

# Child Cancer Foundation

## SUMMARY

Consultation with young people in 2006 revealed a high demand for specific age-appropriate services during and after cancer treatment. CLIC Sargent is responding to this feedback by increasing its support to young people in 2007: creating new specialist posts, increasing its range of services and consulting with young people on an ongoing basis.



## CLIC Sargent Young People's Services Report 2006-2007

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### OVERVIEW

CLIC Sargent is committed to delivering support specifically designed for young people, based on direct feedback from young people. Between June and September 2006, we consulted with 68 young people (11-24 years) with a prior diagnosis of cancer. They were contacted through youth support workers at treatment centres across the UK and at CLIC Sargent youth events. Using postal surveys and telephone interviews, we asked young people what services they wanted *during* and *after* treatment.

Findings support a high demand for group activities, such as meetings, social events and holidays, both during and after treatment. Young people report that they appreciate the opportunity to meet and talk with other young people in a similar position to themselves. There was also a request for more one-to-one support, and help returning to work and school. In addition, when asked what CLIC Sargent should be telling politicians and the public, young people most commonly responded with a request for age-appropriate treatment and care.

Based on the feedback we have received, CLIC Sargent is increasing its support to young people in the 15-24 age group. In 2007, we are creating new specialist posts, increasing our range of services and continuing to ask for young people's input at all levels.

***Young people with cancer need all the emotional and physical and financial help that they can get.***

*Female (20 yrs),  
Age 19 at diagnosis*

***After years of treatment you look like any other person, but on the inside you're not.***

*Female (15 yrs),  
Age 6 at diagnosis*

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## The CLIC Sargent Young People's Charter

### We promise to:

- Offer you a range of support specifically designed for young people.
- Treat you as an individual in your own right, and with respect and dignity.
- Offer you financial support and information, and point you to help that may be available elsewhere.
- Support you when you're dealing with other professionals and organisations.
- Use our voice as the UK's leading childhood cancer charity to give young people a voice nationally.
- Support research and services to help improve treatment and care for young people with cancer.
- Offer our support for as long as you need it.

## Outcomes for Young People identified by 'Every Child Matters'

- Be Healthy
- Stay Safe
- Enjoy and achieve
- Make a positive contribution
- Achieve economic well-being

## WHY IS WORKING WITH YOUNG PEOPLE IMPORTANT?

The National Institute for Clinical Excellence (NICE) introduced new guidance in August 2005 entitled, "Improving Outcomes for Children and Young People with Cancer." In this document, it is reported that the incidence of cancer diagnoses in the 15–24 age group is nearly *twice* that in the 0–14 age group; and outcomes can be significantly worse<sup>1</sup>. In line with NICE guidance, CLIC Sargent is increasing support to young people in the 15+ age group.

Currently, there are seven specialist units for young people with cancer across the UK. More commonly, young people are treated either in paediatric units or adult wards (where there is little opportunity for interaction with people their own age). Young people can therefore feel isolated and, in the absence of specialist youth workers, can have difficulties accessing practical help such as benefits, grants, and educational materials. A life threatening illness like cancer can disrupt emerging independence, relationships, education, work and other personal pursuits.

Our model of psycho-social support for young people (see box) is closely related to outcomes identified by the government in the Every Child Matters<sup>2</sup> report (see box below) and the National Service Framework<sup>3</sup>. We recognise how important it is for young people to receive specialist support during treatment for cancer and to resume normal life after treatment. We also recognise that many young people will have to live with long term side effects and confront their own mortality.

CLIC Sargent is working in partnership with the NHS and other charities like Teenage Cancer Trust (TCT) to put young people's needs at the front of the NHS cancer plan. In order to make informed decisions, CLIC Sargent is committed to seeking the views of young people on our delivery of youth support services.

## HOW DID WE CONSULT WITH YOUNG PEOPLE?

Between June and September 2006, 68 young people in total were contacted with the help of CLIC Sargent youth staff in treatment centres across the UK and at CLIC Sargent youth events.

We received completed questionnaires from 62 young people about their needs during and after treatment. All respondents (27 males, 35 females) had a prior diagnosis of cancer; with the majority (73%, n=45) having completed treatment. The average age at first diagnosis was 11.7 years (range: 1-19 years). At point of survey, the average age of respondents was 16.8 years (range: 11-24 years). All statistics in this report are based on the results of the survey.

We also conducted in-depth telephone interviews with a further six participants about their experience of cancer treatment as young people. All interviewees (4 males, 2 females) had completed treatment. Their average age at diagnosis was 15.6 years (range: 7-20 years) and their average age at point of interview was 19.6 years (range: 17-23 years).

1 0-14 age standardised incidence 122 per million; 15-24 ONS data, age standardised incidence 213.9 per million. NHS National Institute for Health & Clinical Excellence, Aug 2005. Available at <http://guidance.nice.org.uk/csgcyp>

2 Every Child Matters, HMSO Green paper, Sept 2003. Available at <http://www.everychildmatters.gov.uk/children>

3 National Service Framework for Children, Young People and Maternity Services, Sept 2004: [http://www.dh.gov.uk/en/Policyandguidance/Healthandsocialcaretopics/ChildrenServices/Childrenewservicesinformation/DH\\_4089111](http://www.dh.gov.uk/en/Policyandguidance/Healthandsocialcaretopics/ChildrenServices/Childrenewservicesinformation/DH_4089111)

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***We aren't children, and more places like TCT wards would be really good.***

*Male (24 yrs),  
Age 16 at diagnosis*

***Some things happen that you can't ask your folks about and you feel embarrassed to ask the nurses or doctors. It would have been nice to have had younger people to ask advice, share stories and experiences. It would have been nice to talk to someone going through a similar experience.***

*Male (21 yrs),  
Age 20 at diagnosis*

***If you get on with the staff it boosts your morale. I had a CLIC Sargent Social Worker on the ward I was in. She was absolutely great. She knew how to interact with young people.***

*Male (21 yrs),  
Age 20 at diagnosis*

## WHAT DID YOUNG PEOPLE TELL US?

### Group activities are important

Demand for group activities is high (74% of respondents reported using group activities). The most common group activities *during* treatment were: social activities (32%), group meetings (31%) and holidays (25%). *After* treatment, holidays and residential weeks (53%) were the most favoured.

While a third of respondents mentioned barriers to joining groups (e.g., difficulty with mobility, with access, sickness, too busy, or lack of confidence), only 2 respondents reported not wanting to take part in any group activity at any time. Young people's comments suggest that group activities are valuable because of the opportunity to be with and speak to other young people in similar circumstances to themselves. This may be particularly valuable when young people are not treated on age-appropriate wards.

### One-to-one support is needed

Nearly two-thirds of respondents reported using one-to-one support already, in addition to group activities. Almost a quarter of young people reported wishing they could have *more* one-to-one support. Young people reported having little privacy on wards, and requested time to discuss more personal issues with a support worker.

### Be there when needed

Young people use CLIC Sargent support services for a range of practical, emotional and social reasons. After group and one-to-one support, financial advice and help with claiming benefits (66%) features highly. Also, more than a third of the respondents (40%) received support with transitioning back to school, college or work.

### Support from CLIC Sargent that was appreciated

Young people reported that their top three 'most helpful' types of support were, in order of preference: (1) holidays and residential activity breaks; (2) one-to-one support and (3) support to their family. Support to their families is equally important to young people as receiving support for themselves.

'What else was helpful or important to you?'

- **ADVICE:** 'Advice and encouragement were helpful.'
- **CONFIDENCE:** 'Making me feel confident with myself.'
- **FRIENDSHIP /LISTENING:** 'Just being there for me.' 'To listen to my views on issues that affected me.' 'A friend to talk to at any time.'
- **HELPING TO LINK:** 'When they talked to my school and brought back messages from my friends.'
- **SOCIAL:** 'Lots of fun and games when I've been feeling less good.'
- **PRACTICAL:** 'Provision of laptop was helpful.' 'Sponsor money for wish.'

### Tell politicians about age appropriate care

When asked what was the most important thing to tell politicians and the general public about young people with cancer, a third (32%) of the respondents identified age-appropriate care and support.

***In an adult ward, you are surrounded by older people who talk about different things, have different views, and are not as positive as younger people. They can be negative. I want to talk about University and going out.***

*Female (21 yrs),  
Age 20 at diagnosis*

***The CLIC Sargent involvement has been vital throughout: including home visits, and a friend to talk to at any time.***

*Male (15 yrs),  
Age 13 at diagnosis*

### Young person on a paediatric ward:

**Paul was diagnosed with Acute Lymphoblastic Leukaemia at age 14, and again at age 18. He is now 19 and has finished treatment:**

"I was in a paediatric day unit quite a bit. I found it frustrating as there were a lot of 3-6 year olds screaming, running around with parents getting agitated. It was especially frustrating when I wasn't feeling well. These are my main memories. I tried to do school work, but it was homework for 7- 9 year olds. It was too easy for me; not worthwhile doing; not challenging. They had a teaching room and teachers for young children. They were primary teachers. But for me, they didn't know what to do. In any case, it wasn't the first thing on my mind, to continue studies. After treatment, I was put back a year at school which wasn't easy. I'm not a particularly social person and found it difficult to go back one year."

### Young person on an adult ward:

**Chris was 16 when diagnosed with Burkitt's Lymphoma and is now aged 17. Chris has finished his treatment and is in remission:**

"It took two days to diagnose me. The hospital ward was full of old people and I sat in my room and did nothing. There was a ward for little kids, but the doctors thought it was not suitable for me. It annoyed me because the children's area was full of play-stations, games consuls, board games, a telephone, DVDs and videos. I was in the hospital for two months. If they had a teenage area, I could've gone there to see others my own age, to talk to, and have stuff to entertain me like a laptop, DVDs, television on a trolley, board games you can play when your friends come to visit. My time in hospital would have been easier if I'd had people to talk to, closer to my own age. My friends totally forgot about me. No one bothered to come in."

## HOW IS CLIC SARGENT RESPONDING TO YOUNG PEOPLE'S FEEDBACK?

**We are expanding services to young people in 2007 in eight key areas:**

### 1. One-to-one support for young people:

- 5 new specialist posts were filled in 2006, bringing the total to 24 posts.
- A further 15 specialist posts are budgeted for in 2007.
- We are running mentoring schemes for young people using volunteers.

### 2. Group activities in hospital and outside:

- Regular young people's groups have been introduced into 3 more centres and the expansion will include more specialist staff and volunteers.

### 3. More information:

- The CLIC Sargent website now has a message board for young people<sup>4</sup>, and a map of existing and planned specialist posts<sup>5</sup>.
- Newsletters: produced in Northern Ireland, the South West and Manchester.
- Publications: "Chemotherapy, Cakes & Cancer"<sup>6</sup>, top tips from a young patient, (February 2007) and a book of survivors' stories due out in Summer 2007.

<sup>4</sup> <http://www.clicsargent.org.uk/Aboutchildhoodcancer/OnlineCommunity/Messageboards>

<sup>5</sup> <http://www.clicsargent.org.uk/Whatwedo/Youthservices>

<sup>6</sup> For a copy please contact the Child Cancer Helpline on 0800 197 0068

**“More group activities so you get to meet more people like yourself. Also more support when we have to move to the adult side of medical, which is scary.”**

*Female (15 yrs),  
Aged 6 at diagnosis*

**“Young people with cancer are not something to be looked down on, we are 'normal' people too.”**

*Male (18 yrs),  
Aged 16 at diagnosis*

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Child Cancer Helpline  
**0800 197 0068**  
Mon – Fri: 9am till 5pm

Or e-mail:  
[research@clicsargent.org.uk](mailto:research@clicsargent.org.uk)

#### 4. Holidays & residential weeks

- We have increased the availability of holidays and residential breaks: a new caravan on the East Coast (England); youth residential weeks at Malcolm Sargent House (Scotland) and Barrattstown (Republic of Ireland).

#### 5. More social contact:

- There has been a substantial increase in group activities for young people (and for their friends and siblings too) as we have put more staff in specialist posts.

#### 6. Improving communications:

- Youth workers using SMS mobile phone texts to contact young people.
- Consultations with young people: using technology to enhance communications.
- CLIC Sargent is building a database of young people who want to take part in feedback and surveys.

#### 7. Research into needs:

- CLIC Sargent is supporting research that is looking at the use of technology on the wards to help young people manage their symptoms while on treatment.
- Research into young people and their transition back to school or work.

#### 8. Advocacy messages on age appropriate treatment centres:

- We continue to work with the NICE implementation group and to be partners with TCT to support and campaign for specialist units.
- We are making sure that young people are present and representing the views of their peers in CLIC Sargent, the NHS and other forums throughout the UK.

## CONCLUSIONS

### The results of our consultation confirmed the importance of:

- Offering age-appropriate services where needed.
- Facilitating contact with other young people during and after treatment.
- Expanding our treatment-to-school and treatment-to-work transition support work.
- Producing accessible information for young people and the people supporting them (e.g., family, friends and professionals).
- Continuing to influence the development of age-appropriate treatment centres.
- Delivering on our Charter by consistently seeking the views of young people.

**Any quotes or citations from this report may be used, as long as the source is acknowledged.**

With thanks to all the young people who agreed to participate in this study, and the CLIC Sargent staff nationwide who helped collect data and interview respondents.