dysfunction<sup>120,121</sup>, as well as psychological and psychosocial difficulties related to sexual health including poor body image, psychological stress and fear of rejection<sup>122</sup>. These difficulties can impede emerging sexual identity, sexual practices and psychosexual development.

It is important for practitioners not to assume that a young person is not sexually active. In the UK, the second National Survey of Sexual Attitudes and Lifestyle<sup>123</sup> found that the average age for first heterosexual intercourse was 16 years for both males and females<sup>124</sup>. Although since reduced, the UK had the highest teenage birth and abortion rate in Western Europe<sup>125</sup>. The third National Survey<sup>123</sup> reported changes in sexual behaviours, with an increase in the number of opposite-sex partners reported and more people reporting same sex experience. Although young people under 25 years continue to experience the highest rates of sexually transmitted infections (STIs)<sup>126</sup>, this age group are the least likely to access contraceptive and sexual health advice, placing them at high risk of unplanned pregnancy and STIs<sup>127</sup>.

Young people in general report needing more information about psychosexual matters including sex, relationships, STIs, and contraception from schools, parents and healthcare professionals<sup>128</sup>. (see Chapter 2 for further information)

### Safe sex during treatment

There is not a strong empirical base of evidence pertaining to any aspect of sexual health in young people with cancer to draw upon. There have been some research studies relating to psychosexual issues in young people with cancer (e.g. Dobinson *et al.*), which, although they raise valid points, fail to address certain specific sexual health information young people with cancer require in order to achieve safe sex practices. This may be a factor contributing to why these

## TOP TIPS

### sexual behaviour

- Condom use should be recommended as many cytotoxic medications can be present in sperm and vaginal fluids and this can cause irritation. Give advice about where condoms can be accessed.
- Oral contraceptives may not be effective due to chemotherapy side-effects e.g. vomiting, diarrhoea.
- Chemotherapy and radiotherapy (dependant on site) can result in foetal defects if given during pregnancy.
- Pregnancy tests should be carried out at the start of treatment as a routine policy even if the young person believes they are not pregnant.
- Foetal defects may occur in pregnancy up to one year after chemotherapy has finished, dependant on what drugs were used. Advice should be tailored according to the risks relevant to each young person's individual treatment regimen.
- Ensure discussions around contraception occur at appropriate points throughout treatment, not just the beginning or end.

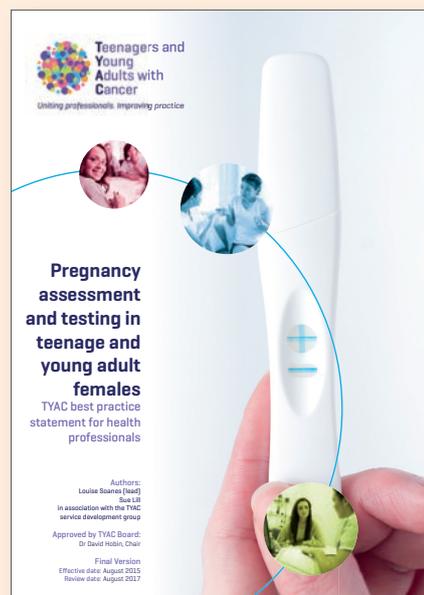
issues are often neglected by healthcare professionals in everyday practice. Young people may not consider their sex life could be affected by cancer treatment, either emotionally or physically, or that some treatments can pose short-term risks to sexual partners, as well as longer-term risks to children conceived during or for a period after treatment<sup>129</sup>. It is therefore imperative that TYA teams discuss these issues with young people at the beginning of treatment.

Some of the salient factors that are not discussed within the literature but are essential for young people to know about while receiving cancer treatment include the risk factors associated with anal and oral sex and advice regarding whether it is safe to have anal or oral sex. It would appear that there is no evidence at all in recommending platelet and neutrophil thresholds for anal sex. It has been established that the TYA population are more likely to have neutropenic septic deaths than any other age group<sup>130</sup>. There is no current evidence to guide healthcare professionals with regard to a platelet threshold for anal sex and therefore it is essential to discuss potential risks with young people. Clear guidance should also be offered on the safety implications regarding oral sex when chemotherapy is present in bodily fluids.

Laurence *et al.*'s<sup>129</sup> outline of sexual health advice is useful to consider when working with young people with cancer.

### Sexual health information needs of young people with cancer

While sexual relationships are essentially private matters, good sexual health is important for individuals and



To download the Best Practice Statement Pregnancy testing, please go to the TYAC website: [www.tyac.org.uk](http://www.tyac.org.uk)

society<sup>131</sup>. Sexual health covers advice and services around contraception, relationships, STIs and termination of pregnancy (abortion). Addressing the sexual health information needs of TYAs with cancer appears inadequately explored in research and within published literature in general. There is also, in general, an absence of written information for young people on issues pertaining to sexual health whilst experiencing cancer treatment.

Healthcare professionals' reluctance to discuss young people's sexual health alongside typical TYA risk-taking behaviours may pose significant health risks. Best practice guidelines suggest that healthcare professionals must strive to provide specialist care and have a clear understanding of the specific needs of this age group<sup>59</sup>, yet supporting teenage and young adult patients as they cope with issues relating to sexual health can be an immense challenge for many professionals. Nevertheless, if these young people are to have a chance of functioning effectively, practitioners must continue to find ways to seek out support and guidance, confront barriers, implement successful interventions and ultimately find ways to engage with this sensitive but crucial problem (see Canada & Schover<sup>132</sup>; Vadaparampil *et al.*<sup>122</sup>; Kelly<sup>133</sup> for some useful examples).

### ALCOHOL AND SUBSTANCE USE

Adolescence is the time when young people are more likely to take risks and seek new sensations which may lead to use of substances such as alcohol and other drugs<sup>134</sup>. By far the most common substance consumed by teenagers and young adults is alcohol. While national surveys point to an overall decline in alcohol consumption by 16-24 year olds between 2005 and 2014, when young adults drink they remain the most likely of any age group to consume more than the weekly recommended amount in one day. Men are more likely to drink alcohol and in higher amounts<sup>135</sup>. Reasons for engaging in alcohol use in the teenage years include pressures to maintain status with peers, to be part of social rituals and to increase confidence/mask self-consciousness<sup>136</sup>.<sup>137</sup> Alcohol consumption has also been linked to an 'expanding consumerist alcohol culture'<sup>136</sup>.

Although there is a steady decline in the incidence of smoking tobacco by young people since UK data was first collected in 1996, smoking is known to be a significant complicating health factor across the life-course<sup>138</sup>, which also impacts cancer treatment<sup>139</sup>. Likelihood of smoking increases with age, with girls and young women more likely to smoke than boys or young men, although boys and young men smoked more cigarettes a week<sup>137</sup>. Recent research with young adult survivors of childhood cancer highlights concerning levels of daily smoking<sup>109</sup>.

In a recent Government sponsored survey for England and Wales around 1 in 5 (19.4%) 16-24 year olds are reported to have used illicit drugs in the last year (cannabis, ecstasy, powder cocaine), more than double any other age group<sup>140</sup>. Ecstasy use in the young adult population had increased

from 3.9% to 5.4% in annual surveys. The proportion of young adults in 2014/15 classed as frequent drug users (5.1%) was over twice the overall adult population surveyed (16-59 years). Use of new psychoactive substances (NPS) was also concentrated in the young adult population (16-24 years), in particular young men. NPS refers to newly available drugs which mimic the effects of illicit drugs such as cannabis or ecstasy, which may or may not be illegal to buy and are often referred to as 'legal highs'. NPS use was more likely among those who had also used illicit drugs in the last year, and consumed alcohol or attended a pub or nightclub in the past month<sup>140</sup>.

Reasons for using substances vary, with social, economic and cultural factors playing a part in their initiation and maintenance in young people's behaviour<sup>141</sup>. Whatever the reason, the statistics above confirm that alcohol, smoking and drug exploration remain relatively common in this age group, particularly young men and those who are socialising with peers. These factors require careful consideration when working with young people in a cancer setting given their vulnerable health status, during and following treatment.

### PROMOTING RISK REDUCTION AND OVERALL WELL-BEING

Central to addressing these important issues in ways that promote risk reduction, informed decision-making and enhanced overall well-being is taking opportunities to have open and frank conversations with young patients throughout the treatment trajectory that do not criticise or blame. Practitioners must have the knowledge and skills to speak of these issues in matter-of-fact ways that clearly explain their relevance to the young person's clinical care and foster a non-judgemental environment for sharing information about any inherent risks. They must be aware of their own beliefs and values in relation to substance use and be clear about confidentiality, its limitations and how the information will be used.

It is likely that the young person has not shared this information with parents or family, so these matters warrant sensitive and respectful negotiation in the best interests of the young patient. Practitioners must also understand the vital importance of peer support and acceptance for young people with cancer and be realistic about the role of substance use when with peers, particularly when treatment extends over years. Finding ways to ascertain and attend to the young person's interests and priorities and allow them to make supported and informed decisions is pivotal to effective intervention. Practitioners should have readily available access to written resources and know when and how to refer for specialist drugs and alcohol services. While adequate screening for risk behaviours during treatment and in follow-up care is therefore recommended<sup>109,142</sup>, to be effective, this must be achieved in partnership with the young person.

## TOP TIPS

### for talking about risk behaviours

- It is helpful to think about the young person's engagement with cancer services as an opportunity to provide essential health education on a range of risk behaviours.
- Explain to young people how risk behaviours are relevant to their health and clinical care.
- Be clear about confidentiality, its limitations and how you will store and use the information shared.
- Think about your own beliefs, attitudes, skills and experience towards facilitating psycho-education for young people regarding risk behaviours.
- Consider personal and professional development learning gaps, strengths and prejudices in supervision. This aspect of work is not for everyone and it is advised this should only be undertaken by staff with the requisite specialist skills and knowledge. Draw on the expertise and support of colleagues.
- Do not assume that young people are not engaging in risk behaviours.
- Use a validated holistic needs assessment to ensure important issues are not overlooked.
- Ask questions in a straight-forward manner that allow young people to talk openly about areas of their life they may not have spoken about before.
- Find out about the young person's priorities and concerns, which may help to understand their behaviours.
- Where possible, be flexible when planning treatment and take into account young people's priorities.
- Work together with the young person to reduce risk, inform decision-making and enhance overall well-being.
- Build a resource of age-appropriate written resources.
- Consult on any emerging concerns or dilemmas and know how to refer for specialist services when required.
- Regularly revisit these issues throughout the treatment trajectory and into follow-up

## FERTILITY PRESERVATION

Reproductive health is consistently ranked by young people with cancer as one of the most important issues following treatment<sup>143</sup>. Most young people expect to be able to conceive children naturally in the future and infertility can be a devastating consequence of treatment, which has a negative impact on their quality of life<sup>144</sup>. It is well recognised that chemotherapy, radiotherapy and some surgical procedures can adversely affect fertility. Several factors determine whether a young person's fertility will be affected, including their diagnosis, specific type and dosage of treatment, location of tumour and stage of sexual maturity. Fertility is impacted either by a direct effect on the gonad or by compromised gonadal function via a harmful effect to another endocrine organ, such as the pituitary<sup>145</sup>.

Discussion and effective management of potential reproductive health sequelae are challenging components of care for the multi-disciplinary team<sup>146, 147</sup> as members may not feel prepared to provide young people with sensitive and accurate information about the potential risk of impaired fertility in a clear, timely and age-appropriate manner. Limited options for fertility preservation, coupled with vague policy recommendations, can give rise to variations in information-sharing between healthcare professionals and young patients, particularly as it involves sensitive discussions regarding the short and long-term effects of cancer and treatments on fertility and reproduction<sup>147</sup>.

Interventions to preserve fertility must occur quickly before treatment begins. However, the young person may have only just learned of their cancer diagnosis and may still be reeling from the shock, which makes informed decision-making particularly difficult.

Anecdotal evidence suggests that practice regarding fertility discussion at the beginning of treatment varies across the UK. Younger adolescents may find it difficult to understand the importance of fertility discussions and may be unable to envisage how this may impact on their future many years later. It can help if the young person is supported by healthcare professionals who are experienced in discussing fertility issues with young people e.g. experienced TYA nursing staff or Clinical Nurse Specialists.

While parents can be a source of support, helping the young person assimilate the information, on occasion parental protection can also create communication challenges. It is usual for parents to want to shield their children from distress and, depending on the age of the young person, parents may attempt to manage and withhold certain aspects of information, including that of fertility<sup>146, 148, 149</sup>. This can create conflict for healthcare professionals which can be exacerbated by cultural or religious differences. It is important to discuss these issues clearly and with sensitivity with the young person directly and with significant others or family members when present (with consent from the

young person). Discussions specifically around how to sperm bank, including masturbation, may be more effective without parents present.

Teams treating young people should have access to specialised reproductive and fertility expertise that can provide newly-diagnosed patients with access to the full range of information to make informed decisions regarding fertility issues. Services and referral pathways for fertility advice and preservation vary between centres and teams should therefore establish what is available and how the process is managed locally. Wright *et al*<sup>147</sup> conclude that tailor-made culturally sensitive information should be shared with each young person. This should consist of:

- **Honest and open discussions with all patients, including those where risk of infertility is high and preservation chances unlikely and those where infertility is unlikely**  
.....
- **The option for young people to speak to their clinician either in private, or with their parents**  
.....
- **A written summary of the discussion**  
.....
- **An opportunity to reassess their fertility as standard**  
.....
- **End of treatment advice about contraception and any pregnancy risks**  
.....
- **Reinforcement that infertility might only be temporary.**

## MALE PATIENTS

Sperm production is primarily compromised because the seminiferous epithelium becomes damaged and the population of stem cells that normally differentiate to produce sperm post-puberty either become depleted or are unable to differentiate after treatment has finished<sup>150</sup>. Semen cryopreservation is the only widely available method for the preservation of fertility in males and is relatively inexpensive. Although a simple and successful fertility preservation strategy<sup>151</sup> the technique is not proven in pre-pubescent males<sup>152</sup>.

Semen cryopreservation should be offered routinely to all sexually mature adolescent males at risk of infertility impairment<sup>153</sup>. Semen samples, obtained through masturbation, are frozen and stored for their future use in reproduction. Although there is no physical danger or risk associated in producing the sample, the emotional toll can be high<sup>154</sup>.

There is a wealth of literature pertaining to fertility in young people with cancer. However, the focus tends to be on practices, experiences and outcome, rather than the emotional difficulty, including the difficulty staff have in discussing the issue frankly. Effective promotion of sperm banking requires excellent communication between experienced staff and the young person and sometimes their chosen family members. Simplifying verbal and written information on a case by case basis and ensuring it does not devalue the young person's level of intelligence is paramount<sup>155</sup>.

Staff should pay particular attention to younger teenage patients who may not fully understand or appreciate the



importance of fertility issues and how this may affect them much later in life. When discussing fertility options and preservation with young patients staff must facilitate long-term thinking to assist them consider the implications that their decision will have in later life. Sperm banking is most often carried out in a specialist fertility clinic or hospital. Some young people, however, may be too unwell to travel and teams should enable them to provide a semen sample in the ward environment with appropriate transfer to the specialist centre.

Sperm banking for young men can sometimes be a difficult and embarrassing process. Sperm banking often takes place in a very clinical environment early in the treatment journey and often when patients may be feeling unwell and particularly anxious. Young people should be encouraged to make use of suitable visual aids according to their sexual orientation and, if appropriate, partners should be accommodated. Cultural and religious rules or expectations around masturbation should also be explored before sperm banking is arranged to avoid causing offence or embarrassment.

It is also important that staff counsel male patients appropriately and ensure they have realistic expectations with regard to sperm banking. Age-appropriate written information should be developed and utilised in all cancer units caring for young people. This information should include simple terms, be descriptive and to the point. Nothing should be presumed, including that the young person knows how to masturbate, which may need to be explained in detail.

Patients may wish to sperm bank but fail for a number of reasons. Young males may be propelled into a level of sexual knowledge for which they are unprepared and ill equipped to process. For example, a 13-year-old boy who may not yet have started to masturbate could be confronted with the decision to sperm bank having only just been told that he has cancer. Furthermore, when completing consent for semen cryopreservation, the young person is required to consider posthumous use of sperm. Mortality is a difficult and potentially distressing topic to broach at diagnosis as this may be the first time that the young person has been faced with the life-threatening potential of their disease.

These issues can be barriers to effective semen cryopreservation. Failure to achieve semen cryopreservation can lead to feelings of failure and inadequacy and it must be reinforced from the outset that not all sperm banking is successful. Unfortunately, the precise effects on fertility in any one individual are often difficult to predict.

#### **FEMALE PATIENTS**

From around birth, females have approximately 400 eggs of which they release one single gamete (egg) from the onset of puberty, every month throughout their reproductive life, to the time of the menopause. This continues through contraceptive use and pregnancy. The main effect of chemotherapy and radiotherapy on the female reproductive system is a reduction in the size of the follicle pool which can lead to early menopause<sup>145</sup>. Amenorrhoea is common after cancer treatment and can be transient, permanent,



acute or chronic<sup>156</sup>. Although menses are often used as a parameter of fertility within oncology literature, this is not a reliable measure as it is possible for a woman who does not menstruate to become pregnant, while some women with regular menstruation may not be able to reproduce<sup>156</sup>.

As the fertility preservation options are currently so limited in female patients, appropriate and timely discussion is of vital importance. Staff must ensure that patients are provided with sufficient information and fertility is sensitively discussed from the outset.

At present there are no proven and consistent methods of protecting ovarian function from chemotherapy or radiotherapy and there are currently no treatments offered in the NHS for pre-pubescent females<sup>152</sup>. Oocyte (egg) or embryo cryopreservation is the standard care that should be offered to young women prior to commencement of therapy where possible<sup>153</sup>. However, they need to be well enough to undergo ovarian stimulation and care must be taken to ensure that this

will not worsen their condition. Time is a major limiting factor as the need to commence treatment usually supersedes the ability to undergo treatment for oocyte or embryo storage. This process is time-consuming and involves hormonal stimulation, oocyte retrieval followed by either oocyte cryopreservation or *in vitro* fertilization (IVF) after which the embryo is cryopreserved. IVF necessitates using a sperm donor. This can be a difficult decision even if the young person is in a stable relationship.

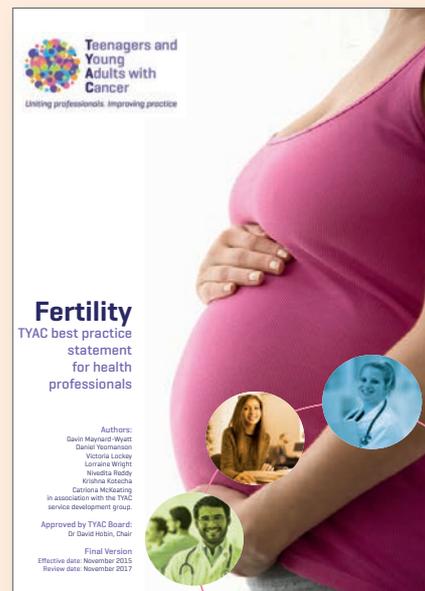
Technologies are being utilised to remove ovarian tissue, which contains immature oocytes, and to cryopreserve cortical tissue strips, as well as removal of individual follicles prior to the commencement of treatment<sup>157, 158</sup>. Cortical tissue strips can be implanted after completion of treatment in an attempt to restore ovarian function. Although these methods have resulted in a small number of live births, their efficacy has, however, not been proven<sup>159</sup>.

Young females describe feeling dissatisfied with the information they are given by healthcare professionals with regard to fertility preservation<sup>160</sup>. This may be due in part to the lack of options available but also may reflect a lack of knowledge amongst healthcare professionals. Sadly, the treatment options in fertility preservation for females remain limited. There is much to learn and further advances are required if we are to optimally secure the reproductive futures of cancer survivors<sup>145</sup>.

## TOP TIPS

### for fertility preservation

- Fertility preservation is a complex sub-specialty of cancer care. It is important that young people understand the changes that happen to them as they mature, and the impact that treatment may have on their fertility.
- Always tell the truth and use words at a level they can understand.
- Information should be given to every young patient, regardless of whether the risk of infertility is high or low.
- Check understanding by asking the young person to repeat to you what they have heard.
- Young people should have the option to speak with a clinician privately or with a trusted support person/parent
- Provide a written summary of the discussion
- Make sure there are opportunities to reassess fertility as standard
- Provide clear advice about contraception and any pregnancy risks when treatment is complete
- If you don't feel you have the expertise to lead a discussion about sperm banking or fertility preservation liaise with your TYA Cancer Lead Nurse.



To download the Best Practice Statement Fertility, please go to the TYAC website: [www.tyac.org.uk](http://www.tyac.org.uk)



TEENAGE  
CANCER  
TRUST  
JAMIE CARROLL

TEENAGE  
CANCER  
TRUST  
NURSE

TEENAGE  
CANCER  
TRUST

# CHAPTER FIVE: STAFFING CONSIDERATIONS

Authors: Maria Cable

## WORKFORCE NEEDS

NHS workforce planning aims to ensure that it has the right number of staff, with the right skills, values and behaviours to deliver high quality care. These same objectives need to be taken into account when considering the teenage/young adult (TYA) cancer care workforce. What is important is that workforce planning is carried out in a systematic and evidence-based way that considers the needs of current and future workforces, particularly as TYA cancer care services develop and change. This process should take account of the specialist needs of young cancer patients, families, peers and the roles of those within the wider multi-disciplinary team (MDT) within healthcare systems, which may vary across nations.

In the UK it is noteworthy the significant contribution the voluntary sector has made in terms of identification of the need for specialist services and roles and subsequent funding. Examples include the funding of specialist units by Teenage Cancer Trust and the appointment and funding of a variety of professional roles, such as Nurse Consultants, Clinical Nurse Specialists (CNS), Youth Support Workers (YSW) and medical staff. Other examples include CLIC Sargent who provides funding for social work positions in TYA cancer care and Macmillan who fund late-effects and other site-specific Nurse Specialists.

## CONTINUOUS PROFESSIONAL DEVELOPMENT

It is widely acknowledged that young people with cancer benefit from the expertise of both site-specific MDTs and TYA MDTs<sup>17</sup>. Given the relatively recent emergence of the specialism and the small numbers of young people with cancer diagnosed annually across the UK, it is unrealistic to expect undergraduate health professions' curricula to raise these issues in detail in their programmes. Continuous Professional Development (CPD) specific to TYA cancer care tends to occur beyond registration. This can take many forms of delivery such as 'on the job' training, attendance at study days, conferences and formal academic accredited courses and modules such as those developed by Coventry University which are delivered online or in blended learning formats. As specialist teams and services emerge managers need to be mindful of having a flexible workforce that is knowledgeable of the specific needs of young people with cancer, which is also supported to develop as practitioners within their own professional disciplines.

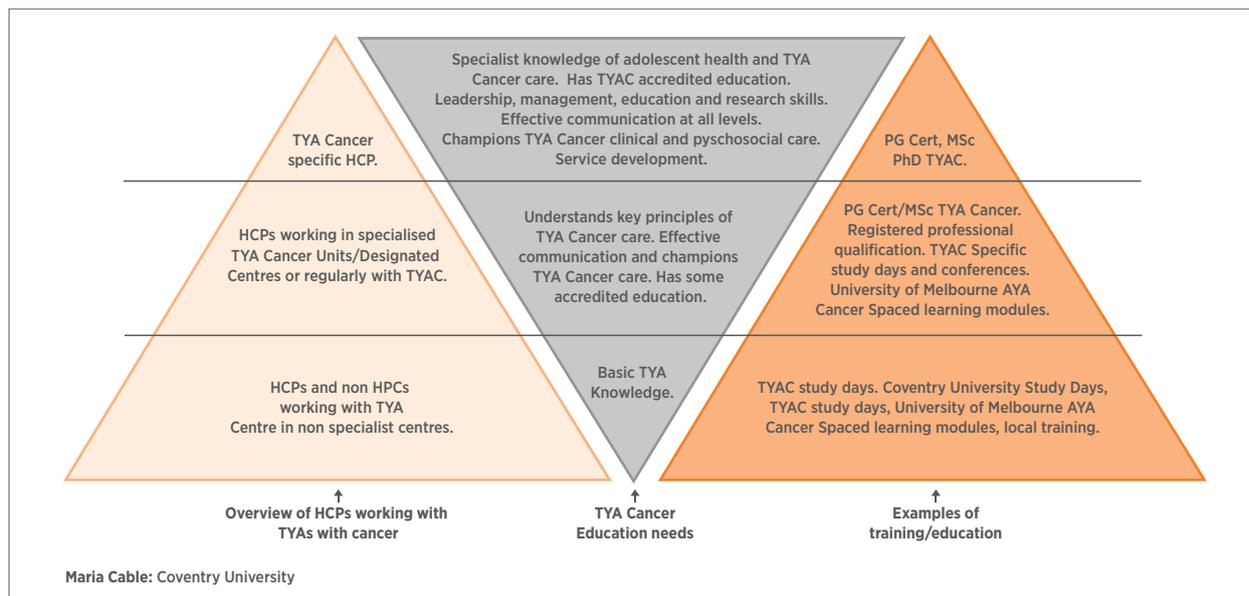
As TYA cancer care continues to evolve as a specialism so too do the number of specific professional roles. Accordingly, a range of education approaches are required to foster a workforce that is skilled, knowledgeable and competent in meeting the needs of young people with cancer in whatever role or service they find themselves. While there will be generic learning needs, the professional development needs of a Social Worker in a designated unit will vary to those of a TYA CNS or a Radiographer, which can be met by the growing number of accredited and non-accredited learning events and opportunities available in the UK. The value of practice experience shadowing experts in the field is also not to be underestimated.

A Nursing Competence and Career framework, developed by Teenage Cancer Trust and endorsed by Royal College of Nursing<sup>161</sup>, sets out a series of competencies for a range of nurses working in various settings. Many of these competencies are transferable beyond the nursing profession and could act as a foundation for multi-professional teams to review and refine their own professional frameworks. Taylor *et al.*<sup>162</sup> defined healthcare professional competencies for working with teenagers and young adults with cancer which relate to skills, knowledge, attitudes and communication. This work reports what differing professional groups identify as important, with the key themes focussing on being able to:

1	work in partnership with young people;
2	listen to the concerns of young people;
3	identify the impact of disease on a young person's life;
4	know how to provide age-appropriate care.

As there are recognised benefits of multi-professional or inter-professional education (IPE) as to improved health outcomes<sup>163</sup> and greater collaborative working and learning<sup>164</sup>, it seems fitting that there is much to be learned with, from and about each other<sup>165</sup> in TYA cancer care. Due to the broad range of professionals who come into contact with this patient group, their education and training needs will inevitably differ, with those who work solely with young people with cancer requiring an in-depth understanding of the issues, whereas those with less frequent contact will require a more basic understanding of the key components

**Figure 5.1:** Education for Health Care Professionals working with TYA with Cancer



of TYA cancer care. Service managers therefore need to acknowledge the levels of knowledge required across the whole of the healthcare team. This could include ancillary staff in specialist areas who often come into contact with young people with cancer too. Trying to determine the training needs of staff working within TYA cancer care is something that will be decided at local level. Suggestions for education and training for varying types of staff dependant on their contact with young people with cancer are made in **Figure 5.1**.

### Essence of TYA Cancer Education

Central to all TYA education and training are the following key principles:

1	Understanding adolescent development from bio-psychosocial perspectives
2	Understanding the main cancer types that affect young people and their treatments
3	Understanding what constitutes age-appropriate care and the role of the multi-professional team and wider services in delivering care
4	Understanding the importance of assessing the individual young person in the context of their adolescent development, cancer and its treatments.
5	Recognising specific factors pertinent to TYA cancer care, such as access to clinical trials, delays in diagnosis, communicating with young people and their families, impact of cancer on young people's development, education, employment and relationships, TYA late-effects, palliative care, end of life care and the various transitions they face.
6	Recognising professional practice matters in regard of staff support, professional boundaries, communication skills, legal and ethical issues.

## LEARNING OPPORTUNITIES

Box 5.1 summarises organisations who provide TYA specific education and learning opportunities.

### Box 5.1: Organisations providing TYA specific education and learning opportunities.

- **Coventry University** in partnership with Teenage Cancer Trust offer a range of accredited and non-accredited programmes of study ranging from an online Post Graduate Certificate in Teenage/Young Adult Cancer Care to tailor made study days. Teenage Cancer Trust can offer some financial assistance to cover course fees for UK students.  
**For further information visit** [www.coventry.ac.uk/teenagecancercourses](http://www.coventry.ac.uk/teenagecancercourses).
- **TYAC** a membership organisation that brings together professionals caring for Teenagers/Young Adults with Cancer which provides TYA cancer specific information and creates learning and networking opportunities. TYAC host their own TYA Cancer specific study days and signpost to other relevant learning opportunities.  
**For further information visit** [www.tyac.org.uk](http://www.tyac.org.uk)
- **Teenage Cancer Trust** care committed to the professional development of staff working with teenagers and young adults with cancer and offer a range of development opportunities such as nursing leadership scholarships, partnering with Coventry University for accredited and non-accredited programmes, organising international conferences, developing a series of competence documents for professionals.  
**For further information visit** [www.teenagecancertrust.org.uk](http://www.teenagecancertrust.org.uk)
- The **Centre for Adolescent Health, University of Melbourne** offers two free online learning modules in adolescent cancer. Cancer Care for Adolescents and Young Adults Part I and II are aimed at clinical and non-clinical professionals working with young people with cancer, or anyone with a professional interest in the field.  
**For further information visit** <http://cah.qstream.com>

## SPENDING TIME WITH YOUNG PEOPLE

Staff spending time with patients is particularly important to this age group<sup>72</sup>. Young people appreciate time to have procedures explained and to discuss treatment. They may wish to discuss intimate feelings with staff, share anxieties or simply chat about everyday matters. Whatever the nature of the conversation, research shows that young people value staff spending time with them and have negative experiences and memories of hospital when staff do not devote this time<sup>16</sup>.

Tailoring care to meet the unique needs and interests of individual young people and their families as they progress along their particular illness trajectory requires careful

“All the unit staff are simply amazing people and will do everything they can to help any situation. Staff are always smiling and positive. Without the staff I would never have found my career in nursing.”

Kim, 21, Ewing's Sarcoma

consideration and on-going exploration and negotiation. Young people may at some point want time alone to talk to healthcare professionals and this opportunity should be provided but, equally, some may always want a parent or carer present. It may be difficult to negotiate this one-to-one time but not finding the opportunity can affect and influence the quality of conversations<sup>166-168</sup>.

Where possible, this private time with staff should be negotiated with family members. Equally, family members should have their own needs met by treating teams and the support of a good team will help facilitate this. There may be times, however, when young people wish to be 'quiet' and may simply want time alone, so this should also be recognised and respected.

“Staff treat us equally to adults and assist us when necessary.”

Edward, 16

## COMMUNICATION AND THERAPEUTIC RELATIONSHIPS

All staff working with young people with cancer, their families and significant others including peers, need to be mindful of the significance of these relationships to the young person

from the outset of the cancer journey. The development of a successful therapeutic relationship with patients and families through effective communication poses some of the greatest professional challenges in TYA cancer care and, if successful, some of the greatest accomplishments.

Challenges may include the young person:

- Not sharing the same views as the clinician about treatment and/or care plans.
- Finding it difficult to understand medical terms.
- Not sharing the same communication style as their treating professional<sup>169</sup>.
- Struggling to cope emotionally with the impact of illness and treatment.
- Misinterpreting the professional relationship with the healthcare provider as one of a 'friend'.

“I prefer communication to be directed at me and my parents because it keeps us both informed.”

Josh, 18

Central to any communication is that the young person feels that they have been consulted and involved in the process<sup>170</sup>. Establishing direct communication with each young person on an individual basis is vital, ensuring appropriate sensitivity to their needs and preferences<sup>107</sup>.

Promoting treatment adherence is an extremely important part of the healthcare provider-patient relationship, which can significantly impact clinical outcomes. It is recognized as a complex, multi-faceted process, perhaps all the more so during adolescence and young adulthood, which demands further investigation<sup>171</sup>. What is evident, however, is that an individual approach is required, with patient choice and involvement noted as key. It is important, therefore, that decisions are reached in partnership with the young person, in discussion with their parents or other significant support people (see **Chapter 4 for more information on adherence**).

TYA have different information needs than younger children, as they have greater capacity to assimilate information about their cancer and its treatment<sup>172, 173</sup>. Decker *et al.*<sup>173</sup> noted that young adults need on-going informational support as they work through the experience and adjust to the diagnosis of cancer. Providing clear information allows the young person and their carers to contribute to the

“I have had a lot of bad news. I feel it's best to be upfront, it makes me sad but you have to sort it out.”

Daniel, 23, Sarcoma

management of their illness and make the best decisions for their on-going health<sup>171</sup>.

Due cognisance and diligence is required when communicating about sensitive, ethical and legal issues, such as consent for treatment, sharing confidential information and safeguarding matters. At times, young people may wish to 'protect' parents from emotional burdens and may not disclose certain feelings, concerns or information when parents are present. Parental protection is also a factor that can create communication challenges. This stems from the instinctive reaction to protect their child and can on occasion complicate healthcare professionals' communication with the young person and their family<sup>174</sup>. Recognising and responding to verbal and non-verbal cues and being able to explore with the young person and their family the meanings of attitudes and behaviours is a key element of effective communication with this age group. It is essential for staff to be able to communicate effectively with young people about sensitive issues, while remaining welcoming and inclusive of important family members. Obtaining young people's permission to share information with family members should always be established. In Wright *et al's* study<sup>147</sup> in relation to fertility information needs, Harry, aged 16 years is quoted as saying:

“They didn't talk to me about it, they talked to my mum about it. That was quite awkward!”

Harry, 16

Young people may be uncommunicative at times, may not ask questions or may not wish to be given too much, or any, information. However, this should not be interpreted as a lack of interest. The depth of information and discussion with young people must be sensitively negotiated by the healthcare professional with the young person, in consultation with the young person's key supportive relationships. The important issue is to consult young people regarding all aspects of care and to seek to understand verbal and non-verbal cues in order to ensure accurate interpretation of situations and behaviours. It is always wise to discuss your interpretations with the young person to avoid making unfounded assumptions about

their wishes. It is therefore imperative that health and social care professionals working with this patient group possess well developed or advanced communication skills.

The wish to be alone or accompanied during consultations is likely to vary between individuals according to age, personality, family relationships, health status and stage of illness and treatment. It is recommended that the young person is offered the opportunity to speak with the healthcare team alone<sup>167, 168</sup>. Offering to meet with the young person alone provides them with a forum in which to address any issues that they do not feel comfortable discussing in company.

The above has in part been adapted from the Royal College of Nursing's guide for working with young people<sup>175</sup> and 17 year old Jessica Platt<sup>176</sup>, treated for pneumonia in hospital, who wrote a set of useful tips on how to communicate with teenagers.

### CONFIDENTIALITY AND ITS LIMITATIONS

Central to all aspects of care for young people with cancer is respecting confidentiality<sup>113</sup>. Confidentiality between young people and their healthcare professionals forms the basis and maintenance of trusting and collaborative relationships<sup>175</sup>, never more so than when discussing sensitive issues such as sexuality, risk-taking behaviours and mental health issues. Ford *et al.*<sup>177</sup> advise that assurance of confidentiality increases the adolescent's willingness to disclose sensitive topics. Only in particular situations e.g. where concerns about the health, safety or welfare of the patient, or others, outweighs the right to privacy, should confidentiality be breached. White and Viner<sup>168</sup> advise using conditional



## TOP TIPS

### for communicating with young people

- Ensure that the young person knows that they can have a trusted adult with them at the time of a discussion or consultation, or they can consult with healthcare professionals by themselves. Ask the young person first; it is their choice.
- Assure the confidential nature of their consultations but also make it clear to the young person the occasions when information may have to be shared and why.
- Should the young person choose to meet with healthcare professionals alone, check out what help they need, if any, in relaying information to family members.
- Young people need professionals who they can trust, as opposed to being their friend.
- Honesty and openness are central to all communication.
- Do not claim to be an expert or have all the answers, use the wider multi- professional team.
- Be positive and non-judgemental - empathise with the young person and demonstrate your efforts to understand their situation and feelings.
- Use a style and manner that is appropriate for that individual – it is OK to use humour where appropriate.
- Allow adequate time for discussion, summarise and offer to revisit issues or repeat information.
- Be aware of how age and cognitive development impacts a person's understanding and communication ability.
- Before providing any additional information, ensure that you ascertain the level of information that the young person is seeking.
- Actively encourage questions and suggest that they write down any that they may have.
- Encourage and allow the young person to express and label their feelings (e.g. crying, or talking about concerns, fears, anger and anxieties).
- Respect that young people may not always want information or to talk; allow them the space and time to process the information at their pace.
- Reassure young people that if a meeting or conversation has to be stopped or is interrupted, you will revisit them.
- Reliability and consistency is vital when working with young people.

confidentiality, where they advocate that it is important that staff give clear indications of when confidentiality might be breached, with whom and for what reasons. By doing this, healthcare professionals will be empowering the young person to decide what to disclose. When wishing to share information with others it is always good practice to discuss this with the young person and seek their consent where possible. Carefully exploring with the young person any fears they might have about certain information being shared with another party is crucially important. These conversations can help determine the most appropriate course of action, providing on-going support for the information-sharing process, addressing real concerns and allaying any unfounded fears.

### USING TECHNOLOGY AS A COMMUNICATION TOOL

Technology is increasingly used in communicating with young people, whether it is to advertise events or as a means to communicate with key health professionals on health or clinical related matters. As the use of social networking sites (e.g. Facebook, Twitter, Instagram) is an inherent part of youth culture some clinical areas are increasingly using social media sites such as Facebook to set up a page to promote activities and support groups. Staff use of social networking sites to communicate with and between young patients is increasingly common. It is important that clear information is provided to patients about the purpose of such sites and that this should not be confused with promoting social interaction that may infringe professional boundaries. Before setting up

social media sites as a communication/support tool for young people careful consideration must be given to key elements such as:

- **how to ensure the well-being of the young people using the site;**
- **the purpose of the social media site;**
- **management of online conduct of staff and patients, which will require moderation with clear processes for raising concerns;**
- **how professionals should present themselves online;**
- **clarity with regard to professional responsibility to represent their organisation online.**

Further guidance is available online through various professional regulatory bodies such as Nursing and Midwifery Council, General Medical Council, and the Health Professions Council (see **Chapter 2 for more information on social media and connectivity**).

The balance between healthcare communication, social communication and personal communication must be carefully negotiated. It is strongly advised that all staff working with young people should not share personal information unless it is directly associated with treatment or organised activities via text, email or internet sites, nor enter into any form of ‘everyday’ social conversation. Social networking sites can be useful and do have a place in TYA cancer care but must be carefully monitored for appropriate use amongst both staff and patients to ensure professional boundaries are not blurred. There should be clear expectations set by clinical managers and other senior staff regarding the maintenance of appropriate boundaries and members of staff should feel able to seek support and advice from senior colleagues if they feel unsure about any specific situation.

## PROFESSIONAL BOUNDARIES

Gutheil and Simon<sup>178</sup> define a professional boundary as the edge of appropriate or professional behaviour, transgression of which involves the therapist stepping out of the clinical role. These boundaries are the defining lines that help protect the patient and the professional who cares for them, irrespective of whether they are a registered health or social care professional. As in all aspects of developing therapeutic relationships staff may find that they run the risk of overstepping what is an acceptable boundary. These non-visible boundaries can relate to the workplace, professional and/or interpersonal boundaries. Staff must ensure that working relationships are not misunderstood by young people or confused with friendship or other personal

relationships. It is particularly important to remember that professional relationships must also comply with legal frameworks around safeguarding children and young people.

All professionals working with young people have the potential to cross boundaries. However, there are a number of risk factors that appear to increase the likelihood within TYA cancer care<sup>179</sup>:

- **The informal nature of the TYA hospital setting.**
- **Length and intensity of treatment and patient/professional interaction.**
- **Patient group vulnerability (age, development, fear, dependence).**
- **Use of modern technology for communication channels (text/email/social media).**
- **Relaxed communications style with young people.**
- **The emotional demands of caring for this patient group.**

Managing relationships with young people can be challenging for healthcare professionals, particularly for inexperienced members of the team. Staff are expected to foster a friendly and age-appropriate approach. In addition, some staff may be of a similar age to the patients they are caring for. These factors can introduce unique challenges to maintaining appropriate professional boundaries with young people. Young people are particularly vulnerable during the developmental period of adolescence, even without a cancer diagnosis. Anecdotal evidence from TYA cancer experts suggests that young people with cancer often come to think of staff as ‘friends’, which they need to be mindful of in terms of maintaining professional distance.

In order to form effective relationships with young people staff may be tempted to share personal facts about themselves, their lives or their problems with the patient. This is often done out of naivety or the desire to encourage the young person to ‘open up’. However, this behaviour often encourages the young person to feel that the healthcare professional has become a personal ‘friend’, jeopardising the maintenance of the stable, therapeutic and professional relationships that the young person requires during their treatment. The professional caregiver can also find that they have jeopardized their own professional responsibility, registration and bring their organisation into disrepute<sup>180</sup>.

## GETTING TOO PERSONAL

Healthcare professionals have a duty of care and should know what constitutes appropriate professional practice, whereas a patient, especially a young person, is in an unfamiliar situation and may not know what constitutes

appropriate behaviour in this setting. Professionals have a duty to handle individual situations sensitively and professionally. Members of staff should seek early advice if they feel concerned about any aspects of their communication or relationships with young people. Young people may challenge boundaries that are set by staff and show a lack of understanding of the need for professional boundaries. The team should have a consistent approach and standards in place to guide practice. This will ensure all staff maintain professional boundaries, which will ultimately benefit the therapeutic patient/staff relationship.

Physical contact in TYA care may be necessary to offer comfort and support in times of distress. However, it is important that staff do not display inappropriate physical affection which may be misconstrued by young people and their families. It is essential that staff do not initiate inappropriate physical affection (e.g. physical hugging or kissing as a greeting) and staff should avoid becoming overly familiar with both young people and their families. All healthcare professionals should be aware of potential issues and be able to recognise behaviour that may indicate possible breaches in sexual boundaries between the patient and professional.

### WARNING SIGNS FOR CROSSING OF PROFESSIONAL BOUNDARIES

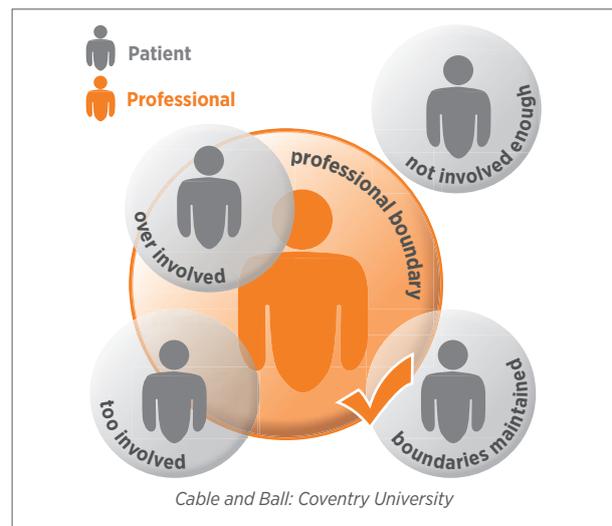
(Adapted from Parkes & Duker<sup>181</sup>)

- Frequently thinking about the patient/family when not at work.
- Spending time with patients outside working hours as a non-representative of their organisation.
- Planning the needs of other patients/family around the favoured patient.
- Sharing personal information with the patient/family.
- A feeling of 'ownership' of the patient's life issues.
- Not wanting to handover to a colleague.
- Behaviour that encourages the patient/family to rely on particular professionals.
- Feelings of jealousy/hostility if other staff work with or look after the patient/family.
- Staff feeling that they look after a particular patient/family 'best'.
- Flirtatious or overt sexual content in interactions with the young person/family member.

Should any of these warning signs be identified in the behaviour of a colleague, these concerns should be raised immediately with the person and shared with their manager.

Whilst some services may have a key worker approach to caseload management, staff should be mindful to discourage over-reliance on one member of staff. It is important that the young person is encouraged to develop professional relationships with the wider team in order to promote equitable care for all young people and that the team shares this responsibility. Whilst at times the boundary may be unclear for patients and professionals, all registered/regulated health and social care professionals must work within their spheres of professional practice and demarcate a healthy boundary for the sake of their own practice and patient well-being (Figure 5.2). Regulatory bodies have set out guidance on what is expected in terms of professional practice and boundary protection<sup>182-184</sup>.

**Figure 5.2:** Maintaining professional boundaries



### STAFF SUPPORT

A body of research indicates that working in the helping professions is rewarding but emotionally demanding<sup>185, 186</sup>. Caring for patients with cancer is considered inherently stressful for healthcare professionals and can lead to burnout and psychological distress<sup>25, 187-191</sup>. Unsurprisingly, McCloskey and Taggart's<sup>192</sup> exploration of occupational stress among children's palliative care nurses identified the presence of stressors within their role concurrent with literature in other fields of nursing. They revealed that there were specific stressors associated with the emotional and ethical demands of caring for very ill children and the impact of the nurses' relationship with the child and their family. While not all young people with cancer will receive palliative care, some may and these factors are likely to apply here too. Although there is currently little empirical evidence of the impact of

## TOP TIPS

### professional boundaries

- All staff working with young people should receive training in professional boundaries in TYA cancer care.
- Managers should ensure staff have clear policies and procedures to follow to ensure the risks of compromising professional boundaries are minimised.
- TYA staff should be aware that patients may view them as 'friends,' may develop sexual feelings towards them or communicate inappropriately. These situations should be dealt with quickly and with sensitivity.
- While the use of mobile phones and networking sites may be appropriate for use with young people with cancer in a service/professional capacity, these need careful monitoring by senior staff and should never be used for sharing personal information/personal contact details.
- Particular support should be given to younger healthcare professionals whose age may increase the risk of blurred professional boundaries. Similarly, inexperienced staff or students may require extra support.
- Staff should maintain their professional status with patients and their carers. Over-familiarity and befriending patients and their carers will contribute towards blurred boundaries.
- Treating teams should be aware of potential signs and triggers that indicate a member of staff may be struggling to maintain professional boundaries.
- All professional groups should uphold the policies set down by their registration bodies with regard to using social media.

emotional distress and burnout on staff in TYA cancer settings, professional experience suggests the likelihood of its existence and proposes that efforts should be made to support staff well-being in this emotionally demanding context.

A particularly important quality for helping professionals is emotional intelligence, as it can help staff adapt positively to stressful working conditions, manage emotional demands, foster effective coping strategies, improve well-being and enhance professional growth<sup>193-196</sup>. Emotional resilience may be described as 'the general capacity for

flexible and resourceful adaptation to external and internal stressors<sup>197</sup>.

Strategies to pro-actively assist staff with reducing psychological distress and burnout and foster emotional resilience include:

- **Encouraging all members of the MDT to have clinical supervision.**
- **The provision of reflective practice to acknowledge the emotional impact of working with young people with cancer.**
- **Opportunities for staff support including peer support and critical incident debriefing.**
- **Staff training and development opportunities specific to TYA cancer care.**
- **Mentoring and peer coaching to enhance collegiate support.**
- **Self-care activities such as mindfulness and relaxation.**

Underpinning all of these measures should be a supportive culture of caring within the multi-professional team and effective leadership to ensure the workplace has the capacity to manage actual and anticipated clinical workloads and the emotional demands on staff.

## SAFEGUARDING VULNERABLE TEENAGERS AND YOUNG ADULTS

All those who work with children and families have a duty to safeguard children and young people, whether they are working directly with that child/young person or not. Many of those working with children and young people may not hold a professional qualification or be regulated by a professional body but can be providing personal and intimate care. All staff working with young people and families, irrespective of their role, must be aware of the signs of abuse and neglect and be able to act to protect children and young people from harm.

Safeguarding concerns can arise across a number of areas, such as neglect, strongly encouraging/ forcing the child or young person to have treatment they do not want, child sexual exploitation, Female Genital Mutilation or online abuse. Safeguarding is a complex issue and all professionals who have contact with children, young people and families should receive training to support them to be mindful of the risks and to know how to take the appropriate action when required. The Working Together to Safeguard Children<sup>198</sup> policy clarifies the responsibilities of professionals to strengthen the focus away from processes and onto the

needs of the child/young person. We are reminded that no single professional can have a full picture of a child's needs and circumstances and, if children and families are to receive the right help at the right time, everyone who comes into contact with them has a role to play in identifying concerns, sharing information and taking prompt action<sup>198</sup>.

All professionals must be aware of local safeguarding policies and have a clear understanding of what actions to take should they have concerns about the safety or welfare of a child or young person. Awareness of local and national agencies who offer advice and support is recommended.

HM Government<sup>198</sup> state that effective safeguarding arrangements in every local area should be underpinned by two key principles:

1	Safeguarding is everyone's responsibility: For services to be effective each professional and organization should play their full part; and
2	A child/young persons-centered approach: For services to be effective they should be based on a clear understanding of the needs and views of children and young people.

Anywhere that cares for young people should ensure that every team member, including volunteers:

- **Have an enhanced Disclosure and Barring Service check.**  
.....
- **Have an honorary contract in place where NHS contracts are not applicable (to be arranged via Human Resources Departments).**  
.....
- **Have access to up-to-date training and support in caring for vulnerable young people.**  
.....
- **Know who to contact where abuse of any kind is suspected, or confirmed, or a young person is felt to be 'in need'.**  
.....

Where professionals are in contact with young people under the age of 18, it is particularly important that they:

- **Are aware of local safeguarding protocols and child protection procedures.**  
.....
- **Feel confident that they know who to speak with initially should they have any concerns regarding the welfare or safety of a young person.**  
.....
- **Are aware of the identity of the Senior/Named Designated Safeguarding professionals in their Trust/Region and how to contact them.**  
.....
- **Attend updated child protection training.**

## YOUNG PARENTS IN THE HOSPITAL SETTING

TYA cancer services can come into contact with patients who themselves are parents and as such child welfare and safeguarding systems apply in regard of both the under 18 year old parent and their child (**also see Chapter 2**). Facilitation of the best interests of the patient and the family system to which they belong need to be negotiated, drawing on the wider multi-professional team for support and guidance. In these circumstances it is advisable to refer young parents with cancer following diagnosis to the Social Worker attached to the unit or ward who can work with the young patient to establish how best to support them, their child and their extended family during treatment, establishing any additional supports that may be required.

There may be particular circumstances when a young parent requests that their child stays with them in hospital. Determining if this is possible or appropriate requires tactful negotiation and both the welfare and safeguarding needs of the parent and the child need to be considered in the context of the law and best interests of the patient and their child. If the child is permitted to visit or stay with the parent, careful negotiation needs to be considered taking into account legal and safeguarding responsibilities, visiting times, facilities for having younger children in clinical environments, impact on the parent, the health protection needs of the child and other patients.

Often no clear policy exists in such circumstances and local arrangements can be made taking all aspects into account. In these situations, legal implications apply and subsequent guidance should be sought.



# CHAPTER SIX: HOLISTIC NEEDS AND SUPPORTIVE CARE

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## INTRODUCTION

The complexity of providing care to teenage and young adult (TYA) cancer patients is compounded not only by their specific health and social needs but by the fact that they can fall 'into the gap' between paediatric and adult services. Whiteson<sup>73</sup> suggests that in a medical context, TYA with cancer are a neglected group, suffering as a result of the apparent disadvantaged position they find themselves in. Providing holistic care is complicated by the spectrum of diseases, psychosocial and family histories that the TYA patient presents with, as well as the diversity of treatments they require. The nature of treatment varies between tumour types. For example, a patient with a Hodgkin lymphoma will require mainly outpatient treatment, whereas a patient with an osteosarcoma will face lengthy inpatient stays. The care pathway may well incorporate several medical consultants and their teams across different hospital sites, potentially even different NHS Trusts, in order to best meet the medical needs of the patient. TYA cancer care is less about a discipline incorporating a specific set of illnesses, occurring to a particular age group, but rather the need to address the way the service provides that care<sup>75</sup>.

## HOLISTIC NEEDS ASSESSMENT – WORKING IN PARTNERSHIP WITH THE YOUNG PERSON AND THEIR FAMILY

***'An holistic assessment will consider all aspects of a person's needs and that they are seen as a whole'***<sup>199</sup>

Understanding the needs of young people with cancer and their family is key to ensuring they receive the care, support and information they require after their cancer diagnosis. The NHS England Standard Contract for TYA with cancer 2001 reflects previously published national guidance that children and young people with cancer, and their families and carers, require their psychological and social needs to be assessed at key points on their care pathway and to receive support based on their identified needs. Furthermore, the recently published Cancer Strategy for England 2015-2020<sup>201</sup> reinforces this and suggests that holistic support should be provided from diagnosis, encompassing physical, financial, psychosocial, information and support needs.

Assessment of need must reflect what having cancer and its treatment means for the young person and should be patient-driven, not based on professional assumption. The basis for providing holistic and supportive care therefore stems from sound assessment of needs alongside a collaborative approach with the young person and family. Patients presenting with cancer bring with them a lifetime of relationships, experiences and challenges that combine to become the individual. The team must provide holistic care in the context of the young person's individual, relational and social circumstances, including consideration of ethnicity, culture, race, spirituality and religion.

Needs will invariably change as the young person progresses through treatment and levels of intervention may vary dramatically between patients over the course of their treatment. All young people will need regular support and information from both their site-specific team and TYA Multi-disciplinary Team (MDT). However, levels of support required will differ in each individual case. It is therefore essential for teams to discuss any required support with a young person throughout the cancer care pathway, particularly at significant events (i.e. diagnosis, changes in treatment plan, end of treatment, recurrence etc.)

Many young people, after the diagnosis of cancer, find their lives have changed and are unable either to pick up previous plans or to adjust their prior hopes and expectations. TYA teams must consider strategies to address these needs, to assist the young person adjust to a life following their cancer experience. This concept is consistent with the aspiration identified within 'Living with and beyond cancer: taking action to improve outcomes'<sup>202</sup>. It described providing people with cancer with the information they need to make decisions and take control of all aspects of their cancer journey, thus shifting towards support for self-management. Within the TYA population this is seen as a priority given the range and complexity of needs that these patients can present with and the potential for future health concerns. Opportunities to empower and encourage the self-management skills early-on during treatment may give each young person the best chance when re-engaging with their life trajectory once treatment has been completed.

## ASSESSMENT TOOLS

Richardson *et al.*<sup>203</sup> define a patient needs assessment tool **‘as a collection of questions, scales and other means of obtaining information which together provide a consistent and comprehensive system, through which patients’ range of needs for support and care can be explored’**. When considering which assessment tool would be appropriate for this population there are many to choose from, including:

- Macmillan Electronic Holistic Needs Assessment (eHNA)  
.....
- How I am? (University College London Hospitals)  
.....
- Distress Thermometer\*  
.....
- Cancer Rehabilitation Evaluation System (CARES)  
.....
- Cancer Care Monitor (CCM)  
.....
- HEADSS or HEEADSS<sup>204\*</sup>  
.....
- Creating better Health Outcomes by Improving Communication about Patients’ Experiences (CHOICES)  
.....
- Pepsi-cola Aide-memoir\*  
.....
- The Needs Near the End-of-Life Care Screening Tool (NEST)  
.....
- Patient Needs Assessment Tool (PNAT)  
.....
- Sheffield Profile for Assessment and Referral to Care (SPARC)\*  
.....
- Teen & Young Adult Worry & Memory Thermometers (Royal Marsden)  
.....
- Symptoms and Concerns checklist<sup>203</sup>  
.....
- Integrated Assessment Map (IAM)\*  
.....
- Other assessment tools which are profession or organisation specific E.g. Star assessment (CLIC Sargent)  
.....

\* Described below

When deciding the most appropriate assessment format consideration should be given to whether a particular tool has been validated for this age group and whether it focuses on a particular area of need e.g. psychosocial needs, but misses out other potential areas of need. It is

important to remember that an assessment is not simply a tool to get answers to questions but, crucially, should be used as a comprehensive framework to facilitate meaningful conversation between young people and healthcare professionals. If standardised across a service this promotes unity and consistency within an MDT and ensures all areas of need are explored and discussed (as long as the young person is comfortable to share such information). Assessments require a degree of formality, yet consideration should be given to ensure that rather than just a professional asking questions of the young person, the opportunity for self-assessment and partnership working is promoted.

Holistic Needs Assessments matter because they:<sup>199</sup>

1	Identify people who need help;
2	Encourage patients to consider their own needs;
3	Promote partnerships with healthcare professionals;
4	Encourage self-management;
5	Help teams to target support and care efforts;
6	Improve informed decision-making.

### SOME EXAMPLES OF ASSESSMENT TOOLS:

#### THE DISTRESS THERMOMETER:

The Distress Thermometer is the most widely used rapid screening tool for assessing psychological distress in people affected by cancer and can be used to support holistic needs assessment. Patients are instructed to circle a number to indicate stress experienced in the last week. Concerns about its use are that it ignores practical and personal concerns and that distress is multi-factorial, including both emotional and physical aspects<sup>205</sup>.

#### HEADSS OR HEEADSS

The HEADSS<sup>206</sup> (further developed to HEEADSS<sup>204</sup>) adolescent psychosocial risk assessment is recommended in many countries and assists health professionals to develop rapport with a young person, while systematically gathering information about their world, including family, peers, school and intimate matters. HEEADSS is an acronym: **H**ome environment, **E**ducation and employment, **E**ating, peer-related **A**ctivities, **D**rugs, **S**exuality, **S**uicide/depression, and **S**afety from injury and violence. Although not commonly used in TYA care, it has been shown to identify areas for intervention and prevention and develops a picture of the young person’s strengths and protective factors.

#### THE PEPSI-COLA AIDE-MEMOIRE

The Pepsi-Cola is an aide-memoire based on the ‘pepsi-cola’ acronym: **P**hysical, **E**motional, **P**ersonal, **S**ocial support, **I**nformation/communication, **C**ontrol, **O**ut of hours, **L**iving

with your illness, **A**fter care. This covers all points to consider in the assessment. It can also include brief information on resources and referral pathways<sup>207</sup>.

### THE SHEFFIELD PROFILE FOR ASSESSMENT AND REFERRAL FOR CARE (SPARC)

The SPARC has an explanatory paragraph plus 45 questions covering seven areas of potential need. For most questions patients rate the degree to which they have been distressed or bothered by a symptom or issue in the past month using the responses: **0** 'Not at all', **1** 'A little bit', **2** 'Quite a bit' and **3** 'Very much'<sup>208</sup>.

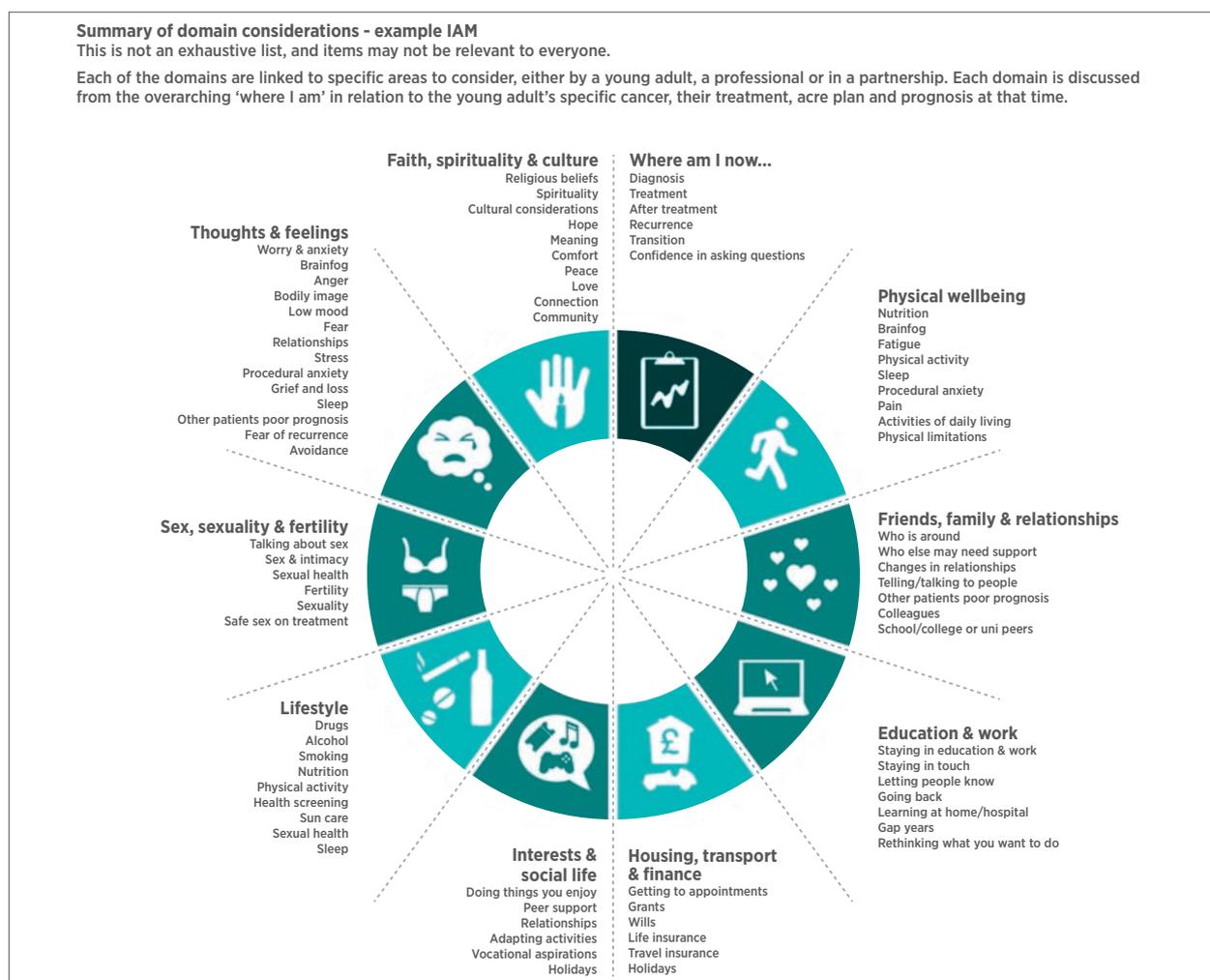
### INTEGRATED ASSESSMENT MAP OR IAM

The IAM (Integrated Assessment Map) is a TYA-specific holistic needs assessment tool first developed for use by the TYA South West clinical service in the UK. It has been further developed into an online portal designed to provide patients with the facility for self-assessment of needs and to offer them resources for self-management.

As with most holistic needs assessment tools, the IAM is a framework for a conversation and provides a semi-structured format for conducting a comprehensive, bio-psychosocial assessment of a young person's needs. Need is indicated (scale 0 - 3) in ten domains which include Physical Well-being; Family Relationships; Education/Work; Emotional Well-being; and 'My Condition Now' (reflecting their perception of need around the impact of their diagnosis, treatment, prognosis etc.).

In each of the domains it is important to encourage the young person to consider how their cancer diagnosis has or may affect this part of their life. They may already be thinking about many of the domains, but by discussing them with a healthcare professional, it is hoped this process will assist them identify any areas of concern or issues where they require more information or help. Information and resources should be provided (if available) to supplement the discussion and encourage self-management (**Figure 6.1**).

**Figure 6.1:** The I.A.M. – Integrated Assessment Mapping



## THE I.A.M. – INTEGRATED ASSESSMENT MAPPING

### Scoring Guidelines – Summary matrix

Levels provide indicator of young person’s and/or professional’s identification of need, risk or concern for each domain.

YOUNG PERSON	PROFESSIONAL
<b>Level 0</b> Domain left blank	<b>Level 0</b> Not known: Action point required to speak with young person about any need, risk or concerns
<b>Level 1 – UNIVERSAL</b> Young person has not indicated any additional request for support over and above the routine service offered by site specific MDT plus access to TYA universal offer	<b>Level 1 – UNIVERSAL</b> Needs identified can be met through routine cancer MDT and TYA universal offer. e.g.: <ul style="list-style-type: none"> <li>● CLIC Sargent introduction and grant</li> <li>● Support via IAM, access to Help! and self-management information/resources, signposting and navigation</li> <li>● Invitation to social events and peer support</li> <li>● Access to wellbeing 1-1s and groups</li> </ul>
<b>Level 2 – TARGETED</b> Young person has indicated this is an area they would like additional information and/or individual support with because they have identified their own additional needs	<b>Level 2 – TARGETED</b> Professional(s) in team around young person have identified an area they have moderate concerns about and would like to actively offer targeted additional assessments/interventions using the available bio-psycho-social support resources within TYA and cancer MDTs e.g.: <ul style="list-style-type: none"> <li>● Level 2 psychological assessment and support/emotional support*</li> <li>● Supported engagement in wellbeing groups or 1-1 for specific lifestyle change</li> <li>● Support with educational/vocational needs</li> </ul>
<b>Level 3 – SPECIALIST</b> Young person has indicated they have a complex need / are very concerned about something in this area and agree to accessing specialist multi agency support	<b>Level 3 – SPECIALIST</b> Professional(s) in team around young person have identified a complex need / significant risk factor which indicates the need for specialist assessment and intervention available within the TYA and Oncology MDTs or requiring an additional multi agency referral e.g.: <ul style="list-style-type: none"> <li>● Level 3 -4 mental health assessments and interventions*</li> <li>● Adult/child safeguarding assessment and plan</li> <li>● Palliative care team/pathway</li> <li>● High intensity wellbeing support provided by TYA/site specific MDTs/team around the young person</li> <li>● Referral to wellbeing or supportive care services outside Cancer MDT /TYA MDT</li> </ul>

\* As defined by NICE IOG – Supportive care

## HOLISTIC NEEDS - AREAS OF CONSIDERATION BASED ON THE IAM

### PHYSICAL WELL-BEING

Young people require both support and advice in regard to their physical well-being as a consequence of a cancer diagnosis and any associated treatments. Examples of information that is often required include advice regarding safe exercise during treatment and a specific need for help in staying motivated and being ‘kept on track’. Managing physical changes associated with treatment (e.g. weight gain/loss), coping with cognitive changes (brain fog) and skin and hair care all must be considered. This area includes any individual needs through prior or acquired disability or

sensory impairment, as well as the common physical impacts of cancer and treatment. Discussion should include current or previous exercise status, fatigue, diet and nutrition.

Cancer can affect a young person’s body image and physical activity. Cancers such as sarcomas and brain tumours sometimes bring with them a level of disability that can either be visible or discrete. Either way, some long-term effects can single a young person out from their friends and curtail what they considered to be their ‘normal life.’ These issues can lead to lower self-esteem, isolation and fear for their future. It is also important to consider the effects of medication, e.g. steroids, which can lead to body changes such as increased weight, fat distribution changes, acne and mood changes which can be significant and concerning for the young person.

There are many questions relating to physical well-being following a cancer diagnosis that require discussion. These include:

## NUTRITION

- Does the young person need to increase/decrease their weight?
- How can they change their diet to improve symptoms e.g. sore mouth/feeling sick?
- Is there anything they can do to increase their energy?
- Do they want advice about how to eat well on a budget?
- Do they have any beliefs about foods that can treat cancer?
- Do different foods affect their mood?

## BRAIN FOG

- Do they know what brain fog is?
- How can they help improve their concentration?
- Is it normal to feel like this, even if they are not having chemo?

## FATIGUE

- What are their energy levels like?
- Do they want support to help feel more energized?
- Do they know how to pace themselves so they can enjoy the days/times when they feel more energised?

## PHYSICAL ACTIVITY

- Is it safe to exercise while they are having treatment?
- Can exercise improve their mood and make them feel less tired?
- What is the best type of exercise for them?
- What can they do if they consider themselves not to be sporty?
- Can they exercise too much/hard?

See Chapter 7 for more information on supporting a young person's physical well-being and the role of physiotherapy.

## FAMILY, FRIENDS AND RELATIONSHIPS

There are many considerations when supporting young people to manage relationship challenges and maintain supportive relationships with family, friends and significant others throughout the illness trajectory. These relationships are known to be critically important for the young person's current and future well-being, helping them to feel supported and stay connected through treatment and re-engage with life when treatment is complete. However, many patients describe how their diagnosis profoundly changes existing relationships and they often feel they are unable to tell family and friends how they are feeling for fear of imposing an extra burden on them or feeling responsible for their family's distress<sup>209</sup>.

There are many questions about relationships young people may find useful discussing with the support of a healthcare professional, including:

- How and when do they tell friends and family about their diagnosis?
- How much do they tell them?
- What if they don't understand?
- How to manage the distress of others?
- How can they keep in touch with their friends?
- Do they want to meet other young people with cancer?
- What support is out there for their family and friends?
- How will the side effects of treatment affect their ability to socialise with their friends?
- Do they have to be careful about how much they see people during treatment?
- How will cancer affect their relationship with their boyfriend or girlfriend?

### Supporting families, carers and significant others

Young people often rely on their close support network to help them cope when going through treatment. This will mostly be their parents, siblings and extended family, although some will have partners and children themselves and have established families of their own. Assessments and interventions should therefore include the needs of the young person together with the needs of parents, siblings, partners, children and significant others. Identified needs will change over time and should be revisited throughout the treatment pathway. Immediate carers often struggle with a range of

practical difficulties, as well as managing their own distress and emotional well-being at this challenging time<sup>210, 211</sup>. A family-centred approach should be adopted while keeping the young person's welfare and best interests as the guiding principle and it is essential that any care provided to the patient is multi-dimensional and incorporates the needs of their family. Familial issues – such as difficulties with work, increased costs due to travel, living away from home, increased family stress, caring for other siblings, care for their own children and anxiety and depression in other family members – must be addressed<sup>1</sup>.

It is important to use the support of the TYA MDT to address the needs of the young person's support network, which can be complex and multi-faceted. Teams should consider the following:

- **What does the young person's relationship network look like? Who are the important people in their lives? There may already be complexities within the family unit that need to be considered, or difficulties may develop as a result of the strain of a cancer diagnosis.**  
.....
- **What are the information needs of the young person's support networks? Do they have any different questions? Do they feel fully informed about the young person's treatment? Have all available resources been accessed?**  
.....
- **What are the practical needs of the young person's support networks? For example, do carers need assistance with travel to and from the hospital? Do they have other dependents?**  
.....
- **What emotional support is required by family members and carers? Have they been given time and the opportunity to talk about the young person's situation? Would the support of other parents or guidance to online parent/carer networks be beneficial?**  
.....
- **The financial impact of a cancer diagnosis also needs to be given careful consideration and support accessed for families and carers. Travel and accommodation costs are of particular concern for patients and parents who may have to travel significant distances to access specialist care and experience prolonged hospital admissions. The parents of many young people either have to leave work for a period of time or negotiate a reduction in working hours while their child is going through treatment. Such changes in circumstances can place financial pressure on the family, at an already difficult time. These issues can be exacerbated when treatment is prolonged.**  
.....
- **A number of voluntary organisations offer a wide range of support services to families and carers, including financial assistance.**

### Partner

If a young person is in a relationship, a diagnosis of cancer is likely to have a significant impact. It is important to recognise any concerns both partners may have and to find ways to keep their relationship healthy and fulfilling. They may have to delay plans they have made and might be feeling anxious about the future. It can be helpful to think about smaller, short-term goals to focus on, for example, going out for dinner once a month, signing up for a course, or planning a short break for the end of treatment. It is common that TYA teams can assist in facilitating access to free holidays if this is possible during or after treatment. If the young person has been told that the treatment may adversely affect their fertility, this can be a significant source of distress and worry, particularly if they intended to start a family. Communication is really important, so helping the young person talk about these issues with you in the first instance, will help them address these with their partner directly.

### Siblings

A diagnosis of cancer is likely to affect the young person's relationship with a brother or sister. The young person may be spending less time at home, or may be sleeping more, playing less, doing less to help around the house. Siblings may ask questions about the young person's treatment and may want to help or stay with their brother or sister during treatment. Family circumstances and dynamics, such as the age of the sibling(s), will affect how much information is shared between family members. Siblings may be extremely distressed and anxious about the patient, yet may feel excluded from information exchanges. It may be helpful to facilitate some time alone between siblings and offer them the chance to ask questions, or encourage parents to set aside this time and consider the information needs of the patient's siblings. Additionally, there may be opportunities for young people to spend some quality time with their siblings at a TYA activity or event.

### Friends

Being diagnosed with cancer can make a young person feel different from their friends and they may feel as though their thoughts and feelings are different from the people they were close to before. They may find that some friends are very supportive and others are not so supportive, which can be upsetting. Staying in touch with friends and accepting their support, can help to keep spirits up during treatment. However, some people find social networking sites can be upsetting, and watching friends 'move on' can be very tough. For some young patients it can be helpful to speak to other young people in a similar situation, or they may find it helpful to ask a particular friend that they trust to pass on information to the rest of their social group so they can keep in touch. Some people use email rather than social networking sites, or join different social networking sites for 'cancer' and 'non-cancer' chat. Working through these questions with a young person 'normalises' their concerns and may provide them with meaningful strategies to address such concerns.

### Other young people with cancer

With better access to age-appropriate units and facilities across the UK, young people with cancer have increased opportunity to meet other young people in a similar situation. The benefits of this are discussed later in the chapter. However, there can be complexities when young people get to know peers with cancer and they may benefit from having a conversation with a member of their TYA team. This can arise following the death of a peer when a young person may experience survivor guilt. Teams should know when to refer a young person for additional psychological support.

### EDUCATION AND WORK

Absences from school in teenagers and young adults with cancer occur most commonly in the year after diagnosis. These absences can result in lower educational attainment, which has been linked to lower likelihood of future employment<sup>212</sup>. Whether patients are currently in education, work or looking for work, a cancer diagnosis could have a significant impact on what to decide to do in the future. It is generally a good idea following diagnosis to encourage young people to start thinking about those decisions so they can make plans. Maintaining good communication with their school, college or employer is key to managing this area of their life and although school might not be the first thing on their mind, friends can be a great source of support. Some young people also report study as a means of distraction during treatment. Some useful areas to explore include:

- Is the young person at school/college or university?  
.....
- Do they have a full time or part time job?  
.....
- What are their career or education aspirations? Do they have a clear idea of how to achieve these?  
.....
- Do their employers or educational system know about your diagnosis and are they supportive?  
.....
- What kind of support would be helpful to manage their study/work commitments?  
.....
- Do they know how to access the help they need?  
.....
- How may treatment side effects impact their work/study?  
.....
- Can they take a break from work/study without losing their job/college place?  
.....
- How do they keep in contact with their friends at work/school/college?  
.....
- Will they have any long-term side effects that will affect their ability to work/study?

### Education

Education is a right accorded to all young people of school age and the MDT have a responsibility to support young people to continue to access education during treatment where possible and help facilitate any necessary reintegration after treatment. The ability to remain in education is a major concern for young people from the point of diagnosis<sup>212</sup> and it is widely accepted that maintaining engagement with peers and extra-curricular activities is known to have a positive effect on a young person's future re-integration into education<sup>213</sup>.

Good communication is central and every effort should be made to establish key contacts at the school, college or university in order to provide the best possible support for the young person and their family. Local Education Authorities are a good source of help and guidance and should ensure adequate provision of education to those of compulsory school age.

If a young person is due to take exams while in hospital or receiving treatment, they may require additional support. The MDT should liaise with the school and exam boards to advocate for any special requirements, such as extra time, a scribe or acknowledgement that performance may be affected due to illness or treatment side-effects. Requests to exam boards usually require a medical letter supporting this request and should be submitted as early as possible.

Parents often request that information about a young person's diagnosis and situation be shared with teaching staff and the young person's peers. Teenage Cancer Trust offers a free education programme delivered by specialist teams in many parts of the UK, designed to offer a safe environment in which to talk about cancer and clarify associated myths. Where requested, sessions can be arranged with the young person's peer group to address any additional questions. This can help support understanding and reduce the fear of peer rejection, which can be underestimated<sup>212</sup>. These sessions can be offered at diagnosis and again at reintegration, if there has been a significant period of absence.

### Employment

Given the importance of employment opportunities on young people's future life chances, it is vital to establish their stage of career development and ambitions as early as possible. Prior to diagnosis, young people may be in part/full time employment or seeking employment. Research suggests that a cancer diagnosis affects these two groups quite differently<sup>212, 214</sup>.

### Young people in employment at diagnosis

Young people who leave work directly following a diagnosis are less likely to be employed over their life time. It is essential therefore that the MDT should, where possible, support the young person to remain engaged with their employer throughout treatment and follow-up care<sup>215</sup>. In some cases, the young person will want to carry on working to provide a focus other than cancer and treatment or may

need to keep working for financial reasons. Whatever the reason, every opportunity should be provided to support their continuation of work.

However, it may be difficult and sometimes impossible for the young person to continue their employment as they did prior to diagnosis but with support it may be possible to negotiate reduced hours or flexible working. As soon as the young person has a confirmed cancer diagnosis they are protected under the Equality Act 2010<sup>216</sup> in the UK and in most cases employers are expected to make 'reasonable adjustments' to support employees. Cancer is classified as a disability from point of diagnosis so if an employer asks health-related questions for equality monitoring purposes it is advised the young person inform them of their diagnosis. Focused conversations with specialists at the Citizens Advice Bureau (CAB) or other advice centres can help prepare young people for questions they may be asked related to their diagnosis and any work absences. Ensuring the young person is adequately prepared for these conversations can have a positive impact on their chance of gaining employment.

The MDT should guide and/or offer advice to enable the young person to speak confidently to their employer and establish their employment rights. Reasonable adjustments an employer could make include:

- **Allowing time off for appointments and treatment (this may not be paid unless stated in their contract).**  
.....
- **Providing flexibility in working hours.**  
.....
- **Adjusting performance targets to reflect any change in working hours and time off.**  
.....
- **Ensuring suitable access and work conditions.**  
.....
- **Modifying duties or moving temporarily to 'light duties'.**

Young people may be reluctant to tell their employer that they have cancer for a number of reasons. However, if employers are not made aware of the young person's new health status they cannot be expected to make reasonable contract adjustments.

It is important to note that the type of cancer and the treatments received will have a differential effect on the young person's ability to remain engaged with work. Young people diagnosed with central nervous system tumours or leukaemia and those who receive cranial radiotherapy experience the most difficulty in finding long-term employment<sup>215, 217</sup>. These groups of patients are likely to need additional support in order to maintain or re-engage with work.

In the case of self-employment, while professionals within the MDT may be able to offer advice and guidance it is recommended that self-employed young people contact their professional association, their accountant and bank manager.

### Young people seeking employment at diagnosis

Young people not in education or work at diagnosis are identified as most likely not to gain long-term employment<sup>212, 214</sup>. Given the increased vulnerability of this patient group, it is important to recognise that they are likely to require additional support post-treatment in order to achieve their potential.

MDT professionals should know where and how to access the various 'get into work' or 'back to work' schemes currently available. There are also organisations that can provide useful services for those young people ready to return to full time work. In many cases young people will need to take gradual steps into employment. Engaging in voluntary work or work experience can be a useful first step, improving self-confidence, self-worth and motivation as well as enhancing their curriculum vitae (CV). Young people seeking work are also protected under the Equality Act 2010 and should not be discriminated against on account of their diagnosis. However, there will be some jobs and careers that may no longer be possible due to the impact of cancer or treatment. Young people in these circumstances may need help to adjust and establish new goals.

### HOUSING, TRANSPORT AND FINANCE

Many people find that a diagnosis of cancer adversely affects their finances and can cause financial problems. There are ways to access financial help to cover some or all travel costs and to help with any extra financial burden they may have encountered as a result of their diagnosis. A CLIC Sargent Standard Grant is a one-off grant that is offered to young people aged 16 to 24 who have been diagnosed with cancer. It is available as soon as the young person is referred and can help meet the unexpected extra costs that a cancer diagnosis can bring. Statutory sources of financial and other forms of support include:

#### Employment and Support Allowance (ESA), which provides:

- **financial support if a young person is unable to work;**  
.....
- **personalised help so they can work if they are able to.**

A young person might be transferred to ESA if they have been claiming other benefits such as Income Support or Incapacity Benefit.

#### Personal Independence Payment (PIP)

This can help with some of the extra costs caused by long-term ill health or a disability for people aged 16 to 64 years and will be dependent on the effects of the condition (not the condition itself). The young person will be required to fill out an assessment to calculate the level of help they are entitled to and this will be regularly reassessed to ensure they are getting the right support.

### Carer's Allowance

This is a payment to help anyone who is looking after someone with substantial caring needs. They do not have to be related to or live with the person they care for but they must be 16 years or over and spend at least 35 hours a week caring for them.

### Blue Badge scheme

This provides a range of parking concessions for people with severe mobility problems who have difficulty using public transport so they can park close to where they need to go. The scheme is run by local councils and operates throughout the UK. A young person should contact their local council for more information.

### Below are some areas to explore with young people in relation to housing, transport and finance:

- What type of housing do they have? E.g. Owner, renting, living with parents.  
.....
- Who do they live with?  
.....
- Do they have their own room?  
.....
- Is their accommodation still suitable for their needs if their mobility or physical well-being has been adversely affected by treatment?  
.....
- Do they drive?  
.....
- Are they allowed to drive?  
.....
- Are there good transport links for treatment?  
.....
- Are there any short or longer-term financial worries?  
.....
- Where are family/friends staying while they are in hospital?  
.....
- Do they need help with travelling costs?  
.....
- Are they in receipt of sick pay?  
.....
- Are they self-employed? If so, do they need additional support?

It is important to consider with the young person their financial and housing situation prior to diagnosis, what the impact of cancer and its treatment has been on their well-being and support needs, what new plans are in place or have they considered and if any additional information or support is required.

### INTERESTS, SOCIAL LIFE AND PEER SUPPORT

Finding out that you have cancer is a worrying time for any young person. Their previous interests or hobbies may no longer be considered significant. It is important to emphasise that it is okay to continue to do the activities they were doing before diagnosis unless they have been specifically told not to do so by a healthcare professional.

Some areas to consider with a young person regarding their interests and social life:

- How do they relax?  
.....
- Do they do any physical activities?  
.....
- What are their hobbies?  
.....
- What are their plans for their future?  
.....
- Do they like to travel? Have they any trips planned?  
.....
- Are they worried that they will not be able to continue with an activity or hobby?  
.....
- How careful do they have to be while on treatment?

As with the previous domain, considering what the young person enjoyed before their diagnosis is important in order to establish the impact of cancer and its treatment on those interests (if any). This will include discussing specific areas such as sports where treatment may limit activity. It is important to remember that any short-term or longer-term change or loss in ability may also impact on the young person's vocational hopes, e.g., musicians, military, athletes etc. and limit the opportunities for contact with friends.

### Providing social support

Age-appropriate services have the potential to promote positive psychosocial adjustment to treatment<sup>36</sup>. Activity programmes within and outside the hospital environment are a useful means of maintaining peer group support. Young people often gain a huge amount from spending time with other young people who are in a similar situation. The MDT has a role to play in facilitating social support, which will help the young person adjust to life with cancer and can improve confidence and self-esteem.

### Activities

Services, programmes and events need to be planned in partnership with young people. This will ensure that their needs are met and resources are used effectively. Specialist TYA cancer ward-based activities might include art, music, drama and animation workshops, movie evenings, quiz afternoons, pool competitions and games days. These activities allow young people to focus on something other than

**Figure 6.2:** Teenage Cancer Trust Youth Support Co-ordinator Activity Risk assessment

	<b>Teenage Cancer Trust Youth Support Co-ordinator Activity Risk Assessment</b>			Activity:		
	Date of activity:	Number of Staff:	Number of Young People:			

Hazard	Risks of Hazard	Who is at risk	Severity of risk VH/H/M/L/VL	Likelihood of risk VH/H/M/L/VL	Control measures put in place (include owner and timescales if appropriate)	Resulting severity of risk VH/H/M/L/VL	Resulting Likelihood of risk VH/H/M/L/VL

Activity Risk Assessment Sign Off			
Risk Assessor Name:		Date of Assessment:	
Risk Assessor Signature:		Date Signed:	
Countersignature Name:			
Countersignature Signature:			

VH = Very High  
 H = High  
 M = Medium  
 L = Low  
 VL = Very Low

'being ill' and can help a young person maintain motivation for life in their new circumstances, encouraging them to work individually or as a group on small projects with achievable outcomes. Regular support groups can become a welcomed social event in a young person's diary. Such groups can offer continuity by providing a regular time and place for young people to meet up and get to know and support each other away from the hospital environment. Group activities might include meals out, theatre and concert trips, sports events and trips to theme parks. When young people are accessing social activities it is advised that consent forms and risk assessment forms (Figure 6.2) are utilised. Those aged 18 years and under should have their parents or carers complete the paperwork with the onus of responsibility for disseminating information on the young person. Those over 18 years should be responsible for their own behaviour and actions.

Staff supervising young people away from the hospital environment should ensure they have adequate insurance, public liability cover and a lone workers' policy in place. Advice and guidance is usually available from finance departments and departments utilising lone workers including information regarding insurance and liability cover.

**Find Your Sense of Tumour (FYSOT)**

FYSOT is a national conference organised by Teenage Cancer Trust and named by young people. The conference brings young people from all over the UK together over two days to learn more about their cancer, ask questions, meet other young people and have fun. FYSOT has been running for over 15 years and it provides young people with an opportunity to increase their confidence, self-esteem and build support network<sup>218</sup>.

**“It’s an amazing experience to meet so many new people who can understand and relate to what you’ve been through.”**  
 Young person, FYSOT 2015

Teenage Cancer Trust run two of these conferences per year, one for 13-17 year olds and another for those 18 years and above.

**LIFESTYLE**

Following a diagnosis of cancer many young people worry that they have done something to “cause” the cancer or that the cancer is a result of their lifestyle choices. It is important to explore this further if it is a source of concern for the young person. For some young people being diagnosed with cancer causes anxiety and concern about their health and lifestyle choices while others may choose to continue living life as before.

Some areas to consider with a young person regarding lifestyle choices include:

- Do they smoke?  
.....
- Do they know where to go to receive support to stop smoking?  
.....

- Do they drink alcohol? If so how much and how often?

.....

- Do they need information about drinking alcohol on treatment?

.....

- Do they take any other recreational substances? If so, what is the substance and frequency?

.....

- Would they like any support or additional help with any of the above areas?

Discussion may include an assessment of any risk behaviours and assurance that the young person is fully informed about lifestyle choices including any potential adverse impact on their longer-term health outcomes e.g. smoking and exercise (See Chapter 4 for further information on exploring risk-taking behaviours with young people).

### SEX, SEXUALITY AND FERTILITY

This domain considers the impact of the cancer and its treatment in relation to the young person’s sexual identity, sexual and intimate relationships, sexual health and fertility. Encouraging young people to keep themselves safe when they are in a sexual relationship can have a significant impact on their health and well-being. As well as protection from sexually transmitted diseases and infections staying safe in sexual relationships means protecting themselves from situations that might be upsetting. For example,



drinking alcohol heavily or using drugs can affect young people’s decision-making and alcohol in particular can lower inhibitions. This can result in young people engaging in activities that they may not usually such as having unprotected sex or sending photos of themselves to others that they later wish they hadn’t. Helping young people think through any risk-taking behaviours and their hopes and fears for relationships with others is an important way of helping them to have safe relationships.

Developing one’s sexuality, the expression of sexual interest, orientation and preference, is a normal part of adolescence and young adulthood. It is multifactorial and encompasses issues such as developing intimate relationships, gender identity, sexual orientation, religion, and culture. Young people may be just negotiating some of these factors when diagnosed and this may have a profound impact on their well-being, relationships and subsequent development. It is important therefore that the MDT are mindful of these issues and discussions are handled in an appropriate and supportive way.

Fertility is an issue of great concern for this age group and many patients can be confused and frightened about the potential impact of cancer treatment<sup>219, 220</sup>. Young people with cancer should be provided with full information delivered in a clear, timely and supportive manner. Verbal information should be supported by age-appropriate written resources. It is often helpful for the young person to be supported by healthcare professionals who are experienced in discussing fertility issues with young people, e.g., TYA nursing staff. It is also important that the young person is given the option to have a support person or family member present during consultations. This can help them take in and understand the information provided. Teams treating young people should have access to specialised reproductive and fertility expertise that can provide newly-diagnosed patients with access to the full range of information to make informed decisions regarding fertility issues. Services and referral pathways for fertility advice and preservation vary between centres. Teams must therefore establish what is available and how the process is managed locally (See Chapter 4 for further information). Some areas to explore include:

- Can they have sex during treatment?
- .....
- What effects can cancer treatment have on their sexuality and sexual function?
- .....
- Who can they talk to about any worries about sex?
- .....
- Is safe sex still important?
- .....
- How do they tell their boyfriend/girlfriend/partner if they don’t want to have sex?
- .....

- How will cancer treatment affect their fertility?  
.....
- What should they say to their boyfriend/girlfriend/partner?  
.....
- What types of treatment might affect their fertility?  
.....
- What can they do to help protect their fertility?  
.....
- Where can they get information about their fertility when treatment is complete?

### THOUGHTS AND FEELINGS

The emotional impact of cancer and its treatment can have a significant effect on a young person’s mental health and well-being. This area encompasses discussion around a number of topics including the young person’s beliefs about their cancer and its treatment, what this means for their current life and any hopes or concerns about the future.

Consideration of the young person’s cognitive ability and the impact of the cancer and its treatment on memory, attention and problem solving for example are also covered in this domain. These issues must be taken into account when considering any changes in thoughts, feelings and behaviours relating to other domains, e.g., risk-taking or coping strategies and the impact on lifestyle and/or physical well-being. Prior or acquired learning disabilities should also be considered here.

It is common for young people living with cancer to have thoughts and feelings such as worry, sadness and anger. It is perfectly normal to experience any or all of these feelings and not everyone will want or need to see a psychologist at the hospital. However, if these feelings are significantly affecting the young person’s sleep, appetite or day-to-day activities, then psychological support is recommended. Areas to explore with the young person include:

- Have they been feeling unusually low for a while?  
.....
- Are they sleeping more or less than usual?  
.....
- Have they been feeling uptight, tense or wound up?  
.....
- Are they forgetting things?  
.....
- Have they been worrying more than usual?  
.....
- Are they having trouble enjoying things?  
.....
- Are they having trouble concentrating?

See Chapter 7 for further discussion of how to explore a young person’s thoughts and feelings about cancer and promote their psychological well-being through treatment.

### Mental health

Thinking about prior or acquired mental health needs (e.g. depression or anxiety) including any risk of self-harm would also arise here. Understanding preferred coping strategies and how they fit with the adjustment and adaptation challenges presented by cancer and its treatment are also covered in this domain. For more detail on supporting young people’s mental health see Chapter 7.

### FAITH, SPIRITUALITY AND CULTURE

See Chapter 4 for further information.

Faith, spirituality and culture (FSC) are important and different elements in everybody’s lives. They are not one and the same thing yet they are often intertwined. A diagnosis of cancer can prompt people to think about the aspects of their life they consider important and look for meaning or purpose. Often this happens whether or not people have a faith position or religion and they may find themselves asking questions like ‘Why me?’ and ‘Why now?’. An individual’s distinct FSC views and practices may shape, challenge or influence the way in which cancer and its treatments are experienced. Discussion in this domain involves asking what these issues mean for the young person. This may include exploring religion, faith and spirituality but also their wider beliefs about the world.

### Religious considerations

There are many religions which have beliefs and customs that may need to be considered in a healthcare setting, e.g., dietary requirements, customs after death and organ donation. Discussing these needs with the young person can help support their wishes. There are useful online guides to religious beliefs and customs relevant for healthcare teams. Consulting with the Spiritual and Pastoral Care Team may also be of benefit.

Some issues to consider in relation to FSC:

- What are the young person’s beliefs?  
.....
- Do they have any faith or spiritual needs?  
.....
- Who are their existing sources of religious support?  
.....
- Are there any treatments or procedures that may conflict with their beliefs?  
.....
- What are their life goals?  
.....
- Where the young person already has a faith position or spirituality, what impact has cancer had on this aspect of their lives?

### Cultural considerations

It is essential for the MDT to have an understanding of the young person’s cultural background. Additionally, it is

important to value diversity, recognise the dynamics of cultural interactions between the young person, their families and the wider social circle and consider approaches that take those diverse interactions into consideration. Having an awareness of one's own cultural views and biases and understanding diverse views in a respectful and non-judgemental way are important issues of professional competence.

## TOP TIPS

### for making a holistic needs assessment

- Best practice is delivered through a combination of expert medical management and expert age-appropriate holistic needs assessment.
- Ensure holistic needs assessments are continued throughout treatment and after it has been completed, recognising that individual circumstances will change during the care pathway.
- Holistic needs should be assessed in partnership with the young person, their family and healthcare professionals.
- Holistic needs assessments can help identify needs and provide the basis for early intervention.
- Adopting an appropriate holistic assessment tool can provide a consistent and comprehensive framework to enable meaningful discussion between healthcare professionals and young people about important areas of change following diagnosis.
- Holistic needs assessments should consider the practical and emotional needs of the young person's support network including parents, siblings, partners, friends and significant others.
- Ensure robust referral pathways for psychology, psychiatric services and counselling are in place to refer patients when necessary. Referral pathways should also be in place for social work, physiotherapy and occupational therapy.
- Relevant resources should be made available to promote self-management throughout the cancer care pathway.

A diagnosis of cancer can pose additional difficulties for some individuals from certain religious or cultural backgrounds. As a result, families may want to keep a cancer diagnosis from other community members and may need additional help from treating teams to help them negotiate this.

### Useful websites:

The following websites have pages that cover many of the areas cover in holistic needs:

- <https://www.teenagecancertrust.org/>
- <http://www clicsargent.org.uk/>
- <http://www.macmillan.org.uk/>
- <http://www.tyahelp.co.uk/>

### Specific resources:

#### Work & Education:

- <https://www.gov.uk/browse/disabilities/work>
- <http://www.greatwithdisability.com/>
- <http://www.workingwithcancer.co.uk/>
- <https://www.gov.uk/government/publications/education-for-children-with-health-needs-who-cannot-attend-school>

#### Lifestyle:

- <https://quitnow.smokefree.nhs.uk/>
- <https://www.drinkaware.co.uk/>
- <http://www.talktofrank.com/>

#### Faith, spirituality and culture:

- <http://www.queenscourt.org.uk/spirit/>
- [http://www2.rcn.org.uk/data/assets/pdf\\_file/0008/372995/003887.pdf](http://www2.rcn.org.uk/data/assets/pdf_file/0008/372995/003887.pdf)
- <https://www.aamc.org/download/300720/data/osrspiritualityresources.pdf>
- <http://www.nes.scot.nhs.uk/media/3723/spiritualcaremattersfinal.pdf>



**TEENAGE  
CANCER  
TRUST**

# CHAPTER SEVEN: PROMOTING WELL-BEING AND RESILIENCE

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## THE IMPORTANCE OF WELL-BEING AND RESILIENCE FOR YOUNG PEOPLE WITH CANCER

### TYA VULNERABILITY

Young people with cancer are recognised 'as a small but in many ways a uniquely vulnerable group of cancer patients'<sup>199</sup>. They experience a 'dual crisis' when the normative developmental stressors derived from the tasks transitioning from adolescence to young adulthood<sup>221</sup> combine with the challenges associated with an unexpected cancer diagnosis<sup>222</sup>.

While research has shown many young people diagnosed with cancer learn to adapt to life with illness and find positive ways to cope and make meaning of this unanticipated experience<sup>55, 223, 224</sup>, there is nonetheless a broad ranging international research consensus that young people who develop cancer at this pivotal stage in the life-course are at risk of developing psychosocial problems both during and after the cancer treatment trajectory. This suggests there is a need for a better understanding of the constituents of age-appropriate care, effective psychosocial support and provision of supportive interventions during and post-treatment<sup>16, 225-229</sup>.

The risk of developing psychosocial difficulties is hardly surprising given the well-documented wide-ranging array of significant challenges that young people with cancer must face. These include significant restrictions to everyday life, the physical experience and adverse effects of illness and treatment (both short and longer term), social identity challenges, relationship and life course disruptions, and loss of control while coping with the life-threatening nature of many cancer diagnoses and managing ongoing existential uncertainty and isolation<sup>55, 74, 230-234</sup>. There is also a recognition that a single uniform experience of cancer does not exist with variable challenges and coping strategies, depending on the cancer site, type and duration of treatment protocol, prognosis, age, gender and each young person's unique physiological and psychological response to presenting stressors in the context of their family and peer relationships and broader social support networks<sup>105, 235</sup>.

### GOOD OUTCOMES ARE MORE THAN SURVIVAL

The Children and Young People's Improving Outcomes Guidance (CYPIOG) recognised that good outcomes

'encompass more than improved health, in terms of survival, mortality and morbidity'<sup>1</sup>. These guidelines specifically note that improving outcomes for young people with cancer must also include a focus on quality of life, self-esteem, participation in daily life and the ability to mature successfully to adulthood. Rehabilitation services for example, are advised to seek 'to improve overall physical, emotional, social and educational outcomes during and after treatment'<sup>1</sup> and supportive care should aim to 'help the patient and family to cope with cancer and its treatment throughout the cancer journey...to help the patient maximise the benefits of treatment and provide the best quality of life'<sup>1</sup>.

While these broader outcomes are articulated in a number of ways in the CYPIOG<sup>1</sup> and ascribed different emphasis depending on the particular strand of care delivery, it all points to the importance of extending our vision as service providers to include not only the disease and its medical treatment but also the experience of the ill young person and their holistic health and well-being as they progress through treatment and beyond. This emphasis on promoting a holistic sense of well-being is all the more important with the recognition that advances in cancer treatment have led to improvements in survival rates<sup>236</sup> but often with complicating treatment late-effects<sup>225, 237</sup>. With cancer increasingly becoming thought of as a chronic disease, which can result in long-term disabilities requiring on-going care and support<sup>238</sup>, it is imperative to remember that for many young people with cancer, survival is 'not necessarily a simple end to a cancer story'<sup>225</sup>.

### CURRENT AND FUTURE WELL-BEING: DEVELOPING RESILIENCE

This broader emphasis on holistic well-being is affirmed in TYA literature, which acknowledges that for young people with cancer undergoing treatment the problem is not solely future survival but 'survival in the present'<sup>239, 240</sup>. In a TYA survey in the UK, 73% of young people rated quality of life and survival as equally important<sup>241</sup>. This focus on the present concurs with Thomas *et al.*'s<sup>242</sup> conclusion that while young people have 'an increasing capacity for abstract thought enabling the realisation of concepts that generally lie outside their immediate experience, such as death, most nonetheless place greater emphasis than mature adults on the immediate demands of the present, rather than future concerns or possibilities'.

While enhancing TYA well-being during treatment is therefore a valid outcome in its own right, it is also thought to have the additional potential effect of increasing the capacity for future well-being as a young person learns new ways of coping with illness and treatment-related challenges. Psychosocial interventions to promote well-being in the early stages of treatment may therefore assist with longer-term coping and the development of resilience, defined as a process for identifying and developing resources and strengths to manage inevitable stressors<sup>243, 244</sup>. It is in this context that the promotion of young people's well-being and resilience are considered key healthcare goals.

## POSITIVE HEALTH CONCEPTS: FROM RISK TO RESOURCE

TYA studies have been criticised for over-emphasising pathology models of addressing psychosocial adjustment, which are thought to reduce complex lived experience into predetermined psychological variables such as measures for anxiety and depression<sup>245</sup>. Researchers have suggested there should be a greater use of meaning-based and positive health concepts to understand TYA experience to explore how care provision might be supportive<sup>246-248 233, 243</sup>. This shift mirrors developments in the broader public health policy arena, which increasingly utilises positive health concepts such as 'well-being' and 'resilience' when a broad definition of health outcome is required. Both concepts adopt a strength or asset-orientation, which shifts emphasis from illness and disease to wellness. This recognises a person's well-being as being a state of constant flux and well-being promotion as a process of utilising resources to manage unavoidable stress<sup>249</sup>. A person's well-being is therefore maintained by a balance of stressors and resources, which are thought to be embedded and shaped by an individual's unique psychosocial and cultural context<sup>243, 249</sup>. In this way the capability of populations and individuals to participate fully in the health development process is also accentuated<sup>250</sup>.

### WELL-BEING

While the concept of well-being is recognised as a complex and contested construct it is increasingly applied to public health policy as a 'potentially unifying concept for health improvement, which encompasses a range of medical and non-medical priorities, differing values and objectives that in the real world cannot be separated'<sup>251</sup>.

Although conceptually distinct and operationalised in a number of ways, well-being as an integrated term has been found to encompass subjective well-being constructs such as happiness, wellness, contentment and joy and psychological well-being constructs such as autonomy, engagement, confidence, self-esteem, self-acceptance and life satisfaction, which is closely associated with 'quality of life'<sup>252-256</sup>. Well-being as a single multidimensional construct is considered a combination of '*feeling good*' and '*functioning*

*effectively*'<sup>257</sup> and encompasses physical, psychological, social and emotional components, including self-esteem, quality of life, participation in life and positive social relationships. The importance of well-being concurs with the underpinning philosophy of the World Health Organisation (WHO) which defines health as 'a state of optimal physical, mental, and social well-being and not merely the absence of disease and infirmity'<sup>258</sup>.

### RESILIENCE

Resilience too has a number of theoretical conceptualisations. It is generally considered a dynamic process involving an interaction between both risk and protective factors, which are internal and external to the individual. These act to mediate the effects of adverse life events<sup>259</sup>. It is important to note that resilience does not imply an invulnerability to stress but rather an ability to recover from challenging events with support<sup>260</sup>. Some conceptualisations focus on resilience as an *outcome* emphasising the maintenance of functionality, while others focus on resilience as a *process* of adaptation to a risk-setting, seeking to understand the mechanisms that act to modify any negative impacts and the developmental processes by which young people successfully adapt<sup>261</sup>. This process orientation leads to the identification of resilience promoting factors, which are generally considered at three different levels: the individual level (resources, competencies, talents and skills); social level (family and peer network); and societal-level (e.g. community, school, support services). Resilience as a social ecological concept<sup>262</sup> defines resilience as more than an individual's capacity to cope and recognises that for young people with complex needs living in adverse circumstances (such as young people with cancer), the design and delivery of professional support systems are crucial<sup>263</sup>.

## PROMOTING WELL-BEING AND RESILIENCE IN YOUNG PEOPLE WITH CANCER

Over recent years these positive health concepts and others such as coping, adaptation, adjustment and quality of life have been adopted and adapted by TYA cancer clinicians and researchers as a means of theorising about how healthcare systems can provide age-appropriate care. A range of interventions are proposed to support young people with cancer in ways that expressly take account of what is important to young people and build on existing individual and social resources in order to enhance an overall sense of wellbeing, both in the short and longer term<sup>16, 105, 172, 224, 243, 246, 247, 264</sup>.

### THE ROLE OF ALLIED HEALTH AND PSYCHOSOCIAL PROFESSIONALS

While many ways of promoting well-being and resilience are discussed in other chapters of this publication, including the provision of age-appropriate care (**Chapter 4**) and holistic and

supportive care (**Chapter 6**), this chapter explores common psychological, psychosocial, social and physical challenges experienced by young people with cancer and headlines the unique contribution of allied health and psychosocial professionals such as Psychologists, Physiotherapists, Occupational Therapists (OT), Social Workers and Youth Support Co-ordinators in supporting young patients' well-being and promoting resilience. Access to appropriately skilled professionals is identified as a vital component of TYA cancer care in the CYPIOG<sup>1</sup>, which stresses the need for timely input at all stages of the cancer pathway including diagnosis, acute care, supportive care, rehabilitation and palliative care.

## PSYCHOLOGICAL WELL-BEING

### MENTAL HEALTH AND YOUNG PEOPLE

Unidentified mental health difficulties in young people can lead to educational disruptions resulting in underachievement, substance misuse, self-harm, suicide, violence and poor sexual health<sup>265</sup>. Mental health problems are significant in adolescence and young adulthood, affecting around one in ten children and young people and rising to one in five young adults<sup>265</sup>. Mental health disorders in young adults are surprisingly common<sup>266</sup> with three quarters of all lifetime cases of psychiatric disorders beginning by the age of 24 years<sup>267</sup>. Interestingly, although young adults as a whole are the most likely age group to develop mental health problems, they are the least likely to recognise that they have a problem that might benefit from intervention<sup>268</sup>. They are also the most likely to think that they should handle mental health problems by themselves<sup>269</sup>. This can result in delayed intervention with recent research indicating a ten-year delay between young people displaying first symptoms and getting help<sup>267</sup>. These are considered missed opportunities for early intervention<sup>265</sup>, which could significantly reduce life-course impairment<sup>270</sup>.

### MENTAL HEALTH AND YOUNG PEOPLE WITH CANCER

Some mental health difficulties are thought of in terms of a stress-vulnerability model<sup>271</sup> where any person who is under enough stress could be tipped into experiencing symptoms reaching the threshold for a mental health diagnosis. While it is to be expected that young people with cancer will experience mental health challenges associated with the changes in their circumstances and living with the uncertainty of illness and perhaps debilitating and restricting treatment protocols, if any symptoms are sustained or start to impact significantly on their everyday lives, consultation with or referral to a Clinical Psychologist or Psychiatrist is important. MDT members should know who the Clinical Psychologists and Psychiatrists are and how to refer patients to them.

### CLINICAL PSYCHOLOGY: WORKING WITH MENTAL HEALTH DISORDERS AND PROMOTING TYA RESILIENCE

Clinical Psychologists working in cancer do not only work with diagnosed mental health disorders they can also help

foster young people's resilience, help them adjust to new circumstances, tolerate treatments, communicate with their family/friends about difficult topics, support them through complex decision-making and help them process their thoughts and feelings. Some members of the MDT such as OTs also have specialist mental health training and may be able to offer valuable interventions for mild to moderate emotional difficulties such as anxiety, low mood, low self-esteem, and anger.

This section not only addresses mental health *disorders*, but also suggests how healthcare professionals can support young people before their distress reaches a critical level. Research indicates how young people value the support they receive from all staff members involved in their care, including medical, nursing, social care, allied health professionals and auxiliary staff<sup>16, 272</sup>. Some 'top tips' are provided to help practitioners to:

- **Support young people to manage their distress effectively;**  
.....
- **Become more aware of when to refer a young person for more specialist support;**  
.....
- **Notice their own feelings and look after themselves.**

As discussed in **chapter 2**, when young people are diagnosed with cancer it often disrupts their typical developmental pathways, physically, socially, psychologically and educationally/vocationally. Young people vary widely in their emotional maturity, their independence in decision-making, their support network and the issues that are most significant to them. Cancer affects everybody in the young person's multiple systems, e.g., family, school/university and friendship groups. In particular, it is known to greatly impact parents and families, whose own well-being can be compromised<sup>273, 74</sup>. Relationships with families and parents are noted as a great resource as well as a source of distress and conflict<sup>235, 275</sup>. When assessing young people's psychological and psychosocial needs, it is therefore important to take all of these factors into consideration and liaise with the wider MDT, in particular the Social Worker who is likely to know important family members.

### PSYCHOLOGICAL DISTRESS

Research in relation to distress in young people with cancer has reached varied conclusions. Allen *et al.*<sup>273</sup> found 38% of 12-20 year olds reached diagnostic criteria for depression at the time of receiving the cancer diagnosis, with recent research reporting higher levels of distress in the TYA population as compared with the general cancer population<sup>276, 277</sup>. However, other research proposes that while higher levels of anxiety and depression were present at diagnosis in comparison with healthy peers, over time young people found ways to adapt to illness with reports of psychological well-being steadily

improving and displays of post traumatic growth<sup>223</sup>. It should also be noted that distress in and of itself is not necessarily a problem as young people functioning well under high stress often show higher levels of emotional distress compared to low stress peers<sup>278, 279</sup>.

Given that depression and anxiety are common psychological diagnoses in adolescence<sup>280</sup> and the challenge of encouraging young people to seek timely professional help<sup>281</sup>, it is advisable for health and social care professionals to be alert to symptoms of significant psychological distress in the TYA cancer population. Symptoms of anxiety and depression can include<sup>282</sup>:

- **Lack of interest in previously enjoyable activities;**  
.....
- **Feelings of hopelessness;**  
.....
- **Social withdrawal;**  
.....
- **Feeling anxious and tearful;**  
.....
- **Sleeplessness;**  
.....
- **Change in appetite;**  
.....
- **Lack of motivation/apathy;**  
.....
- **Finding it difficult to concentrate;**  
.....
- **Having unexplained aches and pains;**  
.....
- **Having suicidal thoughts;**  
.....
- **Self-harming.**

#### **HOW TO IDENTIFY PSYCHOLOGICAL DISTRESS**

In the context of becoming diagnosed with cancer at a young age, many of the above symptoms are to be expected and may also be the side-effects of some treatments. This can make it difficult to distinguish whether the young person requires better symptom management or support from a mental health professional. A good place to start is by trying to engage the young person in a conversation about how they are coping to give an indication of what might be most helpful to them. If symptoms continue for more than two weeks consistently it is usually advisable to consult a mental health professional.

Recognising symptoms early will allow timely help and support from healthcare professionals. Young people are more inclined to seek help for mental health problems if they:

- **Have some knowledge about mental health issues;**  
.....
- **Have some knowledge about the sources of help available to them;**  
.....

- **Have established trusting relationships with healthcare professionals.**  
.....

The relationship between the young person and key members of the TYA MDT is critical in helping them feel able to talk about the emotional aspects of their experience and feel as though they have been heard and understood. This can be achieved by encouraging emotion-talk and effective listening. (**See also Chapter 6**).

#### **Helping young people talk about emotions**

In the same way we might assume that we should only talk to our dentist about our teeth, some young people might assume that they should only talk to nurses or other healthcare professionals about medical or physiological issues so if not asked directly how they are feeling emotionally, they are unlikely to raise this issue as they may believe it is not relevant to the professional role.

- A useful way to open conversations with young people is by explaining that psychological distress is “common” in cancer rather than “normal”. It may not be ‘normal’ for the young person in the context of their life but can be helpful to know that others share similar feelings.
- It can feel less pathologising to use terms such as “when low mood is around” or “when you are experiencing low mood” rather than “you ARE depressed”. This avoids implying there is a pathology located inside that individual, which could be understood as a personal weakness that they can do little about rather than an understandable response to their new and challenging circumstances.
- When enquiring about a young person’s emotional state, try not to ask “how are you feeling?” because it can be hard for people to reflect on how they are in that current moment. It is also a social nicety and we all know the socially expected response is “fine thank you. How are you?” The young person is more likely to open up if you ask “how have you been feeling since I last saw you?” This is because it is easier to reflect on the past, e.g., “I WAS feeling tearful” versus “I AM feeling tearful”. It sounds less like a social formality and as though you are genuinely interested, which gives them permission to talk about their feelings.
- It is useful to think back to the last time you felt you were not being listened to effectively. What was the person doing? Were they in a rush? Did they interrupt you? Did they change the subject? Did their eyes glaze over? Although busy professionals all do this from time to time, it signals to the young person that they are not interested in listening to them and as a result they might not be willing to share their distress and miss out on receiving support. When busy, it is difficult to always provide effective listening. In such situations it can be useful to say to the young person at the start “What

you are saying sounds really important. I actually only have 10 minutes right now and what you have said so far sounds like it is deserving of more time so can we arrange to meet later on or tomorrow when I will have more time to properly sit and listen?”.

- Often it is reassuring for young people to know how long a healthcare professional has with them so they are not worrying while they are talking that they are using up time that the healthcare professional does not have to spare. Being transparent about this at the start also allows the healthcare professional to be fully focussed without having to feel frustrated about closing down the conversation so they can leave.
- Encourage young people to be open about their psychological experience and emotions by explaining that it is *understandable* that they might feel uncharacteristically tearful or anxious given their diagnosis, treatment, and uncertainty about the future but this does not mean that they cannot receive some support to help them manage these feelings. Pain is expected but we still treat it with analgesia. Psychological pain is similar and can be talked through with a healthcare professional as there are a lot of psychological tools and strategies that can help.

## ANXIETY

Many young people (and their parents) experience anxiety throughout their cancer journey<sup>273</sup>. While some anxiety is

to be expected and appropriate in the circumstances, it can become problematic when it starts to interfere with the young person's ability to engage in everyday life, such as struggling to go outside or maintain friendships. It is important to remain alert to the possibility that prolonged, heightened anxiety can escalate to a point where it becomes a problem in itself, which can lead to panic attacks, health anxiety, paranoia, obsessive compulsive disorder, phobias, difficult family communication and social interaction. Anxiety may happen in specific situations or be associated with particular tasks such as being in public places (agoraphobia) or being with other people in social situations (social anxiety). Anxiety may present in specific ways such as panic attacks, which can be debilitating and frightening.

Family members are likely to take on specific roles and may be holding onto different aspects of distress<sup>273, 274</sup>, which can manifest in different coping strategies, some of which are more or less helpful. For example, it is commonplace for parents to worry about their child, and the young person in turn to worry about their parents worrying. This process can become a vicious and counter-productive cycle as family members seek to protect and shield one another from their own anxiety. Some young people/family members might externalise their anxiety by showing their worry and seeking repeated reassurance from different members of the MDT, in effect they are asking the professionals to 'contain' their anxiety for them. Others might show their anxiety through irritation and aggression. It is important to remember that each person is coping with a large amount of uncertainty and loss of control.

## TOP TIPS

### to support emotion-talk and effective listening

- Remember to ask how young people are coping emotionally not just physically, otherwise they may assume they cannot talk to you about their feelings.
- Help young people understand that being distressed or feeling low or worried after a cancer diagnosis is 'normal'.
- Help young people identify any fears or concerns so you can clarify any unfounded fears and ensure they get access to accurate information.
- If you are busy, state this and arrange another time to come back and take time with the young person. Make sure you honour this commitment.
- Explain that there are services available to help young people talk about their feelings and help them get through treatment.
- Help young people identify other trusted adults they can talk to.
- Appreciate their courage in speaking to you and encourage them to keep reaching for support.

## TOP TIPS

### when working with anxiety

- It can be useful to name anxiety early on and help the young person, their friends and family think about the function of worry for them and how they manage it. It can be helpful to name these processes in front of everyone.
- Remember that it is normal for family members to seek to protect and shield one another from their own anxiety.
- Supporting young people to think about the type of support they would like from friends and family can be helpful. Encourage the young person to directly request this form of support.
- Encourage young people to tell their friends whether they want them to mention cancer and ask questions or if they would prefer not to talk about it, whether they wish to be contacted daily and by what method. This helps the young person's friends know how best to support them rather than feeling awkward and withdrawing from the young person.
- It can also be helpful to ask young people to think back to other difficult times in their lives and ask how they coped then with uncertainty.
- Help draw young people's attention to what they **CAN** do and where their strengths lie.

### Responding to psychological distress: what can you do?

Once the young person feels secure enough to disclose their feelings, what should the professional do? Below are some interventions which can help.

#### **Anxiety management**

Advice and education on what anxiety is and methods for managing anxiety are essential and can be provided by a Psychologist or an OT who has additional mental health training.

**Psychoeducation:** It can be useful to provide some psycho-education about why anxiety exists i.e. the 'fight or flight' phenomenon, to help the young person avoid misinterpreting the physical symptoms of anxiety as having a sinister cause. This can sometimes happen with panic attacks. An explanation of anxiety that a healthcare professional could offer the young person is: If a caveman saw a lion he would feel anxiety, which would flood his body with adrenaline to make his heart pump faster and his muscles fill with blood ready for action so that he could either run away quickly or prepare to fight the lion. The physical symptoms of anxiety are our body's way of preparing us to face a threat but in this setting it is counter-productive because the threats or triggers for anxiety

are doctors or chemotherapy or even the word 'cancer' and you cannot run away or fight, so you need to manage the physical symptoms of anxiety differently. Helping the young person to understand their experience of anxiety in this way can help reframe their racing heart as benign anxiety rather than a heart attack and can help them calm down more readily.

#### **Relaxation and breathing exercises:**

Young people can be taught relaxation techniques or shown breathing exercises for anxiety where the young person exhales for 2 seconds longer than they inhale to reduce the amount of oxygen in the blood. For some of the younger people it can be helpful to encourage them to blow bubbles to regulate their breathing (e.g., inhale for 5 seconds, exhale for 7). Additionally, people can imagine blowing all of their tension and fears into the bubble which then floats away. It is useful to explain that breathing in this way effectively reduces anxiety at a biological level as well as giving the young person a feeling of control and distracting them from the anxiety trigger by focussing on the breathing task. This can help calm the young person if they are acutely anxious or if they are beginning to have panic attacks generally.

**‘Worry time’:** It can be useful to suggest that if the young person is awake at 3 am worrying they should write down the worry then focus on it at a set ‘worry time’, i.e., in the morning when they are able to think more rationally and talk it through with another person rather than ruminating alone in the dark.

**Diary:** Writing down worries can make people feel like they are taking control of their anxiety. Often naming something and seeing it written down can make it seem more manageable. It can also feel helpful to have expelled the worry from one’s mind onto a page where it will stay safe, not be forgotten and can be addressed properly at their next appointment with you.

**Identifying triggers:** Recognising thoughts that trigger anxiety and helping young people identify strategies to manage them.

**Challenging avoidance:** More specialist support can use a graded approach with the young person to challenge anxiety and avoidance of activities, such as slowly building up time in a place where the young person feels anxious.

### Helping with depression

**Get to know the young person:** Just listening to a young person and empathising with their distress can make them feel less alone and more understood. For professionals who are going to have a lengthy relationship with a young person, it can be useful at the very beginning to tell them that you would like to get to know about them and their lives before they were diagnosed with cancer, to try to help them feel connected to the positive aspects of their pre-cancer identity.

**Plan small tasks:** In addition, it can be useful for the young person to plan daily activities. If the young person plans *small, achievable* tasks each day, they will obtain a feeling of success and accomplishment. The tasks can be incredibly small but it is important for the young person to retain a sense of purpose and have access to feelings of satisfaction.

### Promote independent functioning:

Normative young adulthood typically involves the development of increasing independence from one’s parent/family system, so maintaining some independent function and self-care tasks can be helpful. Some of the information about psychosocial well-being later in this chapter and the role of the OT and others may be helpful in this regard. However, it is also important to acknowledge that the young person has undergone a change in their self-perception into the role of a ‘patient’ and may therefore go through phases of needing to revert back to earlier dynamics of dependence with their parents, even perhaps to the point of sleeping in the same bed for a few nights. It is important not to pathologise this and allow families time and space to find a new way of adapting to the changing needs of the young person. If the young person does not wish to maintain their independent functioning it is likely that this is because it plays a protective function for them at that point, so it is advisable not to push them too hard if they are resistant. Every young person is different.

### Physical exercise

Physical exercise is usually positive for low mood because it releases endorphins, leads to a sense of achievement and often gives the young person access to fresh air and other people. Exercise tasks should be set up with the support of the physiotherapist as small, achievable goals to give the young person the experience of success, e.g., a 3-minute walk in the garden or from one end of their road and back or some arm stretches in their bed. It is important to validate this achievement *in the context of their current ability*.

**Psychoeducation:** It is useful to explain that at times of low mood, our thoughts, emotions, body and behaviour all influence one another in a negative spiral, e.g., when our body feels heavy and tired, our mood can feel flat and heavy and this mood tends to prime our thoughts to fall in sync and be somewhat negative or sad. Our behaviour is to withdraw socially and lie on the sofa with our sad thoughts. This is how low mood feeds itself. So although it can feel counter-intuitive to do anything active like a walk, it is helpful to break the cycle

of low mood. As evidence to support this a professional could design an experiment with the young person where they rate their mood out of 10 before doing some exercise then again after to see if it has changed.

**Be patient:** There is a limit to what can be done to reduce low mood when a young person is facing cancer. The young person might need space to just 'be' with their feelings of sadness but in the knowledge that there is someone who is interested in them, understands that they are feeling sad at the moment and can organise to be available to talk with them or access professional support at another time should they wish.

### *Problem solving*

**Help young people generate their own solutions:** Problem solving is a key part of how professionals can offer support to a young person. They usually have enough authority figures telling what they 'should' be doing, so it is more effective to help young people generate their own solutions. This can be achieved by asking questions about how they have coped in the past, what is helping them cope now, what resources and people are around for them and what they themselves want and CAN do.

**Help make problems specific and measurable:** For example, "if it was one month from now and the impact this problem has on your life had reduced and you were feeling happier, what would be different and how would I know?". If a young parent feels that they cannot look after their child like they used to, help them to think about other ways they can show their love and care for the child, for example "you cannot lift your child up right now but are there other ways you can care for her, such as asking her to sit on your lap for a cuddle or reading her a story?".

**Find out what young people enjoy:** It is important to remind young people (and their partners and family members) to be kind to themselves and try to find "pockets of happiness" each day in amongst the sadness and difficulty, where they treat themselves to something they enjoy, e.g., a bubble bath, a piece of music, a foot rub or a favourite meal.

## TOP TIPS

for helping young people manage psychological distress

- If you see a young person is feeling low, don't ignore it. Ask how they are coping and help them talk about their feelings.
- Remember to ask young people how they are coping emotionally as well as physically. Asking directly ensures young people know that they can talk with healthcare professionals about their emotional well-being as well as their physical health.
- Enquire about family members' emotional well-being also. Supporting family members will have a beneficial effect on the young person also.
- Show an interest in getting to know the young person. Spend some time finding out about their lives, important people and what they enjoy. This can help the young person feel listened to and that illness has not taken over their lives or identity.
- Help the young person remember the good aspects of their life and what they can do, or are looking forward to.
- Listen to the young person's worries and empathise. Help them feel they are not alone and you can help them access appropriate support if needed.
- Draw on the expertise and support of the wider MDT team. Contact with the physiotherapist, the OT, the Social Worker or the Youth Activity Co-ordinator may help the young person get through treatment.
- If the young person's low mood and distress persist and is interfering with their everyday life, refer to the Clinical Psychologist for more specialist mental health support.
- Help the young person understand that distress is normal in the context of a cancer diagnosis, and with the right support they will find ways to get through this tough time.

### Onward Referral

Psychological distress is an understandable and appropriate reaction to a cancer diagnosis, which does not always require onward referral to specialist mental health services. Sometimes just telling their Clinical Nurse Specialist or another health or social care professional and knowing that they understand can help the young person cope. However, if a young person's psychological distress reaches a worrying level or manifests in unhelpful or even harmful behaviours, the MDT should always consult or refer to Psychology or Psychiatry for supportive interventions. It is important that MDT members are aware of these referral pathways and are familiar with the referral process. Consent should always be gained from the young person involved, unless they are deemed to be at risk of immediate harm. Don't be afraid of mentioning psychology to the young person. If you are concerned that the young person might think you believe they are 'mad' or there is a stigma surrounding psychology, it can be helpful to mention this yourself and ask if they have such concerns. Research with young people indicates that many would have wished for unhindered access to psychological support, with some who had sought support reporting the referral process as difficult to manage<sup>16</sup>.

## OTHER IMPORTANT MENTAL HEALTH PROBLEMS

### Self-harm

The term 'self-harm' is used when an individual intentionally injures or harms themselves. Self-harm is usually a private and always a sensitive often misunderstood and confusing behaviour. As a result, there is a shortage of reliable information about self-harm in young people that does not result in the use of accident and emergency or other health services. It is estimated that young people presenting to hospitals represent less than 10% of the adolescent population who self-harm<sup>283</sup>. The available data suggests the majority of people who self-harm are aged between 11 and 25 years<sup>266, 284</sup>. A large study found that although 7% of 6,020 school pupils had self-harmed in the previous year, only 13% of those had presented to hospital<sup>285</sup>. Young people who self-harm are between 50-100 times more likely than the general population to die by suicide in the future<sup>286, 287</sup>.

### Reasons for self-harming

In a population based survey of 1,258, 18-20 year olds in Scotland<sup>288</sup> the most common reasons given for self-harm were:

- Relief of anger;
- Relief of anxiety;
- Wanting to forget about something;
- Desire to end life (this reflects suicidal intent discussed below).

Other reasons can include<sup>289</sup>:

- To punish themselves;
- To bring their distress to the attention of others.

It is imperative that health and social care professionals working with young people are alert to the possibility of self-harm and are able to refer promptly to Psychiatry or Clinical Psychology.

### Methods of self-harm

The following have been reported as the most common methods of self-harm amongst young people<sup>288</sup>:

- Cutting
- Scoring
- Scratching
- Taking dangerous tablets
- Burning (rare)
- Punching (rare)

## TOP TIPS

### when concerned about self-harm

- Tell the young person you are concerned for them and reassure them that with help they can find safer, alternative ways of coping with adversity.
- Ensure the young person is aware of the risks of self-harm.
- Recognise signs of distress and talk openly with the young person about how they are feeling.
- Listen to the young person's worries and problems and take them seriously.
- Help them identify any aspects of their lives that are going well.
- Check out who else is aware of the young person's self-harm.
- Help the young person share this information with trusted adults in a sensitive and supportive manner.
- Ensure the young person is referred to appropriate mental health services as soon as possible.

### Suicidal Ideation

After cardiovascular disease and cancer, suicide is the next most common cause of death<sup>290</sup>. Suicide is the leading cause of death for men and women aged 20-34 years, accounting for 26% of male fatalities and 13% of female deaths<sup>291</sup>. Suicide rates are consistently highest among young men and more than double in 20-24 year olds compared to 15-19 year olds<sup>292</sup>. Young people who attempt to take their own lives often feel hopeless or do not know where or how to get help. Young adults aged 15-30 diagnosed with cancer have an increased risk of suicide attempts compared to age-matched peers in the general population. This could be because young people have not had long enough to develop effective coping strategies for stress<sup>293</sup>.

The risk of suicide is higher when a young person<sup>294, 295</sup>:

- Is male;
- From a lower income group;
- Has untreated depression or when they have a psychiatric diagnosis;
- Is self-harming or has a history of self-harm;
- Is misusing drugs or alcohol;
- Has previously attempted or planned suicide;
- Has a relative or friend who died by suicide or attempted suicide;
- Is socially isolated;
- Is involved with the criminal justice system;
- Feels hopeless;
- Has a history of abuse;
- Has painful or physically disabling illnesses including chronic pain;
- Is LGBT (lesbian, gay, bisexual, transgender) identified.

#### Talking about suicidal thoughts

Asking the young person if they have ever thought about ending their life will NOT cause them to carry it out or put the idea in their head. Instead it will ensure a young person knows that they can talk about these feelings with healthcare professionals and access support. A useful response can be to state that suicidal feelings are “worrying” to show them the importance of what they are saying and communicate that you are taking them seriously.

There are various aspects of suicide that are worth asking about but it is important to **always refer** to mental health services or consult a psychiatrist. Here are some useful areas to include in questions and conversation about suicidal thoughts:

<b>Ideation:</b>	Ask directly if they have thought about ending their life or killing themselves. Do not be afraid to use these words.
<b>Intent:</b>	Ask about whether they intend to end their life.
<b>Plans:</b>	Ask whether they have considered how they would kill themselves. Find out if they have access to means e.g., prescription drugs, ligature etc.
<b>History:</b>	Ask if they have ever felt like this before or attempted to kill themselves before. If so how, or if not, what stopped them? Has anyone close to them ever attempted or died by suicide?
<b>Protective factors:</b>	What would stop them from killing themselves, e.g., family, religious beliefs?
<b>Knowledge of resources:</b>	Ask the young person what they can do if they feel unsafe. Ask if there is anyone else who knows they are feeling this way. Help them to identify trusted adults in their lives who would be able to help. These can be people in their informal personal network or trusted professionals they have got to know. Tell them the options, e.g., speak to a loved one, speak to a trusted adult, go to accident and emergency, call an ambulance, call the Samaritans (give them the number or one for another crisis helpline), call NHS Direct, contact their GP

#### THE MOST IMPORTANT THING TO DO IF SOMEBODY EXPRESSES SUICIDAL THOUGHTS is to SHARE THE INFORMATION.

Document everything and share the information, create a safety plan with the young person and the other health and social care professionals providing care to them. It may be important to share concerns with the young person’s family or loved ones. This should be carefully negotiated with the young person first and where possible consent sought. If the young person states they do not wish to tell their family, enquire what they are worried about. Sometimes young people’s worries are unfounded. Encouraging the young person to reach out to trusted adults can be a good first step in accessing support. It is important however to then follow-up with the trusted adults and the young person to support and facilitate access to appropriate professional care.

## TOP TIPS

### when concerned about suicidal thoughts

- Don't be afraid to ask about suicidal thoughts, plans and past attempts! Your question will not put the idea in a young person's mind.
- Teams working with young people should be mindful of a young person's mood throughout treatment and be aware of any history of self-harm or suicidal thoughts/actions.
- Suicidal thoughts should always be taken seriously.
- **Always** consult with senior colleagues and together decide the most appropriate plan of action.
- Explore with the young person whether they have made suicide plans.
- Help the young person identify trusted adults in their lives who they can share their feelings with.
- Always follow-up with trusted adults to ensure they are aware of the young person's suicidal thoughts or plans.
- Help the young person create a safety plan.
- If a young person has suicidal thoughts, they should be referred to appropriate mental health services as soon as possible.
- If a young person is actively suicidal, they may require an immediate mental state assessment.
- Be familiar with your organisation's suicide prevention policy and the numbers for on-call psychiatry and other local resources.
- Safety planning and risk of suicide require consistent reassessment on every contact until the risk has abated and stabilisation achieved.

## PHYSICAL WELL-BEING

### COMPROMISED WELL-BEING: THE PHYSICAL SIDE-EFFECTS OF CANCER AND TREATMENT

The specific diseases and treatment regimens that young people with cancer experience cause a vast array of physical side-effects, both in the short and long-term.

At their most profound, physical deficits can limit a young person's ability to function independently and to engage in normal daily activities. At a time of life when peers are starting to forge independence from parents, spending most of their

time with friends and making decisions about their future, this can be devastating. Even seemingly minor deficits can impact on a young person's everyday life and social interactions.

Young people have identified physical limitations as their greatest unmet need during treatment, which also impacts their psychosocial well-being<sup>296, 297</sup>. Addressing physical deficits can help reduce the physical burden of cancer in young people and minimise the disease impact on the young person's life.

### PHYSIOTHERAPY: PROMOTING WELL-BEING THROUGHOUT THE ILLNESS TRAJECTORY

The aim of the Physiotherapist working with young people with cancer is to enable a minimum level of dependency and to optimise quality of life regardless of life expectancy. This involves directly addressing the physical side-effects of cancer and its treatment and facilitating an active lifestyle in order to maximise general health and well-being and prevent secondary complications.

Physiotherapy with young people requires a flexible approach. Having the service available later in the day than standard physiotherapy hours (e.g. 10am-6pm instead of 8am-4pm), having an informal referral system including self-referral and using text message and email to communicate are all aspects of service delivery noted to increase treatment compliance and engagement. Working closely with the wider

“Physiotherapy is useful for relieving pain in areas such as my back and legs.”

(male, aged 22, acute myeloid leukaemia)

“Physiotherapy helped me walk again and get my leg stronger. Now I almost feel like my good old self again!”

(female, aged 17, following limb salvage surgery for osteosarcoma)

“No matter what happened (and a lot has) physiotherapy always made me feel there was something I could do to help myself and I left feeling better afterwards”

(male, aged 20, following stem cell transplant for acute myeloid leukaemia)

MDT allows regular exchange of information, which will help tailor physiotherapy input appropriately.

The physical side-effects of cancer and its treatment can extend well beyond treatment completion. Survivors of young adult cancers have lower quality of life than their peers and more days of poor physical health<sup>298</sup>. On-going physiotherapy is therefore vital to continue addressing physical deficits and to maximise quality of life.

Groups who will be in particular need of on-going physiotherapy include:

- **Those who have been treated for brain and central nervous system lesions:** Their needs will often be complex and neurological recovery (where possible) is slow. For severely affected individuals input may be required from specialist neuro-rehabilitation teams in dedicated units. Appropriate discharge planning and community support is vital for such patients. For those with less extensive neurological deficits it is important to have access to physiotherapy as and when needed.
- **Those who have had limb salvage surgery or amputations:** Rehabilitation following these operations is lengthy and complex and young people often aren't well enough to fully engage with physiotherapy until their chemotherapy treatment is completed. Referral to the individual's local musculoskeletal physiotherapy service or wheelchair and prosthetic centre is needed to ensure input continues after cancer treatment ends.
- **Those who have had a stem cell transplant:** Due to the intensity of this treatment individuals may become extremely deconditioned and lose independent function. Graft versus host disease can cause musculoskeletal deficits and individuals are at risk of repeated infections such as chest infections. Physiotherapy may be required to address these issues.
- **Those suffering from osteonecrosis as a result of steroid treatment:** This is a disabling orthopaedic condition causing pain, joint restrictions and reduced mobility. In young people this is mainly seen following treatment for leukaemia particularly acute lymphoblastic leukaemia. Physiotherapy is required to minimise symptoms and maximise function.

“Recovering from cancer is a difficult process and even though it's a year since my treatment finished, I still feel very weak and tired a lot of the time, and as a consequence, I don't really get out much.”

(male, aged 23, following treatment for rhabdomyosarcoma)

## TOP TIPS

### for promoting physical well-being

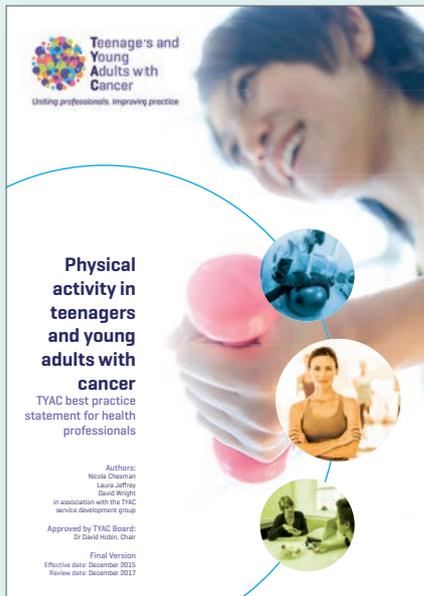
- Ensure that physical ability/function is part of the holistic assessment process so that timely referral can be made to physiotherapy.
- Promote basic physical activity throughout the patient pathway where possible.
- Provide opportunities for exercise during and after treatment, either through specialist professionals or by engaging services from the young person's local community.
- Ensure access to physiotherapy continues into survivorship.
- Consider referral to physiotherapy throughout the patient pathway, including end of life care.

Even as the goals of cancer treatment change to palliation and end of life care, physiotherapy can help young people adapt to their changing physical ability and work towards their personal goals. Input may include providing equipment and advising on techniques to facilitate independent mobility and function where possible, positioning for pain relief and breathlessness management.

### PHYSICAL ACTIVITY AND EXERCISE

Physical activity is an essential component of a healthy lifestyle. In the general cancer population regular physical activity improves quality of life, physical and psychosocial function and has been linked to increased disease-free survival<sup>299, 300</sup>. Regular physical activity is recognised as an effective way for people during and after cancer treatment to minimise the side-effects of their disease and treatment and to optimise general health status. Moderate levels of physical activity during and after cancer are recommended by leading national bodies<sup>299, 301, 302</sup>.

However, young people during and after cancer treatment have tended to not do enough physical activity<sup>303</sup>. The level of activity has been shown to be below that recommended to maintain basic health and to prevent common long-term conditions such as diabetes mellitus, coronary heart disease and obesity<sup>302, 304, 305</sup>. Given the potential number of years that young people may live with and beyond cancer, plus the elevated risks for health problems due to the side-effects of cancer treatments increasing levels of physical activity and exercise is essential to maximise health and well-being.



To download the Best Practice Statement Physical activity, please go to the TYAC website: [www.tyac.org.uk](http://www.tyac.org.uk)

Young people themselves recognise this need, with 88% of young people at the 2013 Find Your Sense of Tumour conference feeling that their treating hospital should provide them with exercise advice. Only 28% reported having access to organised exercise and 32% had received exercise advice<sup>306</sup>.

**“Really great fun, met new people and it’s a good way to gain my energy back”**  
(female, aged 20, following participation in an exercise scheme after treatment for leukaemia)

The potential causes of reduced activity and exercise include a reduction in both routine activities of daily living (such as walking, climbing stairs) and in more intensive exercise activities (such as going to the gym, playing sport). Physical deficits can present significant barriers to engaging in activity and may make young people more dependent on those around them for routine tasks. Prolonged hospital admissions, which may include enforced isolation due to immuno-compromise may provide little stimulus or opportunity to spend time out of bed and it may be physically difficult due to feeling generally unwell. Young people may be unable to engage in their usual everyday activities outside of treatment, such as work, education and social activities. Emotional barriers to activity and

## TOP TIPS

### for promoting exercise and activity

The reasons behind reduced activity are often multiple and complex, requiring a multi-faceted approach.

- Address any physical deficits which may act as barriers to activity and exercise
- Work with the wider multi-disciplinary team to identify and support TYAs with emotional barriers to activity.
- Provide advice and education on the importance of activity and exercise to young people and their wider support network as soon as possible during the cancer pathway. This advice should be adapted to individual circumstances and abilities.
- Create an inpatient environment which promotes activity and independence.
- Establish a timetable of organised activities and encourage young people to use different spaces on the ward instead of remaining in their room or treatment bay
- Investigate what exercise opportunities already exist in the young person’s locality (e.g. GP exercise referral, disability sport) to provide an exercise opportunity if this is not available through the hospital.

**“I gained my health and energy back after long-term treatment”**  
(male, aged 19, following an exercise scheme after treatment for a brain tumour)

exercise may also be present, such as low mood, poor self-confidence and anxiety (discussed in other parts of this chapter). Young people and their families may feel anxious and fearful of causing harm by doing “too much” or the “wrong” thing, and believe that rest is best. In addition, it is part of normal development for TYA to need more sleep and to feel more tired than adults so poor activity levels may be an exacerbation of normal behaviour<sup>307</sup>.

Interventions to increase physical activity in young people during and after cancer treatment have resulted in increased quality of life, reduced fatigue, increased physical fitness and improved mood and confidence<sup>303, 308, 309</sup>. Appropriately qualified Physiotherapists and

exercise professionals are well placed to deliver exercise programmes and advice what can help young people maintain an appropriate level of physical activity and prevent/minimise health complications. Dependent on the young person this could vary from facilitating usual activities of daily living to re-engaging them in high level exercise and sport.

### **FATIGUE**

Young people with cancer experience significant and disabling fatigue both during and after treatment<sup>307</sup> necessitating a multi-disciplinary approach including Physiotherapy, OT and other health professionals such as dietitians. Fatigue has been linked to distress and poor quality of life and is a barrier to engaging in normal activities<sup>303, 307</sup>. Physical activity is recognised as the most effective way of managing adult cancer related fatigue and studies involving young people have also shown improvements<sup>307, 310</sup>. Young people therefore need education and guidance around fatigue and how to introduce appropriate activity levels to avoid a cycle of increasing fatigue and reduced activity.

## **TOP TIPS**

### to help young people cope with fatigue

- Help young people recognise that fatigue negatively affects anyone’s ability to function and can constrain independence for a period of time.
- Provide information and advice about strategies to manage fatigue and conserve energy.
- Help the young person understand the need to adjust to change, accept some dependency and that fatigue symptoms may be unpredictable.
- Help the young patient establish realistic expectations and personal goals.
- Utilise the opportunity provided by reduced energy levels to help the young person establish what is important to them and what their priorities are.
- Help young people adapt their lifestyle to meet changing energy levels; providing equipment and adapting the environment where necessary.
- Educate and advise young people on the importance of physical activity in managing their fatigue, and provide guidance and support in achieving an appropriate activity level.

## PSYCHOSOCIAL WELL-BEING

### THE PURSUIT OF 'NORMAL'

Young people suffering cancer face many unique psychosocial challenges, the illness and its treatment delaying or derailing normative social achievements. Research has indicated that although coping strategies vary from person to person depending on the stage of illness and the young person's pre-cancer lives, a prevailing goal for many young people was to achieve what they called 'normalcy'<sup>38, 105</sup>. For some, this meant 'picking up' where they had left off before diagnosis, while for others it involved the creation of a 'new normal'<sup>234</sup>. This pursuit of 'normal' is thought to be uniquely important to this age group of patients due to their developing sense of personal identity<sup>229, 234</sup>. For most young people it is therefore important to try and maintain as much normality as possible throughout their diagnosis and treatment to help sustain their coherent sense of identity.

### PROMOTING PARTICIPATION IN LIFE

A number of members of the MDT can assist in this regard in particular the OT, Social Worker and Youth Support Co-ordinator. Encouragement to engage in normal activities such as work, education and social activities can help a young person retain a sense of normality throughout treatment. This in turn can reduce psychological difficulties such as anxiety or low mood, helping the young person gain a revised sense of achievement and purpose. It is important to talk to the young person about what is important to them, what they would like to be able to do, while ensuring personal goals are reasonably achievable within in a specified time frame.

## TOP TIP

### for promoting motivation

- Encourage the young person to design their own goals. This can help them identify progress and also enhances emotional well-being and maintains motivation. It is often helpful to involve parents/carers/family to provide encouragement.

### OCCUPATIONAL THERAPY: ADJUSTING TO LIFE WITH AND BEYOND CANCER

OTs work closely with young people to assess the impact of their cancer diagnosis on their daily lives, helping to optimise independence so that they can do the things they want to while living with cancer. OTs also help support young people following completion of treatment exploring with the young

person what they would like to do in their everyday life as well as any longer-term ambitions and helping them to address barriers (whether physical or psychological). The role of the OT is to assist young people adjust to living with or beyond cancer by<sup>311</sup>:

- Helping the young person access meaningful occupations and activities;
- Reducing or managing physical symptoms (pain, fatigue, breathlessness);
- Reducing psychological symptoms (anxiety, low mood, low self-esteem, anger);
- Supporting the development of coping skills and promoting positive mental health;
- Increasing independence in tasks and activities;
- Improving or maintaining physical function;
- Improving quality of life.

“Occupational Therapy helped me to regain ‘normality’ at the end of treatment. After having so many setbacks she really helped by being there to talk to and looking at practical ways to get my life back on track”  
(24 year old male, Leukaemia)

“I struggled with lack of confidence at the end of my treatment. I found it impossible to hold conversations with people and avoided going out. This made me feel really down and also annoyed with myself because after what I'd been through having cancer I should be able to do anything. My Occupational Therapist helped me to think differently about myself and I was able to build my confidence back with her support”  
(22 year old male, 2 years remission for Lymphoma)

### PROVIDING EQUIPMENT

Sometimes equipment is required to maximise independence and special consideration needs to be taken when addressing equipment provision for young people. Equipment may involve larger items such as bath-boards, toilet frames, shower stools, or wheelchairs to promote safety and

independence but the young person may be reluctant to accept equipment due to the way it looks. However, this can be overcome through sensitive discussion and negotiation. It is also important for the OT to assess the person in their home environment and liaise with appropriate community services such as social services if larger adaptations are required such as stair lifts, bathroom adaptations or re-housing if their current living situation is inappropriate for their needs, e.g. living in a flat with many stairs and no elevator if they use a wheelchair.

“I was having trouble bending to pick things up due to joint problems so the Occupational Therapist gave me some equipment to help me be more independent. I have been able to use the helping hand/grabber to get dressed myself but also use it to play with my nephew and niece and their toys. I can be involved in fun things now too and not feel like a boring auntie anymore!”

(22 year old female living with long-term side effects from stem cell transplant for Leukaemia)

There has been a gradual recognition that rehabilitation does not simply involve getting young people to function independently again. It means affirming people's lives no matter what stage of illness even toward end of life. OT continues to be important in helping young people toward the end of life to maintain as much independence as possible. Equipment may also help with comfort and safety at the end of life.

## SOCIAL WELL-BEING

One of the most pressing challenges identified by young people is the perception that their social identities and existing relationships with peers, family and friends are altered following diagnosis<sup>231</sup>. In addition to other members of the MDT, Social Workers and Youth Support Co-ordinators play useful roles in addressing these challenges.

### FAMILY SUPPORT

#### Changing family relationships and compromised well-being

Young people with cancer have identified family relationships and in particular their mother as vital sources of support<sup>74, 243, 275</sup>. The impact of a TYA cancer diagnosis is known to have a profound and long-lasting effect on the well-being of all family members as established relationships are thrown into crisis (Grinyer, 2008). Not unlike the ill young person, family members and in particular primary carers and parents experience overwhelming changes to life as previously known. They too report feeling powerless and must adapt to new roles and responsibilities, live with the uncertainty of an unknown future and increased financial concerns<sup>312</sup>.

Adolescence and young adulthood is known to be an important phase in the individual and family life cycle with particular challenges for both young people and parents alike<sup>103, 313</sup>. With the onset of life-threatening illness, parents and young people are often thrown together in unexpected ways and spend more time together than they may have for many years. This can be challenging for both as they must negotiate the fluctuating dependence and independence associated with cancer treatment.

Young people can struggle with their normative developmental drive for autonomy while simultaneously

## TOP TIPS

### when discussing equipment

- Spend time explaining to the young person what the equipment is for and how it can help.
- Give examples of other young people who have found equipment helpful or ask them to talk to the young person about their positive experience of the equipment.
- Encourage them to try the equipment so they can experience the benefits.
- As much as possible, work with the young person to find equipment that is more pleasing to the eye. Items can be purchased privately that are more age-appropriate. In the UK the NHS has a wheelchair voucher scheme that gives patients the option of purchasing their own wheelchair (more stylish options) with an NHS contribution

desiring the safety and comfort of childhood, which is intensified when faced with life-threatening illness<sup>222</sup>. They may wish to exert their independence at a time when parental dependence is mandated by the demands of illness<sup>210</sup>. These contradictory impulses have been known to evoke feelings of frustration and lack of control. As well as a source of emotional support parents are known to play an important role with regard to the young person's medical needs, supporting treatment adherence, appointment attendance, information exchange and healthcare vigilance<sup>312</sup>. They too must get used to the layout, language and professional dynamics of a healthcare setting and find ways to establish their role in this highly professionalised environment<sup>314</sup>.

While noting the importance of supportive healthcare professional relationships, parents also report struggling to find their place in the healthcare system, feeling at times unwelcome and on the periphery<sup>312</sup>. Negotiating and managing communication that prioritises the rights and needs of the individual young person while understanding the importance of family support raises complex challenges for healthcare professionals, young people and families alike<sup>222</sup>. Coping with these multiple challenges is known to negatively impact family well-being, with some research indicating that the long-term negative impact on parental well-being may be greater than on the adolescent survivor<sup>274</sup>. While NICE recognises the central role that families and carers play in supporting patient well-being it is acknowledged that their own needs often go unrecognised and professional support is not always available<sup>315</sup>.

### **Social Work: supporting young person and family resilience**

The Social Work role in TYA cancer care is multi-faceted addressing the emotional, practical and financial needs of each young person as well as supporting key carers and the wider family network to help manage these unforeseen challenges<sup>316</sup>. While primarily hospital-based, Social Workers also visit young people and their families in their homes and communities liaising closely with teachers, schools, colleges and significant others. In the UK, these positions are often funded by the Local Health Authority or charities such as CLIC Sargent.

### **PEER SUPPORT**

Young people living with cancer often report social isolation as they struggle to maintain friendship or initiate new relationships to maintain effective social support<sup>228</sup>. Peer contact with other young people living with cancer is recognised as an important source of emotional support and a critical component of 'age-appropriate care'<sup>16, 317, 318</sup>.

### **Group activities: Promoting peer contact and relationships**

Recognising the significance of peer support at this developmental life stage, which is often compromised by cancer and its treatments<sup>231</sup>, peer groups can help young people share experiences, talk about concerns and have fun. In this way, young people are supported to regain some control over their lives. OTs, Youth Support Co-ordinators and other members of the MDT are trained in group work. This can be especially useful to encourage peer support.

## **TOP TIPS**

### **for supporting family well-being and resilience**

- Get to know the names of important family members. Help families feel welcome in the hospital environment.
- Family's lives are interconnected. Supporting family relationships will enhance the well-being of the young patient.
- Remember that family members will have their own struggles and needs that may require support. Refer to Social Work if you become aware of unmet family needs.
- Most families are doing their best in difficult circumstances. When conflict emerges between parents and young people, keep in mind the context of normal adolescent development and the abnormal experiences and challenges for all family members presented by TYA cancer.
- When faced with a dilemma, work closely with the young person and family members, always prioritise the best interests of the young patient but seek to understand the challenges for parents and find ways to support them also.
- The shock of a TYA cancer diagnosis and entrance to an acute healthcare system can elicit alienation, under-confidence and passivity in young people and their families. Healthcare professionals can help families navigate the system, providing explanation and orientation, enabling familiarity and predictability at a time of great uncertainty.

While more common in specialist TYA units, organising group activities or other social events, which encourage peer contact is possible and all the more important in non-specialist treatment centres where young people will not naturally meet other young people and families facing similar concerns. Groups can have a variety of purposes from psychosocial support, to educational and information giving, encouraging engagement in functional activities. The creative possibilities are endless.

### Youth Support Co-ordinators: promoting youth development

The role of the Youth Support Co-ordinator within the MDT is unique to the UK. Funded by Teenage Cancer Trust these post holders tend to be based in Teenage Cancer Trust units. Their role primarily is to complement the work of the MDT by providing unique support services tailored to patients' needs as young people, rather than illness. They view patients as young people who happen to have cancer not cancer patients who happen to be young. They offer one-to-one support and organise age-appropriate group activities to keep young people active, engaged and connected with others, including their friends who have a cancer diagnosis and those who don't. The non-clinical role of the Youth Support Co-ordinator aims to create space and activities in an informal and relaxed atmosphere that facilitate opportunities for young people to foster resilience and continue to develop socially and emotionally.

### Body Image Support Group

Some young people struggle with the changes to their body image induced by cancer treatment and the potential long-term side-effects. This can have a psychologically damaging effect on young people who just want to fit in and appear 'normal' to their peers<sup>16</sup>. A body image support group enables young people to meet other people going through a similar experience. This gives them the opportunity to talk about how changes to their body have made them feel and to learn tips for improving confidence. Conversations within the group cover a wide range of themes ranging from feelings around hair loss, weight changes, scars, skin changes, to loss of limbs and fertility. Following attendance at the Body Image Support Group facilitated by the OT at The Christie Hospital (Manchester, UK), young people reported improved confidence levels. They also stated that they had found it beneficial to talk to other young people and felt less alone with their feelings about body image changes.

### Functional activity groups

Age-appropriate functional activity groups can also be facilitated such as baking groups, preparing meals and pizza groups. Young people who attend such groups indicate that it is beneficial to meet other patients who understand a little more about how they might be feeling and gain a great deal of peer support from these interactions. The groups also help address issues such as healthy eating and promote nutritional intake for patients who often dislike hospital supplied meals.

## TOP TIPS

### for TYA activities

- Engaging a young person in an individual or group activity can be a useful context to encourage dialogue, discussing thoughts and feelings in a relaxed environment. Activities can also help young people make new friends and get support from other young patients, reducing feelings of isolation and promoting normal peer contact.
- Make sure activities are meaningful and interesting for the young person, based on activities they enjoy, for example using cooking activities, games consoles or playing pool.
- Consider engaging young people's families as this can help strengthen important relationships and feel welcoming and inclusive.
- Start small and be creative. Build relationships with other members of the MDT or wider hospital staff who may be interested in becoming more involved and may have a particular interest, skill and original ideas that could be helpful.
- Think about involving charities such as CLIC Sargent, Teenage Cancer Trust or Northern Ireland Cancer Fund for Children as they may have expertise that you can utilise in your setting.
- It is helpful to regularly complete patient satisfaction audits to find out what young patients think of TYA services. Young people themselves may have very helpful suggestions for improving TYA services.

Group attendance also provides psychosocial and physical rehabilitation, where patients are actively encouraged to move away from their bed areas. Being occupied and distracted by activity can help to reduce anxiety and low mood.

### Arts projects

Other possible TYA activities include arts and media projects, such as the JTV cancer support project, which allows young people to share their experiences of cancer creatively (<http://jtvancersupport.com>). One such project took place in the adult treatment centre of Belfast City Hospital where the TYA Social Worker and hospital Artist in Residence collaborated on an Arts project 'Moment by Moment', funded by local

charity. This project worked with young people and their families on the ward and in day-patient contexts using mediums such as screen printing and multi-media to talk about and depict their illness experiences in different ways or simply try a new activity. Project participants were supported to talk about difficult times, what had helped along the way, their hopes for the future, celebrate happy times and simply have fun. Healthcare professionals could also join in. Art pieces were then displayed on the ward and a DVD created. Such projects can provide a focus, helping young patients and family members talk about cancer in different ways, meeting other young people and families going through similar experiences. Such events can help young people and families break the silence, fear and isolation that often surrounds illness, make new relationships and find their voice and confidence in the unfamiliar hospital environment.

## PROFESSIONAL WELL-BEING

### THE IMPORTANCE OF SELF-CARE

One of the most important things professionals can do in their job is to look after themselves. Professionals are human too. It is highly likely that they will experience their own psychological distress and emotional reactions to some of the young people with whom they work. This might not just be sadness or hopelessness, but might also be feelings of frustration or anger. For example, it can be hard sometimes to be compassionate and empathetic to a young person who is very upset about something considered to be fairly minor in comparison to the difficulties of the young person they may have just seen before them.

### SELF-CARE IN ENDINGS

It is important to acknowledge that members of the MDT may form close relationships with the young people they work with. They often also get to know their families and witness some of the emotions they experience along the cancer journey. While some young people will get better, some will not and some will sadly die.

Although close relationships may have been built with the young person, the professional may not get a chance to say goodbye or attend the funeral. Moreover, they may find out about their death in informal settings such as a corridor conversation on way to a clinic, which may cause distress. Since they worked with the young person in a professional capacity, the 'professionalisation' of the relationship can influence professional's beliefs about how much they 'should' grieve their death and what grieving in a healthcare role 'should' look like. Current literature encourages professionals to ignore the word 'should' in this instance and acknowledge their feelings. Smith & Martin<sup>319</sup> have written a useful chapter about mourning and grief in a professional context.

Reflective practice groups and team debriefs can be important for working with people who are dying. It is

important to remember that practitioners are human too and that they may experience distressing emotions in relation to some deaths. Practitioners are entitled to feel upset when a young person dies and this is not something that should be suppressed or criticised, even if the death was anticipated

## TOP TIPS

### in self-care

- Try to switch off when leaving work.
- Recognise the limits to what can sometimes be done.
- Talk to colleagues.
- Share clinical responsibility within the team.
- Use clinical supervision and reflective practice groups.
- Seek personal psychological support if needed.
- Remember to be kind to yourself and look after your own needs as well as those of others.
- Take regular breaks and use annual leave.
- ***Looking after your own well-being will help you promote the well-being and resilience of the young patients you care for and their families.***



**TEENAGE  
CANCER  
TRUST**  
FIND  
YOUR  
SENSE  
OF  
TUMOUR

CANCER TRUST FIND YOUR SENSE OF TUMOUR

**TEENAGE  
CANCER  
TRUST**

# CHAPTER EIGHT: LIVING WITH AND BEYOND CANCER

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## INTRODUCTION

The increasing success of cancer treatment has resulted in a growing number of young people who have survived their cancer. Recent figures show that 26,700 people are living with or beyond cancer, having been diagnosed as a 15-24-year-old<sup>320</sup>. This tells us how many young people survive for up to 20 years and gives an indication of the numbers of TYA patients who may go on to have survivorship needs later in life.

For these young people with cancer ending treatment may not represent 'the end of the cancer story'<sup>225</sup> with many reporting the experience as a life-changing event with consequences for their physical, psychological and social well-being in the short, medium and longer-term. The long-term side-effects or late-effect sequelae are often specific to the type of cancer or the treatment that the young person has had and can range from relatively minor deleterious impact to very significant conditions. Physically, as young people live with cancer there are accumulated effects of the treatment on healthy tissues and organs and in rare cases, secondary malignancies or organ failure may develop. Psychosocial late-effects can also have an impact on short and long-term quality of life.

Patients at risk of long-term effects are a vulnerable group who should be reviewed on a regular basis. Protocols, referral pathways and risk strategies that identify patients who are at high, medium and low-risk of developing serious late-effects (according to disease and treatment types) should be implemented by treating teams. The psychosocial long-term effects of cancer may be addressed through individual and group survivorship programmes. These programmes support patients to achieve psychological and emotional well-being and to resume education or career pathways (see **Chapter 6 and 7**). They also provide financial advice and help young people find ways to manage the emotional impact of cancer treatment.

## PREPARING FOR LIFE AFTER TREATMENT

The impact of cancer as a young person may last much longer than the treatment itself and it is important to start

the preparation for transition into post-treatment support as early as possible. Young people report that going through such a traumatic experience at a critical period in the life-course and having faced issues their peers will never have contemplated, makes them re-evaluate what is important in their lives and many come through the experience with a valued new perspective<sup>321</sup>. On treatment completion there may be a period of adjustment as the young person tries to re-establish their life trajectory. A young person's cancer experience, although it will always be part of their story, should not come to define who they are. Instead, young people should be supported to recover and move forward with future plans and ambitions. This can be achieved by allowing them to talk of their experiences, identifying and affirming important coping strategies, resilience and personal and professional resources and integrate the learning from their cancer experience into their lives and hopes for the future.

Maintaining a sense of control should where possible, start from diagnosis with young people supported to continue with existing activities through treatment<sup>322</sup>. Young people are known to value opportunities to maintain a sense of normalcy throughout treatment<sup>59, 229</sup>. Minimising the disruption caused by cancer by supporting continued engagement with friendships, education, employment and social opportunities if at all possible throughout treatment can help young people retain a link to their life before cancer and facilitate their on-going life-course development. This can make the transition into post-treatment support and follow-up care less daunting<sup>229</sup>.

As treatment nears completion support from peers who face similar challenges and staff who are skilled and experienced in supporting young people through this period is invaluable in helping young people process their experience<sup>59, 229</sup>. However, it is equally important that young people do not become overly dependent on TYA cancer services, which are unlikely to be equipped to meet their needs in the long-term. In some cases, it may be necessary to signpost or facilitate referral to local support programmes or specialist services. TYA services should be designed to facilitate rapid engagement post-diagnosis and phased disengagement post-treatment with strategies put in place to support young people to move forward (see also **Chapter 6**).

## TOP TIPS

### preparing young people for life after treatment

- Support in maintaining a sense of control and normalcy through treatment is recommended. This can be achieved by facilitating friends visiting hospital during treatment, encouraging the young person to maintain contact with education/employment in some capacity and accommodating the young person's life outside hospital through flexible treatment planning where possible.
- Goal setting throughout treatment and beyond is encouraged to help young people plan for the future.
- At the appropriate time encourage return to work or education if this is realistic. This may be on a staged or part-time basis. For those for whom return to previous vocation is not achievable, help them explore new opportunities.
- Any limitations regarding the use of TYA services should be made clear from the outset. For example, access to peer support groups post treatment may be time limited and decrease in frequency over time.
- There should be a mechanism for identifying young people who are likely to require additional support to help establish their life after treatment. Carrying out a holistic needs assessment will help highlight unmet needs.

## LIFE AFTER TREATMENT

The survivorship of young people with cancer has been on the NHS Improvement and National Cancer Survivorship Initiative (NCSI) agenda in recent years. The Children and Young People work stream was one of seven work streams conducting improvement work as part of the NCSI<sup>202</sup>. Their aim was to address the challenges faced by the NHS due to the increase in cancer prevalence and the evidence of unmet needs for young cancer patients, many of whom need a range of clinical and non-clinical services to support them to manage their own care and take back control of their lives<sup>323</sup>.

To support this, the NCSI developed the Recovery Package, which aims to improve outcomes for young people through providing access to tailored support relevant to their unique needs, encouraging independent healthy living and reducing the long-term demand for services<sup>202</sup>. This programme also enables specialist teams to offer individualised stratified follow-up care ranging from supported self-management to multi-professional support provided by the treating team<sup>323</sup>. The Recovery Package consists of four key components (**Figure 8.1**):

**Figure 8.1:** The NCSI recovery package<sup>202</sup>



### TREATMENT SUMMARY

This is a document developed for the patient and copied to their GP. It is produced by the specialist team at the end of treatment and subsequent trigger points, such as following further treatment. It provides information relating to the young person's diagnosis, specific treatment and an on-going management plan. The document summarises potential late-effects, provides alerts to symptoms of recurrence, a secondary on-going management plan, GP actions and any on-going surveillance. A summary of information is given to the patient. This includes treatment goals and lifestyle advice as well as key contacts and access routes back to the treating team in the event of future concerns.

The document supports improved information sharing between secondary and primary care. It can also be used by young people for other practical purposes such as returning to work or gaining travel insurance<sup>324</sup>. For young people who started treatment as a child it can be an important document to support retrospective understanding of their illness and treatment and transition to adult services where necessary (**Figure 8.2**).

**Figure 8.2:** Example of a treatment summary for young people with acute lymphoblastic leukaemia

<p><b>PLEASE READ THIS DOCUMENT</b></p> <p><b>Treatment Summary</b></p> <p>Insert GP Contact Details and Address</p> <p>Dear</p> <p><b>Re: Add in patient name, address, date of birth and record number</b></p> <p>Your patient has now completed their initial treatment for cancer and a summary of their diagnosis, treatment and ongoing management plan are outlined below. The patient has a copy of this summary. When meeting this patient in a GP appointment, please consider that symptoms being experienced could be a late effect on their cancer treatment.</p>			<div style="border: 1px solid black; width: 100px; height: 100px; margin: 0 auto;"> <p>trust logo HERE</p> </div>
<p><b>Diagnosis:</b> Acute lymphoblastic leukaemia</p>	<p><b>Date of Diagnosis:</b></p>	<p><b>Organ/Staging</b> <b>Local/Distant</b></p>	
<p><b>Summary of Treatment and relevant dates:</b> <b>Cumulative anthracycline dose:</b></p>		<p><b>Treatment Aim:</b> Curative</p>	
<p><b>Possible treatment toxicities and / or late effects:</b> Many people will be cured of leukaemia and most will be healthy once they have recovered from their treatment. A few people will have health problems related to their previous treatment. These are known as late effects and may include: Heart problems (cardiomyopathy) Numbness or tingling of the fingers or toes (peripheral neuropathy) Increased risk of infection Early menopause Reduced fertility Fatigue, poor concentration and forgetfulness Secondary cancers including skin cancers and blood cancers Thyroid problems Please see the excellent information on the Cancer Research UK website <a href="http://cancerresearchuk.org">cancerresearchuk.org</a> and follow links about cancer, your cancer type, ALL, treating ALL, side effects, long term side effects). Or you can ring their helpline on 0808 800 4040. If you are concerned that you have any of these symptoms, please contact the hospital team if you are still coming to leukaemia clinic, or your GP after you have been discharged.</p>		<p><b>Advise entry onto primary care palliative or supportive care register</b> No</p> <p><b>DS 1500 application completed</b> No</p> <p><b>Prescription Charge exemption arranged</b> Yes/No</p>	
<p><b>Alert Symptoms that require urgent review by the specialist team:</b> Unexplained bruising or bleeding Shortness of breath on exercising Recurrent or unusual infections If you are concerned that you have any of these symptoms, please contact the hospital team if you are still coming to leukaemia clinic, or your GP after you have been discharged. If you are seeing your GP, please request an urgent full blood count.</p>		<p><b>Contacts for re referrals or queries:</b> <b>Whilst on active follow up (still attending leukaemia clinic) patients should contact:</b> <b>In Hours:</b> Leukaemia nurse specialist, xxxxx: <b>Out of hours:</b> Haematology emergency telephone number: xxx</p>	
<p><b>Secondary Care Ongoing Management Plan</b> (tests, appointments etc.) You will be followed up in the leukaemia clinic for a minimum of 3 years. These appointments will involve blood tests and may involve bone marrow samples if we are able to monitor your disease in this way.</p>		<p><b>After discharge from leukaemia clinic, patients should contact their GP if they have concerns, who may refer them back to their leukaemia consultant or ring the on-call haematology registrar for urgent advice.</b> Other service referrals made: (delete as necessary) District Nurse, AHP, Social Worker, Dietician Clinical Nurse Specialist, Psychologist Benefits/ Advice Service, Other</p>	
<p><b>Required GP actions in addition to GP Cancer Care Review</b> (e.g. ongoing medication, osteoporosis and cardiac screening) Monitoring for hypertension, diabetes and ischaemic heart disease. No ongoing medication.</p>			
<p><b>Summary of information given to the patient about their cancer and future progress:</b> You have been given treatment for acute myeloid leukaemia with a curative aim. Please speak to your clinician if you would like more definitive information about prognosis.</p>			
<p><b>Additional information including issues relating to lifestyle and support needs:</b> Smoking is strongly discouraged. Standard precautions should be taken when out in the sun. You are encouraged to maintain a healthy lifestyle, including regular exercise and a healthy diet. This is to reduce the risk of secondary cancer and to improve your fitness.</p>			
<p><b>Completing Doctor:</b></p>	<p><b>Signature:</b></p>	<p><b>Date:</b></p>	

### HOLISTIC NEEDS ASSESSMENT

A holistic needs assessment and care plan should be undertaken at key points along the pathway which facilitate the young person to identify their own support needs (**see chapter 6 for more detailed explanation of holistic needs assessment**).

### CANCER CARE REVIEW

A Cancer Care Review is a conversation between the young person and GP after diagnosis to improve understanding, answer queries and assess support requirements. Where possible, TYA services should consider facilitating this review with primary care to ensure a smooth transition.

## TOP TIPS

### for implementing the recovery package

- Site and treatment-specific agreed templates should be developed by treating teams.
- All young people should be provided with a treatment summary within six months of treatment completion.
- The detail of the treatment summary should be explained to the patient by their consultant or clinical nurse specialist to allow the young person to ask questions and have any worries or concerns about their future answered.
- Treatment summaries should be updated with any significant changes to the young person's circumstances.
- Holistic Needs Assessments should be carried out at key points in the young person's pathway, including at the end of treatment (see chapter 6).
- Care plans should be produced in partnership with the young person at the end of treatment.
- Teams should make young people aware of end of treatment support and identify any appropriate end of treatment programmes that are available; e.g. The Way Forward Programme.
- Teams need to be aware that the transition into follow-up care can be extremely difficult and support to find appropriate community support services is vital.

### HEALTH AND WELL-BEING CLINICS

Access to Health and Well-being clinics and education events tailored to the individual needs of young people following treatment should be facilitated. Teenage Cancer Trust is in the process of piloting their 'Way Forward Programme' in 8 regions across the UK. This 2-day residential programme aims to promote self-management, provide a safe environment for therapeutic conversations and to also provide practical advice on a range of topics such as; fertility, insurance, work, physical and mental well-being. For more information, see [www.teenagecancertrust.org](http://www.teenagecancertrust.org).

In response to the Five Year Forward View<sup>325</sup> the Independent Cancer Taskforce published their strategy to improve cancer outcomes by 2020. They recommend that by 2020 all people with a cancer diagnosis should be offered the elements of the recovery package<sup>326</sup>. NHS England has subsequently published guidance<sup>327</sup> on how services could be commissioned to support people living with and beyond cancer. This guidance recommends an integrated and tailored approach to follow-up care to improve patient experience of services and increase understanding of their healthcare needs and confidence once discharged to primary care. This can avoid unnecessary appointments, referrals and unplanned admissions, allowing young people to re-establish their lives post-treatment.

## LATE-EFFECTS

### PHYSICAL LATE-EFFECTS

Improvements in cancer therapy have resulted in a growing number of young adult cancer survivors who, compared to the general population are at increased risk of a range of late-effects which may not only limit their quality of life but also cause life threatening conditions<sup>328-331</sup>. Although the primary diagnosis can be associated with on-going consequences, the type of cancer therapy delivered, age at treatment, gender, and underlying genetic vulnerability will influence the late-effects experienced<sup>332</sup>. The most common late-effects experienced by young adult cancer survivors are subsequent primary cancers (SPC), cardiovascular disease, including coronary artery disease, chronic heart failure and valvular dysfunction<sup>329, 330</sup>. Endocrinopathy such as abnormal gonadal function, obesity, metabolic syndrome and neuro-cognitive deficiencies also occur<sup>331-333</sup>.

Close monitoring of young adult cancer survivors' health is therefore important because they are at risk of late treatment-related side-effects and SPC, which may be delayed in onset and progressive<sup>328, 332, 334</sup>. The need for long-term surveillance grounded on a personalised risk-adapted approach based on the cancer therapy delivered has been identified<sup>335</sup>.

To provide holistic, patient centred care, young adult cancer survivors require a multi-disciplinary team (MDT) approach from health professionals who are trained with the necessary competencies and skills in late-effects care<sup>336, 337</sup>. Clinical

Practice Guidelines provide healthcare professionals with evidence-based guidance to inform the delivery of late-effects services<sup>332, 338</sup>. A summary of treatment, which includes a plan of follow-up and list of potential late-effects, should be provided to the primary care team and the young adult cancer survivor on completion of treatment, this should be reviewed and updated with any subsequent treatment. A designated key worker can facilitate continuity of care and a follow-up strategy, which is individualised to the young person should be developed<sup>332</sup>.

### Subsequent primary cancers

There is an increased lifelong risk of developing a SPC, which can occur at any site of the body<sup>339-341</sup>. Those who are younger at diagnosis, female and have a family history of cancer are at a higher risk of developing a SPC. Radiotherapy also increases the risk of developing a SPC, with cancers occurring more frequently within the original radiotherapy field<sup>342</sup>. SPCs have been linked to chemotherapy, with higher risk associated with epipodophyllotoxins and anthracyclines<sup>340</sup>.

### Fertility issues

An important issue for young people is the effect of their disease and its treatment on future fertility and the potential implications for their children. Both radiotherapy and chemotherapy can affect fertility. The degree of damage is related to the chemotherapy agent and dose<sup>343</sup> and site of radiotherapy<sup>332</sup>. Alkylating agents are particularly gonadotoxic and can cause long-term fertility impairment in both sexes and premature menopause in women<sup>344, 345</sup>.

In addition, pelvic radiotherapy in women is associated with sexual dysfunction issues both pre-conception and during pregnancy<sup>344, 345</sup>, while radiotherapy to the testes causes permanent impairment of sperm production in male patients<sup>332</sup> (**see also Chapter 4**).

### Cardiac effects

TYA cancer survivors treated with anthracyclines and radiation involving the cardiac field have an increased risk of developing cardiovascular complications, which can present many years following treatment<sup>329, 332, 334</sup>. Patients should be advised about the importance of having a healthy lifestyle, which includes avoidance of smoking, taking exercise and maintaining a healthy weight<sup>329, 332</sup>. Surveillance should include monitoring of cardiac function using echocardiography which is carried out at intervals dependant on individualised risk<sup>332</sup>.

### Endocrine

Endocrine and metabolic late-effects occur frequently in young adult cancer survivors and can develop many years following treatment<sup>346</sup>. Hypothyroidism, growth related issues and gonadal dysfunction are amongst the most common late-effects<sup>346</sup>. Factors influencing the development of these late-effects include radiation to the head and neck or total body irradiation<sup>332, 333</sup>. When compared to the general

population survivors are at an increased risk of developing metabolic syndrome, which includes insulin resistance, central obesity, hypertension and dyslipidaemia<sup>347</sup>. Metabolic syndrome, which is associated with premature death due to vascular disease and diabetes has been found to be more prevalent in survivors who have had cranial radiation, whole body irradiation or acute lymphoblastic leukaemia<sup>332, 333</sup>.

### Central nervous system

Functional impairment, such as visual problems, hearing loss, motor, sensory, coordination issues and seizures, can occur as a result of cranial or craniospinal irradiation and intrathecal chemotherapy<sup>332, 348</sup>. Cataracts are the most common ocular late-effect, occurring in patients who have received steroids, radiation to the eye, central nervous system radiotherapy<sup>334</sup>. At highest risk of developing neurological late-effects are survivors of central nervous system tumours associated with diagnosis, surgery, chemotherapy and radiotherapy treatment<sup>334, 349</sup>. Cognitive impairment and structural abnormalities occurring following radiotherapy are associated with age at treatment and dose of radiation<sup>332</sup>.

## PSYCHOSOCIAL IMPACT OF TYA CANCER SURVIVORSHIP

A review of the psychosocial consequences experienced by young people with cancer revealed three areas of significant challenge: education and employment; social well-being; and psychological impact<sup>350</sup>.

### Education and employment

TYA cancer survivors are faced with unique challenges, including the difficulty of maintaining their work and educational goals during this important transitional period in the life-course<sup>351, 352</sup>.



In order to reduce the negative impact treatment has on education, where possible young people should be supported to maintain communication with their school throughout treatment and be encouraged to attend or engage in distance learning. For those who are unable to maintain contact dedicated post-treatment support may be necessary. This is a key function of the TYA MDT with best outcomes achieved when a professional with a dedicated educational remit takes responsibility for ensuring young people's educational needs are being met. This involves co-ordinating regular liaison between hospital, educational and employment establishments and statutory bodies to reduce school dropout and support young people into employment.

Young survivors may also face difficulties with employment if they enter the workforce with less job experience because of time spent in treatment or have developed a cancer-related disability<sup>353</sup>. The economic recession has undoubtedly impacted upon this as available employment opportunities have become increasingly competitive. A significantly greater proportion of young cancer survivors are reported as being out of work or unable to work compared with young people with no cancer history<sup>354</sup>. (See also Chapters 2, 4 and 6)

### Social Well-being Challenges

Young adult cancer survivors have significantly more problems with social functioning compared to older adults<sup>355</sup>. Many report difficulty socialising with others their own age as they feel out of touch with their peers<sup>353</sup> or are concerned about how they will be viewed after disclosing their cancer status<sup>356</sup>. Young cancer survivors also report a decrease in perceived emotional support from peers over time, with contact with friends drifting as the treatment trajectory progresses<sup>357, 358</sup>. Social phobia is noted as a significant late-effect of cancer during adolescence and young adulthood<sup>359</sup>.

Young adult cancer survivors report feelings of social isolation, which is thought to be more pronounced among those who did not meet other young adult cancer survivors during or after treatment<sup>360</sup>. While not desired by all, providing an opportunity to meet other young survivors is considered important in the post treatment phase<sup>361</sup> and has been identified by young people as an area that could improve post-treatment care<sup>362</sup>. Social development is inextricably linked to quality of life<sup>362</sup> and therefore screening for psychosocial well-being should be included in long-term follow-up to ensure timely supportive interventions are implemented.

Given the challenging effects a cancer diagnosis has on young people's social functioning relationships can be significantly affected. While many young people talk of how cancer has brought them closer to their family there is no doubt that cancer during adolescence and young adulthood complicates and may have a negative impact on relationships with families, partners and significant others with often significant adjustment being required by all in the short and longer-term<sup>363</sup>. This can add to feelings of social

isolation and distress. The concern is the extent to which this social isolation continues into later life for survivors of TYA cancer. Dieluweit<sup>364</sup> undertook a study investigating the social outcomes of adolescent cancer long-term survivors, concluding that survivors experience delayed social development as well as substantial differences in their family life and living conditions compared to healthy peers. These differences included their marital status, the proportion achieving parenthood and their living situation 5 to 26 years after the initial diagnosis. Support to re-engage with peers and find some resolution to any family relationship difficulties is essential to support future well-being and needs to be a key component of post-treatment support.

It is known that long-term survivors of childhood and adolescent cancer are less likely to marry or have long-term intimate relationships than the general population<sup>364</sup>, which is an indicator associated with lower general life satisfaction<sup>362</sup>. For young people involved or thinking about becoming involved in intimate relationships, the effect of cancer treatment on sexual function, fertility and overall future health may represent significant barriers to successful romantic and sexual relationships. Young cancer survivors have a higher incidence of psychosexual developmental delay with young men achieving fewer psychosexual developmental milestones than young women<sup>364</sup>. The psychosocial consequences of potential loss of fertility cannot be underestimated and must be addressed during treatment and in late-effect clinics. This loss can be exacerbated as young people end treatment and wish to plan for children.

### Psychological impact following treatment

Research exploring the psychological impact of surviving TYA cancer to date has been limited. However, evidence is growing exploring how young people cope in these challenging circumstances and highlight how healthcare services can affirm and promote personal strengths and resilience<sup>105, 224, 233, 246, 247, 264, 365</sup>. There is no doubt that TYA cancer survivors face numerous psychological challenges that can negatively impact their overall psychological well-being and there is a clear need for further research targeted at the psychological well-being of TYA cancer survivors.

While many cope well in challenging circumstances, long-term survivors of adolescent cancer are thought to be at risk for clinically relevant symptoms of depression, anxiety and post-traumatic stress disorder and an increased use of mental health services is often seen relative to older survivors<sup>366-369</sup>. Some studies found that compared to older adults with cancer, young adults report poorer quality of life<sup>370</sup>. Post-traumatic stress disorder has been identified in a sub-set of TYA cancer survivors<sup>371</sup> as have depression, anxiety, low self-esteem, and sexual problems<sup>352</sup>. A study conducted by Hobbie *et al*<sup>372</sup> revealed that more young adult survivors experienced increased post-traumatic stress symptoms than survivors who had not yet reached young adulthood.

Young people often report fear of recurrence post-treatment, which is strongly related to survivor quality of life and psychological well-being<sup>373</sup>. Feelings of uncertainty that accompany recovery, along with the recognition of the frailty of life, may influence survivors in how they manage their lives after cancer and limit the choices they make<sup>374</sup>. This highlights the importance of comprehensive long-term follow-up for TYA cancer survivors, which includes surveillance of psychological late-effects in order to identify survivors needing psychological assistance even years after medical treatment. To ensure that survivors with longer-term adjustment problems are adequately identified psychosocial assessment should be routinely carried out with professionals administering psychological screening instruments in clinics on a regular basis.

There is also a need for psychological interventions post-treatment to address the specific concerns of young cancer survivors so they are supported to manage life's challenges and prevent long-term mental health problems. Most

importantly, mental health professionals should be part of the MDT when planning and performing follow-up care. Interdisciplinary collaboration is essential in follow-up.

Good communication with parents, primary healthcare professionals and teachers should be established at diagnosis to support adjustment, manage the many challenges and promote optimal TYA psychological and psychosocial health and well-being throughout treatment and into follow-up care.

## LONG-TERM FOLLOW-UP

Empowering young people by providing them with the information and resource to manage their own health and potential late-effects facilitates their transition out of cancer-related services, helping them re-establish their developmental momentum and get on with life after cancer. Lower risk groups are particularly well managed via nurse led services in order to promote their independence. Professional competencies have been developed to identify the skills needed to provide nurse led services to establish an effective and sustainable model of care<sup>375, 376</sup>. Some areas may have a dedicated Survivorship/Late-Effects Nurse to deliver services where others may incorporate this into the role of the TYA or site specific specialist nurse.

With an increasing amount of children, adolescents and young adults surviving cancer and the increasing complexities of treatment, it is essential that the sustainability of services is considered. While the core principles remain constant, local availability of services will vary from healthcare Trust to Trust and as needs arise, business cases should be developed to ensure the growing demand for clinical and non-clinical support services can be met for this growing population.

Consideration also needs to be given to those young people who will transition out of the TYA age range during follow-up. Service developments in TYA care need to be mirrored in adult services so that young people access adult late-effects services. Fortunately, the work of the NCSI is being adopted across services so parallel developments should exist. (**See also Chapter 3 for further information on transition**)

## TOP TIPS

### in long-term follow-up

- Long-term follow-up (LTFU) needs to be financially sustainable and demands need to be catered for by appropriate service provision.
- LTFU service development needs to be mirrored in adult and paediatric services to facilitate transition at both ends of the TYA age continuum.
- Risk stratification is central to identifying those in need of on-going medical follow-up and those who, with support, can adopt a self-directed follow-up approach.
- Treatment summaries and care plans are essential to educate and inform the patient and primary care providers, and facilitate self-directed follow-up.
- Nurse led services are ideal to optimise self-management and empower young people to take responsibility for their long-term health management.
- Holistic needs assessments enhance psychosocial assessment and a move to develop and validate a nationally recognised age appropriate tool should be supported.



# CHAPTER NINE: PALLIATIVE AND END OF LIFE CARE

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Sadly, for some teenagers and young adults (TYA) with cancer cure is not possible either because their outlook is poor from diagnosis or because despite anti-cancer treatment their cancer progresses or recurs. When cure is not possible the goal of treatment and care is to help the young person live as well as they can. Palliative care plays a pivotal role in achieving this goal.

## WHAT IS PALLIATIVE CARE?

Palliative care has been defined as an active and holistic approach to care, which embraces physical, emotional, social and spiritual needs to enhance quality of life<sup>377</sup>. Effective palliative care requires a multi-disciplinary team (MDT) approach to supporting the young person and their family and encompasses the assessment and management of unpleasant or distressing physical or psychosocial symptoms, which may be caused by disease, or a consequence of treatment itself<sup>378</sup>.

Although palliative care has traditionally been associated with people with advanced or progressive disease it is now more widely recognised that the provision of palliative care should be triggered not by diagnosis or even prognosis, but according to need and palliative care often has a role to play even alongside curative treatment. Palliative care is an integral component of the care continuum and where it begins in the patient's cancer experience can vary. Recognising patient clinical trajectories may help healthcare teams plan care to meet their patient's multi-dimensional needs better and help patients and carers cope with their situation<sup>379</sup>. The integration of specialist palliative care teams should be seen earlier in the TYA cancer journey to maximise quality of life and ensure a seamless pathway.

## WHAT IS DIFFERENT ABOUT PALLIATIVE CARE FOR YOUNG PEOPLE?

Young people who are dying face complex challenges. As they are forced to confront their own mortality they are also contending with normal developmental milestones such as developing independence and autonomy and will continue to share many of the same concerns as their peers e.g., around body image or relationships<sup>380</sup>. Perhaps

the most poignant challenge is the stark contrast between the world of emerging possibilities in the transition to adulthood and the young person's diminishing capabilities as their disease progresses.

For many young people knowing that their cancer cannot be cured makes how they will be remembered, and their desire to 'make their mark' on the world even more important<sup>381, 382</sup>. In their attempts to achieve their goals and lifetime ambitions in the limited time they have they may have different priorities to their families, peers and healthcare professionals and they may undertake a high degree of risk-taking to see these ambitions fulfilled. Delivering palliative care to young people with cancer therefore requires a level of flexibility and negotiation that is not always innate to services and for professionals to 'think outside the box' to help young people to live as they wish to live for the time they have left. For example, appointments may need to be negotiated around activities that are important to the young person or the team may need to consider how they can support a young person to fulfil their wishes as safely as possible when they conflict with medical advice. Understanding the young person as an individual and establishing what is important and meaningful to them will enable all those involved to develop a plan to help achieve these goals.

What cannot be underestimated is the emotional burden for professionals delivering palliative and end of life care in these extraordinarily emotive circumstances<sup>381, 383</sup>, where a young person who should be embarking on a long life is instead facing untimely death. It is essential that there are appropriate mechanisms in place to support professionals who undertake this challenging, yet very rewarding role.

## TALKING ABOUT DYING AND DEATH

At a point when it is known that a young person cannot be cured and will die from their cancer it is important that this information is conveyed in a sensitive and developmentally appropriate way. Consideration should be given as to who within the clinical team is best placed to provide this information to the young person and their family as well as how this should be conveyed and who should be present. The approach should be tailored to the individual and

their personal circumstances and deliver key messages clearly, in an age-appropriate manner using accessible and unambiguous language<sup>384</sup>. It is important to check the young person understands what has been said and to offer opportunities to explore their concerns and questions.

Even when a young person talks openly about dying, it does not always mean they have accepted this as their fate and many young people and families retain hope for a cure, even when there is very little chance<sup>380</sup>. It is normal for young people to move across a 'continuum' of acceptance and denial, one minute planning for their death, the next planning for their future, as they try to reconcile themselves to the idea that their future will not be as long as they had expected<sup>385</sup>.

Honest, open and sensitive communication with young people can help explore their priorities and wishes and reduce anxieties. This is not a one-off conversation but rather a series of conversations to help them understand what is happening, to identify their concerns and to establish what is important to them as this may change over time. Many young people want to be involved in decision-making<sup>386</sup>. However, their level of involvement is very much dependent of what decision is being made and some young people choose not to be involved in detailed discussions, which may default to parents and carers.

Young people themselves are likely to be reticent to open conversations about death and dying as they may be frightened, unsure how to express themselves and uncertain about what they want to know. Equally, family members may understandably be afraid of upsetting the young person<sup>387</sup>. Managing these unique communication preferences and complexities in such emotive circumstances presents real challenges for even the most experienced professionals. However, young people facing the prospect of their own death need opportunities to explore their feelings without fear of upsetting other family members. Utilising the skills of other MDT members or available services, such as psychology, social work, chaplaincy and youth support, to provide this support can be useful at this time. The young person may have already built up a connection with one of the team that could be drawn on in these circumstances. This is important and skilled work. This should be carefully discussed within the team and the designated team member should be supported in this work.

It is also essential to help key family members talk about death and dying as they too are likely to struggle with accepting, talking about and planning for their young person's impending death. They also are likely to have fears and may not know how to broach the subject with the young person themselves, younger siblings and other family members. Providing significant family members with opportunities to speak openly about their concerns can in turn help the young person feel freer to talk about their fears and wishes openly with the people they love.

## FOCUS OF CARE

It is possible for young people to live for many months or even years with advanced disease. It is especially important during this time to consider the burden of treatment and care on the young person's quality of life and to support them in making informed decisions about their treatment and care. For example, there may come a time when the disadvantages of palliative treatment outweigh the benefits. Continually reviewing the goals of treatment and care and adjusting them in line with response and patient wishes can help ensure that quality of life is maximised. It is important for young people to know that no decisions are 'set in stone'. Knowing they can change their mind gives young people confidence when making difficult decisions. Young people and their families may not always agree on these decisions, and professionals play a key role in helping families talk about these difficulties and reach conclusions in the best interests of the young person. At all times the young person's wishes should take precedence.

“I knew that what I told my nurse in the hospice wouldn't go any further, even though my Dad wanted to talk to me about having more treatment that I knew would not cure my cancer and didn't want to listen to me! I tried to tell him that I didn't want any more treatment I was fed up constantly battling and feeling so crap...”  
(JJ 2012)

## PALLIATIVE CARE AND SYMPTOM MANAGEMENT

Many young people experience distressing or unpleasant symptoms as a result of their cancer or its treatment. The most common include:

- Pain  
.....
- Nausea and/or vomiting  
.....
- Breathlessness and/or cough  
.....
- Anxiety and/or depression  
.....
- Constipation  
.....
- Fatigue  
.....
- Altered sexual function

Prompt and accurate assessment and management of distressing symptoms is necessary to promote quality of life and for young people to build and maintain trust in the professional caring relationship. It is important that there are robust arrangements in place to facilitate this and that the young person knows who to call if they need help, day and night.

Many physical symptoms can be exacerbated by emotions<sup>388</sup>. Furthermore, physical symptoms can act as a 'reminder' to the young person about their situation and new or escalating symptoms may raise the young person's anxieties about what this signifies. With this in mind, young people may deny or under report symptoms as a mechanism for 'normalising' what is happening<sup>385</sup>.

The approach to symptom management should be considered in the wider context of young people's lives, to support them to live as they choose in the time they have remaining. For example, they may prefer to endure a symptom than to forego an important event or they may choose not to take a sedative medication if it will affect their ability to drive. Background information regarding the young person's attitude towards treatment adherence, their information needs and preferences, the role of their parents/families/carers in supporting their well-being and any other particular anxieties should be established by the team. It is useful for healthcare professionals to explain the reasoning behind treatments as this can often lead to better treatment adherence. In this situation where so much is out of their control, young people may benefit from choices and involvement in relation to symptom management.

### **PSYCHOLOGICAL AND SPIRITUAL CARE**

When young people are told their cancer is no longer curable it will be a distressing time for the young person, their family and carers. Facing death and dying is a challenging experience for all involved, with some gaining strength and support from their faith while others may feel that their faith has let them down. Spirituality is not just about faith or religion but also encompasses people's world view and how they make meaning of their life. Recognising, facilitating and supporting young people and their family's spiritual needs is particularly important toward end of life.

### **FINANCIAL AND SOCIAL ISSUES**

It is well known that having or being affected by cancer carries a financial burden<sup>389, 390</sup>. For young people affected by cancer and their families, it is no different during the palliative care stage. This may be due to a young person being no longer able to work or financially support themselves or family members having to take time off work or give up work to look after the young person. It is important to make young people and their families aware of the financial and social assistance they may be entitled to and where they can go for expert advice about their specific situation. Social Workers are usually good sources of information in this regard.

### **FAMILIES AND CARERS**

Support for carers is paramount at this stage in the illness trajectory. It is important to give regular opportunity for discussions, which allow carers to ask questions that they may feel unable to in the young person's presence and access practical support. They may also wish to express their feelings of anticipatory grief, the experience of mourning which begins before a person dies, in a supportive and safe setting<sup>391</sup>. This process can manifest itself in a number of ways including psychological, social and physical symptoms. Home visits are an ideal opportunity to keep these important lines of communication and support open. It may be possible for hospital health and social care professionals who know the young person and family to provide outreach services or to liaise with community-based colleagues. TYA social workers often provide this role. Teams must be skilled in assessing and treating symptoms of anticipatory grief through a holistic approach and recognise the impact this has on relationships in order to support families effectively<sup>391</sup>.

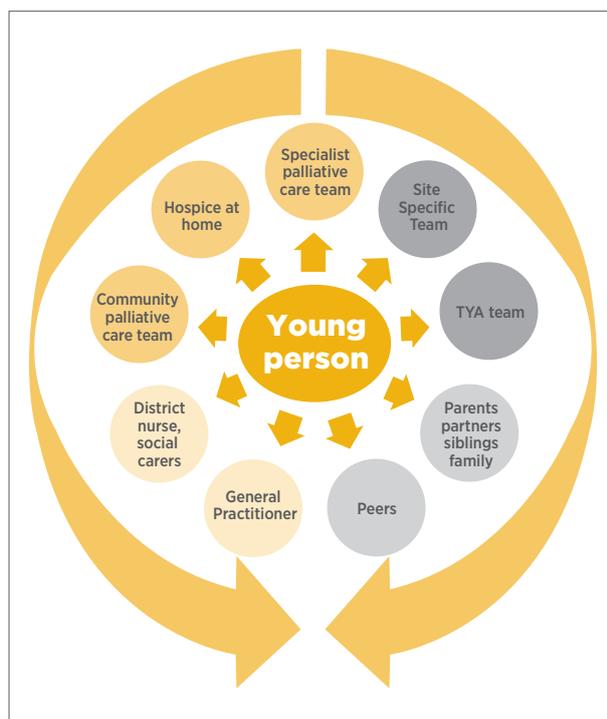
Siblings also need to be supported and given time and attention. Opportunity to discuss "normal" feelings should be provided and siblings should be referred for appropriate support at the right time. Coping mechanisms should be routinely assessed and if appropriate refer for pre-bereavement support. Equally some young people have babies and young children of their own. In these circumstances the young person not only has to deal with their own impending death but anticipate the implications of this on their child or children's lives in the future. Integrating the young person's concerns into the care planning process is essential.

### **CO-ORDINATING CARE**

Having a co-ordinated care approach at the end of the young person's life is important for the young person, family and healthcare professionals during significant care transitions. NHS England<sup>392</sup> advocate that every young person with cancer should have a key worker who will coordinate their care. Often it is the TYA clinical nurse specialist (CNS) in their role as key worker and through their existing relationship with young people and their families, who is in an ideal position to support the young person and family from the point of diagnosis and at times of any significant news, not just when bad news is given. Given their knowledge and experience they are often well placed to guide and support the young person and their family throughout the illness trajectory. In circumstances where there is no TYA CNS or the TYA CNS role does not have an outreach remit, it is important that a key worker is identified as a point of contact for the young person and their family. The key worker may also need to change should the young person's health status and care needs change e.g., transfer to community-based care. Whatever the circumstances it is vitally important that at all times significant family members know who they can contact for support with any concerns.

This can be particularly challenging for families given the range of healthcare professionals likely to be involved in providing end of life care (**Figure 9.1**).

**Figure 9.1:** TYA CNS or Key Worker Role



Partnership working with community teams, GPs and specialist palliative care is essential to ensure that the young person has access to the appropriate expertise and support. Some young people and their family may have negative associations with the word “palliative” and the TYA team has an important role to play in helping the young person understand what palliative care services can offer.

## END OF LIFE CARE

### PLANNING FOR END OF LIFE

End of life care for young people can be complex due to the nature of tumour types common to this age range. The dying process in young people with cancer can be prolonged in the absence of other co-morbidities. Preparation for where and how a young person wishes to die can be an important part of coming to terms with a terminal diagnosis and the prospect of dying, and needs to be handled with sensitivity. Some young people who acknowledge they are dying take great care in deciding what they wish to do prior to their death and planning their end of life care. This includes talking to or leaving messages for friends and family and planning their funeral. A proactive approach to these conversations may help the young person to start thinking about the ‘what ifs’ and articulate their priorities about how

they may want to be cared for as their disease progresses and the use of tools such as an Emergency Health Care Plan (EHCP) may be helpful when facilitating end of life discussions, although they may need to be presented in a developmentally appropriate way. The timing and approach to these discussions needs to be very carefully considered for each individual, with the professional taking the young person’s lead. Many young people do not wish to discuss plans for end of life while they are still well and able to lead a normal life.

“I don’t want to talk about dying; I’m too busy living”  
(Amie 2016)

Planning for end of life care involves complex co-ordination and pivotal to this is the role of the TYA CNS or another healthcare professional in the role of keyworker. It is valuable if the identified key worker can facilitate joint visits with palliative care nurse specialists, hospital teams, GPs, district nurses and hospice staff to facilitate seamless care. Young people may need care from multiple services and may need to transfer between different healthcare settings. Some young people will continue to live between their own home, university/college and the parental home. Others may have partners/spouses and children of their own, while others may live with or move back into the family home with their parents. Information sharing is crucial to ensuring a seamless pathway for the young person and ensuring they don’t have to tell their story repeatedly.

### PLACE OF DEATH

Young people should be supported to die in their place of choice; this may be at home, in hospital or in a hospice. Many young people express a desire to die at home. Guidance for families to engage and navigate the transition from hospital to community or hospice care is essential at this time. Given that many young people have complex symptoms and care needs at the end of life, collaborative working between the TYA team, specialist palliative care services, community teams and young people and their families is essential and can make a real positive difference to their experience and to the family’s coping following the young person’s death.

Consideration should be given to the young person’s wishes, what services and support are available and the practicalities of delivering end of life care in the place of choice. Parents and partners often provide whatever care is needed at this time and it is important to consider their capacity to do this and recognise the strain on them, and potentially their relationships and provide appropriate emotional and practical support.

Pathways and commissioning arrangements for palliative and end of life care for this age group may not be as well established as for adults or children and therefore pre-emptive planning and multi-agency working is key to ensuring that young people receive high quality end of life care. It may not always be possible for a young person to die in their place of choice. In this situation, clear and honest communication is essential to ensure that young people are offered realistic choices and expectations are not raised when they cannot be met.

### **END OF LIFE CARE**

When it is clear that the young person is dying, they and their family/carers may not all be at the same level of acceptance of the inevitability of death. Sensitive communication at this time is essential keeping the young person at the centre of care, while supporting other family members.

In the last days and hours of life, particular attention should be paid to ensuring the young person's comfort and dignity and ensuring any symptoms are appropriately managed. If the young person is able and wants to, they should be involved in discussions and decision-making. All efforts should be made to ensure that any preferences or wishes that they have previously articulated are upheld. Honest and sensitive communication is essential to ensuring that the young person and their family feel supported and know what to expect. They should be encouraged to spend this precious time in a way that is synonymous with the young person's wishes.

## **BEREAVEMENT SUPPORT**

### **IMMEDIATE FAMILY AND SUPPORT NETWORK**

It is not unusual for young people to have spent many months as a hospital inpatient prior to their death and as a result, families often build strong relationships with the healthcare team. Bereavement support groups can be useful to help carers cope with not only the loss of their young person, but also the transition away from dependence on the ward or unit. It is important for professionals to recognise anticipatory grief displayed by the patient and family and support this appropriately<sup>393</sup>. There should be a structured time scale for groups with signposting and referral to other support groups/agencies in the local area for people with more complex bereavement presentations or longer-term needs. In young people's bereavement care the needs of all those who have had a significant relationship with them should be considered. It is important to have a team approach to bereavement support so one member of the team is not providing support to all relatives and peers. Sharing and coordinating this support is especially important where there are complex family dynamics. In these circumstances, involvement of the TYA MDT is useful to allocate appropriate professionals to help support bereaved families.

Some carers however may not wish to return to the hospital after the death of their loved one so establishing the availability of local bereavement support is essential for all teams who care for young people. Support services can usually be identified through local palliative care teams, charity organisations, hospices, GP practices and religious groups. Recognition that everyone copes in different ways and requires different support mechanisms is essential in finding the best approach for each family. Where there are young children specialised child bereavement support should be considered and offered. An opportunity to discuss the death or treatment trajectory or offer to meet the consultant after the young person's death may be beneficial for some families.

### **SUPPORTING CANCER PEERS WHEN A DEATH OCCURS**

One of the core philosophies of specialist TYA care is peer support. Sometimes young people form strong friendships with other patients. Even where strong friendships are not evident young people still have an awareness of others around them and what they are going through. When a fellow patient dies it can have a great impact on the young people around them. As well as the distress of losing a friend they may well have concerns for their own survival and some may experience guilt that they have survived whilst their friend has died<sup>394</sup>. Healthcare professionals caring for young people should have insight into these issues to ensure that the potential impact is recognised and appropriate support provided. This may involve one-to-one support, informal discussion, counselling or inclusion in memorial services.

Whether or not to tell other young people about a death of a peer and when to do this can be difficult. One option is to wait until patients ask how the person is. This gives them control of the information particularly about how and when they find out. Some may choose not to ask because they do not wish to know. However, with the accessibility of social media young people often hear about the death of another patient very quickly and this may be in an environment where they have limited access to support e.g., alone in their bedroom. Staff should be aware of this possibility and be able to sensitively inform young people of the deaths of other patients and address any issues or concerns that arise for individual young people. If the death occurs in a ward environment, young people and families are usually aware of what is happening and should be informed by experienced staff on an individual basis. All young people and their families will have their own unique response to the information. It is crucial that they are allowed time to talk through their feelings if they choose and are given support.

### **SUPPORTING STAFF WHEN A YOUNG PERSON DIES**

The death of a young person can also have a significant effect on team members. It is not unusual for young people to attend a ward, department or unit for many months or years and this often results in strong relationships forming

## TOP TIPS

### for palliative and end of life care

- Specialist palliative care teams should be available early in the TYA cancer journey to maximise the young person's quality of life and ensure a seamless care pathway.
- Remember that while the young person is confronting their own mortality, they are also dealing with normal life stage developmental milestones.
- Be careful not to make assumptions about young people's understanding, thoughts or wishes. A young person talking about their impending death does not necessarily mean that they have accepted their fate and they may still harbour hopes for a cure.
- Managing symptom control should be discussed and negotiated with the individual young person, to allow them to continue to partake in normal developmental activities as far as possible.
- Some young people will want to be involved in decision-making about their end of life care and others will not. This needs sensitively discussed and agreed at different times as they may change their minds.
- Seeking consent to talk with significant family members is good practice when young people do not wish to engage.
- On-going meaningful conversations to assist young people understand what is happening and talk about death and dying are essential mechanisms to assist them identify their priorities and wishes, and help reduce anxiety. These are not one-off conversations but require relationship-building and excellent communication skills to support young people to address fears and express their wishes.
- Healthcare teams should also attend to the needs of significant family members, ensuring that they understand what is happening and are provided with opportunities to openly discuss any concerns.
- A key worker should be identified to help the young person and family negotiate any care transitions. Toward end of life, family members should know who they can contact if they have any concerns about the young person's well-being or care.
- Healthcare teams can find supporting the unique needs of the young person and their family challenging and emotionally taxing. It is imperative that there is psychosocial support available to the team as well as the young person and their family.
- Discussing an end of life care plan for end of life with young patients and their families is recommended. This process can be helpful for the young patient and their family and assist in building trusting relationships with the healthcare team. A number of end of life planning tools exist and provide good guidance for this process. This plan should be revisited as young people may change their minds.
- In the event of a young patient's death, consideration should be given to the support needs of other young cancer peers and their families who may have known them.
- Clinical teams should develop internal guidance or policy for funeral attendance and staff support/supervision in order to promote staff well-being and ensure consistent support to every family post-bereavement.
- Mortality and morbidity meetings are recommended to facilitate professional discussion and learning and contribute to professional peer support

between the young person, their families and staff members. Staff should be given the opportunity of counselling. Some teams have access to psychologists who can also offer support to individuals or the team as a whole. Other alternatives may be clinical supervision or a planned staff debriefing to allow staff to share their feelings and support one another. It should be recognised that everyone will have different ways of dealing with grief and may not wish to discuss their feelings. Ensuring all staff have access to formal support systems allows people the choice and opportunity to make decisions about the support they require.

Regular Mortality and Morbidity Meetings to review patient deaths are important events for discussing cases, professional learning as well as contributing to the governance of patient safety. These meetings are also excellent opportunities to facilitate peer support and help the healthcare team identify the aspects of the young patient and their family's care that went well and any challenges, exploring and clarifying individual and team learning and the need for any system changes. TYA MDTs should be encouraged to set up Mortality and Morbidity Meetings as part of their Service.

### **ATTENDING FUNERALS**

Staff attendance at funerals can be a way of representing the team, providing support to the family and a method of closure for staff. However, care should be taken to ensure equal representation from the team occurs at all funerals. Many other young people and families who are cared for in a TYA environment also naturally build close relationships and as a result often attend the funerals of fellow patients.

Experience highlights that inconsistency in the numbers of staff attending the funeral of a young person is often noted by families and inequalities in staff representation can cause unintended hurt. While staff attendance at young patient funerals is encouraged as representation of the ward or unit, staff should be actively discouraged from attending in their own personal time. A policy or local guidance for funeral attendance should be drafted to provide clarity for staff attendance. Those staff who choose to attend all funerals in their own time may need support to clarify their role and professional boundaries. Equally staff should be discouraged from contacting carers independently after the young person has died.

The following team policies are recommended:

- **Bereavement support**  
.....
- **Attendance of funerals**  
.....
- **Staff support/supervision**  
.....
- **Professional Boundaries (in line with each professional body's policies)**

In the situation where cure is not possible effective palliative can help young people live as well as possible. Young people have unique needs and these needs and priorities should remain central to their care. A young person dying from their cancer will always be tragic event. However, a holistic approach to care, effective team working and honest and sensitive communication which recognises the young person and family as equal partners can make a huge difference to their pre and post-bereavement experience.



# CHAPTER TEN: YOUNG PEOPLE AND RESEARCH

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## RESEARCH IN THE NHS

Research evaluates scientific advances, generating evidence to inform optimal treatments and care for patients, as well as informing the development of health policies. High quality, rigorous research forms the basis of the evidence-based care we give to patients and underpins the way we deliver services. The importance of research to the NHS is reflected in the NHS Constitution, which stipulates that “*the NHS commit to inform you of research studies in which you may be eligible to participate*”<sup>395</sup>. This is facilitated by a series of research networks across the country, which promotes access to research for all patients in the NHS. The treatments and care delivered to cancer patients today are a result of previous research, generating evidence on how to improve survival and quality of life.

The aim of this chapter is to suggest ways in which you, as a healthcare professional, can keep informed of the latest evidence, get involved in research and how you can make young people aware of research in your Trust.

## RESEARCH GOVERNANCE

Research governance in the UK is the standard for conducting research in the NHS and is defined by a series of frameworks (specific for England, Scotland, Wales and Northern Ireland<sup>396</sup>). Supporting this are clearly defined processes outlined by the Health Research Authority (HRA: <http://www.hra.nhs.uk/>). If you are actively undertaking research in the NHS it is recommended (and is mandatory in some Trusts) that you undertake Good Clinical Practice (GCP) training (<https://learn.nihr.ac.uk/course/index.php?categoryid=5>). This will ensure that you

**Table 10.1:** Differentiating between research, audit and service evaluation

	Research	Service evaluation	Clinical audit
<b>Purpose</b>	<ul style="list-style-type: none"> <li>Designed to generate generalisable new knowledge; testing hypotheses</li> </ul>	<ul style="list-style-type: none"> <li>Designed to answer: ‘what standard does this service achieve?’</li> </ul>	<ul style="list-style-type: none"> <li>Designed to answer: ‘does this service reach a predetermined standard?’</li> </ul>
<b>Focus</b>	<ul style="list-style-type: none"> <li>Addresses clearly defined questions, aims and objectives</li> </ul>	<ul style="list-style-type: none"> <li>Measures current service without reference to a standard</li> </ul>	<ul style="list-style-type: none"> <li>Measures against a standard</li> </ul>
<b>Interventions</b>	<ul style="list-style-type: none"> <li>QUAN - Involves evaluating or comparing interventions, especially new ones; QUAL – explore how interventions and relationships are experienced</li> </ul>	<ul style="list-style-type: none"> <li>Involves an intervention that is already in use in practice. The choice of treatment is decided according to guidance, professional standards and/or patient preference</li> </ul>	<ul style="list-style-type: none"> <li>Involves an intervention that is already in use in practice. The choice of treatment is decided according to guidance, professional standards and/or patient preference</li> </ul>
<b>Data collection methods</b>	<ul style="list-style-type: none"> <li>Usually involves collecting data that are additional to routine care (but may include data collected routinely). May involve treatment, samples, investigations or procedures additional to routine care.</li> </ul>	<ul style="list-style-type: none"> <li>Involves analysis of existing data but may include administration of questionnaires or interviews/ focus groups.</li> </ul>	<ul style="list-style-type: none"> <li>Involves analysis of existing data but may include administration of questionnaires or interviews/ focus groups.</li> </ul>
<b>Sample</b>	<ul style="list-style-type: none"> <li>QUAN – may involve allocation to an intervention group; QUAL – clearly defined sampling framework with conceptual or theoretical justification</li> </ul>	<ul style="list-style-type: none"> <li>No allocation to intervention; intervention chosen before service evaluation</li> </ul>	<ul style="list-style-type: none"> <li>No allocation to intervention; intervention chosen before audit.</li> </ul>
<b>Randomisation</b>	<ul style="list-style-type: none"> <li>Can involve randomisation</li> </ul>	<ul style="list-style-type: none"> <li>Never</li> </ul>	<ul style="list-style-type: none"> <li>Never</li> </ul>
<b>Requires REC review</b>	<ul style="list-style-type: none"> <li>Yes</li> </ul>	<ul style="list-style-type: none"> <li>No</li> </ul>	<ul style="list-style-type: none"> <li>No</li> </ul>

QUAN: quantitative methods; QUAL: qualitative methods; REC: research ethics committee

are following internationally agreed ethical, scientific and practical standards.

There is sometimes confusion whether a project constitutes a clinical audit, service evaluation or research. The HRA provides clear guidance on this (**Table 10.1**) and a decision-making tool to help you decide whether or not research ethics approval is required (<http://www.hra-decisiontools.org.uk/research/>).

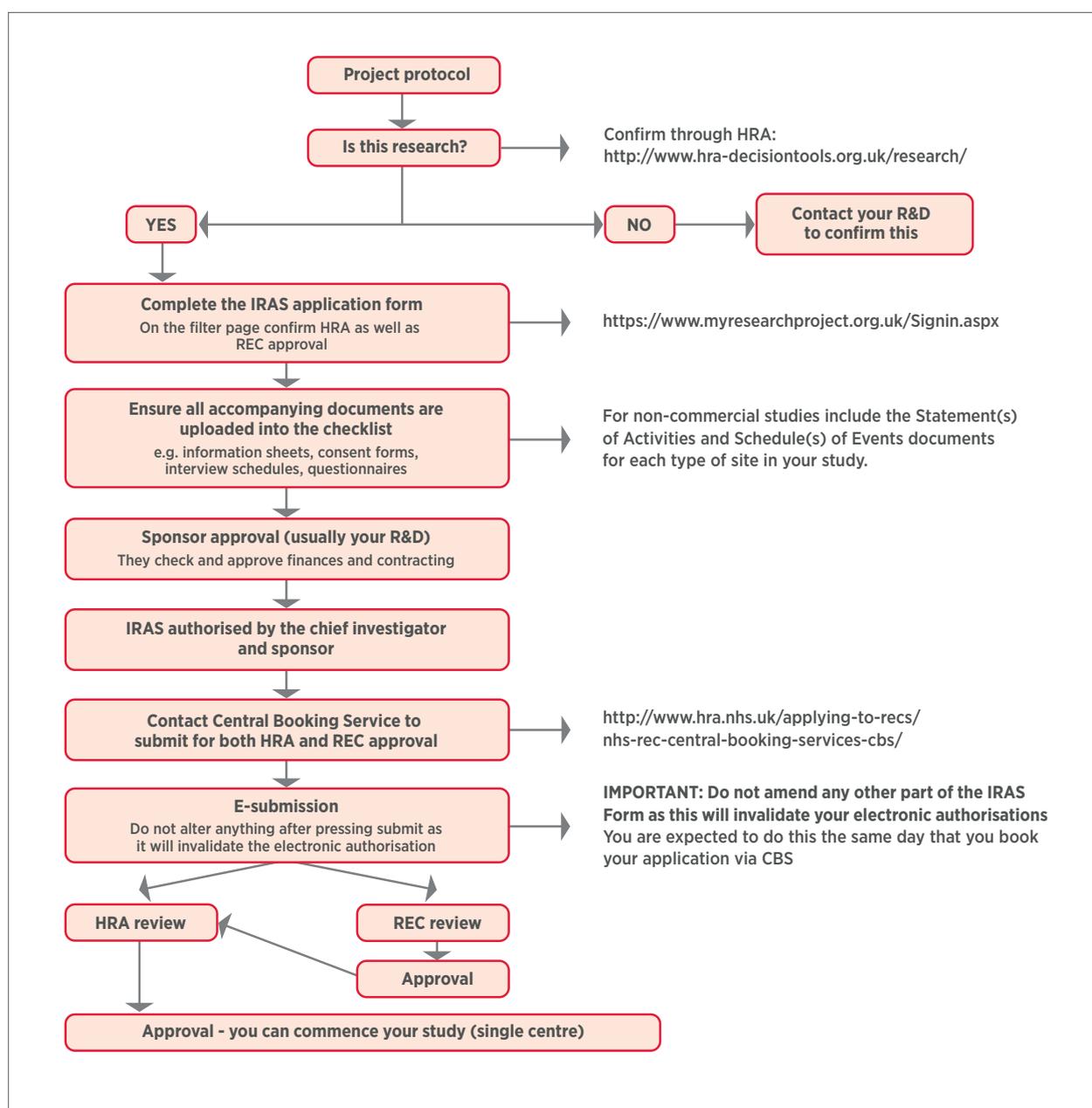
All research conducted with patients, families and carers requires NHS Research Ethics Committee (REC) approval

and all research with patients, families, carers and staff working in the NHS also requires HRA approval (from April 2016 this process superseded requiring local Research & Development (R&D) departmental approval).

**NOTE:** Conducting research without appropriate approvals is contrary to research governance regulations. Doing so may result in disciplinary action.

The process for obtaining approval to conduct research in the NHS is summarised in **Figure 10.1**. You only need to complete one application form through the Integrated Research

**Figure 10.1:** The approval process for conducting research in the NHS



Application System (IRAS; <https://www.myresearchproject.org.uk/Signin.aspx>). This is then automatically submitted to the REC, HRA and other regulatory bodies for research (such as the Confidentiality Advisory Group if you want to use patient details without their consent, National Offender Management Service for research with patients in prison, Medicines and Healthcare Products Regulatory Agency (MHRA) for investigations of medicinal products).

## RESEARCH ACROSS THE TEENAGER AND YOUNG ADULT AGE RANGE

Research with teenagers and young adults (TYA) adds another challenge as it covers a wide age range, including what the REC classifies as children (13 to 15 years old) up

to young adults (24 years old). This has consequences for conducting research, not only on the regulatory processes that have to be followed but also on the design and methods used.

First, when developing and submitting a research proposal involving young people under 16 year olds there are specific regulations that must be followed (e.g. consent and assent forms; parental/guardian consent). Second, you need to consider the impact of including young people 13 to 24 years old on the research design and methods used. Across quantitative and qualitative studies, the topic of your research and the type of themes discussed should guide you in the decisions about the questionnaires selected/developed, interview methods and protocols or the composition of your focus groups (e.g. focus group with a mixed age group or separate age groups).

### TOP TIPS

#### for applying for regulatory approval

- If you are unsure, start by completing the HRA decision tool to determine whether the project you are considering is research.
- If you are proposing to conduct research and you have not applied for approval before, ask someone who has – learn from their mistakes.
- If you get your protocol right at the beginning and consider all the ethical issues, getting REC/HRA approval may take a little time but it is NOT complicated.
- Start by writing your research proposal/protocol. Ask your R&D Department if they have a template. If not look on the HRA website.
- Think of your protocol as a recipe – it should contain enough detail for another researcher to be able to replicate it (your ingredients are the study design, sample and methods of data collection and analysis; the method is a description of what you are going to do).
- Start by thinking about the ethical issues you might encounter in your research and outline what you are going to do to inform and protect your participants. Remember research governance is all about protecting your patients.
- Don't be afraid to ask – the HRA and REC have very helpful online advice and helplines. There is no such thing as a stupid question!
- When conducting service evaluation and clinical audit you should also ensure that you are protecting your participants (patients, carers, staff). You can do this by applying the principles of research governance even if you don't need to get REC/HRA approval.

## TOP TIPS

### for conducting research across the age range:

- If you are developing a quantitative study you need to address these questions:
  - If you are using a validated questionnaire, has it been validated for the full age range (13 to 24 years old)? If not, you may need to use two age appropriate versions.
  - If you are developing a questionnaire, age/developmental differences should be taken into account (depending on the topic).
- In qualitative studies, specifically individual or joint interviews, focus groups and/or workshops, during the development phase you need to take into consideration the inclusion of young people across the 13 to 24 age range (the research topic should guide your decision and if you are being inclusive of age you will need to be prepared to justify your decisions in your REC application).
  - For example, will the inclusion of 14 year olds with an older young people's group impact on what participants share?
  - Are the activities planned relevant for both the younger/older participants?
- You should design age-appropriate participant information sheets and assent and consent processes
  - If a young person is under 16 you have to ask a parent or guardian for consent.
  - If the young person is travelling alone to the venue where the focus group/interview is taking place, make sure you are in contact with parents and that all the safeguarding measures are in place.
  - Consent is not a one-off process but continues for as long as anyone is involved in the research. This means that a young person who agrees to be part of a study (or their parent or guardian) can withdraw consent at any time (and this should be emphasised).
- The researcher is responsible for ensuring participation in the study is not causing distress to the young person or having any adverse effects on their emotional and physical well-being.
  - If the research topics could potentially raise any concerns for young participants and/or their parents, it is important to identify a professional who they can contact to discuss their concerns and receive support and guidance.
  - It is best practice to contact the young person, with their consent, a couple of days after their participation in the study to check they are okay.

### RESEARCH EVIDENCE IN TYA

Despite considerable NHS investment in research, research evidence for TYA with cancer is less robust compared to children or adult cancers<sup>17</sup>. There are a number of reasons for this. Similar to the traditional organisation of cancer services, research studies tend to have their origins in either paediatric centres or adult cancer care. A highly co-ordinated approach to paediatric cancer care and research has generated a substantial body of evidence for children with cancer and similarly for adult cancers, large patient numbers and dedicated tumour groups have forged forward advances in care for adults. As mentioned in Chapter 1, young people experience a range of cancers which do not sit neatly within

children's or adult's services and consequently do not always fit neatly into research structures either. Small in number and scattered across paediatric, TYA cancer centres and adult cancer care the co-ordination of research for this group is far from optimised and does not attract the same investment as paediatric cancers.

### AGE AS A BARRIER TO TAKING PART IN RESEARCH

The inclusion criterion of a study is a set of standards that define who is eligible to take part. These often include tumour type, stage, grade and the fitness of the patient. However, 'age eligibility criteria' are often applied to studies, which have no real scientific or medical justification. The age

range of the patients being studied most often relates to whether the study has been designed by paediatric or adult researchers, with the upper age of paediatric studies ranging from 16 years to 22 years and the lower range of adult studies being typically set at 18 years. Therefore, young people are often excluded purely based on age.

The National Cancer Research Institute's TYA Clinical Studies Group (NCRI TYA CSG) is a national group generating research for young people with cancer. (<http://csg.ncri.org.uk/groups/clinical-studies-groups/teenage-and-young-adults/>). This multi-disciplinary group have made significant advances to ensure new research studies allow younger teenagers to take part and this is reflected in an increased number of young people entering clinical trials when trials are available.

## HEALTHCARE PROFESSIONALS AS A BARRIER TO TAKING PART IN RESEARCH

We have known for some time that young people can be excluded from research based on where they are treated (no available trials in that centre), how old they are, or a lack of studies relevant to young people and their cancer type. However, what we have recently discovered is that healthcare professionals may also exclude young people based on a personal assumption of whether the young person would be likely to take part, or is well enough/emotionally able to consider participation<sup>398</sup>. BRIGHTLIGHT is a national evaluation of TYA services and was open in

over 100 NHS trusts across England. The inclusion criteria were inclusive of all cancer diagnoses and all young people aged 13-24 years who lived in England at diagnosis; the only exclusion criteria applied to the study was nearing death, imprisonment and unable to consent to the study or complete the survey (<http://www.brightlightstudy.com/>).

Recruitment to BRIGHTLIGHT was impressive, with over 1,000 patients recruited making it the largest TYA cancer study in the world. However, that figure fell short of the anticipated 2012 patients. When investigating why recruitment was not ideal the research team discovered that many young people were not being approached about the study. This may be because healthcare professionals recruiting to the study were not familiar with approaching young people about research and have assumed the young person was either going to say no, or was not well enough to consider taking part<sup>399</sup>.

Young people have reported wanting to be able to make decisions about all aspects of their care<sup>398</sup> so it is important that not only is research available to young people but they are also made aware of research projects they may be eligible for (Fern 5A's)<sup>400</sup>.

## THE ROLE OF PROFESSIONALS IN EVIDENCE BASED PRACTICE

There is an expectation that all professionals delivering care in the NHS will keep up to date with new initiatives in their field of practice. The challenge sometimes can be finding the evidence and knowing how robust this evidence is. Just

### TOP TIPS

#### for locating the evidence:

- All members of the NHS are eligible for an Athens account, which allows you to use electronic databases to identify relevant studies and also to access journals (<https://openathens.nice.org.uk/>).
- If you are a member of the Royal College of Nursing the library will undertake a literature review on your behalf (<https://www.rcn.org.uk/library/services/find-an-article>)
- Join TYAC, the organisation supporting professionals working with young people with cancer ([www.tyac.org.uk](http://www.tyac.org.uk)). They circulate a bulletin every week to members, which includes a list of new publications related to young people with cancer.
- Join ResearchGate (<https://www.researchgate.net/home>). You can locate and follow professionals working on areas of care you are interested in. When they publish something new you will get a notification. Often you can download papers from the website; if not you can contact the author to request a copy.

because something is published does not mean it is good. Not everybody has been taught or is confident in critiquing research. However, your local library and university will offer courses on how to critique the evidence and you can also use the guidance proposed by Greenhalgh<sup>401, 402</sup>.

## THE ROLE OF PROFESSIONALS IN FACILITATING RESEARCH

Being aware of the evidence is an important aspect of getting it into practice. What is equally important is

### TOP TIPS

for evaluating the evidence:

- Enquire if there is a journal club in your department and if not, you could consider starting one. A journal club is a small group of people who come together at regular intervals to discuss the latest papers and research findings. This will allow you to become familiar with reading research findings and evaluating their evidence for young people.
- If you are interested in journal clubs you may want to look at a method introduced by McKeever *et al.*<sup>403</sup> for increasing participation and engagement.
- A number of checklists exist which allow you to see if key aspects of the study have been included. There are a range of checklists for different study designs freely available from the EQUATOR network (<http://www.equator-network.org/>)



ensuring participants are recruited to research studies that are underway. While recruiting young people to research may not be part of your role, by being aware of studies available to young people in your Trust you can alert researchers to young people who may be eligible to participate. Generic information is available for young people about participating in research<sup>404</sup> but a member of the research team will need to give young people study-specific leaflets and explain what participation involves.

Young people with cancer are viewed as a 'vulnerable' population<sup>405</sup> but this is not a reason to exclude them. It does mean however that you must carefully review your design and methods to ensure that not only do you not cause harm, but that you make efforts to ensure that young people find the experience of research participation beneficial<sup>405</sup>. As a member of the BRIGHTLIGHT Young Advisory Panel noted:

“At the end of the day it is your decision isn't it? If they give you the option it is up to you to say yes or no. At the end of the day I know they are treating me and they are trying to help me get better but at the end of the day you know how you are feeling inside. OK you might not look it but you know. I have had days when I have looked awful but I feel good on the inside and I have been able to talk to people for a while. If they at least tell you about it and you can be more aware of it. Personally it would make me feel like I'm more important like I am not just a patient I am actually a person and they want me to help other people as well.”<sup>398</sup>

## THE ROLE OF RESEARCHERS WORKING WITH YOUNG PEOPLE

There is a wealth of literature advising researchers on how to conduct research with young people<sup>406-408</sup>. Key to study success is ensuring your research is meaningful to young people. Traditionally, research questions were designed by researchers and healthcare professionals in isolation, with little involvement from the people who are most impacted by the research - patients themselves. In recent years there has been a move to involve patients and the public in research with a view that if the study has been designed with young

people for young people then recruitment and the experience of participation will be better as the research question and the way the study is delivered will be optimal for them.

The NCRI TYA CSG are collaborating with the James Lind Alliance an organisation who specialises in setting research priorities with healthcare professionals, patients and the public. The initiative, funded by Teenage Cancer Trust, CLIC Sargent and Children with Cancer is expected to complete in 2017 and a list of areas for research that are a priority to young people as well as healthcare professionals will be generated. This will be an important resource, which will guide the allocation of funding resources.

### MAXIMISING RECRUITMENT TO RESEARCH STUDIES

The Five 'As' describes a strategy to maximise recruitment to research studies for TYAs with cancer<sup>400</sup>. Briefly

## TOP TIPS

### for involving young people in research

- Keep a database on your ward of research studies in your Trust which young patients could enter. Include researcher contact details so you can call them if you think there is a patient eligible for a study.
- Include research in your MDT meeting so you can review each young person's eligibility for research.
- Do not assume young people are not interested in research. If there is a study available to them then ask the question **“Is it okay for a researcher to come and tell you about a project they are doing that you might be interested in?”** Give them the choice and ensure they know it is also okay to refuse participation.
- Do not assume that if a young person says no that if another opportunity arises they would not be interested in it. Ask again without being coercive or putting pressure on the young person.

described they include Availability, Awareness, Accessibility, Appropriateness and Acceptability. **Table 10.2** gives further

information about the 5As strategy and how you may be able to optimise recruitment for young people in your centre.

<b>Table 10.2:</b>		<b>The Five A's to maximise recruitment of young people to research</b>
<b>Principle</b>	<b>What it means</b>	<b>What you can do</b>
<b>Available</b>	<ul style="list-style-type: none"> <li>● Feasibility of research for rare cancers; resources for rare diseases; activation of trials in all appropriate treatment centres for TYA</li> </ul>	<ul style="list-style-type: none"> <li>● Keep up to date with open trials and other forms of research available in your centre which may be relevant for TYAs and trials or research which are in set up.</li> </ul>
<b>Aware</b>	<ul style="list-style-type: none"> <li>● Healthcare professionals' awareness of trials; awareness of need to offer TYA trial entry; increased patient awareness; increased paediatric and adult communication</li> </ul>	<ul style="list-style-type: none"> <li>● Awareness is related to the availability of trials or other forms of research. Ensure that you and your team are aware of available trials/research in your centre.</li> <li>● Also ensure that young people are aware that research is going on in your centre. There are a number of research leaflets you can get from the Children's Cancer Leukaemia Group<sup>404</sup> and also Cancer Research UK<sup>409</sup>.</li> </ul>
<b>Access</b>	<ul style="list-style-type: none"> <li>● Referral of TYAs to specialist centres; collaboration across adult and paediatric oncologists</li> </ul>	<ul style="list-style-type: none"> <li>● Ensure that young people have access to available trials by offering available research to them.</li> <li>● You can ask young people if it is okay for a researcher to approach them about a relevant study.</li> <li>● You can approach researchers about young people you may have identified as being eligible for their study.</li> </ul>
<b>Acceptable</b>	<ul style="list-style-type: none"> <li>● Perceptions of trial/research by young people; perception of trial/research design by healthcare professionals; acceptability to offer trial/research; compatibility of trial/research with other treatments and life goals</li> </ul>	<ul style="list-style-type: none"> <li>● If you are involved in study design, ensure that young people are involved in developing the design of the study and the information sheets.</li> <li>● If there is a study which is not recruiting well it may be worth having a small meeting with young people to identify any particular aspects of the study which are off putting or whether the information sheets are appropriate.</li> <li>● If you are involved in writing a research proposal, ensure there is a budget for on-going user involvement, which should include travel and sustenance and if possible a voucher for young people's time.</li> </ul>

## TOP TIPS

### for conducting research with young people

- Involve young people from the onset of study concept so they identify early anything that would not be acceptable to young people.
- Include a young advisory group as part of the study team to advise throughout study progress.
- If you are studying across tumour groups and across the traditional paediatric/adult age range, are there researchers available who are capable of cross site recruitment? The Clinical Research Network is not designed in the same way as clinical services so a TYA research nurse may not be available.





# CHAPTER ELEVEN: INTERNATIONAL PERSPECTIVES

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## INTRODUCTION

Having begun with individuals in hospitals identifying clinical unmet need and finding local solutions, TYA cancer care is now spreading gradually around the world. There is much we can learn from this to find ideas we can use ourselves locally, improve outcomes, overcome barriers to service improvement, support each other and enjoy working in a global network of like-minded people. These international developments are summarised below from the perspectives of Europe, North America, Australia and the developing world.

## INTERNATIONAL DEVELOPMENTS: EUROPEAN NETWORK FOR TEENAGERS AND YOUNG ADULTS WITH CANCER

Among 58 million teenagers and young adults (TYA) in the European Union aged 15 to 24, approximately 14,000 new cases of cancer are recorded annually, although many feel this is an underestimate. Although the health services, investment and networks for TYA are less mature than those for paediatrics or adult oncology, specific programs between healthcare providers, academic societies and governments have developed across the European Union in recent years.

In Germany the previously distinct and separated infrastructures for paediatric and adult oncology at age 18 years has recently been bridged by collaboration under the organisation 'Ajet', working on collaborative approaches to care and to transition as patients get older.

In Italy, SIAMO (Società Italiana Adolescenti Malati Oncematologici, [www.progettosiamo.it](http://www.progettosiamo.it)) was founded in 2013 and has formal support from Government and charitable funding to for projects including improving access for adolescents to paediatric oncology protocols, spirituality, pathways to a cancer diagnosis, an early diagnosis campaign in adolescents and a project with general practitioners.

Since 2004 in France improvement plans for care and research have been part of successive national Cancer Plans. There are eight French TYA centres and a

further three specialist units each with a cross-cutting collaborative clinical team, clinical trials, and enhanced psychosocial care. Recent projects include: ESPOIR-AJA, an educational and professional outcomes study 5 years after cancer treated between 15-24 year olds; a study of the mechanisms of information of TYA prior to inclusion in early phase trials; a study of substance addiction including analgesics during and after TYA cancer; and a study of clinicians' adherence versus non-adherence to practice guidelines in the management of TYA in France.

In Spain, an Adolescents with Cancer Committee was established in 2011, and through co-operation between oncologists, patients and charities, the charity AAA, 'Spanish Association of Adolescents and Young Adult with Cancer' ([www.aaacancer.org](http://www.aaacancer.org)) is raising awareness and creating a community for patients ([www.adolescentesyjuvenesconcancer.com/](http://www.adolescentesyjuvenesconcancer.com/)).

Since 2013 in the Netherlands healthcare professionals from regional centres have co-operated on TYA projects dedicated to 18-35 year old patients, including a national digital community around quality of life and adverse effects of treatment. Improvements in hospital food have been a recent priority. The recent award of a prestigious Dutch Cancer society fellowship will bring improved understanding of the needs of TYA with cancer in Holland.

In other countries there are individual projects, such as the Canteen charity in Ireland, guideline development and unmet needs studies in Scandinavia, and a joint professional training scheme for adolescent care in the Czech Republic.

Increasing collaboration between paediatric and adult oncology is identified as the single largest wish of professional groups across Europe, followed by a wish for national health policy in this area. Studies including health economics are awaited with great interest.

Over and above these strong and exciting efforts The European Network for Cancer in Children and Adolescents ('ENCCA') was developed within the European Seventh Framework Programme for Research (FP7, 2011-2015). This integrated stakeholders involved in paediatric oncology to raise standards of care across Europe and reduce inequity. One part of ENCCA was dedicated to TYAs: "Improving Outcomes for Teenagers and Young Adults with Cancer".

The ENCCA TYA project has undertaken 6 tasks:

- 1) Create a European multi-disciplinary Network for Teenagers and Young Adults with Cancer (ENTYAC), which has recommended development of specific practice guidance relevant to TYA with cancer.
- 2) Promote TYA multi-professional education, including contributions to more than 10 international conferences.
- 3) Understand and improve access to trials including an index of age eligibility across EU trials, and work with the Innovative Therapies for Children with Cancer (ITCC) organisation to adjust age eligibility.
- 4) Develop data linkage between cancer registries to establish Europe-wide comprehensive epidemiology, including projects to collate and publish incidence and survival.
- 5) Promote healthy lifestyles, including reviews and guidance on fertility preservation and secondary prevention.
- 6) Place patient and support organisations at its heart, including more than 400 survivors in an international survey in nine languages across 13 countries.

Further co-operative professional education projects, epidemiology projects and clinical reference network development are under discussion.

A key feature of ENTYAC is the central involvement of so many stakeholders; patients, caregivers and charities as well as professionals. Young people guide ENTYAC in the optimal delivery of services and may influence politicians differently from professionals.

ENTYAC believe that TYA centres must:

- **Not have restrictive age cut-offs but treat according to need in the community they serve.**  
.....
- **Provide an environment where TYAs feel supported, to complete their treatment successfully and tailor-make supportive care to each TYA and their family/carers.**  
.....
- **Include:**
  - a) **Multi-disciplinary staff who embody an active co-operation between paediatric and adult oncologists, or alternatively, a dedicated TYA team co-ordinating the two specialities.**
  - b) **A specialist team dedicated to providing age-appropriate TYA care (e.g. dedicated nurses, social workers, psychologists, teachers, activity organisers) who are adequately trained.**
  - c) **Dedicated adequate physical spaces alongside other young people;**

- d) **A fertility preservation program;**
- e) **A transition program to support TYA who have had cancer in childhood who still need care and to help older TYA patients thrive when receiving adult care later in life.**
- f) **Comprehensive clinical trial availability and demonstrable excellence in recruiting TYA in the different tumour types arising in adolescence and young adulthood<sup>76</sup>.**

ENCCA WP 17 projects concluded after 2015 but ENTYAC continues as a dedicated pan-European multi-level program and is at the heart of the SIOP-E strategic plan for childhood and adolescent cancer 2015-2020<sup>410</sup>. ENTYAC can serve as a European structure to be accessed by regulatory authorities, organisations, healthcare providers, academic societies and international oncology co-operative groups, as well as patient and parent groups.

## INTERNATIONAL DEVELOPMENTS: USA PROGRESS IN ADOLESCENT AND YOUNG ADULT ONCOLOGY

Since the emergence of adolescent and young adult (AYA) oncology as a concept there has been a healthy interest in the field in America. Pioneers like Professor Archie Bleyer and Professor Stu Siegel were instrumental in publishing relevant research and influencing the professional community worldwide. There has also been a strong advocacy movement with organizations like Planet Cancer, Livestrong (formerly Lance Armstrong Foundation), Stupid Cancer and most recently Critical Mass, forging change and collaboration.

Within the professional research community, the South West Oncology Group (SWOG) and the Children's Oncology Group (COG) have collaborated to stimulate more research that combines a paediatric and adult focus.

The National Comprehensive Cancer Center Network (NCCCN) is an important national alliance of the principal academic American cancer centers. It develops a wide range of professional guidance and there is a standing AYA oncology group of doctors that have produced clinical guidelines in AYA. The NCCCN guidelines are just that and there is no requirement to adhere to them although they are widely accepted as best practice.

There was very little progress in the development of specific AYA programs and facilities until 2012. In that year Teen Cancer America was created and the first program in the US was developed at UCLA in California. Around the same time Seattle Children's Hospital completed a facility and program and Rainbow and Babies Children's Hospital completed

their Angie Fowler Institute in 2013 with a substantial investment in program and research at the Seidman Center in Cleveland. All of these programs had been modelled on and/or supported by Teenage Cancer Trust in the UK during their development. Since then, Teen Cancer America has been stimulating further progress. Facilities and programs have been developed with their support and guidance as the charity has established itself by providing expert consultancy and funding throughout the US.

Facilities and/or programs for the AYA Oncology population have also been successfully completed or will shortly be developed at Memorial Sloan Kettering in New York, Moffitt in Tampa, Children's Hospital of Philadelphia, Baylor University Hospital in Fort Worth, Comer Children's Hospital at the University of Chicago, Lucille Packard Children's Hospital at Stanford, Cincinnati Children's Hospital and the Smilow Center at Yale. There are several others making progress at major academic cancer centers such as Vanderbilt at the University of South Carolina, Duke at the University of North Carolina and North Western University, as well as community hospitals such as St John's in Los Angeles and Bon Secours in Greenville, South Carolina. In all, over 70 hospitals have approached Teen Cancer America to discuss their programs and how they can focus on AYA Oncology. The movement is definitely getting stronger.

Critical Mass, acting as the principle advocacy organization holds annual meetings for the AYA professional community. It is now beginning to concentrate on providing political advocacy. There is also the emergence of regional AYA meetings such as Cleveland in Ohio and the Texas series. The Society for Adolescent and Young Adult Oncology (SAYAO) has become an important organization enhancing the status of its professional journal and in establishing a series of annual scientific meetings that focus on specific disease areas affecting the AYA community. Research is broadly led by COG and SWOG but there are also multi-center collaborations emerging to pioneer new studies.

At a national level initiatives such as the Cancer Moonshot and the 21st Century Cures Act will improve the focus on the rare cancers that affect young people and the streamlining of the bureaucratic regulations that surround research in the US. This should improve both access to and participation in clinical trials. The Affordable Care Act has broadened access to insurance to many underserved communities. It has also provided enhanced protection to AYA's who can now remain on their parents' insurance until 25.

The historic silos of paediatric and adult hospitals present a structural challenge to overcome in order to create change that can enable an AYA focus. Some paediatric hospitals are extending the age range they treat as a solution for the population they serve. Collaborations can be challenging when institutions may not be a part of the same health system and may even be commercial competitors. Furthermore, over 70% of AYA's are treated

in community hospitals and not in the academic centers. Some geographical areas are so large that communities can be a long distance from academic centers and so they rely significantly on community hospitals for their oncology services. Some areas have health systems that are dominated by a single provider. Others will have many to choose from or can be directed to one by their insurance company. Academic hospitals are growing substantially and acquiring community services because the Affordable Care Act rewards them for providing whole population services that incorporate community facilities and providing services throughout the patient pathway. However, the Act is not endorsed in every state (although increasing numbers do support it). Thus services provided to the AYA population can vary substantially.

Some of these structures and challenges are not that different to the UK silos found within the NHS and other systems around the world. Nor are the challenges proving to be insurmountable as the evidence of so many new AYA developments demonstrates. What is likely to emerge is a range of solutions underpinned by philosophy and standards that adapt to the specific structures that exist within regions. The independence of individual hospitals or health systems to deviate their practice is significant compared to a national health system. Whilst in some respects that can create inequalities, it is also a strength in that hospitals can be much more self-determining in their approach. Thus the capacity to move faster and adapt to meet the needs of the AYA population is significant if chosen at an institutional or health system level.

Now we look forward to Teen Cancer America hosting the Global AYA congress in 2017 and there is substantial collaborative effort invested in making that a success.

## THE AUSTRALIAN YOUTH CANCER SERVICES

Each year approximately 1,000 Australians aged 15 to 25 will be diagnosed with cancer and 150 will die from it. The incidence of cancer in this cohort is set to rise by 2-5% through until 2020.

In 2005 CanTeen Australia advocated for the need for specialist youth cancer centres across Australia during the Senate Committee Inquiry into cancer services. Following this CanTeen worked with Cancer Australia to develop *The National Service Delivery Framework for Adolescents and Young Adults with Cancer*<sup>411</sup>, which provided a foundation for best practice AYA cancer care. During this time CanTeen also approached the Government, supported by five other national charities, with a request for funding. In 2008 and again in 2013, the federal Government confirmed substantial funding to develop specialist treatment and support services for AYA cancer patients. This funding is administered by CanTeen Australia, which distributes funds

to health services and other organisations across Australia and plays an active role in shaping the Youth Cancer Service (YCS) to deliver the vision of world-class cancer treatment and support for young Australians.

Currently, the YCS has an extensive national footprint, reaching 70% of all newly diagnosed young Australian cancer patients. The service provides specialist multi-disciplinary treatment and care in five lead hospitals and a network of over 20 additional hospitals nationally. Supporting the provision of best practice care the initiative also entails critical national projects led by CanTeen. These include professional development and networking initiatives, national research, national young patient data collection and meaningful engagement of AYA consumers through local and national advisory groups. Six national expert advisory groups guide the work of the YCS: Strategic, Leadership (consisting of the clinical lead and service manager from each lead site), Research, Education and Training, Data, and Youth (ensuring contribution of the healthcare consumer perspective).

Activity data routinely collected by five lead sites and nationally collated has shown a significant reform in care towards an innovative model of coordinated multi-disciplinary care with 91% of all new YCS patients having their treatment discussed at a Multidisciplinary Team (MDT) meeting.

Key service delivery strengths of the YCS include a consistent national approach that allows for local variations with a minimum standard of care as articulated by the Charter of Rights, effective provision of fertility information and psychosocial care (completion of the AYA Oncology Psychosocial Screening Tool) to newly diagnosed patients (85% and 78% respectively), young people having access to specialist clinicians and staff with a deep understanding of AYA needs and MDTs with expertise and specialist knowledge of specific diseases and tumours, and enhanced opportunities for young people to access clinical trials.

Regarding national projects, health professional workforce development has included: national professional development network days, each attended by approximately 100 YCS affiliated staff, hospital executives, non-Government organisations and other cancer organisations; an International AYA Oncology Congress and Youth Summit in 2015; the Nurse Research and Clinical Innovation Mentor Program, which saw 16 nurses from across the YCS network come together and develop their research knowledge, skills and competencies and establish clinically relevant projects in their respective teams; and scholarships supporting enrolment in post-graduate AYA oncology courses.

Other national projects have focussed on data and research. Jurisdictional activity data collected quarterly has enabled tracking of key indicators, driven service improvements, efficiency gains and growth in priority areas. Detailed analysis of cancer incidence and mortality data has also been undertaken in consultation with the YCS Data Advisory Group to determine trends in individual AYA cancers over the last three decades along with an analysis of worldwide AYA data to benchmark Australia internationally, review projections of cancer incidence and mortality rates for AYAs and explore trends in hospital admissions data for this age group. The collection of a national minimum AYA dataset has also been piloted with each jurisdiction.

Overseen by the YCS Research Advisory Group, a national AYA cancer research priorities project<sup>412</sup> assisted in investment decisions and progressing the best available treatment and supportive care interventions. Nine Medical, Psychosocial, and Health Service Delivery AYA Oncology research projects have been funded over the course of Phase 2, with several co-funded with the Australian and New Zealand Children's Haematology and Oncology Group (ANZCHOG).

An updated national strategy, the Australian Youth Cancer Framework for AYAs with Cancer (AYCF) is currently being developed to articulate the vision and key priorities for AYA cancer care in Australia over the next 5 years. The AYCF is broad in scope, articulating direction for policy, research priorities, professional development, gaps in evidence and further development of services and care for young people with cancer and their families.



## INITIATIVES TO INCREASE ACCESS TO CLINICAL TRIALS FOR AYAS WITH CANCER

CanTeen and the YCS proactively sought to enrol AYA patients in trials, invested in clinical trial research and advocated to government.

## STRONG ADVOCACY ON PRIORITY ISSUES FOR AYA CANCER

CanTeen advocated to Governments and other stakeholders in line with the six priority research areas. For example, CanTeen undertook campaigns to improve Medicare item numbers for fertility preservation (in collaboration with FUTuRE Fertility) and increasing access to clinical trials.

## AYA CANCER GLOBAL ACCORD

CA partnership between Teenage Cancer Trust in the UK, CanTeen in Australia and Teen Cancer America in the USA has seen the establishment of the Adolescent and Young Adult Cancer Global Accord, which will see a yearly AYA cancer focussed conference hosted on a rotating basis between Australia, the UK and USA. This will help to build a common international vision for best practice AYA cancer care and enable the sharing of expertise and resources.

## INTERNATIONAL DEVELOPMENTS: DEVELOPING COUNTRIES

One of the great medical advances of the last 50-60 years, at least in high income countries (HICs), has been the improvement in survival for children with cancer from little expectation of cure in the 1960s to 75-80% long-term survival now<sup>413, 414</sup>. Survival for TYA with malignancies has not improved quite as fast<sup>415</sup> attributed to differences in the cell biology of tumours seen in the 16-25 age range<sup>416</sup>, plus delays in diagnosis<sup>417</sup> and higher rates of treatment non-adherence<sup>102, 418</sup>. However, the greatest disparity is not between children and young adults diagnosed in HICs but between both children and young people living in low/middle income countries (LMIC) and those in resource-rich ones. For them survival rates are between 30% in middle-income countries and under 10% in low-income ones<sup>419, 420</sup>. It is important to note that 80% of children, teenagers and young adults live in resource limited countries.

Cancer emerges as a threat to life as the traditional “killers” of infections (especially malaria, Tb, HIV, gastroenteritis, pneumonia and measles, often complicated by malnutrition) are reduced as they have been by a very major investment of effort and money following the development of the Millennium goals in 1990<sup>413</sup>. In all but 49 countries at least a 40-50% reduction of maternal, infant and under 5 year mortality (reduced from 12 to 6.9 million in 2011) will be achieved by 2015<sup>421, 422</sup>. In 2008 Margaret Chan, Director

General of the World Health Organisation stated “The rise of cancer in less affluent countries is an impending disaster”. There has been an increasing emphasis on non-communicable diseases but even so children and young people with cancer are still frequently overlooked.

The relative rarity of cancer in young people (2%), different patterns of tumours seen in children and young adults and minimal ability to apply preventative measures for such tumours all lead to neglect of the coming problem<sup>423</sup>. Those who are trying to develop services for young people have to overcome a number of major challenges. Firstly, poverty of individual families; in most LMIC they have to cover the cost of all their diagnostics and therapy. National poverty with other overwhelming health priorities, other societal problems (natural or man-made), no registration of case numbers (so nobody knows the cancer burden for the population) and of course the lack of skilled or trained staff/ability to retain staff all make a focus on cancer less likely. Secondly, one of the major problems faced in LMICs is a lack of public and professional awareness of the signs and symptoms of cancer in young people out in the communities, leading to late or misdiagnoses. International Twinning partnerships have been increasingly trying to help those in low-income countries to deal with these challenges<sup>424</sup>.

A recent survey has shown that there is considerable variation in the age when children are deemed to become adults, not just for medical reasons. The most common cut-off age is the 13th birthday in LIMCs in Africa and much of Asia, very similar to many UK hospitals up until the 1960s. There is a worldwide trend as economies improve to move that age up to the 16th birthday and even create a generic ward for adolescents (e.g. in the Red Cross Hospital Cape Town). Paediatricians treating young people with cancer are increasingly continuing to follow them in their clinics beyond aged 16 years but if further treatment is required then referral to adult services is required. In both Marrakech and Beijing wards are being developed specifically for teenagers up to aged 18 years. In Bangladesh the Government has passed a bill to increase to 18 years the age of maturity. Dr Francine Kouya who looks after both adults and children at a hospital in the North West Region of Cameroon has conducted a retrospective observational study on TYA cancer patients over a 5 year period. She identified lack of cancer recognition leading to late diagnosis and often inability to offer therapy. There was under-representation of TYA cases but over the period there was an annual increase from 10 in 2009 to 25 in 2013.

In summary it would appear that the development of age appropriate teams dedicated to the care of TYA and specific units for them is confined to high income countries at present but there are efforts to change that in a few hospitals. However, very late diagnosis, public and professional lack of recognition of cancer in young people and even a perception of incurability is still extremely common in many communities worldwide.



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