I have finished my treatment… what happens next?

A guide for older children and teenagers who
have completed treatment for cancer

Children's Cancer and Leukaemia Group – www.cclg.org.uk

This booklet was originally written by Katherine Green, Moira Bradwell and Annie Griffiths on behalf of CCLG Publications Committee, comprising multiprofessional experts in the field of children's cancer.

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You have finished your treatment for cancer...

This is probably the moment you have been waiting for since your diagnosis. For some it can be a difficult time, and you may experience a range of feelings. You might be surprised you are not feeling as happy as you thought you would.

We hope this booklet will answer some of the questions you have and will help you to relax and enjoy your time now you have completed treatment.

We have included some practical points about what happens at the end of treatment as well as talking about how you might be feeling at this time.

> "We had a celebration party/fundraiser, having a goal to aim for made the end of treatment more exciting rather than daunting."

Feelings and emotions

Whatever you thought it would be like, many young people are surprised at the mixture of happy and worried feelings they have during the first few weeks and months after treatment.

This section explains that all these feelings are normal and why you might have them. We've also included some tips on coping with these feelings.

Excited and worried all at once!

The end of treatment means many changes, some of which you might have been looking forward to for a long time:

- No more feeling sick
- No more tablets
- Going back to school
- Your hair growing back
- Stopping taking steroids
- Spending time with your friends
- Having your line out
- Spending less time at hospital

Although many of these changes may make your life easier, there may be times when you feel worried.

One main concern for many young people is that you don't get any guarantees that your treatment has worked.

Of course, it's normal to worry about this. But, if you think about it, no one gets a guarantee about being healthy – not even pop stars, Olympic athletes or the Royal family! Anyone could get cancer or another serious illness, so in a way, everyone has that slight worry. Further on in this booklet, there are some tips on what might help when you're having a 'worried' day.

What about celebrating?

You may want to mark the end of your treatment by doing something special, like a meal with your family, planning a party with your friends or going on a day trip or holiday. You could also do something you have not been able to do before, such as swimming.

Some young people don't feel like celebrating because they are worried about the future or can't do everything they used to.

Even if there are lots of challenges ahead, by getting through all that tough treatment you've done something pretty amazing, so give yourself a pat on the back and some sort of treat – even if it's only a huge pizza or an extra long lie in!

How to cope with worry

Everyone feels different at the end of their treatment. Not everyone worries, but some people do and it is perfectly normal. You may find that thoughts about what has happened, and about your health and future, can keep you awake at night and stop you from moving on and enjoying life.

If this happens to you, some of our tips for coping with worry may help:

- Find someone to talk to. Worries that just go round and round in your head tend to get bigger. If you can tell a friend or teacher or someone in your family, you might find you feel better even if they can't completely take the worry away.
- Some people find they need to talk to a counsellor, especially if their worry won't go away or if it's stopping them from enjoying themselves. In some parts of the country there are also groups where young people who have had cancer treatment can get together. Another way to find out how other people in your position feel is through websites. We've listed some helpful websites at the back of this booklet.
- Write a list of the things that worry you, then next to it write what you can do about each of these things. If there's nothing you can do, there's no point in worrying – how about deciding not to? Lists can be good if you can't find a good person to talk to or if you're worrying in the middle of the night. Sometimes just putting things down on paper helps you to feel more on top of problems and to find ways to deal with them.
- Use up the energy from your worrying in another way. Best not to take it out on the cat or your little brother, but doing something energetic like kicking a football around or even hitting your pillow may help!

Above all remember the facts:

- Most cancers in children and young people don't come back, ever.
- The changes of the cancer coming back get smaller and smaller the longer you have been off treatment.
- For many cancers, there's still a chance of cure even if they do come back.

Coping with family life

Most young people notice that lots of other things change in their families while they are having their treatment. To start with of course, lots of people worry about you. You may have had family and friends giving you presents and phoning to ask about how you were doing. The people in your family probably gave you extra attention too. Sometimes this can be too much and get on your nerves, but at other times it can be helpful to know how much people care when you're not feeling too good.

Some young people find that they miss this special treatment and find they don't feel as important as they did when they were ill. It can sometimes be hard getting used to being treated the same as everyone else. There are other young people though who really wish their family would treat them as normal. Your mum or dad will probably have needed to keep an extra close eye on you while you were having your treatment, making sure you had your medicines and checking for side effects. Lots of parents find it really hard to stop doing this when treatment is over. Like you, they may worry about the chance of the cancer coming back. You know that you feel OK, whereas they don't. It can really get on your nerves to be asked if you are alright all the time, but it's good to remember why your family might be worried. If this is a problem in your family you could agree to tell them if you feel at all ill, if they will agree not to ask you all the time!

Brothers and sisters

When you were ill, things probably changed a lot for your brothers and sisters too. A lot of brothers and sisters feel really left out, especially if they didn't get presents or treats like you did. They may have found it hard to be without your mum or dad if you had a lot of time at the hospital with them. Now that you're off treatment, they may worry about your health too or may feel left out if you are still getting extra attention.

What about boyfriends and girlfriends?

Many young people say that they feel "different" from their friends when they have been through cancer treatment. It can be hard to feel confident when you have lost your hair and are not your usual weight. Making new friends when you look different or can't do everything that other people can do, can feel like a big challenge. It's the same when it comes to girlfriends and boyfriends.

It's good to remember that almost everyone you meet will also feel that there are parts of themselves or their background that they would like to change. A lot of the people you meet will feel that they couldn't have coped with your illness and the treatment you've had. It's up to you who you tell about your illness, but remember that often the people who you are open with will feel much more able to tell you about their own worries. Having had cancer doesn't stop you having normal relationships and getting married just like your friends.

> "I feel upset and moody. I don't like talking about what has happened to me."

Coping with coming back to the hospital

Some people enjoy seeing old friends back at the hospital, but some young people dread going back once they've finished treatment. It's natural to feel frightened that the doctors will find a problem with your health, but remember that at most follow-up appointments there are no problems found at all. It can be hard not to compare yourself with other patients, but remember that no two cancers are the same and no two people are the same.

The hospital can be a reminder of all the tough times you had during treatment. It can be hard too seeing other children and young people going through their treatment. It's especially hard if you find out that someone you know from the hospital has been ill again. Lots of young people say that they get a mixture of feelings if this happens. It's natural to feel relieved that you're healthy when you hear bad news – that's something everyone feels, but it's common too to feel guilty that you're well when others aren't. Feeling guilty can be hard work. It's usually better to find a way to do something practical instead. You could send a card if you know the person who is ill again, or how about getting involved in some fundraising or another activity?

Follow-up and coming to clinic

When you first finish treatment, you will need to come frequently to the clinic. This is usually every 4-6 weeks in the first year, sometimes more often especially if you have a central line.

As time goes by you don't have to come so often, usually every three months in the second year, until by the time five years have passed you are only seen once a year. If you had some of your treatment at a shared-care hospital you may still have some visits there.

Why should I come to the clinic?

At first the visits are to check there are no signs of the cancer coming back. As time passes, the visits are to make sure there are no longer-term problems caused by your treatment.

Coming to clinic is also an opportunity for you to ask questions about the treatment you had, and gives you the chance to talk about any worries or concerns you may have.

What happens when I come back to hospital?

Usually you will be weighed and measured at each visit. This is to check you are growing as expected. You may need an x-ray, a blood test or occasionally a heart scan, depending on what treatment you had.

You will be seen by the same doctors and nurses you saw during treatment, but the clinics may be held at a different time or day.

How long will I keep coming back to clinic?

This will depend on the treatment you had, but most people are seen for many years after finishing treatment. Eventually it may only be every 1 – 2 years.

> “It helped knowing how often I had to come back, and to have someone who knew me and I knew them.”

I want to forget all about my illness, why do I have to keep coming back?

It is very understandable to feel like this, and if you can be discharged from the clinic, you will be. For most people this isn't possible, because some treatments that cure cancer may occasionally cause other health problems, which don't become noticeable until some years later. For example, some treatments can affect your thyroid gland and you may need to take further medication.

Coming to clinic can also help others. By seeing you at the clinic and finding out how you're getting on, doctors can learn a lot, and may be able to use this information to improve treatment for other young people with cancer.

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

Going to the clinic isn't just about making sure you're not getting ill again, but also about making sure that you're staying healthy. There are some things you can do to minimise the risk of a second cancer, such as not smoking, eating a healthy diet and exercising, and not getting sunburnt. For more information, see pages 20-21.

Practical issues

When will my hair grow back?

It will start to grow back as soon as you stop having treatment. It can take a while to thicken up. Sometimes when it grows back it may be slightly different in colour, thickness and how curly it is.

When can I stop worrying about infection?

When your treatment finishes your blood count should be back to normal within about a month. If you have had a bone marrow transplant it may take longer for your body to be able to fight infections normally again. For the first six months after treatment stops you will need to let the hospital know if you come into contact with chicken pox or measles.

When can I have my line out?

As soon as possible after your treatment is finished and any scans or tests are completed. You will need a general anaesthetic to have it removed, so you have to spend the day in hospital.

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

You will not need many blood tests now but some will be important. No one likes blood tests but unfortunately they may still be necessary so if you don't have a line you will either have a thumb prick or a needle.

How long do I have to wait before I can go swimming again after my line is taken out?

You usually don't have to wait too long to have a bath or go swimming once your Hickman line or Portacath has been taken out. Once everything is healed up (which usually takes around 2 weeks) then you may be able to swim. This is best checked with your doctor or nurse specialist.

Will I still have to take any medicines?

You may have to continue to take some antibiotics (e.g. Septrin) for a few weeks after treatment has stopped, or for longer after a transplant.

After this most people don't take anything, but sometimes there are some medicines to take. Some hormones (messenger chemicals in your blood) can be affected by treatment, especially after radiotherapy to the head, so you might have to take tablets or injections to replace them e.g. thyroxine – thyroid hormone.

When will my weight be back to normal?

You may have lost or gained weight depending on your treatment. Hopefully when your taste and appetite return you will be able to get back to healthy eating and your weight will get back to normal. This may take some time, but the important thing is to eat healthily and, if you can, take some exercise.

Will I need more immunisations?

Yes, you usually need to repeat the immunisations you had as a baby. These will usually be given by your GP, and your doctor will advise on when the timing is right to have these.

What do I do if I feel unwell?

If you have a temperature and still have a central line, or are neutropaenic, you will have to come to the hospital. Once your line is out and your blood is back to normal, it is usually best to see your GP first, then they can decide if you need to go back to the hospital. If you had a bone marrow transplant you need to ask the hospital what you should do if you feel unwell.

Who can I contact if I am worried about something?

If you want to talk to someone between visits to the follow-up clinic, you can talk to your keyworker. If they can't help they will arrange for someone else to contact you. There are also some websites that you might find helpful at the end of this booklet.

What should I look out for/ worry about?

Young people who have had cancer treatment still get coughs and colds and aches and pains. It is hard not to worry about getting ill again but try to remember that if you feel unwell that it is far more likely to be an everyday illness than anything serious. There are very few things you can look out for. You will be checked over at clinic visits and should mention anything you have been anxious about to the doctor or nurses. As time passes and life gets back to normal, it should get easier not to worry so much.

Is there anything I can't do?

For most people, there's no reason you shouldn't do all the activities you did before you were ill. If your treatment has left you with any problems, such as mobility or concentration, you may not be able to do everything. Your friends and school/college will be able to help you join in as many things as possible and maybe try some new activities.

Sometimes I still feel tired...

When you finish treatment you may still feel tired because you are not as strong as you were before. It will take time to return to your normal life. You may have lost weight and are not used to joining in everything you did before. It takes time to build up your stamina, but you can help by eating a good balanced diet and introducing activities gradually. Everybody is different but hopefully you will soon be able to attend school/college full time and join in sport and other activities both in and out of school/college.

How can I find other people my age who've had cancer that I can talk to?

There are several organisations for young people who have had cancer. Some are listed at the end of this booklet. There may also be a group who meet at your treatment centre that you might like to join. If no group exists you may like to set one up.

What if your body can't fully repair itself?

Sometimes cancer, or cancer treatment, causes damage that the body cannot repair. If this has happened to you, your doctors will have talked to you about this. If you had treatment for a tumour in your brain or spinal cord you may not be able to do all the things that you could before you were ill.

Some young people find that the way they look is permanently changed by the cancer or treatment. These things are extra hard and may make you feel that finishing treatment won't make your life much easier. It takes a lot to get your head round changes that might last for the rest of your life and that make you different from your friends. Most young people have times when they feel sad and often very angry that this has happened, but most young people also find that in time they can adjust and really enjoy life again.

Even if a full recovery isn't possible you will get stronger in the weeks and months after finishing treatment. Some people find that because there are some things they can't do, they can do some other things extra well. For example, people who use wheelchairs often have very strong arms which help them to manage despite problems with their legs. We've listed some organisations in the back of this booklet that can give you and your family help so that you can still get the most out of life.

> “Your priorities change and give you a totally different perspective on life. This can make it hard just to go back to ‘normal’.”

School/college and other issues

Returning to school/college

Returning to school/college can be both an exciting and anxious time for you. You may have already managed to attend school/college while you were on treatment or maybe you had some home teaching.

Your Nurse Specialist will, with yours or your parents' permission, contact the school and liaise with the appropriate staff to help make your return to school/college as easy as possible, and let them know about any particular needs you may have. Hopefully, before you return to school/college there will be an opportunity for you, your parents and a member of the hospital team to have a meeting with your teachers. This meeting will give you the chance to talk about any worries you may have and it will also be an opportunity to tell the school/college about your treatment and how it affected you.

How can I get ready for going back to school/college?

You may feel worried that you have missed a lot of school/college and feel there are gaps in what you have managed to learn while you were on treatment. You may be wondering how you will fill the gaps and start working on all the same subjects at the same level as your friends and classmates.

Remember:

- If you have had home teaching you will have covered a lot of the same work as your classmates, but perhaps not all of the subjects.
- When you work with a home tutor one-to-one you achieve much more in less time than it would take in a classroom, so you may be ahead in some subjects.
- Continuing with extra tutoring at home or at school/college will help you get back on track.
- Talking to you parents and teachers about things you are having trouble with will help them come up with a plan that will give you what you need in school/college.
- School/colleges are used to helping pupils who have been ill and should be able to set up any extra help you need.
- For many young people, after they've been back at school/college for a couple of weeks, they feel like they've never been away.

Physical appearance/activities

There may be some visible signs of your cancer and treatment, while other effects of the cancer are not visible.

Thinking about the things on this list may help you with going back to school/college:

- 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?
- Do you need to wear a hat or scarf to school/college?
- Are there any activities you cannot take part in?
- If walking is difficult for you, will the teachers allow more time between classes?
- If it's hard to get around or you are in a wheelchair, will the teachers move the classes around so that you can get to them?
- Do you need to sit in a certain place in the classroom in order to make it easier to hear or see what's happening?
- If you still have a line/port, and are worried about being knocked in the corridor, can you ask to leave lessons five minutes early to avoid the crowd?
- Could you go back to school/college part time if you get tired easily and find a full school/college day too much?

What about friends?

- Telling friends about your cancer is the best way to overcome any uneasiness they may have about what has happened to you. You may want to remind them that cancer is not contagious and that they can't 'catch' cancer from you.
- You may want to arrange to meet your friends before you go back to school, especially if you haven't seen them in a while, so that you can get reacquainted. You can also tell them about things you might need help with, like carrying your bag.
- Be as open and honest with teachers and friends as you can, they are there to help you as much as you will let them.
- It may be helpful to find one teacher who you can talk to who will make sure your return to school/college is as smooth as possible.
- Build on the friendships you already have, and look for people who may be new friends.
- Try joining a group, a club or a sports team.

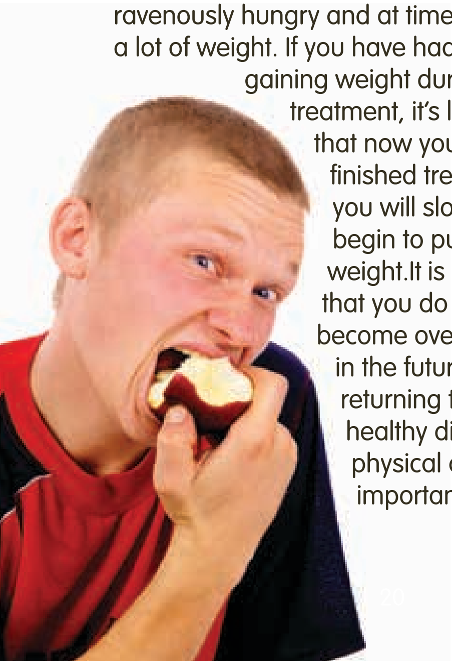
Remember there are people who can help you with these things if you want. You will not have to talk to friends on your own. Teachers are there to help you. Your parents and hospital staff will also support you in talking about any of these things.

Healthy living

Now that your treatment is finished you need to think about getting your energy back and staying as fit and healthy as possible. Some survivors of childhood cancer may be at risk of second cancers, so by being aware of potential health risks, you have the chance to possibly reduce their impact by changing your lifestyle.

Diet and exercise

Cancer and cancer treatment affect everyone in different ways. You may have had trouble with your appetite, making you lose weight, or you may have had tablets that made you ravenously hungry and at times gain a lot of weight. If you have had trouble gaining weight during treatment, it's likely that now you have finished treatment you will slowly begin to put on weight.It is important that you do not become overweight in the future, so returning to a healthy diet and physical activity is important.



The advantages of a good diet and physical activity are:

- They help to heal your tissues and organs that have been damaged by the cancer and its treatment.
- They build up your strength and stamina.
- They reduce the risk of developing other health problems as you grow older.
- They help you to generally feel fit and energetic.

The every day food that you eat should contain a balance of the following five food groups:

- Bread, cereal and potatoes
- Fruit and vegetables
- Milk and dairy
- Meat, fish, pulses and nuts
- Foods containing fat and foods and drinks containing sugar. (Foods in this group are not essential to a healthy diet.)

When you were undergoing treatment, you may not have been able to do any exercise. If you are finding it hard to start doing more exercise, try thinking about how you can make it easier to get started. You could try walking or cycling to school/college or whenever you go out. By starting with something easy, you are more likely to keep going.

Sunbathing

It's well known that exposure to the sun can cause skin cancer. A tan shows that the skin has battled to protect itself from exposure to the sun. In order to minimise the risk of skin cancer, it is essential to use a high factor sunscreen. When it's really hot, keep out of the sun or cover up with long-sleeved tops, and wear a hat. Finally, don't ever be tempted to use a sunbed! They use intense rays which are especially damaging.

Smoking

Sometimes you may find yourself in situations where there is pressure to have a cigarette, maybe with a group of friends or at a party. Smoking has been clearly linked with cancer – it is not a good idea for anyone to smoke. Some cancer treatments can increase the risk of a second cancer and you may be at even more risk if you smoke.

> “I found that meeting other young people and doing normal things, like bowling etc, really helped me come to terms and cope with coming off treatment.”

Transition

What's transition?

As a teenager, when your cancer treatment is several years behind you, you may attend a follow-up clinic just for teenagers, if your hospital has one.

In some cancer centres, young adults who were treated for cancer as a child and have been off treatment for more than five years have their follow-up visits in an 'adult' hospital.

The process of supporting you to move from the familiarity of the family environment of your hospital to being cared for by a different team or at a different hospital is called 'transition'.

To help you feel ready to move on, you'll be supported by the doctors and nurses in clinic to understand your cancer, the treatment you had and the follow-up clinics, and to gain more independence and start making decisions for yourself. You will be given health care advice, and the staff will talk more to you and less to your parents.

Long-term follow-up care for teenagers and adults will vary in each cancer centre. Your own doctors and nurses will explain the transition process in your hospital in more detail.

CCLG has produced a booklet called Aftercure, and an accompanying website www.aftercure.org. Aftercure is a guide 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.

Useful information

Children's Cancer and Leukaemia Group (CCLG)

cclg.org.uk

An organisation for professionals treating children with cancer. Provides an extensive range of accredited award-winning information resources for patients and families including Contact magazine.

Aftercure

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.

JTV Cancer Support (formerly Jimmy Teens TV)

jtvcancersupport.com

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

Teenage Cancer Trust

teenagecancertrust.org.uk

Provides specialist services for teenagers and young adults with cancer.

Health Talk Online

healthtalkonline.org
youthhealthtalk.org (for young people)

Both websites contain information about cancer and have video and audio clips of people talking about their experiences.

CLIC Sargent

clicsargent.org.uk

Provides information and support for young people living with cancer.

Macmillan Cancer Support

macmillan.org.uk

Provides a wide range of information for young people living with cancer and cancer survivors.

2bMe

2beme.org

An American site provided by the Look Good…Feel Better for Teens program, providing information and advice on dealing with the appearance related changes that cancer treatment brings and other issues relevant to teenagers with cancer.

CCLG supports the 1,700 children who develop cancer each year in Britain and Ireland. As an association for healthcare professionals involved in their care, it works to benefit children through development of the highest standards of care. CCLG is a major provider of accredited information for patients and families.

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