



I have finished cancer treatment

What happens next?

An information guide for older children and teenagers on follow-up care and re-adjusting to life after finishing cancer treatment



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Children's Cancer and Leukaemia Group

Century House, 24 De Montfort Street, Leicester LE1 7GB

Tel: 0333 050 7654

info@cclg.org.uk

www.cclg.org.uk

 [ChildrensCLG](#)

 [CCLG_UK](#)

 [CCLG_UK](#)

Registered charity number 1182637



It's finally happened and you have finished treatment!

After months or even years of tests, side effects, scans, hospitals, doctors and ward life, you will likely feel happy and relieved that you are now out on the other side. But perhaps it all feels a bit strange and you don't feel as happy as you expected?

Many young patients are surprised by the mix of different emotions that they experience in the weeks and months after finishing treatment, and this is completely normal. You might find that you have lots of questions about your cancer experience and what the future will hold for you.

We hope this booklet will answer some of these questions and help you to re-adjust to everyday life again.



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Your feelings

Finishing treatment is a proud moment and you might want to celebrate getting through tough treatment with a holiday or just relaxing with family and friends. It's completely your choice what you feel like doing to mark the end of treatment.

But you might also be feeling a bit unsettled or lost too. This might not be what you were expecting and it can be frustrating when everyone thinks you should be 'back to normal'.

There is no right or wrong way to feel and every person is different. Having cancer is a life-changing experience so it will take time for you to process what has happened. You will also likely feel tired for a few months or longer as your mind and body adjusts. This is why it is best to take things slowly and not make any big decisions straightaway.

It is also good to not have too many high expectations of life being exactly the same as before as it may not be at first. Being prepared for this can help make re-adjusting a bit easier.

Many young people say they feel lots of different emotions when treatment has finished:

HAPPY



SAD



RELIEVED



ISOLATED



POSITIVE



ANGRY



EXCITED



ANXIOUS



What happens now?

Q When will my hair grow back?

A Your hair will start to grow back as soon as you stop having chemotherapy. It can take a while to thicken and sometimes it may grow back in a slightly different colour, thickness and may even be curlier. However, for a small number of patients who have had radiotherapy treatment to their head, hair may not thicken up or regrow in certain areas. There is help and support available and your nurse will help answer any questions you have.

Q When can I stop worrying about infections?

A Don't worry, your blood count should be back to normal within a month. During the first six months, you will need to tell your parents or let your hospital nurse know if you have come into contact with anyone who has measles or chicken pox. If you have had a bone marrow transplant or rituximab treatment, it may take a bit longer for your body to be able to fight infections normally again. Your health team will advise you.

Q When can I have my line out?

A This happens as soon as possible after your treatment has finished and any scans or tests are completed. You will need a small operation with a general anaesthetic to remove it.

Q What happens if I need a blood test after my line is out?

A You will not need many blood tests now but some will still be important. If you don't have a line then you will either have a thumb prick or a needle.

Q Why do I still feel so tired?

A You may feel tired for quite a while because your body's strength and energy levels need to recover. It can take a few weeks and even months to build up your stamina again, however, you can help give your body a boost by eating a good balanced diet and staying active.

Q When can I go swimming again?

A You usually don't have to wait too long to have a bath or go swimming once your central line or port has been taken out. Once everything is healed (which usually takes around two weeks) then you may be able to swim. This is best checked with your doctor or nurse.

Q Will I still have to take any medicines?

A The good news is that many patients do not need medications once treatment finishes. You may have to continue with some antibiotics (such as Septrin) until your blood counts have recovered. After a bone marrow or stem cell transplant, a lot of medicines are needed to begin with but this reduces over time.

In some cases, you may need to carry on with some medications for life, but your doctor or nurse will explain this to you. This is usually to replace hormones that your body needs, to be able to carry on functioning properly. You might also need specific medication in the future.

Q When will my weight get back to normal?

A Your sense of taste and appetite should return to normal, although this might not happen if you had radiotherapy to your head and neck. Being able to eat properly again will help you get back to your usual weight. If you have put on weight, particularly from taking steroids, then look at what and how often you are eating to see if you can make any positive changes such as eating smaller portions, fewer snacks and less sugar. You can ask your doctor or nurse for help in managing your diet and losing weight safely. Being more active can also help with weight loss.

Q Will I need more immunisations?

A Yes, you usually need to repeat immunisations after chemotherapy (and more after a stem cell transplant). These will usually be given by your GP. Your doctor or nurse will explain more about this to you and your family.

Q What do I do if I feel unwell?

A Tell your parents or carers so that they know how you feel. If you have a high temperature and still have a central line, or are neutropenic, then you will need to come into hospital. If six months have passed since finishing treatment and your blood counts are fully back to normal, you can see your GP first, who can decide if you need to go back to the hospital.

Q What should I look out for or worry about?

A Young people who have had cancer treatment still get coughs, colds, aches and pains like everyone else. It is hard not to worry about becoming ill again but try to remember that it is far more likely to be a common virus than anything serious. But if you are still worried, then tell your parents, GP or keyworker or wait until your next clinic appointment.

About clinic appointments

Why do I have to come to clinic?

It is understandable to feel like you just want to forget it all and move on with life. However, we know that sometimes cancer and its treatment can cause long-term problems later in life, which is why it is important to be aware of any changes in your body and make sure you still come to clinic to be checked.

It is really important to attend follow-up clinic appointments.

At first, the visits and scans are to check there are no signs of cancer coming back and that you are growing and developing as expected.

As time passes, the focus changes and will become more about managing any long term problems called 'late effects', and giving you lots of advice about looking after your own health.

Your late effects follow-up team may also include other specialists such as physiotherapists, psychologists, support workers and counsellors.

Coming to clinic gives you the chance to talk about any questions, worries or concerns you may have since finishing treatment.

Remember: no question is silly or embarrassing so ask whatever you like – your team will have heard it all before!



What are late effects?

A simple definition is any health-related problem that happens months or even years after finishing treatment as a result of the cancer itself or its treatment. They can be physical effects or emotional ones and your team will talk to you about any that may be relevant to the specific treatment you had.

How often do I come to clinic?

When you first finish treatment, you will need to come frequently during the first year. As time goes by you won't have to come so often, usually every three months in the second year, until you are only seen every few years.

What happens during the appointment?

You will be weighed and measured at each visit to check that you are growing as expected. You may also need an x-ray, blood test or occasionally a heart scan or lung function test.

You may be seen by the same doctors or nurses you saw during treatment or you may be seen by a specialist late effects team.

How long will I keep coming back to clinic?

This will depend on the treatment you had and what your risk is of developing side effects but most people are seen for many years after finishing treatment. Your clinic team will plan with you how long your follow-up care needs to be hospital based and when you can have support from your GP alone.

Is there anything I can do to stop getting cancer again?

Cancer can happen to anyone and there is no obvious reason why you developed cancer before. However, we do know that how we choose to live our lives can help lessen the risk of serious illnesses such as diabetes, heart disease and cancer. There are some things that you can do to help stay healthy (see page 18).

Moving to adult care (16-18 years old)

If you were treated for cancer as a child or teenager, your follow-up care will gradually transfer from your children's team or teenage cancer unit to adult services. This may mean being reviewed by a different team at another hospital. The process of preparing, planning and moving is called 'transition' and happens over many months around the ages of 16-18 years old if you have finished treatment. The transition can start as early as 13 years old if you had cancer as a child and have been in long-term follow up for more than five years.

Although this change can feel strange and even a bit scary, you will be fully supported by your doctors and nurses and you will be able to ask lots of questions. It also means that you can start to manage your own health care as you become older and become more confident at knowing how to talk to medical staff about how you feel and any issues that you may have.

The whole team as well as yourself and your parents will work together to make the change happen as smoothly as possible.

Things you might be worried about

"I'm worried that the cancer will come back"

You are not alone. This is a big worry for all patients who have finished treatment, and uncertainty can be hard to cope with. Feeling unwell in any way can make you worry even more. This is understandable and if you are worried then it can help to talk to your counsellor or psychologist at the hospital. The chances of cancer coming back become less and less as more time passes, and most cancers in children and young people do not come back. If cancer does come back, it may be treated successfully again.

"I'm scared about coming back to the hospital"

Attending hospital appointments can be hard as you may feel anxious about having more tests and scans, and feel worried about what the doctors might find. This is normal for all patients and their families but it is reassuring to know that any issues will be picked up early.

Being back in hospital again can bring back many memories, and it can be hard seeing other young people who are still having treatment. However, you might feel happy to see familiar faces and friends again and they will be delighted to hear all your news since finishing treatment.

"I feel guilty"

It is common to not only feel relief at being cancer-free but also to feel guilt too. You might feel guilty because you survived when maybe your friends or other patients who had cancer didn't, even though cancers are different in each person. You may also feel guilty that having cancer has put extra pressure on your parents or family.

These feelings can be very isolating but are completely normal and understandable. Talking about how you feel with someone who will listen without judging, like a friend or counsellor, can help you to work through how you feel.

"I'm left with side effects of having had cancer"

Sometimes cancer, or its treatment, causes damage that the body just cannot repair. These can be physical changes such as how you look, behave or move about or they can be emotional side effects such as anxiety and fear. These can affect your confidence and how you feel about yourself.

It is really hard to deal with changes that are out of your control and it is ok to have days when you feel sad or angry. It is important that you explain how you feel at your follow-up appointments so your team can find the best support that will help you the most as there may be ways of helping and managing side effects better.

Looking ahead

Having cancer is a life-changing experience and how you feel about yourself now can be different to before your diagnosis. It can be useful to remind yourself about all the things that make up **'you'** such as your likes, dislikes, values, and dreams.

While you may want to forget that you ever had cancer, accepting that your experience will always be a part of who you are, and what you have achieved, can help make you feel stronger and more resilient about moving on.



No one would ever choose to have cancer but many young survivors say that it has made positive changes in their relationships and values, and has left them with a greater appreciation of life and the opportunities it can offer.

You might feel more focused and driven about what you want to do now, and you might find that you have changed your mind about some things. It helps to stay open-minded and flexible about your future plans as you begin to recover from the effects of cancer and its treatment.



Changing relationships

With family

When you were going through treatment, you will have had your parents, brothers or sisters, grandparents and other family members worrying about you and maybe giving you more attention than before you were diagnosed. Sometimes, this might have been too much but, at other times, it was good to have others around you.

You might find that things have now changed as family life is expected to 'get back to normal' with school routines and parents going back to work. This can make you feel a little lost or you may even miss the extra attention. However, as time passes, you will re-adjust and gain more independence again.

Lots of parents find it hard to stop worrying about you when treatment is over. You know that you feel ok, whereas they don't.

You might feel that they are being too overprotective but it's natural for parents to feel this way. Talking to your family about how this is making you feel, and listening to their worries too, can help you to support each other.

With brothers and sisters

When you were having treatment, life probably changed a lot for your brothers and sisters too. They may have felt left out, upset, lonely, scared and even jealous of the extra attention given to you. They may worry about your health or be worried that they did something to cause your cancer. You might find that your relationship has changed a little bit or your experience might have brought you closer together. Spending time with each other again by playing, walking to school or just watching a film at home can help things feel more normal again, even if you do start fighting with each other!



With friends

Having fantastic friends as your support network can make all the difference to how you feel by being there for you and keeping life as normal as possible.

But you might feel as though you have missed out on a lot too. Missing lots of school and feeling tired can make fitting back in with your friends more difficult. It can also be hard to feel confident around others too if you feel self-conscious about your appearance.

Friends can seem to avoid you or say insensitive things but this is usually because they feel awkward and don't know what to say to you. You might feel that they just don't understand what you have been through and this can be upsetting. Asking them to still treat you the same as before can help.

Talking honestly about your cancer is the best way of overcoming any uneasiness as well as letting your friends know how they can help you. You might get asked a lot of questions so it can be a good idea to think up some answers to common ones.

Many young people say that they feel 'different' from their friends when they have been through cancer treatment. Your outlook on life may have changed so that friends can seem to become childish or annoying for worrying about trivial things. Your change in perspective can make you feel out of step with everyone



Here are some things you can say to your friends:

"I was unwell for a while but I feel much better now"

"I know I look different, but I'm still the same me"

"Sometimes, my treatment makes me tired. If I seem a bit grumpy, it isn't anything to do with you"

"If I'm tired, can you carry my bag and wait for me after lessons so I can walk slowly with someone?"

"Please still invite me to parties or to go out. If I'm not well enough to come, I'll let you know"

You can't control how people behave or what they say to you but you can control how you let them affect you.

else and this can be frustrating. Try not to let this get you down or blame your friends as you will adjust in time. Remind yourself of the important life skills you now have by living through your experience such as strength and maturity.

Back to school or college

You might feel both excited and nervous at the thought of going back to school or college. You might be looking forward to getting back into your normal routine and being with all your friends again. Or you may be feeling worried about your schoolwork, feeling tired in lessons or looking and feeling different to everyone else. This is completely normal and understandable but teachers and school can help make going back a bit easier.

Before going back

With yours or your parents' permission, your keyworker or nurse will usually have contacted your school or college already to talk about how best to support you at school and to take away as much stress for you as possible. You may have been able to keep up with what your class has been learning about in school through a hospital school, home tutor or studying online.

Meeting your teachers with your parents and keyworker is a perfect chance to talk about any worries you may have and to let them know how your treatment and experience has affected you. Some questions to ask could include:

- Q** Would you like a teacher or someone from the hospital to talk to your class/year about your illness, so people know why you look/feel different?
- Q** Do you need to tell them if you will be wearing a hat, scarf or wig to school?
- Q** Are there any activities you cannot take part in at first such as PE or design and technology?
- Q** If it's hard to move around or you are using a wheelchair, can the teachers move the classes around so that you can get to them more easily?
- Q** Could you go back to lessons part time if you become tired easily or find a full school/college day too much?
- Q** Can you ask for a member of the school team (non-academic or pastoral) to be someone who you can regularly talk to about how things are going?

Our teacher's guide gives lots of tips and information on how teachers can support young people in school, and you might find it helpful to read these for ideas on what might work for you too. www.cclg.org.uk/infohub



Things you might be worried about

Falling behind in schoolwork

If you have missed lots of school during treatment, you may feel worried that you have fallen behind. Your keyworker will have encouraged your teachers to coordinate with your hospital school or home tutor to help keep up with what your class is learning about in school.

If you still think that you have missed a lot of school work, then talk to your teachers with your parents to help get you back on track. You could do extra reading or study online or you could carry on with extra tutoring at home or at school. Remember that when you work with a tutor on a one-to-one basis, you will achieve much more in less time than it would take in a classroom so you may even be ahead in some subjects.

Looking different

You may still have visible signs of having had cancer and treatment, and these can feel like a really big deal as you don't want people to stare or talk about you. A few people may say something when they first see you but after time has passed, they won't bother as they will become used to you being back.

Difficulty in moving around school

Feeling tired or having weak muscles or ankles from certain chemo drugs can mean you are not able to move around as quickly as before. If you are using a wheelchair, then steps may be a problem too but your keyworker will talk to your school about using ramps to help or having certain lessons on the ground floor.

Being with schoolfriends again

Before you go back, it might be a good idea to meet up with a few close friends first so that you can catch up on any social chat and also get used to being in their company again. Treatment can be lonely and isolating so it can take a bit of time to adjust to being in a noisy crowd of young people again.

Friendship groups can naturally change a lot at school and you may find that groups are a bit different to how they were before. This might make you feel unsettled or not really sure where you fit in but these feelings will pass in time as you become used to everyone in the class again.

Remember

Your school wants you to do well – if there is anything you think they can do better to help and support you then talk to your teacher and headteacher so that they can do something about it. You or your parents can also talk to your keyworker for further advice and help.

Things to try...

- + Sit at the front to see and hear better
- + Quiet space to sit and rest
- + Keep you involved with school and class activities
- + Leave the classroom five minutes early to avoid the 'corridor crush'
- + Have a pass for toilet breaks/ lunch/water
- + Schoolwork broken down into simpler chunks or visual diagrams to help learning when feeling tired
- + Help with any bullying from others
- + Allow extra time to walk between classes

How to cope with difficult feelings

You may find that thoughts and worries are always on your mind and you can't seem to focus on anything else. They can keep you awake at night and can stop you from enjoying life fully. Distracting yourself with other activities can help with feelings of anxiety.

You might also find the following tips helpful:

Accept how you feel and be kind to yourself

It's easier to hide behind a happy front or say 'I'm fine'. But you can feel overwhelmed and stressed by trying to hide how you really feel.

Talk to others about how you feel

This can help stop negative thoughts building up in your head. A different perspective can help you to look at things differently. Talking to someone who you trust such as your parents, brothers or sisters, grandparents, friends or teachers can be a good way of processing your thoughts and making you feel a bit better.

Be with your friends

This can help to keep your mind occupied by doing the fun things you normally do with them such as gaming, playing football or having a sleepover.

Write down how you feel

Sometimes you may not want to share how you feel with anyone else and this is ok. Writing down your thoughts and feelings in a notebook or diary can help break them down so that they become more manageable and less scary.

Be active

This can be as little as going for a short walk down the road. Research shows that doing exercise and being outside in the fresh air can help lift mood and release any tension or nervous energy that you might be holding in the muscles of your body.

Finding others who feel the same

Sometimes, the only people who understand how you feel are those who have also faced cancer. You may have made friends on the ward, online or through groups and organisations such as holiday camps and it can be helpful to talk to others who might share the same worries.

Knowing when you need **extra help**

Sometimes, the full impact of having had cancer can hit a few weeks, months or years later. This can happen at any time in your life and many survivors have experienced this, especially at times of stress such as taking exams, changing schools, starting university or work.

Don't struggle on your own. Everyone has bad days but you might find that if your feelings are becoming stronger, you feel more anxious or you are struggling to cope with each day, then it might help to talk to someone who can support you better such as your hospital psychology team, GP, or a counsellor.

It is important to talk to your parents, family or someone you trust, and your follow-up nurse, so that they know how you feel and can help you.

Counselling and psychological therapy can give you techniques and strategies to manage strong feelings, control how you respond to others and situations, and helps process negative thoughts that might be overwhelming you.



Staying healthy

Once you feel well enough, you can start making positive changes to increase your energy levels, build up strength and stay as fit and healthy as possible by keeping a healthy weight. This can help you to feel better too.



- ✓ Eat a well-balanced diet rich in oily fish (like salmon or sardines), fruit and vegetables
- ✓ Cut back on fizzy drinks, sugary and high-fat snacks such as biscuits, chocolate or crisps
- ✓ Drink plenty of water to stay hydrated
- ✓ Keep active
 - » Try setting small goals to help you get motivated. Instead of going in the car, try walking or cycling.
- ✓ Sunbathe safely (use SPF30 with at least 4 star UVA rating or above to avoid sunburn and protect against skin cancer). Never use sunbeds!
- ✓ Look after your teeth
 - » Brush twice a day, use floss or interdental brushes for between teeth and visit the dentist at least twice a year. This is because cancer treatment can affect teeth.
- ✓ Check for any changes in your body
 - » If you notice any new lumps, bumps, mole changes or there is a new symptom that you are worried about, please talk to your parents, GP or hospital team.
- ✓ Safe sex
 - » Using contraception helps avoid sexually transmitted diseases and unwanted pregnancies (even if you have been told that cancer treatment may have affected your fertility levels).



- ✗ Don't eat too many processed foods and meat
- ✗ Don't smoke or vape to protect against heart and lung problems and avoid cancer
- ✗ Don't take drugs so chemical substances do not affect your body
- ✗ Don't drink too much alcohol to protect your liver
- ✗ Avoid being overweight for better overall health and to lessen your cancer risk

Help and support

Aftercure.org

Information for teenage and young adult survivors of childhood cancer that covers long-term follow-up, information about possible late effects of your cancer or its treatment, and moving on.

ChildLine

www.childline.org.uk
Call 0800 1111

Free, private and confidential service for anyone under 19 years old (phone and online) where you can talk about anything that is worrying you.

JTV Cancer Support

jtvancersupport.com

Offers a valuable resource of short films from young people with cancer.

NHS Every Mind Matters

www.nhs.org

Online practical help and support for mental health.

NHS Moodzone

www.nhs.uk/conditions/stress-anxiety-depression

Tips and advice for boosting mental health and wellbeing.

Samaritans

www.samaritans.org
Call free on 116 123

Free and confidential 24hr emotional support (phone and online).

Young Minds

youngminds.org.uk

Help and advice for mental wellbeing in young people.





Teenagers and Young Adults with Cancer

Having cancer is hard at any age, but for a teenager or young adult it's unthinkable.

'Normal life' suddenly stops and young people find themselves thrown into a scary unknown world of hospitals and cancer treatment. This has a devastating impact at a time when they are already coping with changes in how they think and feel as adolescents.




Teenagers and Young Adults with Cancer (TYAC) recognises that teenagers and young adults

(ages 13-24) have different and specific needs. This is why we work tirelessly to make sure that every teenager and young adult with cancer is treated and cared for in a sensitive and age-appropriate way with the right to fast diagnosis and best treatment, no matter where they live.

TYAC is the UK's professional association for those involved in the treatment, care and support of teenagers and young adults with cancer. By providing information on best practice and new developments, training

and support to our members, and through funding and supporting research into teenage and young adult cancer, we aim to improve the quality of life and likelihood of survival for young people with cancer. TYAC is part of Children's Cancer and Leukaemia Group (CCLG).

info@tyac.org.uk
www.tyac.org.uk

-  TYACancerOrg
-  TYACancerOrg
-  TYACancerPro



Children's Cancer and Leukaemia Group

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. CCLG publications on a variety of topics related to children's cancer are available to order or download free of charge from our website.

Children's Cancer and Leukaemia Group
24 De Montfort Street
Leicester LE1 7GB

Registered charity
number 1182637

0333 050 7654
info@cclg.org.uk
www.cclg.org.uk

-  ChildrensCLG
-  CCLG_UK
-  CCLG_UK