CLIC Sargent

Caring for Children with Cancer

MORE THAN MY ILLNESS

Delivering quality care for children with cancer

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1. DOCUMENT INFORMATION

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Please refer to Appendix B for the steering group membership.

1.2 DATE

February, 2009

1.3 TARGET AUDIENCE

Commissioners and service providers from across the health, education and social care sectors.

1.4 BRIEF ABSTRACT

This report recommends a model of future service delivery that commissioners and service providers from across the health, education and social care sectors can use when developing community based services for children and young people with cancer, and their families.

The model encompasses holistic non-clinical care and support delivered both from the hospital and in the community (for example social care and education services) and clinical care delivered in the community.

1.5 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.

1.6 CONTACT DETAILS

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2. FOREWORD

Although survival rates are over 70%, cancer remains the single largest cause of death from disease in children in the UK. In many respects the care and support we offer to children with cancer is amongst the best in the world and we should be proud of this. However, there remains real inequity in the availability of the services we provide both in and close to children's own homes.

Children with cancer want to lead ordinary lives, and being at home, or closer to home, gives them the opportunity to do exactly this. For this to happen safely we must provide quality, community based clinical care that is seamlessly integrated with specialised hospital services. The practical elements of support a family needs in times of crisis, such as financial support, suitable housing and childcare for siblings, must also be anticipated and provided for.

But this is not all. Like all other children, children with cancer also have a right to achieve their potential, both during their treatment and in laying foundations for their future. This encompasses educational achievement, social achievement and emotional stability. In summary, children with cancer should have the right to achieve the five Every Child Matters outcomes; the cornerstone of key Government policies such as the Children's Plan.

There is already some support available to help children with cancer keep up with their education, and to develop socially and emotionally. However, this support is patchy, often uncoordinated and often dependent on where you live, or the individuals involved in your care. We must work towards providing the 'gold standard' of care for all, irrespective of age, geography or individual circumstances.

Knowing which services you are entitled to receive, and from which agency, can also be incredibly confusing. I believe that children with cancer, and their families, should not have to fight for services or navigate the care pathway alone — this should be the responsibility of an empowered key worker. However, this is only possible if professionals from all agencies are committed to genuinely collaborative ways of working.

I would like to thank all of the young people and their families who took part in the consultation carried out for this review — their contribution has been crucial in developing the recommendations detailed in this report. I hope this report goes some way to improving the future provision of community based services for children with cancer, and their families. Furthermore, I urge that the principles of care outlined in this report are used to further develop services offered to children with other complex health needs.

I would also like to thank all of the professionals — nurses, social workers, consultants, teachers and others — that gave up their time to inform and shape this report. On behalf of the working group, I would also like to thank and commend the project team from CLIC Sargent who provided excellent support throughout. The key now is for commissioners and providers to work together to implement the recommendations so that all children have the option of spending more time at home during their treatment and, most importantly, the opportunity of reaching their full potential.

Professor Mayur Lakhani CBE FRCP FRCGP DCH
GP and Independent Chair
'More Than My Illness'

THE STEERING GROUP WOULD LIKE TO EXPRESS ITS SINCERE THANKS TO GEOFF THAXTER, WHO DEDICATED HIMSELF TO IMPROVING SERVICES FOR CHILDREN WITH CANCER. GEOFF IS SADLY MISSED BY ALL THOSE WHO WORKED WITH HIM.

3. EXECUTIVE SUMMARY

In 2005, the National Institute for Health and Clinical Excellence (NICE) published guidance on how the NHS in England should deliver services to children[1] with cancer. The guidance, 'Improving Outcomes in Children and Young People with Cancer', aims to bring about significant and lasting changes in the care of children with cancer, improving both clinical outcomes and the experience of children and families.

The Department of Health and the NHS established an implementation group[2] to deliver the NICE guidance. In 2007, the implementation group agreed with CLIC Sargent's[3] suggestion that, to support the full implementation of the guidance, a review into the community based care and support needed by children with cancer and their families was required.

This review has been led by CLIC Sargent, supported by the implementation group, with input from an independent steering group of experts from across the country[4]. The implementation group requested that the review take into account not only the community based clinical care and support needed by children with cancer, but also the non-clinical needs of these children and their families. These include emotional, educational, social, practical and financial needs.

3.1 AIM OF THE REVIEW

The review aimed to develop a model of future service delivery, as information for commissioners and service providers from across the health, education and social care sectors to use when developing community based services. Once implemented, all children with cancer should have equal access to good quality, holistic community based care, therefore enabling them to achieve the five Every Child Matters outcomes.

1 For ease of reading this report will refer to both children and young people as 'children'.

2 Improving Outcomes Guidance for Children and Young People with Cancer Advisory Group

3 CLIC Sargent is the UK's leading children's cancer charity.

4 Details of the steering group's membership can be found in Appendix B.

The Every Child Matters outcomes are:

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

It is anticipated that children with other complex health needs may also benefit from the principles of care outlined in this report.

3.2 SCOPE

The model of care described in this report is aimed specifically at children up to 18 years of age, and their family. Between the ages of 16 and 18 needs can diverge greatly, highlighting the importance of managing this key transition point carefully.

For some young people aged between 16 and 18 most elements of this model will adequately meet their needs, for example those young people still in full time education and living at home. For some, elements of a slightly different model of care will be needed. This second model of care is under development and will address the needs of young people aged 16 to 24 years of age. Service providers should use their professional judgement based on an assessment of need to decide which model best meets the needs of young people aged 16 to 18.

The recommendations address all stages of the care pathway from diagnosis through to end of treatment, including transition towards long term survivorship and relevant aspects of cancer related end of life care. Long term care and support for both survivors and the bereaved are not addressed in this model. These areas of work are addressed by other reports and initiatives such as the National Cancer Survivorship Initiative[5], Better Care: Better

5 www.improvement.nhs.uk

Lives[6] and ACT's National Networks Project[7].

The report focuses on holistic non-clinical care and support delivered both from the hospital and in the community (for example social care and education services) and clinical care delivered in the community (but not in the hospital).

The model is applicable to all areas of the UK.

3.3 APPROACH

Children with cancer, their siblings and their families were asked what their greatest areas of need are when not in hospital. A range of other stakeholders, including professionals such as nurses, social workers and teachers, and representatives from charitable and Government organisations, were then asked what they thought was important when delivering care in the community, and what they considered the greatest areas of need to be[8]. Previous consultation and research was also analysed[9].

Through this process the most important community care and support needs were identified. The steering group of experts have translated these needs into a new model of care that describes how care can be planned and co-ordinated, and the types of resources and services that should be available to children and their families throughout the care pathway. The recommended model of care is described in this report.

3.4 SUMMARY OF RECOMMENDATIONS

"Being sick is the easy bit. It is the other things — school, confidence, getting back to having friends, your emotions — that are really difficult. And yet children and young people are being left to cope with all of this on their own." Manvir Randhawa, young cancer survivor, age 19

Children with cancer have a right to achieve their potential, both during their treatment and in laying foundations for their future. Fulfilling true potential should encompass educational achievement, social achievement and emotional stability, as well as leading a long and healthy life. To help children with cancer to achieve their full potential, a well coordinated, genuinely multi-agency approach should be taken to delivering services.

Children with cancer want to lead ordinary lives, and being at home, or closer to home, gives them the opportunity to do exactly this. To enable children with cancer to spend more time at home, good quality community based clinical care should be available to all children regardless of where they live.

A summary of the review's key recommendations are outlined below.

Key worker

Every child and their family should have a key worker responsible for the coordination of their care and support in the community.

- Although the key worker may not deliver care personally, they are responsible for ensuring the child and their family receive appropriate clinical and non-clinical care throughout the care pathway. To achieve this the key worker must work closely with professionals in various sectors and healthcare settings;
- The key worker will, in the majority of cases, be a specialist nurse experienced in oncology and attached to a principle treatment centre;
- The key worker must be supported in their role by professionals such as specialist oncology social workers, psychologists, community children's nurses, GPs and teachers; both in terms of adequate levels of staffing and in their commitment to multi-agency ways of working.

6 Department of Health, (2008), *Better Care Better Lives*

7 www.act.org.uk

8 Full details of the consultation results are available on request from CLIC Sargent.

9 For a full list of references please refer to Appendix D.

Assessment and care planning

Every child and their family should have their needs systematically assessed and reassessed using the Common Assessment Framework. Some aspects of care may require specialist assessment, for example for clinical needs, continuing care needs and special educational needs. An individual care plan should be developed as a result of assessment.

- Assessment should take place as a minimum on diagnosis (within seven days) and on discharge (a two part assessment taking place both pre and post discharge);
- Assessment should also take place when there are significant changes in the child's treatment and as the child reaches major transitions in their life;
- A Community Multi-disciplinary Team (CMDT) should be convened to assess a family's needs and to plan care prior to discharge from hospital;
- Children should be actively involved in the assessment and care planning process;
- The key worker is responsible for ensuring assessment and care planning is carried out, although the key worker may refer elements of the assessment to other professionals, for example non-clinical assessment to specialist oncology social workers.

Round the clock support

Every child and their family should be able to easily access support and advice at all times of day and night.

- As a minimum this service should be offered by the principle treatment centre;
- Appropriate case records should be available to those delivering support;
- Families should know who and how to call for support.

Information and empowerment

Every child and their family should be given information to enable them to understand and manage their illness, and to empower them to make informed choices about their care.

- Information should be delivered in an appropriate format and at the right time.

Tailored packages of care

For each child and their family, the assessment and care planning process should enable the development of comprehensive packages of care tailored around individual needs. As a minimum, the packages of care should take account of clinical, educational, social, emotional, practical and financial needs.

The services identified in the packages of care should be delivered by health, education and social care professionals working in partnership with each other and the family.

3.5 NEXT STEPS

Implementing the model of care

These recommendations are provided as information for commissioners and service providers from across the health, education and social care sectors to use when developing community based services. Full implementation will depend upon:

- Developing an approach to commissioning that facilitates genuine partnership working;
- Recruiting and training a sufficiently resourced and skilled workforce;
- Translating the standards described in this report into a meaningful set of measures that enable the ongoing evaluation of outcomes. The measures should be embedded within those currently being developed by the Improving Outcomes Guidance for Children and Young People with Cancer Advisory Group and the quality measures

to be developed as a result of 'High Quality Care for All: NHS Next Stage Review Final Report'[10].

The recommendations outlined in this report are based on extensive research and analysis. However, it is likely that they will need to be further refined during the initial implementation phase. The model of care should also be rigorously evaluated during this period to demonstrate whether changes in outcomes result for children and their families as a consequence of this model.

It would be useful if the first sites to implement the model operated different models of shared care[11], therefore demonstrating how to implement the recommendations in varying environments, and any differing impact on outcomes for children and their families.

Implementation should commence in 2009.

Recommendations for future work

Whilst undertaking this review, a number of key areas of work were identified that would significantly enhance the care and support offered to children and families. Falling outside of the original scope of this review, it is recommended that these areas of work are addressed in future initiatives:

- Development of a national standard for family held records, and evaluation of their content and usefulness;
- Development of a paediatric oncology formulary to assist GPs in delivering support to children in the community. This could cover, amongst other things, common chemotherapy drugs used for children, side effects and how to deal with them, nutritional support and mouth care;
- Provision of treatment summaries for children. This would include easily understood details of the treatment they have received, toxicities they encountered, likely long term and late effects, and information relevant to future lifestyle choices;
- Identification of the specific needs of children and families from black and minority ethnic backgrounds, and how to meet those needs[12].

How to meet the specific needs of young adults aged between 16 and 24 will be addressed in the second phase of this review. This work has already commenced and recommendations are due to be released in 2009.

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

11 For an explanation of shared care please refer to Appendix A

12 Appendix C outlines details of consultation with service users from black and minority ethnic backgrounds undertaken as part of this review.

4. INTRODUCTION

4.1 THE IMPACT OF A CANCER DIAGNOSIS

Cancer in children and young people is a relatively rare diagnosis, with approximately 1,700 children aged up to 15 years and 2,300 young people aged 16 to 24 years diagnosed each year in the United Kingdom[13]. It is estimated that approximately 400 young people are aged 16 to 18 (inclusive) at diagnosis[14]. Although the numbers of new cases each year is small and survival rates overall are over 70%[15], cancer remains the single largest cause of death from disease in children in the UK.

The diagnosis of cancer in childhood has a huge impact on a child, their family and their wider social circle in a number of ways. One of the reasons for this is the treatment process, which often involves complex treatment in specialist centres many miles from home and sometimes leading to being separated from friends and extended family for long periods of time. There is also the protracted uncertainty of the outcome of the disease. For most parents the initial diagnosis of cancer is associated with the prospect of their child's death, despite the many reassurances that are given.

Children with cancer and their families have diverse health, social, emotional, psychological, educational and employment needs and require a range of specialist and general services to meet these needs over a long period of time. From a health perspective, children require primary services (such as GPs and health visitors), secondary services (such as those provided by local district general hospitals) and tertiary services (delivered by principle treatment centres) throughout the period of their care.

In terms of education, children with cancer can experience significant disruption to their learning. For example, children with Acute Lymphoblastic Leukaemia (the most common type of cancer in the 0 to 15 age group) continue treatment for between two and three years and can miss some of their education through being in hospital and having to attend appointments for treatment over a protracted period of time.

It can be difficult for children with cancer to continue with social activities with their family and friends, particularly when time is spent away from home. This can lead to poorly developed interpersonal skills, feeling isolated and can be a cause of low self esteem.

There can be serious consequences for the rest of the child's family. Everyday family life is difficult to maintain when one parent has to take on the additional role of carer, sometimes many miles from home. In many cases one parent has to give up paid employment, compounding the financial impact of a cancer diagnosis. Siblings are, understandably, often overlooked during this time.

Children also require long term follow up and support to identify and treat long term adverse effects. Long term effects can impact on all areas of life including education, emotional wellbeing, social networks and financial stability.

4.2 THE CURRENT MODEL OF SERVICE DELIVERY FOR CHILDREN WITH CANCER

The focus for the planning and delivery of cancer treatment for children is based in a few very specialised principal treatment centres (PTCs), of which there are currently 21 in the UK (15 are in England). The development of expertise in all aspects of children's cancer care in a limited number of highly specialised centres has contributed enormously to the huge increase in survival rates over the past 40 years. It does, however, mean that some children are treated in hospitals hundreds of miles from home.

13 National Registry of Childhood Tumours

14 Estimated by J Birch (2008)

15 Survival rates for 13 to 24 year olds are 74% (Birch et al, British Journal of Cancer, 19th August 2008, *Survival from cancer in teenagers and young adults in England, 1979 to 2003*)

Many centres have developed patterns of working that facilitate some aspects of care being shared with a hospital more local to the child's home, known as 'shared care'[16]. Shared care can be delivered at different levels dependent on the facilities and expertise available at the local hospital. This arrangement can greatly reduce the disruption to family life, but can cause anxiety for families if communication between care settings is not well managed. Families may still have to travel considerable distances for routine tests and care if these cannot be provided at their local hospital.

All the specialist centres and some of the shared care hospitals have paediatric oncology outreach nurse specialists (POONS) who meet families around the time of diagnosis and help to provide expert clinical care in the community. These services provide continuity for children and families, but the type of service provided varies considerably across the country. Many of these posts have been funded by charities on a pump priming basis and others are part funded by charities indefinitely.

Community children's nursing teams working in partnership with POONS are able to offer a comprehensive range of care and support. Community children's nurses can carry out many routine tests and provide expert clinical care thereby reducing the number of hospital visits and time spent away from home and school. However, these teams are not yet in place in all areas of the country.

The provision and co-ordination of education for children with cancer is very variable. Children often have difficulty keeping up with schoolwork and teachers do not always understand the difficulties faced by children returning to school after treatment ends. Only one centre in the country[17] employs staff who are solely dedicated to ensuring that each child has an educational support plan and access to all available educational resources.

Hospital teachers exist in all PTCs to provide teaching for children up to the age of 16 who are in hospital for two weeks or more at a time during school terms. Many children with cancer are in hospital for repeated short periods of time so may fall outside the remit of what is provided as a statutory service.

Specialist oncology social workers based in PTCs, and in some shared care units, provide a crucial support service for families. They help parents and families cope with the emotional stresses and strains of caring for a child with cancer. They can also help families deal with the demands of daily life, including the care of siblings, work and financial commitments.

These social workers are either part funded, or, in the vast majority of cases, entirely funded by charities. Children with cancer rarely receive support from local authority social care services as children with other needs are often prioritised, for example children who are looked after, registered as disabled or the subject of a child protection order.

Service delivery for young people aged 16 to 18 has developed along similar lines to the paediatric model outlined above. Currently, specialist age specific services exist in some areas for teenagers and young adults, but are almost non-existent in other areas.

4.3 RECENT DEVELOPMENTS IN SERVICE DELIVERY

In 2005, the National Institute for Health and Clinical Excellence (NICE) published guidance on how the NHS in England should deliver services to children and young people with cancer. The guidance, 'Improving Outcomes in Children and Young People with Cancer', applies to children with all types of cancer, leukaemia and lymphoma, and covers the full age range (up to and including 24 years of age). The guidelines aim to bring about significant and lasting changes in the care of children with cancer, improving both clinical outcomes and the experience of children and families.

16 The development of agreed levels of shared care is supported by NICE, (2005), *Improving Outcomes for Children and Young People with Cancer.*

17 St James' Hospital, Leeds

The Department of Health and NHS have established an implementation group[18] to deliver the NICE guidance. The group has developed quality measures for all children's cancer services to enable inclusion in the NHS Peer Review Programme. In adult cancers, the peer review process has been a useful driver for improving service quality.

Agreeing the location of the Teenage and Young Adult PTCs is underway, and discussions continue regarding the implementation of shared care for this age group.

In 2007 the implementation group agreed with CLIC Sargent's suggestion that, to support the full implementation of the NICE guidance, a review into the community based care and support needed by children with cancer and their families was required. This report summarises the outcome of this review.

18 Improving Outcomes Guidance for Children and Young People with Cancer Advisory Group

5. GUIDING PRINCIPLES

Several principles have guided the design of this model of care and should continue to guide its future implementation. They are important in each element of the model. The principles align closely to key themes identified in other Government policy and strategies.

5.1 EQUITABLE ACCESS TO QUALITY SERVICES

This model of care should be adopted in all areas of the UK. Good quality, holistic care delivered in the community should be available to all, irrespective of age, geography or individual circumstances.

5.2 SAFE AND EFFECTIVE CARE AS CLOSE TO HOME AS POSSIBLE

Care and support should be delivered as close to the child's home as possible. Delivering care at or near to a child's home must, however, always be clinically safe and effective. This overriding need is acknowledged by NICE in the 'Improving Outcomes for Children and Young People with Cancer' guidance[19].

If care is to be sustainable and equitable, the drive for providing care closer to home may at times need to be flexible, to allow for differences in the availability and distribution of resources.

NATIONAL CONTEXT: DELIVERING CARE AS CLOSE TO HOME AS POSSIBLE

- High Quality Care for All: NHS Next Stage Review[20] places 'providing convenient care closer to home' and 'ensuring care is effective and safe' at the core of the Review.
- Our Health, Our Care, Our Say recommends that 'more care should be undertaken outside hospitals and in the home'.
- Children's Health, Our Future advises that children should 'be assessed and treated in an appropriate place and then returned home — with support — as soon as possible.'
- The Independent Review of Palliative Care Services for Children and Young People in England recommends that commissioners should increase their focus on community services to help manage and support children with palliative care needs to stay at home.
- Better Care: Better Lives recommends there should be 'choice in preferred place of care and expansion of community services'.
- It is anticipated that the forthcoming Child Health Strategy will emphasise the need for increased provision of community children's nursing.

19 NICE, (2005), *Improving Outcomes for Children and Young People with Cancer*

20 Full references for sources referred to in the 'National Context' boxes can be found in Appendix D

5.3 AGE APPROPRIATE CARE

When planning and delivering services, the needs of different age groups should be carefully considered. Services should reflect both the child's developmental and chronological age. This is true for all services including health, education and social care.

NATIONAL CONTEXT:
DELIVERING AGE APPROPRIATE CARE

- The NICE 'Improving Outcomes for Children and Young People with Cancer' guidance is clear that 'care should be appropriate to the child's or young person's age and type of cancer'.
- The Teenage Cancer Trust has funded project manager posts in most specialist commissioning groups to further assist the implementation of age appropriate care for young people.
- The Cancer Reform Strategy stresses the importance of providing care in an age appropriate setting.
- CLIC Sargent funds young people's social workers working on adult wards.

5.4 INTEGRATED, WHOLE SYSTEMS APPROACH

The model of care outlined in these recommendations is a holistic model that relies on a truly collaborative approach amongst professionals. To achieve these recommendations professionals from PTCs and local health services must work closely alongside professionals from the education and social care sectors.

Where possible the services outlined in this model should be commissioned on a whole pathway basis. This includes both community based health services and services delivered from hospital settings. Locally based education and social care services should be commissioned jointly with health services.

NATIONAL CONTEXT:
INTEGRATED APPROACH TO SERVICE DELIVERY

- Every Child Matters sets out a model for change with integration at every level. It also emphasises how services for children and young people need to be co-ordinated and built around their needs.
- High Quality Care for All: NHS Next Stage Review states that 'for the children's pathway….services need to be more effectively designed around the needs of children and families, delivered not just in health settings but also in schools and children's centres'. The review also advises that accountability should be for the whole patient pathway. 'Partnership working between the NHS, local authorities and social care' is strongly advocated.
- Better Care: Better Lives states children and families 'need more and better services provided on a multidisciplinary and multi-agency basis'.
- World Class Commissioning states that all Primary Care Trusts must work with others to optimise effective care.

Role of Children's Trusts[21]

Children's trusts are local partnerships which bring together the organisations responsible for services for children, young people and families in a shared commitment to improving children's lives. The organisations involved can include local authorities, strategic health authorities, primary care trusts, schools, colleges and third sector organisations.

Their role includes:

- Identifying children at risk of failure, intervening early to make sure children can thrive;

21 Content taken from Department for Children, Schools and Families, (2008), *What is a Children's Trust?*

- Narrowing the gap — especially in educational attainment — between vulnerable children and others;
- Reducing child poverty.

Children's trusts do this by:

- Always acting to put children's needs before organisational structures;
- Promoting joint working between all professionals working with children;
- Ensuring effective commissioning of services for children by using resources flexibly and creatively, for instance by aligning or pooling budgets;
- Overcoming unnecessary barriers to sharing and using information;
- Making sure that those working in front line services are receiving the support they need to help children and families;
- Listening to the views of children and young people.

The Department for Children, Schools and Families has stated that, by 2010, Children's Trusts should have in place consistent high quality arrangements to identify all children who need additional help and to intervene early to support them.

5.5 CHILDREN AND YOUNG PEOPLE INVOLVED IN SERVICE DESIGN AND DELIVERY

Children should be fully involved in the assessment, planning and delivery of their care as soon as it is felt they are old enough to understand what is being discussed. This is particularly important where treatment is over a long period of time and where adherence with oral medication can contribute significantly to the long term success of treatment.

After cancer treatment children need to make health and lifestyle choices. If children have experience of health related decision making, they are more likely to make healthy lifestyle choices.

Parents are often asked to speak on behalf of their children but it is important to involve children directly, as the adult's interpretation of a child's needs may not always be the same as the child's interpretation.

"Involving the child medicine user, not just the parent or carer, is a very important part of achieving the right decision about prescribing or other treatment options for that child." Health professionals should "talk directly to children and young people, using terminology they can understand, and ask them what they want to know about their medicines and give them information and advice."[22]

NATIONAL CONTEXT:
INVOLVING CHILDREN AND YOUNG PEOPLE

- Children's Trusts emphasise the need to listen 'to the views of children and young people — as well as their parents and carers — about what services they need and what are available, and involving them (and their parents and carers) in delivering them'.
- The National Service Framework for Children, Young People and Maternity Services recommends that children should be enabled to take responsibility for their own health, social and emotional development.
- The Children's Plan advises that 'services need to be shaped by and responsive to children, young people and families, not designed around professional boundaries'.
- Every Disabled Child Matters believes 'disabled children and their families should shape the way that services are planned, commissioned and delivered'.

22 Dr Sheila Shribman, National Clinical Director for Children, Department of Health (5th November, 2007)

5.6 CHILDREN AND YOUNG PEOPLE ARE SURVIVORS FROM DAY TWO

Children should be regarded as ‘survivors’ from day two, the day after diagnosis. This early acknowledgement of survivorship status highlights the need for early individual assessment of both health and, importantly, non health needs. Services that minimise the impact of the challenges faced once treatment ends can then be more easily and rapidly accessed. The key challenges identified by survivors of childhood cancer are around education, employment and issues such as isolation[23].

In order for children and their families to be empowered to effectively manage their health after cancer treatment ends, it is essential that they are provided with comprehensive, understandable summaries of all the treatment they have received. It is important that the summary contains details of major toxicities experienced during treatment, as well as potential long term or late effects that may be encountered. Also required is information to help the child make healthy lifestyle choices in the future.

It is recommended that this should be taken forward by the National Cancer Survivorship Initiative[24].

The definition of being a survivor from day two, the day after diagnosis, was established by cancer survivors themselves[25]. This definition has been embraced by the National Cancer Survivorship Initiative.

23 These challenges were identified at the ‘Talking Cancer Day’ and the Survivors Taskforce’s ‘National Survivors Conference’.

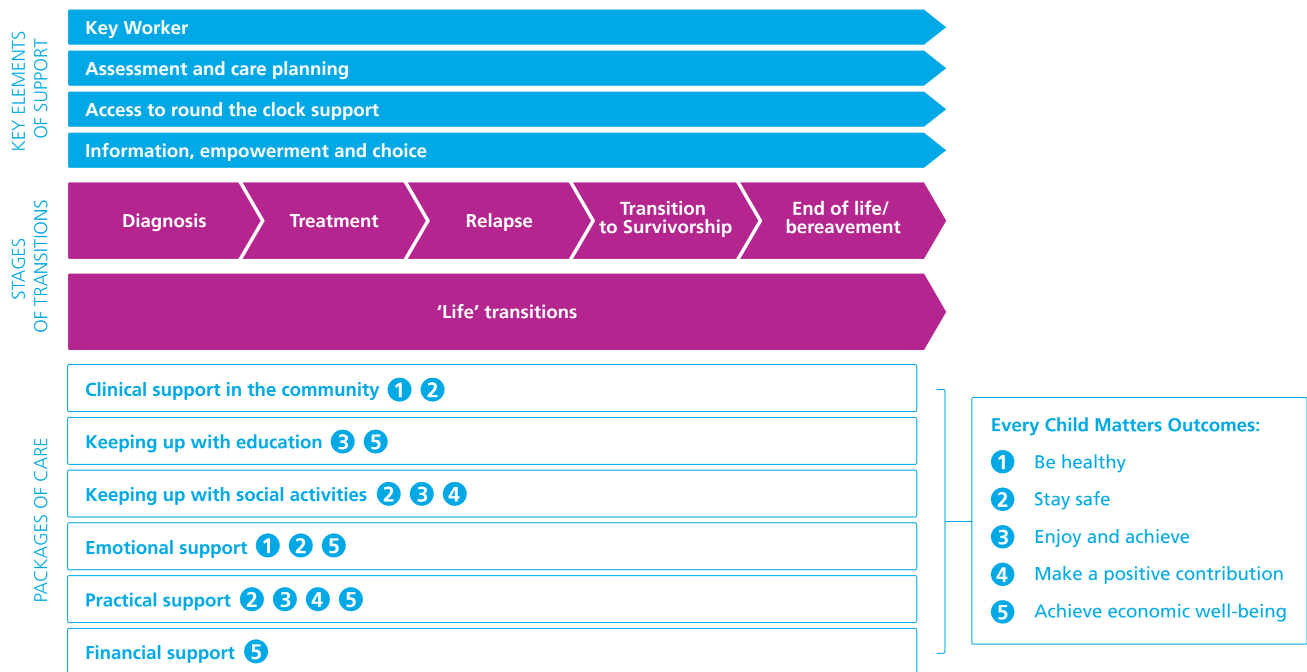
24 National Cancer Survivorship Initiative: www.improvement.nhs.uk/cancer/survivorship.html

25 National Cancer Survivorship Initiative, March 2008

6. AN OVERVIEW OF THE RECOMMENDED MODEL OF CARE

The diagram below gives an overview of the model of care recommended in this report.

Figure 1: Overview of the model of care



6.1 KEY ELEMENTS OF SUPPORT

A child's and family's needs are individual and will change significantly during cancer treatment. To meet these individual and changing needs, commissioners and service providers should ensure that each family has access to four key elements of support. These should be provided both in the hospital and the community, and throughout the care pathway. The elements are:

- A key worker;
- Systematic assessment and care planning;
- Round the clock support;
- Information, empowerment and choice.

6.2 PACKAGES OF CARE

A family's needs should be systematically assessed at key points along the care pathway. Based on this assessment a number of support services may be required by the family. The types of support services that should be available to families, on the basis of need, are outlined in a series of 'care packages'. These services may be delivered by the key worker or by other professionals such as teachers, GPs, community children's nurses and social workers.

The care packages reflect the six most important areas of need identified by children with cancer and their families. The areas of need, which reflect the five Every Child Matters outcomes, are shown below.

Areas of need	Every Child Matters Outcomes
• Clinical support in the community	• Be healthy, stay safe
• Keeping up with education	• Enjoy and achieve, achieve economic well-being
• Keeping up with social activities	• Stay safe, enjoy and achieve, make a positive contribution
• Emotional support	• Be healthy, stay safe, achieve economic well-being
• Practical support	• Stay safe, enjoy and achieve, make a positive contribution, achieve economic well-being
• Financial support	• Achieve economic well-being

7. KEY ELEMENTS OF SUPPORT

7.1 KEY WORKER

Every child and their family should have a key worker responsible for the coordination of their care and support.

Why is this important?

A child diagnosed with cancer, and their family, have wide ranging needs including clinical, educational, emotional, financial and practical needs. As a result, numerous professionals from a variety of agencies can be involved in delivering care and support. Where the family is cared for in a PTC that is far away from home, professionals from different geographical areas may also be involved.

Understanding, accessing and coordinating this support can be an overwhelming experience for families. The system can often appear confusing and fragmented. This can be particularly distressing at key transition points such as on discharge from the hospital, and at these times parents can feel very isolated and unsupported.

NATIONAL CONTEXT: KEY WORKER

- The NICE 'Improving Outcomes for Children and Young People with Cancer' guidance recommends that each child or young person with cancer should have a key worker.
- Aiming High for Disabled Children states that a key worker is crucial in improving the overall quality of life of families with disabled children, reducing parental stress and enabling families to make better use of other services.
- The National Service Framework for Children, Young People and Maternity Services (Standard 8) notes that studies of key workers 'consistently report positive effects on relationships with services, fewer unmet needs and greater family well-being'.
- ACT: The Transition Care Pathway states that 'apprehension about transition can be greatly reduced when there is a clearly identified key worker designate for young people to identify with and to take forward the co-ordinated planning of care within adult services'.
- Every Child Matters recommends that 'children known to more than one specialist agency should have a single named professional to take the lead on their case and be responsible for ensuring a coherent package of services to meet the individual child's needs'.
- Every Disabled Child Matters calls for every family with a disabled child to be entitled to a key worker.
- High Quality Care for All: NHS Next Stage Review identifies the need for a lead professional in developing personalised care plans.
- The Children's Plan proposes to pilot a key worker system to 'bring services together around the needs of a family'.
- Our NHS, Our Future outlines how a named professional should provide a point from which the NHS and its partners can organise services around the needs of individuals.
- Better Care: Better Lives states that every child should have 'an identified key worker/lead professional with responsibility and authority for negotiating and coordinating packages of care'.
- Supportive and Palliative Care Services for Adults with Cancer 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'.

Role of the key worker in supporting children with cancer

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

The care and support should be family-centred, not only child-centred. The key worker should strive for an open and supportive relationship with the child and their family, and this should be developed through regular and proactive contact.

A role description for the key worker is outlined below. This role description augments that set out in the NICE ‘Improving Outcomes for Children and Young People with Cancer’ guidance[26].

The key worker should:[27]

Assessment and care planning	• Ensure the child and family's needs, both clinical and non clinical, are assessed (please refer to section 7.2 for further detail) • Ensure a care plan is maintained (please refer to section 7.2 for further detail)
Co-ordinating service delivery	• Be a named individual who, where required, acts as a single point of contact for multiple services • Liaise with agencies and professionals, at both a practice and strategic level, in all sectors and healthcare settings as well as across geographical boundaries • Enable a shared understanding of goals and approaches amongst those closely involved in the child and family's care • Ensure information is shared across agencies and amongst practitioners • Convene a Community Multi-disciplinary Team (CMDT) meeting (please refer to section 7.3 for further detail)
Enabling the child and family	• Coordinate the provision of information and ensure that it is timely, tailored to the age of the child or young person and the needs of the family, and understood’[27] • Ensure families know about and can access the services to which they are entitled • Act as an advocate and help the family to develop their self-advocacy skills • Empower children and families, where possible enabling them to increasingly take on coordination of the child's own care plan

26 NICE, (2005), *Improving Outcomes for Children and Young People with Cancer*
27 NICE, (2005), *Improving Outcomes for Children and Young People with Cancer*

Providing specialist cancer support	• 'Ensure that the child, young person and family as well as local primary care professionals acquire new skills as required, for example the care and management of nasogastric tubes or gastrostomies, care of central lines.'[28] • Ensure understanding of cancer treatment and side effects • Advise the child and family as well as local primary care professionals on pain and symptom management • Support local agencies and professionals more generally in knowing what to expect from a cancer diagnosis and how to manage the consequences
Coordinating transition to adult services	• Establish links with a counterpart in the receiving adult service • Meet with the new adult specialist • Conduct joint transition planning between the child and adult services key worker • Gradually 'hand the baton' to the new adult specialist/key worker • For further information refer to the guidelines set out in Better Care: Better Lives[29] and ACT: The Transition Care Pathway[30]
Delivering palliative and terminal care	• '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 required.'[31] • Provide specialist expertise and advice for symptom management and end of life care • 'The key worker may provide direct clinical care and expertise at this time if appropriate.'[32 33] • At the right time, co-ordinate the communication of care plans and end-of-life decisions to the child and family and other care professionals involved in the care of the child • Maintain ongoing contact with the child and family • Monitor changing needs • For further information refer to the guidelines set out in Better Care: Better Lives[34]

28 NICE, (2005), *Improving Outcomes for Children and Young People with Cancer*

29 Department of Health, (2008), *Better Care Better Lives*

30 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*

31 NICE, (2005), *Improving Outcomes for Children and Young People with Cancer*

32 NICE, (2005), *Improving Outcomes for Children and Young People with Cancer*

33 This is because symptom management may require more hands on expert care than some community children's nurses may be confident to deliver. Also, the intensity of care that is needed may require more resources than are available in community children's nurse teams.

34 Department of Health, (2008), *Better Care Better Lives*

Who is the key worker?

The key worker is, in the majority of cases, a specialist children's nurse experienced in oncology and able to carry out the key worker role described above.

Where possible the key worker should be the same person throughout the care pathway. Where needs change significantly, the key worker can change if needs are better met as a consequence.

Local generic key workers or staff from other disciplines may, occasionally, become the key worker where this is agreed to be the most appropriate way to meet the child and family's needs. In such cases it is crucial that there is a clear, written agreement as to who is responsible for which of the child and family's needs.

At transition into long term follow up, or following bereavement, the continuing need for a key worker should be reassessed. It is unlikely that, in these cases, the specialist children's oncology nurse is the most appropriate care professional to meet these continuing needs.

The assessment and co-ordination of non-clinical care should be referred to a specialist oncology social worker, although final responsibility for ensuring the child and family receive appropriate non-clinical care must remain with the key worker.

Where treatment is primarily delivered by the PTC, the key worker should be based at the PTC.

Where a child receives the majority of their care within a designated shared care centre, and a specialist nurse is based at the shared care centre, the specialist nurse at the shared care centre may take on the role of key worker (as defined in this model). This must be agreed by the family and made clear in a formal agreement made between the PTC and shared care centre.

Key workers should not work alone but as part of a team of key workers. This allows continuity of care and support to children, families and other professionals during times of planned and unplanned absence.

Accountability

Although the key worker may not deliver clinical and non-clinical care personally, accountability for ensuring the child and family receive appropriate care and support rests with the key worker. The key worker is accountable to both the family they are caring for and their employer.

Responsibility for ensuring the child and their family receive appropriate care cannot be shared between professionals but must always remain with one key worker.

To fulfil their role description the key worker must be empowered, able to access resources and have credibility in the eyes of all the agencies involved. In cases where the key worker has concerns regarding the level of care delivered by other agencies and professionals, the key worker should in the first instance raise the concerns with the professional in question. If the concerns are not resolved the key worker should then escalate these to the PTC multi-disciplinary team (MDT) and/or within the line management structure of the professionals in question[35].

The key worker's relationship with community lead professionals

Some children may be assigned a local lead professional or key worker by their primary care trust or local authority. If the majority of the child's care and support is delivered in the community, the local lead professional may carry out most of the elements of the key worker role described above.

However, the specialist nurse key worker must retain ultimate responsibility for ensuring the child and family receive appropriate cancer related care and support. This will mean working closely with the local lead professional, and the responsibilities should be formally agreed.

35 These processes will be refined further as the model of care is implemented.

Resourcing the key worker role

A guideline level of resourcing for the **key worker** is given in the ratio below:

> Key worker to family: 1:20 to 1:40 new cases per year[36]

The key worker ratio assumes that:

- The key worker is carrying out the role described above and does not have additional responsibilities, such as routinely delivering 'hands on' clinical care;
- This ratio is underpinned by adequate numbers of supporting roles. Supporting roles include specialist oncology social workers, community children's nurses and administration support.

A guideline level of resourcing for the **specialist oncology social worker** is given in the ratio below:

> Specialist oncology social worker[37] to family: 1:40 new cases per year[38]

The Royal College of Nursing recommends a ratio for the number of **community children's nurses** needed for all children. It is suggested that 20 full time equivalent community children's nurses are needed to provide round the clock nursing support to a total population of 50,000 children.

The guideline ratios outlined above may vary in different areas of the UK due to local variables, for example the size of the geographical area covered or the density of population. The ratios are based upon a standard mix of cancer types and may need alteration where particularly complex issues are prevalent (for example in centres treating more neuro-oncology cases, or in centres specialising in bone tumours). The ratios may also vary during the transitional implementation period, for example where community children's nursing teams are not yet available to routinely provide 'hands on' clinical care in the community.

36 Ratio proposed by the review's steering group, to be tested once implementation has commenced.

37 Refers to qualified social workers only.

38 Approximate ratio used by CLIC Sargent social work services.

The ratios do not include management structures.

The ratios, including the level of administration support required, will be tested and refined as the model is implemented. Throughout implementation, these ratios will be rigorously evaluated.

Current gaps in resourcing

Key worker: It is estimated that approximately 20 to 50 more posts are required to meet the key worker ratio recommended above.

This calculation assumes that:

- There are 1,700 children aged up to 15 and approximately 400 young people aged between 16 and 18 (inclusive) diagnosed with cancer each year;
- Paediatric oncology outreach nurse specialists/clinical nurse specialists perform the key worker role;
- There are currently approximately 56 of these posts in PTCs throughout the UK working predominantly with the paediatric age range;
- Approximately ten of the above posts are working predominantly with 16 to 24 year olds only[39];
- There is currently an additional minimum of 21 posts based in shared care hospitals[40].

Specialist oncology social worker: It is estimated that approximately 25 more posts are required to meet the ratio recommended above.

This calculation assumes that:

- There are 1,700 children aged up to 15 and approximately 400 young people aged between 16 and 18 (inclusive) diagnosed with cancer each year;

39 Not all of these posts are whole time equivalents, not all work exclusively with children with cancer and some currently work with young people outside of the age range covered by this model of care.

40 This number is difficult to accurately state as many shared care hospitals employ staff members in roles similar to clinical nurse specialist roles but involving the delivery of 'hands on' care to inpatients, outpatients and patients in the community.

- There are currently 55 specialist social workers for the paediatric age range and 19 for young people aged 16 to 24.

Community children's nurse: Work is currently being carried out by the Department of Health and others to identify the number of additional community children's nurses needed for all children. Current indications are that approximately 60% of the country is served by community children's nursing teams, although not all of these teams offer a full service to all children. Additionally, not all teams offer an out of hours service, which is essential for end of life care.

CASE STUDY: KEY WORKER

Klara is the single mother of a fifteen year old daughter, Lucy, diagnosed with Acute Lymphoblastic Leukaemia in October 2006. Lucy was initially in hospital for two and a half weeks and then visited hospital for treatment as a day patient up to four times a week in the first year.

"Now I can speak to the new leukaemia nurse specialist at the hospital who came into post six months after Lucy's diagnosis. The nurse is a contact point and patient advocate who has the time to talk things through. He acts as an anchor point to the family, helping us with advice, smoothing our way in the hospital process, and explaining the complexities of treatment and how to manage the side effects of drugs. He's available on the end of a mobile phone which is brilliant support when you need it and you're on your own at home.

I can talk to him about symptoms and he will let me know what action I need to take — whether that's a doctor's review, different drugs or immediate admission to hospital. It takes so much of the strain away when you're coping at home. He also acts on suggestions to change hospital systems if they aren't working. He improved the protocol sheets.

It would have been better if he had been in post right at the start. In the beginning, I had no experience of the medical world, how to communicate, what questions to ask and how to make sense of things. I was latching on to people I could communicate with, like the registrar, but this was very confusing because she was very busy, and I didn't even realise that this is a training post so when she left to continue training I felt devastated. I didn't feel like there was any continuity. If the nurse specialist had been there this would have been easier."

7.2 ASSESSMENT AND CARE PLANNING: USING A STANDARD FRAMEWORK

Every child and their family should have their needs systematically assessed and reassessed using the Common Assessment Framework. Some aspects of care may require specialist assessment, for example for clinical needs, continuing care needs and special educational needs. An individual care plan should be developed as a result of assessment.

Why is this important?

A family's needs are often wide ranging, highly individual and likely to change during treatment. In order to understand the changing care and support services required by a child and their family, their needs must be systematically assessed and reassessed. A care plan can then be developed that details clearly the individual responsibilities of each professional in caring for the family. This is particularly important as numerous professionals from different agencies and geographical areas are often involved in caring for a child with cancer and their family.

NATIONAL CONTEXT:
ASSESSMENT AND CARE PLANNING

- Every Child Matters initiated the development of the Common Assessment Framework so that care and support is based on a systematic assessment of all areas of the child's well being and development.
- The NICE 'Improving Outcomes for Children and Young People with Cancer' guidance 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'.
- High Quality Care for All: NHS Next Stage Review 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 Future notes the general 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 Adults with Cancer 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 Care proposes a standard framework to assess continuing care needs.

Recommendations

- ➜ The individual needs of every child with cancer, and their family, should be systematically assessed using the Common Assessment Framework and a care plan developed to meet their needs. In addition, more specialised assessments may also be required;
- ➜ The assessment of need should be holistic, considering as a minimum all of the areas outlined in this report, including the need for round the clock support (please refer to section 7.4), information (please refer to section 7.5) and the services identified in the care packages (please refer to section 8);
- ➜ Families should be able to be fully involved in the assessment of their needs and development of their care plan. Children should be involved in discussions about medication and other treatment as soon as it is felt they are old enough to understand;
- ➜ The key worker is responsible for ensuring assessment and care planning has been carried out, although the key worker may refer the non-clinical assessment and care planning to a specialist oncology social worker;
- ➜ Assessment should take place as a minimum on diagnosis (within seven days) and on discharge (a two part assessment taking place both pre and post discharge);
- ➜ Assessment should also take place when there are significant changes in the child's treatment and as the child reaches major transitions in their life;
- ➜ 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;
- ➜ For children who are identified as having continuing care needs, the National Framework for Assessing Children and Young People's Continuing Care should be used.

What is the Common Assessment Framework?

'The Common Assessment Framework (CAF) is a shared assessment tool for use across all children's services and all local areas in England. It aims to help early identification of need and promote co-ordinated service provision.

The CAF is a key part of delivering frontline services that are integrated and focused around the needs of children and young people. The CAF is a standardised approach to conducting an assessment of a child's additional needs and deciding how those needs should be met.

The CAF is aimed at children and young people with 'additional needs'. This is a broad term used to describe all those children at risk of poor outcomes as defined by Every Child Matters[41]'

Using the CAF

Children with cancer should be considered as having 'additional needs'. Therefore, as a minimum, professionals should use the CAF Pre-assessment Checklist to carry out and record assessment of need.

In some cases the needs of the child and family will require that more detailed assessment is carried out in some or all areas and a care plan developed accordingly. An example of a more detailed assessment framework is the Special Educational Needs assessment or the National Framework for Assessing Children and Young People's Continuing Care.

The CAF Pre-assessment Checklist should be used to reassess needs at key points in the care pathway for all children.

All professionals involved in assessing the needs of children should be trained in using the CAF.

- Please refer to the guidelines in CAF: Practitioners Guide[42] for further instruction on how to use the framework.

Clinical needs

In addition to using the CAF Pre-assessment Checklist, detailed assessments of every child's clinical needs are required.

Involving children

Children often have little involvement in their consultations[43]. Involvement can be limited to purely social interaction and is often unlikely to involve shared decision making. Involving children in their consultation can improve health outcomes and be empowering for the family. This is considered good practice by the General Medical Council[44].

ADVICE FOR PRACTITIONERS WHEN CONSULTING WITH CHILDREN[45]

- A triangular seating arrangement promotes triadic talk;
- A child obscured by an adult inhibits participation;
- Allow the child or the adult carer to say why they have come;
- The child is not likely to speak unless invited to by one of the adults;
- To invite the child to speak use the child's name, look at the child, ensure the parent/adult can see that the doctor/nurse is looking at the child, if the adult answers for the child address a subsequent question to the child while looking at the child;

41 Department for Children, Schools and Families, (2007), *Common Assessment Framework: Managers' Guide*

42 Department for Children, Schools and Families, (2007), *Common Assessment Framework: Practitioners' Guide*

43 Cahill P., *Top tips in 2 minutes*, Br J Gen Pract 2008; 58: 520–521

44 General Medical Council, (October 2007), *0–18 years: guidance for all doctors.*

45 Extract from Cahill P., *Top tips in 2 minutes*, Br J Gen Pract 2008; 58: 520–521 (reproduced with permission)

- Give the child time to answer;
- Listen to the child.

Who is responsible for carrying out the assessment and developing the care plan?

The key worker is responsible for ensuring all needs are adequately assessed and appropriate care plans are developed.

Aspects of this process should be referred to other professionals, for example non-clinical assessment to specialist oncology social workers and education assessment to teachers. Other professionals may be both better skilled to carry out these assessments and able to access additional resources not directly available to the key worker.

The key worker should formally review all assessments and care plans to ensure they are complete and that approaches to joint working and individual accountabilities are clear for each professional involved.

Role of the Specialist Social Worker

The specialist oncology social worker has an important role to play in assessing the family's non-clinical needs, developing a care plan and delivering against this plan. The responsibilities of the social worker include:

- Carrying out baseline assessment and reassessment of non clinical needs
- Being an active member of the community multi-disciplinary team (please refer to section 7.3)
- Providing access to cancer related support groups
- Offering counselling and befriending
- Helping to access financial support, for example benefits and grants
- Helping to access education support, for example liaison with schools
- Helping to maintain employment, for example advising on employment rights, writing CVs, liaising with employers
- Helping children and families to maintain links with existing social networks by, for example offering advice, liaising with clubs and groups
- Accessing needed equipment in hospital such as laptops, telephone, web cams
- Signposting to additional support

When should needs be assessed?

Needs should be regularly assessed and the care plan regularly reviewed.

As a minimum, this should be done at the following points along the care pathway:

- Diagnosis — as soon as possible and within 7 days;
- Discharge — a two part assessment, assessment to be undertaken both before discharge and once the child is at home. The clinical and practical elements of the home based assessment should be undertaken within 48 hours of discharge. The other elements should take place within 10 days;
- When there are significant changes in treatment, including transition to palliative care or survivorship and relapse.
- For transition to palliative care services please refer to the guidelines set out in Better Care: Better Lives[46].

Assessment and care planning is also required as preparation for particular times of transition in the child's life. These can include:

- Each "key stage" in education (pre school, key stage one, two and three, post 16 education);
- Starting work;
- Transition to adult health and social care services;
- Transition to becoming an independent individual, who makes their own decisions and manages their own care.

46 Department of Health, (2008), *Better Care Better Lives*

The specific format of these assessments will depend on the type of transition involved and the child's individual circumstances.

- For transition to adult services please refer to the guidelines set out in Transition: Moving on Well[47] and ACT: The Transition Care Pathway[48].

Dissemination and management of information

Children, their family and the key worker should have access to the assessments and care plans, and copies of the relevant sections should be given to the relevant professionals involved in the child's care. This may include professionals from the PTC MDT, shared care MDT and local community team. The duplication of assessments carried out by professionals working in different teams or settings should be avoided.

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

CASE STUDY:
ASSESSMENT AND CARE PLANNING IN A PRIMARY CARE TRUST AND LOCAL AUTHORITY

Mark Whiting is a consultant nurse for children with complex health needs. Mark talks about the assessment system used in Hertfordshire.

"Following referral, a series of detailed assessments are undertaken. Whenever possible these assessments are coordinated and undertaken jointly by staff from two or more agencies (such as health and social work). Assessments are then presented to a formal Continuing Care Panel which includes representatives of the Primary Care Trust and the Local Authority as well as the local children's hospice. Packages of care are individualised to each child and family, and their particular circumstances and needs. In the future we hope to streamline assessment processes further by incorporating the use of the Common Assessment Framework (CAF), including e-CAF."

7.3 ASSESSMENT AND CARE PLANNING: A COMMUNITY MULTI-DISCIPLINARY TEAM

A community multi-disciplinary team (CMDT) should be convened to assess a family's needs and plan care prior to every child's discharge from hospital

Why is this important?

In some areas of the UK specialist nurses contact general practitioners and community children's nursing teams around the time of the first discharge of a child with cancer, or when cure is no longer an option and palliative care has to be planned. This is not the case everywhere and in many places local healthcare professionals do not feel well informed or adequately involved in the care of these children.

GP practices offer a crucial source of support. However, where there has been a delay in a cancer diagnosis, families can lose trust in their local GP. Re-engaging GPs in the care of children helps to rebuild trust, therefore enabling families to access valuable and ongoing support in the local community.

Although the majority of children diagnosed with cancer will survive their disease, a significant number will die as a result of their cancer or its treatment. For the vast majority of these children, their home is the preferred place of death. If GPs and other local professionals are re-engaged with families soon after diagnosis and feel informed during treatment, it is much easier for them to be actively involved in end of life care.

47 Department of Health; Department for Children, Schools and Families, (2008), *Transition: moving on well. A good practice guide for health professionals and their partners on transition planning for young people with complex health needs or a disability*

48 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*

A CMDT would ensure smooth transition from hospital to home and actively involve local service providers in the ongoing care and support of the child and family.

NATIONAL CONTEXT: CMDTS

- The role of community teams is emphasised by the ACT Transition Care Pathway, which states that an integrated care pathway should be owned and developed locally by an MDT.
- The role of children's community teams is also described in the National Service Framework for Children, Young People and Maternity Services (Standard 6). Children's community teams are expected to provide support to children and their families to help 'prevent hospital admission, facilitate early discharge, and care for children with complex needs. Ideally, these should work across a number of settings, for example, hospital, home and school, improving continuity and maximising the available skills'.
- The NICE 'Improving Outcomes for Children and Young People with Cancer' guidance defines clearly the role and members of the various hospital based MDTs in paediatric and teenage and young adult cancer care. Although the guidance refers to the importance of continuity of care, often over many years and in many settings, it does not go so far as to suggest the need for CMDTs.
- High Quality Care for All: NHS Next Stage Review states that 'partnership working between the NHS, local authorities and social care partners will…lead to a patient-centred and seamless approach' therefore helping 'people's transition from hospitals back in to their homes'. The review also notes the importance of family doctors, pharmacies and local partnerships in taking a leading role to help people to stay healthy.

Recommendations

- ➜ A core CMDT should be convened prior to the first discharge of every child with cancer;
- ➜ When children are not inpatients at or around diagnosis, the first CMDT should be convened within 14 days of a firm diagnosis;
- ➜ The key worker is responsible for convening the CMDT;
- ➜ The CMDT sets review dates and agrees who will lead the reviews;
- ➜ Significant changes in the child's condition or transition points should also trigger a review;
- ➜ The meeting may be face to face or virtual, for example via teleconference or email, and may involve multiple individual meetings;
- ➜ Families should be encouraged to attend where this is appropriate.

Membership of the CMDT

As a minimum membership should include the following professionals:

- Key worker (from either the PTC or shared care)
- Representative from shared care (if the key worker is from the PTC)
- GP
- Lead community children's nurse and/or district nurse
- Local education representative, for example the child's teacher or Connexions representative
- Social worker (either hospital or local authority based)
- Family member (where appropriate)

Depending on the initial assessment of need, other professionals may need to attend or be informed. These could include:

- Children and Adolescent Mental Health Service (CAMHS) worker
- Family support worker
- Health visitor

- Dietician
- Occupational therapist
- Physiotherapist
- Other allied health professionals
- Community paediatrician
- Pharmacist
- Play specialist
- Youth worker
- Activity co-ordinator

Responsibilities of the CMDT

As well as responsibilities relating to their profession, all members of the CMDT should:

- Actively participate in care planning;
- Deliver the services identified in the care plan;
- Support and train colleagues to deliver care and support.

The key worker's responsibilities related to the CMDT include:

- Convening the CMDT;
- Ensuring the membership of the group reflects the child's needs;
- Explaining its purpose to members;
- Explaining individual and overall responsibilities to members;
- Recording the decisions made at the CMDT;
- Providing copies of the assessment and care plan to members of the CMDT;
- Disseminating relevant information to other practitioners involved in the care of the child;
- Ensuring two way communication with MDTs in other settings;
- Enabling the child and their family to be involved in the assessment and care planning process, where possible;
- Explaining the outcomes of the CMDT to the child and their family.

Role of the GP and the Primary Health Care Team

The situation of a child with cancer receiving complex hospital based specialised care, over long periods of time, can create confusion about the role, responsibility and expectations of the primary health care team. As more aspects of care are delivered in the community, the need for more clearly defined roles and responsibilities for these professionals becomes increasingly important. This is particularly relevant in view of the varied capacity and capability of primary care practices.

Maintaining a relationship between the family and the primary health care team is crucial. It is imperative that the primary health care team remain engaged with the child and family. It is important to acknowledge that these professionals have a key supporting role to play.

Specific recommendations in relation to the primary health care team are that:

- Cancer should be recorded and coded in the electronic records;
- Routine primary care, first contact care and child health surveillance should not be suspended unless there are explicit reasons for doing so, which should then be recorded;
- An accurate medication list is available enabling the safe management of medicines. Hospital pharmacists have a valuable role in ensuring that GPs are sent, ideally electronically and by secure means, a list of drugs which GPs are expected to prescribe.

CASE STUDY: CMDT

Anne Thompson, a paediatric oncology outreach nurse specialist (POONS) at the Royal Victoria Infirmary in Newcastle, talks about the importance of working in partnership with local GPs.

"We liaise a great deal with community GPs working closely with them to establish the preferred means of effective communication. With complex and palliative patients, the POONS team create individualised symptom management packages carefully discussed with the GP and paediatric oncologist to facilitate 'streamlined' prescribing. After a death, the GP and POONS meet to debrief, including identifying potential future service improvements. This debriefing work helps to build ties and can increase learning on both sides. GPs will often invite the POONS team to present at their practice meetings.

It works well as a partnership because, while the POONS team often take the lead in the clinical care of the children, it is ultimately the GP who is, and will continue to be, responsible for supporting the family over the long term."

7.4 ACCESS TO ROUND THE CLOCK SUPPORT

Every child and their family should be able to easily access support and advice at all times of day and night

Why is this important?

When families return home they can feel isolated. This contrasts to the intense support provided when a child is an in patient at a hospital. Being able to contact someone for clinical advice at all times of day and night could prevent a hospital admission, identify a needed admission, reduce anxiety and help families feel more supported.

NATIONAL CONTEXT:
ROUND THE CLOCK SUPPORT

- The NICE 'Improving Outcomes for Children and Young People with Cancer' guidance notes the need for 24-hour specialist medical and nursing staff cover at the PTC, including offering telephone advice to shared care centres and families.
- A key strategic goal for service development set out in Better Care: Better Lives is '24-hour access to multidisciplinary community teams and, when needed, specialist palliative care advice and services'.

Recommendations

- When the key worker or other sources of support are not available, the PTC oncology ward should be contactable for guidance at all times;
- Whoever is delivering the support at the PTC must have access to the child's clinical notes and be able to access the non-clinical CAF related assessments and care plans;
- Where care is delivered mainly from a shared care centre there should be formal agreement between the PTC and shared care as to the first point of contact for families;
- Advice given by telephone should be recorded in the patient's records and communicated to other professionals as appropriate;
- The child and family need to know who and how to access support. The key worker is responsible for ensuring this is known;
- Families should feel confident that they can call the PTC at any time if they are in doubt. The key worker is responsible for ensuring this is understood by the family.

CASE STUDY:
ACCESS TO ROUND THE CLOCK SUPPORT

Sophie is the mother of Patrick, three years old, who has Acute Myeloid Leukaemia. Patrick has finished his initial treatment, which involved spending one month at a time in hospital with a one week break in between.

“The first time we went home it was for a week and a half, and it was fantastic to be home. We didn’t get help that time, although I think the nurse may have come to say hello. The second time we thought a nurse was coming, but no one arrived. We were very concerned as Patrick’s red blood cells were going down. We phoned the nurse at the weekend but she didn’t pick up the message until Monday. It was then that we went back into hospital. Patrick needed platelets and red blood cells. In the beginning I felt on my own, and I’ve only just really started to ring the principle treatment centre if I’m worried. I didn’t know if it was OK to ring, no-one told us who to ring.”

7.5 INFORMATION, EMPOWERMENT AND CHOICE

Every child and their family should be given information to enable them to understand and manage their cancer, and empower them to make informed choices about their care

Why is this important?

Having information about the disease, the potential impact of the disease and the support they are entitled to, can help children and families to feel a greater sense of control at what is a very stressful time. Appropriate and timely information can empower families by enabling them to make choices about the care and support they receive.

Research carried out in 2004[49] demonstrated that many children with cancer, and their families, felt that information was not given to them at the right time or in the right format. Although much has been done to address these issues, this remains a challenge for families and children today. More recent research[50] has shown that health and social care information varies greatly in terms of quality, accessibility and availability across England.

NATIONAL CONTEXT: INFORMATION

- High Quality Care for All: NHS Next Stage Review 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’. The review also advocates the exploration of ‘personal budgets to give individual patients greater control over the services they receive’.
- The Information Accreditation Scheme will certify organisations that produce health and social care information. The scheme aims to provide a way for service users to know that the information they are using is reliable and to raise the overall standard of health and social care information.
- Information Prescriptions will be nationally recognised as a source of information about services and ensure that information is seamlessly and formally integrated into the service delivery process. These prescriptions will be given to everyone with a long-term condition or social care need in consultation with a health or social care professional.

49 S.Clarke, W.Mitchell and P.Sloper, University of York, (July 2004), *Care and Support Needs of Children and Young People with Cancer and Leukaemia and their Families*

50 Picker Institute, (November 2006), *Assessing the quality of information to support people in making decisions about their health and healthcare*

Recommendations

- Children and families should have access to information about their disease, the care and support they are entitled to receive and their individually planned care;
- Information should be accessible in terms of style, language and format, for example translated, interpreted or appropriate for families with special communication needs;
- Information should be delivered to children and families at the appropriate time;
- Information needs should be routinely considered as part of the assessment process;
- It is the responsibility of the key worker to ensure the above is achieved.

Family held records

Many PTCs have used family held records as a way of ensuring that families have all the information they need in one place. These patient/parent held records contain a variety of information including:

- Information about the PTC and/ or shared care centre;
- Contact numbers for advice and support;
- The child's care plan;
- Information on line management and mouth care;
- Blood test records.

Although in line with national initiatives, the approach to using family held records has been largely individual to PTCs. It would be helpful if a co-ordinated national approach were taken. It is therefore recommended that a national approach to using family held records is developed. This would ensure high quality information is consistently given to all families.

8. PACKAGES OF CARE

The services outlined in the packages of care below should be available to all children with cancer, and their families. It should be noted that not every family will need, or want, all of the services outlined in these care packages. Instead, the services they require should be defined by the assessment of their needs at particular stages in the care pathway.

The services in the care packages are both clinical (delivered in the community) and non-clinical (delivered in the hospital and community) and have been grouped into general areas of need, all identified as important by children, families and service providers. All areas are interlinked, for example emotional support can be delivered, in part, through enabling a child to maintain their social networks.

The care packages are structured around four stages of the care pathway: diagnosis, treatment, transition to survivorship and end of life care/bereavement.

- For further detail on services that should be available during end of life care and for bereavement, please refer to the recommendations outlined in Better Care: Better Lives[51].
- Services that should be available to survivors are being developed by the National Cancer Survivorship Initiative[52].

The services in these care packages will be delivered by a variety of professionals such as the specialist oncology social worker, local authority social worker, community children’s nurse, teacher and psychologist.

Commissioners can use the care packages when both assessing the extent of current service provision in their area and further developing service provision.

Professionals can also use the care packages as a prompt when carrying out an assessment of need and developing a care plan.

8.1 CLINICAL SUPPORT IN THE COMMUNITY

Why is this important?

Most families want to spend more time at or near home. To achieve this, the provision of safe, effective and coordinated clinical care in the community is absolutely essential.

Families need to feel secure and supported, and this can be achieved partly through improving their own confidence and clinical skills, as well as those of the local primary care team. Having access to round the clock advice and support is particularly important in managing clinical needs.

NATIONAL CONTEXT:
CLINICAL SUPPORT IN THE COMMUNITY

- Every Child Matters outcomes: ‘be healthy’, ‘stay safe’
- The National Service Framework for Children, Young People and Maternity Services (Standards 6 and 8) describe the ‘need for the development of community children’s nursing teams to ensure that there is a sufficient pool of nurses to undertake clinical care in the community’.
- The Royal College of Nursing and WellChild campaign ‘Better at Home’ is calling for greater investment in children’s community nursing teams to support children and families with long term and complex health needs being discharged earlier from hospital by providing clinical care at home.

51 Department of Health, (2008), *Better Care Better Lives*

52 National Cancer Survivorship Initiative, (September 2008), www.improvement.nhs.uk/cancer/survivorship.html

- In 1997 the House of Commons Select Committee recommended that community children's nursing services should be available 24 hours a day, seven days a week. This 24 hour support is particularly important for children and young people during palliative or end of life treatment.
- It is anticipated that the Children's Continuing Care Framework will highlight the need for more children's community nursing teams to address the increasing demand for complex care in the community.

CARE PACKAGE: CLINICAL SUPPORT IN THE COMMUNITY

Care pathway stage	Service	Who needs the service?
Prior to first discharge	• Information and training to enable the child and family to manage the illness at home • Explanations of clinical terms • Contact details and instructions (in the family held record where available) for what to do if they need additional support and in emergencies • Provision of required clinical equipment and medication • Involvement of the family in the discharge planning process • Initial joint home visit (where possible by the key worker and children's community nurse)	• Child • Family
	• Involvement of the local primary care team in planning the discharge • Liaison with local primary care team to ensure they have the necessary skills to provide care for the child	• Local primary care team
Treatment	• Delivery of appropriate clinical care at home e.g. IV chemotherapy, central line care, blood sampling, growth factors, symptom assessment and management • Information and training to enable the child and parents/carer to manage the illness at home, for example managing the central line in terms of dressings and flushing of lines. Parents/ carers need ongoing support with carrying out these procedures from the community team. • Explanations of clinical terms • Access to round the clock advice and support for both emergency care and general care and support	• Child • Family

Care pathway stage	Service	Who needs the service?

Survivors — transition	• Transition from appropriate follow up to check for and manage:
	  • Recurrence of disease
	  • Ongoing effects of treatment
	  • Emerging late effects
	• Sufficient, detailed individual information about the original disease, exact treatment and likely ongoing and late effects of treatment
	• Opportunities to discuss choices about lifestyle and health issues
	• Information and training to enable the child and family to manage the illness at home
	• Explanations of clinical terms
		• Child
		• Family

End of life/ bereavement	• Support in making the transition from curative to palliative and end of life care • Facilitate care and death in place of choice • Planning for and management of symptoms • Information and training to enable the child and family to manage the illness at home • Explanations of clinical terms • Access to round the clock community nursing support • Access to round the clock specialist palliative care advice and support	• Child • Family
	• Planning of the confirmation of death process • Confirmation of death • Registration of death • Access to a cold room	• Family

Role of the Community Children's Nurse

The community children's nurse is an expert assessor and provider of nursing care outside of hospital. In order to reduce time spent in hospital and the frequency of visits to hospital for routine care, community children's nurses provide hands on, age appropriate clinical and supportive nursing care in the child's local community. Responsibilities include:

- Carrying out a joint assessment of clinical needs with the key worker;
- Providing planned care and support to the child and their family out of hospital;
- Being an active member of the community multi-disciplinary team (please refer to section 7.3);
- Accessing clinical supplies and equipment for community use, for example feeding pumps, needles and syringes;
- Ongoing clinical support and liaison with schools;
- Provision of palliative care at home.

It should be noted that the community children's nurse is not a specialist in paediatric oncology and therefore must be supported by the child's key worker to ensure that ongoing, safe clinical care is provided when the child is not in hospital.

CASE STUDY: CLINICAL SUPPORT TO PREPARE FOR DISCHARGE FROM HOSPITAL

Rajinder is the mother of Andrew, four years old, who has Acute Lymphoblastic Leukaemia. Andrew has finished initial treatment. Following a long hospital stay Rajinder describes the preparation they had for returning home.

"In the parent held record there is a list of the things that the nurse will train you to do before you can take your child home. The training took place exactly as it said. The ward nurse showed me how to do the task, got me to do it, assessed if I was competent and confident and signed it off. This was done with medicines, taking Andrew's temperature, looking after the Hickman line, changing the dressing and doing nasogastric feeds. There was plenty of time allowed for this and I'm really proud I learned these things easily. They expect it to take two days to learn everything about the medicines and it took me just two hours. There were some things I just had to get on with but there were other things where I had a choice about whether I did them or not. Being able to change the dressing and clean the Hickman line is essential to me but flushing the line and taking bloods are things I've been shown how to do but at this point in time I don't want to — I might reconsider this in the future, there's no pressure."

8.2 KEEPING UP WITH EDUCATION

Why is this important?

Children with cancer are likely to have their education disrupted due to prolonged or repeated periods of hospitalisation and frequent health appointments. Learning capacity can also be impacted by certain types of cancer, for example in the case of some brain tumours. Education systems can struggle to accommodate the individual needs of these children. These factors can contribute to children with cancer achieving less than their peers in education and subsequently in employment.

There is also an important emotional component to keeping up with education. Going to nursery, school or college is a major part of a child's life and is intimately related to their social networks.

It is essential that children with cancer, and other medical needs, benefit from innovative practice that offers support during all stages of their treatment.

NATIONAL CONTEXT:
KEEPING UP WITH EDUCATION

- Every Child Matters outcomes: ‘enjoy and achieve’, ‘achieve economic well-being’
- Keeping up with education was identified as a key need by the children NICE consulted with during the development of the ‘Improving Outcomes for Children and Young People with Cancer’ guidance.
- The Children’s Plan wants ‘every young person to achieve their potential’ and for participation in education to be encouraged and enabled.
- The Department for Children, Schools and Families guidelines ‘Access to Education for Children and Young People with Medical Needs’ offer minimum national standards of education for children with cancer and others who are unable to attend school, and emphasise the importance of good communication between all relevant partners. The guidelines specify how young people can keep up with education during treatment, as well as how young people can be supported back into education after treatment.
- The Children’s Plan proposed extending the age of compulsory education up to 18 years of age. The Education and Skills Bill introduced this requirement: by 2013 all 17 year olds, and by 2015 all 18 year olds, should be participating in some form of education or training.
- The National Service Framework for Children, Young People and Maternity Services (Standard 6) states that ‘PCTs and NHS Trusts will work in collaboration with LEAs to contribute to the national Public Service Agreement on maximising school attendance’. The standard states that ‘local protocols include the identification of a named health contact and a named teacher who are jointly responsible for the reviews of health care plans for each child in school’.

Role of Teachers At Nursery, School And College

In partnership with local authority, health and other agencies, teachers in the child’s local education institution have a crucial role to play in delivering care and support to children with cancer. Some of their key responsibilities are outlined in the care package below[53].

CARE PACKAGE: KEEPING UP WITH EDUCATION

Care pathway stage	Service	Who needs the service?
Diagnosis	• Identify and name a contact teacher for the family. If the responsible person is the head teacher, or special educational needs coordinator (SENCO), it may be helpful for one other governor to have an interest in special educational needs. For mainstream (non-special) schools, the governing body may also appoint a committee to monitor the school’s work for children with special educational needs. For independent schools, the contact is likely to be the head of learning support	• Child • Sibling • Family • Friends • Teachers

53 Content taken from Petersen Broyd, Pritchard-Jones, Edwards, (2008), *Pupils with cancer: A guide for teachers* and suggestions from NAHT

Care pathway stage	Service	Who needs the service?
Diagnosis (cont.)	• Ensure the school has a clear policy for pupils with medical needs that specifies aims, objectives, actions and outcomes • Notify the local authority or educational welfare officer of prolonged absence for medical reasons • Carry out a baseline assessment of educational need as part of the CAF or specialist assessments e.g. special educational needs assessment • Draw up an individual education plan • Provide suitable work and materials for the child • Liaise with home and hospital teaching services • Arrange home tuition and liaise with the home tutor • Ensure sibling needs are considered and their teachers are informed • Inform staff and pupils according to the family's wishes	
Treatment/Survivors — transition	Communication with family • Keep in regular contact with the child and family Supporting the child • Ensure suitable work is provided by individual subject teachers • Provide opportunities for extra support and catching up with work • Include the child as far as possible in all activities • Adjust expectations of academic performance • Regularly revise the pupil's timetable and school day as necessary to protect core subjects above others • Provide strategies for improved learning, concentration and memory • Arrange for special educational support and staff training • Ask the examinations officer to make special arrangements	• Child • Sibling • Family • Friends • Teachers

Care pathway stage	Service	Who needs the service?
Treatment/Survivors — transition (cont.)	• Discuss with the child changes to procedures for examinations • Prepare for transitions — inform new teachers, school and support staff • Follow up signs of distress, poor performance or school phobia • If required, arrange access to an educational psychologist (parents of pupils in independent schools will need to manage this themselves) • Arrange for ease of movement around the school • Arrange for access to IT/communications equipment and other supports Working with other pupils • Inform pupils sensitively about developments and changes • Invite a nurse and other professionals to speak to pupils • Encourage fellow pupils to maintain contact with the child • Teach the class general awareness of illness and supportive strategies • Prevent teasing and bullying through teaching strategies, clear communication and sanctions Liaison and communication amongst teaching staff • Inform staff sensitively about developments and changes • Invite a nurse and other professionals to speak to members of staff • Arrange home tuition and liaise with the home tutor • Liaise with hospital teaching services • Circulate letters about infection risks when requested by the family or health professionals • Agree changes to school rules and circulate arrangements to all staff • Inform staff about long term effects such as fatigue	• Child • Sibling • Family • Friends • Teachers

Care pathway stage	Service	Who needs the service?
End of Life / Bereavement	• Accommodate the needs and wishes of the child and their family through careful planning and communication • Enable the child to attend school on a part time or social basis, if this is desired by the child and their family • Ensure, with the pupil's or parents' permission, that contact is maintained through brief visits where possible, cards and letters, texts, emails, or social networking sites • Plan and set up a system of good communication • Identify a member of staff responsible for co-ordinating information and support • Identify a member of staff to keep in touch with the family • Understand and support the peers and teachers who are grieving • Answer questions from pupils • Make contact with professionals who will be able to support the school and offer advice and counselling • Consider setting up support for staff as well as pupils. This can be done by telephone or email as well as in person	• Child • Sibling • Family • Friends • Teachers

- For further guidance please refer to Pupils with Cancer: A guide for teachers[54]

Role of the Local Authority Responsible for Education: Home Tuition[55]

It can be very helpful for parents if early on the school establishes the likely need for home tuition and contacts the local authority with a view to setting it up. Treatment centre staff can arrange for a letter in support of home tuition from the child's hospital consultant.

The local authority is responsible for ensuring that pupils:

- Are not at home without access to education for more than 15 working days;
- Have access to education from the start, if it is clear that they will be away from school for long and recurring periods;
- Receive an education of similar quality to that available in school;

54 Petersen Broyd, Pritchard-Jones, Edwards, (2008), *Pupils with Cancer: A guide for teachers*

55 Petersen Broyd, Pritchard-Jones, Edwards, (2008), *Pupils with Cancer: A guide for teachers*

- Get a minimum entitlement of five hours teaching per week if they are educated at home because of illness, as long as their health permits it.

Local authorities should have a senior officer in charge of overseeing the arrangements. They should also have a written policy setting out how they will go about meeting their responsibilities. Early liaison between parents, school, children's services and the treatment centre is important.

The local authority has no legal responsibility to provide home tuition for children who are normally educated in independent schools. However, some local authorities will provide home tuition for these children if asked.

THE SPECIAL EDUCATIONAL NEEDS CODE OF PRACTICE: STAGES[56]

School action

The special educational needs coordinator (SENCO) takes responsibility for the young person's needs, and any extra help that is needed is provided by the school from existing resources. An individual education plan (IEP) describes the pupil's difficulties, and the strategies and provision suggested for meeting the identified targets and goals. Regular reviews of the IEP will allow any changes needed to be incorporated. The review should be at least twice a year and the parents and pupil should be able to contribute to the IEP content.

School action plus

For complex needs and poor progress the pupil should be placed on 'school action plus' of the SEN code of practice. Specialist staff from outside agencies may be involved in assessing the pupil and offering advice on how best to meet the pupil's needs. The local authority or health authority can help with input from specialist staff such as a speech and language therapist or educational psychologist. The parents are included or informed about these arrangements.

Full statement

A full statement of SEN is appropriate where a pupil requires additional support over and above what the school is able to provide. With parental consent the local authority will make a statutory assessment of need and outline the special help and support required to meet them. Parents can, in some cases, express a preference for their child to attend another school better suited to meet the needs of the child.

The statement supports the young person's education up to the age of 19 and is reviewed annually. The local authority should be informed as soon as a need is identified, even if the pupil is not yet back at school full time. The process of getting everything in place can be lengthy so it is in the pupil's best interest to make an early start.

CASE STUDY: KEEPING UP WITH EDUCATION

Simon Pini is a learning mentor at St James Hospital in Leeds. Learning mentors are not generally employed in hospitals to work with children and young adults with cancer. Where learning mentors do not exist, elements of this role could be incorporated into the roles of other appropriately trained professionals. Simon talks about working with Katherine, a young person undergoing treatment for cancer.

"I met Katherine when she was undergoing intensive chemotherapy for a bone tumour. She then had a major operation to replace a bone in her leg as well as several other operations. Katherine had a deferred place at a local university and, over the time I worked with her, decided to change course and universities several times. I offered flexible support, such as finding information and liaising with university departments, adapting my support as needed while Katherine's interests changed and she thought about

56 Content taken from Petersen Broyd, Pritchard-Jones, Edwards, (2008), *Pupils with Cancer: A guide for teachers*

her future. I believe that focussing on future goals helped Katherine through her treatment, and that all the discussions we had and options we looked at led her to a final decision that suited her and that she was happy with. This summer, Katherine graduated with a 2:1 and options for the future."

8.3 KEEPING UP WITH SOCIAL ACTIVITIES

Why is this important?

Children with cancer are likely to have their normal social activities disrupted because of ill-health and prolonged or repeated periods of hospitalisation. Additionally, children are often very conscious of appearing to be 'different' from their peers and are more likely to suffer from low self-esteem. Both maintaining existing social networks and also developing new networks related to their illness is important in two respects. These networks can be an important source of emotional support, and they can also enable children to continue developing social skills; crucial in helping them to become successful survivors.

Children also value highly being able to maintain overall fitness and physical activity while undergoing cancer treatment. However, it can be difficult for children to re-engage with physical activities after treatment, which may contribute to problems associated with inactivity in later life. Physical recreation is usually undertaken as part of a group or social activity, but for children who are out of school often this can become difficult. When in school, many children on treatment are not permitted to participate in physical activities, even though this may be both desirable and achievable with some small adaptations. Helping children to maintain a level of physical activity and fitness when in hospital could also be possible using modern technologies such as Wii Fit.

NATIONAL CONTEXT:
IMPORTANCE OF SOCIAL ACTIVITIES

- Every Child Matters outcomes: 'stay safe', 'enjoy and achieve', 'achieve economic well-being'
- Play England aims 'for all children and young people in England to have regular access and opportunity for free, inclusive, local play provision and play space'.
- Youth Matters sets out a vision for 'empowering young people, giving them somewhere to go, something to do and someone to talk to' as well as 'encouraging more young people to volunteer and become involved in their communities'.
- 11 Million 'Fun, Friends and Freedom' found that some older children want opportunities to socialise in safe environments without being judged or pushed towards structured youth provision.

CARE PACKAGE: KEEPING UP WITH SOCIAL ACTIVITIES

Care pathway stage	Service	Who needs the service?
Diagnosis	• Baseline assessment of normal social network and activities (e.g. relationship with school friends, membership of clubs) • Opportunities for the child to maintain existing social networks e.g. access to email, telephone • Opportunities for the child to participate in hospital based recreational and physical activities e.g. through play, reading, computers, arts etc.	• Child

Care pathway stage	Service	Who needs the service?
Diagnosis (cont.)	• Liaison with existing social networks re hospitalisation, diagnosis and its immediate impact	• Child • Sibling
Treatment	• Opportunities for the child to participate in activities with others in a similar situation e.g. young people's cancer support groups, sibling days, camps and holidays	• Child • Sibling
	• Help to enable the family to continue to participate in normal family activities	• Child • Family
	• Opportunities for the child to participate in physical and fitness activities	• Child
Survivors — transition	• Help to enable child to fully re-integrate into ordinary social networks and physical/fitness activities • Opportunities for the child to participate in activities with others in a similar situation	• Child
End of Life / Bereavement	• Help to enable the child to continue to participate in social activities for as long as is possible • Help to enable the child to say goodbye to their peers	• Child
	• Liaison with existing social networks to manage the impact of the child's death	• Child • Sibling
	• Enable the sibling to continue to participate in social activities	• Sibling

CASE STUDY: KEEPING UP WITH SOCIAL ACTIVITIES

Manvir was diagnosed with leukaemia when she was 16 years old. Here she talks about how her cancer impacted on her socially.

"Keeping up with my social life was hugely significant in my experience of having cancer as a young person. I found that after starting treatment I lost a lot of my confidence and wasn't able to identify with others my age. I was diagnosed with leukaemia when I was 16, just before I was due to start college. I found starting this new chapter in my life especially difficult as I had very little confidence and found it hard to talk to new people and make new friends.

I was very conscious that I looked different as I had lost my hair and a lot of my weight, and that I wasn't around for a lot of the time because I was ill or in hospital. I found that because I was not able to go out to parties and meet up with my friends, I couldn't really talk to them in the same way. I felt that people also found it hard to identify with me as my everyday experiences were

very different from from their experiences. I didn't like talking about cancer or hospital or chemo to my friends as it just felt awkward and depressing, but I felt like I couldn't get involved in their conversations either because I wasn't able to go out with them and so I didn't know what they were talking about. This made me feel even less confident and made me feel like I was alone in this experience.

Over time, as I got better and was able to spend more time with others my age, my confidence came back. One of the significant ways of helping me regain my confidence was going on trips away to meet others my age with cancer in a more social setting than in hospital. This allowed me to see that I wasn't alone and I was able to talk openly about having cancer and our shared experiences. I felt like I could be myself as I didn't have to explain things all the time. In my experience these trips were essential in building my confidence and esteem, and helping to reduce feelings of isolation.

I think that if there were ways to integrate existing friends into these trips, it may overcome some of the problems with keeping up with friends, not being able to share experiences, and not having things to talk about. I also think it would help peers to understand cancer more and consequently make them feel more comfortable talking about it."

8.4 EMOTIONAL SUPPORT

Why is this important?

Children often receive a great deal of emotional support from their parents, family and friends. However in some cases more specialised support is needed. Children often want to protect their families and therefore may need someone else to talk to.

Parents may also need emotional support to help them come to terms with the cancer diagnosis, as well as to enable them to provide emotional support to their children. Parents need to be able to access emotional support in a variety of forms, for example talking informally to the professionals engaged in the clinical care of the child, or calling a helpline.

Spending more time at home can help families maintain existing support networks but may also reduce some other aspects of emotional support, for example the support gained by being on the ward with other families going through a similar experience.

NATIONAL CONTEXT: EMOTIONAL SUPPORT

- Every Child Matters outcomes: 'be healthy', stay safe, 'make a positive contribution'
- In the Happy and Healthy report, 11 MILLION found that 'relationships with staff and professionals that are sustained over periods of change within children or young people's lives, particularly during periods of transition, create a positive sense of well-being and continuity'. This model of care aims to keep families together and to provide consistency in professional support.
- The Children's Plan wants 'every young person to achieve their potential'.
- The National Service Framework for Children, Young People and Maternity Services (Standard 9), aims to ensure that 'the emotional well-being of the child, young person and their family is regarded as an integral part of service provision. All staff working with children and young people with a physical illness should have an understanding of how to assess and address the emotional well-being of children.'
- The Government has set out its commitment to improving the health and wellbeing of children and young people over the next three years in a new Public Service Agreement (Improve the Health and Wellbeing of Children and Young People, PSA 12).

CARE PACKAGE: EMOTIONAL SUPPORT

Care pathway stage	Service	Who needs the service?
Throughout the pathway • Support groups e.g. parents groups, sibling groups, family groups • Counselling/befriending — face to face or over the telephone • Spiritual support		• Child • Family
Diagnosis	• Support for families as they receive news of the cancer diagnosis (breaking bad news) • Baseline assessment of emotional resilience	• Child • Family
	• Psychological assessment	• Child
Treatment/Survivors — transition	• Rapid access to therapeutic support, psychology and psychiatric services	• Child • Family
End of Life / Bereavement	• Specific support at the transition from curative to palliative care (breaking bad news) • Help to prepare for end of life care and death • Rapid access to therapeutic support, psychology and psychiatric services	• Child • Family
	• Specific bereavement support	• Family

Role of the Psychologist, Psychiatrist, Child and Adolescent Mental Health Service (CAMHS)

As well as social workers offering emotional support to the child and their family, psychologists, psychiatrists and practitioners from CAMHS also have a crucial role to play. These professionals can offer more specialised support for both the family and other professionals involved in caring for the child. Their responsibilities include:

- Carrying out baseline assessment and reassessment of need;
- Being an active member of the community multi-disciplinary team (please refer to section 7.3);
- Providing rapid access to services;
- Supporting and training other staff involved in the care of the child.

CASE STUDY: EMOTIONAL SUPPORT

Hannah is the mother of 17 year old Liam, diagnosed with Ewings Sarcoma with secondaries in his lungs. Liam is currently at home. He is on treatment at a Teenage Cancer Trust unit as an outpatient, and waiting for surgery.

"It would be good if someone came to see Liam at home while he is in bed on chemo as he has issues now. He needs a counsellor. It was ten months before he was diagnosed, nobody believed he was ill. Before he was diagnosed he did four days at college and two days at work. He can't do that now, he won't be able to do that in the future. He puts on a face and doesn't want to talk. He also needs a friend, someone to talk to who has similar experiences. The hospital has done a lot, but we are not as involved now. We do a lot of things together instead."

8.5 PRACTICAL SUPPORT

Why is this important?

Having practical support such as help with the housework, shopping and the school run enables families to maintain more of a 'normal' family life, spend more time together and facilitates families being at home for more of the time. Needs are often highly individual, but tailoring a care package to meet a family's particular needs is highly valued by families.

Practical support can be provided through family and friends, through a family support service or through families receiving individual budgets to spend on support services.

NATIONAL CONTEXT: PRACTICAL SUPPORT

- Every Child Matters outcomes: 'stay safe', 'enjoy and achieve', 'make a positive contribution', 'achieve economic well-being'
- Individual Budgets aim to enable people needing social care and associated services to decide the nature of the services they need, as well as make choices as to where to purchase such services from.
- Aiming High for Disabled Children and the short breaks transformation programme states that 'short breaks should not just be used as a crisis intervention, but should also be used routinely to help parents and carers to maintain and improve the quality of care they naturally wish to provide.'

CARE PACKAGE: PRACTICAL SUPPORT

Care pathway stage	Service	Who needs the service?
Diagnosis	• Suitable accommodation close to the PTC for the family • Family support service for school run, house work etc. (in own home or relative/friend's home) • Signposting to agencies able to provide practical support e.g. cleaning services, childminders • Rapid access to interpretation/translation service including language, sign language	• Child • Family
Treatment	• Suitable accommodation close to the PTC for the family • Pre-discharge support to prepare the home • Short break provision for parents/carers • Rapid access to aids and equipment, especially wheelchairs • Transport to and from hospital • Family support service for school run, house work etc. (in own home or relative/friend's home) • Signposting to agencies able to provide practical support e.g. cleaning services, childminders • Rapid access to interpretation/translation service including language, sign language	• Child • Family
Survivors — transition	• Rapid access to aids and equipment and appropriate housing • Help to support independent living • Rapid access to interpretation/translation service including language, sign language	• Child • Family
End of Life / Bereavement	• Short break provision for parents/carers • Rapid access to aids and equipment, especially wheelchairs • Family support service for school run, house work etc. (in own home or relative/friend's home) • Signposting to agencies able to provide practical support e.g. cleaning services, childminders • Rapid access to interpretation/translation service including language, sign language	• Child • Family

CASE STUDY: PRACTICAL SUPPORT

Anne Harris is the Director of Care for Rainbow Trust. The Rainbow Trust is a charity delivering practical and emotional support to families through family support workers. Family support workers are just one way of helping families with the practical tasks of everyday family life. Anne says:

"Practical support can benefit families in a number of ways, for example:

- Helping parents to remain in work or keep up with work;
- Helping families transition back to home;
- Helping parents continue with their household and child-care duties;
- Supporting siblings;
- Helping to reduce isolation in the home."

8.6 FINANCIAL SUPPORT

Why is this important?

Families who have children with complex health needs spend a much higher amount of money per child than families whose children are not ill[57]. The financial impact of cancer can be significant and immediate due to the additional costs associated with travel to specialist centres, food, childcare, phone bills and other important items.

These factors are compounded by the fact that families often experience a reduction in income at this time due to balancing care responsibilities and paid work responsibilities.

Finding and retaining employment can also be a challenge for young people who have or have had cancer, either due to the effects of the disease and its treatment or, for example, because employers do not take into account the young person's experience when considering their educational achievements.

57 Department of Health, Department for Education and Skills, (2004), *National Service Framework for Children, Young People and Maternity Services*

NATIONAL CONTEXT: FINANCIAL SUPPORT

- Every Child Matters outcome: 'achieve economic wellbeing'
- The National Service Framework for Children, Young People and Maternity Services states that families with disabled children (this includes those who are not disabled but have complex health needs) spend three times as much per child compared to the national average spend per child.
- There is a Government target to halve childhood poverty by 2010 and eradicate it by 2020. Currently one in five children is estimated as living in poverty. One or more parents not being in paid full-time employment is a key contributing factor to childhood poverty. Families of disabled children (including sick children) are over represented in the poverty tables.
- Consultation carried out by NICE when developing the 'Improving Outcomes for Children and Young People with Cancer' guidance showed a need for benefits advice for families.
- The Cancer Reform Strategy recommends that 'as part of integrated services, commissioners should ensure that all people affected by cancer are given information about what financial help (including welfare benefits) is available and how to access that help and their rights under the Disability Discrimination Act.'
- Our NHS, Our Future aims to 'introduce Fit for Work services, to help people who want to return to work but are struggling with ill health to get back to appropriate work faster.'
- Access to Disability Living Allowance for most families is 12 weeks after diagnosis.
- Cost of Cancer, the Macmillan Cancer Support campaign, highlights the financial difficulties faced by adults with cancer and carers of cancer patients.

- Cut the Red Tape, a CLIC Sargent campaign, highlighted that 83% of families incur significant extra costs associated with their child's cancer treatment and 68% reported worrying financial difficulties following the cancer diagnosis due to additional costs and reduced working hours.
- The 'Working with Cancer' guidelines offer employers advice and guidance on how to deal with cancer-related issues in the workplace.
- The Parents Have a Right to Care campaign tells us that 91% of parents changed their working patterns after their child was diagnosed with cancer, and some parents had to give up work altogether. CLIC Sargent has produced a model policy to help employers support these carers in work — for the benefit of their business and of the child's family

CARE PACKAGE: FINANCIAL SUPPORT

Care pathway stage	Service	Who needs the service?
Diagnosis	• Baseline assessment of financial need • Help to access immediate funds e.g. charitable grants • Help to apply for Disability Living Allowance and other benefits • Help to manage current employer — notify employer of diagnosis and immediate impact (via young person/family where possible), give advice regarding employment rights	• Parents/carers of children under 16 years • Young people aged over 16 • Significant others of young people aged over 16
Treatment	• Help to manage current employer — ongoing impact • Help to access all forms of financial support e.g. benefits, grants	• Parents/carers of children under 16 years • Young people aged over 16 • Significant others of young people aged over 16

Care pathway stage	Service	Who needs the service?
Survivors — transition	• Career advice • Help to gain work experience placements • Help to gain employment e.g. advice on CV writing, explaining absences and illness, using life experiences • Help to manage employers e.g. negotiating attendance at ongoing appointments, securing reasonable adjustments • Advice on how to address insurance/ mortgage and related issues	• Young people aged over 16 (both at diagnosis and for younger children once they reach this key transition point)
End of Life / Bereavement	• Help to access support for funeral expenses • Support to achieve long term financial stability	• Parents/carers • Significant others

CASE STUDY: FINANCIAL SUPPORT

Megan Cruise, helpline & grants manager at CLIC Sargent, talks about the Citizen's Advice Bureau benefits advisers who provide email and phone advice to CLIC Sargent staff and service users.

"Families embark on a difficult and lengthy process when applying for benefits, particularly Disability Living Allowance. Some benefit applications can be complex and time consuming for our local staff and benefit rules and entitlements change on a regular basis.

In order to make better use of local staff resources, the CLIC Sargent Helpline team has expanded to include two benefits advisers from the Citizen's Advice Bureau (working 16 hours a week in total).

To have people directly employed by the Citizen's Advice Bureau available to families and care professionals, means that people are receiving the most up to date and accurate advice. The service ensures that families do not suffer through lack of knowledge of their rights and responsibilities or of the services available, or through an inability to express their needs effectively. The feedback received about this service from our local staff has been very positive."

APPENDIX A: DESCRIPTIONS AND DEFINITIONS

Child/children

In this report child/children refers to all children and young people up to and including the age of 18.

Clinical nurse specialist

The clinical nurse specialist is a specialist nurse who 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.

Community

In this report community is defined as anywhere the child and family are when they are not in a hospital. This includes being in their own home, in another person's home, at school and at work.

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 focuses on preparing for an anticipated death and managing the end stage of a terminal medical condition; this includes care during and around the time of death and immediately afterwards. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support.'[58]

58 Department of Health, (2008), *Better Care Better Lives*

Family

'Family includes informal carers and all those who matter to the patient.'[59]

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 child and their family when a range of services are involved and an integrated response is required.

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 children and families throughout the cancer journey.

National Institute for Health and Clinical Excellence (NICE)[60]

The National Institute for Health and Clinical Excellence is an independent organisation responsible for providing national guidance on the promotion of good health and the prevention and treatment of ill health. NICE produces guidance in three areas of health:

- Public health — guidance on the promotion of good health and the prevention of ill health for those working in the NHS, local authorities and the wider public and voluntary sector;
- Health technologies — guidance on the use of new and existing medicines, treatments and procedures within the NHS;
- Clinical practice — guidance on the appropriate treatment and care of people with specific diseases and conditions within the NHS.

59 Department of Health, (2008), *Better Care Better Lives*
60 www.nice.org.uk

Paediatric oncology outreach nurse specialist (POONS)

Paediatric oncology outreach nurse specialists are specialist nurses providing outreach services for children diagnosed with cancer. They support children and families from the point of diagnosis through to end of life care, where this is needed.

Palliative care

'Children's 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 for the child and support for the whole family, and includes the management of distressing symptoms, provision of respite and care from diagnosis through death and bereavement.'[61]

Principle treatment centre (PTC)

All children with cancer are diagnosed at one of the 21 principle treatment centres in the UK. The PTC makes the definitive diagnosis and initiates treatment. The PTC directs the child's cancer treatment throughout the care pathway.

Shared care centres/paediatric oncology shared care unit (POSCU)

Shared care centres, or POSCUs, are local hospitals working in partnership with a PTC to provide some aspects of the care a child with cancer needs. 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 child. Levels of shared care are agreed with each PTC.

61 Department of Health, (2008), *Better Care Better Lives*

APPENDIX B: STEERING GROUP MEMBERS

Name	Title	Place of work
Professor Mayur Lakhani	GP (Chair)	Leicestershire
Clare Daly	Clinical Nurse Specialist, (incoming Chair of Paediatric Oncology Outreach Nurse Specialist Group)	Great Ormond Street Hospital
Simon Davies	Chief Executive	Teenage Cancer Trust
Professor Tim Eden	Honorary Professor of Teenage and Young Adult Cancer Medical Advisor	University of Manchester Christie Hospital NHS Trust Teenage Cancer Trust
Dr Carole Easton	Chief Executive	CLIC Sargent
Chris Gibbs	Chair of National Alliance of Childhood Cancer Parents Organisation	Birmingham Children’s Hospital
Dr Faith Gibson	Senior Lecturer in Children’s Cancer Nursing Research	UCL Institute of Child Health Great Ormond Street Hospital for Children NHS Trust
Kath Hill	Social Work Team Leader	Birmingham Children’s Hospital
Louise Hooker	Project Manager, Children and Young People’s Improving Outcomes Guidance	National Cancer Action Team
Lynn Leighton	Paediatric Oncology Outreach Nurse Specialist	Medway Hospital
Katrina McNamara-Goodger	Head of Policy & Practice	ACT: The Association for Children’s Palliative Care
Liz Morgan	Professional Advisor — Children and Young People	Department of Health
Sue Morgan, MBE	Consultant Nurse, Teenagers and Young Adults	Leeds General Infirmary
Dr Bruce Morland	Chair of Children’s Cancer and Leukaemia Group	Birmingham Children’s Hospital

Name	Title	Place of work
Rachael Olley	Operations Manager	National Alliance of Childhood Cancer Parents Organisation
Sam Smith	Consultant Nurse, Teenagers and Young Adults	Christie Hospital
Louise Soanes	Consultant Nurse, Teenagers and Young Adults	Royal Marsden Hospital
Janet Vickers	Nurse Consultant in Paediatric Palliative Care, (Chair of Paediatric Oncology Outreach Nurse Specialist Group)	Royal Liverpool Children's Hospital
Mark Whiting	Consultant Nurse, Children with Complex Health Needs	West Hertfordshire Primary Care Trust
Joan Woodruff	Hospital Teacher	Royal Marsden Hospital

Special thanks to CLIC Sargent's Research and Development Team for their support during the consultation phase of this work.

APPENDIX C: CONSULTATION WITH BLACK AND MINORITY ETHNIC GROUPS[62]

Families from black and minority ethnic (BME) groups were contacted during the consultation period of this review. Overall, 7.6% of the consultation's survey respondents were 'non-white'. This is in line with previous consultations[63]. However, the figure was lower than that of overall cancer registrations amongst 0 to 15s[64]. There were also indications that language difficulties prevented some families from completing the survey.

In addition to the survey, four semi-structured interviews were held with families from BME backgrounds (three interviews were with parents and one was with a young person). The aim of the interviews was to identify particular needs of BME families that might not have emerged through the other elements of consultation.

The interviews showed that, although many families have common core needs (such as finance, education and transport), each family's circumstances are highly individual. These circumstances included individual factors such as cancer type, age of the child and pre-existing psychosocial needs.

The interviews also suggested that some families from BME backgrounds could have greater difficulty accessing support and services. Issues that may have affected access included immigration and asylum seeking processes, language and discrimination.

The recommendations proposed in this report focus on meeting individual needs and therefore should improve the care offered to families from BME backgrounds. However, it must be acknowledged that the specific needs of these groups have not been researched beyond the consultation outlined above.

Further research in this area would be welcomed. It is anticipated that this will be addressed in part by the National BME Cancer Patient Advisory Panel, funded research[65] and during the initial implementation phase of the model of care recommended in this report.

62 Content taken from CLIC Sargent, (2008), *More Than My Illness: Summary of Consultation Report*. The report is available on request from CLIC Sargent

63 Social Policy Research Unit, York University, (2004), *Care and Support Needs of Children and Young People with Cancer and their Families;* National Institute for Health and Clinical Excellence, (2005), *Improving Outcomes in Children and Young People with Cancer*

64 Data communicated to CLIC Sargent from the National Registry of Childhood Tumours, Oxford University: Registrations by ethnic group received via CCLG centres 2001-2005 showed 12% of registrations were from 'non-white' groups

65 For example research (funded by CLIC Sargent) into the psycho-social impact and service needs of South Asian children and young people with cancer and their families.

APPENDIX D: REFERENCES

- Association for Children's Palliative Care, Children's Hospices UK, (2008), *A Practical Guide to Commissioning Children's Palliative Care Education and Training: Planning and developing an effective and responsive workforce*
- Association For Children's Palliative Care, (2007), *Holistic Common Assessment of Supportive and Palliative Care Needs for Adults with Cancer*
- 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*
- Baggott C, (2002), *Nursing care of children and adolescents with cancer*
- Petersen Broyd, Pritchard-Jones, Edwards, (2008), *Pupils with cancer: A guide for teachers*
- Bignold, Ball and Cribb, (1994), *Nursing Families with Children with Cancer: the Work of the Paediatric Oncology Outreach Nurse Specialists*
- Bonnie Stevens et al, (2004), *Home chemotherapy for children with cancer: perspectives from health care professionals*
- Cahill P, BJGP, (2008: 58: 520-1), *Top Tips in 2 minutes*
- Castledine, (1982), *The role and function of clinical nurse specialists in England and Wales*
- Charles-Edwards-I, (2003), *Making healthcare decisions with children*
- CLIC Sargent, (2008), *More Than My Illness: Summary of Consultation Report*
- *CLIC Sargent, (2006), Work Care Balance Survey*
- Coordination Network UK, (2007), *Key Worker Standards Care*
- Department for Children, Schools and Families, (2007), *Common Assessment Framework: Managers' Guide*
- Department for Children, Schools and Families, (2007), *Common Assessment Framework: Practitioners' Guide*
- Department for Children, Schools and Families, (2007), *The Children's Plan: Building Brighter Futures*
- Department for Children, Schools and Families, (2008), *What is a Children's Trust?*
- Department for Education and Skills, (2001), *Access to Education for Children and Young People with Medical Needs*
- Department for Education and Skills, (2005), *An Exploration of Different Models of Multi-agency Partnerships in Key Worker Services for Disabled Children: Effectiveness and Costs*
- Department of Education and Skills, Department of Health, (2006), *Joint Planning and Commissioning Framework for Children, Young People and Maternity Services*
- Department for Education and Skills, (2006), *What to do if you're worried a child is being abused — summary*
- Department of Health, (2008), *National Framework for Assessing Children and Young People's Continuing Care (consultation)*
- Department of Health, (2008), *An Accreditation Scheme for Health and Social Care*

- Department of Health, (2008), *Better Care Better Lives*
- Department of Health, (2007), *Cancer Reform Strategy*
- Department of Health, (2008), *Carers at the Heart of 21st Century Families and Communities*
- Department of Health, (2008), *Care Programme Approach (CPA) Briefing: Parents with mental health problems and their children*
- Department of Health, (2007), *Children's Health, our Future: A review of progress against the National Service Framework for Children, Young People and Maternity Services*
- Department of Health, (2008), *High Quality Care for All: NHS Next Stage Review Final Report*
- Department of Health, (2004), *National Service Framework for Children Young People and Maternity Services*
- Department of Health, (2007), *The National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care Services*
- Department of Health, (2006), *Our Health, Our Care, Our Say: A new direction for community services*
- Department of Health, (2008), *Our NHS, Our Future*
- Department of Health; Department for Children, Schools and Families, (2008), *Transition: moving on well. A good practice guide for health professionals and their partners on transition planning for young people with complex health needs or a disability*
- Disability Discrimination Act 2005: www.direct.gov.uk www.equalityhumanrights.com
- Eaton, (2000), *Children's Community Nursing Services; Models of care delivery. A review of the United Kingdom literature*
- Education and Skills Bill
- Evans and Kelly, (1995), *Bringing Support Home for Families of Children with Cancer*
- Every Child Matters: www.everychildmatters.gov.uk
- Every Disabled Child Matters: www.edcm.org.uk
- Foss T, (2005), *New NICE guidance for young people with cancer*
- Gallini A; Hooker L, (2005), *Young people's and carer's views on the cancer services they receive*
- General Medical Council, (2007), *0–18 years: guidance for all doctors*
- Gibson, F, Soanes, L, Sepion, B, (2004), *Perspectives in paediatric oncology nursing*
- Hawes R, (2005), *Therapeutic relationships with children and families*
- HM Treasury; Department for Children, Schools and Families, (2007), *Aiming High for Disabled Children*
- House of Commons Health Select Committee, (1997), *Health Services for Children and Young People in the Community*

- Hummelinck A; Pollock K, (2007), *The relationship between healthcare professionals and the parents of chronically ill children: negotiating the boundaries between dependence and expertise*
- Hunt, (1996), *Paediatric Oncology Outreach Nurse Specialists: The Impact of Funding Arrangements on their Professional Relationships*
- Individual Education Plan, Special Educational Needs: www.direct.gov.uk
- Langton H, (2000), *The child with cancer family-centred care in practice*
- Mitchell W; Clarke S; Sloper P, (2006), *Care and support needs of children and young people with cancer and their parents*
- National Children's Bureau, Care Planning for Looked After Children: www.ncb.org.uk
- National Institute for Health and Clinical Excellence, (2005), *Improving Outcomes in Children and Young People with Cancer*
- Nolbris M; Enskar K; Hellstrom A, (2007), *Experience of siblings of children treated for cancer*
- Norberg A; Boman K, (2007), *Parents' perceptions of support when a child has cancer: a longitudinal perspective*
- Office of the Third Sector, (2007), *Third Sector Review*
- Scottish Government, (2009), *National Delivery Plan for Children and Young People's Specialist Services in Scotland*
- Svavarsdottir E, (2005), *Caring for a child with cancer: a longitudinal perspective*
- Tatman and Woodroffe, (1993), *Paediatric home care in the UK*
- Taylor B, (2006), *Giving children and parents a voice: the parents' perspective*
- Theurer M; Tomlinson D, (2002), *Increasing children's compliance with oral chemotherapy through partnership*
- Thornes R, (2001), *Palliative care for young people aged 13-24 years*
- Whiting, (1990), *Home Care for Children*
- World Class Commissioning: www.dh.gov.uk
- Patterson J; Holm K; Gurney J, (2004), *The impact of childhood cancer on the family: a qualitative analysis of strains, resources and coping behaviours*
- Platt, (1959), *Welfare of Children in Hospital*
- Play England: www.playengland.org.uk
- Professor Sir Alan Craft and Sue Killen,(2007), *Independent Review of Palliative Care Services for Children and Young People in England*
- Upton P; Eiser C, (2006), *School experiences after treatment for a brain tumour*
- Woodgate R; Degner L, (2002), *'Nothing is carved in stone!' uncertainty in children with cancer and their families*
- Woodgate R, (2006), *Siblings' experiences with childhood cancer: a different way of being in the family*
- Youth Matters: www.dcsf.gov.uk/publications
- 11 MILLION, (2008), *Happy and Healthy*

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