A BLUEPRINT OF CARE FOR TEENAGERS AND YOUNG ADULTS WITH CANCER
DOCUMENT INFORMATION

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TARGET AUDIENCE

Healthcare service providers, healthcare staff, charitable organisations and any other health organisation involved in the care of teenagers and young adults with cancer.

CONTENT AND PRESENTATION

This document provides practical advice, guidance and ‘tips’ for anyone working with teenagers and young adults with cancer and describes the complex components of providing ‘age-appropriate’ care. This document can also be used as an aid for those developing future healthcare services for young people.

The beginning of this document provides an executive summary. The contents page provides details of headings and sub headings to signpost the reader to relevant sections. Each section provides a ‘Top Tips’ box that can be used as a quick reference guide to summarise key points and useful tips for practitioners.

Appendices are provided at the end of the document. These appendices provide examples of local practice guidance, policies, protocols, assessment tools and information resources that can be adapted for use by organisations and healthcare staff.

ABBREVIATIONS

AHP - Allied Health Professionals
CNS - Clinical Nurse Specialists
CYPIOG - Children and Young People’s Improving Outcomes Guidance
DOH - Department of Health
NCAT - National Cancer Action Team
NICE - National Institute for Health and Clinical Excellence
NWCI - North West Cancer Intelligence Service
SSMDT - Site Specific Multidisciplinary Team
TYA - Teenage and Young Adult
TYA MDT - Teenage and Young Adult Multidisciplinary Team
CAMHS - Child and Adolescent Mental Health Services

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ABOUT TEENAGE CANCER TRUST

Teenage Cancer Trust is dedicated to making sure every young person between 13 and 24 diagnosed with cancer has the best possible quality of life and chances of survival by providing access to the best possible care and professional support from the point of diagnosis. The charity funds, builds and maintains specialist units within NHS hospitals that bring young people together to be treated by teenage cancer experts in an environment tailored to their needs. For more information visit: www.teenagecancertrust.org.

ABOUT TYAC

Teenagers and Young Adults with Cancer (TYAC) is a membership organisation which helps all professionals involved in the care of young people with cancer to work together to improve knowledge and services. For more information visit: www.tyac.org.uk
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This document makes an important contribution to describing the core elements of care for young people facing the challenge of cancer. Those involved in its production have shared their experiences and their values to help ensure that care is as good as it can be for a group of patients who, too often, remain at risk of missing out on the best possible holistic care when diagnosed with cancer. The group involved should be commended for capturing the elements of good practice and committing these to paper. So often ‘the best practice’ of care that involves tried and tested approaches delivered consistently over time with good outcomes, fail to be recorded. This is the first important step in describing what we all want to achieve; excellence in teenage and young adult cancer care. The document will affirm for those in the field what is important, and for those developing new services, it will provide a much needed first point of guidance that will shape the environment, philosophy and approach to care of their unit. The document might also indicate to teams where innovation and practice development opportunities might be available as we continue to shape services through patient and family input.

Significantly, there are also important messages about what remains to be known and much of this can only be achieved through more research, more education, resources and support. An evidence base for care of this population is being described with researchers in medical, nursing and the social sciences dedicating their time to programmes of research in the field of teenagers and young adult cancer care. But there is much more to be done and we would agree that this document must stay live, with revisions that will capture new evidence as it becomes available. Other routes to sharing evidence, such as education and better use of resources must remain a priority to maintain teenager and young adult cancer care as a distinct specialty.

The distinct nature of the specialty is captured in this document, leaving readers in no doubt about what defines the care needs of this group as separate from children and adults. Readers are recommended to use the contents page to signpost their reading, but also use the appendices for further resources. Reading should not stop here, readers are also recommended to use the Internet resources listed and seek out supporting evidence as it becomes available on Pubmed. Our sense of enquiry and the need to know ‘why’ and ‘what can be done differently’ are essential qualities if we are to continue to strive for the best outcomes for those in our care. Make the most of all the ‘Top Tips’ and expert knowledge contained in this document, and continue to share best practice that can only benefit the young people in your care.

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EXECUTIVE SUMMARY

There is growing recognition, both in the United Kingdom (UK) and overseas, that teenagers and young adults with cancer have specialist needs that differ to those of both children and older adults. The National Institute for Health and Clinical Excellence (NICE) published its Improving Outcomes Guidance for Children and Young People with Cancer (CYPIOG) in 2005 and this is currently being implemented within England and Wales.

The focus of this Blueprint of Care is to complement the key recommendations of the CYPIOG by defining the complex elements and characteristics of age-appropriate care. By exploring the specific issues that arise in teenage and young adult (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 teenage and young adult patients diagnosed with cancer between the ages of 16 and 24 years treated within Principal Treatment Centres, TYA Designated Hospitals or District General Hospitals (DGH) across the UK. For some younger teenagers (aged 13-15 years) parts of this Blueprint of Care will also be relevant and healthcare professionals should use their judgement following individual patient assessment on the application of the practice principles and guidance in such younger patients. This Blueprint of Care is not intended to apply to patients treated for cancer during childhood who have now reached the teenage and young adult age range.

This document can be used as a learning resource for staff, providing information to multidisciplinary 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. Principal Treatment Centres, 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 does not replace recommendations made in the CYPIOG in England and Wales. Although the CYPIOG is being implemented in England and Wales only, its principles are relevant and applicable throughout the UK and beyond and are therefore used as a central reference point throughout. This document is intended to share expertise with other professionals who are now in the position of initiating development of TYA services and can be used to guide some 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 years in the UK from both the National Health Service (NHS) and independent sectors. The recommendations are also based on feedback from teenage and young adult cancer patients/survivors, together with consultation with other leading bodies in the field of TYA cancer in the UK.

The development of this document has been challenging in that much of the guidance has been based on the growing body of experience in this field and consensus, as opposed to being based on research evidence. The development of the document was informed by:

- The CYPIOG Advisory Group
- Existing literature and research
- Knowledge and experience of the four UK based Teenage Cancer Trust Nurse Consultants for teenagers and young adults with cancer
Knowledge and experience of a growing body of TYA Lead Nurses, Youth Support Coordinators, TYA Clinical Nurse Specialists (CNSs) and TYA Allied Health Professionals (AHPs)

A nationwide consultation exercise across other professional bodies – see below consultation with TYAs

Empirical evidence, where available

A ratification process from TYA expert groups across the UK

This document is the beginning of the process, not an end product and it will be re-evaluated and revised every two years. As the availability of empirical evidence increases, it is anticipated that this ‘Blueprint of Care’ may evolve to become ‘clinical practice guidance’.

CONSULTATION

Healthcare professionals, Allied Health Professionals, voluntary organisations and national professional groups participated in the consultation process of the draft document and were invited to submit amendments, comments and revisions, which where appropriate were incorporated into the final document. Invited to participate in the consultation process were:

- Teenagers and Young Adults with Cancer – TYAC - over 200 members
- Children and Young People Improving Outcomes Guidance Implementation Advisory group
- TYAC Multidisciplinary Forum (formerly Teenage Cancer Trust Multidisciplinary Forum)
- Teenage Cancer Trust

KEY MESSAGES

Staff caring for teenagers and young adults with cancer should be knowledgeable regarding developmental stages including social, emotional, psychological and physical development and assess individual needs according to developmental stage.

- Understanding each young person as an individual, taking into account their interests, past experiences, relationships, future aspirations and coping strategies will enable teams to develop an individual care package that will support the young person effectively through the cancer pathway
- 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, particularly relevant to the in-patient setting
- Cancer in a young person can result in a fundamental loss of control regarding life choices and freedom to make decisions. Mutual goal setting between the young person and professional helps to promote a sense of control for the young person
- Allow and encourage negotiation and flexibility in routine and treatment regimes where possible. This can support autonomy and may encourage compliance with treatment regimes
- Staff should recognise the fundamental 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

These key messages and core principles are further detailed and reinforced throughout the document.
INTRODUCTION AND BACKGROUND

The Platt Report\(^1\) first drew attention to the specific needs of the adolescent patient in 1959 and the Calman Hine Report\(^2\) went on to acknowledge the particular issues faced by young people specifically with cancer in 1995. A plethora of local practice guidelines have emerged over the past two decades suggesting that teenagers and young adults are best accommodated in separate facilities for either children or older adults\(^3\). Teenage Cancer Trust was launched in 1990 in the UK as a source of advocacy and support for this patient group\(^4\).

Over the past ten years, specialist Teenage Cancer Trust units have been developed in a number of centres across the UK, with more undergoing planning and development. The units are staffed by teams with expertise in both the medical and psychosocial management of this patient group. However, in recent years it has been estimated that only a small proportion of young people are cared for in specialist units, with the remaining population receiving treatment in District General Hospitals (DGHs)\(^5\). Although it is likely that the numbers of young people being cared for in specialist units are increasing, many will continue to receive care in more general settings and some may choose to be cared for locally.

The development of TYA services and expertise has gained momentum with independent organisations such as Teenage Cancer Trust, CLIC Sargent and Macmillan working closely with professionals to develop and support services and staffing posts. As a result, teenage and young adult cancer as a specialty in its own right has gained increasing recognition in recent years, both in the UK and internationally. Currently, TYA cancer services are undergoing significant and rapid change, largely as a result of the publication and current implementation of the CYPIOG, the development of TYA specialist posts and the support of independent charities.

The National Institute of Clinical Excellence (NICE) published the CYPIOG in August 2005\(^6\), the purpose being to provide recommendations on cancer services for children and young people with cancer based on the best available evidence. The guidance covers all cancers in children and young people from birth to twenty four. The guidance is currently being implemented throughout England and Wales and recommends that patients aged 16 - 18 should be treated in Principal Treatment Centres and those aged 19 - 24 should be offered a choice regarding their place of care. Principal Treatment Centres are designed to offer expert medical care, an age-appropriate environment, comprehensive psychosocial support, a network of peers and entry into clinical trials, all coordinated by a multidisciplinary team with expertise in the management of this patient group. Teenage and young adult patients who choose to be treated locally should also have access to age-appropriate care, support and services.
MULTIDISCIPLINARY TEAM WORKING, MODELS OF CARE AND PATIENT PATHWAYS

HOLISTIC PATIENT ASSESSMENT
The unique needs of this patient group and the provision of dedicated TYA hospital facilities have been documented over the past four decades. This is an international debate, with growing recognition that specialist services are needed to address the physical, social and emotional needs of this ‘neglected’ group of patients. The complexity of providing care to teenage and young adult cancer patients is compounded not only by their specific health and social needs, but by the fact that they fall ‘into the gap’ between paediatric and adult services. Whiteson (2003) suggests that in a medical context, teenagers and young adults with cancer are a neglected group, suffering as a result of the apparent disadvantaged position they find themselves in. 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.

Care provision and ‘best’ medical management for teenage and young adult cancer patients is multifaceted. Figure 1 (Palmer and Thomas 2008) illustrates how best practice is achieved through the combination of an age-appropriate holistic approach together with medical strategies for improving outcomes.

Figure 1: (Palmer and Thomas 2008)
All parts presented in Figure 1 play a vital role in ensuring young people get the best care, in the most appropriate environment, delivered by experts. One element cannot be separated from another without a detrimental effect on patients and their families. Providing holistic care is further complicated by the spectrum of diseases, psychosocial and family histories that the teenage and young adult patient presents with, as well as the diversity of treatments that 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.

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 circumstances including ethnicity, culture, race, spirituality and religion.

“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.” (National Institute for Health and Clinical Excellence, 2005)

Needs will change as the young person progresses through treatment. Levels of intervention may vary dramatically between patients over the course of their treatment journey. All young people will need regular support and information from a member of the TYA MDT; however levels of support required will differ in each individual case. Figure 2 (Adapted from Fitch 2000) clearly illustrates this.

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**Figure 2:** Model of Supportive Care Provision (Adapted from Fitch 2000)
TOP TIPS
Teenage and Young Adult Care

- Best practice is delivered through a combination of expert medical management and expert age-appropriate psychosocial management. Treating teams should access services/support offered by TYA Principal Treatment Centres.
- Screen all patients using a psychosocial assessment tool and refer on to support services as appropriate (e.g. psychology, counselling, occupational therapy).
- Ensure psychosocial assessment and screening is continued throughout treatment, recognising that individual circumstances 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.

Resources

- Palmer, S. and Thomas, D. 2008. A practice framework for working with 15-25 year old cancer patients treated within the adult health sector: OnTrac@PeterMac (Adolescent and Young Adult Cancer Service). Melbourne, Australia
- www.nhs.uk/young-cancer-care/Pages/teenage-young-adult-cancer-units.aspx
Cancer care is now defined and delivered by teams of professionals, with a wide-ranging background of disciplines, coming together to form an MDT. This MDT is involved in the diagnosis, staging and treatment plan of all patients. The complex breadth of services that young people will need to access will transcend both organisational and institutional boundaries. It is recommended that the best approach to medical and support management of young people is in partnership between the TYA MDT and the Site Specific MDT (SSMDT). The CYPIOG outlines the core members, whose expertise and skills are required to form a TYA MDT (Appendix 1).

Regular TYA MDT meetings, bringing together the expertise of a wide-ranging group of professionals ensures that:

- Patients are considered from a range of viewpoints and expertise, both disease-specific and age-specific
- Shared learning amongst professionals is promoted
- There is increased probability of timely, appropriate treatment and continuity of care
- Regular professional discussion is likely to lead to improved clinical policies, more effective care delivery and participation in audit and research

Barriers and facilitators of multidisciplinary team working have been identified and published (Doyle 2008)\(^1\). Holland (2009)\(^4\) discusses the challenges and benefits of TYA MDT’s, acknowledging the need for significant changes in attitude in order to create new ways of working and overcome barriers to joint working in the development of the TYA MDT. Holland’s experience is reflective of national experiences as a whole, in setting up a successful TYA MDT.

- **Time constraints:** Finding a suitable day and time to suit all is unrealistic. Rotating the day and time may allow more professionals to attend. The use of technology can also be useful, utilising conference calls or video conferencing. There are also current local projects exploring the efficacy of secure virtual platform meetings that may influence the future of MDT functioning.
- **Perceived duplication:** Justifying the necessity for teenage and young adult patients to be discussed at both site specific 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.
- **Demonstrating outcomes:** Perceptions and the value placed on psychosocial care are variable amongst some healthcare professionals. Many consider that it is not required when making treatment decisions. Key points and action plans need to be captured and benefits of the additional knowledge need to be made clear, for example reasons for non-adherence may be addressed.
- **Feedback:** Communication to referring sources must also show actions and outcomes so that there is a clear benefit to the referrers for patients being discussed. This should enable them to provide more holistic TYA care. Data can then be reviewed and audited regularly alongside referrals to demonstrate benefits and purpose of the MDT discussion.
- **Resources:** 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. The MDT will fail if there is no MDT Coordinator to complete the administration created by a meeting with such complex inputs and outputs.
- **Improvements in outcome:** Specialists in TYA care must regularly come together to question, explore and develop services, in order to advance the survival rates for this age group.
- **Increased clinical trial recruitment:** It is well-documented that young people experience poor clinical trial entry\(^5\). TYA MDT meetings are advocated as a means for improving this.
- **Multi-agency working:** 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 experience.
- **Education and shared learning:** For all involved in a TYA MDT meeting, the opportunity to communicate and share practice should be welcomed. The broad backgrounds and specialties of those involved in a TYA MDT can bring great educational benefits to the group.
- **Improved transition:** 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 further in the chapter.
- **More equitable services:** Patients may have previously been cared for in isolation, never meeting another TYA going through cancer, in an environment more suited to either paediatrics or adults, by professionals with little or no TYA experience; once the TYA MDT is aware of a patient, an age-appropriate approach can be adopted.
• Overcoming professional boundaries: In an ideal world adult and paediatric services would work in harmony; the setting up of a TYA specific MDT is a big step towards this ideal.
• TYAC registration: One of the responsibilities of the TYA MDT meeting is to complete the TYAC registration form (Appendix 2). This was introduced by TYAC, in partnership with the North West Cancer Intelligence Service (NWCIS) to gather data on TYA cancers, monitor the implementation of the CYPIOG and to evaluate the effectiveness of services. Data collection of all 16 - 24 year olds who are newly diagnosed with cancer, commenced in January 2009. The registration form is designed to supplement the national dataset for teenagers and young adults with cancer, as it is the only source of data on a number of important variables, such as clinical trial information, mentioned earlier as lacking in the teenage and young adult patient cohort. Data collection for this group is in its infancy, but already it is generating information that will be useful for all involved in TYA cancer care.

The National Cancer Action Team have recently published Guidance on Effective MDT Working (NCAT 2010). Teams should familiarise themselves with this guidance to maximise the functioning of Multidisciplinary Teams and MDT meetings (see resource box).17

CARE PATHWAYS 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.18

The often transient lifestyle of teenagers and young adults (due to educational, family and social factors) means that young people 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. As such, this lifestyle also has implications for both these issues.

The CYPIOG Advisory Group produced illustrative pathways for young people newly diagnosed with cancer and shows the vital link between TYA MDTs and site-specific MDTs. All of which should be underpinned with “informed patient choice” (Appendix 3). Choice, regarding place of care must be unbiased, informed and delivered in a timely manner. The NHS Choices website is now available and provides clear, appropriate and comprehensive information in order to support young people making an informed choice at the beginning of treatment regarding place of care.

TOP TIPS

TYA Multidisciplinary Teams

- A local TYA MDT operational policy should be in place outlining formal notification procedures.
- All teenage and young adult patients irrespective of place of care should be formally notified to a TYA MDT for TYAC registration, discussion and treatment planning.
- A TYA MDT should meet once a week or as guided by patient numbers.
- A TYA MDT coordinator is essential to successful functioning, coordination of meetings and the TYAC notification process.
- Good open, honest communication acknowledging all contributions by all levels of professionals is vital to effective MDT functioning.
- Consider technology i.e. video conferencing, internet use to facilitate discussions with site specific MDTs (SSMDT).
- Provide a forum for holistic consideration of each patient which includes both medical and psychosocial management.
- Consider a separate psychosocial TYA MDT in addition to the treatment planning MDT.
- Ensure good communication channels are developed between hospital teams, Key Workers and community teams/services.
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 of research, clinical trials and data management are also included. This broad scope is in contrast to existing IOG documents for adult cancer services, as they are focused on site-specific diagnosis and treatment. In this sense all teenage and young adult patients’ care provision is guided by at least two IOG documents and, potentially, a third if palliation is required. Best practice in TYA care can only be achieved through collaborative working between site specific teams and TYA teams.

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 healthcare systems.’ (Department of Health 2006)

Ginsberg et al (2006) identified the following barriers to transition:

- **The patient** may exhibit dependent behaviour, immaturity, severe illness, disability, psychopathology, lack of trust in caregivers and poor adherence to treatment
- **The family** may have an excessive need for control, emotional dependency, psychopathology, overprotectiveness, lack of trust in caregivers and heightened perception of disease severity

Teenage and young adult cancer patients fall into distinct groups with transition needs. These consist of those who present on the cusp of paediatric and TYA services (15 - 18 year olds) at presentation and those at the top end of the TYA age range (24 - 25 year olds) who will require transitioning into adult services.

The TYA MDT should play a key role in managing the transition of patients to and from different services, providing an essential forum for discussion and planning. Members of the core team will represent expertise in both paediatric and adult fields, and therefore discussion around best place of care to commence or recommence treatment can be held. The transition of a teenager from paediatrics into TYA or adult care will be facilitated by the paediatric team who will already have a holistic understanding of the patient. Likewise, the transition of a young person from TYA care to adult services should be facilitated by the TYA team.

Transition in many disciplines operates independently and as a discrete service. For example transition nurse roles, already operate across numerous disciplines e.g. cystic fibrosis and congenital heart disease. Staff caring for teenage and young adult and paediatric patients should develop local transition policies and pathways in order to support young people moving beyond paediatric and TYA services.

TOP TIPS

Transition

- Treating teams should ensure a Transition Policy for teenagers and young adults is in place identifying patients for whom transition is a relevant issue (i.e. from paediatric to TYA services or from TYA services to adult services).
- Good transition planning may take several months and should be multidisciplinary.
- Transition planning should be initiated within the TYA MDT.
- Transition is less stressful if patients are well prepared for transition into other services.
- Provide sufficient notice to transition patients ensuring they are well prepared in advance.
- Give young people the opportunity to visit new wards/clinics to make an informed decision about their place of care.
- Investigate the potential for a specific transition role within the MDT or identify a member of staff who is responsible for transition as a key role.
THE DEVELOPMENT OF YOUNG PEOPLE AND ITS IMPLICATIONS IN TYA CANCER CARE

“The key values of Teenager and Young Adult care is to allow the teenager to mature through their illness developing a sense of self, as the research shows that a young person’s developing sense of self can be altered or harmed by a cancer experience.” McClement and Woodgate (1997)

The World Health Organisation has described the interplay between teenage and young adult development and chronic illness.

Table 1: Chronic illness or disability and adolescent development (Adapted from Suris and Viner 2007)

<table>
<thead>
<tr>
<th>Effects of illness on development</th>
<th>Effects of developmental issues on illness or disability</th>
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<tbody>
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<td>Biologically</td>
</tr>
<tr>
<td>▪ Delayed puberty</td>
<td>▪ Increased caloric requirement for growth may</td>
</tr>
<tr>
<td>▪ Short stature</td>
<td>▪ negatively impact on disease parameters</td>
</tr>
<tr>
<td>▪ Reduced bone mass accretion</td>
<td>▪ Pubertal hormones may impact upon disease</td>
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<td></td>
<td>▪ Biological</td>
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<td>▪ Poor adherence and poor disease control due to:</td>
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<tr>
<td>Psychological</td>
<td>▪ Poorly developed abstract thinking and planning</td>
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<td>▪ Regressive behaviour</td>
<td>▪ (reduced ability to plan and prepare using</td>
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<td>▪ Adoption of sick role as personal identifier</td>
<td>▪ abstract concepts)</td>
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<td>▪ Egocentricity persists into late adolescence</td>
<td>▪ Difficulty in imagining the future; self-concept as</td>
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<td>▪ Impaired development of sense of sexual or attractive self</td>
<td>▪ being ‘bullet-proof’</td>
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<td>▪ Exploratory (risk-taking) behaviours</td>
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<td>Social</td>
<td>Associated health risk behaviours</td>
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<td>▪ Reduced independence at a time when independence is normally developing</td>
<td>▪ Chaotic eating habits may result in poor nutrition</td>
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<td>▪ Difficulties in peer relationships</td>
<td>▪ Smoking, alcohol and drug use often in excess of</td>
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<tr>
<td>▪ Creating new intimate (couple) relationships</td>
<td>▪ normal population rates</td>
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<td>▪ Social isolation</td>
<td>▪ Sexual risk-taking, possibly in view of realization of limited life span</td>
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<td>▪ Educational failure and then vocational failure; failure of development of independent living ability</td>
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Adolescence is marked by a rapid developmental phase which includes changes in physical, cognitive, physiological and social behaviour. With the multitude of changes and challenges occurring in the life of the ‘healthy’ young person, they are often susceptible to added pressures or stresses. The normal difficulties of adolescence still have to be faced by a young person with a cancer diagnosis, together with very complex challenges associated with the disease and its treatment. The challenge for healthcare professionals is to support this normal development process throughout a complex cancer journey. Working with young people requires a detailed understanding of their development and behaviour, in order to support them in the most appropriate way.

Development varies significantly between individuals and age is rarely an accurate reflection of a person’s level of maturity. Each young person should be individually assessed and maturity may fluctuate throughout the cancer trajectory.
A cancer diagnosis and its treatment may affect a young person in many ways and these include areas such as:

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

Care provided during this time must be based on a personalised approach that recognises each patient’s individual needs according to their diagnosis and circumstances. Consideration should be given to each person’s cultural, religious, spiritual and ethnic identity. Care needs to be flexible, consistent and adapt as the patient moves through different stages of their transition into adulthood. Multidisciplinary care should incorporate psychosocial and supportive care to maximise the physical, cognitive, psychological, social and existential functioning into adulthood. More importantly, care should extend beyond the direct treatment focus and the young person should be actively assisted to achieve their full potential.

**PHYSICAL CHANGES AND BODY IMAGE**

Physical transformation occurs during the teenage years, due to the complex influence of hormones. These influences result in a number of changes, which can be confusing, confronting and destabilising to the young person. As they move from childhood to adulthood they experience significant bodily changes as they progress through puberty. It is important how they view themselves as their body image becomes central to their world and can have a negative impact on their self-esteem. Some young people look forward to physical development into adulthood as it gives them a sense of maturity. However, others may find this phase difficult and embarrassing.

**PHYSICAL AND PSYCHOLOGICAL EFFECTS DURING CANCER TREATMENT**

Teenage and young adult cancers and cancer treatment can affect physical development and physical appearance in a variety of ways that significantly impact on the psychological coping of a young person. Examples of treatment and treatment side effects that may impact on physical appearance/development include:

- Radiotherapy and/or surgery for central nervous system tumours can halt or interrupt the physical development of young people affecting height, weight, and sexual development
- Hair loss and skin changes from chemotherapy and radiotherapy
- Amputation or disfigurement
- Weight loss/weight gain

Other cancers that can affect body image and physical activity are cancers such as sarcomas and brain tumours, sometimes bringing with them a level of disability that can either be very 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 lowered self-esteem, isolation and fear for their future.

It is also important to consider the effects of medication, e.g. steroids, 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.

The changes in physical appearance of a young person related to their cancer treatment can pose additional difficulties and issues for some individuals from certain religious or cultural backgrounds. For example, 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.

**FERTILITY**

It is recognised that treatment with chemotherapy and radiotherapy may affect fertility. The impact of cancer and treatment may vary between male and female patients, tumour types and treatment regimes.

*“Doctors did talk about fertility openly and even though this upset me, I just kept on thinking that I value my life more than anything.”*

Nicole, 17, Medulloblastoma

Research shows that 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. Teenagers and young adults with cancer should be provided with full information delivered in a clear, timely and direct manner. Anecdotal evidence suggests that practice regarding fertility discussion at the beginning of treatment varies across the UK. Patients at the younger range of the TYA population at the time of diagnosis find it difficult to understand the importance of fertility discussions and are unable to envisage how this may impact on their future many years later.
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 (with consent from the young person) to have significant others or a family member present during consultations to reinforce information. 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 therefore teams should establish what is available and how the process is managed locally.

MALE PATIENTS

The only widely available method for the preservation of fertility in males is through cryopreservation of semen. When discussing cryopreservation of semen with patients it is important to highlight that the samples are obtained through masturbation in order to prepare patients for the process. Patients as young as 13 years have been shown to have a normal sperm count and in TYA units have been successfully able to sperm bank. Therefore, sperm banking should be offered to all young men at risk of infertility. Staff should pay particular attention to younger teenage patients who may not fully understand or appreciate the importance of fertility issues and how this will affect them much later in life. It is important staff take the time to discuss the issue of young men ‘changing their mind’ later in life. For example a 15 year old patient may not be at all focused on how treatment may affect his ability to have a family at the age of 25 years. Staff must facilitate long-term thinking in young people with regard to fertility options and preservation.

Usually sperm banking is carried out in a specialist fertility clinic/hospital. However, some young people may be too unwell to travel and therefore teams should enable them to provide a semen sample in the ward environment and appropriate transfer of sample 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. Young people should be encouraged to take suitable material according to their sexual orientation and if appropriate, partners should be encouraged to attend. Cultural and religious rules/ expectations around masturbation should also be explored before sperm banking is arranged to avoid causing offence or embarrassment.

It is also vitally important that staff counsel male patients appropriately and ensure they have realistic expectations with regard to sperm banking. Patients may wish to sperm bank but may fail due to being so unwell; this leads to feelings of failure and inadequacy and it must be reinforced from the outset that not all sperm banking is successful.

FEMALE PATIENTS

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. Ovaries can be partly or completely removed, in addition egg/embryo storage is possible. However, the efficacy of female fertility preservation remains unclear and some preservation procedures need to take place over a period of time. The need to treat the cancer usually supersedes the ability to undergo treatment for egg or embryo storage.

Resources
- www.youngpeopleshealth.org.uk
- www.teenagecancertrust.org
COGNITIVE, PSYCHOLOGICAL AND SOCIAL CHANGES

During adolescence young people expand their concept of the world, develop new cognitive capabilities and begin to question their own beliefs and those of other adults. Development of cognitive thought requires continuous adjustment in behaviour when trying to make sense of their world. Typical behaviours may include:

- Pushing boundaries and ignoring rules and regulations as they don’t see where they fit within them
- Inconsistent thought processes are common during the cancer pathway. They may fluctuate between mature and childlike behaviours depending on a particular situation
- Responding to peer group pressure which may influence a young persons behaviour during treatment
- Risk taking or experimentation without thought to consequences

The development of ‘self concept’ and the emergence of the young person as an independent human being is a process fraught with anxieties and insecurities. Young people may not yet be comfortable with their new bodies, thoughts, emotions, impulses and desires and this can create an inner conflict. The ability to communicate and discuss inner conflicts may be challenging and young people may attempt to deal with these difficulties by becoming non communicative, argumentative or non-compliant.

Social development includes a process of increased socialisation and societal integration which occurs throughout adolescence. Social challenges include developing sexuality, personal relationships, separation from parents, developing personal values and ethics and career preparation.

Of particular importance to socialisation is peer group interaction. Peer interaction is pivotal to the developmental process. Belonging to different groups of friends and being accepted by others with likeminded views is central during this life stage. In relation to peer group development, it is important to note that bullying is most common during adolescence. This may be related to young people vying for a position or struggling to belong within a peer group. Peer group acceptance can supersede the importance and status of family relationships and values. This can lead to family conflict especially if the groups or individuals are not deemed as ‘acceptable’ to their families. In addition, young people can become introspective and spend a lot of time alone, sleeping for long periods of time and engaging in solitary activities such as watching DVDs, playing games and internet browsing. Typical solitary behavior may further contribute to the alteration of parental and family relationships.

Healthcare professionals should provide support to all family members and encourage continuation of established family relationships; whilst recognising that conflicts and tensions may exist.

THE TEENAGE AND YOUNG ADULT CONTEXT

A young person’s responses to a cancer diagnosis must be understood from a developmental perspective if they are to be managed appropriately. The young person is attempting to respond to the cognitive, psychological and social changes of adolescence. When coupled with a diagnosis of cancer they can experience emotional and psychological distress which may be extreme. Emergence into adulthood can bring family relationship issues to the forefront.

Parents may re-evaluate their relationship with the young person when a cancer diagnosis is made. During illness, the dependant relationship is often re-established through anxiety and concern for the young person. The way they react to this shift in roles is dependent on the relationship before their diagnosis and the stage of the separation process at the time of diagnosis. Some young people rely on their parent/carers to be there with them, others find it embarrassing and stifling. In addition, regressive or childlike behaviour may be observed. Changes in the parental relationship are often a source of family conflict that will need careful management and support from the TYA healthcare team.

It must be recognised that some patients may be parents themselves. Young parents in some circumstances may resume an adolescent role thus affecting their behaviour as a parent. However, others may cope well with parental responsibilities but find it difficult to talk to their child about their cancer or be unsure what information to disclose.

Conflicts of interest can occur regarding the care of a child between the patient, their parents or partners where a child of the young person is involved. If their cancer cannot be cured, they will have the added burden of choosing who will look after their child/children after their death. In some situations legal issues may arise. If this is likely the young person should be supported to discuss and document their wishes where possible.

Young people may be diagnosed during a time when they are beginning to establish an important personal or sexual relationship. A cancer diagnosis is challenging even in strong relationships, as it can test partners’ perseverance and care. New relationships can be very vulnerable to existing parental relationships. Conflict may occur in establishing who the significant carers are for that young person. Patients may revert to parental care at this time and new partners can feel isolated.
Or conversely, young people may become more reliant on partners which may leave parents feeling unneeded and lead to a young partner feeling overburdened.

When communicating and interacting with teenagers and young adults with cancer it is essential to respond to individual needs and situations. It is often appropriate to communicate with young people as you would an adult by listening to their needs and evaluating their responses.

However, it is also useful to understand that the young person’s interaction and understanding can change quickly back to child-like behaviour, so adaptability is the key to successful interaction. It is essential that whilst the patient is central, parental and other family involvement is crucial in all aspects of care and decision making. Healthcare professionals will need to adjust their communication and skills to meet individual situations.

SPIRITUALITY AND RELIGION

Patients who receive a cancer diagnosis often begin to think about the meaning and purpose of life. They ask questions like ‘Why me?’ and ‘Why now?’ This kind of questioning can be called philosophical, existential or spiritual and is common to people of no faith and to people of faith. Evidence suggests that addressing spiritual concerns and receiving good spiritual care contributes to patients’ sense of wellbeing and quality of life, and can help with issues such as the resolution of grief. Staff should therefore facilitate discussions with young people and include spirituality as part of ongoing patient assessment. Teenage and young adult patients may question treatment efficacy and may wish to explore spiritual issues such as loss of hope and fear of dying. The interdependent relationship between the parents and the young person can also lead to covert protection (collusion) of each other’s feelings, which can sometimes obstruct the exploration of these deeper issues. Having the opportunity to talk with someone in the TYA team can help. It is useful to involve wider health teams including chaplaincy/spiritual care staff and palliative care teams.

“The one thing that kept on going round my mind was, why me? The uncertainty was whether I was going to live and had they correctly diagnosed me – maybe they got me mixed up with somebody else. At the time, survivorship issues didn’t really affect me, I was only thinking about life and death and that was it.”

Nicole, 17, Medulloblastoma

TOP TIPS

TYA Development

- Facilitating young people to maintain a sense of ‘normality’ is vital to effective coping.
- Encourage and support continuing education and/or work where possible and appropriate. Where patients are treated locally the TYA team at the Principal Treatment Centre should be able to help with education/employment issues.
- Provide information and support appropriate for the young person’s developmental stage.
- Support and facilitate the young person to maintain social contact with their usual peer group in order to avoid social isolation.
- Provide opportunity for the young person to meet and spend time with other young patients - this can enhance coping with cancer and its treatment.
- Create an environment where the patient has some control over their care and treatment.
- Young people may change normal behaviour patterns when going through cancer treatment; regression may be observed in some patients.
- Young people may be egocentric and don’t always consider the consequences of their behaviour and actions.
- Treating teams should take into account the needs of the wider family and dependants; offering support or referral to appropriate services.
- Recognise that often there are conflicting views between parents and young people; staff should help to resolve conflicts as soon as possible whilst maintaining a sensitive approach.
BEHAVIOUR AND RISK TAKING

SMOKING
Smoking is an addiction and therefore it may be difficult for a young person to stop once a habit has formed. This should be recognised and appropriate support provided. Smoking cessation programmes (often available through NHS rehabilitation and complementary therapy services) or through external organisations (Appendix 4) may be useful and should be offered and encouraged.

Often the very nature of treatment enforces smoking cessation in cancer patients due to prolonged and intensive in-patient stays. However support in the form of nicotine replacement therapy, acupuncture, hypnotherapy and counselling should be offered and may prove useful. Young people often find support groups a good way of stopping smoking and it may be that staff can find a local group to put them in contact with.

It is important to note that the time of diagnosis may not be the right time to encourage smoking cessation as this may add to a young persons stress and anxiety. Young people often feel angry that they have been diagnosed with a cancer unrelated to smoking. They may have feelings of rebellion in this situation and may continue to smoke. Healthcare professionals should assess each individual situation, offering timely and appropriate information regarding smoking cessation. Young people who do smoke and continue to smoke should be treated in a non judgemental and sensitive manner if they feel unable to stop. Staff enforcing smoking cessation will inevitably result in distress to the patient and alter patient/staff relationships. Smoking cessation can be revisited during the cancer trajectory in order to encourage a healthy lifestyle in the long-term.

ALCOHOL
There is evidence of a dramatic rise in alcohol consumption by young people in the UK. It can be viewed as a developmental phenomenon and indeed the reasons for alcohol use at this life stage are varied. Young people have often cited social motives, enhancement motives and (significantly fewer) coping motives as their impetus.

Treating teams cannot control or dictate a young person’s drinking habits whilst on treatment. However, if it is felt a young person does have a dependency on alcohol (presenting an unhealthy coping strategy), then it is advisable to offer signposting to external organisations. The government document Youth Alcohol Action Plan suggests that young people should take ownership of the problem and should be supported with accurate information about the harmful effects of alcohol. This will enable them to make informed decisions.

The signs of alcohol use in young people include:
- Being able to smell alcohol on their breath
- Increased moodiness
- Secrecy and discipline problems

Treating teams should assess patients’ normal alcohol consumption and disclose dependence to the wider team. External referral should be initiated (Appendix 4) if there are any concerns about increased use, or indication of reliance on alcohol as a coping strategy. However, this will need discussion with the individual patient.

SUBSTANCE USE
For many, a feature of this life stage is experimentation or the initiation of substance use. The use of substances often develops in the transitional stage of adolescence when they are enduring puberty and physical maturation, are becoming independent from the family unit and are influenced more heavily by their peers. Engaging in risky behaviours such as experimenting with substances can be considered to be a crucial part of this life stage. Whilst the vast majority of young people do not go on to partake in substantial substance misuse, any substance use has potential for danger in the long-term.

It is important to acknowledge the differences between occasional, short-term and more problematic long lasting substance use and misuse amongst young people. In the case of teenagers and young adults with cancer, use can become problematic when utilised as a coping mechanism. It is therefore advisable that treating teams are alert to the use of any substances by a young person in their care and that the individual is appropriately referred and supported by experts in substance misuse.
The reasons for using substances vary; social, economic and cultural factors play a major part in the initiation and maintenance of substance misuse in young people. It has been found that young people also report using substances for positive and negative drug effect, to socialise with their peers and to cope with a negative effect.

The use of recreational drugs in particular (both legal and illegal) presents an important and under-recognised issue in TYA cancer care. Data from the 2003/4 British Crime Survey indicate that drug use amongst young people (16 - 24 years old) increases as they get older and over a quarter (28%) of those aged 16 - 24 had used an illicit drug in the previous year. The most widely used drug was cannabis (24.8%), followed by ecstasy (5.3%) and cocaine (4.8%); the use of other Class A drugs remained stable at around 8%. It is clear therefore that all professionals working with young people need to be aware of the use of drugs as a potential issue.

Substances utilised by a young person may include:

- Alcohol (legal from 18)
- Tobacco (legal from 18)
- Marijuana (grass, hash, pot, ganja, skunk)
- Inhalants or solvents (glue sniffing)
- Stimulants (E, MDMA or pills)
- Cocaine and crack cocaine
- Heroin

There are many warning signs of drug use and abuse in teenagers. The challenge is to distinguish between the normal, sometimes volatile, ups and downs of the teen years and the red flags of substance abuse:

- Being secretive about friends, possessions and activities
- Demanding more privacy, locking doors, avoiding eye contact, sneaking around
- Skipping class, declining grades, suddenly getting into trouble at school
- Missing money, valuables or prescriptions
- Acting uncharacteristically isolated, withdrawn or depressed
- Using incense, perfume or air freshener to hide the smell of smoke or drugs
- Using eye drops to mask bloodshot eyes or dilated pupils

(www.helpguide.org)

If staff recognise these symptoms in a young person and they cannot be attributed to their cancer treatment, it may be advisable to seek advice and help from community organisations who have staff trained to help any young person involved in substance use (Appendix 4). This must always be done with the consent of the young person.

It is essential to be aware of any young person who is a drug user as this might affect care. Staff should be supportive and non-judgmental and be able to signpost the young person for counselling if it is felt necessary or is asked for.

**SEXUAL HEALTH**

- In the UK, the average age for a young person to become sexually active is 16 (both males and females).
- Young people in the UK are more sexually active than in most other countries in the developed world.
- A significant proportion (estimated to be between a quarter and a third) of young people in the UK have had sex by the time they are 16.
- They are the group least likely to access contraceptive and sexual health advice, putting them at high risk of unplanned pregnancy and sexually transmitted infections (STIs).
- In 2008, teenagers and young adults (aged 12 - 24 years old) accounted for 65% of all Chlamydia, 55% of genital warts and 50% of gonorrhoea infections diagnosed in genitourinary medicine clinics across the UK.

Professionals caring for young people should expect to have to discuss sex and sexuality with young people; it is usually a very important and normal part of their life and development. ‘Risk taking’ behaviours are common within this population and when young people are sexually intimate it is helpful if they have access to advice about agencies that can answer any questions and help them (Appendix 4). It is not essential for treating teams to be experts about young people’s sexual health, but they do need the confidence to talk about the subject with young people and refer on appropriately. TYA teams should carefully consult and counsel the young person regarding the risks of unprotected sex and give advice regarding action that is required.

Some questions to consider asking young people might be:

- Is the young person sexually active?
- Do they have a partner?
- Are they gay, straight or bisexual?
- Are they transsexual/transgender?
- Do they practice safe sex?
- Do they use barrier methods i.e. condoms to avoid pregnancy during treatment and to protect partners (chemotherapy risk, STI risk)?
Research indicates that teenage and young adult patients have more concerns related to sex and sexuality than their healthy peers. They may also have had limited access to information about this subject (due to absence from school, college, etc) and have become isolated from their peers who would be their normal source of information and discussion about sex and sexuality.

Young people may not consider that their sex life can be affected by treatment for cancer or that many treatments can pose both short-term risks to sexual partners, as well as longer-term risks to any offspring that are conceived during or for a period after treatment. It is therefore imperative that TYA teams address and discuss sexual health when working with a young person when having cancer treatment.

Laurence et al (2004) outline some of the issues and advice that are useful to consider regarding sexual health when working with a young person with cancer:

- 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 provided
- 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 teenagers and young adults with cancer believe 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 their individual regimen
- Don’t assume that young people are not sexually active during treatment
- Ensure discussions around contraception occur at appropriate points throughout treatment, not just at the beginning or end

TOP TIPS

Risk Taking

- It is important to assess the presence of risk taking behaviours prior to commencing treatment. Screening tools should be used as part of holistic patient assessment.
- Staff treating young people with cancer should be aware of the signs and symptoms that indicate participation in risk taking behaviour.
- Young people should be encouraged to discuss risk taking behaviour with staff in order to identify potential problems. However remember, young people may choose not to disclose risk taking.
- Ensure confidentiality is respected if appropriate, however inform the young person that information may be disclosed on a need to know basis if it is in the best interests of the patient to involve other staff members.
- Promote and advocate healthy lifestyle choices, whilst remaining supportive and non judgemental should young people participate in risk taking behaviour.
- Local conduct and operational policy should be in place to ensure young people are aware of boundaries whilst in hospital and staff are supported to challenge risk taking behaviours within the hospital environment.

Resources

- Association for Children’s Palliative Care. 2008. Let’s Talk About Sex: Let’s Talk About You and Me. Relationships, sexual health and sexuality guidance for those working with young people with life threatening conditions and their families. ACT, Bristol
- Department for Education and Skills. 2007. Improving Access to Sexual Health Advice Services for Young People in Further Education Settings. DfES Publications, Nottingham
- www.helpguide.org
MENTAL HEALTH CONSIDERATIONS

THE FACTS

- Undiagnosed mental health difficulties in young people can lead to lower educational achievements, substance abuse, violence and poor reproductive and sexual health.
- Between 10-20% of young people in Europe are estimated to have one or more mental or behavioural problems.

Mental health difficulties can potentially have a huge impact on how young people tolerate and cope with treatment. It is therefore essential that the treating team attends to their mental as well as physical health. If a young person is identified as possibly requiring input from a Mental Health Specialist, they should be referred to appropriate services as soon as possible.

DEPRESSION AND ANXIETY

Depression and anxiety are common psychological disorders in childhood and adolescence.

However, the disinclination of young people to seek timely professional help for difficulties is increasingly acknowledged as a major challenge to effective treatment.

Depression in particular appears to be more prevalent in this age group and has been associated with poor educational attainment, antisocial behaviour, eating disorders and alcohol and drug abuse. Due to the far-reaching impact of such difficulties it is advisable that ongoing assessments regarding these disorders should be carried out by teams working with young people who are being treated for cancer.

Symptoms of anxiety and depression can include:

- Lack of interest in normal activities
- Sleeplessness
- Low mood
- Feeling worried and upset
- Physically feeling shaky, nauseous or faint
- Withdrawal

Further indicators of depression are:

- Having suicidal thoughts
- Self harming
- Inability to enjoy usual interests and avoidance of usual activities
- Finding it difficult to concentrate
- Not wanting to see family and friends
- Having unexplained aches and pains
- Eating less or more than usual
- Problems sleeping

Recognising these symptoms will allow timely help and the assistance of a healthcare professional. If they are empowered to do so, it has been shown that young people are more inclined to seek help for mental health problems if they:

- Have some knowledge about mental health issues and sources of help
- Feel emotionally competent to express their feelings
- Have established and trusted relationships with potential help providers

Young people should be referred to Social Work, Counselling, Occupational Therapy, Psychology and Psychiatry as necessary for relevant interventions. It is important that treating teams are aware of these 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.

Teams should also be aware that low mood is an understandable, realistic and appropriate reaction to a cancer diagnosis. Help should be offered where appropriate but it must also be acknowledged that young people diagnosed with cancer are vulnerable. Low mood may simply be a reasonable coping mechanism in a very difficult situation.

SELF HARM

The term ‘self harm’ is used when an individual intentionally injures or harms themselves. It can be considered to be a symptom of someone who has serious problems. Self harm is considered to be relatively common and potentially on the increase within the teenage and young adult population.

Indeed, it has been found that 7-14% of young people will self harm at some point in their lives. Studies have also found that young women are more likely to self harm than young men (8.4% v 5.8%).
**REASONS FOR SELF HARMING**

The main motive behind self harm in young people has been found to be the need to relieve one’s self of negative emotions. In addition, the Child and Adolescent Self Harm in Europe Study found that the following were the most common reasons for self harm:

- To find relief from a terrible state of mind
- Wanting to die

They found that less common reasons included:

- To punish themselves
- To bring their distress to others attention

Young people most at risk are also found to be, amongst other populations, those who are sick. It is imperative that staff working with the teenage and young adult population are alert to the possibility of self harm in patients and are able, with the consent of the young person, to signpost an effectively (i.e. to psychiatric services, CAMHS etc).

**METHODS OF SELF HARM**

Young et al (2007) found that the following were methods used by young people in order to self harm:

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

If you are working with a young person who self harms, you can help by:

- Reassuring them that, with help, it is possible to stop
- Ensuring the young person is aware of the risks of self harm
- Recognising signs of distress and finding some way of talking with the young person about how they are feeling
- Listening to their worries and problems and taking them seriously
- Offering sympathy and understanding
- Help with solving problems
- Staying calm and in control of your own feelings
- Ensuring they are referred to appropriate mental health services as soon as possible

**SUICIDE**

Young people who attempt to commit suicide usually feel unable to solve their problems or don’t know where, or how, to get help. There is a popular notion that rates of suicide in young people have continued to rise, however it’s being increasingly recognised that this is not in fact the case. Figures have been stable in young women and actually declined in young men.

However, the risk of suicide is higher when a young person:

- Is depressed, or when they have a serious mental illness
- Is using drugs or alcohol when they are upset
- Has previously attempted or planned suicide
- Has a relative or friend who tried to kill themselves
- Is socially isolated

Teams working with young people should always be mindful of an individual’s mood, any history of self harm or suicidal tendencies and lack of ability to cope with their clinical situation. Suicidal thoughts, or attempts, should always be taken seriously and acted upon. Young people should be referred to appropriate services as soon as possible.

**EATING DISORDERS**

Eating disorders (including obesity), although rare, are a significant public health problem today. Epidemiological data has shown that the period of increased risk for developing eating disorders is during adolescence and early adulthood; with the highest prevalence being in adolescence and young womanhood.

**ANOREXIA NERVOSA AND BULIMIA NERVOSA**

Someone with anorexia nervosa is continuously preoccupied with being overweight (even if they are extremely slim or underweight) and controls their weight by limiting food intake. Someone with bulimia nervosa will have similar concerns with weight. However, they will alternate between eating next to nothing and bingeing and purging. Both of these eating disorders are more common in girls, but do occur in boys.

The signs and symptoms:

- Weight loss or unusual weight changes
- In girls, periods being irregular or stopping
- Missing meals, eating very little and avoiding ‘fattening’ foods
- Avoiding eating in public; secret eating
- Large amounts of food disappearing from the cupboards
- Believing they are fat when underweight
- Exercising excessively
- Becoming preoccupied with food; cooking for other people
- Going to the bathroom or toilet immediately after meals
- Using laxatives regularly
It may be difficult to tell the difference between a serious eating problem and the under-eating associated with cancer treatment due to lack of appetite. However, it is useful to gain an insight into individual eating habits before treatment begins to gauge what is normal for each young person. Initial patient assessment is a useful time to explore the young person’s relationship with food/diet. Early recognition of the problem and referral to specialist services is essential, as an established eating disorder in a young person can cause significant problems as they go through treatment.

In addition it may be useful to monitor what a young person is eating post treatment. Following cancer treatment individuals may have become aware of the positive effects of losing weight and modify their food intake in order to stay slim/thin.

**COMPULSIVE OVEREATING**

Overeating is also an eating disorder and can be indicative of significant psychological distress. Young people who suffer from overeating usually do so to avoid confronting their emotions and problems. They are likely to understand that their eating habits are abnormal but use food as a coping strategy.

Establishing if overeating is a real problem for an individual:

- Is it a pre-existing condition or one that has developed during treatment due to changed relationships with food and their body?
- Is it a side effect of treatment (such as steroids)?

Gaining help from outside agencies and including Dieticians and psycho-oncology services can often be helpful for these individuals.

It is important to try to co-ordinate effective management of physical and psychological aspects of eating disorders. However, it must be noted that these conditions are extremely complex and outcomes remain very variable, with adverse outcomes commonly extending into adulthood. Expert help should be sought by TYA treating teams for developing or pre-existing disorders.

**TOP TIPS**

**Mental Health**

- Be aware that some mental distress/anxiety is appropriate and can be a normal coping mechanism during cancer treatment.
- Staff treating young people should have a baseline knowledge of mental health issues and be able to recognise the signs and symptoms of common mental health problems in this age group.
- Identification of potential mental health issues in teenage and young adult patients should be discussed with the wider MDT and specialist advice sought.
- Ideally a mental health professional should be part of the treating team from the beginning of treatment.
- Be aware of local resources and services that are available and refer young people to specialist mental health services if a problem is identified.
- Staff should be alert to a young person who is unusually upset, withdrawn or irritable; allowing time for them to discuss difficulties will allow staff to put timely interventions in place where appropriate.
- All young people who display or discuss self-harming behaviour or possible suicidal tendencies should be taken seriously and have an immediate specialist mental health assessment. Appropriate support services must be in place before leaving hospital.
- When discussing any mental health issues with a young person, explore issues around confidentiality. Confidentiality should be respected but may not be possible in all circumstances where a mental health issue has been identified.
- Where possible, the decision to breach confidentiality should be discussed with the young person providing explanation and reasoning.
- Involve any pre-existing specialist mental health teams that the patient may already be engaged with i.e for eating disorders.
PRACTICE PRINCIPLES AND RECOMMENDATIONS

TREATMENT ENVIRONMENTS

It is essential that young people are 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 country has made this easier to achieve. However, many health trusts don’t have such facilities and so flexibility in adult and paediatric environments is required.

Units without dedicated facilities should encourage the creation of an environment that promotes a sense of familiarity and safety for the young patient. This involves encouraging the patient to bring personal items into the hospital such as pillows, duvets, photographs, games, and laptops. However, staff must also adhere to local infection control policies and restrictions.

“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

“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

Allowing the use of mobile phones is crucial to ensure young people have a lifeline to peers and family through text and phone calls. Social networking sites (e.g. Facebook and Twitter) are commonly used by young people and access to the Internet should be provided. This promotes a sense of normality and avoids the young person from being left out of the loop in social networks. It can also be a useful way for staff to communicate with patients when they are outpatients and in the community.

Provide written information with suggested examples of things to bring in for periods of hospital admission. Consider having fittings in rooms and bays, such as notice boards for cards, mementos and photographs which will help to create a more personal space.

The ward should be flexible in accommodating individual patient and family routines. Hospital food and routine mealtimes are often unpopular in the teenage and young adult population. 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. Flexible mealtimes, visiting hours and a flexible ward routine (i.e. late waking times) also contribute to a more age-appropriate environment.

“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

Many young people gain support from having someone staying with them; this is common practice in paediatric and teenage and young adult units but not necessarily in adult areas. However, it is recommended that this be offered to all young people. Many may not require it 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 in the hospital could be sought.

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

Young patients should have access to appropriate recreational equipment. This might include music, electronic games, books, pool and table tennis tables, computer and internet access, and magazines. It is also desirable that young patients have access to drinks and snacks. It is important that young people have access to a dedicated space for relaxing away from their bed, where social interaction can take place.
Developmentally appropriate entertainment and recreation facilities should be available for young patients and their siblings, in waiting areas and during waiting times. These recreational activities should be viewed not as secondary to multidisciplinary treatment but as part of the holistic care of teenage and young adult patients. Such recreational activities:

- Promote a feeling of normality
- Reduce the sense of being in a hospital setting
- Provide enjoyment
- Assist with apathy and depression
- Promote social interaction
- Encourage young people to have higher expectations of their treatment period

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. This is especially true if you are providing young people with laptops or PCs, as opposed to them using their own. 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 certain websites which are deemed inappropriate can be blocked. IT departments should be able to assist with these measures.

“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

It is recognised that the creation of specific environments for teenage and young adult patients in all cancer centres is not practical at present and there are 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 adult patients, whose outlook both clinically and psychosocially is very different.

In adult hospitals that don’t see enough young patients to justify a dedicated TYA room, the most appropriate place for these young people is a single room. If no such room is available, care should be taken to ensure that the young person is surrounded by people of a similar age.

PRIVACY AND DIGNITY AND SAME SEX ACCOMMODATION

The delivery of same sex accommodation is an important target in the NHS in order to meet the privacy and dignity of patients and improve the quality of care. However, delivery will be challenging and may be particularly complex in some specialist areas.

It may not always be possible to meet same sex accommodation on a TYA Unit. Work has taken place with the Department of Health with the following practice guidance put forward:

“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.”

- 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 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 and this includes the patient being admitted and the existing in-patients

(See Appendix 5)

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 is extremely disruptive to many aspects of life for both the young people and their carers. Many still want to attend school or university or just have time at home to socialise ‘normally’ with their peers. Reducing the length of time in hospital, where possible, will enable the young person to spend more time within the normal home environment.
“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

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

- 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.
- 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.
- Some young people may wish to negotiate treatment times to fit around school or work. Flexibility by treatment teams is crucial to support this.
- Ensure the young person gets 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 GP surgeries or at local hospitals along with weights for chemotherapy dosing. Results can then be sent to treatment centres to allow treatment to be made and ready for the day the patient attends.
- Many young people may want to organise their attendance times themselves to maintain choice and control.
- Ensure chemotherapy regimens are prescribed and ready prior to admission.
- Try to organise tests and investigations to occur on the same day to avoid repeated hospital visits over a number of days.
- Ensure any medication that needs to be taken home on discharge is ordered and ready the day before.
- Accept that some patients may want to go home in the middle of the night if hydration/treatments are completed at that time and facilitate this where appropriate.
- Develop shared care arrangements with local hospitals in line with recommendations in the CYPIOG; this can reduce the impact treatment has on a young person’s time by providing some tests and treatments closer to home.

TOP TIPS
Non Compliance

- 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 if necessary.
- Avoid making unnecessary demands – don’t make them 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.
- Explain the reasons for adherence relative to that individual’s perspective.
- Ensure treatment, where possible, fits around their lifestyle.
- Keep the young person informed at all times, making sure they are actively involved in decisions to give them a sense of power and control.
- Ensure they have positive relationships with the health professionals involved with their care.
- Encourage young people to express their concerns and foster open communication.

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 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 clear, precise and visible and should promote behavioural boundaries that are appropriate to the hospital or treatment setting. Ground rules may be incorporated into local behavioural or operational policies. These can outline acceptable and unacceptable behaviour, consequences of breaching local policies and address issues such as drug/alcohol use, bullying, theft and vandalism and behaviour towards staff and other patients (Appendix 6).

NON-COMPLIANCE AND ADHERENCE

Non-compliance with treatment plans is often observed in the teenage and young adult population. It is not easy to convince a young person of the benefits of adherence to treatment. It is hard for them to fit medications into their lifestyle and side effects can be disturbing and difficult to manage. Treatment may be resisted if there are unresolved feelings about their condition.
PROVIDING AGE-APPROPRIATE INFORMATION

All patients should be given written information in order 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.

The teenage and young adult demographic is extremely computer literate and they are likely to attempt to find further information about their disease on the Internet. 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 teenage and young adult patient and their carers (see Appendix 7 for suggested resources).

“Everybody was really helpful offering clear and to the point information.” Josh, 18

TOP TIPS

Treatment Environments

- Provide a ‘home from home’ environment for young people.
- Personalisation of the environment should be encouraged allowing ‘ownership’ of 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).
- Teenage and young adult patients should be able to use a mobile phone and laptop whilst in hospital, these are often ‘lifelines’ to peers and family.
- 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 tables.
- Where a dedicated 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.

- Department of Health. 2010. The Christie NHS Foundation Trust: Delivering Same Sex Accommodation to Teenagers and Young Adults with Cancer. HMSO, London
- Royal College of Nursing. 2002. Getting it right for teenagers in your practice. RCN, London
- Royal College of Nursing. 2006. Use of text messaging services: guidance for nurses working with children and young people. London
- www.teenagecancertrust.org
- www.macmillan.org
- www.clic4tic.org.uk
- www.nhs.uk/young-cancer-care/Pages teenage-young-adult-cancer-units.aspx
STAFFING CONSIDERATIONS

STAFF TRAINING
The best standard of care for teenage and young adult patients is undoubtedly provided by clinicians who have been specifically trained to care for them. It is imperative that staff working with young people have sufficient understanding of the psychosocial needs of this age group and the strategies of care required to meet those needs. In the UK, there is a growing body of clinical expertise in the care and management of young people with cancer. Despite the rapid expansion of TYA cancer care as a specialty, the development of formal education programmes and post-registration qualifications is still in its infancy. There are a number of TYA cancer-specific education programmes and conferences in the UK and these should be considered for any member of the multidisciplinary team working with this patient group. Educational opportunities and TYA conferences/study days can be found by visiting www.teenagecancertrust.org, www.tyac.org.uk and www.coventry.ac.uk.

SPENDING TIME WITH YOUNG PEOPLE
Staff spending time with them is particularly important to this age group. Young people appreciate time to have procedures explained and to discuss treatment. They may wish to disclose intimate feelings with staff, discuss anxieties or simply chat about everyday things. Whatever the nature of the conversation, research shows that young people, in particular, value staff spending time with them and have negative experiences and memories of hospital when staff don’t devote this time.

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

Young people may 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. Where possible, this private time with staff should be negotiated with family members. Equally, family members have their needs met by treating teams and the support of a good team will help facilitate this. Young people need to be allowed 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 RELATIONSHIPS
The involvement of both patients and the parents/carers in TYA care is essential to the management of illness in this age group. Good communication and building therapeutic relationships with patients and families are, perhaps, some of the greatest challenges in TYA cancer care and require highly developed communication skills on the part of the healthcare professionals working with this patient group.

Challenges may include the teenage and young adult patient:
- Not sharing the same views as the clinician
- Finding it difficult to understand medical terms
- Not sharing the same communication style as their treating professional

“I prefer communication to be directed at me and my parents because it keeps us both informed.” Josh, 18

The treating team may recommend the best care plan and treatment possible but it is vital that the young person feels that they have been consulted and involved in the process. Research has shown that overly-controlling relationships with parents and/or treating teams have a negative impact on treatment adherence among young people (Kyngas et al 2000). Furthermore, patient choice has become a key feature in the provision of healthcare services and, as such, it is important that decisions are reached in partnership with the patient.

Young people with cancer may want detailed information and expect significant participation in decisions about their care (Jenkins 2001; Fallowfield 1995; NHS Centre for Reviews and Dissemination 2006). It is vital that patients and parents are provided with clear information about their cancer, their treatment and any choices that they may have. Providing clear information allows the young person and their carers to contribute to
the management of their illness and make the best decisions for their ongoing health (NICE 2005; Kyngas et al 2000).

However, there is a fine balance between ‘true’ patient choice, adherence to treatment and information provision in this patient group. For example, young people are often seen to try to ‘protect’ parents from emotional burdens and may not disclose certain feelings, concerns or information when parents are present. Similarly, parents may act as ‘gatekeepers’ and want to withhold information from the young person. Both these scenarios can pose significant challenges for the treating team and need sensitive handling. Staff working with this age group must be able to recognise non-verbal cues and be able to interpret the meanings of attitudes and behaviours.

“I would like my parents to be told the same as me, at the same time, nothing hidden from either of us, but to address us both.” Daniel, 23, Sarcoma

Young people may be uncommunicative at times, may not want to ask questions or 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 led and guided by the young person and the healthcare professional must respect this. The important issue is to consult young people regarding all aspects of care and to understand verbal and non-verbal cues in order to interpret situations and behaviours. It is therefore imperative that healthcare professionals working with this group possess highly developed advanced communication skills.

The wish to be alone or accompanied during consultations is likely to vary between individuals according to age, personality, family relationships and stage of illness and treatment. However, it is recommended that, at some stage during their consultation/s, parents, partners or other family members are asked to leave so that the clinician can consult with the young person alone. Meeting with the young person alone provides them with a safe forum in which to address any issues that they don’t feel comfortable discussing in company.

“I have had a lot of bad news. I feel it is best to be upfront, it makes me sad but you have to sort it out.” Daniel, 23, Sarcoma

Practical suggestions for communicating with young people:

- Ensure that the young person has a trusted adult with them at the time of a discussion or consultation but is also able to 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.
- Be approachable but professional. Young people need a trusted professional and not a friend; however, it is often useful to personalise your interactions with them, discussing things that they are interested in and enjoy.
- Be open and honest with the young person. This is vital in building a trusting relationship with them.
- You are not expected to be an expert or have all the answers, use the wider TYA MDT. Be honest when you do not know the answer.
- Be positive and non-judgmental - 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 - use humour where appropriate.
- Allow adequate time for discussion, summarise and offer to revisit issues or repeat information.
- Always assess the young person’s understanding before providing additional information and ensure that you judge 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 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.

The above has, in part, been adapted from the Royal College of Nursing’s guide to working with young people and communicating with young people. Further advice and information can be obtained from this guide.

CONFIDENTIALITY

Confidentiality is fundamental to ensuring that teenage and young adult patients receive the best possible care. Confidentiality between young people and their healthcare professionals is particularly important in the building and maintenance of trusting and collaborative relationships; in particular, discussing sensitive issues such as sexuality, risk-taking behaviours and mental health issues. However, it is important that these areas are explored to ensure a full assessment of the young person is made so that care can be tailored to meet individual needs. Staff must use their professional judgement in order to make decisions on information that may remain confidential between the patient and
that particular healthcare professional, whilst also identifying information that should be disclosed to other team members. The essence of patient confidentiality should be on a ‘need to know’ basis and have the best interests of the patient at the centre of any decisions that are made.

Patient confidentiality may be difficult to negotiate as the boundaries between the young person and their parents or carers are often blurred and ambivalent. In some circumstances, the parent receives information first in order to ‘protect’ the young person from receiving distressing news. The level of parental or carer involvement should be negotiated with the young person and communicated to the parents. Healthcare professionals must appropriately manage complex relationships between the young person and their parents/carers whilst adhering to legal and ethical requirements relating to confidentiality and informed consent. Staff must also be honest with young people and be clear if they feel that information they have discussed should be disclosed to others in order to protect their best interests.

**PROFESSIONAL BOUNDARIES**

“Professional boundaries separate therapeutic behaviour of the healthcare professional from any behaviour which, well intentioned or not could lessen the benefit of care to patients”. College and Association of Registered Nurses of Alberta 2005⁶⁶.

Maintaining professional boundaries is an emerging issue in TYA care. There is little in the way of theoretical guidance and much of the work that is available draws on psychiatry, elderly care and mental health.

All professionals working with young people have the potential to cross boundaries, however there are a number of risk factors that increase the likelihood within TYA cancer care:

- 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/Facebook)
- Relaxed communications style with young people
- Emotionally demanding patient group

Managing relationships with young people can be challenging to healthcare professionals, particularly for inexperienced members of the team. Staff are expected to foster a friendly and age-appropriate approach. In addition, 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 the teenage and young adult population. Young people are particularly vulnerable during the developmental period of adolescence, even without a cancer diagnosis. Anecdotal evidence from TYA experts suggests that young people with cancer often come to think of staff as ‘friends.’ Inexperienced staff may become ‘over-familier’ with patients and professional boundaries can become blurred.

In order to form good relationships with teenage and young adult patients, 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 share information 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’; potentially causing dependence on certain individuals within the team. This can jeopardise the maintenance of stable, therapeutic and professional relationships that the young person requires during their treatment.

Increasing use of technology amongst young people has resulted in changes in the way healthcare professionals and teams offer information and support young people through their cancer treatment. The use of mobile phones and texting is increasingly used in TYA care to advertise or make arrangements for activities or for patients to report symptoms or healthcare

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**TOP TIPS**

**Staffing**

- Staff caring for young people should have access to and be encouraged to attend TYA specific courses and conferences
- Staff working with young people should be encouraged to utilise and join existing national TYA professional networks which offer expertise, peer support and mentorship (e.g. TYAC/TYAC MDF)
- Young people may demand more time from staff than other patient groups. Spending time with them is crucial in developing a therapeutic relationship and staff should be supported in meeting this need
- At least some core members of staff caring for young people should undertake an Advanced Communication Skills Course
- Confidentiality issues are important to explore with young people, including the limits of confidentiality
- Staff support is essential when caring for this patient group. Teams should establish staff support mechanisms or consider accessing staff support services from the Principal Treatment Centre
- Recognise that non-adherence amongst this age group is not uncommon. Staff treating young people should possess good negotiation skills and be able to assess where adherence to treatment regimes may be an issue
worry/concerns to healthcare staff. The use of social networking sites (Facebook, Twitter) has become part of everyday teenage and young adult ‘culture.’

TYA Units are increasingly using sites such as Facebook to set up a page to advertise activities and support groups. Social networking sites are a relatively new phenomenon. However, staff use of social networking sites to communicate with teenage and young adult patients is increasingly seen. There is a ‘fine line’ between healthcare communication, social communication and personal communication. It is strongly advised that all staff working with young people should not share any 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 are useful and have a place in TYA care but must be carefully scrutinised for appropriate use amongst both staff and patients to ensure professional boundaries are not blurred. There should be clear expectations set by ward 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. It is recommended that staff who will be working with young people receive appropriate training and managers provide appropriate policies and procedures and recommended codes of conduct.

The Nursing and Midwifery Council have recently published Guidance on the use of social networking sites (NMC 2011)\(^2\).

Staff working within TYA care should ensure they have read and adhere to this guidance.

Key points of the guidance are as follows:

Nurses and midwives will put their registration at risk, and students may jeopardise their ability to join our register, if they:

- Share confidential information online
- Post inappropriate comments about colleagues or patients
- Use social networking sites to bully or intimidate colleagues
- Pursue personal relationships with patients or service users
- Distribute sexually explicit material
- Use social networking sites in any way which is unlawful

If you identify yourself as a nurse on Facebook, you should act responsibly at all times and uphold the reputation of your profession:

- Do not use social networks to build or pursue relationships with patients and service users, even if they are no longer in your care.
- If you receive a friendship request from a current or former patient, Facebook allows you to ignore this request without the person being informed, avoiding the need to give unnecessary offence.
- Do not discuss work-related issues online, including conversations about patients or complaints about colleagues. Even when anonymised, these are likely to be inappropriate.
- Never post pictures of patients or service users.
- Remember that everything you post online is public. Presume that everything you post online will be permanent and will be shared.

It is reasonably common for teenage and young adult patients to develop sexual feelings towards staff members. The growth of sexual awareness is inherent within the adolescent development period. 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. Physical contact in TYA care may be necessary to offer comfort and support in times of distress; however, young people and their families may display physical affection that may not be appropriate and may be misconstrued. It is fundamentally important that staff don’t initiate inappropriate physical affection (e.g. physical hugging or kissing as a greeting) and staff should avoid becoming over familiar with both young people and their families.

Healthcare professionals know what constitutes appropriate professional practice, whereas a patient is in an unfamiliar situation and may not know what appropriate behaviour in this
Warning signs for possible crossing of professional boundaries (adapted from Parkes and Jukes)

- Frequently thinking about the patient/family when not at work
- Planning needs of other patient/family needs around the favoured patient
- Sharing personal information with the patient/family
- A feeling of ‘ownership’ of the patient’s life issues
- Not wanting to hand over 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’

setting is. Healthcare professionals have a duty to handle individual situations sensitively and professionally and again, members of staff should seek early advice if they feel concerned. Teenage and young adult patients may challenge boundaries that are set by staff and show lack of understanding of the need for these 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.

SAFEGUARDING VULNERABLE TEENAGERS AND YOUNG ADULTS

When treating patients under the age of 18 and vulnerable young adults in any hospital setting, it is important to be aware of young people at risk and of safeguarding issues. Units that care for this age group will need to consider local safeguarding policies and procedures.

All services for young people should demonstrate strong up-to-date safeguarding arrangements, even when care is delivered in an adult-focused health setting. Two national documents that should be considered are the Department of Health Guidance Working Together to Safeguard Children (1999) and Framework for the Assessment of Children’s Needs and Their Families (2000).

Units that care for young people should ensure that every team member including volunteers:

- Have an enhanced criminal record check (CRB)
- Have an honorary contract in place where NHS contracts are not applicable (to be arranged via Human Resources Departments)
- Has access to up-to-date training and support in caring for vulnerable young people
- Know who to contact where physical, sexual or emotional abuse is suspected or confirmed or a young person is felt to be ‘in need’

In units which care for young people under the age of 18, it is particularly important that staff members:

- Are aware of the identity of the Senior/Named Designated Safeguarding professionals in their Trust and how to contact them.
- Are aware of local safeguarding protocols and child protection procedures and ensure they are accessible on their unit. Up-to-date child protection training should be provided.
EMPLOYING A PREVENTATIVE APPROACH TO PSYCHOSOCIAL NEEDS THROUGH A MULTIDISCIPLINARY TEAM

Cancer treatment often involves an accumulation of stress over time. A young person who was coping at diagnosis may need additional support to get through their treatment journey at subsequent stages. Ongoing assessment to monitor psychosocial needs should be carried out routinely and regularly. This is to identify and offer interventions before a young person (or their families) emotional or psychological state becomes fragile. Indeed, a full psychosocial assessment should be conducted (using, for example, the HEADS assessment, Quality of Life assessment and/or the Distress Thermometer – see Appendix 8) by treating teams during care planning and at regular intervals throughout the cancer journey. It is also useful to adopt a ‘family-centred approach’ to care i.e. assessing and monitoring how those surrounding and supporting the young person are coping. Formal psychosocial reassessment of the young person should be undertaken at further key stages in the cancer trajectory:

- Diagnosis/care planning
- Treatment commencement
- During treatment
- Treatment completion
- Early survivorship
- Relapse
- Palliative care

TOP TIPS
Supportive Care

- It is essential young people are not defined by their cancer diagnosis and a holistic psychosocial approach should be adopted, accessing age-appropriate resources where possible.
- Providing access to existing TYA teams and services will help ensure a holistic care package can be developed for each young person.
- Having a good understanding of each patient, their interests and hobbies etc. will ensure that age-appropriate and relevant services are offered.
- A family-centred approach is often beneficial when caring for young people. Immediate carers will often encounter emotional and psychological distress themselves and treating teams should be alert to any issues and refer to support services as appropriate.
- Services may also look to develop supportive care groups or events for the carers of teenage and young adult patients. Key team members (Social Workers, Psychologists etc) can be integral to these developments.

- Peers are often cited as being the most important support network for young people. It is therefore imperative that young cancer patients have the opportunity to meet peers of a similar age who are undergoing treatment. Treating teams should advocate for this and provide services to allow this to happen.
- Involving young people in service developments will ensure that services are age-appropriate and meet young people’s needs. Formal service user groups/youth forums can be developed to allow this to happen.
- Conduct policies, risk assessments and consent forms should be developed and utilised for those providing social support/group work/activities and events for young people, both within and external to the hospital environment.
- Although age-appropriate social support services should be available to young people during treatment and in remission, dependence on services in the long-term should be discouraged.
- Time limits on participation in services should be in place and young people should be prepared for exiting services in a timely manner.
The teams and services offered to young people will be dependent on what is available locally. This may involve specialist roles within the hospital team or accessing external community support. Services should be provided during active cancer therapy, long-term follow-up and palliative care, as well as for families after bereavement. In addition to core medical and nursing staff, the wider TYA team should ideally consist of a Nurse Consultant or Lead Nurse, Social Worker, a Youth Support Coordinator/Youth Development Worker, an Education Mentor and a Counsellor or Psychologist. These individuals, in addition to other Allied Health Professionals such as occupational therapy and physiotherapy, are essential to supporting young people throughout their treatment journey and beyond. Where possible, these dedicated roles should be part of the TYA MDT, but otherwise input should be sought from relevant hospital departments.

**Resources**
- World Health Organisation. 2010. Adolescent Job Aid. WHO, Switzerland
- www.nya.org.uk
- www.youthinformation.com
- www.ellenmacarthurtrust.org
- www.jimmyteens.tv
- www.siblinks.org
- www.clicsargent.org.uk
- www.lookgoodfeelbetter.co.uk
- www.teenagecancertrust.org

**LIVING A ‘NORMAL LIFE’**
Many treatment regimes are lengthy which is disruptive to the normal routines of young people and thus may impact on their quality of life. Treating teams should encourage young people to retain as much normality and usual routine as possible during their cancer treatment.

Teams should have a level of involvement with young people that enables them to recognise what matters to each individual and be flexible in planning their care (for example, in relation to treatment dates and clinic appointments). This may include allowing young people to take leave from the ward environment for an agreed period or allowing them to attend ‘rite of passage’ events such as 18th or 21st birthdays, end of school events, graduations, weddings, etc. Adopting this flexible approach can result in improved relationships with young people, the development of trust and in the long-term can aid adherence to treatment.

**EDUCATION, TRAINING AND EMPLOYMENT**
All young people of school age and those in further and higher education have the right to their education despite their medical situation. The treating team has a responsibility to ensure that young people have access to education and training as they wish. This allows young people:
- To focus on something other than treatment
- To look to, and focus on, their future
- To keep up with studies, thereby reducing the amount of education that needs to be caught up with after treatment
- To maintain links with friends more easily

“Having to take some time out doesn’t always mean it is the end of education. It can just be put off for some time until treatment has finished, or until you feel ready to continue with it.”
Kim, 21, Ewing’s Sarcoma

Teams should ensure that they:
- Can offer a private place where young people can study
- Have a contact person at the school/college/university
- Agree timely communication with education contacts and liaise with them regarding special considerations for the young person’s study whether at hospital or the institution
- Offer facilities to study e.g. computer access
- Are available to manage information needs of, and support for, education staff, friends and other students
- Are supported to take examinations in hospital

If managed well, and by the right person, staying in or at least connected to education can ensure a young person remains motivated and involved with ‘normalising’ activities. Educational institutions normally respond well to help and advice from the treating team and advice should be given to them on how best they can help the young person to be involved.
Similarly, young people may have jobs and careers from which they may have to take time off. Ensuring adequate support from their employers can be particularly difficult for them when they have only recently started in work and they may lack confidence in seeking the support they need. They should be assisted with this, usually by a Social Worker or Education Mentor or Hospital Teacher. They should be supported, as appropriate, in negotiating flexible working with reduced hours, or in keeping jobs open for when they can return to work after treatment.

**PEER RELATIONSHIPS**

Peer relationships are central to the world of the developing young person. Indeed, friends are frequently seen by young people as their major source of social support\(^3\). Ettinger et al (1993)\(^2\) found that reaching out and finding support from peers was an important aspect of coping in young people\(^3\). Many find that their relationships with their peers are adversely affected and they can become socially isolated when they are diagnosed with cancer. There are a number of possible reasons for this:

- A young person’s friends will likely be young people themselves and may not possess the emotional skills necessary to deal with their friend’s diagnosis.
- Peers may feel unsure about how to help or worry about saying and doing the wrong thing.
- Peers may withdraw their support at a time when it is needed most as they have insufficient coping skills.
- Young people often find that life is ‘on hold’ when they are on treatment as their friends ‘move on’ with life, achieving milestones and planning their futures.
- Young people may withdraw from their peers as being with healthy peers can be upsetting, frustrating or cause feelings of anger.
- Young people in treatment may miss out on crucial social activities as they are in hospital, feeling too unwell or actively avoid social situations because of how they look or feel\(^4\). This can lead to misunderstanding from friends and detachment can occur.
- Young people may feel and look different from their friends resulting in a range of negative responses from teasing, to ignoring, to open ridicule\(^5\). This can result in loss of confidence in social situations and a young person may withdraw.

- Emotions that are evoked in friends are sometimes unhelpful, e.g. sympathy or lack of empathy\(^6\), and result in frustrations for the young person because they want to remain as normal as possible.

It has been found that those young people who have been through treatment have smaller social networks than those who have not\(^7\). Allowing young people to maintain links and build new relationships with peers is crucial to their development and wellbeing during treatment.

It is recommended that staff support the young person with tips and ideas about how they can maintain friendships during treatment and gain support from their peers who are also in treatment (www.clicsargent.org.uk).

For most young people a large part of normal life is spent socialising with their peers. Treating teams/services should endeavour to be inclusive of peers and provide a welcoming place to visit that is age-appropriate, a private place for young people to gather and information for peers that will help them cope with their friends’ illness. Hospitals are often unfamiliar and can be threatening for many young people and teenagers. More appropriate design can make friends and siblings feel more comfortable and make them more likely to visit\(^8\). Organising opportunities for existing friends to spend time with patients is crucial as this will allow patients to maintain pre-existing friendships.

**PROVIDING SOCIAL SUPPORT**

It is important that young people have the opportunity if they wish to spend time with others who are on, or have undergone, treatment, both on the ward and away from the hospital environment. This helps to ensure adjustment and continued personal development, particularly as they may be absent from their normal social environments and peers (at school, college or work). When developing services, teams may want to consider:

- What activities do the young people want organised?
- Ensure activities are accessible, i.e. in different locations and at appropriate times
- Organise various activities that wont exclude those with disabilities
- Where possible, help with funding and transport
- Self esteem and confidence issues could be a barrier to young people getting involved so be flexible – would they join in if they could bring a friend or sibling?

It is crucial to consult young people when planning social and recreational activities, rather than making assumptions about what they might want or enjoy.

Where possible, the multidisciplinary team supporting the young person should include a professional who focuses on helping them continue to develop and not lose the social links and activity with peers that is so crucial to their wellbeing. Where available, the role of a Youth Support Coordinator or Youth Development Worker, can be an invaluable member of the MDT. Their main focus is ensuring young people don’t become socially isolated and have access to relevant experiences that allow them to continue to function and develop as a young person. Service user forum groups and support or activity programmes based both on wards and in the community are useful means of maintaining peer group support.

Ward-based activity might include art, music, drama and animation workshops, movie evenings, quiz afternoons, pool competitions and games days etc. These activities allow young people to focus on something other than ‘being ill’ and can be useful as a motivational technique as they encourage young people to work on small projects resulting in achievement. The input of external facilitators can be useful within the ward environment. For example a weekly programme involving musicians, artists, Complementary Therapists, etc can help engage young people and add structure to an inpatient stay. The fact that young people then have a choice of whether to engage in these activities or not can be empowering and help them to feel more in control of their situation.

There are also a number of off-ward activities that are worth considering for young people, which could be organised by a Youth Support Coordinator/Youth Development Worker or another appropriate member of the team. Regular monthly social support groups can be a useful social event in a young person’s diary. This offers continuity and a regular time and place for young people to meet up, get to know and support each other away from the hospital environment. Such group activities might include meals out, theatre and concert trips, sports events and trips to theme parks etc. Ideas for these activities should be led by the young people, i.e. their opinion should be sought on what trips/events should be offered.

Residential activity is particularly useful to young people as the sole focus is on interacting and getting to know others in a similar situation, without other friends or family being present. Of particular note is Teenage Cancer Trust’s ‘Find Your Sense of Tumour’ conference which is organised annually. This three day event includes formal presentations from professionals and young people and more importantly allows for valuable social time.

When organising activities it is important that they are inclusive. Those with disabilities should be considered and plans made accordingly. Young people from different backgrounds, cultures and religions etc should also have appropriate services, provided they are mindful of their needs and expectations. Young people that don’t have English as their first language should also have measures put in place to ensure they can engage with activities if they wish.

**RISK ASSESSMENTS AND CONSENT FOR SOCIAL ACTIVITIES**

When young people are accessing social activities it is advised that consent and risk assessment forms are utilised (Appendix 9). Those aged 18 and under should have their parents or carers complete the paperwork, with the responsibility resting with them to disseminate the information. Those over 18 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 under which to work. Advice and guidance is usually available from finance departments and departments utilising lone workers including information regarding insurance and liability cover.

**SERVICE USER GROUPS**

We cannot be sure that we are getting services right for young people unless we ask them. To ensure that teams and services are addressing support needs successfully, where possible, a ‘service user group’ should be established. This may simply involve a small group of young people meeting once a month, with staff facilitators, to give their opinion on what is positive and what needs changing about the services they are currently accessing.

Such groups offer developmental opportunities for young people, i.e. they learn or develop communication and group work skills as well as gaining experience of formal settings such as service meetings, conferences and workshops. The group can meet local, regional and national need and can be utilised as a consultation or research group.
REINTEGRATION

It is necessary for young people to have access to support services throughout treatment and after completion of treatment, with some requiring support several years after treatment. However, it is important that young people don’t become dependent on services in the long-term. Their cancer experience will always be a part of them, but it should not become their sole identity. Therefore, it is suggested that, in a timely manner, young people are encouraged to reintegrate back into ‘normal’ life. To encourage this and to help young people move on, measures should be put in place:

- Limitations (regarding age and length of time using services) should be made clear when young people begin to utilise services. For example, support groups might have a two year membership restriction, or an age limit of 26.
- There should be a gradual process employed in disengaging young people from services. For example, support groups can be offered on a monthly basis then reduced to three monthly after an initial two year period.
- Encouragement should be given to return to education and employment; Youth Support Coordinators and Education Mentors can assist young people post treatment with this.

That is not to say that young people should then be left with no support but should be directed to other community-based groups and services which they can utilise if necessary.

CARING FOR THE FAMILY AND SUPPORT NETWORKS

Utilising the support of family and close carers is one way that many young people cope when they are going through treatment. Assessments and interventions should include the needs of the TYA patient together with the needs of siblings, parents, partners, children and significant others. This should be revisited throughout the treatment trajectory. Where possible, a family-centred approach should be adopted while keeping the young person’s welfare at the centre of care.

Support can be provided in the form of both 1:1 and group work. Social Workers are normally key roles in providing 1:1 care and group support can be facilitated by the whole team. Group work may include informal meetings, formal workshops dealing with stress and anxiety or pamper days as an example. All services should be dictated by the users. Service evaluation research should be conducted as to what the service users needs are and what supports they would like in place.
Family involvement should always be on the terms laid down by the young person (this will be influenced to some degree, by the age of the individual) and a flexible approach should be adopted.

Treating teams should consider the following:

- Information needs of the young person’s support networks – do they have any questions? Do they feel fully informed about their treatment and have all resources that they can access been highlighted to them?
- Practical needs of support networks – for example, do carers need assistance with travel to and from the hospital? Do they have other dependents?
- Support needs of significant others – are they given time and opportunity to talk about the young person’s situation? Would the support of other parents or guidance to online parent/carer networks be beneficial?

From a practical point of view, the costs associated with a cancer diagnosis can cause significant worry for the young person and their family. 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.

To support the young person and their family, it is recommended that they are provided with access to information about their rights to benefits. Assistance from Social Workers, not-for-profit organisations and community agencies can be invaluable in accessing financial help. Charities such as CLIC Sargent and Macmillan Cancer Support can also provide financial assistance.

The needs of siblings in particular should be considered. Recognising the impact that their brother or sister’s diagnosis can have on their own lives is crucial. They can often feel deprived, lonely and vulnerable when the attention of their parents is focused so strongly on the needs of the sick family member. Distress and challenging behaviours are sometimes seen in siblings, particularly those who are children or younger teenagers.

Siblings may not have established sufficient support networks independent of the family or develop the coping skills or strategies to negotiate such a challenging situation. Siblings should, therefore, be offered an opportunity to meet other siblings in a similar situation. Treating teams should also provide opportunity for siblings to talk to staff, to answer questions and alleviate anxiety. Support for siblings may be available regionally and national programmes should also be highlighted to families (Appendix 10). Staff should familiarise themselves with both local and nationally available resources.

As more young people achieve long-term survival, the consequences and late-effects of cancer and its treatment regimes are becoming more evident.
Physically, the surviving patient has the accumulated effects of the cancer treatment on healthy tissues and organs and in rare cases, secondary malignancies or organ failure may develop. 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\(^9\). Psychosocially the late-effects include emotional and social sequelae that can impact short and long-term quality of life.

Patients at risk of long-term effects 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 survivorship programmes. These support patients to achieve psychological and emotional wellbeing and to resume education or career pathways, provide financial advice and ways to manage the emotional impact of cancer treatment.

**PHYSICAL LATE-EFFECTS**

- Certain types of cancers particularly those which affect growth hormones i.e. pituitary and thyroid cancers or their treatments can have a huge impact on quality of life and even developmental stage. For example, cranial irradiation can cause cognitive dysfunction and surgery for other tumours can cause decreased mobility or affect intellectual ability. Young people who experience such late-effects will require high levels of input from treating teams and may require referral to other services to help them cope with their altered situation.
- Young people may well have worries about their fertility and abilities to have children either as a direct result of the cancer (for example cervical, ovarian and testicular tumours) or as a result of the treatments given for a variety of malignancies, such as high dose chemotherapy or total body irradiation. Treating teams should consider this concern at the end of treatment and advise regarding fertility testing and counselling where appropriate.
- Some chemotherapy agents, such as anthracyclines, can be toxic to the cardiovascular or renal system with the potential to cause long-term heart and lung problems. Therefore, it is important patients have access to long-term follow up.

**PSYCHOLOGICAL AND EMOTIONAL LATE-EFFECTS**

In the same way that patients having cancer treatments require a multidisciplinary approach to ensure holistic care, this is also true for long-term follow-up care.

Many young people may appear to have coped well during treatment, but the reality of what they have been through only becomes apparent when they are no longer having contact with their treating teams. Indeed, some young people have shown evidence of post traumatic stress following completion of the treatment pathway. Therefore, psychological and emotional wellbeing should be considered at follow up appointments and any concerns should be flagged up with the treating team and referrals made where necessary.

Cancer treatments can have long-term effects on patients socially in terms of how they manage themselves, how they interact with others and what future life prospects are available to them. For example, young people may have altered their views and choices about career and education. Where possible, staff should be in place to help them get on a career path or get back into education as soon as they are ready and it is possible. Education Mentors, Social Workers and Youth Support Workers may be in the best position to tackle these issues.

Young people may also find themselves socially isolated after treatment. It is necessary therefore to ensure they have access to services for young people who have had treatment so they can spend time with others who have been through similar experiences.

Survivorship programmes, end of treatment groups and social groups should be developed to ensure this can happen.

**CONSIDERATIONS FOR SERVICE PROVISION IN LONG-TERM FOLLOW-UP CARE**

The survivorship of teenagers and young adults with cancer has been on the NHS Improvements and National Cancer Survivorship Initiative (NCSI) agenda in recent years. The Children and Young People (CYP) work stream which is part of NHS Improvement is one of seven work streams conducting improvement work as part of the NCSI.
The aim of this national initiative is to improve models of aftercare provided for those patients surviving cancer, many of whom will need a range of clinical and non-clinical services to enable each of them to live a happy, healthy normal life after their initial treatment for cancer.

Psychosocial survivorship programmes have been developed in certain centres and regions\(^\text{92}\). These developments show examples of good practice which could be developed or accessed by teams within other regions.

"I found the course to be very helpful and enjoyable. All of the information was clearly given and we were given plenty of opportunities to ask as many questions as we required. It was also interesting to share experiences with other patients. Everything was thoroughly useful.”
From a young person who has accessed a TYA Survivorship Course (2011)

These are relatively new services in teenage and young adult cancer care and there may be challenges in establishing robust late-effects teams (both physical and psychosocial). However, investing in early interventions for this group of patients may be cost-effective both to the patient in terms of quality of life and to the health service in terms of treatment and service provision costs.

Teams developing or providing long-term follow up should consider:

- What are the referral criteria and can the demand created by these criteria be catered for by the service?
- Should all cancer patients be followed up by the late-effects service or just those in medium to high risk categories?
- Should age limits be placed on the service?
- Are transition arrangements in place as the patient transcends TYA to adult services?
- Could risk summaries be produced at the end of treatment, identifying potential complications?
- Which specialties are, and might be, involved e.g. endocrine, renal, cardiology, respiratory, andrology services and are they part of the late-effects service?
- Should oncologists continue to see these patients as well as referring on to appropriate specialties that would deal with their specific late-effects?
- When should patients be discharged from the late-effects service, if at all?
- What other healthcare professionals should be involved? Physiotherapy, Occupational Therapy, Social Workers, Psychologists, Complementary Therapists?
- Would support groups be helpful for patients and would these be feasible to make available?
- Should the clinics be Doctor or Nurse led and if so what are the criteria for referral to each of these?

**TOP TIPS**

Survivorship

- Surveillance of physical late-effects and structured late-effects protocols should be in place at the end of cancer treatment.
- All young people should be provided with a formal Treatment Summary. This should detail any possible late-effects of treatment and outline follow up procedure.
- The young person should be advised when they can expect follow up appointments as part of this process.
- At risk patients should have ongoing medical consultations to monitor and/or treat late-effects.
- The psychosocial needs of young people may extend beyond the end of treatment and services should be in place to support young people with any difficulties they experience post treatment.
- Teams treating young people locally may wish to access post treatment support and services from existing TYA Principal Treatment Centres.

Teenage and young adult specific survivorship programmes have been established in some areas. Teams should consider accessing these programmes for their patients.

**Resources**

- NHS Improvement 2010. ‘Building The Evidence: Developing the winning principles for children and Young people, Children and Young People Cancer Survivorship. HMSO, London
- www.improvement.nhs.uk/cancer
- www.ncsi.org.uk
PALLIATIVE CARE: PRINCIPLES AND PRACTICE RECOMMENDATIONS

End of life care planning is a highly complex process which must focus on the individual and unique needs of the young person and their family. Multidisciplinary teams are responsible for ensuring, as far as possible, that a tailor-made plan of care is developed based on what the young person’s wishes are. Such a plan ensures that the patient and family are empowered and enabled during end of life decisions. Having a well documented plan may help to avoid the chance of a crisis situation as the young person’s condition deteriorates. The plan must also be flexible and reviewed regularly to ensure any changes in their wishes are known to all those involved and acted upon appropriately.

TALKING ABOUT DEATH, DYING AND PLACE OF DEATH

“Young people facing the prospect of their own death need opportunities to explore their feelings without fear of upsetting other members of their family.” (Joint Working Party on Palliative Care for Adolescents and Young Adults 2001)

Throughout treatment, young patients require and expect honesty from their treating team; this promotes trust and confidence between all parties. It is essential that honesty is maintained in the palliative care phase even though this can be difficult for all those involved. However, it must also be recognised that maintaining honesty differs to disclosing information.

When a decision has been made about a change in the goal of treatment, treating clinicians must begin to inform the young person and their families. The Joint Working Party on Palliative Care for Adolescents and Young Adults (2001) acknowledges that discussions often don’t occur as clinicians are uncomfortable with what to say, families are uncertain or because everyone involved believes the young person is ‘best not knowing.’ Honest and open discussions must be adopted and occur in a timely manner. Young people may wish to control the pace and depth of the information they receive. Staff should acknowledge that not all young people will want or ask for full information and this should be respected. Some may choose not to be involved in detailed discussions, but request that their family members are. These specific scenarios should be negotiated on an individual basis and above all the preferences of the young person should be paramount.

Confidentiality issues are particularly difficult when working with this age group; parents of older young people don’t have the automatic right to information. Information can only be disclosed to parents with the patient’s permission.

“It is me that is the one who has been diagnosed with cancer so I wanted to know everything that the doctors needed to say, good or bad. However I did want my mum to be there to make sure she understood everything in case I missed anything. I wanted to know everything there was to know about my diagnosis even the statistics because even though you knew some things were going to sound terrifying, I just didn’t want to be lied to.”
Nicole, 17, Medulloblastoma

The psychological needs of young people facing death are particularly challenging and access to supportive care is essential. Young patients who are facing death need an opportunity to explore their feelings without fear of upsetting family members or partners. The value of having an opportunity to speak openly in a confidential environment with a trained Health Professional (Nurse/Doctor/Social Worker/Bereavement Counsellor/Chaplain/Palliative Care Specialist etc) should not be underestimated. At the same time, the individuality of the young person must be recognised and some young people may not wish to discuss these issues even though they understand very clearly the situation they are in.

Ensuring they are aware of whom they can speak to if and when they feel ready is essential. When facing death and dying, some young people and their families gain strength and support from their spirituality. This may or may not involve religious beliefs; so recognising, facilitating and supporting spiritual needs is crucial.

Young people should be supported to die in their place of choice; this may be at home, in a hospital or in a hospice. Many patients have complex symptoms at the end of life which require specialist palliative input. It is important to recognise that due to the complex nature of TYA palliative care, collaborative working between the TYA team and existing palliative care services is essential.

A BLUEPRINT OF CARE FOR TEENAGERS AND YOUNG ADULTS WITH CANCER
Timely referral will assist in symptom control as well as the planning of end of life care and support. Certain wishes may be difficult to support, depending on the services available in local areas. When choices are discussed they should be realistic, ensuring expectations are not raised when they cannot be met. Establishing what services are needed and available prior to discussions with the patient and family will avoid unnecessary distress if patient expectations cannot be met. Every centre should have developed links to other services for immediate access for the patient and their family.

It is worth noting that an increasing number of Children’s Hospices are now developing services for young people up to the age of 25. Children’s Hospice UK is the umbrella organisation for Children’s Hospices where further information on local hospices can be accessed. Use of national and local frameworks such as The Gold Standards Framework and the Liverpool Care Pathway is recommended.

**BEREAVEMENT SUPPORT**

**IMMEDIATE FAMILY AND SUPPORT NETWORK**

It is not unusual for many young people to have spent many months in a ward or unit prior to their death and, as a result, families build strong and close relationships with the team there. Bereavement support groups can be useful to help the family deal, not only with the loss of the young person, but also the transition away from dependence on the ward or unit.

It is recommended that any bereavement support groups that are established are run by appropriately qualified professionals. This is necessary to ensure the support is structured and allows families to move on through the process rather than remaining stuck in a certain stage of grief. There should be a structured timescale with signposting and referral to other support groups/ agencies identified to move and support the family through the grief process.

Many families may not want to return to the hospital, so establishing what local bereavement support is available is essential. Support can usually be found through local palliative care teams, hospices, GP practices, charitable organisations and religious groups. Recognition that everyone copes in different ways and requires different support mechanisms is essential in finding the best approach for a family. Where patients have children, specialised paediatric bereavement support should be considered and offered. Teams need to be aware of what is available in their areas. An opportunity to discuss the death or treatment journey can be useful for the family and they should be offered a meeting with the consultant to do so.

**PATIENT**

One of the core philosophies of TYA care is to maintain peer support. As a result young people often form strong friendships with fellow 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 survivorship guilt. Staff 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 patients about a death and when, can be a difficult consideration. 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 don’t wish to know. If the death occurs in a ward environment, patients and families are usually aware of what is happening and should be informed by experienced staff on an individual basis. All patients and their significant others 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 the support if needed.

**STAFF**

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

Staff should be given the opportunity to have counselling which may be either formal or informal. Many teams have access to psychologists who can offer formal support. Other alternatives may be clinical supervision or a planned staff debriefing to allow staff to share their feelings if they wish to. It should be recognised that everyone will have different ways of dealing with their grief and may not wish to share it. Ensuring all staff have access to formal support systems allows people the choice and opportunity to make decisions about the support they need.

Staff attendance at funerals can be a way of representing the team, providing support for the family and a method of closure for staff. However, care should be taken to ensure equal representation occurs at all funerals. Many other patients and families who are cared for in a TYA environment naturally build close relationships and as a result often attend the funerals of their 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 causes hurt to them. Wherever possible, staff should be actively discouraged from attending in their own time. A policy or local guidance for funeral attendance is useful to provide clarity and boundaries for staff attendance. Although staff attendance at all funerals is encouraged as representation of the ward or unit, staff who regularly attend all funerals (which is not part of their job) may need support with regard to professional boundaries.

**TOP TIPS**

**Palliative Care**

- Specialist palliative care teams should be involved in symptom control during the treatment stage of the TYA cancer pathway. This ensures relationships are already established prior to palliative care.
- Introducing young people to a hospice, community team or specialist palliative services should be carried out as soon as treatment changes from curative to palliative or from the outset if it is likely the young person will become palliative.
- Inform young people and their families honestly and in a timely way, when progression occurs and treatment goals change.
- Staff must assess for verbal and non-verbal cues from the young person in order to ensure information is delivered at the young person’s pace and depth; recognising that not all young people want to know fully their situation or circumstances.
- Recognise that not all young people want to discuss end of life issues. This should be respected.
- Information should not be enforced on the young person, ‘not everyone wants to know’.

- Young people may not want to talk in front of families to avoid causing them distress. Staff should offer time alone with the young person to allow space to talk.
- Discussions should be carried out by experienced staff that know the young person and family well and have an established relationship. This may be the Consultant, Key Worker or member of the Palliative Care Team.
- Develop a clear documented multidisciplinary plan of care taking into account the wishes of the young person and their family.
- Consideration must be given to the preferred place of care. This may be home, hospital or hospice.
- Assessment of preferred place of care should be carried out promptly to ensure services can meet individual needs.
- The death of a young person may impact on fellow patients and families. Staff should ensure this is recognised and appropriate support is offered to other patients and their families.
- Working with young people during end of life can be stressful for the clinical team. Informal and/or formal staff support should be available to all teams.

**Resources**

- www.understandingchildhood.net
- www.childhospice.org.uk
- www.mcpcl.org
- www.maggiescentres.org
Teenage and Young Adult palliative care is particularly complex and services will differ from region to region. TYAC have developed TYA Palliative Care Pathways for professionals to use to help them navigate through the complex processes and issues within Palliative Care for young people.

PALLIATIVE CARE PATHWAY

Recognition that treatment intent is not curative
Confirm at MDT discussion.
NB: Treatment with palliative chemotherapy or RT, including consideration and entry into Phase I or II trials, does NOT preclude entry onto pathway

Key worker¹
Identified/confirmed and documented

Discussion with Young Person (YP) +/- family²
- Ensure honest, sensitive, timely and open communication.
- Provide choice in all areas of decision making, including amount of information and sources of information.
- Provide written information if requested.
- Discuss and agree management plan.

Holistic needs assessment
Multi-agency, coordinated by key worker
Consider the following:

Family/Friends:
- Ensure holistic family-centred support addressing emotional, spiritual & practical (incl. financial) needs.
- Respect cultural beliefs
- Facilitate partner/spouse/parent involvement in care planning where appropriate/possible.
- Support for adjustment to changing relationships with YP.
- Consider/facilitate support for friends where needed.
- Consider issues of custody of children and other dependents.

Young Person (YP):
- Assessment to include
  - Assessment and management of physical symptoms
  - Assessment of need for rehabilitation - dietetics/OT/ PT/SALT
  - Addressing psychological/existential distress +/- relevant professionals
  - Respect of cultural beliefs
  - Provision of opportunities for as much involvement in decision-making as wanted, including access to written information
  - Individualised care package.
- Provide practical support including access to short breaks, additional housing adaptations, transport support and completion of DS1500.
- Facilitate Advance Care Planning - ongoing discussion of preferences/wishes (including place of care and death, will making, DNAR ADRT² etc) - if desired/appropriate.

Key worker/team:
- Close, accurate and timely communication between professionals to ensure that needs are met and that care is optimal.
- Consider meeting of relevant professionals +/- YP +/- family to optimise communication/care provision.
- Adopt a broad multi-disciplinary approach including YP and family.
- Provide care in place of choice i.e. hospital, hospice, home. Offer respite care where appropriate.
- Enable access to ongoing education (support in school/college/work) and employment opportunities wherever possible/appropriate.

Co-ordination and delivery of care in place of choice
Optimal communication

Review
At regular intervals, review all aspects of care
Consider transition to adult services³

End of life care pathway
When prognosis = days / weeks

¹Each family will be supported by an experienced and knowledgeable key worker who will coordinate and lead care.
²Decision re which professional(s) should be at this discussion should be made in consultation with the YP and family – usually includes relevant consultant, key worker and palliative care specialist (CNS or consultant)
³ADRT – Advanced Decision to Refuse Treatment (for >18)
⁴ACT Transition Pathway: Decision to transition to adult services at this stage in a person’s illness must be considered carefully
END OF LIFE CARE PATHWAY

Recognition that end of life is approaching
i.e. that prognosis is days / weeks

Holistic needs assessment
Multi-agency, coordinated by key worker1
Consider the following:

Family/Friends:
• Ensure holistic family–centred support addressing emotional, spiritual and practical (including financial) needs
• Respect cultural beliefs
• Ensure partner/spouse/parents are involved in and aware of discussions with YP
• Offer support for any discussions with siblings/dependents
• Consider needs of wider family/friends
• Where appropriate, inform family of Child death review process, if YP <18

Young Person (YP):
• Review wishes/preferences and desire for information about condition, treatment plan, place of care and death, resuscitation
• Ensure careful symptom assessment and management
• Address psychological/existential distress.
• Consider need for dietetics/OT/PT/SALT
• Respect cultural, religious and spiritual beliefs
• Address medical/nursing/equipment needs/financial support
• Consider discussion about organ donation/wishes for care after death/funeral planning/will making (may require legal support) etc.

Key worker/team:
• Close, accurate and timely communication and co-ordination between professionals, to ensure that needs are met and care is optimal
• Where appropriate address the need for equipment and medication within the patient’s home to facilitate care
• Facilitate/document plan of care and support that includes out of hours

Planning meeting (local) to include
• Key worker
• Primary health care professionals – GP, nursing staff
• +/- YP
• +/- Family members
• Relevant specialists (including palliative care, and support from primary treatment centre if appropriate)

End of life care plan
(Disseminated to ALL relevant professionals)
• Symptom control plan, provision of medication
• Treatment escalation plan
• Support from professionals (contact numbers, out of hours support etc)
• Plan in the event of an unexpected death/crisis
• DNAR discussion and decision
• LCP2 where appropriate
• YP/family’s plans/wishes for care after death

Review and communication
At regular intervals, all aspects of care

After death

Bereavement

Family/friends
• Offer support, choice and information – “What to do after death”, leaflet caring for and preparing the body, funerals

Young Person
• Fulfil wishes
• Consider and ensure care and preparation of body in place of choice

Environment
• Removal of equipment
• Removal and disposal of medication
• Audit and checking of medication documentation
We have come a considerable way during the past twenty years in the development of specialist Units and staff with experience and expertise in caring for this patient group. Teenage and Young Adult (TYA) cancer is now recognised as a specialty in its own right and the future of TYA cancer care is exciting. Multidisciplinary posts within the Health Service have developed working exclusively with young people including nursing, Youth Work, Social Work and Community posts. As a result of teams working together and sharing knowledge, practice has developed and led to this first edition of the Blueprint of Care.

This Blueprint of Care captures and reflects professionals sharing experience and expertise in order to guide and assist those who may be in the early stages of developing care for this age group. It provides guidance and practical advice to healthcare professionals planning and providing services for young people with cancer. It can be used in conjunction with other national guidance to assist in the development of solutions that aim to meet the unique service needs of this client group. Can be used as a foundation by colleagues around the world where teenage and young adult specialism is emerging to follow in the footsteps of our UK achievements.

It is intended that this document will continue to evolve and adapt through the continuous contribution of staff working within this field. As many healthcare professionals attempt to deliver high quality care for young people, progress and solutions should be documented and shared. Developing the Blueprint of Care is a fantastic advancement but the real value comes through implementation when we can start to see examples of best practice and the resulting positive impact on the lives of young people.

The development of future service frameworks and guidance depend on collaboration so by sharing challenges and successes we can continue to innovate and develop the services that young people with cancer need. We will be looking to document progress and capture solutions and ideas going forward. Teenage Cancer Trust will work with TYAC to highlight success, inform and support you in your endeavour for service excellence in the emerging specialism of teenage and young adult cancer.

The patient remains central to this work and it is hoped that the Blueprint of Care will support healthcare professionals in delivering the age-appropriate and individualised care that teenagers and young adults with cancer have a right to.

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MULTIDISCIPLINARY TEAM CORE MEMBERSHIP

Lead Clinician
Consultants with clinical practice in the following
- Leukaemias
- Lymphomas
- Germ Cell Malignancy
- Bone and /or soft tissue sarcomas
- Brain and CNS Malignancy
Paediatric Oncologist
Lead Nurse of the PTC
Specialist Nurse
Young Peoples Social Worker
Youth Worker / Activity Coordinator
MDT Coordinator and Secretary

Extended Membership

Member of Palliative Care Team
Physiotherapist
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
## TYA CENTRE: PATIENT NOTIFICATION
(for ages 15 to 24 years)

<table>
<thead>
<tr>
<th>Surname/family name</th>
<th>Forenames:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Address:</td>
<td>Diagnosis: (histological type of tumour) Please attach copy of pathology report, immuno-phenotyping, cytogenetics For leukaemia please give highest pretreatment leucocyte count in box below as applicable:</td>
</tr>
<tr>
<td></td>
<td>Primary site:</td>
</tr>
<tr>
<td>Postcode:</td>
<td>Laterality:</td>
</tr>
<tr>
<td>Country of residence at diagnosis:</td>
<td>Date of diagnosis:</td>
</tr>
<tr>
<td>Town of birth:</td>
<td>Age at diagnosis:</td>
</tr>
<tr>
<td>Birth date:</td>
<td>Date used as date of diagnosis: (see Code List 2)</td>
</tr>
<tr>
<td>Ethnic Group:</td>
<td>Basis for diagnosis:</td>
</tr>
<tr>
<td>NHS Number:</td>
<td>Registering trust:</td>
</tr>
<tr>
<td></td>
<td>Patient’s hospital number:</td>
</tr>
<tr>
<td>Referring trust:</td>
<td>Referring consultant (name):</td>
</tr>
<tr>
<td>Referring consultant (name):</td>
<td>Specialty of referring consultant:</td>
</tr>
<tr>
<td>Specialty:</td>
<td>Specialty:</td>
</tr>
<tr>
<td>Was diagnosis made at this trust?</td>
<td>If this is a second or subsequent primary tumour give brief details of previous primary(ies):</td>
</tr>
<tr>
<td>Reason for referral to registering trust:</td>
<td>Diagnosis 1</td>
</tr>
<tr>
<td>Other reason for referral:</td>
<td>Diagnosis 2</td>
</tr>
<tr>
<td>Main treating trust for this diagnosis:</td>
<td>If patient is from a multiple birth give sex (M or F) of twin etc. sibship including case:</td>
</tr>
<tr>
<td>Other hospital name:</td>
<td>Other conditions in the patient (see Code List 8 Congenital Anomalies for instructions):</td>
</tr>
<tr>
<td>Consultant (name):</td>
<td></td>
</tr>
<tr>
<td>Specialty of consultant at treating trust:</td>
<td></td>
</tr>
<tr>
<td>Specialty:</td>
<td></td>
</tr>
<tr>
<td>Other specialist treating trust for this diagnosis:</td>
<td></td>
</tr>
<tr>
<td>Shared Care Hospital trust at first diagnosis:</td>
<td></td>
</tr>
<tr>
<td>Is patient in a clinical trial?</td>
<td></td>
</tr>
<tr>
<td>Name of clinical trial</td>
<td></td>
</tr>
</tbody>
</table>

### DIAGNOSTIC MDT(S)

<table>
<thead>
<tr>
<th>Name:</th>
<th>Date</th>
</tr>
</thead>
</table>

### TREATMENT DECISIONS AT MDT(S)

<table>
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<th>Chemo:</th>
<th>Start date:</th>
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<tr>
<td>Radio:</td>
<td>Start date:</td>
</tr>
<tr>
<td>Surgery:</td>
<td>Start date:</td>
</tr>
<tr>
<td>Other:</td>
<td>Start date:</td>
</tr>
</tbody>
</table>

Form completed by: Date
Example A: Patient aged 16 – 24 years referred to a site specific MDT that is NOT based at a Principle Treatment Centre (Young People).
Example B: Patient aged 16-24 years referred to a TYA MDT or Site-Specific MDT that is based at a Principal Treatment Centre (Young People).

* In the PTC host trust the ‘local adult service’ will be always provided within the TYA facility, other than in exceptional cases of patient choice.
## Non cancer related resources for young people

### Sexual Health/Sexuality
- Brook Young Peoples Information Service [www.brook.org.uk](http://www.brook.org.uk)
- NHS Choices [www.nhs.uk/livewell/sexandyoungpeople](http://www.nhs.uk/livewell/sexandyoungpeople)
- NHS Choices [www.nhs.uk/worthtalkingabout](http://www.nhs.uk/worthtalkingabout)
- Lesbian and Gay Foundation [www.lgf.org.uk](http://www.lgf.org.uk)
- NHS Choices [www.nhs.uk/Livewell/Sexualhealthtopics](http://www.nhs.uk/Livewell/Sexualhealthtopics)

### Mental Health
- The National Counselling Directory [www.counselling-directory.org.uk](http://www.counselling-directory.org.uk)
- Child and Adolescent Mental Health Services [www.camhs.org.uk](http://www.camhs.org.uk)
- Young Minds Charity [www.youngminds.org.uk](http://www.youngminds.org.uk)

### Alcohol and substance use
- NHS Choices [www.nhs.uk/livewell/Alcohol](http://www.nhs.uk/livewell/Alcohol)
- Talk to Frank [www.talktofrank.com](http://www.talktofrank.com)

### General health and youth organisations
- Youth Health Talk [www.youthhealthtalk.org](http://www.youthhealthtalk.org)
- A Guide to Rough Times [www.guidetoroughtimes.co.uk](http://www.guidetoroughtimes.co.uk)
- National Youth Agency [www.nya.org.uk](http://www.nya.org.uk)
If a patient who is assessed as lacking capacity is admitted to mixed-sex accommodation, their family, carer or advocate should be consulted.

Patients should be protected at all times from unwanted exposure, including casual overlooking and overhearing.

On mixed-sex wards, bedroom and bay areas should be clearly designated as male or female accommodation.

In all areas, toilets and bathrooms should be clearly designated as male or female.

Transgender people should be accommodated according to their presentation: the way they dress, and the name and pronouns that they currently use. (see PL/CNO/2009/2).

For many children and young people, clinical need, age and stage of development may take precedence over gender considerations. (see PL/CNO/2009/2).

Greater segregation should be provided where patients’ modesty may be compromised (e.g. when wearing hospital gowns/nightwear, or where the body (other than the extremities) is exposed. (see PL/CNO/2009/2).

Greater protection should be provided where patients are unable to preserve their own modesty (for example following recovery from a general anaesthetic or when sedated). (see PL/CNO/2009/2).

Staff should make clear to the patient that the trust considers mixing to be the exception, never the norm.

Patient preference should be sought, recorded and where possible respected. Ideally, this should be in conjunction with relatives or loved ones.

Section Three – Further information or ideas to consider in DSSA in Young Adult Units

There is evidence that many young people find great comfort from sharing with others of their own age and this can sometimes outweigh their concerns about mixed-sex accommodation. However, the mixing of sexes should be the exception and not the norm and must be agreeable with all patients concerned and their relatives, carers or advocates.

Flexibility may be required. For example, young adults might prefer to spend most of their time in mixed areas, but to have access to same-sex spaces for specific treatment needs or to undertake personal care.

All young adults have the right to a chaperone and to request care by same-sex staff. Same-sex staff will be provided on request when available.

Young adults will be given information about same-sex accommodation on or before admission, so that they understand what to expect and any restrictions that may be placed on them. Where information is written, this should be in a language and format appropriate for the age group of the patient.

The young adult’s accommodation preferences should, where possible, be sought and recorded using the principles of informed consent. Where the young adult lacks the ability to make a decision, the parent, carer or advocate’s opinion must be sought.

Ideally young adults views on privacy and dignity should be sought on admission with actions taken within an agreed time frame.

In planning new facilities or the refurbishment of existing facilities, design will support segregation of accommodation by age, toilets and bathrooms by sex as far as possible.

DSSA and privacy and dignity policies and their relevance will be explained to patients, relatives and carers of all age groups.

DSSA guidance and escalation procedures will be included both in organisation and area specific induction training and regular update training provided.

All newly admitted patients and or their carers must be given information about the configuration of the unit/ layout of the ward and its same sex facilities, and have the opportunity to ask questions.
Consideration will be given to how individual wards/departments caring for young adults can adhere to the DSSA agenda. This would ideally be evidenced through an options appraisal, acted upon and communicated to all staff.

Section Four - Resources

- DSSA Diagnostic Tool
- DH National Service Framework for Children Families and Maternity
- DH Transition: Getting it Right
- DH Transition: Moving On
Title: Operational Policy- Working with Teenagers & Young Adults

PURPOSE:
To provide clear guidance and procedure to young people and staff of the (Unit Name) on behaviour and conduct. To ensure patient support groups have clear membership criteria and to ensure patients have clear guidance regarding operational issues on the (Unit Name)

POLICY APPLICATION:
(Unit Name)

RESPONSIBILITIES FOR IMPLEMENTATION:
Lead Nurse
Ward Manager
Unit staff – clinical & non-clinical

DATE ISSUED:

DATE REVISED:

REVIEW DATE:

AUTHORS:
(Insert Name and Job Title)

REFERENCES:
See final page of policy

INTRANET CATEGORY FOR LOCATION:
Policies/Guidelines – Organisational practice

APPROVED BY: CLINICAL AND RESEARCH GOVERNANCE COMMITTEE
DATE:
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1. PURPOSE OF POLICY
The policy provides information and guidance on patient/staff conduct and procedures to follow in the event of untoward incidents. The policy is to ensure the trust provides appropriate care and environment for teenagers and young adults where needs are complex and operates in accordance with national and local guidance. The policy will also act as guidance and information to patients of the (Unit Name).

2. DEFINITION OF CHILD/TEENAGER/ YOUNG ADULT
Under the Children Act 1989, a young person up to the age of 18 years is defined as a child. Responsibility extends to the child with disabilities until 19 years. Young adult refers to all young people from the age of 19 years up to the age of 24 years who are cared for on the (Unit Name).

The above definitions apply to all patients or those who are visitors to the (Unit Name).

3. DEFINITION OF STAFF GROUP
The term ‘staff’ within this policy refers to any member of (Unit Name) staff, clinical and non-clinical and qualified/non-qualified. The term staff also refers to any other paid/unpaid/ or voluntary staff working with/ or in contact with (Unit Name) patients.

4. DEFINITION OF PREMISES
The term premises used within this document refers to the (Unit Name) in its entirety, the ward, oasis room, day services, Victoria House, outpatients and offices.

Outside the (Unit Name) and anywhere within the grounds of the main hospital is also referred to as the premises for the purpose of this policy.

5. MISUSE OF DRUGS AND SUBSTANCES
Drugs/substances are defined to mean those that are legal, such as tobacco and alcohol, solvents and illegal drugs such as cannabis, ecstasy, amphetamines (speed), heroin etc.

The hospital operates a non-smoking policy and smoking is strictly prohibited on the premises.

It is prohibited to store, supply or consume alcohol on the premises. In the case of alcohol, exceptions will be made during social activities outside the hospital in these cases all young people aged 18 years and over are responsible for their own conduct. (Unit Name) staff who may be present during the activity, although not fully responsible for young people, are expected to exercise common sense when supervising young people that may be consuming alcohol.

It is prohibited to store, consume, supply or smoke illegal drugs on the premises or on any activity associated with the (Unit Name).

Any member of (Unit Name) staff has legal and professional obligations when dealing with drugs and young people and therefore must respond and report any patient or visitor who contravenes the above.

All (Unit Name) staff must report any misuse of drugs incident to their line manager and document in writing using the trust incidence form within 48 hours.

Staff must not allow young people onto the premises if they are aware that the person is in possession of illegal substances and must report to line manager immediately any young person who is found in possession of drugs on the premises. (Excludes possession of tobacco)

Staff are encouraged to intervene in any drug related incident in a way which will create minimum harm to themselves and other people. Ensure a second member of staff is in assistance if this is deemed appropriate. Any incident a member of staff deems as serious/dangerous must be reported to the duty manager and/or the police. Medical assistance should be obtained if the member of staff deems this is necessary.
The police MUST be contacted if any of the following occur:

- Any violence occurs that endangers staff or other young people
- Where adults over the age of 18 years are involved in supplying drugs on the premises.

6. VERBAL/PHYSICAL ABUSE & BULLYING

We expect all staff to be treated courteously and with respect. Violence or abuse towards staff is unacceptable. Likewise we expect all patients and visitors to the (Unit Name) to be treated with the same courtesy and respect by our staff.

Staff recognise that individuals may act out of character in times of distress, trouble or upsetting circumstances. However, some behaviour that may be angry, demanding or persistent or make unreasonable demands on staff may be deemed unacceptable.

Unacceptable behaviour (oral or written)

Any physical violence or behaviour/language that may cause staff to feel afraid threatened or abused. This includes threats, acts of physical violence, verbal abuse, derogatory remarks and excessive rudeness.

Threat or use of physical violence or extreme verbal abuse to staff or other patients will be reported to line manager and any physical abuse will be reported to the police. All incidents must be reported using the Trust Incident report Forms.

The (Unit Name) does not tolerate any patient being bullied by another patient. Bullying may be the tormenting, intimidation or verbal harassment of an individual. The intimidation of an individual may be actual or threatened and may be verbal, written, electronic or transmitted. Bullying will not be tolerated on the premises or on any outside activity associated with the (Unit Name). All reports of bullying will be taken seriously and investigated by senior staff.

7. ACTIVITIES AND TRANSPORT

A risk assessment is undertaken and recorded prior to all activities. However, any patient or other young person must make their own judgement on whether to undertake an activity and must be aware of any risks associated with that activity.

Young people participating in any activity associated with the (Unit Name) are expected to conduct themselves in an appropriate manner. For young people over the age of 18 years, alcohol, in small quantities will be tolerated on outside activities, however young people are expected to consume alcohol within reasonable limits and maintain appropriate behaviour and conduct at all times. Excessive swearing and foul language will not be tolerated on any outside activities. Any failure to adhere to this may result in expulsion from further organised activities.

The (Unit Name) provides a ‘ward mobile phone’ for patients to access the support co-ordinator on any matters relating to activities. Patients can text or phone this number and the query will be dealt with as soon as possible. Please do not use this facility for enquiries about appointments, changing appointments, information regarding other patients or personal matters.

Young people are asked where possible to arrange their own transport to events. However we understand that there may be difficulties or individual circumstances where this is not possible and are happy to provide transport in these cases. Patients who are currently on treatment or up to 6 months out of treatment will be a priority for transport. In general, transport will not be provided for patients who are more than 6 months out of treatment; however we are happy to discuss individual cases. Transport will not be provided for patients who are drivers and car owners.

In the event that you are using transport arranged by the (Unit Name) the following will apply:

Transport home will be provided for organised events up until 12 midnight. After this time individuals are expected to make their own arrangements.
Young people must behave appropriately and responsibly when using transport arranged and any reports of inappropriate behaviour will be investigated and may result in any offer of future transport being withdrawn.

Any young person attending an event using their own transport and who is suspected of drink driving will be reported to the staff group leaders, encouraged to hand over their vehicle keys and may be reported to the police at the discretion of the staff member.

8. PERSONAL INFORMATION

PROFESSIONAL BOUNDARIES/RESPONSIBILITIES

In order for staff to maintain confidentiality to patients, staff are not allowed to share any information regarding other young people. This may be personal information (address/telephone numbers) or information regarding other patient’s illnesses, treatment or progress. Young people are therefore advised not to ask staff regarding other patients.

Staff must maintain their professional boundaries at all times. Patients are advised not to ask for personal information regarding individual staff members. Likewise, staff should not share detailed personal information with patients.

Staff should not accept inappropriate/valuable personal gifts or favours from patients and their families.

Parents and carers are responsible for the supervision of children under 16 years who are visitors to the unit, at all times.

Parents and young children are not allowed to use the oasis room unless by prior arrangement with ward manager under special circumstances

9. MOBILE PHONES/INTERNET/TELEVISIONS

The trust recognises the importance of mobile phones as a vital means of communication in young people and therefore the use of mobiles in and around the (Unit Name) is permitted. We do ask you use silent/vibrate mode if you are on the main ward to ensure other patients are not disturbed.

The (Unit Name) provides wireless access to the internet that patients are allowed to use via the ward laptops. All internet activity within the trust is monitored. Users of the trust internet are advised that if found to be accessing any inappropriate sites/information; this will result in a ban of future internet use. Patients are not allowed to use their own laptops for accessing the trust internet system.

We provide a television at each bed space on the (Unit Name) Patients and visitors are asked to keep the volume at appropriate levels so as not to disturb other patients.

10. TEEN TO TWENTIES

Teen to twenties is a monthly social group for people who are going through treatment or up to 2 years out of treatment. The two year period commences once treatment is complete. All patients on active treatment for cancer (including relapsed patients) can attend teen to twenties.

11. SURVIVORS of CANCER (SOC)

SOC meets every 3 months and is for those who are over 2 years out of treatment. SOC has a maximum age range of 29 years or a membership limit of 3 years.

12. PATIENT INVOLVEMENT

(Name of Patient Involvement Group) is an active patient forum for up to 15 members. This is a formal group involved with various projects (local and national) to improve and develop future services for teenagers and young adults with cancer. This group is also used in consultation processes to give TYAs with cancer a ‘true’ voice. Members of the (Name of Patient Involvement Group) are allowed to stay on the (Name of Patient Involvement Group) Board until they are aged 26 years (maximum)/and/or serve on the board for a maximum of 4 years. Members may, if they wish, leave before this and their place will be offered to the first
placed person on the waiting list. As a member of the (Name of Patient Involvement Group), failure to attend 3 consecutive meetings may result in you being asked to withdraw from the board.

13. THEFT/DAMAGE
The (Unit Name) has purchased a wide selection of equipment for patient use including laptops, DVD’s, Playstation, TV’s etc. We ask that all equipment on the (Unit Name) is treated with respect and care and is returned to a member of staff after use. Anyone found to wilfully damage property or is involved in theft of any property will be reported to the Police.

14. REFERENCES

Royal College of Nursing, Getting It Right for teenagers in your practice- 2002

Warrington Youth Service: Policy and Guidelines for dealing with drug and alcohol related incidents- 2007

Medicines Act 1986

The Children Act 1989

Misuse of Drugs Act 1971

Royal College of Nursing, Caring for young people- guidance for nursing staff- Sept 2002

Royal College of Nursing, Protection of nurses working with children and young People- December 2002
# APPENDIX 7

## AGE-APPROPRIATE RESOURCES

<table>
<thead>
<tr>
<th>Resource</th>
<th>Website</th>
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</thead>
<tbody>
<tr>
<td>2 Be Me</td>
<td><a href="http://www.2bme.org">www.2bme.org</a></td>
</tr>
<tr>
<td>Bone Cancer Research UK</td>
<td><a href="http://www.bonecancerresearch.org.uk">www.bonecancerresearch.org.uk</a></td>
</tr>
<tr>
<td>Cancer Back Up</td>
<td><a href="http://www.macmillan.org">www.macmillan.org</a></td>
</tr>
<tr>
<td>Cancer Help UK</td>
<td><a href="http://www.cancerhelp.org.uk">www.cancerhelp.org.uk</a></td>
</tr>
<tr>
<td>Cancer Quest</td>
<td><a href="http://www.cancerquest.org">www.cancerquest.org</a></td>
</tr>
<tr>
<td>Canteen</td>
<td><a href="http://www.canteen.org.au">www.canteen.org.au</a></td>
</tr>
<tr>
<td>CCLG</td>
<td><a href="http://www.cclg.org.uk">www.cclg.org.uk</a></td>
</tr>
<tr>
<td>Forward Cancer Support</td>
<td><a href="http://www.cforward.org.uk">www.cforward.org.uk</a></td>
</tr>
<tr>
<td>CLIC Sargent</td>
<td><a href="http://www.clicsargent.org.uk">www.clicsargent.org.uk</a></td>
</tr>
<tr>
<td>Clic 4 Tic</td>
<td><a href="http://www.click4tic.org.uk">www.click4tic.org.uk</a></td>
</tr>
<tr>
<td>DOH</td>
<td><a href="http://www.dh.gov.uk">www.dh.gov.uk</a></td>
</tr>
<tr>
<td>Ellen McArthur Trust</td>
<td><a href="http://www.ellenmacarthurtrust.org">www.ellenmacarthurtrust.org</a></td>
</tr>
<tr>
<td>Jimmy Teens</td>
<td><a href="http://www.jimmyteens.tv">www.jimmyteens.tv</a></td>
</tr>
<tr>
<td>Kids Health</td>
<td><a href="http://www.kidshealth.org">www.kidshealth.org</a></td>
</tr>
<tr>
<td>Lance Armstrong</td>
<td><a href="http://www.livestrong.org">www.livestrong.org</a></td>
</tr>
<tr>
<td>Leukaemia Research</td>
<td><a href="http://www.lrf.org.uk">www.lrf.org.uk</a></td>
</tr>
<tr>
<td>Look Good Feel Better</td>
<td><a href="http://www.lookgoodfeelbetter.co.uk">www.lookgoodfeelbetter.co.uk</a></td>
</tr>
<tr>
<td>Lymphoma Association</td>
<td><a href="http://www.lymphoma.org.uk">www.lymphoma.org.uk</a></td>
</tr>
<tr>
<td>Macmillan</td>
<td><a href="http://www.Macmillan.org.uk">www.Macmillan.org.uk</a></td>
</tr>
<tr>
<td>Maggie’s Centres</td>
<td><a href="http://www.maggiescentres.org">www.maggiescentres.org</a></td>
</tr>
<tr>
<td>National Cancer Institute</td>
<td><a href="http://www.cancer.gov">www.cancer.gov</a></td>
</tr>
<tr>
<td>NCRI</td>
<td><a href="http://www.ncri.org.uk">www.ncri.org.uk</a></td>
</tr>
<tr>
<td>NHS Direct</td>
<td><a href="http://www.nhsdirect.nhs.uk">www.nhsdirect.nhs.uk</a></td>
</tr>
<tr>
<td>NICE</td>
<td><a href="http://www.nice.org.uk">www.nice.org.uk</a></td>
</tr>
<tr>
<td>NMC</td>
<td><a href="http://www.nmc-uk.org">www.nmc-uk.org</a></td>
</tr>
<tr>
<td>Planet Cancer</td>
<td><a href="http://www.planetcancer.org">www.planetcancer.org</a></td>
</tr>
<tr>
<td>PONF</td>
<td><a href="http://www.rcn.org">www.rcn.org</a></td>
</tr>
<tr>
<td>RCN</td>
<td><a href="http://www.rcn.org.uk">www.rcn.org.uk</a></td>
</tr>
<tr>
<td>R U Thinking</td>
<td><a href="http://www.ruthinking.co.uk">www.ruthinking.co.uk</a></td>
</tr>
<tr>
<td>Siblinks</td>
<td><a href="http://www.siblinks.org">www.siblinks.org</a></td>
</tr>
<tr>
<td>Teenage Cancer Trust</td>
<td><a href="http://www.teenagecancertrust.org">www.teenagecancertrust.org</a></td>
</tr>
<tr>
<td>Teens Living With Cancer</td>
<td><a href="http://www.teenslivingwithcancer.org">www.teenslivingwithcancer.org</a></td>
</tr>
<tr>
<td>TYAC</td>
<td><a href="http://www.tyac.org.uk">www.tyac.org.uk</a></td>
</tr>
<tr>
<td>Willow Foundation</td>
<td><a href="http://www.willowfoundation.org.uk">www.willowfoundation.org.uk</a></td>
</tr>
<tr>
<td>Winston’s Wish</td>
<td><a href="http://www.winstonswish.org.uk">www.winstonswish.org.uk</a></td>
</tr>
<tr>
<td>Youth Cancer Trust</td>
<td><a href="http://www.yct.org.uk">www.yct.org.uk</a></td>
</tr>
<tr>
<td>Youth Health Talk</td>
<td><a href="http://www.youthhealthtalk.org">www.youthhealthtalk.org</a></td>
</tr>
<tr>
<td>Young Heroes</td>
<td><a href="http://www.makeabigdifference.org">www.makeabigdifference.org</a></td>
</tr>
</tbody>
</table>
Patients name:

First please circle the number (0-10) that best describes how much distress in general you have been experiencing over the past week, including today.

Second, if any of the following has been a problem for you over the past week, including today, please tick the box next to it. Leave it blank if it does not apply to you. Then rank your top 4 difficulties (1 would be the biggest problem, 4 would be your fourth biggest concern)
## A BLUEPRINT OF CARE FOR
TEENAGERS AND YOUNG ADULTS WITH CANCER

<table>
<thead>
<tr>
<th>Highest ranked concerns</th>
<th>RATING</th>
<th>Description and history of problem</th>
<th>Plan of action</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>3.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4.</td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>
HEADSS for Adolescents (HEADSS)

Keywords:
Adolescents

Background:
This is an interview instrument for finding out about issues in adolescents’ lives. It was developed by Cohen and colleagues (Cohen et al, 1991)

Developer(s):

Copyright:
Publisher: Elsevier

ASSESSMENT

Home
- Who lives with the young person? Where?
- Do they have their own room?
- What are relationships like at home?
- What do parents and relatives do for a living?
- Ever institutionalised? Incarcerated?
- Recent moves? Running away?
- New people in home environment?

Education and employment
- School/grade performance – any recent changes?
  Any dramatic past changes?
- Favourite subjects/worst subjects? (include grades)
- Any years repeated/classes failed?
- Suspension, termination, dropping out?
- Future education/employment plans?
- Any current or past employment?
- Relations with teachers, employers, school/work attendance?

Activities
- On own, with peers (what do you do for fun? Where? When?)
- With family?
- Sports – regular exercise?
- Church attendance, clubs, projects?
- Hobbies – other activities?
- Reading for fun – what?
- TV – how much weekly? Favourite shows?
- Favourite music?
- Does young person have car? Use seat belts?
- History of arrests? Acting out/crime?

Drugs
- Use by peers? Use by young person? (include tobacco, alcohol)
- Use by family members? (include tobacco, alcohol)
- Amounts, frequency, patterns of use/abuse and car use while intoxicated?
- Source – how paid for?

Sexuality
- Orientation?
- Degree and types of sexual experience and acts?
- Number of partners?
- Masturbation? (normalise)
- History of pregnancy-abortion?
- Sexually transmitted diseases – knowledge and prevention? Contraception? Frequency of use?
- Comfort with sexual activity – enjoyment/pleasure obtained? History of sexual/physical abuse?

Suicide/Depression
- Sleep disorders (usually induction problems, also early/frequent waking or greatly increased sleep and complaints of increasing fatigue)
- Appetite/eating behaviour changes
- Feelings of ‘boredom’
- Emotional outbursts and highly impulsive behaviour
- History of withdrawal/isolation
- Hopeless/helpless feelings
- History of past suicide attempts, depression, psychological counselling
- History of suicide attempts in family or peers
- History of recurrent serious ‘accidents’ Psychosomatic symptomology
- Suicidal ideation (including significant current and past losses)
- Decreased affect on interview, avoidance of eye contact, depression posturing
- Preoccupation with death (clothing, media, music, art)

REFERENCES
ACTIVITY CONSENT FORM

If you are 18 or over and would like to take part in activities or events, please complete, sign and return this form to (insert staff members name here) ........................................... at:

Insert ward and hospital address here

Due to health and safety reasons you will not be allowed to participate in activities or events until a completed and signed copy of this form has been received.

This form will cover your attendance at all future activities and events whilst you remain a patient with us.

Your name: .............................................................................

Your date of birth: ......................................................................

Your Home address: ......................................................................

..............................................................................................

..............................................................................................

..............................................................................................

..............................................................................................
Details of your next of kin (parent/guardian/partner etc) who we should contact in the event of an emergency?

Name: ...........................................................................................................
Relationship to you: ......................................................................................

Tel no home: ................................Tel no work: .................................
Mobile: ...........................................................................................................

Please supply details of a further contact should the above not be available:

Name: ...........................................................................................................
Relationship to you: ......................................................................................

Declaration

I consent to taking part in activities/events/support groups (including trips away form the ward and residential breaks)

I understand that it is important for my safety and the safety of others that any rules and instructions given by the staff in charge must be followed.

I understand that while hospital staff and helpers are in charge they will take all reasonable care of my wellbeing and safety, and unless they are negligent cannot be held responsible for any loss, damage or injury suffered during activities or events.

I understand that it is my responsibility to ensure that I have all the necessary medications with me whilst attending activities/events.

Your signature: .........................Date:.........................
ACTIVITY CONSENT FORM

If you are happy for your son/daughter/dependent to take part in hospital activities or events, please complete sign and return this form to (insert staff members name here) .............................. at:

Insert ward and hospital address here

No young person will be allowed to take part in activities or events without a fully completed copy of this form.

Young adults/adults aged 18 years and above should complete the young person’s form, sign it at the bottom of the second page before an event or activity takes place.

This form will cover the young person’s attendance at all future events or activities whilst a patient at this hospital.

Parent/guardian’s name: .................................................................

Young person’s name: .................................................................

Young person’s date of birth: .............................................................

Home address: ..........................................................................
.................................................................................................
.................................................................................................

How can you be contacted in the case of an emergency? ....................
.................................................................................................
.................................................................................................

Tel no home: ...................... Tel no work: ...............................
Alternative (if not available) ........................................................................................................

Mobile: ................................................................................................................................

**Declaration**

I consent to my son/daughter/dependent, named above, taking part in activities/events/support groups (including trips away from the ward and residential breaks)

I have ensured that my son/daughter/dependent understands, as far as reasonably possible, that it is important for his/her safety and the safety of the group as a whole, that any rules and instructions given by the staff in charge are followed.

I understand that it is my responsibility to ensure that my son/daughter/dependent has all the necessary medications while they are attending trips/events.

I understand that while hospital staff and helpers are in charge they will take all reasonable care of my son/daughter/dependent, and unless they are negligent cannot be held responsible for any loss, damage or injury suffered to my son/daughter/dependent during activities or events.

Parent/Guardians signature: .................................. Date:.................................

Please indicate relationship to the young person .............................................................

........................................................................................................................................

ALL COMPLETED FORMS SHOULD BE RETURNED TO .........................
Consent Form

Child’s full name: Hospital Number:

Date of Birth: Gender:

To the parents (or those with parental responsibility for the child)

☐ Please read this form and the attached letter of information very carefully.

☐ Please check that all the information on this form is correct. If it is, and you agree to your child participating in this visit/trip/holiday/event, please sign the form where requested.

If there is anything that you do not understand about the trip or you would like more information before agreeing, please call the person who sent you this form.

1. DETAILS OF THE VISIT

Travelling from: LIVERPOOL LIME STREET

To: London Euston

Staying at Ramada Hotel Hyde Park

Visiting Royal Albert Hall and sight seeing in London

Mode of transport/s: Virgin Train (Taxis and Underground when in London)

Dates: 24th-25th March 2010

Times: 09:20

Meeting point: Liverpool Lime Street

Return collection point: Liverpool Lime Street

I am the parent/person with parental responsibility (your name)

I agree to --------------------------------------------------------- (child’s name) taking part in this visit/trip/event and I confirm that I have read the attached information letter.

2. I AGREE:-

a) To the child participating in the activities described below

As attached

b) I understand that there is a need for ---------------------------------------- (child’s name) to behave responsibly and I have no reason to believe that he/she will not behave responsibly.
c) I agree to the method/s of travel -----------------------------------------------

3. MEDICAL INFORMATION ABOUT YOUR CHILD

The Child’s Consultant ----------------------------------------------- (Consultant’s name) has been approached by those organizing the trip and has confirmed that the trip is suitable in regard to the current treatment plan.

a) Is your child currently taking any medication?
   □ Yes  □ No

If Yes please give details (name of medicine/s, dosage, frequency). Please ensure your child has sufficient medication to last for the whole of the trip.

b) Does your child self medicate?
   □ Yes  □ No

c) Is your child allergic to anything?
   □ Yes  □ No

Please outline the child’s special dietary requirements

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d) Does your child require/use any specialist equipment (mobility aids/oxygen/special feeds)?
   □ Yes  □ No

Please list what it is, what it is used for (emergency intervention, daily use), who it is provided by (Alder Hey Hospital/GP/O.T).

---

---

---

e) Do you consent to the group leader/volunteer giving such intervention as detailed above (if required)?
   □ Yes  □ No
If no please detail the medical or emergency medical intervention that you do not give consent for

<p>| |</p>
<table>
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</thead>
</table>

f) When did your son/daughter last have a tetanus injection?

---------------------------------------------------------------

I confirm that I will inform the Group Leader __________________ as soon as possible of any changes in medical or other circumstances between now and the commencement of the trip.

4. EXTRA INFORMATION

Is there anything else that you would like us to know about the child, or do you know of any reason why this trip may not be suitable for the child now?

---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------

---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------

5. DECLARATION AND CONSENT

I agree to ________________________________ (child’s name) receiving medication as instructed and any emergency dental/medical or surgical treatment including anaesthetic or blood transfusion, as considered necessary by the accompanying volunteer or local hospital.

I ________________________________ am the parent/person with parental responsibility for the child confirm that I have read and understood this form. I have supplied all relevant information relating to the child and all of their medical conditions and medication requirements. I know of no reason why the child should not go on this trip.

I agree with the details set out at paragraphs 1, 2, 3, 4 and 5.

Signed………………………………………………………………………………
Full name in capitals…………………………………………………………
Relationship to child…………………………………………………………
Dated………………………………………………………………………………
This form must be returned to the Group Leader prior to the trip/event/activity by the date specified in the attached letter. A copy will be kept in the Child's medical records.

6. EMERGENCY CONTACTS

Name:………………………………………………………………………

Home Address……………………………………………………………

Work telephone number………………………………………………

Home telephone number………………………………………………

Mobile telephone number……………………………………………

ALTERNATIVE EMERGENCY CONTACT (must be provided)

Name………………………………………………………………………

Relationship……………………………………………………………..

Address…………………………………………………………………..

Home telephone number………………………………………………

Work telephone number………………………………………………

Mobile telephone number……………………………………………

NAME OF FAMILY DOCTOR

Name………………………………………………………………………

Address…………………………………………………………………..

Telephone number…………………………………………………….
APPENDIX 10

Information and support for siblings.

**SIBS**

www.Sibs.org.uk (for information)

info@sibs.org.uk (for email responses on specific issues and tips for coping and information on siblings issues)

01535 645453 – to contact

‘Sibs’ is the UK organisation for people who grow up with, or have to cope with, a brother or sister with a disability or chronic illness. The aim is to provide information and support.

**For younger siblings** (i.e. up to 18 years) Email responses and info on the website is available.

**For adult siblings** (i.e. 18+) One hour telephone support sessions, workshops for adult siblings and information on dealing with adult sibling issues is available.

How to contact - You can contact them by email or phone (above).

(This organisation can also provide support for parents including; one hour free telephone support (with 3 weekly follow-up calls and/or emails), workshops for parents on supporting siblings and information on supporting siblings)

**SIBLINKS**

www.siblinks.org

Website containing useful information about sibling issues and details of the available phone network. An online discussion forum is also available.

Suitable for: teenage/young adult siblings

How to contact – Website address above

**Compassionate Friends**

www.tcfsiblingsupport.org.uk

**For Bereaved Siblings**

**Compassionate Friends**

www.tcfsiblingsupport.org.uk

**Cruse** - ‘After someone dies’ A leaflet about death, bereavement and grief for young people.

www.crusebereavementcare.org.uk. 0208 939 9530

Young people’s helpline – 0808 808 1677

Young people’s website – www.rd4u.org.uk

**Child Bereavement Trust** (also cover young people’s bereavement) –

www.childbereavement.org.uk

Support & Information Service Telephone number: 01494 446648

**Winston’s Wish** – The leading childhood bereavement charity and the largest provider of services to bereaved families in the UK.

www.winstonswish.org.uk

Helpline - 08452 03 04 05

General Enquiries: 01242 515157

Fax: 01242 546187

Email: info@winstonswish.org.uk

**The Gaddum Centre** - Manchester Charity - Advocacy, Bereavement Counselling for Children

www.gaddumcentre.co.uk

0161 429 7492

0161 834 6069

**Book:** *Badger’s parting gift* - A ‘remembrance’ book dedicated to keeping loved ones that have passed on, still a part of our lives.
A BLUEPRINT OF CARE FOR TEENAGERS AND YOUNG ADULTS WITH CANCER

Teenage Cancer Trust
3rd Floor, 93 Newman St
London W1T 3EZ
Tel: + 44 (0) 20 7612 0370
Email: tct@teenagecancertrust.org
Website: www.teenagecancertrust.org
Teenage Cancer Trust is a registered charity: 1062559 (England & Wales); SC039757 (Scotland)

Teenagers and Young Adults with Cancer
4th Floor, Hearts of Oak House
9 Princess Road West
Leicester LE1 6TH
Tel: + 44 (0) 116 249 4483
Email: info@tyac.org.uk
Website: www.tyac.org.uk