



Children's
Cancer and
Leukaemia
Group

the EXPERTS
in CHILDHOOD
CANCER

GOOD
CANCER

Living beyond cancer

Information and support for those who had
cancer as a child, teenager or young adult

www.cclg.org.uk



About this guide

This booklet has been written by experts on late effects of childhood cancer. It will help answer questions about what happens next and how your diagnosis and treatment may affect your future life. You may also find it helpful to share this with your parents, family and friends.



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After treatment

Many children, teenagers and young adults are treated successfully for cancer. There are now over 40,000 survivors of childhood cancer in the UK who are supported with specialist health care and advice.

As a survivor of childhood cancer, it is important you are offered the opportunity to understand your previous treatment in a specialist long-term follow-up clinic. You may know a lot about your illness or you may know very little.

Long-term follow-up clinics provide you with an opportunity to learn about and plan the monitoring and support you may need, together with your follow-up team. Follow-up at this stage aims to detect and manage any issues caused by your cancer or its treatment to ensure you have the best possible quality of life.

Approximately two out of three survivors will have an issue or 'late effect' related to their treatment. For some this will be very minor, for others it may be more major. Developing late effects is different for everyone, it depends on:

- your type of cancer
- your age when you were treated
- the treatment you received

We hope this booklet will help answer some questions and encourage you to ask your key worker or follow-up team about anything that they have not covered.

It is important to remember that although your cancer experience will always be a part of you, it doesn't need to define the person you are.

You may have been treated for a tumour or condition that was not cancerous but, because of the treatment you had, this booklet still applies to you. If this is the case, your doctor will explain why.

This booklet is part of a package of information which also includes dedicated web pages for childhood cancer survivors www.cclg.org.uk/living-beyond-cancer



The website offers the latest specific factsheets about the effects of different treatments on different parts of your body, depending on the treatment you had.

Your long-term follow-up team should provide you with an end of treatment summary or care plan. Keep this somewhere safe for easy access if you ever need to know the details of your treatment. For example, you may need it for appointments during pregnancy or for a pre-employment health check when starting a new job.

Long-term follow-up is not just to support you with medical problems. Some survivors talk about experiencing job discrimination or difficulties obtaining health or travel insurance. This is a good reason for you to know about your illness, its treatment and potential effects later in life, so you can talk to people about your cancer.

“ The feeling of being a survivor is not daily but the gratitude for being able to continue never fades. One element I have relished in my life has been as a surprising ambassador for survival and I will always reach out to people as an example of a hopeful outcome.”



"Having just fought for my life, why should I now limit myself for the rest of it? Cancer presented itself to me as a problem and I wanted to do something about it. And, while I often cursed the stress, it all became worth it the day I finished my PhD."

Catherine

"Yes, my cancer has played a massive part in my decisions in life, but now - unlike before - I control my future, not my cancer."

Josh



"Although I've faced many difficulties, I now realise that it's enhanced my best traits and I'm a better version of myself. Finishing treatment is all about rediscovery - your life may not be what you once envisioned, but you can find a new path."

Chloe

Follow-up and future care

This section answers some common questions you may have about follow-up care and what to expect.

Why come to clinic?

Cancer is treated in different ways and sometimes the treatments can cause long-term issues. Cancer treatment includes:

- chemotherapy – anti-cancer drugs
- radiotherapy – radiation treatment
- surgery
- biological therapies – newer therapies used to stimulate the immune system such as monoclonal antibodies or vaccines
- stem cell or bone marrow transplant

Sometimes, only one of these treatments is used and sometimes two or even three types of treatment are used in combination. Each of these treatments, in addition to treating the cancer, can also affect normal cells/tissues and this may only become apparent many years after finishing treatment. The long-term issues caused by treatment are called 'late effects' as they occur after all the treatment has finished.

If you were treated as a child, most information will have been given to your parents or carers. As a young adult, the information should be given to you and coming to clinic gives you the chance to ask questions. Many people will look on these visits as reassuring, a way of checking that everything is alright and if there are any problems these can be addressed.

Will I always have to come?

This is an individual decision between you and your follow-up team. It will depend on both the treatment you had and other factors such as your general health and social circumstances.

It is hoped that coming to follow-up clinic will give you the information and education to allow you to manage your own health needs with the support of your GP. You will, however, continue to have access to your long-term follow-up team when needed.

Can I bring my parents or partner to the clinic?

If you feel more comfortable coming to clinic with someone, you can bring your parent(s), partner or close friend. You may prefer to come on your own; the choice is yours.

"Since my treatment finished 10 years ago, I have been to university, graduated with a first and trained as a teacher – all the goals I wanted to reach! I wouldn't take back having cancer. I've learned how strong I am and have become even more determined to succeed!"

Kelly



"Since beating cancer I have felt empowered and energized by life and I have had some amazing opportunities come my way. I have recently bought my first house with my boyfriend and our gorgeous pet greyhound. Life has never been better!"

Lizzie

Will my cancer come back?

There is a risk that anyone can develop cancer, this risk increases with age. Survivors and their families naturally worry that cancer may come back again but most people in long-term follow-up are considered cured. A small number of people who had cancer when young do develop another cancer later on. There are two main reasons for this:

- some cancer treatments can themselves increase the risk of other cancers
- although rare, some families have a higher risk than others because of inherited risk factors

You can help reduce your chances of cancer recurring by eating a healthy diet, taking regular exercise and not doing things that we know are linked with cancer, such as smoking and sunbathing.

What should I do if I feel ill?

You should go and see your GP or out-of-hours healthcare service. They will decide if you need referral to the hospital. If you are very worried you could call the hospital's contact number on your treatment summary card, but usually it is better to go through your GP or similar local service.

Does having had cancer mean you get more tired?

Not usually. If you feel more tired than your friends doing the same activities, you should mention it at your clinic visit. Your doctor will decide if more investigations are necessary and discuss these with you.

Am I entitled to free prescriptions?

Patients who are receiving medication for the late effects of cancer can apply for a medical exemption certificate in order to receive free prescriptions.

To find out more, see:

www.nhs.uk/nhs-services/prescriptions-and-pharmacies/who-can-get-free-prescriptions



“Despite having my right leg amputated during treatment for osteosarcoma, I now travel the world playing wheelchair basketball. I fell in love with the sport when I went along to a roadshow and haven’t looked back since! I am proud to have competed for Team GB in three Paralympics. Amazing!”

Gaz

Your feelings and emotions

Diagnosis and treatment for cancer is a difficult and stressful time for children, teenagers and young adults and their families.

During your treatment, you and your family were focused on getting through day-to-day life and juggling hospital, school, work and siblings.

New feelings can emerge after treatment has finished as you begin to come to terms with your experience. Whatever you are feeling now is normal and right for you.

You may feel some of the following emotions:

- relief and happiness
- fear of the cancer returning
- frustration about how your life has changed
- sadness about the loss of a regular childhood
- guilt that you have survived when others didn't
- feeling different from peers
- vulnerable because of your cancer experience
- invincible because you have survived and can therefore do anything (this can sometimes lead to unhealthy or risky behaviour)
- worried about your health
- resentful as parents may become over-protective
- unexpected triggers and emotions caused by anniversaries of cancer events
- distress and anxiety due to the diagnosis of a late effect related to your cancer treatment or a new health issue

Many children and young adults treated for childhood cancer and their families cope well with moving onto the next chapter in their lives.

Years later, some survivors find that they have undergone positive, meaningful and beneficial changes in themselves and their values as a result of surviving their experience.

Sometimes, however, coping with physical problems or other stresses related to your cancer experience can make you feel down or distressed. These feelings can be triggered by reminders of the upsetting aspects of treatment.

If you feel sad or anxious, and the feelings last more than a couple of weeks or interfere with your day-to-day life, it's important to seek medical help. Please talk to your follow-up team or GP if this is the case. It can also be helpful to talk through your worries with people who you can trust. For further information, please see [nhs.uk/mental-health](https://www.nhs.uk/mental-health)

Survivor groups (including online and local meetings) can offer opportunities for you to meet other survivors to share experiences and to talk about ongoing issues.



"I feel so much stronger about my personality. I firmly believe that nothing is impossible. No matter what happens in my life in future, I know that the secret for me is to find the good reasons why I should fight, and to simply ignore the disadvantages."

Megi

Common questions asked

When can I put it all behind me? I don't want to think about cancer any more

It's understandable to feel this way; however, you cannot change the fact that you had cancer. The healthcare team will only continue to see you if you need regular check-ups and if there are tests that you need occasionally. Please discuss any anxieties or difficulties you have about coming to the clinic rather than just not turning up. Your diagnosis of cancer will always be part of you, but it's not the whole you. You may find your experience of having cancer has given you new strengths or views on life. You need to think about your future.

The way I look reminds me of my treatment

You may have been left with some changes to your appearance after your treatment which may make you feel self-conscious or different to everyone else. These feelings are very common and your long-term follow-up team will be able to talk to you about these differences and discuss ways in which they can help you.

Should I worry about getting ill again?

Most young adults don't worry about things like cancer or heart problems. However, it is natural for survivors to be fearful about the possibility of a relapse or late effects. These worries can make you feel different from your friends. However, the chance of getting a second cancer is very small. It is important to attend your follow-up reviews and any monitoring tests that are needed and these can give you reassurance.

Can my experience of cancer help others?

To help us understand more about cancer and find new treatments there are on-going research studies. You may be asked to take part in a study looking at the effects of your cancer or treatment.

Your follow-up team will be able to tell you if there are any long-term follow-up studies relevant to you currently being carried out. Your doctor will explain the study to you and you will need to sign a consent form to participate.

"I'm proud I went from the boy who had cancer twice, to the boy in a top selling boyband. But I think what I'm most proud of is how I've overcome all the different emotional obstacles that cancer can put in your way. I'm proud of my resilience and strength, how determined I am as a person and how I'll never give up on myself."

Lee



"I'd be lying if I said my journey hasn't been a challenge, but I strongly believe my tenacious personality and optimistic outlook on life from an early age has helped me through. I try to live my dreams and be the best person I can be and, despite some of the hardships I've faced, I try not to be bitter, as it can eat you up inside. Instead, I focus on the future, taking small and steady steps to make it a brighter and happier place for everyone."

Cara



We hope that this booklet will help to answer some of the questions you have. Specific information on late effects and how your treatment and diagnosis may affect your life in the future is available at www.cclg.org.uk/living-beyond-cancer

Late effects factsheets

Our specific factsheets cover issues such as:

- eye issues
- hearing issues
- oral health
- growth and development issues
- thyroid gland
- fertility and reproductive health
- heart/lungs/kidneys and spleen health
- bone health
- breast cancer risk
- puberty
- gastro-intestinal issues
- adrenal glands
- metabolic syndrome
- nervous system
- health and wellbeing
- skin
- pituitary gland

Online information

Our website has further information on the following:

- insurance and mortgages
- blood and organ donation
- equal opportunities
- education and jobs
- immunisation and travel advice



Scan the QR
code to take
you to the
website

"Despite being told that the chemotherapy drugs used to treat my cancer may affect my fertility, 20 years later I fell pregnant naturally and had a healthy, happy pregnancy. Our daughter Ella is even more special than any other baby because we were never sure if she would be possible!"

Katherine



"Dear cancer, I beat you aged eight, and today I got my PhD in cancer research. Take that!"

Vicky

"I'm now working hard towards my dream of one day becoming an oncologist and emulating those who inspired me during my own treatment. I want to help people in the same situation I was once in, using my experience to treat patients with a greater deal of understanding and empathy. And more than that, I want to provide hope and inspiration to children and families who are going through such challenging times."

Jack





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Children's Cancer and Leukaemia Group (CCLG) is a leading national charity and expert voice for all childhood cancers.

Each week in the UK and Ireland, more than 30 children are diagnosed with cancer. Our network of dedicated professional members work together in treatment, care and research to help shape a future where all children with cancer survive and live happy, healthy and independent lives.

We fund and support innovative world-class research and collaborate, both nationally and internationally, to drive forward improvements in childhood cancer. Our award-winning information resources help lessen the anxiety, stress and loneliness commonly felt by families, giving support throughout the cancer journey.

If you have any comments on this booklet, please contact us at publications@cclg.org.uk. CCLG publications on a variety of topics related to children's cancer are available to order or download free of charge from our website.

Our work is funded by donations. If you would like to help, text '**CCLG**' to **70300** to donate **£3**. You may be charged for one text message at your network's standard or charity rate. CCLG (registered charity numbers 1182637 and SC049948) will receive 100% of your donation.

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and Scotland (SC049948).



British Medical Association
Patient Information Awards –
Self Care Category Winner



Association of Social
Care Communicators –
Award Winner



Patient Information Forum