

# MORE THAN MY ILLNESS

Delivering quality care for children with cancer  
Summary of Consultation



## CONTENTS

<b>1 EXECUTIVE SUMMARY</b>	<b>4</b>
1.1 PURPOSE OF THIS REPORT	4
1.2 BACKGROUND TO “MORE THAN MY ILLNESS”	4
1.3 SCOPE OF THE CONSULTATION	4
1.4 CONSULTATION METHODOLOGY	5
1.5 SUMMARY OF FINDINGS	5
1.6 FUTURE RESEARCH	5
<b>2 SUMMARY OF NEEDS TO BE ADDRESSED BY THE MODEL OF CARE</b>	<b>6</b>
2.1 BEING ABLE TO GO HOME	6
2.2 KEEPING UP WITH EDUCATION	6
2.3 KEEPING UP WITH SOCIAL ACTIVITIES	6
2.4 TRANSITION AND HOME VISIT SUPPORT	6
2.5 EMOTIONAL SUPPORT	6
2.6 FINANCE AND EMPLOYMENT	7
2.7 PRACTICAL SUPPORT	7
2.8 INFORMATION	7
2.9 SUPPORT FOR THE WHOLE FAMILY	7
2.10 INDIVIDUAL, NEEDS-LED SUPPORT	7
<b>3 APPROACH TO CONSULTATION</b>	<b>8</b>
3.1 METHOD	8
3.1.1 Postal/online survey of service users	8
3.1.2 Interviews with Black and Minority Ethnic Families	9
3.1.3 Evaluation of service user involvement	9
3.1.4 Stakeholder events	10
3.1.5 Web form comments	10
3.1.6 Evaluation of service provider involvement	10
3.1.7 CLIC Sargent Social Work Activity Review	10
3.2 SUMMARY OF RESPONDENT GROUPS	11
<b>4 ANALYSIS OF NEED BY RESPONDENT GROUP</b>	<b>12</b>
4.1 YOUNG PEOPLE	12
4.1.1 Summary of results for general areas of need	12
4.1.2 Being able to go home during treatment	12
4.1.3 Keeping up with school/education	14
4.1.4 Keeping up with social activities	15

4.1.5 Talking to people about thoughts and feelings	17
4.1.6 Being able to get good medical treatment at home	19
4.1.7 Help on money matters: 16 plus age group	20
4.1.8 Work/employment: 16 plus age group	21
4.1.9 Support from family and friends	22
4.2 PARENTS AND CARERS	23
4.2.1 Financial support	23
4.2.2 Practical support	24
4.2.3 Support returning home (during and after treatment)	26
4.2.4 Home visits	28
4.2.5 Emotional support needs	29
4.2.6 Education needs	33
4.2.7 Employment needs	35
4.2.8 Support from professionals	37
4.2.9 Support from family and friends	37
4.3 SIBLINGS	37
4.3.1 General areas of need	37
4.3.2 Specific services required	38
4.3.3 Age considerations	38
4.3.4 Comments	38
4.4 BLACK AND MINORITY ETHNIC FAMILIES	39
4.5 SERVICE PROVIDERS AND OTHER STAKEHOLDERS	39
4.5.1 Stakeholder meetings	39
4.5.2 Web form submissions	40
4.5.3 Comments	41
4.6 SOCIAL WORK ACTIVITY REVIEW	42
4.6.1 Key findings	42
4.6.2 Comments	43
<b>5 A FOCUS FOR FUTURE RESEARCH</b>	<b>45</b>
5.1 ‘TESTS’ OR ‘TREATMENT’ AT HOME	45
5.2 YOUNG ADULTS	45
5.3 REPRESENTATION AND ACCESS	45
5.4 UNMET NEED AND ACCESS TO SERVICES	46
5.5 IN THE LONGER TERM	46
<b>6 ACKNOWLEDGEMENTS</b>	<b>47</b>
6.1 WHO ARE CLIC SARGENT?	47
6.2 THE CLIC SARGENT CONSULTATION TEAM	47

## 1. EXECUTIVE SUMMARY

### 1.1 PURPOSE OF THIS REPORT

This report collates and appraises the outputs of a broad-based consultation, undertaken by CLIC Sargent, on community based support for children and young people with cancer. The report's conclusions will be used by a group of experts, from across the UK, in developing an ideal model of community based care.

The report:

- Identifies the priority areas of need for the families of children and young people with cancer when not in hospital.
- Suggests services that could address such areas of need for inclusion in an ideal model of care.
- Proposes areas where further analysis and research is required.

### 1.2 BACKGROUND TO “MORE THAN MY ILLNESS”

For children and young people with cancer and their families, access to community-based support is not equitable. There are great variations across the UK in the availability, accessibility and delivery not only of specialist cancer and generic community children's nursing support, but also specialist cancer and generic psychosocial support in the community. This is particularly true for young adults above the age of sixteen who do not automatically receive care tailored to their specific needs.

Current healthcare provision for children and young people with cancer<sup>1</sup> is based on guidance issued, in 2005, by the National Institute for Health and Clinical Excellence (NICE). NICE recognised that the needs of children and young people with cancer are different from those of older adults with cancer. The aim of the guidance is to ensure that children and young people with cancer get the best possible and most appropriate care for their age.

<sup>1</sup> 'Improving Outcomes in Children and Young People with Cancer', August 2005, [www.nice.org.uk](http://www.nice.org.uk)

The Department of Health and the NHS established an implementation group<sup>2</sup> to deliver the NICE guidance. In November 2007, the implementation group agreed with CLIC Sargent's 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.

The review would be based on consultation with service users, service providers and other stakeholders. In this report CLIC Sargent summarises the outputs of the consultation and identifies the priority needs to be addressed by the proposed model of care.

### 1.3 SCOPE OF THE CONSULTATION

The consultation encompassed:

- **Services for children and young people aged 0-18 years.** In order to cover the transition from childhood to adulthood the consultation included young people aged 19-24 years. Care has been taken to indicate where the needs of this age group are different.
- **Services for parents/carers of the child or young person and, where needed, significant others** (particularly siblings).
- **All stages of the cancer journey** (from diagnosis through to end of treatment, including transition towards long term survivorship, palliative care and bereavement).
- **Clinical and psychosocial needs** not only in local community care settings but also between hospital care settings.

The following was not covered by the consultation:

- Care within hospitals, except where it relates to needs outside hospital.
- Long term care and support for survivors, although the model will include preparations for becoming a survivor

<sup>2</sup> Improving Outcomes Guidance for Children and Young People with Cancer Advisory Group

while treatment is still being received

- Long term care and support for the bereaved

### 1.4 CONSULTATION METHODOLOGY

The consultation consisted of five elements:

- Postal/online survey
- Telephone interviews
- Stakeholder events
- Comments received via the web
- Results from the CLIC Sargent Social Work Activity Review surveys

### 1.5 SUMMARY OF FINDINGS

Responses to the consultation identified the following needs for inclusion in an ideal model of community based care:

- **Being able to go home** (particularly important for young people and their siblings)
- **Keeping up with education** (particularly education liaison and advocacy)
- **Keeping up with social activities** (existing social networks, time with family and specialist peer support)
- **Transition and home visit support** (including training, home visit support when needed, 24/7 phone contacts, clinical keyworking and co-ordinated care planning)
- **Emotional support** (from peers and also professionals when needed)
- **Finance and employment support** (for parents/carers and independent young adults)
- **Practical support** (to ensure access to services and to maintain an everyday home life)
- **Information** (relating to all other areas of need)
- **Support for the whole family** (particularly siblings)
- **Individual, needs-led support** (including good assessment and re-assessment of needs)

### 1.6 FUTURE RESEARCH

In addition, a number of areas were identified where further research or analysis would be important:

- 'Tests' or 'Treatment' at Home: Further research is needed to establish the types of clinical support that young people would like to receive at home, such as simple procedures (eg. blood tests and line care) or more complex delivery of treatments.
- Young Adults: The needs of young adults aged 19-24 years who are covered by the NICE guidance, but who will not be covered by the model of care, should be investigated in more depth for a second model of care.
- Representation and Access: In further research, the representation of particular service user groups should be expanded and their experiences of accessing services explored: children and young people from black and minority ethnic groups, or with particular cancer types, or from particular age groups; other family members including siblings and fathers; and families with complex or high needs.
- Unmet Need and Access to Services: Further analysis of the survey data is necessary to identify where specific needs are not met and to determine levels of satisfaction with services. Such analysis could highlight key areas for service development and also measures likely to reduce inequity of access to services.

## 2. SUMMARY OF NEEDS TO BE ADDRESSED BY THE MODEL OF CARE

### 2.1 BEING ABLE TO GO HOME

- The top priority overall for young people, this need enables young people and their families to fulfil other needs, such as keeping up with education and maintaining a social support network, but requires a number of support services.
- In support of this finding, service providers say that families should have access to appropriate, safe treatment as locally as possible.

### 2.2 KEEPING UP WITH EDUCATION

- A link between hospital and school/college is important to families, as is being able to communicate needs to education service providers. This suggests a need for education liaison and advocacy.
- Young people also require individual consideration, understanding and opportunities to study appropriate to their age and abilities.

### 2.3 KEEPING UP WITH SOCIAL ACTIVITIES

- Some elements of keeping up with everyday social activities may not have to be provided directly by a model of care but rather may be enabled by allowing young people to spend more time at home and in education (or work).
- However, some young people need assistance in this area in terms of access, resources, liaison (with individuals and organisations) and opportunities to meet other patients.

### 2.4 TRANSITION AND HOME VISIT SUPPORT

- Services should be designed to support and empower the young person and their family throughout treatment to survivorship.
- Families highlighted the following clinical services as priorities:
  - appropriate clinical training for parents and carers;
  - provision of information;
  - access to nursing at home when needed (specialist or generic);
  - clear phone contacts at the main treatment centre; and
  - access to out of hours phone support.
- Service providers suggested means of meeting these needs, in particular having access to 24/7 advice and support as well as a clinical keyworker to co-ordinate care.

### 2.5 EMOTIONAL SUPPORT

- Parents feel more secure when they have access to good clinical support while at home, and also appreciate follow-up phone contact with a key professional.
- Children and young people derive a great deal of their emotional support from non-care professionals. Services that allow young people greater access to support networks (eg. by going home or taking part in a group) and more opportunities to build confidence and self-esteem (eg. through education or respite) are means of providing emotional support for children and young people.
- However, the need for professional support for all members of a family should be assessed regularly.

- There may also be a need to assess what support families could lose by spending more time at home (eg. contact with professionals who know the family and with other parents/carers or peers going through similar experiences).

### 2.6 FINANCE AND EMPLOYMENT

- Financial support is a core need for parents and independent young adults, essential for maintaining a secure home life during and after their child's illness, and should be addressed in a model of care.
- Most families require immediate monetary assistance to cover the extra practical costs of caring for a child with cancer.
- Support may then be required in the longer term with continuing costs (eg. where disability support is required).
- In addition to extra money from grants and benefits, easy access to information and advocacy are also important, for example when liaising with employers and benefits agencies, or just finding out what support is available.

### 2.7 PRACTICAL SUPPORT

- 'Practical support' encompasses a wide range of services which aim not only to ensure a safe and appropriate home environment for a family during and after treatment but also to remove barriers to accessing core services.
- Support may be required for the extended family and friends whose lives may also be impacted by the cancer diagnosis and who may find themselves in a caring role.
- Practical needs are highly individual, so a model of care should stress the need for a comprehensive assessment of psychosocial need.

### 2.8 INFORMATION

- Information is a common thread through many of the areas of need listed above (as advice or in the form of publications).
- Good information could enable families to feel more secure at home and empower them in other areas of need (eg. education and employment).
- Hence, the access to different types of information should form part of an assessment of families' needs.

### 2.9 SUPPORT FOR THE WHOLE FAMILY

- Many of the needs listed above apply to the whole family. Siblings in particular might experience a great deal of disruption to their everyday and emotional life. Their top need is for their brother/sister with cancer to spend more time at home, but this may also have an impact on family life.
- Siblings and other family members may require emotional support, information and practical support (particularly if they are in a caring role).
- Therefore, assessments of need should take into account all affected family members.

### 2.10 INDIVIDUAL, NEEDS-LED SUPPORT

- Providing needs-led support is also a common theme across the strands of the consultation. Some areas of need apply to most families (eg. finance) whereas others apply to fewer families but are essential to these families (eg. help with language issues; professional emotional support).
- In line with this, service providers identified the need for good assessment and re-assessment of clinical and psychosocial need.

## 3. APPROACH TO THE CONSULTATION

This chapter sets out the methodology used for the consultation with service users and service providers. A full description of the methodology, the respondents and the complete results from each element can be found in the appendices to this report (published as a separate document)<sup>3</sup>.

### 3.1 METHOD

#### 3.1.1 Postal/online survey of service users

The aim of this element of the consultation was to identify and prioritise core clinical and psychosocial needs amongst recent service users while not in hospital (parents/carers of all age groups, children and young people who have or have had cancer aged 10 to 26 years and their siblings aged 10 to 26 years). For the purposes of the survey research, a core need was defined as a service required by a majority of respondents.

During the survey design, general areas of need and specific services pertinent to the research question were identified by speaking directly to families (eight semi-structured telephone interviews) and by reviewing the results of existing external and CLIC Sargent consultations.

In the survey, service users were asked, “What support do families need when not in hospital?”. Parents/carers were asked to rate their need for and satisfaction with specific services in a number of areas. In a separate survey, young people and their siblings were asked to rate the importance of receiving support in a number of general areas and their need for specific services in these areas. All respondents were also given the opportunity to say what else they had found helpful or missing. The survey forms can be found in the appendices to this report.

In order to contact families where the child or young person was currently on treatment or had recent experience of services, surveys were sent to open-case families registered with CLIC Sargent between 1st March 2007 and 1st March 2008 (families are registered shortly after diagnosis by a social worker or other care professional). Social workers were able to remove families from the distribution list where appropriate (eg. very recently bereaved families).

Surveys were also sent to families registered with CLIC Sargent’s Parents’/Carers’ and Young People’s research participation groups whose social work support had ended between 1st March 2007 and 1st March 2008 and who therefore had recent experience of services.

A total of 5340 surveys were distributed to 1863 families (a parent/carer, patient and sibling in each family where appropriate). Two distribution methods were used:

- Online Surveys: for parents/carers and young people (18+) open from 26th March-9th April
- Postal Surveys: Postal surveys sent out to all family members between 20-25th March and returns accepted up to 9th April.

A total of 460 service users responded to the survey and were included in the analysis (115 young people, 286 parents/carers and 61 siblings). Responses were received from all regions of the UK and all CCLG (Childhood Cancer and Leukaemia Group) treatment centres and all TCT (Teenage Cancer Trust) units were represented. The sample size was comparable to a recent similar consultation<sup>4</sup> although the actual response rate was lower (due in part to the shorter data collection period).

#### 3.1.2 Interviews with black and Minority Ethnic Families

It was essential to ensure that all service users’ views were represented in the consultation, including service users from black and minority ethnic (BME) backgrounds, who may be under-represented in postal survey research.

Overall, 7.6% of survey respondents were ‘non-white’. This was in line with previous consultations<sup>5</sup> and also with census data on ethnicity in the UK population<sup>6</sup>. However, the figure was lower than that of cancer registrations amongst 0-15s<sup>7</sup>. There were also indications that language difficulties prevented some service users from completing the survey (3 surveys were excluded from analysis due to language difficulties).

Therefore, following the design of the paper survey in March 2007, three semi-structured interviews with parents from BME backgrounds (2 mothers and 1 father), were conducted using the themes of the survey. The aim of the interviews was to identify particular needs of BME service users that might not have emerged during the initial interviews and survey analysis. One of the initial interviews with a young person from a BME background was also re-analysed with this aim.

A summary of the results of this analysis is included in this report, and a breakdown of all interview respondents is provided in the appendices (interview transcripts are not provided for reasons of confidentiality).

#### 3.1.3 Evaluation of Service User Involvement

The survey element of this consultation built on previous consultations relevant to the NICE guidance

by focusing on the need for particular services while not in hospital. Levels of participation compared favourably with those of other consultations.

It should be noted, however, that:

- Most families with a child with cancer age 0-15 years are registered with CLIC Sargent by a social worker or other care professional (eg. a Paediatric Oncology Outreach Nurse Specialist) shortly following diagnosis and should therefore have received a survey. By contrast families in the 16+ age group, and particularly those aged 19-24, are less likely to access age-appropriate services and therefore may not be fully represented on the survey mailing lists. For this reason a second model of care should be developed, informed by additional consultation, for those aged 19-24. The analysis of the survey results presented here takes care to highlight where the needs of this age group may differ from those of younger age groups.
- Analysis of the survey responses identified needs which were common to a majority of service respondents, rather than different patterns of need. High-need families and those with complex needs may require consideration within a model of care.
- In relation to palliative care and bereavement support, while nineteen bereaved parents (out of 62 who were mailed) and 1 palliative family responded to the survey many more were removed from mailings list for reasons of sensitivity. For this reason, the development of a model care should refer to other recent work in this area<sup>8</sup>
- While the interview data was useful in identifying the needs of people who might be under-represented in survey research or whose needs were highly individual, there is scope for increasing representation from BME

<sup>3</sup> For a copy of the appendices to this report, please contact Susan George (Assistant Director of Services, CLIC Sargent): Susan.George@clicsargent.org.uk or 0117 311 2626.

<sup>4</sup> Care and Support Needs of Children and Young People with Cancer and their Families, research conducted by the Social Policy Research Unit, York University, for CLIC Sargent, July 2004, (The York Report): <http://php.york.ac.uk/inst/spru/pubs/child.php>

<sup>5</sup> The York Report, as above; Improving Outcomes in Children and Young People with Cancer: The Evidence Review, August 2005, [www.nice.org.uk](http://www.nice.org.uk)

<sup>6</sup> UK Census 2001, Office of National Statistics, <http://www.statistics.gov.uk/cci/nugget.asp?id=764>

<sup>7</sup> Data communicated to CLIC Sargent from the National Registry of Childhood Tumours Numbers, Oxford University: Registrations by ethnic group received via CCLG centres 2001–2005 showed 12% of registrations were from ‘non-white’ groups.

<sup>8</sup> Better Care, Better Lives: Improving outcomes for children, young people and their families living with life-limiting and life-threatening conditions, February 2008, Department of Health: [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_083106](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_083106)

service users and other under-represented groups, for example through further research.

More generally, it is important to supplement the views of service users with those of service providers. Service users may be able to fully comment only on services they have experienced. Service providers may be able to comment on a broader range of services, including how to optimise outcomes for families and meet families’ needs.

### 3.1.4 Stakeholder events

In April 2007, two facilitated meetings were arranged for service providers and other key stakeholders to explore the needs of children, young people and their families when not in hospital. Those who could not attend were invited to send submissions by email. Forty-six people took part, including 41 service providers and 5 service users.

The nominal group technique was used to facilitate discussion in small groups at the meetings. All participants were asked 3 key questions:

- What are the top 5 care/support needs of children/young people and their families when they are not in hospital (considering if these vary by age, point in cancer journey, diagnosis)?
- Who currently (in your “patch”) meets these needs (considering if these are the most appropriate people, who else may be appropriate if no-one is currently meeting these needs)?
- What are the current “blocks” to children/young people and families receiving good community based care and support (considering this in your own “patch” and nationally)?

Only the first of these questions is considered in this report as the primary focus of the consultation was to identify and prioritise core needs.

The top 5 responses to Question 1 from small groups at each meeting and from email responses were collated. The resulting list of eleven high priority needs for families is set out in this report. The full list of needs generated during this exercise, and a

description of the method and participants, can be found in the appendix to this report.

### 3.1.5 Web form comments

Because those participating in the workshops were fewer than hoped for, the CLIC Sargent external website hosted information about the consultation and provided a web form on which people could submit their comments. Five relevant submissions were made using the web form and are therefore summarised in this report.

### 3.1.6 Evaluation of service provider involvement

In total, 51 service providers and other stakeholders participated in the consultation in facilitated meetings or via email/internet (previous consultations relating to the NICE guidance have not involved service providers in this way).

While greater attendance at the facilitated meetings would have been desirable, further input from clinical service providers will be obtained through representation on the Expert Working Group who will review the evidence from this consultation in order to develop the model of care.

The Expert Working Group will also be able to take account of the views of many more service providers (clinical and non-clinical) and service users by drawing on the internal review of social work activity conducted by CLIC Sargent at the same time as the consultation. This second review, discussed below, will provide a means of assessing the reliability of psychosocial needs identified in the other four elements of the consultation for the community care review.

### 3.1.7 CLIC Sargent Social Work Activity Review

In order to ensure that the services provided by CLIC Sargent social workers are needs-led and equitable across the UK, CLIC Sargent initiated a “Social Work Activity Review” in August 2007. The review was

designed to inform and enhance the charity’s existing Social Work Framework.

**CLIC Sargent social workers:** The first stage was to find out from social workers the full range of services and activities offered to families and young people. A survey was sent to CLIC Sargent social workers in August 2007 and 56 out of 81 eligible social workers responded by November 2007. A group of five social workers (one from each of five regions of the UK) advised on the analysis of the survey responses.

The first result from the review was a “top ten” list of social work priorities for families.

**Service users:** In the second stage of the review, service users were asked if they agreed with the “top ten” priorities identified by social workers. A survey was produced and issued to members of CLIC Sargent’s research participation groups (individuals who have agreed to take part in research). A total of 2317 surveys were distributed to 1485 families and 419 responses were received (79 from young people and 340 from parents/carers). All CCLG centres were represented, as were 6 TCT units (plus other wards). Data collection took place from 7th February – 10th March 2007.

**Other Service Providers:** A similar survey was also sent to CLIC Sargent social workers’ multidisciplinary team (MDT) colleagues (or ward colleagues where

there was no MDT). Data collection took place from 7th March-31st March 2007.

698 surveys were sent out and 230 were returned (of which at least 202 were from non-CLIC Sargent staff). Twenty different roles were represented amongst the respondents, as were eighteen CCLG centres and seven TCT units (plus other shared care, local and adult wards).

### Contribution to the Community Care Review:

In the third stage of the review the objective was to develop a consensus about the core social work services to be offered by CLIC Sargent to all children, young people and families (including care required while not in hospital). The findings are reported here. By comparing these findings with the results of other strands of the consultation, it should be possible to evaluate their reliability in terms of psychosocial need.

## 3.2 SUMMARY OF RESPONDENT GROUPS

Table 1 below shows the different types of respondents for each of the five strands of the consultation. Further detail is available in the appendices.

The 1263 individual contributions to the review comprised a broad range of service users and stakeholders, thus enabling a reliable set of needs to emerge from the consultation.

Table 1: Different types of respondents for each of the five strands of the consultation

Method	Respondent Groups				
	Service Users			Service Providers	Total*
	Young People	Parents/Carers	Siblings		
Survey	115	284	61	-	460
Interviews	1	10	-	-	125
Stakeholder Events	2	3	-	41	46
Web Form	-	-	-	5	5
Social Work Activity Review	115	340	-	286	741
Total*	233	637	61	332	1263

\*A very small number of participants may have participated in more than one element of the consultation.

## 4. ANALYSIS OF NEED BY RESPONDENT GROUP

### 4.1 YOUNG PEOPLE

Young people were asked to rate a number of general areas of need as ‘not important’, ‘important’ or ‘very important’. For every general area they were then asked to indicate whether they had ‘received’, ‘not received’ or ‘not needed’ each of a list of specific support services (eg. for the general heading ‘Keeping up with Education’ the specific support services included ‘explaining to teachers what is going on’ and ‘getting a home tutor’). For each general area at least two further open box questions were asked: “What else has been helpful” and “What else do you need now”. The results were broken down by age at treatment. The full analysis for both rating questions and open-box questions can be found in the appendix to this report.

#### 4.1.1 Summary of results for general areas of need

The results in Table 2 below show the percentage of respondents who rated each of the general areas of need as ‘important’ or ‘very important’ combined. The results are analysed by age at treatment, and are arranged from most to least important.

For both age groups combined, ‘being able to go home’ was rated significantly more important than all

other needs ( $p < .05$ ). ‘Keeping up with social activities’ was also rated highly but ‘getting good medical treatment at home’ was rated as less important.

The findings also showed that age at treatment might be associated with how needs were prioritised. For example, there was much less variation amongst younger respondents, with at least 70% of respondents rating each area of need as important ( $p < .05$ ).

Diverging pathways in study and work after the age of 16 years may be an important factor; for this reason, the older age group were also asked about finance and employment. For the older age group, ‘work/employment’ was rated significantly lower than other needs.

Each of the general areas of need are explored in more detail below, taking into account the specific services associated with each need and the comments which young people made about each area of need as well as age at treatment.

#### 4.1.2 Being able to go home during treatment

Almost all young people said that it was ‘important’ or ‘very important’ to be able to go home during treatment. This need was rated higher than any other.

**Table 2: Percentage of respondents who rated each of the general areas of need as ‘important’ or ‘very important’ combined**

	Up to and including 15 years (n = 52)		16 years and older (n = 63)		Total (n = 115)	
	Freq.	%	Freq.	%	Freq.	%
Being able to go home during treatment	50	96%	61	97%	111	97%
Keeping up with social activities	46	88%	60	95%	106	92%
Talking to people about your thoughts and feelings	41	79%	50	79%	91	79%
Keeping up with school/education	48	92%	39	62%	87	76%
Getting help on money matters	na	na	45	71%	45	71%
Getting good medical treatment at home instead of in hospital	37	71%	34	54%	71	62%
Work/employment	na	na	19	30%	19	30%

‘Going home’ may enable young people to fulfil other needs (such as keeping up with school and friends) but may require support services (such as education support and clinical support at home) that may not be immediately apparent to all young people.

#### Younger age group (0 to 15 years at treatment)

The specific services relating to ‘going home’ that were required by the younger age group were ‘information that you need’ and visits from ‘someone to explain what to expect about your illness’. Information and explanations could enable a young person and their family to manage the practical aspects of their illness at home and also make the family feel supported and more confident about managing the illness in the future.

The most frequent comments about ‘what else has been helpful’ or ‘is needed now’ related to help from professionals at home, especially nurses, who could

- perform simple procedures at home (meaning fewer hospital visits),
- talk to the young person and
- provide the information and explanations that young people need.

There is an emotional component to this need. In particular, open-box comments indicated that young people want to know what will happen next and how things will develop in the future. Related to this, young people also indicated that they like being close to their family. Being able to go home might allow young people access to emotional support from their families and surroundings.

**What else has been helpful?**  
“Having a nurse come round to take blood instead of me going to hospital.”  
*(Male, age 15, On treatment)*

“My mum, my dad, my brother being there.”  
*(Female, age 13, On treatment)*

**What else do you need right now?**  
“I would like somebody to explain how it affects me in the long run.”  
*(Male, age 11)*

#### Older age group (16 plus years)

As for the younger age group, the older age group appreciated being given information that they needed, though ‘explanations’ about the future were needed to a lesser extent.

Open-box comments indicated that the older age group had a greater understanding of the type and range of support services required at home (support from clinical and non-clinical professionals, home visits and close contact with the hospital). This finding perhaps reflected greater independence amongst this age group, some of whom might have greater financial and practical needs than younger age groups.

This age group also appreciated support from their family and friends.

**What else has been helpful?**  
“Helpline (24 hours) at [hospital ward]. I actually needed advice a few times from the helpline.”  
*(Male, age 20, On treatment)*

**What else do you need right now?**  
“Someone to explain what’s next, about appointments, after care, when will my line come out.”  
*(Female, age 19, Off treatment <1yr)*

**What else do you need right now?**  
“Help with filling in benefits forms, information about disability aids/ counselling. As soon as I was discharged back home, I had no social worker.”  
*(Female, age 23 [16 at diagnosis], On treatment)*

### Other findings

Other specific services, for example transport to and from hospital and visits to explain medication and treatment at home, that would enable young people to go home during cancer treatment were needed to a lesser extent than ‘information’ and general ‘explanations’. However, all specific services asked about under the general heading ‘Being able to go home during treatment’ were needed by at least half of respondents.

Parents might have responsibility for these more practical aspects of going home, especially for the younger age group, whereas young people themselves might be more focused on the security of being closer to family and friends.

### Comments

Young people’s reports of how important it is to ‘go home during treatment’ and the support services they need that enable them to do so might be influenced by their experiences to date.

For example, young people who have not had access to age-appropriate services might feel a greater need to be at home than those who have. This could be explored further.

In addition, further research could investigate what aspects of being at home are the most important for young people. For example, whether young people are happy to be day patients if they can sleep at home each night or would prefer some types of procedures to be carried out at home.

If a model of care was to adopt ‘being able to go home’ as a core need it must incorporate a number of support services (eg. clinical, practical and emotional) to facilitate this. It must also recognise that going home can fulfil a number of needs (eg. social and emotional) for young people. Young people prefer to be at home as much as possible. However, when developing the model of care, this need must be balanced with what is safe and offers reasonable value for money.

### 4.1.3 Keeping up with school/education

“Keeping up with school/education” was rated as important to the majority of young people. However, this is an area where needs change with age as young patients make the transition through life stages and choices.

#### Younger age group (0 to 15 years)

Almost all young people treated up to and including 15 years rated ‘keeping up with education’ as ‘important’ or ‘very important’. All of these respondents were of compulsory school age (5-16 years) at diagnosis and treatment, so education was a common factor across respondents in this age group.

The top specific support services required in terms of education were ‘help explaining to teachers what’s going on’ and ‘help keeping up with schoolwork/studies’. Help ‘getting back into schoolwork/studies’ and ‘a home tutor’ were also identified as needed services. However, ‘help preparing for and taking exams’ was required by fewer respondents and was likely to be dependent on age and stage of education.

Open-box comments corroborated these findings, showing that both support networks and studying opportunities are important to young people receiving treatment. Comments indicated a focus amongst this age group on establishing links between hospital and school that could make re-integration easier later on. Future integration back into education could be facilitated both by reducing social isolation during treatment and by providing opportunities to engage in meaningful study so young people do not fall behind in their studies. On the latter point, young people said that support from both the school and a home tutor could both be helpful.

#### What else do you need now?

“Would have preferred a home tutor and assistance from school to keep up to date.”

*(Male, age 15, Off treatment <1 year )*

#### What else has been helpful?

“Not allowed in school due to transplant — school tutor has been helpful. Social worker liaised with school to get friends and teachers into hospital to see me and to send cards and letters etc.”

*(Male, age 14, Off treatment <1 year )*

“One of my nurses and a learning mentor went into school to explain about my condition. This made it easier when I returned to school.”

*(Female, age 15 [13 at diagnosis], Off treatment >1year)*

#### Older age group (16 plus years)

‘Keeping up with education’ was identified as comparatively less important by the older age group. After key exams, generally taken at 16 and 18, fewer young people remain in education and so this was no longer an area of concern for some young people. There was a tendency amongst the over 18s not to answer this question, often indicating ‘not applicable’.

However, many of the 16+ age group were in school, college or university and, similarly to the younger age group, the most needed support service was to have ‘someone to explain to teachers what’s going on’. Open-box comments indicated that being understood and feeling supported by education staff was important in this age group, along with practical help to keep up with studies, such as equipment, books and time.

#### What else has been helpful?

“Matron for making tea and offering me a place to rest, also for kids and understanding teachers.”

*(Male, age 16, On treatment)*

“Disability office at university have been very understanding.”

*(Male, age 22, Off treatment <1yr)*

#### What else do you need now?

“It would have helped if the exam board had been notified about how much time I have had to miss. I have missed approximately 3 months of this year’s work and find college difficult now — this wasn’t considered in my January modules.”

*(Female, age 18, On treatment)*

“Someone to explain to teachers that I am still not completely able to complete all my lessons (teachers expect me to be fine now).”

*(Female, age 16)*

### Comments

In the proposed model it would be interesting to address how children’s and young people’s educational needs could be met. Being able to link between hospital and school/college is important, as is being able to communicate needs to education service providers. This suggests a need for education liaison and advocacy. In addition, the need for individual consideration, understanding and opportunities to learn comes across strongly in young people’s comments.

### 4.1.4 Keeping up with social activities

‘Keeping up with social activities’ was rated as important to the majority of respondents, particularly in the older age group. It could be that being able to socialise with family and friends is one of the benefits and drivers of wanting to go home during treatment and keep up with education. Social networks could provide emotional support and practical help, and might facilitate a feeling of ‘normality’ during treatment or facilitate easier transition back to ‘normal life’ following treatment.

### Younger age group (0 to 15 years)

‘Keeping up with social activities’ was important to most respondents in this age group, though slightly less important than ‘going home during treatment’ and ‘keeping up with education’.

The specific needs/services in this area involved both young people’s normal social network (eg. their ‘normal social life’ and ‘holidays/day trips with your family’) and opportunities to ‘meet other people going through the same thing as you’ (including camps and holidays). As with keeping up with education, this related closely to the young person being able to maintain an everyday life and also establish a support network of understanding people.

The most common open-box comments for this age group related to maintaining a social life, either by actually going out with friends or by just being able to keep in touch. Specialist cancer youth groups were also mentioned, as was just generally being able to spend time with family and friends. A number of young people noted that it was difficult when friends did not understand what they were going through, and some mentioned effects of their illness or treatment which could make it difficult to socialise.

#### What else has been helpful?

“Going out after school with my friends and going out to clubs.”

(Female, age 15, Off treatment <1yr)

“Emails and calls from friends.”

(Female, age 13, On treatment)

“Opportunities with [Patient Support Group] eg. the makeover day and ice skating.”

(Female, age 15, On Treatment)

#### What else do you need now?

“More social activities in my local area that are not too energetic!”

(Female, age 14, On treatment)

“Friends that don’t see you as being any different still inviting you out.”

(Female, 17 years [14 at treatment], Off treatment >1yr)

### Older age group (16 plus years)

‘Keeping up with social activities’ became a higher priority as age increased, just below ‘being able to go home during treatment’. Indeed, those over 18 years tended to give the highest rating of ‘very important’ in comparison to those aged 16-18 who more often used the ‘important’ rating.

As with the younger age group, both normal social activities and contact with other patients was important. The most frequent open-box comments in this age group concerned generally being able to spend time with family and friends and comments about the types of support family and friends could offer. This age group wanted to ‘carry on as normal’ and a ‘normal social life’ was an important part of this. Again, this age group mentioned some of the barriers to maintaining a social life, but also proposed some solutions, such as help from professionals with arranging activities and communicating with friends.

As well as referring to respite from their cancer experience, some comments also concerned specialist services such as youth groups. However, the older age group indicated that they needed camps and holidays to a lesser extent than younger patients.

#### What else has been helpful?

“Having my friends trying to keep everything as normal as possible so I can relax and have a laugh while I’m out of hospital and in between treatments.”

(Male, age 21, Off treatment <1yr)

#### What else has been helpful?

“My parents and partner keeping me company.”  
(Female, age 17, On treatment)

“Getting away and forgetting it all.”  
(Male, age 16, On treatment)

“A friend who can fully understand my feelings. Social worker who could help me manage planning my life as normal.”  
(Female, age 20, On treatment)

“I went away with my parents last year for 3 days as that’s all we could afford. I am having my craniotomy repaired soon but could do with a nice break after, somewhere for the family.”  
(Male, age 18, Off treatment < 1yr)

“Someone to explain to my friends I am still the same person, despite the cancer.”  
(Female, age 17, On treatment)

### Comments

Some elements of keeping up with everyday social activities need not be provided directly by a model of care but rather might be enabled by allowing young people to spend more time at home and in education (or work). However, some young people did indicate that they needed assistance in terms of accessing and liaising with individuals and organisations that offered opportunities for social interaction, relating both to their everyday social life and their cancer experience.

It is likely that ‘keeping up with social activities’ was related closely to other areas of need, such as education and emotional support. Some services that could be incorporated in a model, such as liaison between hospital and school, holidays and camps or groups could address several needs for young people.

Consideration must also be given to those at the upper end of the older age bracket whose normal social support network and needs may be different to younger patients (particularly if the patient lives independently).

### 4.1.5 Talking to people about thoughts and feelings

‘Talking to people about thoughts and feelings’ was important to the majority of young people, and need was at a similar level across age groups. However, fewer young people rated talking about feelings as important as education, social activities and ‘going home’.

Emotional support could be an outcome of many different services that allow children and young people greater access to their support networks (eg. going home or taking part in a group) and more opportunities to build confidence and self-esteem (eg. through education). Socialising, taking part in groups or activities and just being with family and friends are sources of emotional support as well as formal professional support.

### Younger age group (0 to 15 years)

Unlike other sections of the survey, young people were asked who they liked to talk to about thoughts and feelings from a list of five professionals (counsellor/psychologist, youth worker, nurse, social worker and GP/local doctor). The ‘nurse’ was the most popular choice for both the 0-15 age group and the 16+ age group (a third of respondents in each age group).

A number of respondents in this age group also identified formal or informal professional help as useful in their open box comments, particularly continued contact with hospital staff and support during trips home or treatment at home.

However, a high rate of ‘no answer’ to many questions in this section of the survey suggested that ‘talking about thoughts and feelings’ was either something that some young people might not want to directly address, did not identify with, or did not always require from professionals.

In support of this, when young people were asked who else they liked to talk to, just under a third of young people (age groups combined) indicated that they liked to talk to their parents (especially ‘mum’), this figure being higher for the younger age group. Friends were also important to the younger age group, along with other family members.

While family and friends were an important source of emotional support, open-box comments indicated that contact with other young patients could also be important in terms of feeling understood and accepted.

**What else has been helpful?**

“Talking to the ward via telephone when we need advice.”

*(Male, age 15, On Treatment)*

“I can always talk to my mum as well.”

*(Female, age 14, On treatment)*

“Being able to get treatment at home and talk about it at the same time. I have talked to CAMHS [Child and Adolescent Mental Health Services] as well.”

*(Male, age 13, On treatment)*

**What else do you need now?**

“A friend with the same sort of thing.”

*(Female, age 11, On treatment)*

**Older age group (16 plus years)**

As for young patients, the older age group ranked ‘nurses’ as the most popular professional to talk to about thoughts and feelings. However, social workers were also chosen by a quarter of the older age group. It was likely that older patients had more direct contact with social workers and this was reflected in this finding.

The older age group were, however, more likely to mention structured activities they found useful such as writing, keeping a diary and youth groups. Interestingly, twice as many respondents in the older age group answered the open-box questions in this section, perhaps indicating a greater understanding of this area of support.

The most frequent comments, like the younger age group, concerned who else young people like to speak to. Around a third of respondents in this age group said they liked to talk to their parents. There is some indication that support networks change as age increases, with patients in this age group more frequently mentioning their friends or their partner.

**What else has been helpful?**

“Being able to talk to my parents, we shared any worries and thoughts we had. It helped to talk.”

*(Female, age 20, On treatment)*

“Access to a [name of charity] specialist nurse who is available but also calls just to see how I am.”

*(Male, age 23, On treatment)*

**What else do you need now?**

“My friends to understand more and to feel confident and not to feel different.”

*(Female, age 17, On treatment)*

“Continuing support from my family and my doctors.”

*(Male, age 16, On treatment)*

“More contact with other young cancer sufferers — maybe more regular support groups.”

*(Male, age 17, On treatment)*

**Comments**

The findings of the survey suggested that young people sought a great deal of their emotional support from non-care professionals. A model of care could aim to support parents, other family members, friends and partners by providing the skills, resources and contacts required to play this role, as well as supporting the patient directly.

This did not, however, mean there was no role for care professionals in providing emotional support directly to the young person, and a number of young people mentioned that this had been useful. The need for professional support should be assessed regularly and opportunities for supportive interactions and relationships should be made available (eg. through groups or via a regular catch-up contact with professionals).

Further research could address the particular types of support required (eg. through more in-depth work with young people) and feedback from or about those professionals whose roles were not represented in this survey (eg. play specialists and youth workers).

Findings from other sections of the young people’s survey suggested that emotional support could be gained through other areas of need. Being able to go home, keeping up with education, keeping up with social activities and talking to people about thoughts and feelings were all linked.

In all these areas of need, the aim is to support a young person through treatment in such a way as to become a successful long term survivor of cancer. This means enabling the young person to stay in touch with their everyday normal life, but also providing opportunities for specialist help when needed.

**4.1.6 Being able to get good medical treatment at home**

Previous sections have focused on the psychosocial needs of young people with cancer when not in hospital, or the psychosocial benefits of services that enable them to be at home. However, a key need in the first instance is to receive the best and safest medical treatment to both optimise chances of survival and enable the young person to live as healthy a life as possible after treatment.

Interestingly, in comparison to other needs, fewer young people rated ‘being able to get good medical treatment at home’ as important even though almost all respondents said that ‘being able to go home during treatment’ was important. The reasons for this are explored below.

**Younger age group (0 to 15 years)**

Although getting good medical treatment at home was less important to this age group than other general areas of need, it was still ‘important’ or ‘very important’ to the majority of respondents in this age group, and to a greater extent than for the older age group. The focus in this age group was being able to go home rather than the support this might require.

Similarly to ‘thoughts and feelings’, young people were asked to indicate one or more professionals they liked to talk to about their medical needs whilst at home, from a list of five (specialist nurse, local nurse, GP, social worker, someone at the hospital). Just under half of respondents chose a ‘specialist nurse’ and just under half chose ‘someone at the hospital’. In contrast to ‘thoughts and feelings’, open-box comments showed that professionals were the most favoured people to talk to about medical needs, though family and friends still played a role.

Open-box comments also indicated that nurses being able to perform simple procedures (eg. blood-tests and care of lines) at home or locally were valued. Treatment at home was not mentioned specifically, although parents being able to administer medication was mentioned. Both of these could reduce the need for hospital visits. Further research could seek to specify in more detail what aspects of care young people would like to receive at home.

Other specific needs mentioned included support equipment (eg. mattress) and other practical help (eg. disabled sticker for the car). These needs were for practical support rather than clinical support.

**What else has been helpful?**

“Having things like blood taken and transfused in [Shared Care] whilst I am not in [Primary Treatment Centre] on treatment.”

*(Male, age 15, On treatment)*

“My mum giving drugs so I don’t always have to go to hospital.”

*(Female, age 14, On treatment)*

“Community nurse, line care, blood.”

*(Male, age 15, Off treatment <1yr)*

**Older age group (16 plus years)**

Surprisingly, although the need to go home during treatment increases with age, the importance of getting good medical treatment at home seems to decrease (with just over half of respondents in this age group rating this as important).

A reason for the lower ratings of importance could be that fewer young people in this age group had been able to go home as they had not been treated in paediatric services. An additional reason could centre on what young people define as ‘treatment’ and ‘going home’. This is an area that may require further investigation.

The open-box comments for the older age group ranged more widely than for the younger age group, indicating a greater understanding of individual clinical and practical needs. Their comments also indicated greater responsibility for managing the clinical and practical aspects of care at home.

For example, for young people in this age group ‘someone at the hospital’ was the top preference in terms of someone to talk to about medical needs (to a greater extent than the younger age group). Their open-box comments also indicated a need for close contact with the hospital, including out of hours support, and a need for information (both publications and someone to provide explanations). In addition, although the older age group gave lower ratings of importance in this area, they were more likely to comment on the benefits of being treated locally or at home.

**What else has been helpful?**

“Helping me by telling me what should be taken, when, with what.”

*(Female, age 18, Off treatment <1yr)*

“Knowing that the hospital are there for support 24/7, giving me reassurance.”

*(Female, age 17, On treatment)*

**What else do you need right now?**

“Someone coming to the house to talk about it.”

*(Female, age 18, Off treatment <1yr)*

“Better availability of local resources.”

*(Male, age 23, Off treatment <1yr)*

**Comments**

It was surprising that overall young people rated ‘being able to get good medical treatment at home’ as less important than ‘being able to go home’. This could be due to a number of reasons: the clinical requirements of being at home during treatment might not be well understood, young people might feel that they just wanted to go home in between treatment sessions or appointments (eg. as a day patient, or on short breaks) rather than actually receive treatment at home, or there might be times that young people would prefer to be in hospital.

The evidence indicates that it is important for young people (and their families) to be able to monitor their treatment at home and receive follow-up care at home (eg. symptom management and simple procedures) rather than actually receive most of their treatment at home. Further research would be useful in this area and a model of care should take the point of view of a young person into account when assessing what care could or should be delivered at home. This is particularly important for older age groups who may have greater responsibility for the management of their own care.

As with other areas of need, the aim is to empower and support the young person and their family throughout treatment to survivorship and services should be tailored to this end (eg. appropriate clinical training for parents and carers, provision of information, access to community nursing when needed and close contacts with the hospital).

**4.1.7 Help on money matters: 16 plus age group**

Pathways in education and employment diverge after compulsory education, and more young people live independently of their families. Therefore, those aged 16 and over were asked about finance and work.

‘Getting help on money matters’ was identified as being a relatively high priority by the older age group, with most saying this is ‘important’ or ‘very important’. In particular, getting help with grants and benefits was

important. These needs increased with age and were most common amongst those over 18 years of age.

Open-box comments confirmed that grants and benefits were helpful to young people, particularly as they were often unable to work during and following their illness. Often grants and benefits were put towards practical support, especially transport and parking costs. Prescriptions were also mentioned a number of times. Having an advisor or advocate was also helpful, especially when navigating the benefits system.

Financial support from parents was also mentioned, as was an awareness of the financial needs of parents.

The latter was also true of younger age groups, a small number of whom chose to complete the financial section of the survey even though they were directed away from this section. Related to this, there was an indication that finance could be a worry to some young people.

**What else do you need right now?**

“Petrol bills were paid to and from hospital, which was very helpful. My mum had to use holidays at work in order to get paid during treatment in order to still be able to receive the needed wages. Help with this would have made the time easier.”

*(Female, age 18, Off treatment <1yr)*

“Help on benefits, such as how to stop them and if I may still be able to get some money as I won’t be able to work for another year.”

*(Male, age 23, Off treatment <1yr)*

“Perhaps those with long term illnesses should be entitled to free prescriptions.”

*(Male, age 23, On treatment)*

**What else has been helpful?**

“Help on other benefits and getting letters from consultants to support claims.”

*(Female, age 19, Off treatment <1yr)*

“[Financial support] was so helpful because I was not able to work while I was on chemo.”

*(Male, age 19, Off treatment <1yr)*

“Money to pay for train fare into London every day.”

*(Female, age 16)*

**Comments**

Finance is a core psychosocial need for families and independent young adults. A model of care should ensure that financial support is available immediately following diagnosis to support the extra costs of cancer, such as transport between hospital and home, and enable the continuation of a stable home life. Access to financial advice and advocacy should also continue after discharge from hospital. This might include liaison with parents’ or patients’ current or future employers.

In most families, the parents/carers will be the focus of financial support. A child or young person will benefit from less worry and potentially being able to spend more time with their family. It is likely that personal financial need amongst patients will increase with age, assuming that financial independence increases with age. It should also be noted that some people within this age group may have dependents of their own.

However, it may be that not all financial needs can be addressed by a model of care and that some may be resolved through campaigning work such as easier access to Disability Living Allowance (DLA).

**4.1.8 Work/ employment: 16 plus age group**

‘Work/employment’ was not rated as a high priority, with less than a third of respondents identifying this as ‘important’ or ‘very important’.

However, not all of those over the age of 16 were in employment at diagnosis. Of those who were in employment at the time of diagnosis (n = 33), over 50% left their job after diagnosis.

Interestingly, the question asked was ‘how important is work/employment to you now’ (rather than how important it had been during treatment). All of those who indicated that work was important were currently over 18 years.

Together these findings suggest that while some young people over 16 may be in employment, not all are on a career pathway or financially independent. As age increases, work, careers and finance become important to a greater number of young people.

Open-box comments indicated that it was important to be able to look ahead to life after treatment: getting back to normal was important financially and for self esteem and confidence. For those who had left work, or were contemplating starting work for the first time, support when returning to work or finding a job could be helpful. This might involve advocacy, information about rights or preparation for work. For those in employment, having a supportive and understanding employer was also important.

**What else has been helpful?**

“Being able to go back to work part time and work my way up to a decent level of fitness to continue with full time employment.”

(Male, age 21, Off treatment <1yr)

“I found a new job quite soon after my illness. I am enjoying getting back to normal life”

(Male, age 23, Off treatment <1yr)

“A very supportive manager at work.”

(Male, age 23, Off treatment <1yr)

**What else do you need right now?**

“I do want to go to work but I don’t know if I ever will.”

(Female, age 19, Off treatment <1yr)

“Information about work — what happens, in terms of informing employers about my illness, discrimination etc.?”

(Male, age 18, Off treatment <1yr)

“I would like to start looking for work but don’t really know where to begin.”

(Male, age 18, Off treatment <1yr)

**Comments**

Young people’s employment needs increase with age; therefore, the current model of care (0-18 years) may not need to make this a focus. However, needs in this areas should be assessed along with education needs for those aged 16 or over and information or advocacy provided where appropriate. This should be part of an assessed package of psychosocial support that helps a young person make the transition to successful long term survivorship. However, as with financial support, it is likely that parents/carers will be the focus for employment support for the majority of families in the 0-18 years age group.

**4.1.9 Support from family and friends**

In support of findings throughout the rest of the survey, most young people (of both age groups) said they depended on their family ‘a lot’ for support (84%), with the remainder depending on family ‘a bit’ (14%). Young people also received support from their friends, but to a lesser extent (‘a lot’ = 34%; ‘a bit’ = 55%). Some young people did not depend on their friends at all (10%). This suggests that the family plays a significant role in young people’s care and could be considered as a source of support in a model of care. However, friends are not the main support network that young people depend on, but this is likely to be an area of need for some young people.

**4.2 PARENTS AND CARERS**

Parents and carers were asked about their need for specific services in a number of general areas of support: practical; financial; transition from hospital to home; home visits; emotional; educational; employment; help from professionals; support from family and friends.

Respondents were asked to indicate if each service was ‘not needed’, ‘needed but not provided’ or ‘needed and provided’. The following sections comment on the percentage of respondents that felt services were ‘needed and not provided’ plus those that were ‘needed and provided’ (termed collectively as ‘actual need’) in each of the six areas. Where over 70% indicated a need for a service, it was considered a core need (though this figure is influenced by actual levels of current service provision). Core needs are also services where assessment is essential.

A number of open-box questions were also asked, allowing respondents to comment freely about ‘what else has been helpful’ and ‘what has been missing’.

**4.2.1 Financial support**

**Key Findings**

The box below shows the percentage of parents/carers who needed each of the four types of financial support services asked about in this section of the questionnaire.

- Information about grants related to your child’s illness (88%)
- DLA/benefits paper work (80%)
- Receiving financial grants (76%)
- Getting bills paid (32%)

Financial support is an area of high need for parents. The highest area of need is for help with grants and benefits. Open-box comments corroborated the need for support in these areas. Helpful services mentioned in the open-boxes included extra money in the form of grants, financial advice and information, having a financial advocate, help accessing grants from

other charities as well as CLIC Sargent and help with paperwork.

In parents’/carers’ comments there were also strong indicators that immediate financial support was required following diagnosis, either in terms of navigating the benefits system or as actual monetary assistance. The delay in receiving DLA benefits, and the complexity of the forms, remains a problem for families in the first months following diagnosis.

In addition, some parents said that they had not been able to access financial support from a professional at all. Generally, parents would receive help with grant and benefits applications from hospital based staff. However, not all children and young people will be admitted to hospitals or wards with easy access to financial support and advice, or they may require help after discharge and beyond treatment.

Financial support is linked to practical support. Parents mentioned the way in which grants could cover the extra costs of cancer, particularly transport and parking. Help purchasing other practical aids and support was also commented on, such as funding towards support equipment for the home, wigs and clothes. Practical support, and the other related issue of employment support, will be discussed further in the following sections.

Extra help “getting bills paid” was needed by fewer parents than for grants and benefits. This should not be taken to indicate no need, but rather an individual need for some families. Some families have pre-existing financial difficulties made more difficult following the cancer diagnosis. Others might be affected for long periods of time, or have more costs to cover than other families.

**Comments**

Financial support is an area of high need for parents, essential for maintaining a secure home life during and after their child’s illness, and should be addressed in a model of care. Most parents/carers require immediate monetary assistance to cover the extra practical costs of caring for a child with cancer.

Support may then be required in the longer term with continuing costs (eg. where disability support is required). In addition to extra money from grants and benefits, easy access to information and advocacy are also important, for example when liaising with employers and benefits agencies, or just finding out what support is available.

However, there are outstanding issues for parents applying for DLA and other benefits in terms of ease of access and timing. This, and perhaps other issues (such as hospital transport), may be a focus for campaigning rather than a matter of service provision.

**What else has been helpful?**

“[The charity’s] immediate grant of £200 helped with extra childcare expenses for sibling, mobile phone costs, car park fees and petrol. We were very grateful for this unexpected grant. The social worker gave us info re DLA. We also had letters from [the charity] to holiday companies substantiating our reason for cancelling holidays and a letter to the Department of Work and Pensions to support DLA claims.”

*(Mother of child, age 9, On treatment)*

“Having guidance, filling in the forms — as some forms are long and time consuming.”

*(Mother of child, age 4, On treatment)*

“I received a couple of grants from different charities which I used on a few bills, but money has always been tight as my son was in hospital for 16 weeks.”

*(Mother of young person, age 18, Off treatment <1yr)*

**What has been missing?**

“DLA has been very helpful but there is a need to look at the time gap between diagnosis and being entitled to DLA.”

*(Mother of child, age 4, Off treatment <1yr)*

**What has been missing?**

“Unless you track it [financial support] down yourselves and ask, no-one seems to tell you — we found out through other parents.”

*(Mother of child, age 10, On treatment)*

**4.2.2 Practical support**

**Key Findings**

The survey asked parents/carers about a number of areas of practical support. As noted above, most parents require help covering the extra practical costs of cancer. However, levels of actual need for other practical support services asked about are relatively low (see box below). This is likely to be due to the fact that each family will have needs that are specific to their individual circumstances.

- Arranging trips and holidays (47%)
- Finding accommodation in or near hospital (40%)
- Transport to and from hospital (29%)
- Taking care of housework (23%)
- Childcare of other children (19%)
- Language/translation (3%)

Practical needs should be considered in terms of the positive impact for individual families if they were assessed and addressed as part of a cohesive ‘package of care’. Help with such things as transport, accommodation, housework and childcare can free up time and resources for family members to spend more time together, provide time for much needed respite or help to maintain an everyday family life.

Practical support may also be required to enable some families to understand or access services. For example, language and translation issues appear as a very low need in this survey although such services are essential to those who need them. There was some indication that the figure for need in this area could be higher. For example, three parents/carers were excluded from analysis as language difficulties had prevented them from completing the survey correctly.

The open box comments were also important here for identifying other services not directly questioned elsewhere. Importantly, ‘information’ was reported as being the most helpful form of practical help, as publications but also as advice from professionals. The need for information is a common thread throughout most of the survey results for parents, young people and siblings and can empower families to provide practical care and support for themselves while not in hospital.

The support services listed above are diverse and could be provided in a number of other ways: through access to a key professional (eg. who can provide the information and administrative support), access to professionals who can provide the needed service (eg. family support), by providing monetary assistance (eg. to cover immediate costs of child care, transport, cleaning etc.), through campaigning activities (eg. on hospital transport) or from existing support networks such as family and friends.

**Comments**

The key aims for practical support are to ensure a safe and appropriate home environment for a family during and after treatment and to remove barriers to accessing services. This is essential when clinical care is required at home. A model of care should stress the need for a comprehensive assessment of psychosocial need, existing support networks and need for information. Support may also be required for extended family and friends whose lives may also be impacted by the cancer diagnosis and who may find themselves in a caring role.

**What else has been helpful?**

“I was given an organiser with all useful telephone numbers and info which I found very helpful. Excellent face to face communication. Childcare of other children. I had invaluable help with arranging a visa for my mum to come to care for my daughter.”

*(Mother of young person, age 19, On treatment)*

“Friends and family have given me and my son lifts to hospital for treatment as I do not drive. I have been very lucky to have had support from a local children’s charity who provided a play specialist for my son for 3 hours per week for a 6 months period. Without those precious 3 hours which gave me some ‘me’ time, I would never have got through the last year.”

*(Mother of child, age 5, On treatment)*

“We are a large family with great friends so we got loads of practical and emotional help.”

*(Mother of young person, age 23, Off treatment <1yr)*

**What has been missing?**

“I don’t feel I’ve had much support and not aware of what help can be offered eg. help with housework. An update on what help is available physically and financially is needed.”

*(Mother of child, age 4, On treatment)*

“Help with transport to my local hospital, which is 10 miles away and requires two bus journeys. Help with housework, hospital accommodation, respite care, holidays, etc. There has been no support offered to the extended family, either emotional or practical.”

*(Mother of child, age 5, On treatment)*

### 4.2.3 Support returning home (during and after treatment)

#### Key Findings

In order to go home during and after treatment, families need a range of clinical activities to be carried out by care professionals as well as support to enable them to manage the illness at home themselves where they can. The following table shows level of need for a range of clinical transition services.

- Help through being able to phone someone at hospital? (80%)
- Home visits from an outreach nurse after first discharge? (68%)
- Phone calls from the hospital to check on progress? (61%)
- Community nursing support during the day? (60%)
- Training to help you care for your child at home? (56%)
- Help on your first trip home? (40%)
- Community nursing support out-of-hours (24/7)? (38%)
- Support through an ‘end of treatment’ meeting? (36%)

Parents/carers may initially be unsure of how to recognise emergencies and how to manage symptoms, side effects, medication and feeding while at home. Most families said they need to be able to phone someone at the primary treatment centre when necessary and some would like to phone a contact at the local hospital.

As many parents/carers pointed out, times of need can include evenings, late at night and weekends. In addition, a number of parents appreciated being able to phone somebody who knows their child or can easily find out about their child. A timely and good quality phone consultation could prevent a hospital admission, identify a needed admission, reduce anxiety or ensure optimal care at home. Therefore, a core transition need is knowing that a key professional can be contacted by phone 24/7.

Specific hospital co-ordinated clinical services at the point of transition (eg. outreach nursing, training, help on the first trip home and an end of treatment meeting) are needed by fewer parents/carers. This does not mean these services are less important. These and similar services can be vital in terms of ensuring clinical safety and this may not be understood by all parents. In particular, an initial visit from an outreach nurse could help parents resolve any issues of which they are unclear, boost confidence and provide reassurance.

Need for such services may depend on factors such as diagnosis type, distance from hospital and ability of the family to cope. It also may have been unclear to some parents/carers what was meant by terms such as ‘end of treatment meeting’ and ‘help on your first trip home’. For example, need for an end of treatment meeting was higher amongst families that had finished treatment (58% in comparison to 36% overall), and so had more knowledge of what was required.

For example, parents/carers may need clinical preparation or training before leaving hospital, or access to nursing support at home. Training and home nursing could be complimentary, with hospital based professionals training family members to care at home as far as they feel comfortable, whilst also ensuring that clinical safety is maintained at home (and so co-ordinating nursing support where needed).

It was evident in their comments that community nursing services (eg. checking lines and bloods) were very much appreciated by parents/carers, with personal clinical training mentioned less frequently (though still needed). Again, need may be dependent on a variety of individual circumstances. For other parents, the timing of the support they had received was not right, and they felt they needed more preparation or information.

Other helpful types of services that families mentioned included help from other professionals (other nurses, social care professionals and GPs) and other types of clinical/medical support (support equipment, mobility aids, information, advice/explanations and pharmacy/medication support). Home visits were mentioned,

often in relation to these services and professionals. The types and timing of home visits will be dealt with in more depth in the following section.

It is apparent from parents’/carers’ comments that there is a relationship between clinical support and emotional support that must be taken into account when planning community services. Some parents/carers feel alone or abandoned at the end of treatment, do not know who can help them, and want somebody to talk to. Many would appreciate a follow-up call from a professional to check that things are going OK or appreciate home visits for this reason. Emotional support can be provided in many ways and the following sections in this report will discuss emotional support in more depth.

#### Comments

Families require clinical support when returning home, whether at first discharge or at the end of treatment. Preparation for these transitions should start in hospital with the provision of information and training where appropriate. In addition, families should leave hospital knowing who to contact, for what reasons and when.

Having the opportunity to ask about things that are unclear and things that may only become apparent on going home is important and this could be achieved by telephone. Initial help at home from the hospital may also be required for some families. Such a visit could enable the care team to identify any additional needs or safety issues that were not apparent prior to discharge.

Co-ordinated discharge planning is required including an assessment of the family’s competency and individual home circumstances. Community nursing and practical support could then be arranged by the primary treatment centre as required. While it is desirable to enable the family to spend as much time at home as is possible, clinical safety must be ensured.

Palliative care was not addressed in this survey. This is a key area where holistic assessment and care planning is required to enable smooth co-ordination of transition between hospital and home/hospice and continued care in the community. Further research with service providers and families may be required in this area.

#### What else has been helpful?

“Knowing we could ring when she was first given the all clear and having the same support personnel upon her being re-diagnosed three years later. Outreach nurse available by telephone to answer questions and have access to the Consultant at a moment’s notice.”

*(Mother of child, age 4, On treatment)*

“Knowing that support has always been at the other end of the phone 24hrs — that I always receive a very helpful response when I call.”

*(Mother of child, age 2, On treatment)*

“Community nurse calling every week to check bloods was helpful as it made us feel less isolated when not visiting hospital in between treatments.”

*(Mother of young person, age 17, On treatment)*

#### What has been missing?

“Not knowing exactly what I can ask of the [charity] worker and nurses. I have never been sure exactly who would be the best person to contact with a problem. A clearer idea of the role of the [charity outreach] Nurse would have been good.”

*(Mother of young person, age 14, On treatment)*

“Some sort of visit in the early days of returning home from hospital, would have been good. It would have helped to get advice on how we were arranging our son’s bedroom with safety and easy access for him and working out how to organise all the medication, etc.”

*(Bereaved mother of young person, age 17 at diagnosis)*

“No information pack for parents about do’s and don’ts. This is needed badly. You tend to learn information usually by chance or constant questioning of other parents.”

*(Mother of child, age 3, On treatment)*

**What has been missing?**

“It’s all very well to move more care into the community but this puts an enormous burden of nursing care on the families. Trying to work out what is an emergency and when you need to worry etc is a huge issue. Giving loads of drugs, feeding via an NG tube etc. The burden for families is enormous.”

*(Mother of young person, age 15, On treatment)*

**4.2.4 Home visits**

**Key findings**

The need for some form of clinical support is high during transition from hospital to home, but may continue or be replaced by other needs (eg. emotional) throughout treatment and beyond treatment. Hence, in addition to being asked about initial home visits, parents/carers were asked about home visits in general (see box below). The aim of these questions was to identify the types of home support that families require, regardless of the professional delivering the service.

- Home visit to discuss the impact of your child’s illness? (62%)
- Home visit to do tests and treatment at home instead of at hospital? (60%)
- Home visit to explain symptoms and side-effects? (58%)
- Home visit to explain your child’s medicine and care needs (eg. Lines, tubes and protocols)? (57%)

Similarly to clinical services required when returning home, the need for home visit support is in the mid-range. Again, need may be dependent on individual circumstances.

For example, families who live close to hospital may be happy to attend as outpatients or go to clinic for simple procedures, whereas this is more difficult for other families. Some children and young people will need minimal care at home, whereas others may need,

or opt for, more intensive care at home (eg. during palliative care, where treatment is over a long period of time or when there are long term chronic effects). Furthermore, some families will be better able to cope at home for a number of reasons, and may require less one-to-one advice and support.

Unfortunately, the survey did not define or separate ‘tests’ from ‘treatment’. These two areas of home support may require different levels of expertise or specialist knowledge and levels of need may be different. Furthermore, the two types of support might require different types of nursing staff and links with the primary treatment centre. In their open box responses, parents/carers most commonly mentioned community nursing and simple procedures (eg. lines and bloods) when commenting on what else has been helpful or what has been missing.

This does not mean that specialist advice and help (such as symptom management and medication support) is not required and a number of parents/carers mentioned their need for outreach nursing support. Community nursing can also be specialist (eg. from paediatric nurses).

Specialist support might be more important (a) in the early days at home, (b) when intensive care is required (eg. during palliative care) or (c) in ensuring that generic local children’s nursing services are well supported. Specialist support directly to families should also be available before leaving hospital and by phone (as noted in the previous section). Further roles for specialist professionals may be in being a key contact for families, ensuring that all needs are met and in co-ordinating care.

Interestingly, parents/carers needed clinical support to the same extent as more general discussions about the ‘impact of the illness’. Discussions about the ‘impact of the illness’ could have been interpreted in a number of different ways by respondents: clinically and in psychosocial terms. For example, a number of parents noted that the shock of the illness did not hit them until they had spent some time at home.

**Comments**

Similarly to transition needs, home visit needs can first be met by ensuring that families are well prepared before going home and then have access to specialist advice (eg. by phone) while at home.

Co-ordinated assessment and care planning is also important and regular re-assessment is also needed to ensure that the best and most cost effective services are being delivered. There is likely to be large variation in the type of care each family requires at home and the individual circumstances of each family (eg. geographical location) and this can change over time.

Such preparation and assessment could mean that specialist nursing care in the home could be directed towards families in greatest need (eg. palliative nursing) whereas other families could benefit from more generic children’s community nursing (eg. to reduce the need to travel and enable families to spend more time at home).

There is a link between clinical support and psychosocial support, and this is one reason why many parents appreciate outreach nursing: for the continuity of both the clinical and emotional support. However, not all families need one sole contact or continued specialist nursing care. To ensure continuity of care, professionals at the main treatment centre could maintain a role in co-ordinating clinical and psychosocial care at home when direct specialist clinical care is no longer required.

**What else has been helpful?**

“Help with hygiene issues & administering injections (helped by [Charity 1] Nurse). Help with the timetable scheduling of the multiple drugs (initially assisted by [Charity 2] Nurse).”

*(Bereaved father of young person, age 17 at diagnosis)*

“Getting medications to me so I don’t have to drive to collect them.”

*(Mother of child, age 6, On treatment)*

**What else has been helpful?**

“Community nurses were a godsend as made life for our whole family easier and normal.”

*(Mother of child, age 2, Off treatment >1yr)*

**What has been missing?**

“Home support was so hard to come by that we would just return to our child’s treatment centre if there were any problems and sort things out there.”

*(Mother of child, age 3 at diagnosis, Off treatment >1yr)*

“We have to drive regularly to hospital for blood tests this would be better if it could be done at home or local surgery.”

*(Mother of child, age 5, On treatment)*

“Details about the medication, side effects and the impact of my daughter’s illness and what to expect for the whole family physically, emotionally, financially.”

*(Mother of child, age 5, On treatment)*

“I wish my son had ‘hands’ on advice re checking himself from someone he respects — i.e. [Name of charity].”

*(Mother of young person, age 16, On treatment)*

“Someone to check in on us — it is easier to hold on to everything together when at hospital, but harder at home.”

*(Father of child, age 2, On treatment)*

**4.2.5 Emotional support needs**

The shock of diagnosis, the stress and effects of intensive treatment and the difficulty for all family members in facing a life threatening illness in the short and long term means that many families require a high level of emotional support in addition to clinical support. The following sections look at the different types and sources of emotional support families need

### Emotional support from professionals

Parents/carers were asked about their own and their families' need for professional emotional support while at home (see box below).

- Support through being able to phone a professional (77%)
- Telephone calls from a professional checking in (65%)
- Help with your child's behaviour or emotions (53%)
- Counselling for yourself (49%)
- Counselling for your child(ren) (42%)
- Help with your other children and their behaviour or emotions (35%)

Similarly to clinical support, most parents/carers need to be able to phone a professional for emotional support. Many parents/carers would also like a professional to phone them. However, it is unclear from the ratings who this should be.

Interestingly, open box comments indicated that having access to appropriate clinical care helps families emotionally as well as medically. Knowing that there is someone available on the end of the phone 24/7 to provide clinical advice, or having someone visit the house to take bloods, is a source of reassurance to parents. Emotional support may be provided in the course of delivering other services and parents appreciate having someone to talk to other than family and friends.

A family may feel over time that a key clinical professional has become a friend. However, such support may not always be available (eg. where specialist nursing is not required). Other professionals may be the family's main contact, or families may require additional types of emotional support. A range of other helpful professionals were also mentioned by parents/carers including social workers, GPs, play specialists and therapists and family support workers.

Although the ratings showed that counselling and professional help in dealing with their children was needed by fewer parents than phone support, this

is an area where need is dependent on individual circumstances or where parents/carers may not recognise that professional support could help.

There were indications that some parents/carers do not feel supported emotionally, have continuing emotional need or have not had access to specialist help when required. Some would have liked a referral to a counsellor, therapist or psychologist. Many others mentioned specific issues, such as relationship problems or their child's emotions that, if assessed, could have benefited from appropriate therapeutic interventions.

#### What else has been helpful?

“Just having the play therapist on the end of the phone and available for both children, this has been great.”

*(Mother of child, age 5, On treatment)*

“Email contact enabling us to contact the nurse specialist and my son's social worker. My son has enjoyed a visit from his social worker.”

*(Mother of young person, age 21, On treatment)*

“In the hospital I had several discussions with doctors, nurses, charity workers and I feel I am in good hands and there is help out there if I need it!”

*(Mother of young person, age 16, On treatment)*

#### What has been missing?

“Nothing practically. It is emotions that get the better of you especially when routine test time comes. I find it very hard to accept my son's illness. Why him? Is he cured? My 16yr old daughter finds it hard too. My daughter can't go near the hospital. She feels sick when we go for scans and blood tests, she no longer tries to go.”

*(Mother of young person, age 23, Off treatment < 1yr)*

#### What has been missing?

“The weekly visits from my [Charity] support worker have been helpful. But, community psychologist services are greatly needed. Available in hospital, but not practical to travel there for parents only.”

*(Mother of child, age 3, On treatment)*

“Counselling to help us all come to terms with what has happened/is happening. Our marriage is struggling as we both battle to deal with extreme emotions as well as day to day life. We have asked for counselling but it has not happened yet — we both feel angry and stressed and have no one outside the family to talk these feelings through with.”

*(Mother of child, age 2, On treatment)*

### Support from other parents

In addition to support from professionals, parents/carers were asked about their need for support from other parents in the form of groups and other opportunities to network (see box below).

- In a parents' group outside of hospital (39%)
- In a parents' group in hospital (38%)
- Through a befriender or a 'cancer buddy' (35%)
- At coffee mornings (33%)
- Through a parents' phone network (31%)
- Through email contact with other parents (31%)
- At informal weekly drop-ins (30%)

The need for formally arranged support from other parents is low in comparison to other support services reported here.

However, open box comments revealed that this may be because many parents feel that they are able to access this support when they see other parents on the ward. Parents/carers appreciate being able to chat with other parents/carers going through similar experiences about the illness, treatment, diet and recovery.

Informal support may supplement or stand-in for more formalised support. A model of care may wish to recommend that groups and networking opportunities are available for families who visit hospital infrequently, whose initial treatment is comparatively short or who are not treated on a specialist or paediatric wards.

Some parents/carers who would like to have contact with other parents/carers have found it difficult to do so for these reasons, but also due to lack of awareness, lack of a local group, home circumstances or timing. Parent-led initiatives, such as starting a group, may be useful for fulfilling needs in this area.

#### What else has been helpful?

“I find parents get together when we are on the ward and we get chatting about our children's illnesses and it really helps, especially when you are new on the ward, it's nice to talk to someone going through the same thing.”

*(Foster parent of child, age 2, On treatment)*

“Informal friendships made in the hospital when we have exchanged phone numbers. To be able to talk about how I feel to people who completely understand has been invaluable. Meeting and talking to other parents has been the best form of support for me.”

*(Mother of young person, age 13, On treatment)*

“Casual chats while in hospital (eg. while making coffee) very useful! For emotional and practical support and information.”

*(Mother of young person, age 23, Off treatment < 1yr)*

#### What has been missing?

“Ongoing support — now not in hospital so much we lose touch with the other parents as appointments are at different times.”

*(Father of child, age 9, On treatment)*

**What has been missing?**

“I was not given any information about support being available from other parents. I did not know of any other parents that had been in the same situation.”

*(Bereaved mother)*

“I didn’t miss support from other parents but, in hindsight, it would have been useful and would, especially, be useful now.”

*(Mother of young person, age 9, Off treatment < 1yr)*

**Support for other family members**

The box below shows level of need for further emotional support services for other family members. The results below and those previously reported in the section on ‘Emotional Support from Professionals’ are similar in that support for other family members is needed by fewer parents than other types of emotional support.

- Specific support for your other children at home (39%)
- Specific support for grandparents (36%)
- Sibling Activity Days (35%)
- Someone to visit the sibling’s school (32%)

The reported levels of need for this section are influenced by the number of families who have siblings and grandparents to consider. Furthermore, parents/carers will have varying levels of responsibility for siblings (eg. dependent on the age of the sibling) and contact with grandparents. This may be an area where research directly involving the concerned family member may be useful.

Siblings in particular may be affected by changes to home life and family relationships following the cancer diagnosis and hence they were surveyed directly in this consultation (see next part of the results, Section 3.3). Indeed, siblings were mentioned by parents/carers in the open box comments in this section more often than other family members.

Many of these comments suggested that siblings could benefit from formal emotional support such as counselling or sibling days. Other comments were focused on support for the family unit, maintaining an everyday life and sources of support within existing networks such as school and friends. Appropriate information for siblings and other family members was also requested.

Interestingly, family and friends were named as an important source of emotional support for parents/carers. Family and friends can be a source of support, but can also have their own support needs, particularly if they are carers as well.

**What else has been helpful?**

“Friends and family have supported each other — we have been strong for each other.”

*(Mother of young person, age 16, Off treatment < 1yr)*

“My other children know they can access support from websites, from a nurse specialist and from a social worker. I have been too exhausted to support my mother and my mother in law but they are not my priority. My son is. And they can access support other than me within the family.”

*(Mother of young person, age 21, On treatment)*

“Sibling weekends etc. have been very helpful for my eldest daughter as it has been very difficult for all my children.”

*(Mother of young person, age 14, Off treatment >1yr)*

**What has been missing?**

“Support for my daughter at school. No support given to grandparents unless we found it for ourselves. Very difficult to find bereavement counselling for children. Someone for my daughter to talk to would have been nice, someone outside of the family and not emotionally involved in the cancer journey.”

*(Bereaved father of young person, age 13 at diagnosis)*

**What has been missing?**

“Nothing received. We haven’t received anything — support for my daughter’s grandmother and our 2yr old son to have a normal life at hard times would have been very helpful.”

*(Mother of child, age 5, On treatment)*

“Help with family dynamics after treatment, sibling conflicts etc.”

*(Mother of child, age 5, On treatment)*

“Grandparents and other family members need to know all facts and how best to help and detail of illness and implications of illness i.e. temperature”

*(Mother of child, age 1, On treatment)*

**Comments**

Parents and carers identified that there should be emotional support available from a professional and that this should be easily accessible and need not always be structured (i.e. support on the end of a phone). A range of professionals were named as helpful in this area, and often emotional support is one component of the services these professionals deliver (eg. in the case of nurses and social workers).

However, for some family members informal support may not be adequate: there may be pre-existing problems within the family or they may be less able to adapt to the cancer diagnosis in the short or long term. A need for good assessment and then access to specialist help was indicated for some parents. Regular assessments or check-ins may be required as needs may develop over time.

Professional support was identified as more important than parent/carer support groups and networks. However, this finding highlighted a need to balance the benefits of being at home during treatment with what could be lost by not seeing other people while in hospital (i.e. contact with other parents/carers going through similar experiences). The reach of existing support groups could be assessed and opportunities for parent-led initiatives investigated.

One benefit of increased time at home during treatment could be less disruption to family life for other family members, particularly for siblings. Extended family and friends can be a source of practical and emotional support, and therefore may require their own support and access to information if a child or young person spends more time at home. Assessment of psychosocial need must involve a consideration of all family members and significant others.

This survey did not directly address palliative care and bereavement. However, this is a key stage at which a model of care must address emotional needs. Further research may be required in this area.

**4.2.6 Education needs**

The box below shows levels of actual need for a range of education support services. The results overall (all age groups) are shown. However, the findings for parents/carers with children of compulsory school age (5 – 16) are also discussed below.

- Someone to go to school/college/university to explain treatment to teachers/tutors? (60%)
- Hospital teacher to liaise with my child’s school/college/university? (44%)
- Home tutoring for my child? (34%)
- Extra help in the classroom (eg. from a classroom assistant)? (23%)
- Support with taking exams? (18%)

The top education need is for someone to go to a child or young person’s school/college/university to ‘provide explanations for teachers/tutors’. Overall, 60% of parents/carers said they needed this service.

However, need for education support is dependent on the age of the child. Amongst parents of school age children and young people, school visits are a core need (76%), closely followed by the need for liaison between hospital and school (67%). A substantial number of this subset of parents also indicated a need for home tutoring (56%).

Open box comments support the findings above. Parents/carers would like a professional to talk to the school (both to teachers and to peers) about the illness. One consequence of this type of support is increased understanding (clinically, emotionally and educationally) of a child or young person’s needs. ‘School staff being understanding’ was very much appreciated by parents/carers.

Open box comments also indicated that liaison is needed between the hospital, the school and other organisations. Liaison is not necessarily by the hospital teacher. Nurses, social workers and a learning mentor were also mentioned. The times at which liaison may be needed are when re-integrating into school, starting school or other education for the first time, when doing exams, or when a child or young person has special needs.

Children and young people may spend a long time out of education and therefore can fall behind. Others may have short or long term physical or learning disabilities that require special education support. Although needed by fewer parents than for liaison, ‘extra help in the classroom’ was required by some parents.

This was just one of a range of learning support services that parents/carers thought were helpful. Common comments concerned having a dedicated tutor, more one-to-one support in general, more help from teachers in keeping up with education and having a school at the hospital. Some children require specialist support and a number of parents mentioned a need for study equipment, help from the disability team and help from the local authority (eg. with a statement of needs).

As with other areas of support, each child or young person will have individual needs. In the context of education, age is a key factor to consider relating to the availability of services and the type of services required. Advocacy and special consideration in taking key exams will be required at certain stages of education. Other age related services include pre-school support or support with further and higher education — times when education is non-compulsory.

**What else has been helpful?**

“Community nurses explained health needs etc. to school and possible impact on education, children bullying in school etc. Class teacher had already taught a boy on maintenance in a previous school so prepared homework and catch-up at home stuff and arranged support in class.”

*(Father of child, age 9, On treatment)*

“Professional bodies working together to try to obtain statement of needs for my son who has special needs in addition to leukaemia medical needs, in order that the extra help he needs is formally documented and thus provided when he returns to school.”

*(Mother of child, age 9, On treatment)*

“A particularly supportive and understanding school, both staff and pupils maintained educational and social contact throughout his illness and after his death.”

*(Bereaved mother of young person)*

**What has been missing?**

“My child is of playgroup age and although there is a playroom, there is no ‘session”, i.e. it always requires parent involvement. School age catered for.”

*(Mother of child, age 5, On treatment)*

“The school visit by the symptom care nurse would have been more effective if it focused more on the emotional plus educational support my son needed and left out the technical medical side of his treatment. Don’t think my son’s teachers fully understand how tired he gets on chemo.”

*(Mother of child, age 5, On treatment)*

**What has been missing?**

“I found explaining to school teachers difficult, some didn’t know she was ill, communication at exams was poor, very unfair to her when sitting GCSEs.”

*(Mother of young person, age 17, Off treatment <1yr)*

“School work support to catch-up after intensives complete. It should not be up to the individual teachers and schools — too variable. Now he is able to attend school more, a catch-up lesson for the year he missed and the holes in learning it has left would really help. Informally at home with us is not working.”

*(Father of child, age 9, On treatment)*

**Comments**

Similarly to the findings for young people, the results for parents/carers suggest a need for education liaison and advocacy. However, some parents/carers are more focused on educational needs, whereas young people were also concerned with isolation and peer support. Some means of keeping up with education is needed by many families. As with other areas, packages of support could be tailored to meet individual need.

**4.2.7 Employment needs**

Parents/carers were asked about two aspects of employment support. The overall results are shown in the box below, and results within those who were in employment at the time of diagnosis (250 out of 283) are also discussed. Respondents were also asked about their own and their partner’s employment situation, their coping strategies and whether the cancer diagnosis had affected their employment.

**Did someone...**

- Advise you about your employment rights when caring for a child with cancer? (60%)
- Talk to your employer, or help you talk to your employer, about your situation? (38%)

Advice about employment needs is a fairly high area of need overall amongst parents/carers (60%). Amongst those who were employed at the time of diagnosis this figure is higher (67%).

Parents/carers require employment advice because one or both parents in a family are likely to spend a great deal of time at hospital or caring at home and so may require a great deal of time away from work. The survey results showed that in many employed families one or both parents use sick leave (40%), reduce their hours (35%), take unpaid leave (34%), use annual leave (30%) or leave work altogether (26%). Fewer families use flexi-time (21%) or carer’s leave (17%).

Knowledge about personal rights could help guide discussions with employers about time off and right to pay, and so help parents manage the financial effects of the diagnosis, reduce stress and maintain relationships. The most frequent comments from parents/carers about what is helpful is having a supportive, understanding and flexible employer, line manager or organisation.

Advice is needed to a greater extent than having someone to talk to an employer. However, ‘talking’ could be interpreted in a number of ways by respondents. Open box comments indicated that many parents/carers found it useful for a professional (such as a GP, nurse or social worker) to write letters of support to their employer. Such support and other advocacy or liaison may increase employers’ understanding of the family’s situation in the first instance, and be supportive of a family if disputes arise.

Other individual needs might relate to the type of employment and responsibilities that parents/carers have. Further analysis is possible with the current survey data to look at the experience of parents/carers in a range of situations, such as in self-employment, unemployment or those who are employers. Fathers could be a focus in future research, as the majority of the respondents to this survey were mothers (who are more likely to leave work after the diagnosis<sup>9</sup>).

<sup>9</sup> CLIC Sargent Work Care Balance Survey, December 2006  
<http://www.clicsargent.co.uk/Whatwedo/Research/Reportsandpublications>

**What else has been helpful?**

“We have been really lucky in that both our employers have been very supportive and flexible. Also as our daughter is now disabled we have legal rights to ask for more flexible arrangements.”

*(Mother of child, age 8, Off treatment < 1yr)*

“My doctor signed me off automatically until I felt ready to return to work, when treatment was completed. My husbands work allowed him to take off as much time as he needed — a week, plus odd days every month — paid”

*(Mother of child, age 2, Off treatment < 1yr)*

“Union advice confirmed what I thought my husband would be entitled to, the Welfare Rights Team were excellent. My husband’s employers gave him 6 months paid sick leave, they were very supportive.”

*(Mother of young person, age 17, Off treatment < 1yr)*

“Our social worker was very helpful with advice on what my work could do and even wrote to my work to explain what was happening and rang them.”

*(Mother of child, age 2, Off treatment < 1yr)*

**What has been missing?**

“Unfortunately, as I no longer work, my husband is having to put the hours in when he can as he is self employed. This creates friction as really he needs to be with us sometimes and can’t as time off has to be to attend to our other child.”

*(Mother of child, age 12, On treatment)*

“No interaction whatsoever. I am still totally unsure of what my rights are and how much paid/unpaid leave I am entitled to. So much more needs to be done in this area to take away further worry.”

*(Father of child, age 3, On treatment)*

**What has been missing?**

“There was no support available. We just had to get on with it. We kept getting sick notes and sending them in to say why we were not working. Many parents I talked to had awful problems getting them time off work to care for their child. There should be some sort of carer’s leave available to both parents who have a child diagnosed with cancer. As our son was a young adult and had to have life changing brain surgery, it took both of us to care for him. As we had never had anything to do with benefits before it was nightmare trying to find out what help was available to us. The stress of getting into debt and the possibility of losing our house through non-payment of mortgage was a great weight to bear.”

*(Bereaved father of young adult)*

**Comments**

Employment support should be a key component of a model of care. It is not an isolated area of need: support in this area could potentially prevent families from falling into higher categories of psychosocial need (due to financial and practical difficulties). Therefore, assessment of employment need is required shortly following diagnosis and the ongoing impact on employment should be assessed. In the first instance, advice and information is required. Where needed, advocacy and liaison should also be available.

Unfortunately, some parents will need to care for their child over very long periods of time. Clear information about rights, and clear agreements, should be available for both employer and employees. Work in this area could be supported by campaigning activity. Further research could address under-represented populations in this research and groups with particular needs, for example: fathers, unemployed parents and the self employed.

**4.2.8 Support from professionals**

Parents/carers were asked about their need for help from a range of professionals while at home. Over 50% of parents/carers required help from a ‘local community nurse’, a ‘specialist social worker (from the hospital)’, a ‘specialist nurse (from the hospital)’ or their GP. Between a quarter and a half of parents required specialist help from a nutritionist, physiotherapist, psychologist or play specialist. A local social worker or a youth worker were needed by fewer parents.

These results are not discussed further here as the focus of the consultation is to identify core needs and services rather than the professionals who currently deliver these services. There are also likely to be variations in the way this question was interpreted by respondents (eg. ‘local community nurse’ could refer to a range of specialist and generic nursing roles).

**4.2.9 Support from family and friends**

In support of findings throughout the rest of the survey, most parents said they rely on their friends (82%) and family (86%) for support to some extent. This suggests that all significant others should be considered in a model of care, particularly if family and friends are in a caring role. Some families do not have support from family (12%) or friends (17%) and may require more professional support as a consequence.

**4.3 SIBLINGS**

Siblings (10-24yrs) completed the same survey as young people who have/had cancer. They were asked to complete the survey referring to both their own and their brother’s/sister’s needs.

**4.3.1 General Areas of Need**

Table 3 below shows the percentage of siblings who rated each of the general areas of need as ‘important’ or ‘very important’. The results are broken down by the sibling’s age at the time of their brother’s/sister’s treatment. The results are also ordered from most to least important (age groups combined).

Similarly to young patients, ‘being able to go home during treatment’ was rated significantly more important than all other needs (p < .05). However, in contrast to the young patient, siblings rated all areas of need highly. In particular, the brother/sister getting good medical treatment at home was more important amongst the siblings than for the patients themselves.

The findings suggest that models of care should be cognisant of the needs not only of the child or young person with cancer but also those of his or her sibling. Spending large amounts of time at the hospital could have an impact on other members of the family.

**Table 3: Percentage of siblings who rated each of the general areas of need as ‘important’ or ‘very important’**

	Up to and including 15 years (n = 46)		16 years and older (n = 15)		Total (n = 61)	
	Freq.	%	Freq.	%	Freq.	%
Your sibling being able to go home during treatment	44	96%	15	100%	59	98%
Keeping up with school/education	42	91%	12	80%	54	89%
Keeping up with social activities	40	87%	13	87%	53	87%
Your sibling getting good medical treatment at home instead of in hospital	39	85%	12	80%	51	83%
Talking to people about your thoughts and feelings	37	80%	14	93%	51	83%

### 4.3.2 Specific services required

Home life can be disrupted in a number of ways. One or both parents may spend long periods of time at the treatment centre or the whole family may temporarily move closer to the hospital. Parents have less time to spend with a sibling, do not take part in everyday practical and social activities and also may be emotionally focused on the patient. When the patient is at home and requires follow-up care or treatment, home-life may continue to be disrupted. While feeling upset about their brother's/sister's illness, siblings can also feel left out and isolated; their family and other relationships can be challenged.

The survey results showed that siblings rely a lot on their family to explain the medical side of their brother's/sister's experiences and also to talk about thoughts and feelings. It is also important to siblings to be able to keep up with a normal social life (eg. at school or 'going out').

However, siblings would also appreciate more formal services in a few areas: respite (particularly holidays and trips with families); specialist peer support (meeting other siblings); information, explanations and help explaining things to teachers. In terms of information and explanations, this could be in the form of publications or someone coming to the house to explain about the illness. Explanations for a sibling's school also may be important, as the disruption to home life may carry over into the sibling's school life.

### 4.3.3 Age considerations

When the sibling survey data was analysed with respect to age (<15 years and 16+ years) it was apparent that both groups have similar needs. However, fewer older siblings seem to need support. This is understandable in terms of education (fewer will be in education). Other reasons for this finding could be that older siblings may be less likely to be at home. Older siblings might also have a different perspective on the changes to home life and may also take on more caring responsibilities (not addressed in the survey).

### 4.3.4 Comments

A model of care should recognise all affected members of a family following a diagnosis of cancer. The needs of siblings in particular should be taken into account, and a model of care should ensure that the need for emotional support, information and education liaison are assessed at key points throughout the cancer journey.

#### What else was helpful?

**"A thing that has been helpful is when I am sad the teachers allow me to take a friend outside the classroom with me to help me calm down."**

*(Sister, age 10, of patient on treatment)*

**"To be able to have my own time and get away."**

*(Sister, age 16, of patient on treatment)*

**"Having good friends to keep your mind off things."**

*(Sister, age 15, of patient off treatment <1yr)*

**"Drugs/dressings being dispensed promptly to enable the patient to get home quicker. Having procedures fully explained, scans, pick lines etc, chemo. Whilst my sister was undergoing treatment her baby was only 3 weeks old so we had to ensure she spent time with him as well as having respite to recover. This meant lots of support from family and friends and a carer to help with household chores for her/her partner."**

*(Bereaved sister, age 30, age 24 at diagnosis)*

#### What else do you need right now?

**"To fully understand how and why my brother got cancer. Also, what the treatment did to his body."**

*(Sister, age 15, of patient off treatment <1yr)*

**"For my sister not to go into hospital anymore."**

*(Brother, age 17, of patient on treatment)*

**"I find it hard to talk to my family. They have too much to deal with."**

*(Brother, age 16, of patient on treatment)*

### 4.4 BLACK AND MINORITY ETHNIC FAMILIES

Three semi-structured interviews with parents from black and minority ethnic (BME) backgrounds (two mothers and one father), were conducted using the general areas of need in the parent's/carer's survey as topics for interview questions. The aim of the interviews was to identify particular needs of BME service users that may not have emerged during the eight initial interviews that were used during the survey design. One of the initial interviews with a young person from a BME background was also reanalysed with this aim.

The interviews showed that although many families have common core needs, each family's circumstances are highly individual. For example, all four families had concerns regarding finance, housing, education and mobility/transport but individual factors such as cancer type, age of the patient, pre-existing psychosocial need and psychosocial need emerging as a result of the cancer diagnosis were also important features in all interviews.

The interviews suggested that some families from BME backgrounds could have greater difficulty accessing support and services. Issues that may affect access, highlighted by the interviews, include immigration/asylum seeking processes, language and discrimination.

Recommendations for a model of care (based on the additional evidence from these interviews, and in the context of the previously reported survey findings discussed earlier in this paper), are as follows:

#### Recommendations for a model of care

- Individual assessment of financial and practical needs for all families
- Planning and delivery of individualised care
- Ability to deal with complex/high need families
- Campaigning activity to ensure equitable and speedy access to financial & practical support
- Further consideration of the needs of independent young adults (to be addressed in a second model of care for 18-24 year olds)

### 4.5 SERVICE PROVIDERS AND OTHER STAKEHOLDERS

#### 4.5.1 Stakeholder meetings

Forty-six stakeholders (mainly service providers) attended one of two consultation meetings or sent contributions by email. Participants were asked to identify the top care needs of children/young people and their families when they are not in hospital. The question was discussed in small groups. Discussions were wide-ranging and covered not only core needs but also ways of meeting these needs.

The nominal group technique (see appendices) was used to reach consensus within each small group and then across the larger group. Following voting and ranking at the face-to-face workshops and subsequent analysis of email submissions, the top 11 needs were collated (incorporating the top responses at the meetings and from email submissions). The emerging priority areas of need are as follows:

#### Priority areas of need identified by service providers and other stakeholders at the consultation events:

- Access to appropriate, safe treatment as locally as possible (practical clinical support).
- A reliable link to knowledgeable advice and support 24/7.
- Practical non-clinical advice, how to navigate the system.
- Key workers, single point of contact appropriate to stage of cancer journey.
- Help and support to carry on with everyday family life.
- Equitable opportunities to take part in education and training.
- Psychological and emotional support (including all family members).
- Peer support/socialisation.
- Information — choices.
- Preparation for transitions including survivorship and end of life.
- Appropriate palliative care and bereavement support.

The survey research showed that young people’s top need is to be able to go home during treatment. In support of this, stakeholders agree that a priority need is for children and young people to be able to have safe treatment as locally as possible. This would enable families to spend more time at home.

In addition to naming this core area of clinical need, stakeholders were also able to consider possible ways of ensuring clinical needs are met (although this was not directly asked of them in the first instance). Stakeholders recommended having reliable 24/7 contacts and a keyworker as effective ways to meet clinical needs.

Similar suggestions were also made by survey respondents and interviewees. Service users explicitly identified a need for clear 24/7 contacts for clinical advice when returning home. However, the need for a keyworker was not explicitly stated. Instead, service users highlighted areas of need which might benefit from keyworking such as safe transition from hospital to home, liaison between services and organisations, and co-ordination of clinical and psychosocial services.

Stakeholders are also in agreement with the survey and interview research in identifying key areas of psychosocial need: Education, Emotional Support, Practical Support and Peer Support (for the patient). Although financial support was not directly named, this is a component of Priority 3 — having someone to provide practical non-clinical advice and to help navigate the system.

Stakeholders also identified Information as a stand-alone need and not tied any to particular content. In support of this, the survey results suggested a need for information (both in terms of publications and in terms of advice) across all the main areas of clinical and psychosocial need.

Addressing the clinical and psychosocial needs listed above would help family members achieve the two outcomes amongst the list of eleven priorities: (1) Services should help families to carry on with their everyday life and (2) support during treatment should prepare families for successful transition to

survivorship. Again, these were themes apparent in survey responses.

Other strands of research in this consultation were not able to directly address the palliative and bereavement needs of families. Stakeholders clearly identified this area of need and this could be an area where further research is required or where other recent work<sup>10</sup> could inform a model of care.

#### 4.5.2 Web form submissions

During the consultation period, the CLIC Sargent external website hosted a Comments Box for stakeholders to respond with their views. Five relevant submissions from service providers were received and the main points from the submissions are listed in the box below.

##### Main web form comments:

- Agencies coordinating care for families — access to 24/7 care for seamless approach, better support/care
- Good networking between agencies allows for better communication, which facilitates good care/support too
- To offer the same core service across the UK
- To support all members of a family — not just the patient, or just the parents — siblings and extended family too.
- Financial difficulties aggravate an already difficult experience
- Respite care to parents is helpful
- At palliative stage, to be given extra support and attention to allow for 24 hour support

Although the number of submissions was low, the comments tie in with other strands of the consultations. In particular, co-ordinated care and 24/7 access to support were mentioned as means of ensuring that families receive good support at home.

<sup>10</sup> Better Care, Better Lives: Improving outcomes for children, young people and their families living with life-limiting and life-threatening conditions, February 2008, Department of Health: [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_083106](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_083106)

Furthermore, the general areas of psychosocial need while at home identified here tie in with those previously reported: financial support, practical support (which includes respite), and palliative care.

It has also been noted in other strands of the consultation that significant others, particularly siblings, may require support. Siblings are most likely to be affected directly by the disruption to family life. Other family and friends can also be affected emotionally, and may take on caring roles. A model of care could take this into account and specify at what stages assessment of the wider family and friends is required.

One suggestion not raised in any of the other strands of research is about ensuring that access to care is equitable across the UK. This is not an area of need in itself, but the intention is for a model of care to be applied across the UK with the aim of ensuring that all families have access to good quality care.

#### 4.5.3 Comments

Families have been able to inform the “More Than My Illness” review, via survey and interview research, about what support in general and in particular they have found helpful while at home and what else they need. It has been possible from the findings to infer how a model of service delivery might meet their needs and why it is important to do so.

However, the stakeholder meetings and web submissions have produced findings which are more delivery and outcome focused. In particular, service providers have been able to suggest two means of ensuring good clinical care at home (keyworking and 24/7 access to support) that would enable families to spend more time at home and so help with the transition to successful long term survivorship.

Service providers were also able to identify several areas of need not directly addressed in other strands of the consultation: Palliative/bereavement care (which should be considered as a stage of the cancer journey at which assessment is required), information (common to all areas of need) and equity of access across the UK.

On the latter point, the survey data could be used to assess regional variation in access to services. For the present paper the survey results have been used to identify levels of ‘actual need’ (i.e. number of families who need a service). Further analysis could identify ‘unmet need’ and satisfaction across regions (i.e. current gaps in services). The results could be used when implementing a model of care and for campaigning purposes.

## 4.6 SOCIAL WORK ACTIVITY REVIEW

### 4.6.1 Key findings

In summer 2007, CLIC Sargent surveyed its hospital-based social workers to ask them what they think should be the top social work priorities for families. From the survey responses a list of ten priorities was created in collaboration with an advisory group of social workers.

In early 2008, young people (13-24), parents/carers and Multidisciplinary Team colleagues of CLIC Sargent social workers were surveyed. They were asked to rate each priority in terms of its importance, say more about what they would like social workers to do in the community and name any other services they think should be a priority.

The survey results were reviewed internally and a list of top social work priorities was created (see fig. 1 below). The list differed slightly for children’s and young people’s services so that there are six priorities overall. Two further needs rated highly across all respondent groups were identified as underpinning the other priority areas or as principles in service delivery: Needs-led support (including assessment and re-assessment) and patient support (i.e. services for patients as well as parents).

The top social work priorities identified by the Social Work Activity Review are very similar to the general areas

of need identified in the present consultation: Financial, Emotional, Practical and Community Outreach.

‘Community Outreach’ covers two areas of need also identified through the present consultation: Education and Social Activities. When asked what social workers should do to help with life outside of hospital, the top response across all respondent groups was to help with education. Other common responses referred to emotional support, financial support, advocacy and practical support. Young people’s responses also commonly included requests for help keeping up with social activities including opportunities for groups, trips, treats and respite. Quotes in response to this question are included at the end of this section.

Interestingly a common response to this question amongst family respondents was a request for regular support or contact while at home. This ties in with emotional support needs, where families appreciate a known professional calling or visiting to check that everything is ok. Regular ‘checking-in’ while a family is at home is also an opportunity for a professional to monitor a family’s situation.

The survey for the present review did not directly question information or advocacy whereas the Social Work Activity Review has identified these as top priorities for social work. However, as has been noted previously, information needs (publications and advice)

are a common thread throughout many of the general areas of psychosocial need examined in the present consultation. This may also be true of advocacy. For example, the survey data showed that parents’/carers’ employment needs could first be met by providing information and advice and then by providing advocacy where needed.

In addition to corroborating findings from the present consultation, the Social Work Activity Review has explicitly stated that Needs-Led support should be a principle of service delivery. Support should be offered based on good assessment and re-assessment of a family’s needs, including both the patient and the parents.

The results of the Social Work Activity Review also suggest that practical support for parents should be a focus for the younger 0-15 age group while community outreach becomes more of a priority for the older 16+ age group. The review is suggesting that social work services should become more directed towards the patient as the patient transitions through key life stages, such as in education. This finding is supportive of the idea that a slightly different model of care will be required for older patients.

### 4.6.2 Comments

Unlike the present consultation, the Social Work Activity Review did not ask about specific services in addition to general areas of need. However, the high degree of similarity between the results of the two reviews suggests that the consultation process has identified real psychosocial needs. When clinical needs are also taken into account the model of care emerging from the two reviews should be comprehensive.

### Social Work Activity Review Family & MDT Surveys: “What kind of support do families need from a CLIC Sargent social worker to help with life outside of hospital?”

#### Financial Support

“Help with all the forms for benefits was essential for myself as the form looked far too daunting to contemplate on my own especially in the emotional state that I was in at the time. Those benefits allowed me to stay with my daughter and not worry about finances and returning to work. It was also good just to know there was somebody there that you could call on with any worries you had and know that they would either be able to help you or pass you onto some one else who could.”

Parent/Carer

#### Emotional Support

“When you are at home you leave the constant support of the hospital staff and have to take on the responsibility of looking after your child which is difficult when you are in a situation that you have never been in before. Perhaps even a phone call now and then would make you feel as though you still had that support. I think that the family would have benefitted from counselling during and after treatment. We all reacted in different ways with the diagnosis and subsequent treatment and couldn’t really talk to each other. It was all too painful.”

Parent/Carer

Fig. 1



**Advocacy**

“Advocacy, support with schools/ work. An overseer of social care.”

*MDT Member*

“If a child with cancer has special needs at school, it would help to have the backing of a social worker, especially if the LEA has to be contacted for this help.”

*Parent/Carer*

**Information**

“Information about available services, a point of contact for any questions, support for integrating back into their lifestyle, school, jobs etc.”

*MDT Member*

**Practical Support**

“Help out so parents can have their own time and space.”

*Parent/Carer*

“Help with other siblings, i.e. school run, clubs, etc.”

*Parent/Carer*

**School Support**

“Help with getting young people, who have had nothing but treatment for their illness fill their time for a considerable period, get back into ‘normal’ life. Attempting to re-integrate into university life has been very difficult for me, personally. Care should continue after treatment has finished, in order to help survivors readjust to everyday life.”

*Young Person*

**Social Support**

“Something to do while confined to home and while not at school.”

*Young Person*

“Days out with children like myself”

*Young Person*

**Regular Support**

“Ongoing support in all areas, being outside of hospital doesn’t mean all family problems disappear, in fact problems are possibly magnified!”

*MDT Member*

## 5. A FOCUS FOR FUTURE RESEARCH

In addition to identifying a reliable set of needs for inclusion in a model of care (see Chapter 2 for an overview), a number of areas for development and further research have also emerged from the consultation.

### 5.1 ‘TESTS’ OR ‘TREATMENT’ AT HOME

Young people and their siblings say they would like to be able to go home during treatment. However, it is unclear what kind of clinical care families would find acceptable or desirable in a home environment. For example, it could be that young people would happy to attend a clinic during the day and spend the night at home during treatment. Further research would be useful to establish the types of clinical support that young people are happy to receive at home or in hospital.

### 5.2 YOUNG ADULTS

The needs of young adults, 19-24 years, who are covered by the NICE guidance, but not by this model, should be considered in a second model of care. Care has been taken throughout this report to highlight areas where the needs of those aged 19+ years differ from younger age groups (eg. education, practical support, finance and work). In addition, this age group currently does not have full access to age appropriate care. Further consultation with this older age group may be required if a second model of care is developed to meet their needs.

### 5.3 REPRESENTATION AND ACCESS

Further research could seek to increase representation from other particular service user groups and explore related issues of access to services. Areas for research include:

- **Complex and high needs:** Some families, for a variety of reasons, need more services than others, or the services they need require complex work, such as involvement from multiple agencies. The survey research aimed to look at the number of service users who need a particular service rather than identify different patterns of need. Interview data and input from service providers was important to highlight high need families and complex needs, but further research maybe beneficial.
- **Palliative care/bereavement:** Nineteen bereaved parents and 1 palliative family responded to the survey and 20 bereaved families contributed to the social work activity review. However, many more were removed from mailings list for reasons of sensitivity. Again, input from service providers was important to highlight this area of need, but the model of care should also refer to other recent work in this area (eg. the Department of Health ‘Better Care: Better Lives’ guidance).
- **Black and Minority Ethnic Families:** In line with previous research and census data, 7.6% of survey respondents were ‘non-white’. However, the figure is lower than that of cancer registrations amongst 0-15s. Further research may be required in this area.
- **Language:** There was also some indication that language difficulties prevented some service users from completing the survey. This is an issue which could affect both participation in consultations and access to services and should be addressed in future research.

- **Cancer type, access and disability:** A factor that can affect access to appropriate services is cancer type (eg. brain tumour patients may not be treated with other paediatric/TYA cancer patients). In addition, illness and treatment may affect how easily a child or young person can participate in a consultation (eg. due to side-effects or disabilities). Although a wide-range of diagnoses types are represented in the family data collected for this consultation, future consultations could aim to increase accessibility and assess representation of cancer types.
- **All family members:** The whole family unit (the patient, their parents/carers and their siblings) are represented in this consultation. However, similarly to other consultations, the majority of parent/carer participants were mothers. There may be areas, such as employment and emotional support, where it would be useful to increase representation from fathers.

#### 5.4 UNMET NEED AND ACCESS TO SERVICES

Further analysis of the survey data is possible in order to identify where needs have not been met, and identify satisfaction with services, in addition to core needs. Such an analysis could highlight key areas for service development and also regional variation in access to services. Such analysis will be useful when implementing the model of care. The analysis would also be useful for supporting campaigning activity.

#### 5.5 IN THE LONGER TERM

The model of care will not cover long term survivorship or long term bereavement support. However, these may be areas where continued support outside of hospital would be useful for some families. This could be a focus for a future service development.

## 6. ACKNOWLEDGEMENTS

### 6.1 WHO ARE CLIC SARGENT?

CLIC Sargent supports children and young people (age 0 to 24 years old) with cancer, and their families. The charity offers a broad package of services including funding for clinical posts within the NHS (both hospital and community), funding and direct employment of social workers within multi-disciplinary teams (hospital based), specialist “youth worker” posts (both in hospitals and community), and more traditional voluntary sector services including family accommodation near principal treatment centres, holidays, financial support, information and a telephone helpline.

### 6.2 THE CLIC SARGENT CONSULTATION TEAM

The consultation was led by Susan George (Assistant Director of Services) and project managed by Helen Bradbury (Senior Project Manager).

#### **Survey Research, Interviews and Social Work**

**Activity Review:** The CLIC Sargent in-house Research & Development team manage the evaluation of CLIC Sargent services and conduct commissioned research (including a survey for the strategic review of the charity in 2007 and the Social Work Activity Review). The research team were commissioned to conduct the survey element of the present consultation, including the interviews. The team comprised of Pilar Gonzalez Grey, PhD (Head of Research & Development) and Catherine Dillon, PhD (Senior Researcher) assisted by Mylan Nguyen (Research Data Analyst) and the research assistant team (Joanna Day, Naomi Zeider and Mya Ajayi).

**Stakeholder Events:** Susan George co-ordinated the two consultation meetings with service providers. Susan George facilitated the Nurses’ Workshop with Sally Ramsay (CLIC Sargent Trustee). The Stakeholders’ Meeting was facilitated by Carole Easton (CEO, CLIC Sargent), Andrew Cooper (CLIC Sargent Head of Services, South West), Dr Faith Gibson (Senior Lecturer in Children’s Cancer Nursing Research, Institute of Child Health, University College London) and Phil Day (House Manager, Sam’s House [a CLIC Sargent Home from Home], Bristol).

# MORE THAN MY ILLNESS

Delivering quality care for children with cancer  
**Summary of Consultation**

CLIC Sargent  
2009

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