

**SUPPORTING
CHILDREN AND
YOUNG PEOPLE
WITH CANCER**



CLIC Sargent's online community

Helping young people cope with cancer

Helen Gravestock and Ruth Plackett

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This presentation will address

- Research aims – help seeking behaviour and resilience
- Key research findings
 - Seeking support and information
 - Online support
 - Approaches to building resilience
- CLIC Sargent's online community
- Ways forward.

About CLIC Sargent

Every day in the UK, 10 children and young people are given shocking news that will change their lives forever. They are told they have cancer.

CLIC Sargent provides:

- emotional
- practical
- financial
- clinical support.



We are there from diagnosis onwards and aim to help the whole family deal with the impact of cancer and its treatment, life after treatment and, in some cases, bereavement.

Young People's Health Partnership (YPHP)

CLIC Sargent is a member of the YPHP consortium of organisations working with the Department of Health, Public Health England and NHS England as strategic partners to raise the profile of the health agenda across the voluntary youth sector.



**Young People's
Health Partnership**

Background

- Previous CLIC Sargent research found many young people were anxious about the future and the impact of their cancer on their confidence
- We undertook research to better understand young people's help seeking behaviour throughout their cancer journey
- 'Coping with cancer' illustrates our findings and explores how the right support can help young people build resilience and ability to manage their illness and its associated challenges
- In early 2015, CLIC Sargent launched an online community that provides a supportive space where seek and provide others with support.

Project aims

- To undertake research into how young people seek information and support
- To find out from young people with cancer what they would like from an online community
- To develop a supportive virtual space where 16 to 24-year-olds who have, or have had, cancer can talk to other young people in a similar situation.

Research methodology

Literature review

First, a review of relevant literature was undertaken in order to understand the evidence base and its applicability to young people with cancer. This involved a thorough review of the current knowledge base on help-seeking and resilience, collating evidence from a range of sources.

Online survey

Young people with cancer were consulted through an online survey (n=124). All participants were self-selecting and identified through CLIC Sargent's networks. All had been diagnosed with cancer in the UK between the ages of 16 and 24, or were currently within that age range.

Young people's focus group

An additional 14 young people, who had completed the survey, attended a focus group where the survey findings were discussed in more detail.

Interviews with key stakeholders

Interviews were carried out with academics and practitioners to identify their expert views and contextual understanding of help-seeking behaviour and resilience among young people with cancer.

Seeking help to manage challenging situations

- Transition into adulthood can be challenging. Young people have big decisions to make about their future and have a lot to think about and manage:

- * Education/employment prospects
- * Moving from the family home
- * Social pressures
- * Becoming financially independent
- * New relationships

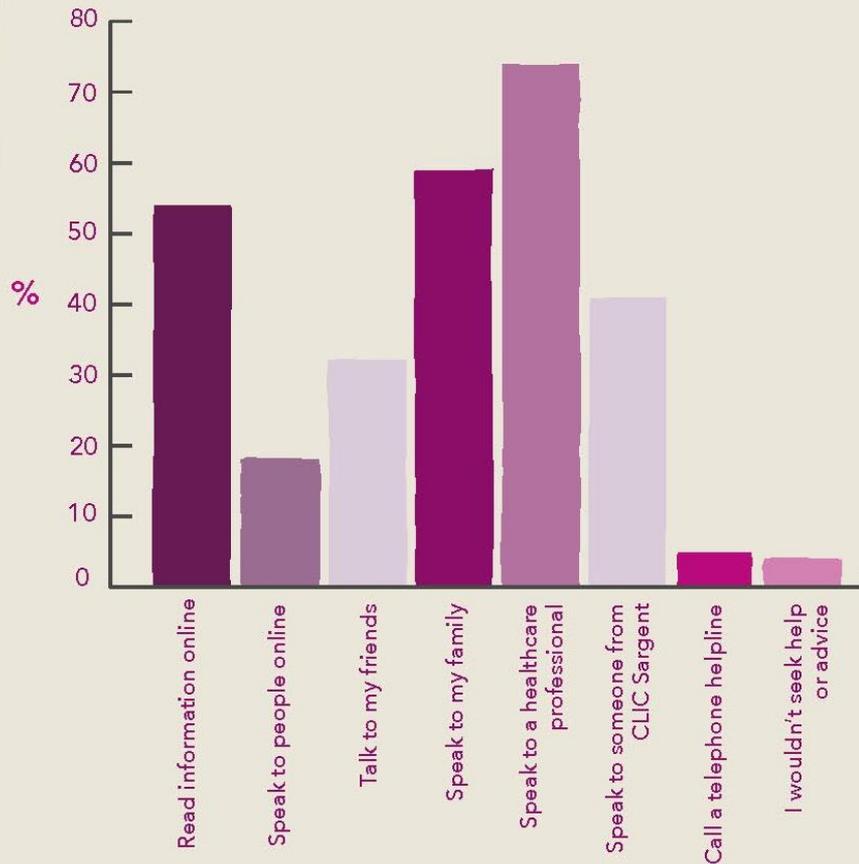
- A cancer diagnosis can be a huge additional challenge
- Seeking help is one way young people cope with problems and stresses that arise.

Young people seek different information on different topics in different ways throughout their cancer journey

Providing young people with a suite of support options gives them the freedom to make the choice which suits them best

Seeking information and support

If you had a problem that was worrying you, how would you prefer to seek help or advice?



- Young people access a range of different people and sources of help, support and information depending on the nature of their needs
- For general health, cancer and treatment issues young people opt to speak with professionals
- However they would rather speak to friends about sex and relationships or go to an online information source.

While online support cannot replace face-to-face support, there is a growing need for quality age appropriate online information

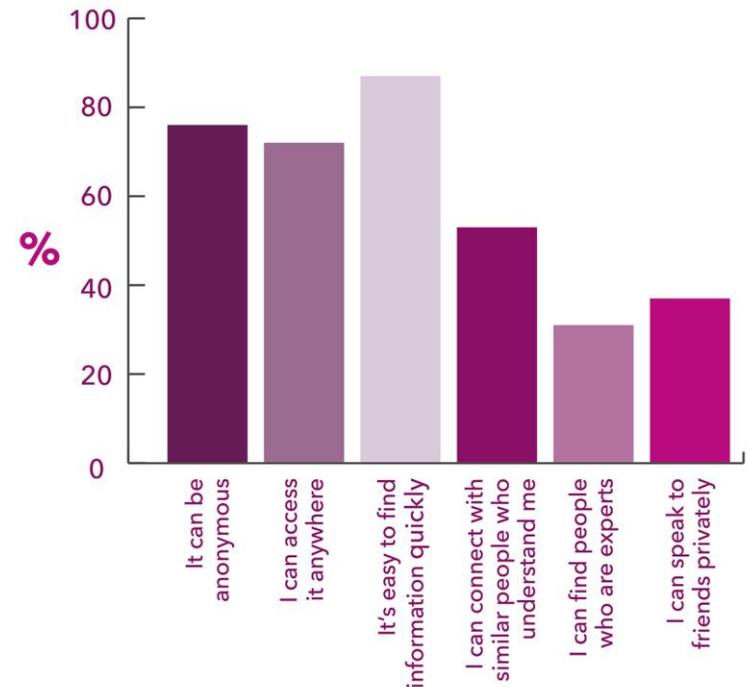
Most (96%) of the young people surveyed use the internet to look for information and advice

Seeking online information and support

78% of young people told us they want to connect and interact online with other young people in similar situations, using social media and forums to share experiences and advice.

- 55% of young people used the internet to give advice to others
- 48% said they used it to discuss issues and concerns with other people
- 78% wanted to interact with people who have been in their situation before them.

WHAT DO YOU LIKE ABOUT THE INTERNET WHEN SEEKING HELP OR ADVICE?



Young people's online information needs will vary throughout their cancer journey

At Diagnosis

Young people can find it difficult to obtain information from their GP or from healthcare professionals, some turned to the internet, despite feeling overwhelmed and alarmed by some of the information they found

During treatment

Young people used the internet less for information purposes and more for distraction, support and staying in touch with friends and family

After treatment

Young people used the internet to look for information about symptoms, signs of relapse, and long-term effects. They felt that there was less professional support available at this stage, leading them to seek out information, support and advice on their own

Access to quality information is key to helping young people with cancer feel confident in managing their illness and building resilience.

Young people can feel anxious when their treatment ends and need more information and support at this point of their cancer journey

Young people with cancer and resilience

- Resilience can be seen as an outcome of *coping* successfully with adversity
- Successful management of problems creates greater resilience

It's useful to conceptualise resilience as an outcome:
the outcome of successfully *coping* with stressful experiences

- The literature on resilience and experts in the field often link it to notions of coping and competence

Approaches to building resilience

We found that there a range of effective approaches to building resilience

- These include approaches focused on the **individual**
- And approaches taking the **wider health and social care system** into account (community approach)



Both are relevant to young people with cancer.



The online community

In response to our research CLIC Sargent's online community was launched in early 2015.

The online community is a mobile-friendly, secure online space for 16-24 year olds, who are on or off cancer treatment.

The community aims to help members find people in similar situations, so that young people can share information and support each through difficult times.

CLIC Sargent

Search

- Post a message
- Trending
- Tags
- Search
- About the community
- About CLIC Sargent
- House rules
- 24 hour support
- Cookie policy
- Privacy policy

1 PERSON REPLIED 

I met with a Clic Sargent support worker today and she suggested I sign up to this, so here I am. :) It seems most people start off by talking about their diagnosis and stuff.

I was diagnosed with Hodgkins Disease/Hodgkins Lymphoma literally just over a week ago 5. I don't know what stage I am yet, but I had a CT scan last Thursday and a PET scan yesterday, so I should find out soon.

I'm finding this all to be a bit too surreal, like it doesn't quite feel like it's actually real. I just wanted to know if it's similar for other people? I also tend to keep trying to joke about it (it's kind of my coping mechanism) and I think I've upset a friend and my mum by doing so...

#HodgkinsLymphoma #JustDiagnosed #HelloImNew

[#HodgkinsLymphoma](#) [#JustDiagnosed](#) [#HelloImNew](#)

Posted a month ago

3 PEOPLE REPLIED

People seem to be starting off by telling their own cancer story so here goes. I'll write down the sped up version because unfortunately mine is quite long. I was first diagnosed seven years ago with an extremely aggressive golf ball sized brain tumour. It was removed and I undertook 6 weeks radiotherapy. I was all clear for several years but then about three years ago the tumour came back in the same place. It was removed i . It then recurred again the following year in the same place. It was removed and I had a second set of radio therapy on the same bit. The year after that the tumour travelled and I had a large one trapping a nerve at the base of my back and a little one at the top of my head. They were removed, a reservoir put in my head for proposed chemo and underwent radiotherapy on my entire head with boost and my entire back with boost. I currently have a small tumour in my back but we are ignoring it as it seems to be dormant. Oh and no chemo as I had to have an emergency removal of the reservoir as it was sticking out and no one noticed. That's pretty much it...sorry for the negativity and any grammar mistakes but I don't really want to read it back through! **#braintumour #radiotherapy #HelloImNew**

[#braintumour](#) [#Radiotherapy](#) [#HelloImNew](#)

Add a message of your own...

How the online community has helped young people

Providing support

‘It’s so good to see so much mutual support in one place.’

Connecting with others

‘I think this is a brilliant site and even in this short while has helped a lot of people.’

Sharing experiences

‘This is a great support community while having treatment and after’



“The online community is a great way to speak to other people of a similar age going through the same thing as me”

Ways forward

This research has enabled CLIC Sargent to reflect on the suite of services it provides to young people

2015+

- 2015 evaluation of CLIC Sargent's online community
- We will continue to monitor trends in digital technology and utilise this to ensure that our online support remains fresh and fit for purpose
- Resilience is being mainstreamed into CLIC Sargent policy agenda:
 - CLIC Sargent 10 year Strategy (June 2015)
 - 'Ambitions for the next 10 years' report (June 2015)

Thank you

For more information please contact:

Helen Gravestock, Research and Policy Manager

helen.gravestock@clicsargent.org.uk

More information about CLIC Sargent's online community can be found at:

<http://www.clicsargent.org.uk/news/29-01-2015-clic-sargent-launches-online-community-young-people-cancer>

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