



Children's
Cancer and
Leukaemia
Group

the EXPERTS
in CHILDHOOD
CANCER

A parent's guide to finishing treatment

Information and support on follow-up and adjusting to normal life when
your child or teenager has finished treatment for cancer



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This edition was reviewed and edited by the CCLG Late Effects Group and the CCLG Information Advisory Group, comprising multiprofessional experts in the field of children's cancers.

With thanks to Dr Heather Borrill, Consultant Clinical Psychologist in Paediatric Oncology at Great North Children's Hospital in Newcastle Upon Tyne for her input.

We are grateful to all those who helped to make this booklet. The quotes in this publication are from parents, patients and carers. They are personal views and do not necessarily represent the view of CCLG. CCLG makes every effort to ensure that information provided is accurate and up-to-date at time of printing. We do not accept responsibility for information provided by third parties, including those referred to or signposted to in this publication. Information in this publication should be used to supplement appropriate professional or other advice specific to your circumstances.

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About this guide

For many parents, reaching the end of treatment can bring mixed emotions. This is the moment you have waited for since hearing your child's diagnosis.

You may feel happy and relieved your child or teen has completed their treatment, but you may also feel anxious that cancer may come back. It can be a very unsettling time. Your child may still have side effects from treatment, and it is important to accept that it will take time for them to recover both physically and emotionally.

This guide contains information on what happens when your child finishes treatment, and explains follow-up care. We have included some practical

questions such as how often your child will be seen, as well as how you may be feeling emotionally when your child finishes treatment.

We hope this guide will help answer some of the questions you have at this time, and support you through this period of readjustment.



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Once active treatment finishes, it can be reassuring to know your child will move onto a specialised follow-up pathway designed to support them throughout their life. They will still be seen in clinic (either in person or virtual) and the frequency will depend on the needs of your child.

At the beginning, this may be every few weeks to months. As time goes by, the time between visits usually increases and once five years have passed, your child may only need to be seen once a year or even less.

What is follow-up care?

At the start, the main focus of follow-up care is on making sure there are no signs of the cancer coming back which is why it is so important to attend follow-up clinics. Your child will be weighed and measured at each visit to check they are growing normally. Blood counts are checked until they return to normal, possibly longer if your child had leukaemia.

Your child may need to be monitored with specific tests and procedures which could include blood tests, scans and other measurements. As well as health checks, follow-up appointments allow children to develop a better understanding of their illness, and help them to take ownership of their health as they become adults.

Your child may also be on an open access pathway where routine appointments are not needed. But you will always have access to the follow-up team for advice at any time.



Your child's treatment summary and care plan should be given to you within the first 3-6 months after finishing treatment.

Your child's line or port – will be removed as soon as possible after treatment has finished and any scans or tests have been completed. Some children treated for leukaemia or lymphoma may have their lines removed before treatment finishes.

Having a line removed is less urgent than having a line inserted, so your child may be placed on a waiting list for this procedure.

Blood tests – may still be necessary once the line is out. This will either be with a thumb prick or a needle. Some children are understandably upset at the thought of this. If it becomes an issue, a health play specialist may be able to work with your child to help them cope better with the blood test.

When your child finishes treatment, you may be given:

- **a treatment summary** – outlining all of the different treatments your child has received including names of chemotherapy drugs.
- **a follow-up care plan** – which is shared with your child and GP, detailing what follow-up visits will be required and whether extra support is needed. This is reviewed and updated regularly. Having a detailed plan of care can help reduce some of the worries you may be feeling.
- **a keyworker** – to support you and your child through the early years after treatment has finished.
- **an end of treatment event invitation** – such events may be coordinated and supported by various members of your child's hospital and community team. Families can ask questions on any topic and it offers an ideal opportunity to talk to other parents at a similar stage. It also gives your child and their siblings a chance to explore their own feelings about their treatment. If available, attending one of these events is an excellent way of finding out how your child will be supported in the future.

What are late effects?

As time passes, the chance of cancer returning lessens. Your child's follow-up appointments will increasingly focus on making sure any long-term side effects of treatment are found early and treated quickly. These are called 'late effects' and can happen years after treatment has finished, which is why follow-up care is important.

Follow-up is an ideal chance to talk through any concerns you, or your child, may have – whether physically or emotionally – with the specialist team who will be happy to help and offer advice. They will see many patients and families who have also finished treatment and so will have lots of knowledge and experience to help with anything you may be worried about.

The team of late effects specialists trained to deal with longer term issues that might occur following cancer treatment in children and young people can include:

- **consultant** (often a paediatric oncologist)
- **specialist late effects nurse**
- **clinical oncologist** (doctor specialising in radiotherapy treatment)
- **endocrinologist** (doctor specialising in hormones)
- **team coordinator**
- any other **health professionals** such as psychologists, support workers or wellbeing advisers



Common questions asked

Will my child need more immunisations?

Yes, most children will need to have their childhood immunisations repeated six months after finishing treatment*. Your child's consultant will advise you on which immunisations need to be repeated and will write to your child's GP so this can be arranged.

**This may be longer following a donor stem cell transplant*

What do I do if my child is poorly or has a temperature?

To begin with, you may find it difficult not to worry every time your child is unwell, even though the most likely cause is a normal childhood illness. This feeling is perfectly natural and will hopefully reduce over time.

In the first few weeks after treatment stops, your child may still be neutropenic, or still have a central line, and will need to come to hospital if they have signs of infection. However, once your child has a normal blood count and no line or port, your child's medical team will advise you whether they want you to contact them or your child's GP first.

Your child's immunity will be low for up to six months after treatment. If they previously needed to take extra medicines when they came into contact with chickenpox or measles, they will still need to take these during this period.

What symptoms should I look out for?

This is understandably a common question. Most children won't have any problems, but there are a few things to look out for:

- many **bruises** at the same time not caused by normal activity (all children get some bruising)
- repeated **headaches** or being sick which is worse first thing in the morning
- **lumps** when your child is otherwise well. Small lumps in the neck, called lymph nodes, are very common in children when they have a viral illness, such as a cold or sore throat.
- **feeling unwell** for a period of time without a known cause

Who can I contact if I am worried?

If you want to talk to someone in between visits to the follow-up clinic, you may be able to talk to your child's clinical nurse specialist or keyworker. They can advise you or arrange for someone else to contact you. Alternatively, you can contact the ward or clinic where your child was treated.

Is there anything my child shouldn't do?

Generally, your child should be encouraged to return to normal activities as soon as they feel better or are able to. Some children are left with disabilities as a result of their cancer or treatment, and may not be able to do all they could before. The professionals supporting you and your child will work with you to make sure that your child can access educational, social, and recreational activities as fully as possible.

Why does my child feel tired?

Some children feel very tired after certain treatments but most will recover within a few months of finishing treatment. When children first finish treatment they often feel tired because they are not as strong as before, they may have lost weight and they are not used to joining in all their usual activities. It takes time to build up their stamina. This is helped by eating a good balanced diet and introducing activities gradually. Your child's school should help with your child's reintegration and support them to join in as many activities as possible. Each child is different but, hopefully, all children are soon able to attend school full time and join in sport.



What about puberty and fertility?

Following treatment, most children go into puberty normally and your child will be examined regularly at follow-up visits to check this. Whether your child's fertility has been affected will depend on the treatment they received. This will have been discussed when your child started treatment. It is often very hard to remember everything that was said at the beginning, so please ask the follow-up team again if you can't remember.

What happens when my child reaches 18 years old?

As children treated for cancer become adults, their care will gradually transfer from paediatric to adult services. There is no single right time for this to happen and a flexible approach is used by most hospitals depending on the time since diagnosis, current health of the patient, and their physical and emotional maturity.

Preparation for moving to adult services should start early around your child's 14th birthday and continues until your child is settled into adult services. This is called transition. It is a planned, coordinated process where your child will be prepared over a number of months or years, given all the information they need and be introduced to their new adult team to make sure there is continuity of care.

Adolescent and adult long-term follow-up care will vary in each cancer centre. If you require any further information on transition, please discuss this with your follow-up team.

You can help the transition process when your child is young by:

- **talking to your child** to help them gain an understanding of their cancer and its treatment
- **explaining the reasons** for them coming to the follow-up clinic
- **encouraging your child to ask questions** and talk directly to the doctor and nurses

They will also be supported by the hospital team to:

- **understand** their cancer, treatment and follow-up
- **gain more independence** and start to make their own decisions
- **find health care advice**



Most parents whose child is approaching the end of treatment feel relieved that treatment has worked, and it no longer needs to play a big part in the life of their family. Families can stop planning around treatment and start to look forward to life away from cancer.

But, for many parents, this relief is mixed with other feelings. Parents now may have time to think about the impact on practicalities such as work, their child's education and finances. Families are often exhausted after months or years of treatment.

Parents sometimes feel they swap the worry about side effects for fears about relapse. Parents now have more time to themselves, but that time may become filled with thoughts of what the family has been through and what the future might hold.

Thinking about the past and diagnosis

Your child's diagnosis is likely to have been one of the most traumatic things your family has experienced. At the time parents are told the news, many are in a state of shock, and there are often many demands on their thoughts and time. Most parents are also managing other challenges, big and small: 'What will I do about work?', 'How can I break this news to my child?' 'There's nothing in the fridge'. The list is endless.

During treatment, many parents do not have the time to really think through the diagnosis and the enormity of what it means. It is when treatment slows down that families can start to take stock of what has happened. For some families, this involves going back through all the events around the diagnosis and the difficult times experienced during treatment.

This can be a distressing process but for some parents it is a useful way of making sense of what has happened. Counselling or other support is available if you are struggling to cope.

“ At the end of treatment, my husband and I thought we would think 'we can't wait, we are going to have a massive party' but actually we felt very deflated and, to be honest, we couldn't get excited treatment had finished. We were reassured this was a perfectly normal reaction. ”

Not feeling like celebrating

Parents often find friends and families are overjoyed their child has reached the end of treatment. They are greeted with big smiles and told how well their child looks. "Isn't it great he's finished his treatment?" Yet most parents find their own reactions are much more cautious.

Many parents say they cannot allow themselves to feel joy at having reached the end of treatment, and can sometimes feel more insecure and lost. How can they celebrate when there is a chance, however large or small, of relapse? Or they may have known children who didn't survive.

For other families, a celebration feels very appropriate. Your child and family have just got through the huge challenge of treatment. That in itself is a great achievement. The celebration might be nothing more than going to the park on what would previously have been a clinic day. Some families choose to have a family party or a celebration at school.

Others find planning a holiday or some other enjoyable event gives them something positive to focus on. Whatever you and your child choose will be right providing it feels right to you.

Feeling alone

During active treatment, families are regularly seeing professionals and other parents at the hospital. Professionals can reassure parents their experiences are not unusual. Other parents in hospital will have knowledge and experience of how it feels to go through treatment with a child. Yet, suddenly, at the end of treatment, fewer hospital visits mean parents have much less access to these sources of support, often at a time when they really need it.

Parents sometimes find even people who seemed to have understood what the family was going through during treatment, now become less available and act as if life is now back to normal. It can be particularly hard at this time to find people who realise the pressures and fears you still feel. With a little explanation, or perhaps by lending them this booklet, friends and relatives can be helped to appreciate the fact you still have concerns and what some of these may be.

Feeling scared the cancer will come back

Parents often tell us the end of treatment feels like the removal of their child's safety net. While treatment is being given, families feel everything possible is being done to beat the cancer. No-one can tell you the disease will not return. Parents sometimes feel they would prefer their child to remain on low dose chemotherapy for life, if it could guarantee the disease would not return.

It is important to remember your child's treatment was carefully designed. Most childhood cancer treatments have, and continue to be, evaluated, changed, and updated. Each change is the result of research that has shown an improvement in cure rates and a reduction in potential side effects. Your child has received a very carefully calculated amount of treatment. There is no evidence any more treatment will help at this point. Some parents are able to put thoughts of relapse to the back of their minds. Others find thoughts of relapse are never far away.

If you are struggling with fears about relapse, it can be helpful to remember the following:

- **most childhood cancers do not come back**
- **the chances of relapse get smaller** the longer your child has been off treatment
- **if the cancer does return**, it may be treated successfully again; many children who relapse are treated successfully a second time around

Coping with anxiety about follow-up appointments

Coming back to the hospital for check-ups can be stressful. Some parents say they feel increasingly anxious as the day of the appointment gets closer. Afterwards, many parents feel much more relaxed and are able to forget about the illness for a while. It can help to remind yourself that the chances of a relapse being found at any follow-up appointment are very small, especially if they feel so well. You may feel that you do not want to risk upsetting them by bringing them back into hospital, but explaining in a way they can understand is important. Often, parents say that while they find it difficult to be reminded of the past, they were given lots of information and feel better prepared to help their child maintain a healthy future.

Coming back to the hospital can bring other stresses too. It can be hard to see other children who are still receiving treatment. For many parents, this brings back difficult memories of their own child's treatment.

Returning to hospital can also mean parents hear news of children they knew during treatment. If the news is bad, it can trigger parents' own fears about their child relapsing. Some parents may also feel guilty their own child is ok.

Coping with significant dates

Anniversaries of the time of diagnosis or finishing treatment can make whatever emotions you feel more intense, and for many that's a mixture of sadness and joy. In time many parents find they can reach a balance between being thankful their child is free from cancer and the sadness over the inevitable losses the experience has brought.

Feeling overwhelmed

Sometimes, once treatment finishes and it is 'all over', the enormity of the whole cancer experience can hit parents hard when they are trying to get things back to normal. Strong feelings can be pushed down during treatment but are then released afterwards or even sometime in the future.

While everyone around them wants to carry on as normal, many parents find that they don't want to be sociable or talk to anyone as they come to terms with what they have been through as a family.

It is normal to feel emotional at this time but, if your feelings are too overwhelming and you are finding it hard to cope or are experiencing ongoing feelings of anxiety or depression, you may benefit from some further help to talk about how you are feeling.

Don't feel afraid or embarrassed to go to your GP if anyone in your family is finding things too much. Asking for help can be hard, but it's important to look after your own wellbeing too (see page 34).



Your child and their feelings

Your child may feel anxious when treatment ends but this depends on your child's age and stage of development. It is worth remembering any child of any age may regress and act much younger than their age when feeling upset. It can be a difficult time for your child or teen to go back to living a normal life. They will need time to adjust emotionally and physically.

Often during treatment, normal parenting boundaries and discipline are more relaxed for understandable reasons. After treatment, it is normal for the child to feel they are not getting as much attention or consideration now as they did when they were poorly and it can be hard to be out of the 'spotlight'.

If your child had steroids during treatment, these can affect behaviour whilst they are on them which then becomes a learned pattern of behaviour. It can then be hard to get things back to normal

again. The goal is to gradually bring your child back into family life with normal everyday tasks such as chores and homework, give a reasonable level of attention and encourage them to try new things.

By talking openly to your child, you are inviting them to share their thoughts about their illness openly too. This will give you a chance to correct any misunderstandings and give them reassurance.

After all, getting back to a normal and fulfilled life is what getting through treatment has been all about and is what everyone has been working towards.



Possible age-specific issues after treatment:**Babies**

- little understanding of their cancer treatment
- possible clinginess when visiting clinic
- help your baby by cuddling and reassuring them at these times

Toddlers/preschoolers

- some understanding of their cancer treatment
- many young children may regress during treatment by becoming oppositional, refusing to toilet train, having more temper tantrums and feeling anxious when separated from parents
- role play by pretending to be a doctor or nurse helps children work through their experiences
- return visits to clinic may not always go smoothly at first but over time they may look forward to visiting friends at the clinic
- allow your child to be as independent as possible and explore the world
- take a consistent approach to parenting and discipline to help them to adjust to normal life

School-aged children

- body image issues such as hair loss and weight gain can make them feel insecure
- friendships are important at this age and there may be issues at school where friends have stopped playing with your child
- support your child to become more confident
- encourage your child to participate and try new things
- keep in regular contact with the school and discuss any concerns you may have

Teenagers

- not only facing cancer and its aftermath but also the normal issues of being a teenager
- may withdraw or become depressed
- may be angry or rebellious, although these are also normal teenage behaviours
- may be very anxious about the possibility of relapse
- may deny the seriousness of the illness by taking risks
- may want to put the whole thing behind them and not look back, however, they may then try to delay or cancel follow-up appointments
 - encourage your teenager to talk to you about how they are feeling, be non-judgemental and open to listening to them
- help your teenager to work towards their future but also help them to understand that it is in their best interest for health care to continue

As your child grows up, they may start to ask more questions about their illness and treatment. Many children will have been too young to remember much about the treatment period. It can then be tempting to try to protect them by not telling them about the details of their illness. Children are usually more aware than adults realise. Some children will learn about their illness from comments made by older siblings, other family friends or their friends. Finding out about the illness in this way can mean they only have part of the story and this may leave them with worries.

Children may miss the friendships they formed with people in hospital who helped them through this time. Children who have a lot of family support are less likely to have problems adjusting back to everyday life, and this is where parents and other family members can make a difference.

A child's behaviour can also be a reflection of what is going on in the wider family, and sometimes parents need to talk to someone separately about their own feelings and responses to having gone through treatment, and how it has affected relationships in the family.

Children and teenagers who have dealt with cancer tend to value life and recognise that the challenges they have faced have made them strong. They often come away from a cancer experience with an appreciation of and sensitivity to life that isn't shared

by their peers. They often express feelings of pride and achievement at having faced this crisis and handled it with success.

How you can help:

- **make time to talk openly** with your child about how they are feeling
- **encourage play and art activities** as ways to express feelings
- **answer questions honestly** and openly in a way they can understand to lessen worries and anxieties
- make sure your child understands **why follow-up visits are important** for their future
- **give lots of empathy** such as 'it must feel hard having to do xxx' to make sure they feel understood and their feelings are acknowledged
- **take a structured and consistent approach with parenting and discipline** such as clear rules of behaviour, with lots of emphasis and rewards when goals are reached, and paying as little attention as possible to unwanted behaviours

There are many parenting self-help books which can help with this (see page 35).

If your child is struggling to cope

Sometimes, the emotional effects of having gone through the cancer experience can hit later in life even when the child was diagnosed quite young. This is common and many young people have experienced this, particularly at times of stress such as changing schools or exams.

If your child, teen or young adult seems to be struggling and you feel extra support is needed, sometimes a counsellor or psychologist can help them to express feelings they may not want to share with you or cause further worry for you (see page 34). In a few cases, survivors can experience symptoms of anxiety and depression which can affect their daily life. It is important to address these issues with your family GP so the right help and support can be given quickly.

Helping brothers and sisters

It is important to be aware of the impact of cancer diagnosis and treatment on brothers and sisters as they will probably be feeling the same fears and concerns that you are which can show through changes in behaviour at home and school.

They may continue to have worries about their sibling's health for some time after treatment and often need reassurance they are loved equally and there are no longer any signs of the cancer left. As brothers and sisters get older, they are likely to need more detailed explanations about the illness, and may also need reassurance it does not run in families.

Sometimes, siblings can also suffer stress reactions too which they can hide for fear of upsetting parents further. If you feel your other children are struggling, your child's keyworker, GP or hospital psychologist can help with extra support by arranging appropriate family therapy or counselling for siblings.

“ We didn't realise the impact on one of our 'well' daughters – she was actually quite distressed but trying to cope so as not to cause us any more problems. She was suffering from flashbacks, bad dreams, and unpleasant thoughts, particularly if under pressure at school. Family therapy was brilliant! ”

Finding a 'new normal'

Although life may not return to exactly how it was before your child was ill, most parents feel that, in time, the family reaches a new normal. For children and young people, this involves returning to nursery, school or college and, as much as possible, to a full range of leisure activities.

For parents, this may be getting back to normal activities such as work or home. For some parents, returning to the workplace can feel like a huge hurdle. If you have not seen colleagues since before your child was ill, coping with their reactions, however kind, can be a challenge. Some parents have found it helpful to visit their work place or meet up with colleagues before their first official working day.

A new normal might mean a return to usual discipline within the family. When a child is ill, it is natural that family rules slide. However, insisting on good discipline now sends a positive message to all children that things are starting to get better. It can be very encouraging to plan a holiday at this stage. If you want to travel abroad, you will need to seek advice about insurance.

School plays an important role in helping a child get back into a normal routine. It offers a structure to their day and a focus on the future. It's where children learn and develop communication and social skills and make friends.

Your child may have been attending school during treatment, but they may have spent days, weeks or even months away from school and friends. The thought of returning to school can be both exciting and daunting. As a parent, it may also be very hard to 'let go' and allow your child to leave the safety of home. Your child may also be anxious, and feel as if they are 'starting all over again'.

Teachers may have already had contact with hospital staff during your child's treatment and further support can be given in helping your child return to school now they are at the end of treatment. It is important that information is given to the school relating to any medical issues still affecting your child. Your specialist nurse may still be a link to the school if necessary. Remember that most children feel strongly they want to be treated as 'normal' in school, so informing the school and the child's school friends of this will help it to happen.

What happens if my child is in contact with chickenpox or shingles?

If during treatment you were told your child had enough of their own immunity against chickenpox then there is no need to take any action if contact is

made. However, if when your child was on treatment you were advised to report any close contact with anyone with chickenpox or shingles, then this continues to apply for six months* following the completion of treatment. After that time, if your child is in contact with anyone who has chickenpox or shingles there is no need for any action to be taken.

What happens if my child is in contact with measles?

For the first six months* off treatment, if your child is in close contact with a confirmed case of measles, then you should report this to your hospital nurse or doctor so appropriate action can be taken. After that there is no need to worry about any measles contact.

Can my child join in PE and swimming?

Yes. Exercise is important for healthy living and, unless there are any obvious reasons why your child cannot be physically active, exercise should be encouraged for at least one hour per day as recommended by experts. Once your child's central line has been taken out and the wound has healed there is no restriction on swimming.

**This period may be longer for children following a donor stem cell transplant. Please ask your own hospital doctor.*

What about discipline and behaviour?

After treatment, some children may take a little time to adjust and occasionally feel anxious or worried at home and school. They may become more tearful or express their frustrations in antisocial behaviour or temper tantrums. Try not to worry about this, most teachers will understand. In time, by attending school regularly, your child will receive encouragement and support in adjusting to life at school. Maintaining boundaries can help to manage behaviour.

Will my child have educational issues?

Most children who have had cancer treatment will have no educational issues at all. For some children, intellectual development may be affected by their cancer or their treatment. This may be down to low energy levels and long absences from school. Some children may need additional support such as extra time during exams and regular breaks. Having treatment can sometimes affect memory, learning abilities, and concentration. Informing teachers of the possible problems that may arise from treatment means that where this is a possibility, children can be watched closely and given extra help if needed.

The following can sometimes increase the risk of educational problems:

- your child's **history of learning issues** before their cancer diagnosis
- **low energy levels** and tiredness
- lots of **long school absences**
- **hearing or vision** affected by treatment
- **physical disabilities** from treatment
- treatment for **brain and spinal tumours**

As your child moves further into the follow-up period, it will be important for teachers to monitor their progress at school, discuss any concerns and recommend if any specific educational testing is required.

If you have any issues or need help and support when your child goes back to school, please ask your child's keyworker at the hospital.



It is important to help your child stay as healthy as possible and reach their full life potential. Making healthy lifestyle choices is essential for those who have survived cancer as we know that treatment given to your child can sometimes affect their health later in life.

During treatment, the effects on appetite and physical activity are different for each child. Some children may have gained weight during treatment while others may have struggled to keep weight on and needed extra supplements and high calorie foods. Some treatments, like high-dose steroids, are more associated with weight gain which can make healthy weight management more challenging but still achievable with the right support. Ask your GP or hospital team to refer your child for extra help if needed.

Most children will begin to put on weight once treatment is finished, or in the case of leukaemia, lose it when they stop taking steroids. As a parent, this will be reassuring to see. However, in order for them to maintain a healthy body in the future, returning to a balanced healthy diet and being physically active is very important.

As your child goes through adolescence and becomes more independent, talking openly about the dangers of risk-taking behaviour such as smoking, drinking alcohol, taking drugs and sexual activity is important to encourage a healthy lifestyle.

Setting a SMART goal

It can seem hard to make lifestyle changes as a family. You can start small by making one or two changes and setting **SMART** goals can help with this.

Specific: set a clear goal such as 'I will walk outside every day'

Measurable: make it measurable such as 'I will go for a 10-minute walk outside every day'

Achievable: don't set anything too hard or challenging

Relevant: choose something that you enjoy and will be motivated to do

Time-specific: set a timescale to see progress such as 'I will go for a 10-minute walk outside every day for a month'.

SMART goals can help with motivation and achievement by tracking progress.

These choices can have a positive effect on your child's health for many years to come such as:

- helping to heal tissues and organs damaged by the cancer and treatment
- building up your child's strength and stamina
- reducing the risk of developing certain types of adult cancers and other diseases in adult life
- reducing feelings of stress and increasing feelings of wellbeing

In general, a healthy lifestyle includes not smoking; eating a low fat, high fibre diet; exercising regularly; avoiding drinking too much alcohol and using a high factor sunscreen (SPF30) or wearing clothing to protect against sunburn.

Specific challenges

If your child has had a donor stem cell transplant

Following a donor cell stem transplant, it can take a longer period of time for full immunity to return. This period is very individual and will depend on:

- type of transplant your child has received (from a family member or unrelated donor)
- how quickly the new stem cells start working fully
- whether your child has had extra drugs to suppress their immunity and graft-versus-host disease.

Your child's doctors and specialist nurses will be able to tell you when it is safe for your child to return to normal activities. Children who have had total body irradiation as part of the preparation for their stem cell transplant may also have some side effects that do not become evident until some time after treatment has finished.

If your child had a brain or spinal tumour

Where a child's tumour has affected their physical activity, cognitive abilities or personality, the end of treatment may not feel like an important milestone. As parents, you still have fears about relapse and the challenge of adjusting to a new normal life. However, you also have to adjust to the possible limitations your child may now face.

For children who have had radiotherapy to their brain, it may be difficult to see what the side effects are until several years later. These children are more likely to need practical and emotional support to achieve their full potential despite possible difficulties.

Summary of follow-up tests and scans

If long-term side effects occur, they can be physical or psychological. They can happen because of the cancer, its treatment, related illness, an underlying condition or because of a treatment-related complication. Approximately two out of three survivors will have an issue or 'late effect' related to their treatment.

Most issues result from chemotherapy or radiotherapy. They depend on four things:

- type of treatment
- site of treatment
- dose of treatment
- your child's age during treatment

Late effects may include issues with growth and development, heart, lungs, kidney function, hormones and fertility. Any identified late effects, monitoring or treatment required for your child will be explained in the follow-up clinic.

Growth issues

Your child will be regularly weighed and measured to check they are growing normally. Decreased growth during treatment is common, and there is usually a period of catch-up growth when treatment finishes.

Radiotherapy to bones such as spine or limbs may effect growth and development.

Radiotherapy to the brain may affect the pituitary gland which produces many hormones, including growth hormone.

Sometimes, a daily injection of artificial growth hormone is needed to help your child grow. Other hormones can also be affected, for example, thyroid hormone and cortisol. These can be replaced with medicines.

Puberty (sexual development)

All children are monitored carefully during follow-up care for signs of puberty. At the follow-up clinic, young people may be asked about normal body changes/puberty and may need to be examined.

- **males** - this may be an examination of the testes and penis, pubic, facial and underarm hair growth. This can be done by a male member of staff, if preferred.
- **females** - this may be an assessment of the stage of breast development, asking about periods, pubic and underarm hair growth. This can be done by a female member of staff, if preferred

The follow-up teams appreciate this can be embarrassing for young people so they aim to handle this aspect of follow-up in a sensitive and

discreet manner. If there appears to be any delay going into puberty, some further investigations will be done. Sometimes, sex hormone therapy may be needed to help start sexual development. If there are problems, they will be referred to an endocrinologist (hormone specialist).

Heart and lungs

Some chemotherapy drugs and radiotherapy can affect the heart and lungs. If your child has had drugs that affect the heart, they will need to have heart ultrasound scans (echocardiograms) during and at the end of treatment, and every few years during follow up.

These scans will carry on for the rest of their lives and for young women these will be increased during pregnancy. Careful monitoring is important because there are often no symptoms. Your child will be referred to a cardiologist (heart specialist) if any problems are found.

Sometimes, it is necessary to do lung function tests. These tests involve measuring lung volumes and are easy for a child to do.

Kidney tests

Having one kidney does not usually cause any long-term problems, as the remaining kidney can cope alone. Certain drugs can cause kidney problems and, if your child received these, they will have had additional kidney tests during treatment. Kidney

function will be checked occasionally at follow-up visits, either by a urine sample or a blood test, or both. It is also important to have your child's blood pressure checked; this is usually done routinely at the clinic visit.

Fertility

After treatment is finished and your child recovers, there will be time to think about their future and growing up. This may lead you to think about them having a family of their own. There is a common belief any cancer treatment causes infertility. This is not true. Many children treated for cancer go on to have their own families. All types of cancer and leukaemia are treated differently and it depends on which treatment your child had and how it will affect their fertility. You will be able to discuss this in more detail with the doctor or nurse specialist in the follow-up clinic.

Second cancer

A very small number of children who are cured of cancer can go on to develop another, different, cancer later on in life. There are two main reasons for this. Firstly, some cancer treatments can increase the risk of developing another cancer. Secondly, some families have a specific risk of developing certain cancers. This is very rare and any concerns will have been discussed with you if your family is in an 'at risk' group. Your doctor or nurse specialist will be able to discuss any worries you have about this.

Our '**Living beyond cancer**' information pack has been written by clinical experts to help your child live a healthy life after having cancer as a child, teenager or young adult:

- **Living beyond cancer guide** to help answer your questions on how your child's diagnosis and treatment may affect their future health
- **Specific factsheets on long-term side effects** to help you understand more about how your child's cancer and its treatment might affect them:

Adrenal insufficiency

Bone issues: Osteonecrosis and osteoradionecrosis

Bone health: Osteoporosis

Breast cancer risk

Eye issues

Female reproductive health

Gastrointestinal issues

Growth issues

Health and wellbeing

Hearing loss

Heart issues

Kidney health

Lung issues

Male reproductive health

Metabolic syndrome

The nervous system: Autonomic

Oral health

Pituitary gland

Puberty: Females

Puberty: Males

Skin and sun protection

Spleen

Thyroid gland



www.cclg.org.uk/living-beyond-cancer

Some people find the end of treatment a positive time when they need much less support. But, for others, it is important to have people who understand that, although treatment has stopped, their worries have not. Try to find people who will let you be very open and honest about how you are feeling. Talking or writing your feelings down can help to make your own thoughts clearer. Some parents find it is helpful to have some time to themselves.

You may find some of these options helpful:

Friends/family members: Whilst your child is on treatment, it is sometimes hard to maintain all of your friendships. At the end of treatment, friends who have remained will hopefully continue to support you even if it's just a friendly chat over coffee.

Your child's health team: The staff you met during treatment will be aware of the difficulties parents and young people face at the end of treatment and will be available for help and advice. A clinical psychologist will be part of your child's health team so do let them know if you need some extra support at this time.

Cancer support groups: Some treatment centres have parent support groups. These groups will usually be able to put you in touch with other parents who are in a similar position. Where these are not available, there may be more general cancer or carer support groups in your area. Details of these are available from organisations such as Macmillan Cancer Support, local community information websites or libraries.

Online communities: Social media groups and forums can also be a source of help and support by hearing from others who have similar experiences. However, some parents find that the inevitable emotional involvement of hearing other people's stories might not be helpful, so it is worth thinking carefully before joining an online community.

Your GP and local services: Your GP will be able to give advice on mental health and wellbeing services in your local area and can refer any family members for extra support. You can also pay privately for counselling or psychological therapy.

Charities: Charities such as Maggie's Centre, Macmillan Cancer Support, Young Lives versus Cancer or your local hospice can also help in arranging therapy sessions for you and/or the whole family.

For information on different types of therapy and help in finding a local therapist, www.nhs.uk/mental-health

Young Lives vs Cancer

www.younglivesvscancer.org.uk

Helpline: 0300 330 0803

Provides practical support and advice for children and young people affected by cancer and their families.

Macmillan Cancer Support

www.macmillan.org.uk

Helpline: 0808 808 00 00

Provides practical and emotional support to anyone affected by cancer.

Maggie's Centres

www.maggiescentres.org

Local practical, emotional and social support for all those affected by cancer.

Advice on healthy eating and living

NHS Better Health

www.nhs.uk/healthier-families

Fun ideas, tips and advice to keep children healthy

NHS Live Well

www.nhs.uk/livewell

Health and wellbeing advice

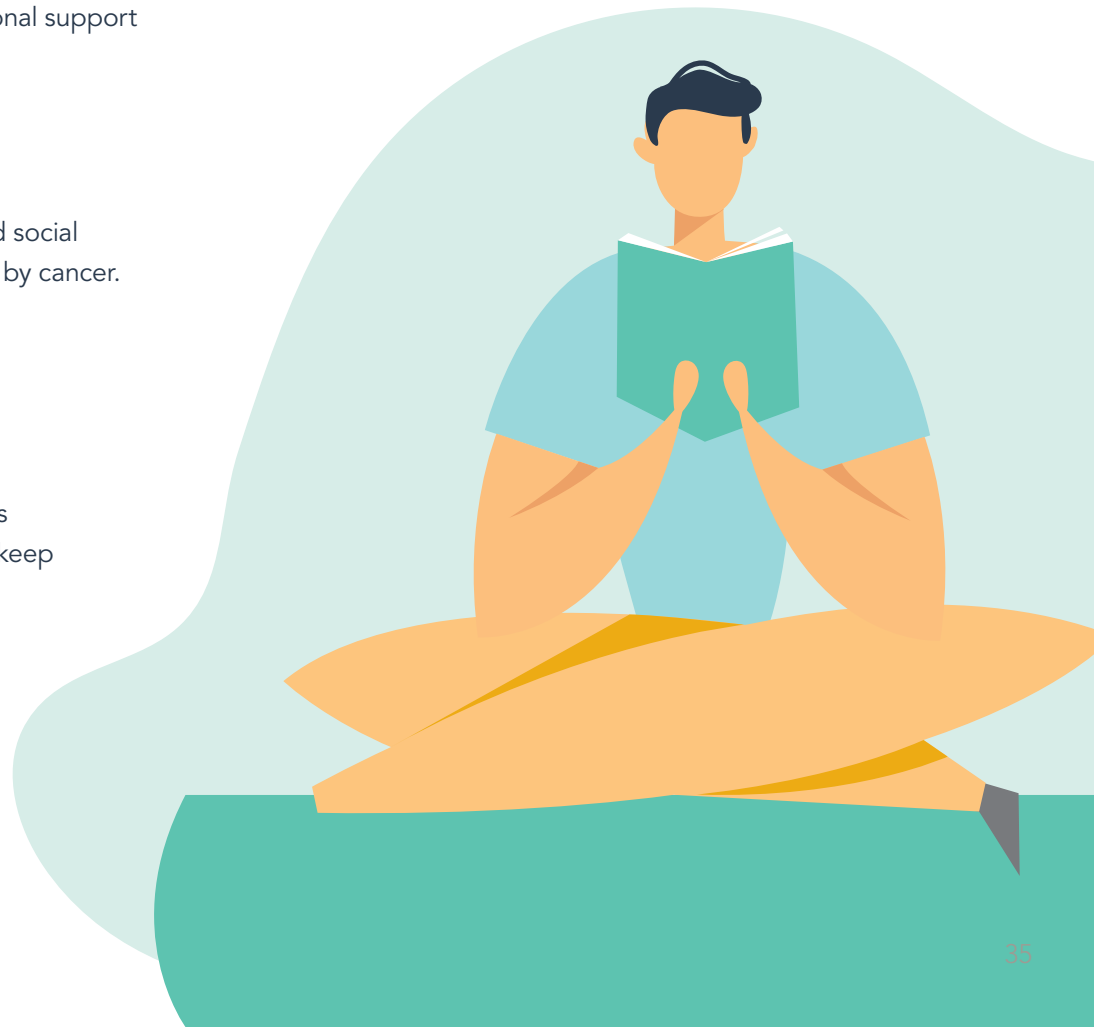
Suggested reading for parenting self-help books

Ain't misbehavin: How to understand your child and get the best from them

Laverne Antrobus (2007)

Calmer, Easier, Happier Parenting

Noel Janis-Norton (2012)





the EXPERTS
in CHILDHOOD
CANCER

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.

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

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.

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

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

 ChildrensCLG
 CCLG_UK
 CCLG_UK

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and Scotland (SC049948).

