

Working with you to support
young people with cancer

www.clicsargent.org.uk

Supporting
young people
with cancer



WHO WE ARE

Every day in the UK, 10 children and young people are told they have cancer.

The shock of diagnosis is just the start. From then on, they will be living with the impact of cancer and its treatment – sometimes for many years to come.

Treatment normally starts immediately. It often takes place many miles from home, and can last for up to three years. A cancer diagnosis affects the whole family in many different ways and the emotional, practical and financial implications can be intensely challenging.

CLIC Sargent is the UK's leading cancer charity for children and young people aged 0 to 24. We provide clinical, practical and emotional support to help them, and their families, cope with cancer and get the most out of life.



INTRODUCTION

This booklet has been written for healthcare professionals working with 16 to 24-year-olds with cancer. It tells you more about CLIC Sargent's work, with a focus on how we can complement the care you offer to young people with cancer. It also sets out our ambition to meet the needs of every young person with cancer in the UK aged 16 to 24.

About CLIC Sargent

CLIC Sargent was formed in 2005, after a successful merger between CLIC (Cancer and Leukaemia in Childhood) and Sargent Cancer Care for Children. Both organisations had a history of supporting children and young people with cancer up to the age of 21.

In 2006, as a response to National Institute for Health and Care Excellence (NICE) improving outcomes guidelines, and feedback from young people and NHS trusts, we extended our support to young people up to (and including) the age of 24.

Who we help

In the UK we provide support to 95% of all children with cancer under 16, and their families. Currently, we support about 60% of 16 to 24-year-olds diagnosed with cancer.

We have ambitious and innovative plans to extend this reach to all young people diagnosed with cancer who need our support. This can only be achieved by working in close partnership with healthcare professionals and NHS colleagues.

To be there for all young cancer patients, we also need to raise more funds and we have a clear fundraising strategy in place to achieve this.

THE NEEDS OF YOUNG PEOPLE WITH CANCER

A cancer diagnosis is difficult at any age, but for young people on the brink of adult life, it can be particularly challenging.

Young people diagnosed with cancer must deal with the impact of diagnosis and treatment, at a time when they are just becoming independent and establishing their own identity. Being diagnosed with cancer also has a huge emotional impact. Young people often feel socially isolated, because treatment prevents them from taking part in normal everyday activities, and can cut them off from friends.

For some young people, a cancer diagnosis means they need their parents to care for them and provide financial support and a place to live, even if they've left home or were about to do so. This can sometimes feel like a backward step and result in practical, financial and emotional issues.

Cancer can interrupt a young person's education, force them to give up a job, or make it necessary to take time out at the start of their career. This might mean a drop in income, combined with the extra costs associated with cancer, such as travelling to and from hospital.

“Because of treatment I couldn't work full-time, and this had a big impact on my personal finances. I had to travel every day to hospital for treatment and costs can really mount up.” Jadi



CLIC Sargent has carried out extensive research and consultation with young people with cancer, to better understand their needs. We've also reviewed evidence gathered by other organisations. The priority non-clinical needs identified by our research (ie More than my illness 2010) include support with:

- Emotional health and wellbeing
- Education
- Accessing employment
- Financial issues
- Reducing isolation
- Health and fitness.

We also know that young people have different levels of need, depending on their cancer diagnosis,

the type of treatment they are having, and what else is happening in their lives. Some young people with cancer require in-depth practical and emotional support to maintain their wellbeing and resilience. Others need a lower level of support, such as information about cancer and its impact, or financial support when they are first diagnosed.

Our latest research (Coping with cancer 2014) found that access to quality support and information is key to helping young people with cancer feel confident in managing their illness and building resilience.

We think every young person with cancer should have access to the age-appropriate practical and emotional support they need,

wherever they are treated, from as soon as they are diagnosed and continuing until after their treatment. We've made achieving this goal our priority.

NHS CANCER CARE FOR YOUNG PEOPLE

In 2005, NICE guidelines were launched to improve outcomes for young people with cancer. The guidelines, and the new quality standards to accompany them, highlight the importance of age-appropriate care and the provision of social care support. In the guidelines CLIC Sargent's young people's social workers were named as core members of teenage and young adult multi-disciplinary teams (TYA MDTs) providing psychosocial support.

There have been significant improvements since the NICE guidelines were introduced:

- TYA MDTs have been established across the UK, ensuring better coordination of care
- Since 2006, when CLIC Sargent extended its support up to the age of 24, we've established young people's social workers at every principal treatment centre (PTC), to provide vital practical and emotional support

- Our young people's community worker roles have been developed, providing vital support in the community with a focus on employment, education and training
- Age-appropriate wards, many of which are funded by Teenage Cancer Trust, have improved the support and experience young people have in hospital.

Depending on their diagnosis, treatment and personal choices, 16 to 24-year-olds may be treated at:

- A TYA cancer PTC, which offers age-appropriate care, or
- A designated TYA cancer unit working in partnership with the PTC, or
- A hospital with cancer services that are not specifically designated for TYA cancer.

To meet the needs of young people wherever they are treated, we have developed a service model, which works in partnership with PTCs and other hospitals, that will significantly improve support for young people with cancer.



HOW CLIC SARGENT SUPPORTS YOUNG PEOPLE WITH CANCER

Young people have told us that they need financial, emotional and practical support, including help to continue or access education, employment and training. This depends on their individual circumstances - some will still be living with their parents, others on their own, or with their own children. Many will be at college or university, looking for work or in employment.

We offer all young people with cancer:

Information

Our information helps young people and their families navigate their way through cancer. Our resources, developed with the help of young people with cancer, explain how

a diagnosis is likely to affect their day-to-day lives, and help them manage the impact of cancer and treatment. They also highlight other sources of support.

We have online information for young people, including videos and podcasts, covering topics such as finances, education and friendships.

Our guide for young people, *Making sense of it all*, is available as a booklet or online and offers essential information, tips and insights to 16 to 24-year-olds who have just been diagnosed with cancer. *Cancer and treatment - a guide for young people* focuses on the medical side of cancer, treatments and side effects.



Financial support

Young people face significant extra costs as a result of a cancer diagnosis, sometimes alongside a drop in income. We offer grants to all young people aged 16 to 24 within a year of their diagnosis to help with, for example:

- Travel expenses
- Household bills
- Education, employment or sporting activities.

Young people can experience unexpected financial difficulties during treatment, like extra childcare costs if they have children. We can provide exceptional grants to young people in these situations.

We also assist young people to access other organisations that provide financial support.

Our free, specialist CLIC Sargent welfare advice service helps young people cope with the practical and financial impact of a cancer diagnosis. Young people can seek advice on a variety of issues such as claiming benefits, including Personal Independence Payment, employment, and debt problems.

“I had just bought a house and was then diagnosed with cancer for a second time, so I couldn’t keep on working and covering the mounting costs for bills. I was really afraid that I wouldn’t be able to keep on top of all the payments, but CLIC Sargent provided me with a grant to help ease the pressure.” Michael

Free accommodation

Our nine Homes from Home, close to specialist hospitals, provide a place where young people and families can stay during treatment, so that long journeys for hospital visits and paying for overnight stays can be avoided.

Free holidays and specialist short breaks

Free holidays at our holiday home in Scotland offer a chance to get away from the everyday challenges of cancer, with the support of our care professionals and medical support close by. We also run specialist breaks for young people, which give them an opportunity to spend time with others who are going through a similar experience.

Peer support

In early 2015 we are launching our new online community for 16 to 24-year-olds who have or have had cancer, providing an environment for them to share experiences and support each other.

In some parts of the UK, we organise peer support social events so that young people coping with the impact of cancer get the chance to spend time with others in a similar situation. We also have groups for young people on social media.

Visit the *Help and support - For young people* section of our website at www.clicsargent.org.uk to find out more about how we can help



Matt was diagnosed with
bone cancer when he was 16



Where available, we offer young people with cancer:

Face-to-face practical and emotional support

Our care professionals provide much-needed practical and emotional support to help young people cope with the impact of a cancer diagnosis and its treatment. They focus on emotional wellbeing and resilience, and help young people feel less isolated. They play an important part in building young people's confidence, helping them to have the self-belief they need to deal with the challenges they face. Our care professionals also provide specialist information and financial support, from diagnosis onwards,

help young people keep in touch with their education if they are at school or college, and their jobs if they are in employment.

We have qualified young people's social workers and specially trained young people's community workers across many areas of the UK. They work together, alongside TYA and other NHS MDTs, to provide young people with targeted and individual support that responds to their needs.

Our young people's social workers can offer in-depth emotional support to young people with complex needs, including those in crisis situations. They are skilled at listening to young people, and are able to meet them in hospital or at home.

Our young people's community workers are trained to help with emotional wellbeing and resilience, with a particular focus on education, employment and training issues. They provide individually-tailored support, close to home or where the young person with cancer is being treated.



“Emotionally it was really good to have someone to talk to. It was so much easier talking to Jacquie, my CLIC Sargent Young People’s Social Worker, than other people. I know I can just give her a call or send her an email and she’s there to help.”

Carly, 24, was diagnosed with Ewing’s sarcoma when she was 20

Many young people who are not having treatment in principal treatment centres do not have access to specialist age-appropriate support. To help bridge this gap we want to expand our services, including by recruiting more young people's social workers and community workers to meet the needs of young people wherever they are treated.

“A cancer diagnosis for our young patients can be particularly difficult for them to come to terms with, but with the support from their CLIC Sargent Young People's Social Worker and Community Worker, they can get the tools they need to work towards their career aspirations or employment choices, whilst receiving their treatment.”

Dr Kanchan Rege, Clinical Director,
Peterborough and Stamford Hospitals
NHS Foundation Trust



“Anita, my CLIC Sargent Young People's Community Worker, has been there to make me emotionally better. The doctors and nurses are there to get you physically better, but actually looking after your emotional health can be more of a task.” Jack, 21, who had acute lymphoblastic leukaemia.

DEVELOPING OUR YOUNG PEOPLE'S COMMUNITY WORKER ROLES

In 2011 we recognised the need to adapt our young people's development worker roles to ensure young people received support in the community. We established the young people's community worker role, in response to evidence that young people who were receiving care outside of PTCs weren't able to access the practical and emotional support they needed, through treatment and beyond.

We started with a pilot scheme. Young people who took part in the evaluation said that the community

workers helped them keep life as normal as possible. They especially valued help with education, and training and employment issues.

The evaluation concluded that this model has the potential to transform the support available to 16 to 24-year-olds, and that the role worked effectively as an integral part of the TYA cancer services for the area, complementing other service provision. We currently deliver this service in nine locations – but our aim is to offer this support throughout the UK.

An award-winning service:

CLIC Sargent was the winner of the *Healthcare and medical research* category at the Charity Awards 2014, in recognition of its pilot of the young people's community worker role. This was also 'highly commended' in NHS England's 2014 Excellence in Participation Awards.



“Tracy filled that gap between leaving hospital and getting back to normal.”

HAROON'S STORY

Haroon was diagnosed with Hodgkin's lymphoma at the age of 23. He was in his last year at Glasgow Caledonian University. Haroon's CLIC Sargent Young People's Community Worker, Tracy, helped him to rebuild his life after treatment.

"I felt fragile when I left hospital after my treatment. Months of chemotherapy and a stem cell transplant had taken their toll. I knew I needed to get my life back on track but I didn't know where to start.

Tracy filled that gap between leaving hospital and getting back to normal.

She found me an exercise class for cancer patients as the steroids I'd taken during my treatment meant I'd put on a lot of weight. Once I was feeling stronger physically, she helped me focus on getting back to work.

Tracy helped me reassess my options. We revamped my CV, practised interview skills and talked through feedback I received. Interviewers told me my lack of work experience was an issue. Having cancer in my last year of university had meant I'd missed out on placements, so Tracy encouraged me to volunteer for charities, like CLIC Sargent, to gain new skills.

I've been in remission 18 months now, and have a job as a business adviser. Tracy's support was key - it kept me motivated whenever I was feeling low."

You can watch a short film about Haroon at www.clicsargent.org.uk/haroon

HANIFA'S STORY

Hanifa, now 25, was diagnosed with leukaemia when she was 23. At the time Hanifa was on maternity leave and her apprenticeship job was terminated. Marion, her CLIC Sargent Young People's Social Worker, helped Hanifa rebuild her confidence and get back on track.

"I met Marion about halfway through my chemotherapy. It was good timing because I was having a lot of trouble with my employers and she was able to help me through it all.

As well as practical help, Marion provided a lot of emotional support. Whenever I had an issue I'd text her, and when I was in hospital she'd come to see me. The thought of going back to work scared me. I felt nervous of even approaching the subject of applying for jobs and going for interviews. Because I had my contract terminated at my old job, I felt like no one was going to accept someone with cancer who is applying for a job. My confidence was really shaken.

Marion helped me rebuild my confidence. She sat me down and spoke to me about getting back on track. She helped me apply for a few courses, some online courses, and explore work experience opportunities. Recently she referred me to a scheme called Fit For Work, to help me get back to where I was before I was diagnosed. In that sense she's done so much for me.

When you're going through cancer treatment you need someone like Marion there. I felt comfortable around her because she was so upbeat. She helped me feel more positive about everything."



"When you're going through cancer treatment you need someone like Marion there."

HOW WE HELP YOUNG PEOPLE - AT A GLANCE

We offer all young people with cancer:

- Age-appropriate on and offline information
- Financial support and welfare advice
- Free accommodation at our nine Homes from Homes
- Free holidays and specialist short breaks.

Where available, we offer young people with cancer:

- Face-to-face emotional and practical support for those who need it.

Listening to children and young people is at the heart of everything we do. We put young people's voices at the centre of all our work.

In 2014 we were awarded a gold award from the National Youth Agency for our commitment to listening to and acting on the views of children and young people.



OUR PLANS FOR THE FUTURE

We want to support all young people with cancer who need us. To achieve this, we have a clear fundraising strategy in place to increase our income by around a third between 2012/2013 and 2017/2018 so that we can:

- Grow our service to meet the needs of all young people with cancer, including recruiting more young people's community workers and young people's social workers in locations across the UK
- Expand our information service for young people
- Launch an online community for young people in early 2015
- Extend our Homes from Home service, to offer this accommodation to more young people.

We will also maintain the vital support we offer to children and their families, as well as young people, by continuing to:

- Deliver financial support and welfare advice
- Offer support through our nine Homes from Home
- Grow and strengthen our social care service for children
- Deliver and coordinate clinical care through our nurses, as close to home as possible, to children diagnosed between the ages of 0 to 16
- Ensure listening to children and young people is at the centre of all we do.

WORKING WITH YOU TO IMPROVE SUPPORT

To help us reach our ambition to meet the needs of all young people with cancer, we want to work with healthcare professionals to understand where the unmet need is locally, and help bridge that gap. As we extend the service over the coming years we will get in contact with local MDTs to plan local service expansion, so resources are targeted effectively.

Working together, we can create a joined-up service that complements what is already in place locally, and provides what young people with cancer need, when and where they need it.

And together, we can offer a level of practical and emotional support that will improve young people's resilience during their treatment and help them to build the life they want after cancer.



Blair, 22, was diagnosed with leukaemia when he was 17

GET IN TOUCH

To find out who to speak to from CLIC Sargent in your area, contact:

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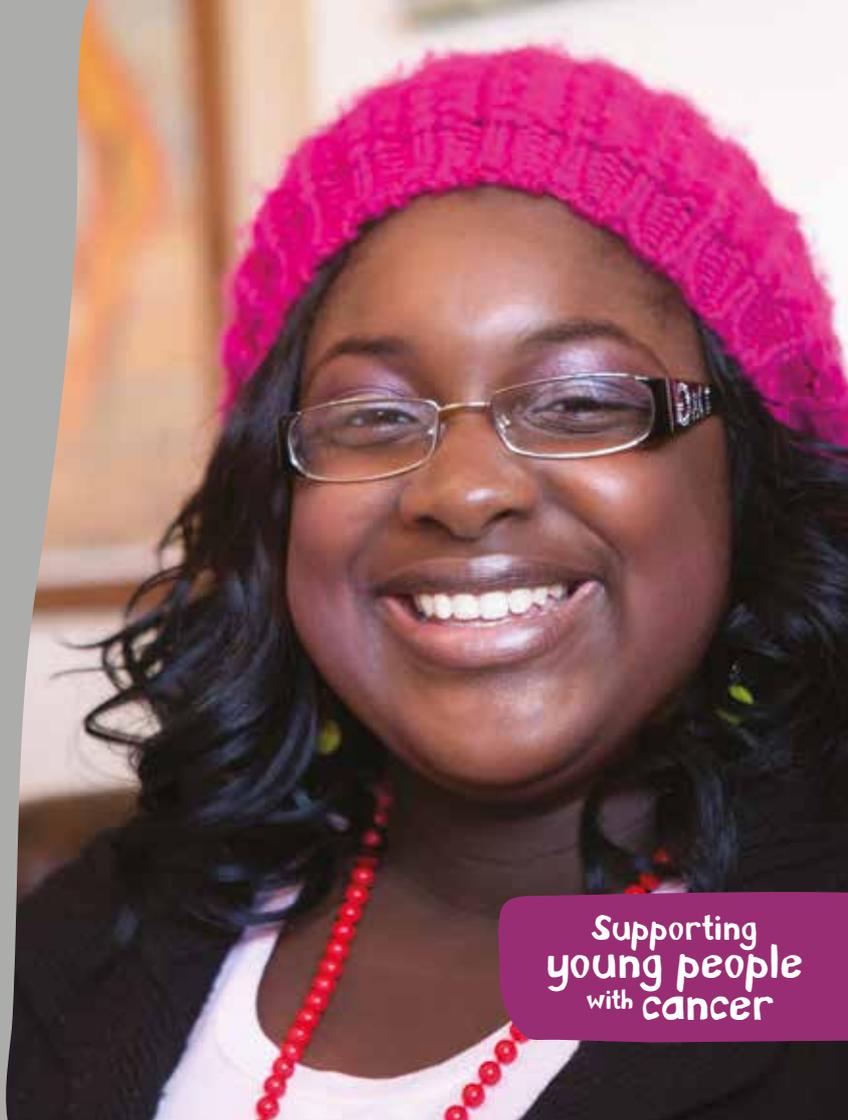
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