

# MORE THAN MY ILLNESS

Delivering quality  
care for children with cancer  
Executive Summary



## 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<sup>1</sup> 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<sup>2</sup> to deliver the NICE guidance. In 2007, the implementation group agreed with CLIC Sargent’s<sup>3</sup> 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<sup>4</sup>. 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.

### 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.

### 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<sup>5</sup>, Better Care: Better

5 [www.improvement.nhs.uk](http://www.improvement.nhs.uk)

Lives<sup>6</sup> and ACT's National Networks Project<sup>7</sup>.

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. 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<sup>8</sup>. Previous consultation and research was also analysed<sup>9</sup>.

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.

### 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.

<sup>6</sup> Department of Health, (2008), *Better Care Better Lives*

<sup>7</sup> [www.act.org.uk](http://www.act.org.uk)

<sup>8</sup> Full details of the consultation results are available on request from CLIC Sargent.

<sup>9</sup> 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.

## 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'<sup>10</sup>.

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<sup>11</sup>, 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:

- 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<sup>12</sup>.

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.

- 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;

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

<sup>11</sup> For an explanation of shared care please refer to Appendix A.

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

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CLIC Sargent  
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