



More Than my Illness

Delivering quality care
for young people with cancer





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Discussion groups were led and analysed by Alisha Newman, CLIC Sargent's Children and Young People's User Participation Manager, and supported by many other CLIC Sargent members of staff.

CLIC Sargent's Research and Development Team supported the design and analysis of the More Than My Illness survey.

DATE

August 2010

TARGET AUDIENCE

Commissioners, providers, practitioners and policy makers involved in providing services to young people aged 16 to 24 who have cancer.

BRIEF ABSTRACT

This report recommends key elements of support that aim to improve the long-term life opportunities of young people with cancer through improving access to high quality community-based services.

WHO IS CLIC SARGENT?

CLIC Sargent is the UK's leading children's cancer charity. CLIC Sargent provides a wide range of services and a large number of care professionals to look after children and young people with cancer, and their families.

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Message from the Chair of the More Than My Illness Review



Cancer services for young people aged 16 to 24 are undergoing a significant period of change as new models of care are implemented to meet the standards set out in the National Institute for Health and Clinical Excellence's Improving Outcomes in Children and Young People with Cancer guidance. However, young people in this age group still face real inequalities in accessing high quality, age appropriate care when compared to younger children and older adults for whom services are much better established.

Young people with cancer are at a vital developmental stage of their lives as they grow into adulthood and establish their independence. We must recognize this and ensure that age appropriate services and support are in place to help them to manage this process well so that they can become successful survivors, able to live life to the full and to contribute to the society in which they live.

This second report in the More Than My Illness series emphasises the importance of supporting young people with cancer to spend more time closer to home so that they can more effectively participate in everyday life, which includes keeping up with friends, family, education and employment.

To make this possible, those involved in the More Than My Illness review strongly believe that every young person with cancer should have a key worker who can facilitate transition from hospital to home and coordinate community-based services once they are there. More Than My Illness also recommends that all young people with cancer have their individual needs assessed using a standardised and holistic framework, and that this assessment is used to identify and access community-based support services.

I would like to thank all the young people and their families and friends who told us their views – your contribution has been absolutely crucial. I would also like to thank all of the professionals that gave up their time to inform and shape this report – this would not have been possible without your considered input. And on behalf of the steering group, I would like to thank and commend the project team from CLIC Sargent who provided excellent support throughout.

The key now is for commissioners, providers and policy-makers to work together to make the recommendations a reality so that more young people have the option of spending more time at home during their treatment and, most importantly, the opportunity of reaching their full potential.

A handwritten signature in black ink, appearing to read 'M Lakhani' with a small flourish at the end.

Professor Mayur Lakhani CBE FRCGP

GP and Chair of the More Than My Illness Review



Message from The Chief Executive



This second report in the More Than My Illness series challenges all those involved in delivering support and care for young people with cancer to truly make holistic care closer to home a reality.

CLIC Sargent fundamentally believes that all young people have the right to fulfil their potential in all areas of their life. A cancer diagnosis is a traumatic and life-changing experience for anyone but the effects on a young person are particularly intense as it fundamentally compromises a young person's ability to adapt to their changing situation during this key transition period in their life.

The recommendations within this report are drawn from the experiences of over 200 young people and their families and address what this group sees as the priority issues. Whilst many of the issues addressed by the report are similar to those covered in the first More Than My Illness model for younger children, the need to implement a key worker led model for the 16 to 24 year olds is even more critical. This is because services are less well established for this age group, and also as this is a key transition period in a young person's life.

The final section of this report sets out some steps that should be taken to implement the model detailed in this report. CLIC Sargent is determined to ensure the report leads to tangible service change and we are therefore:

- Undertaking an internal service strategy review to ensure the principles within the report are applied across our own services
- Taking forward discussions with various bodies with a view to securing funding to pilot and evaluate a key worker led model
- Ensuring our campaigning and influencing strategy draws on the findings of this report with a view to establishing a dialogue on how policy might facilitate wider take-up of a key worker led model

CLIC Sargent is committed to improving outcomes for young people with cancer and we therefore urge decision makers, commissioners, primary care trusts, other voluntary sector organisations, local authorities, children's trusts and other organisations involved in the delivery of support for young people with cancer to consider how best to respond to this report's recommendations.

Lorraine Clifton

Chief Executive, CLIC Sargent
August 2010

Executive Summary

The recommendations in this report aim to improve both the patient's experience and the long-term outcomes of young people with cancer, aged 16 to 24, through improving access to high quality community-based services. Central to this is strengthening the links between local services and specialist hospital based care.

The report draws on the views of young people with cancer and their parents, carers and partners. Over 200 young people and their significant others responded to the More Than My Illness survey. A further 24 young people and their significant others participated in discussion groups. These recommendations follow an earlier report ¹ that focused on the needs of younger children with cancer and their families.

WHAT YOUNG PEOPLE TELL US IS IMPORTANT

Young people of this age are at a vital developmental stage of their lives, growing into adulthood and establishing their independence. Being diagnosed with cancer can impact greatly on this important process. Young people told us what is most important to them during this traumatic time and their needs are summarised below.

Spending more time at home safely	Young people with cancer tell us that spending time at home during treatment is very important as this helps them to keep up with everyday life. To do this young people must be able to gain access to good day-to-day clinical care at home, as well as good information so that they can confidently manage the illness away from hospital. Young people also need quick and easy access to specialist clinical care in hospital when this is necessary.
Keeping up with friends, college and work	Like all young people, young people with cancer need a social life. Spending time with friends is important in developing socially, establishing independence and for emotional support. Keeping up with education, employment and training is important for emotional well-being, increased self esteem and long-term job opportunities.
Physical and emotional well-being	Young people with cancer tell us they need emotional support to help them deal with this traumatic experience. They also need help to look after their general health and fitness, and support with relationships, sexual health and fertility issues.
Practical and financial support	Young people with cancer need help and advice to cope with the financial pressures that a cancer diagnosis can bring. Young people also need help to find suitable housing and transport so that, like other young people, they can begin to establish their own independence and keep up with their ordinary life.
Help to find and coordinate the right support	There are lots of sources of support for young people with cancer, but they need help to know where to look and what to ask for. They also need help to coordinate all of the services delivered by the various people involved in supporting them.

1 CLIC Sargent, (2008), More Than My Illness: Delivering Quality Care for Children with Cancer



IMPROVING ACCESS TO COMMUNITY-BASED SERVICES

The recommendations in this report strongly uphold the standards of care outlined in the National Institute for Health and Clinical Excellence’s Improving Outcomes for Children and Young People with Cancer² guidance. However, to properly meet the needs that young people have highlighted through this review, there must be more of a focus on accessing good quality community-based services than is currently included in the guidance, or likely to be included in the teenager and young adult cancer measures.

The ways in which both current services and the measures could be strengthened are outlined below.

- There must be a greater focus on delivering holistic care and support closer to home.
- The measures for young people’s cancer services must be explicit in further defining the role of the key worker as responsible for ensuring that all non-clinical needs are assessed and met. This includes education, employment, social, emotional, practical and general health and well-being needs.
- The measures should also recognise the role of specialist oncology social workers and youth workers in supporting the key worker to do this.
- So that young people with cancer can spend time at home safely, the key worker must also ensure that the young person’s clinical needs are adequately met by local clinicians such as community nurses and GPs.
- Young people with cancer should have their needs systematically assessed using a universally accepted and holistic assessment framework such as the adult or children’s

Common Assessment Framework³, the Holistic Common Assessment of Supportive and Palliative Care Needs for Adults with Cancer⁴, or the Assessment Framework for Continuing Care⁵.

- The National Cancer Patient Information Programme⁶ and the measures for young people’s cancer services must specify that information on all of the clinical and non-clinical needs identified by young people are met and that the information provided is age-appropriate.

The benefits of these recommendations could be significant

By better coordinating services and helping young people to spend more time at home during treatment, More than My Illness aims to improve young people’s long-term outcomes. Spending more time at home would mean that young people with cancer could more effectively keep up with everyday life, which includes friends, family, education and employment. This can have a significant impact on a young person’s emotional and financial stability, both during treatment and into the future. This is crucial to young people of this age as they are at a vital developmental stage of their lives, growing into adulthood and establishing their independence.

² National Institute for Health and Clinical Excellence, (2005), Improving Outcomes in Children and Young People with Cancer

³ www.everychildmatters.org.uk, www.dh.gov.uk

⁴ Department of Health, (2007), Holistic Common Assessment of Supportive and Palliative Care Needs for Adults with Cancer

⁵ www.dh.gov.uk

⁶ www.cancer.nhs.uk

I. Background

1.1 PURPOSE

The recommendations in this report aim to improve both the patient's experience and the long-term outcomes of young people with cancer, aged 16 to 24, through improving access to high quality community-based services.

Cancer in young people is rare, with 1,900 to 2,000 young people being diagnosed each year. Five year survival rates in this age group are improving for most types of cancer, with 73% of young people achieving five year survival.

As with all young people, these young people have a right to fulfil their potential in all areas of their lives – in work, in education, emotionally and financially, as well as physically and in making a contribution to their community. This report describes the key principles of care that should enable young people with cancer to gain easier access to the local services that are so crucial to delivering the holistic care and support they need.

Important hospital-based service development for young people with cancer is already underway as a result of the recommendations made in the National Institute for Health and Clinical Excellence's Improving Outcomes for Children and Young People with Cancer⁷ guidance published in 2005.

The Improving Outcomes Guidance for Children and Young People with Cancer Advisory Group, which was established by the Department of Health and the NHS to implement the guidance, agreed with CLIC Sargent's⁸ proposal that a review of holistic community-based care and support needs and services was required. This report follows an earlier publication⁹ that recommended a model of care for younger children with cancer.

1.2 AUDIENCE

This report is for any individual involved in developing services for young people with cancer. Those who have a particularly important role to play are commissioners, providers, practitioners and policy makers in both specialist cancer services, and also local health, youth, mental health, education and employment services.

Many of the principles of care outlined in the report are also applicable to young people with other complex health needs.

1.3 SCOPE

The recommendations described in this report focus on improving access to community-based care and support, and strengthening the links between local services and specialist hospital based care. It does not focus on the clinical services provided in hospital. The report also focuses on the treatment phase of the care pathway and the transitions between phases, for example the transition to long term survivorship or the transition to end of life care.

The principles of care outlined in this report can be applied to all areas of the UK. Although the Improving Outcomes for Children and Young People with Cancer guidance only applies to England, the development of specialist teenager and young adult facilities is underway in all countries of the UK, many with funding and support from the Teenage Cancer Trust¹⁰.

The recommendations do not address in any detail issues of transition to diagnosis, long-term survivorship and late effects, or palliative and end of life care. Important initiatives are already underway in these areas, and sources of further information are given below.

- Transition to diagnosis: National Awareness and Early Diagnosis Initiative¹¹
- Survivorship and late effects: National Cancer Survivorship Initiative¹²

⁷ National Institute for Health and Clinical Excellence, (2005), Improving Outcomes in Children and Young People with Cancer

⁸ CLIC Sargent is the UK's leading children's cancer charity

⁹ CLIC Sargent, (2008), More Than My Illness: Delivering Quality Care for Children with Cancer

¹⁰ A charity dedicated to improving the lives of young people with cancer

¹¹ www.nhs.uk

¹² www.improvement.nhs.uk



- Palliative and end of life care: ACT¹³, and the Holistic Common Assessment of Supportive and Palliative Care Needs for Adults with Cancer¹⁴

1.4 Approach

A summary of the approach taken to develop the principles of care recommended in this report is given below.

a) Survey to identify priorities and needs

119 young people, and 91 carers and significant others¹⁵, responded to the More Than My Illness survey. Some of the responses from the young people and their significant others are included in this report.

There was a good spread of respondents in the 16 to 18 age group and the 19 plus age group. There was also a good spread of those who were treated on child, teenager and young adult, and adult only wards.

193 respondents were white, and eight of these had specific language needs. Five respondents were Asian.

b) Discussion groups to identify need and issues with current provision

Five More Than My Illness discussion groups were held, involving both service users and providers. Further detail on the groups is given below.

Young people:

- 2 discussion groups
- 13 participants

Carers and significant others:

- 2 discussion groups
- 11 participants

Community-based practitioners:

- 1 discussion group
- 8 participants

¹³ www.act.org.uk

¹⁴ Department of Health, (2007), Holistic Common Assessment of Supportive and Palliative Care Needs for Adults with Cancer

¹⁵ Someone who has a significant or long term influence on a young person's life such as a partner or close friend

c) Case studies	26 case studies and examples of good and bad practice were identified by young people, their carers and practitioners from a variety of professions.
d) Steered by a working group of experts	<p>A group of experts from a variety of professions helped CLIC Sargent to design the consultation and analyse its outputs, and then translate the needs and issues that were identified into the principles of care recommended in this report.</p> <p>The members of the group are listed in Appendix A.</p>
e) Review of relevant literature, policies and guidance	<p>A comprehensive review of the literature, policies and guidance relevant to young people and young people with cancer was carried out.</p> <p>For further information, please refer to the key points identified in the 'national context' boxes and the references detailed in Appendix B.</p>



2. What Do Young People With Cancer Need?

When a young person is diagnosed with cancer, their clinical needs are the most immediate, and continue to be of paramount importance throughout treatment.

However, young people with cancer aged 16 to 24, as with all young people, also have a range of other important needs. They are in a vital developmental stage as they grow into adulthood and establish their own independence, and managing this well can have a hugely positive impact on their future lives.

Having cancer can impact greatly on the process of growing up, and consequently the needs of young people with cancer are often more acute. But, this group of young people still have a right to fulfil their potential. They not only want to survive their cancer, but they want to be successful survivors, in all areas of their life.

2.1 YOUNG PEOPLE NEED COORDINATED AND INTEGRATED SERVICES TO MEET COMPLEX AND INDIVIDUAL NEEDS

Young people have complex needs

The needs of young people in this age group are complex and can vary enormously depending on their individual circumstances. For example, young people may be living at home with their parents, or they could live alone and may have dependents of their own. Young people may still be in full time education, or they may be employed. Young people may be at university, but return to a family home in another town during the holiday periods.

The wide range of cancers affecting this age group adds to this complexity. Young people may be diagnosed with childhood cancers and adult cancers. The type and method of treatment varies a great deal depending on the cancer type and the choices made by the young person. Treatment can range from chemotherapy and radiotherapy as an outpatient for some lymphomas, to short inpatient stays for surgery with outpatient follow up for testicular cancer, to complex chemotherapy,

radiotherapy and orthopaedic surgery for Ewing's sarcoma and other primary bone cancers.

This can impact on a young person's needs significantly. Being an outpatient is potentially less disruptive to everyday life as more time is spent at home. However, attending hospital regularly for chemotherapy and radiotherapy, and the side effects that these can cause, can impact significantly on a young person's ability to continue with education or employment, for example. Spending long periods of time as an inpatient can interrupt this completely, as well as disrupting existing social networks and other family responsibilities.

Some cancers in this age group are also rare (accounting for less than 5% of cancers in this age group), for example soft tissue sarcomas. This can add to the sense of isolation felt by a young person with cancer, and the need to find emotional and psychological support from both professionals, and other young people in the same situation.

Young people need coordinated services

To meet these complex, varied and changing needs, young people need help from many different services. From the health sector this includes specialist teenager and young adult cancer services, adult cancer services, and local hospital and primary health care services. From the non-health sector this includes youth, education, employment, housing, financial, mental health and social care services.

Practitioners from numerous professions, organisations and sectors must join together to deliver a coordinated service that improves outcomes, and, importantly, does not increase the pressure and confusion that young people and their families can feel when interacting with so many different practitioners.

Are services coordinated and integrated?

The young people and their significant others that participated in the More Than My Illness discussion groups felt that communication between health care professionals and other service providers was

often lacking. This resulted in services appearing to them as fragmented and uncoordinated.

The community-based practitioners that participated in the More Than My Illness discussion group also highlighted a number of coordination and communication issues:

- A lack of communication between hospital-based practitioners and community-based practitioners
- A lack of referrals from hospital-based practitioners, suggesting a limited knowledge of local services and how to gain access to them
- A need to build relationships and trust between the practitioners in these different care settings
- A lack of clarity in terms of roles and responsibilities
- A need for community-based practitioners to be able to easily gain access to specialist support and advice
- Issues with managing the transition between child and adult services

2.2 YOUNG PEOPLE NEED TO BE EMPOWERED BUT ALSO SUPPORTED

It is important that practitioners working with any young person help them to establish their own independence, a crucial aspect of growing into adulthood. This can mean developing emotional independence, making choices, managing risk taking behaviour, becoming financially independent, and living independently. A cancer diagnosis can impact significantly on this key developmental stage, and so young people with cancer often need additional support in these areas.

As well as striving for independence, young people often still need intensive support from family

members. Parents, carers and significant others may want close involvement in the young person's life and the choices they make. Practitioners must not only empower the young person, but also deliver the additional support they need, and involve family members in a meaningful and helpful way.

2.3 YOUNG PEOPLE NEED INFORMATION AT THE RIGHT TIME

Young people need good information and support to help them make positive and informed choices about their life and about their care.

This is particularly important when spending time at home during and after treatment. Young people must have good information on how to manage their illness and what to do in an emergency, to ensure that spending time at home is safe. Knowing what to expect and who to contact also reduces the sense of isolation many young people and their families feel on discharge from hospital.

The young people and their significant others that participated in the More Than My Illness discussion groups felt that information was often lacking. Once back at home they felt ill informed, confused, disempowered and isolated. They also felt that information was often given too early or too late. They requested that more thought be given to both the timing of when information is given and the quantity given at any particular time.

2.4 19 TO 24 YEAR OLDS NEED SUPPORT TO MAKE CHOICES ABOUT THEIR PLACE OF CARE

The need for good information and support to make informed choices is even more acute for 19 to 24 year olds, as they are able to choose between having their care directed by the teenager and young adult multi-disciplinary team, or by the adult cancer centre. This is due to the new models of hospital-based care being established as a result of the recommendations made in the Improving Outcomes for Children and Young People with Cancer guidance. These new models of hospital-based care must be flexible



enough to enable young people to access to specialist services for teenagers and young adults, even if they are being treated at an adult cancer centre.

By choosing to be cared for at an adult cancer centre, the young person is more likely to be closer to home and therefore better able to keep up with education, employment and their existing networks of friends. 96% of young people who responded to the More Than My Illness survey said it was

important to spend more time at or near home.

However, they must be able to maintain links with the teenager and young adult multi-disciplinary team, so that they can gain access to specialist psychological and emotional support from professionals and through meeting other young people with cancer, if this is needed. They may also be able to gain access to specialist clinical care, such as participating in clinical trials.

2.5 Other important needs		
Area of need	What did young people tell us?	What challenges do young people with cancer face?
Clinical care in the community	<ul style="list-style-type: none"> • 89% of young people said it was important to get clinical support at home • 38% of young people said they lacked information about what would happen next • To spend time at home safely, access to clinical care in the community and knowing what to do in an emergency is absolutely crucial 	<ul style="list-style-type: none"> • A disparity in the level of clinical support offered in the community • Carers feel ill informed, unsupported and vulnerable • Accessing appropriate out of hours emergency care is a significant problem
Education, employment and training	<ul style="list-style-type: none"> • 65% of young people said it was important to get education and training support • 45% said it was important to get employment support, and this became more important as age at diagnosis increased • 64% of 16-18 year olds fell behind with studies or did not do as well as they thought they could have • 29% of all young people had to leave education • 93% reported that their employment had been affected • 41% had to leave their employment and 31% took unpaid leave • 43% needed more support with gaining or maintaining employment 	<ul style="list-style-type: none"> • Lack of communication between education and health services • Inadequate/inflexible education support • Lack of financial and practical support for post compulsory education • Lack of confidence in own abilities • Difficulties with finding suitable employment • Difficulties with managing relationships with employers

Area of need	What did young people tell us?	What challenges do young people with cancer face?
Emotional	<ul style="list-style-type: none"> • 88% of young people said it was important to have emotional support when they were at home, and this became more important as age at diagnosis increased • 62% were either unable to gain access to a counsellor or psychologist, or they needed more support from them than they had received 	<ul style="list-style-type: none"> • Feelings of disempowerment and vulnerability • Dealing with loss of independence • Dealing with changed physical appearance • Difficulties with managing relationships • Dealing with fertility issues • Facing mortality
Social	<ul style="list-style-type: none"> • 94% of young people said it was important to be able to maintain a social life during treatment • 50% had not been able to keep up with a 'normal' social life • 47% had not had as much professional help to do this as they needed • 46% had not been able to meet someone going through the same thing as them 	<ul style="list-style-type: none"> • Difficulties with relating to friends and peers • Not being able to take part in usual social activities • Not being able to meet other young people in the same situation
Housing and practical	<ul style="list-style-type: none"> • 49% of young people said it was important to get practical support, and this became more important as age at diagnosis increased • 41% needed more support with aids and adaptations at home 	<ul style="list-style-type: none"> • Difficulties with moving out of home and finding suitable housing • Issues with gaining access to practical support in the home, for example aids and adaptations, home help, child care



Area of need	What did young people tell us?	What challenges do young people with cancer face?
Financial	<ul style="list-style-type: none"> • 72% of young people said it was important to get advice and support on money matters, and this became more important as age at diagnosis increased • 54% needed more financial advice in terms of getting a mortgage, insurance etc. • 34% needed more professional support in gaining access to Disability Living Allowance¹⁶, other benefits and other financial support e.g. accessing grants, negotiating payment holidays • 45% needed more support with transport and travel costs 	<ul style="list-style-type: none"> • Difficulties with gaining access to benefits • Difficulties with meeting additional costs, for example transport costs • Need to become financially independent
General health and fitness	<ul style="list-style-type: none"> • 84% of young people said it was important to be able to maintain a healthy lifestyle • 42% needed more support with this from professionals 	<ul style="list-style-type: none"> • Lack of access to rehabilitation services and dietetic services • Difficulties with maintaining fitness • Need for support with making healthy lifestyle and sexual health choices

2.6 IMPLICATIONS FOR THE MORE THAN MY ILLNESS MODEL OF CARE

The needs and challenges highlighted in this section raise a number of issues that must be addressed by the More Than My Illness model of care. The recommendations must ensure that:

- Support is tailored to meet young people’s individual and changing needs – this requires skilled multi-disciplinary assessments of need
- Young people are able to gain access to local clinical, emotional and practical care and support to meet their needs when at home
- Young people know how to access appropriate emergency and out of hours support when at home
- Young people can gain access to specialist teenager and young adult services when needed
- Services are integrated and coordinated
- Young people are supported to make informed decisions
- Practitioners offer a family centred and supportive approach that also empowers the young person

¹⁶ A tax-free benefit for children and adults who need help with personal care or have walking difficulties because they are physically or mentally disabled.

3. Recommendations for a Future Model of Community Care

3.1 EVERY YOUNG PERSON SHOULD HAVE A KEY WORKER RESPONSIBLE FOR THE COORDINATION OF THEIR CARE AND SUPPORT

The key worker is a navigator, an enabler, a coordinator. The overall aim of the role is to ensure the provision of seamless and holistic care to meet the individual needs of the young person and their family.

“It is important to have a named, well-informed health professional who can either answer queries as they arise or find an answer for you quickly. We had this and it was vital for our peace of mind.”

Parent of a young person with cancer

A role description is outlined below, which aligns to and enhances that set out in the Improving Outcomes for Children and Young People with Cancer guidance.

Assessment and care planning	<ul style="list-style-type: none"> • Ensure the young person's needs are systematically assessed • Ensure a care plan is maintained and followed
Co-ordinating service delivery	<ul style="list-style-type: none"> • Coordinate services across specialist and local health care, across sectors and across geographical boundaries • Ensure continued access to specialist teenager and young adult services • Proactively seek out services that are delivered by other sectors • Be a named contact for the young person and for local practitioners • Ensure a shared understanding of goals, roles and responsibilities - with the young person and amongst practitioners • Ensure appropriate information is shared between practitioners
Coordinating transition to adult services	<ul style="list-style-type: none"> • Establish links with counterparts in the receiving adult service and conduct joint transition planning • Gradually 'hand the baton' to the new adult specialist/key worker • For further information refer to the guidelines set out in Better Care: Better Lives¹⁷ and ACT: The Transition Care Pathway¹⁸

¹⁷ Department of Health, (2008), Better Care Better Lives

¹⁸ Association for Children's Palliative Care, (2007), The Transition Care Pathway: A Framework for the Development of Integrated Multi-Agency Care Pathways for Young People with Life-threatening and Life-limiting Conditions



<p>Enabling and empowering the young person</p>	<ul style="list-style-type: none"> • Coordinate the provision of timely and appropriate information • Act as an advocate and help the young person to develop their self-advocacy skills • Empower young people, where possible enabling them to take decisions and manage the coordination of their own care plan • Involve parents, carers and partners in a meaningful and helpful way
<p>Providing specialist cancer support</p>	<ul style="list-style-type: none"> • Ensure the young person and local primary care practitioners acquire any needed clinical skills to enable them to manage day to day treatment when outside of hospital • Ensure the young person and local practitioners understand what to expect from the cancer treatment and its side effects • Ensure the young person can recognise an emergency or urgent situation, and knows what to do and who to contact
<p>Delivering palliative and terminal care</p>	<ul style="list-style-type: none"> • ‘Coordinate palliative and terminal care to provide specialist advice and support to families and healthcare professionals, with cross-cover to provide a 24-hour service, if required¹⁹.’ • ‘The key worker may provide direct clinical care and expertise at this time if appropriate²⁰.’ • For further information refer to the guidelines set out in Better Care: Better Lives²¹

Who is the key worker?

The key worker should be identified in partnership with the young person and in accordance with their specific needs. A young person’s key worker is likely to change when their needs change, for example on transition to long-term survivorship. However, the key worker should not change too frequently as continuity is also important.

During treatment, when clinical needs are paramount, the key worker is likely to be a specialist nurse experienced in oncology. Clinical skills at this time are very important to ensure that the young person can spend time at home safely. As well as the young person and their family, community nurses and other community-based practitioners also need an experienced clinical contact at the hospital, so that they can safely support the young person when they are at home.

“My GP never contacted me to find out how I was progressing, and when I ran out of crucial tablets I had to travel all the way to Leeds to get another prescription.”

Young person with cancer

19 National Institute for Health and Clinical Excellence, (2005), Improving Outcomes in Children and Young People with Cancer

20 National Institute for Health and Clinical Excellence, (2005), Improving Outcomes in Children and Young People with Cancer

21 Department of Health, (2008), Better Care Better Lives

Accountability

One key worker is unlikely to be able to meet all of a young person's needs. For example, one practitioner is unlikely to have expert knowledge of all the clinical and non-clinical aspects that are important to a young person's care. Young people themselves are also likely to rely on different practitioners for different types of support.

Responsibilities must therefore be shared between practitioners. This includes hospital-based practitioners who work as part of the hospital multi-disciplinary team, as well as community-based practitioners. Formally agreed clarity on each practitioner's responsibilities is absolutely essential, and the young person must understand the different roles of those involved in their care too.

However, sharing responsibilities does not mean that accountability should be shared. Accountability for ensuring assessment and care planning takes place, and for ensuring that identified needs are met, should remain with one person – the key worker. This should be formally agreed with the relevant practitioners and with the young person. This is particularly important when the young person is receiving treatment in a number of care settings. For the young person this means that they know exactly who to contact if they are facing problems with their care or they need additional support.

Some young people may already have a local lead professional, or may be allocated one by their primary care trust or local authority as a result of their cancer diagnosis. If the majority of the young person's care is delivered in the community, the lead professional may be the most appropriate person to fulfil many of the responsibilities of the key worker that are described above. However, the specialist nurse key worker must retain ultimate responsibility for ensuring that the young person and their family receive appropriate cancer related care and support.

Role of the multi-disciplinary team

The key worker's relationship with the hospital-based multi-disciplinary team responsible for directing the young person's care is crucial.

As outlined above, the key worker will share many of their responsibilities with other practitioners, some of which will be members of a multi-disciplinary team. This includes the lead consultant, specialist social worker, activity coordinator, youth worker, psychologist and allied health professionals. In conjunction with the key worker, these practitioners will assess needs, plan care and deliver support; inform, advocate for and empower the young person; and develop partnership working arrangements with local practitioners.

Depending on where the young person chooses to receive their cancer treatment, there may be a number of multi-disciplinary teams involved in caring for the young person. Often multi-disciplinary teams will be on different sites making communication between practitioners more challenging, and the key worker's role in managing these relationships vital.

The key worker role is crucial in developing strong links between the specialist skills of the practitioners working in the teenager and young adult multi-disciplinary team, and practitioners working in other hospital care settings, for example in adult cancer centre multi-disciplinary teams and shared care centres.

Developing strong links to the teenager and young adult multi-disciplinary team is essential for ensuring that the young person can gain access to the specialist emotional, psychological and youth services that are available through a teenager and young adult multi-disciplinary team, even if they are at home or being treated by an adult cancer centre.

For this to be possible for 19 to 24 year olds, it is vital that the Improving Outcomes for Children and Young People with Cancer guidance is fully implemented. The guidance recommends that, as a minimum, all 19 to 24 year olds are notified to the teenager and young adult multi-disciplinary team on diagnosis, even if they choose to be cared for at an adult cancer centre. This process will be crucial to establishing close relationships between specialist teenager and young adult services and adult cancer centres.

The key worker's role in developing strong links between the hospital multi-disciplinary teams



and the community is also essential. This is very important for ensuring the clinical safety of the young person when they are at home. For example, the young person’s GP should be able to easily gain access to information and professional support from the lead consultant, if this is required.

“Travelling to hospital nearly everyday over such a long time was difficult for my friends, family and myself. The opportunity to get support locally would have given me more control over my life.”

Young person with cancer

National context: key worker

- The Improving Outcomes for Children and Young People with Cancer guidance²² recommends that each child or young person with cancer should have a key worker.
- Support for All: the Families and Relationships Green Paper²³ proposes to address the issue of managing of the range of agencies involved in a young person’s care by extending the offer of key worker support to all families with disabled children aged 0 to 19.
- The National Service Framework for Children, Young People and Maternity Services²⁴ (Standard 8) notes that studies of key workers ‘consistently report positive effects on relationships with services, fewer unmet needs and greater family well-being’.
- High Quality Care for All: NHS Next Stage Review²⁵ identifies the need for a lead professional in developing personalised care plans.

- Our NHS, Our Future²⁶ outlines how a named professional should provide a point from which the NHS and its partners can organise services around the needs of individuals.
- Holistic Common Assessment of Supportive and Palliative Care Needs for Adults with Cancer²⁷ states there may be benefits in appointing a key worker whom patients and carers can contact and who is familiar with the planned treatment and care.

3.2 EVERY YOUNG PERSON SHOULD HAVE THEIR NEEDS SYSTEMATICALLY ASSESSED AND REASSESSED USING A HOLISTIC ASSESSMENT FRAMEWORK

Young people should be actively involved in assessing their needs and developing their individualised care plan. Where young people are either cared for by their family or other carers, or where they have care responsibilities themselves, the assessment should also include the needs of the carers or cared for.

A young person’s needs are likely to be wide ranging, highly individual and changeable, both as a result of the young person growing into adulthood as well as the impact of the cancer and its treatment on the young person’s life. In order to both understand and meet the changing care and support needs of young people, their needs must be systematically assessed and reassessed at key points. This includes changes in treatment, transitions including the transition to end of treatment, and life changes such as leaving education, starting work and living independently.

“I was disappointed in the lack of information once I finished treatment – I had no idea what was going to happen in terms of follow-ups or what to do if I became ill again due to infection.”

Young person with cancer

22 National Institute for Health and Clinical Excellence, (2005), Improving Outcomes in Children and Young People with Cancer

23 Department for Children, Schools and Families, (2010), Support for All: the Families and Relationships Green Paper

24 Department of Health, (2004), National Service Framework for Children Young People and Maternity Services

25 Department of Health, (2008), High Quality Care for All: NHS Next Stage Review Final Report

26 Department of Health, (2008), Our NHS, Our Future

27 Department of Health, (2007), Holistic Common Assessment of Supportive and Palliative Care Needs for Adults with Cancer

In order to both minimise the number of assessments a young person must undergo and maximise the timely success in accessing local services, assessment and care planning needs to follow a universally accepted structure. This could be using the adult or children's Common Assessment Framework²⁸ (depending on the individual – the children's Common Assessment Framework could be used if the young person is disabled), the Holistic Common Assessment of Supportive and Palliative Care Needs for Adults with Cancer²⁹, or the forthcoming Assessment Framework for Continuing Care³⁰.

Clear referral pathways from specialist teenager and young adult cancer services, teenager and young adult shared care services and adult cancer services into community-based services must be established. This ensures that young people are able to gain access to appropriate services in their local communities when they need them. Where a number of potential service providers exist the assessment and referral process should empower young people to make informed choices about who is most suited to meeting their individual needs.

A care plan should be developed that details clearly the individual responsibilities of each practitioner in caring for and supporting the young person. This is particularly important as numerous professionals from different agencies and geographical areas may be involved in caring for and supporting a young person with cancer and their family.

The assessment should be holistic, considering as a minimum all of the areas of need outlined in this report.

The key worker is responsible for ensuring assessment and care planning has been carried out, although the key worker is likely to refer the non-clinical assessment and care planning to a specialist oncology social worker.

28 www.everychildmatters.org.uk, www.dh.gov.uk

29 Department of Health, (2007), Holistic Common Assessment of Supportive and Palliative Care Needs for Adults with Cancer

30 www.dh.gov.uk

There should be an agreed system of record keeping that allows all current and previous care plans to be easily accessed by the key worker.

Care plans should be brief, clear and free from jargon.

National context: assessment and care planning

- The Improving Outcomes for Children and Young People with Cancer guidance³¹ notes the need to plan for continuity of care during treatment and follow up of the original disease, as well as for palliative care. The guidance also refers to the need for the key worker to 'ensure the provision of a written care/treatment plan and an initial needs assessment of the child or young person and family to inform the care plan'.
- The National Cancer Survivorship Initiative³² vision sets out that all cancer survivors should have a personalised assessment and care plan
- High Quality Care for All: NHS Next Stage Review³³ emphasises the importance of care planning around needs of patients to create packages of care that are personal to the patient. The Review refers to international best practice, which 'suggests that control by a patient is best achieved through the agreement of a personal care plan'.
- Our NHS, Our Future³⁴ notes the need for personalised care plans, with a named lead professional managing the delivery of the care plan.
- The Holistic Common Assessment of Supportive and Palliative Care Needs for

31 National Institute for Health and Clinical Excellence, (2005), Improving Outcomes in Children and Young People with Cancer

32 www.improvement.nhs.uk

33 Department of Health, (2008), High Quality Care for All: NHS Next Stage Review Final Report

34 Department of Health, (2008), Our NHS, Our Future



Adults with Cancer³⁵ identified the assessment of patients’ individual needs as a critical first step in ensuring that they receive the services they require. The report recommends that, at a national level, work be undertaken to inform the development of approaches and tools for use in routine practice by a range of health and social care professionals.

- The National Framework for Assessing Children and Young People’s Continuing Care³⁶ and forthcoming National Framework for Assessing Adult Continuing Care propose a standard framework to assess continuing care needs.

3.3 EVERY YOUNG PERSON SHOULD BE WELL INFORMED, EMPOWERED AND SUPPORTED TO MAKE CHOICES

Delivering information that is appropriate to the young person’s age and needs, and doing this at the right moment, is absolutely crucial.

Information is important throughout the care pathway, and particularly vital at key transition points such as on diagnosis, on discharge from hospital, and on transition to end of life care or to long-term survivorship.

Information on what to expect, how to manage the illness and its side effects, and what to do in an emergency is essential to ensuring clinical safety when a young person spends time at home. This can also reduce the sense of isolation and anxiety that young people and their families often feel when leaving the intensive environment of the hospital and returning home on their own for the first time.

Information should be delivered by practitioners experienced in understanding the needs of this age group, and skilled in communication methods appropriate to young people of this

age. Practitioners should employ a supportive and family centred approach, but should also enable the young person to establish their independence and to empower them to make informed and positive choices. These choices can include difficult decisions about their treatment and place of care.

As with all young people, young people with cancer must also make numerous other choices, for example in terms of education, employment and training, relationships, participation in risk taking behaviour, and moving out of home. Having cancer can impact significantly on these choices, and so this group of young people may need additional support during this time.

“It would have been useful to have information on what I could have done from home so that I could continue to develop my CV, rather than remaining unemployed.”

Young person with cancer

National Cancer Patient Information Programme

The National Cancer Action Team’s Information Prescriptions Programme³⁷ is driving the development of a new infrastructure for delivering information.

The programme will coordinate the development of a standardised national cancer information pathway for children and young people, which will include both clinical information and more general information on other aspects of life that are impacted by cancer.

The programme is also developing an electronic interface so that all NHS trusts will be able to gain access to the information pathways. All the information included in the pathway will be reviewed by both professionals and young people to ensure it meets the required standards.

It is anticipated that this programme will provide practitioners working with young people with cancer direct access to quality information that meets the young person’s wide ranging needs.

³⁵ Department of Health, (2007), *Holistic Common Assessment of Supportive and Palliative Care Needs for Adults with Cancer*

³⁶ Department of Health, (2008), *National Framework for Assessing Children and Young People’s Continuing Care (consultation)*

³⁷ www.cancer.nhs.uk

National Advanced Communication Skills Training

The National Cancer Action Team established the National Advanced Communication Skills Training Programme³⁸ in 2003.

In 2007 a children and young people's version of the training programme, aimed at senior health care professionals, was piloted. This focused on the common challenges practitioners face when working with this age group, for example breaking bad news, managing aggression, and communicating with adolescents. The pilot was successful and the programme is now being rolled out across the UK.

This programme is crucial to ensuring that senior health and social care professionals, who may often be the young person's key worker, have the required skills to develop relationships with those they are caring for, so that they can deliver effective support and help them to make informed and positive choices.

“The social worker at the hospital was fantastic and really understood our needs as individuals and as a family.”

Young person with cancer

Quality standards for information, advice and guidance

The improvement of general information provision for young people is being driven by the Department for Children, Schools and Families' Quality Standards for Young People's Information, Advice and Guidance³⁹. The standards are aimed at providers of information, advice and guidance, which includes local authorities, Connexions services, learning providers, and voluntary and community-service organisations.

Additionally, the introduction of the National Information Accreditation Programme will mean that major information providers of both health and social care will be information certified. The scheme aims to provide a way for service users

to know that the information they are using is reliable as well as raising the overall standard of health and social care information.

Patient held record

Patient held records have been used in a number of paediatric oncology principal treatment centres for many years as a way of ensuring that families have, as a minimum, a summary of all the information relating to their child's cancer in one place.

It is also widespread practice in paediatrics (following recommendations from the Bristol Heart Inquiry⁴⁰) for parents and carers to receive a copy of all clinic letters sent to GPs, although this does not appear to happen consistently in teenager and young adult services.

There should be a standardised national approach to the use of patient held records for the whole age group (0 to 24), which encompasses the recommendations made by the Improving Outcomes for Children and Young People with Cancer guidance, i.e. including details on contacts in the principle treatment centre, shared care centre and community teams; emergency and out of hours procedures; and diagnostic and treatment summaries.

³⁸ www.cancer.nhs.uk

³⁹ Department for Children, Schools and Families, (2007), Quality Standards for Young People's Information, Advice and Guidance

⁴⁰ www.bristol-inquiry.org.uk



National context: information, empowerment and choice

- High Quality Care for All: NHS Next Stage Review⁴¹ states that the NHS ‘must continue to empower patients with greater choice, better information, and more control and influence’ and enable patients to make ‘decisions about their own care, shaping and directing it with high quality information and support’.
- Youth Matters⁴², sets out proposals designed to improve outcomes for 13 to 19 year olds. One of the proposals is that young people should have ‘better information, advice and guidance about issues that matter to them, delivered in the way they want to receive it’.
- Aiming High for Young People⁴³ emphasises the importance of empowerment, stating that ‘when young people have the opportunity to influence services they are more likely to find them attractive and to access and benefit from them’.

⁴¹ Department of Health, (2008), High Quality Care for All: NHS Next Stage Review Final Report

⁴² Department for Education and Skills, (2005), Youth Matters

⁴³ Department for Children, Schools and Families, (2007), Aiming High for Young People

4. Local Services and Partners

4.1 SERVICES THAT CAN BE DELIVERED LOCALLY

A checklist of the community-based services and support that should be available for young people to access during their treatment is given below.

The need to carefully manage the transition to survivorship, or to end of life care, is common to all the areas of support outlined below. Assessing individual needs and planning care is crucial at these stages. For further guidance on how best to manage the transition to survivorship, please refer to the emerging work of the National Cancer Survivorship Initiative⁴⁴. For further guidance on managing the transition to end of life care please refer to the principles of care outlined in Better Care: Better Lives⁴⁵ and ACT's Transition Care Pathway⁴⁶.

Area of need	Community-based services and support that should be available for young people with cancer
Clinical care	<ul style="list-style-type: none"> • Discharge planning that closely involves the young person and the primary health care team • Named community nurses to deliver clinical care at home • GP surgeries proactively contacting the young person on discharge • Clear pathways to gain access to specialist support in an emergency and out of hours • Explanations of clinical terms and procedures • Training for the young person and their carer to carry out necessary clinical procedures • Provision of clinical equipment and medication • Delivery of clinical care at home e.g. IV chemotherapy, central line care, blood sampling • Symptom assessment and management

⁴⁴ www.improvement.nhs.uk

⁴⁵ Department of Health, (2008), Better Care Better Lives

⁴⁶ Association for Children's Palliative Care, (2007), The Transition Care Pathway: A Framework for the Development of Integrated Multi-Agency Care Pathways for Young People with Life-threatening and Life-limiting Conditions



Area of need	Community-based services and support that should be available for young people with cancer
<p>Education and training support</p>	<ul style="list-style-type: none"> • A named contact in the education institution • A clear set of policies for students with medical needs • Additional learning support to be provided for the young person • Help for the young person to keep staff and pupils informed e.g. in planning frequency and format of meetings and interactions • Physical access to the building • Provision of IT/communications equipment and other supports • For detail on the role of education institutions please refer to Pupils with Cancer: A guide for teachers⁴⁷
<p>Employment and work based training support</p>	<ul style="list-style-type: none"> • Advice on employment rights under the Disability Discrimination Act⁴⁸, and on statutory sick leave and sick pay rights • Advice on how to manage relationships with an employer including: <ul style="list-style-type: none"> • Likely impact of illness on ability to work • Negotiating attendance at appointments • Securing reasonable adjustments • Accessing employee support schemes • Keeping in regular contact to review arrangements • Managing the return to work • Advice on how to manage relationships with colleagues including: <ul style="list-style-type: none"> • What to say to colleagues • Keeping in regular contact through informal visits • Careers advice and tips for gaining employment including: <ul style="list-style-type: none"> • CV writing • Explaining absences and illnesses • Using life experiences positively • Work experience programmes • Coaching, mentoring and skills development programmes • Advice for existing and prospective employers on how to best accommodate employees who are disabled or diagnosed with a life threatening illness • Advice to seek counselling and to take financial advice before taking any major decisions such as giving up work

⁴⁷ Petersen Broyd, Pritchard-Jones, Edwards, (2008), Pupils with cancer: A guide for teachers

⁴⁸ www.direct.gov.uk/disability

Emotional and social support

- Advice on how to relate to friends and how to maintain existing social networks
- Help to arrange activities with friends
- Advice on the types of activities that are suitable to participate in
- Support in coping with and adjusting to permanent physical and cognitive changes
- Access to peer support groups
- Access to therapeutic support, counselling services, local adolescent mental health services, psychology and psychiatric services
- Advice on sources of spiritual support
- Access to self development and confidence building programmes
- Access to the Internet
- NB Participating in education, employment and training can have a very positive impact on a young person's emotions and ability to maintain social networks

Practical and financial support

- Interpretation and translation services
- Advice on and help with arranging suitable housing and re-housing on medical grounds with the local authority
- Help preparing the home for discharge
- Aids, adaptations and equipment, including at home, in educational institutions and in the workplace, and including major building alterations
- Wheelchair provision
- Advice on driving, vehicle adaptations, accessing Motability services, and adapted car purchase schemes
- Help around the home, for example housework, shopping, child care
- Advice on welfare rights and help with applying for benefits
- Help to obtain and manage Direct Payments⁴⁹
- Help to access funds, for example charitable grants and university hardship funds
- Free travel and parking
- Financial advice, for example how to get insurance, manage mortgage issues, negotiate payment holidays and deal with debt
- Budgeting and money management advice
- NB Being financially stable is also important to enable the young person to participate in education, training, and social activities

⁴⁹ Payments given to individuals to choose, organise and pay for the social care services they need, rather than using the services offered by their local authority.



4.2 LOCAL PARTNERS THAT CAN HELP TO SUPPORT YOUNG PEOPLE WITH CANCER

Primary health and mental health care:

- GP
- Practice nurse
- Community nurse
- Mental health professionals
- Occupational therapist
- Speech therapist
- Dietician
- Physiotherapist
- Pharmacist
- Hospice

Local authority:

- Social care services
- Youth services
- Education services
- Housing services
- Transport services
- Leisure services

Education:

- Schools, colleges, universities
- Welfare officers
- Personal tutors
- Careers advisors

Connexions

Jobcentre Plus

Voluntary sector providers e.g. Crossroads, Citizens Advice Bureau, Marie Curie Cancer Care, Macmillan Cancer Support

And, importantly, family, friends and spiritual guidance.

5. What Happens Next?

A great deal of action is already underway to improve services for young people with cancer, for example establishing teenager and young adult multi-disciplinary teams, principal treatment centres and shared care arrangements. However, there is still a long way to go to ensure that the planning and delivery of care for young people with cancer fully addresses all of the needs highlighted by young people.

There is a clear opportunity to make truly holistic care closer to home a priority through the **development of standards and measures for young people's cancer services**. The recommendations outlined above and throughout this report should be included in the development of standards and measures for young people's cancer services.

To drive forward the development of young people's cancer services and the associated measures and peer review processes, the **recommendations in this report should be tested and evaluated**. How to most effectively implement the recommendations and properly embed changes in local working practice should be disseminated across the country.

However, commissioners, providers and practitioners involved in providing services to young people with cancer can also take action now to implement the recommendations outlined in this report, for example by:

- Fully implementing the key worker role described in this report
- Using a universally accepted and holistic assessment and care planning framework
- Ensuring that all specialist health and social care practitioners working with young people with cancer have participated in the National Advanced Communication Skills Training Programme

- Implementing the National Cancer Patient Information Programme and ensuring that the information pathways include accredited information on all non-clinical needs as identified by young people and described in this report
- Ensuring that community-based practitioners are equipped with the skills and knowledge necessary to deliver excellent support young people with life-threatening illnesses

In summary, the More Than My Illness recommendations fully support current policy and associated service developments. However, the recommendations are also a call for these to be strengthened and enhanced so that the holistic needs of young people with cancer are properly and consistently met, and so that young people are better able to access high quality community-based services closer to home.

A FINAL THANK YOU

We would like to thank all of the young people and their parents, partners and carers who contributed so much to the writing of this report. Your views were insightful, balanced and absolutely crucial to developing the recommendations made in this report.

Thank you.



Appendix A: Steering Group Membership

Name	Title	Place of work
Professor Mayur Lakhani	GP (Chair)	Leicestershire
Janet Appleton	Senior Occupational Therapist	University College London Hospital
Bea Brunton	Parent and Coordinator	PASIC: Parents Association for Seriously Ill Children
Robert Carr	Consultant Haematologist	Guy's and St Thomas', London
Simon Davies	Chief Executive	Teenage Cancer Trust
Christine Davis	CLIC Sargent Social Worker	Great Western Hospital, Swindon
Dara de Burca	Director of Services	CLIC Sargent
Helen Easton	Parent	George Easton Memorial Trust
Professor Tim Eden	Honorary Professor of Teenage and Young Adult Cancer Medical Advisor	University of Manchester Christie Hospital NHS Trust and Teenage Cancer Trust
Jacqui Flynn	Parent and Representative	National Alliance of Childhood Cancer Parents Organisation
Faith Gibson	Senior Lecturer in Children's Cancer Nursing Research	UCL Institute of Child Health Great Ormond Street Hospital for Children NHS Trust
Louise Hooker	Project Manager, Children and Young People's Improving Outcomes Guidance	National Cancer Action Team
Louise Jones	Head of Marie Curie Palliative Care Research Unit	UCL
Lynn Leighton	Paediatric Oncology Outreach Nurse Specialist	Medway Hospital, Kent

Name	Title	Place of work
Dorothy MacKinlay	Consultant Clinical Psychologist	City Hospital, Nottingham
Katrina McNamara-Goodger	Head of Policy and Practice	ACT: The Association for Children's Palliative Care
Liz Morgan	Professional Advisor: Children & Young People	Department of Health
Sue Morgan, MBE	Consultant Nurse, Teenagers and Young Adults	St James's University Hospital, Leeds
Alisha Newman	User Participation Manager - Children & Young People	CLIC Sargent
Ursula Peuple	Acting Lead Rare Cancers and Programme Manager: Young People with Cancer London and South East Coast Specialised Commissioning Groups	London Specialised Commissioning Group
Vikky Riley	Consultant Nurse, Teenagers and Young Adults	University College London Hospital
Sam Smith	Consultant Nurse, Teenagers and Young Adults	Christie Hospital, Manchester
Louise Soanes	Consultant Nurse, Teenagers and Young Adults	Royal Marsden Hospital, Surrey
Evelyn Ward	Paediatric Oncology Dietician	St James's University Hospital, Leeds
Lizzie Whitbread	CLIC Sargent Youth Development Worker	Southampton General Hospital



Appendix B: Glossary

ADULT CANCER CENTRE

Centres that direct cancer treatment for adults aged 19 and above. Young people aged from 19 to 24 can choose to have their treatment directed by an adult cancer centre or by a teenager and young adult multi-disciplinary team based at a principal treatment centre.

COMMISSIONING

The processes local authorities, primary care trusts and commissioners of specialist services undertake to make sure that services funded by them meet the needs of the patient.

END OF LIFE CARE

‘End-of-life care is care that helps all those with advanced, progressive, incurable illness to live as well as possible until they die...It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support.’⁵⁰

HOLISTIC

Upholding that all aspects of people’s needs, psychological, physical and social, should be taken into account and seen as a whole.

LATE EFFECTS

Long-term health problems caused by cancer treatment that may not show up until months or years after treatment.

LOCAL LEAD PROFESSIONAL

The local lead professional, allocated by a primary care trust or local authority, coordinates service provision and acts as a single point of contact for a young person when a range of services are involved and an integrated response is required.

OUTCOMES

Outcomes are long-term life opportunities. Every Child Matters⁵¹ identifies the five outcomes that are most important to children and young people. Although they apply to young people aged up to 19, they are important for all young people:

- Be healthy
- Stay safe
- Enjoy and achieve
- Make a positive contribution
- Achieve economic well-being

MULTI-DISCIPLINARY TEAM (MDT)

The multi-disciplinary team is a team of professionals from a number of disciplines, organisations and institutions who work together to deliver care and support to individual young people and families. Specific teenager and young adult multi-disciplinary teams direct the care of 16 to 18 year olds, as well as some 19 to 24 year olds.

PALLIATIVE CARE

‘Palliative care is an active and total approach to care, embracing physical, emotional, social and spiritual elements. It focuses on enhancements of the quality of life and support for the whole family, and includes the management of distressing symptoms, provision of respite and care from diagnosis through death and bereavement’⁵².

PRIMARY HEALTH CARE, PRIMARY CARE TRUSTS

Primary health care includes services provided by doctors’ surgeries, community nursing teams, dental practices, opticians and pharmacies. Primary care trusts are providers of many of these services.

⁵⁰ Department of Health, (2008), Better Care Better Lives

⁵¹ www.everychildmatters.gov.uk

⁵² Department of Health, (2008), Better Care Better Lives

PRINCIPAL TREATMENT CENTRE (PTC)

All children and young people up to the age of 18 have their treatment directed by one of the principal treatment centres located across the UK. The PTC makes the definitive diagnosis, initiates treatment and directs the young person's cancer treatment. Under the new arrangements being implemented as a result of the Improving Outcomes for Children and Young People with Cancer guidance, all young people aged between 19 and 24 will also be notified to a teenager and young adult multi-disciplinary team based at a PTC. However, young people in this age group are then able to choose between having their care directed by the PTC or by an adult cancer centre.

REFERRAL PATHWAY

The processes by which a young person is referred between services to receive specific types of care and support.

SHARED CARE CENTRES

Shared care centres are local hospitals working in partnership with a principal treatment centre to provide some aspects of care closer to home. The type of care provided in a shared care centre depends on a number of factors such as the location of the hospital, the facilities and expertise available, the type of cancer being treated and the age of the young person. Shared care arrangements are not yet fully established for young people with cancer.

SPECIALIST NURSE

A specialist nurse, or clinical nurse specialist, delivers some aspects of clinical care to a defined group of patients, often across care settings. An example is a paediatric neuro-oncology clinical nurse specialist who is a specialist nurse that cares for children and young people with brain and central nervous system tumours.

SPECIALIST ONCOLOGY SOCIAL WORKER

A qualified social worker who specialises in supporting young people with cancer and their families.

SPECIALIST TEENAGER AND YOUNG ADULT CANCER SERVICES

Services that are specifically aimed at meeting the needs of young people aged from 16 to 24 and are accessed through teenager and young adult multi-disciplinary teams based at principal treatment centres.

SURVIVORSHIP

The experience of living with or beyond cancer. The National Cancer Survivorship Initiative⁵³ uses the definition of survivorship from 'day two' after diagnosis.

⁵³ www.improvement.nhs.uk



Appendix C: References

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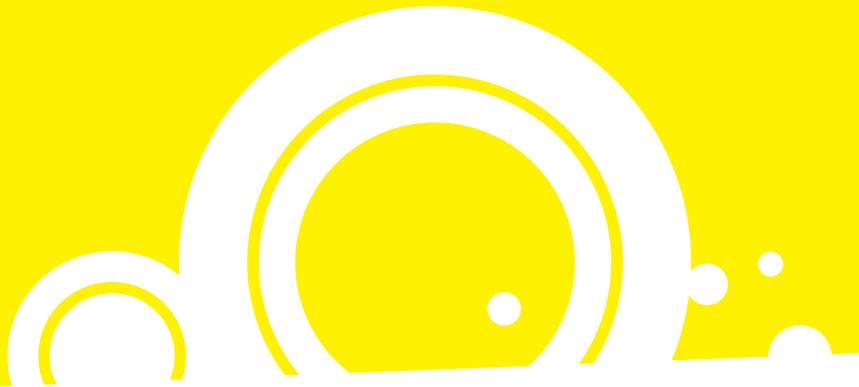
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Delivering quality care
for young people with cancer

CLIC Sargent
2010



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