



# My child has finished treatment

What happens next? A guide for parents



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## Contents

<b>Practical issues</b>	<b>5</b>	<b>Practical issues at school</b>	<b>17</b>
- What happens at the end of treatment?	5	- What about returning to school?	17
- When can the line/port come out?	5	- What happens if my child is in contact with chickenpox or shingles?	17
- What happens if a blood test is needed when the line is out?	5	- What happens if my child is in contact with measles?	17
- What happens at follow up visits?	5	- Can my child join in PE and swimming?	18
- Will more immunisations be needed?	6	- What about discipline/behaviour?	18
- What do I do if my child has a temperature/is unwell?	6	- Educational issues	18
- What should I look out for?	6	- What increases the risk of educational problems?	19
- Who can I contact if I am worried?	6		
- Is there anything my child can't do?	9	<b>Moving on</b>	<b>20</b>
- Why does my child feel tired?	9	- Healthy living after treatment	20
- What about puberty and fertility?	9	- What about vitamin supplements?	20
- Is follow up forever?	9	- What about exercise and physical activity?	20
		- What happens when my child reaches 18?	22
<b>Feelings/emotions</b>	<b>10</b>	- What is transition?	22
- Is it normal to have mixed emotions?	10		
- Why am I thinking about the past/diagnosis?	10	<b>Specific challenges</b>	<b>23</b>
- Why don't I feel like celebrating?	11	- If your child has had a donor stem cell transplant	23
- Dealing with fears of the cancer coming back	11	- If your child has had a brain or spinal tumour	23
- Where did everybody go?	12		
- Sources of support	12	<b>Follow-up</b>	<b>24</b>
- Coping with coming back to the hospital	14		
- Coping with special occasions	14	<b>Useful information</b>	<b>27</b>
- Talking to your child about the illness	14		
- Brothers and sisters	15		
- Finding a 'new normal'	15		



For many parents, reaching the end of treatment can bring mixed emotions. This is probably the moment you have waited for since hearing the diagnosis. You may feel happy and relieved that your child is better, but you may also feel anxious that the cancer may come back; it can be a very unsettling time. We hope this booklet will help answer some of the questions you have at this time and support you through this period of readjustment. 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.

## Practical issues

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### What happens at the end of treatment?

When your child first finishes treatment they will be seen frequently in clinic. How often varies between treatment centres, but is usually every 4-6 weeks during the first year. At the very beginning they may still be seen every 1-2 weeks.

As time goes by the length between visits usually increases to every three months in the second year, until by the time five years have passed your child may only need to be seen once a year.

Your child will probably continue to be seen in a follow-up clinic for many years after all the treatment has finished. They may see the same team of doctors and nurses they knew during treatment although they may transition to a late effects service run by staff who treat adults. If your child was treated at a Shared Care Centre they may still go there for some follow-up visits.

### When can the line/port come out?

As soon as possible after treatment is finished and any scans or tests have been completed. Some children being treated for leukaemia or lymphoma may have their lines removed before treatment finishes. The line or port will be removed under a general anaesthetic, so your child will need to attend hospital as a day case. Having a line removed is less urgent than having a line inserted, so your child may be placed on a waiting list for this operation.

### What happens if a blood test is needed when the line is out?

No one likes blood tests but unfortunately they 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 play specialist may be able to work with the child to help them cope with the blood test.

### What happens at follow-up visits?

The main purpose of a follow-up visit is so the doctor can give your child a general check up and arrange any tests they think are needed. Your child will be weighed and measured at each visit, to check they are growing normally. Blood counts are checked until they have returned to normal, possibly longer if your child had leukaemia.

Initially these will be to check that there are no signs of the cancer coming back. The frequency of scans, including heart scans, X-rays and other investigations will depend on the treatment your child has had. Your doctor will explain this in more detail. As time passes the visits increasingly focus on making sure that any long-term side effects of the treatment are found and, if necessary, treated. The chance of cancer returning lessens as time passes. See pages 24-26 for more details about possible follow-up tests.

## Will more immunisations be needed?

Yes, most children will need to have their baby immunisations repeated six months after finishing treatment. This is especially important if they had high dose therapy or a donor stem cell transplant (see page 23).

## What do I do if my child has a temperature/is unwell?

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 is perfectly natural and will hopefully reduce over time.

In the first few weeks after treatment stops, your child may still be neutropaenic, 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, it is usually best to see your child's GP first. They can decide if you need to go to the hospital.

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 chicken pox or measles, they will still need to take these during this period - see the section on school (page 17).

## What should I look out for?

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

- many bruises at the same time that couldn't have been caused by normal activity (all children get some bruising),
- repeated headaches/vomiting that are 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.

If you are worried about any symptoms your child has, contact your child's treatment centre (see below).

## 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 the Macmillan/CLIC Sargent or other specialist nurse who you had contact with during treatment. 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 can't do?**

A few children are left with disabilities as a result of their cancer or treatment and may not be able to do all they could before, but generally your child should be encouraged to return to normal activities, as soon as they feel or are able to. If your child has been left with a disability, returning to life as before can be very difficult.

### **Why does my child feel tired?**

Some children feel very tired after certain treatments but the majority 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 assist the 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 quite 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 was diagnosed. It is often very hard to remember everything that was said at the beginning so ask the doctor again if you can't remember.

During treatment you may have been given a booklet called 'Children and young people with cancer: A parent's guide'. This booklet has a section on puberty, fertility and other possible long term problems.

### **Is follow-up for ever?**

This depends on a number of things, including the treatment your child had. Follow-up often goes on for many years due to effects being long-term, or presenting some time down the line. It may be necessary to have heart scans or occasional blood tests. Details of some of the tests that may be necessary to check on any long-term side effects are found on pages 24-26.

## Feelings/emotions

### Is it normal to have mixed emotions?

Most parents whose child is approaching the end of treatment feel relieved that the treatment has worked, and that 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.

But for many parents this relief is mixed with other feelings. Parents may also have time to think about the impact on practicalities such as work, 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. At last parents have time to themselves, but that time may become filled with thoughts of what the family has been through and what the future might hold.

### Why am I thinking about the past/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 diagnosis, many are in a state of shock, and there are often very 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 may be available if parents are struggling to cope.

“ I feel on top of the world. We made it! Maybe a little nervous, but mostly excited about our family's future. We can now make plans without worrying about blood counts or hospital visits. Yippee! ”

(Tara, mother of Finlay, diagnosed with ALL)

### Why don't I feel like celebrating?

Parents often find that friends and families are overjoyed that 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 that he's finished his chemo?" Yet most parents find that their own reactions are much more cautious. Many parents say that they cannot allow themselves to feel joy at having reached the end of treatment. 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. The section below talks about coping with these fears.

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 that 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.

### Dealing with fears of the cancer coming back

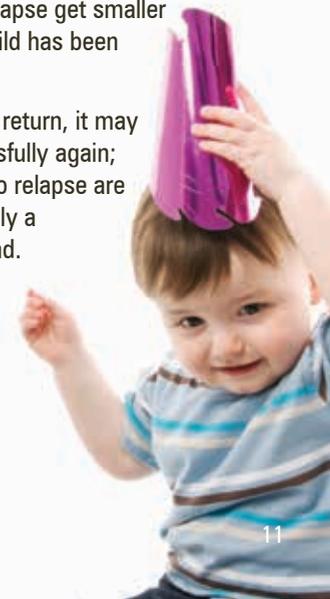
Parents often tell us that the end of treatment feels like the removal of their child's safety net. While the treatment is being given, families feel that everything possible is being done to beat the cancer. No-one can tell you that the disease will

not return. Parents sometimes feel that they would prefer their child to remain on low dose chemotherapy for life, if it could guarantee that the disease would not return.

It is important to remember that your child's treatment was very carefully designed. Most childhood cancer treatments have been changed regularly over the last 30 years. Each change is the result of research that has shown how cure rates could be improved or side effects reduced. Your child has received a very carefully calculated amount of treatment. There is no evidence that any more treatment will help.

Some parents are able to put thoughts of relapse to the back of their minds. Others find that 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 never recur.
- 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.



## Where did everybody go?

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

Parents sometimes find that 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 that you still feel. With a little explanation, or perhaps by lending them this booklet, friends and relatives can be helped to appreciate the fact that you still have concerns and what some of these may be.

## Sources of support

Some people find the end of treatment a positive time when they need much less support. But for others it is very 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 can help to make your own thoughts clearer. Some parents, however, find that it is helpful to have some time to themselves.

You may find that some of these people can be helpful:

### Friends/family members

Whilst your child is on treatment it is sometimes hard to maintain all your friendships. At the end of treatment the friends that have remained will hopefully continue to support you.

### Professionals from your treatment centre

The staff you met during treatment will be aware of the difficulties parents and young people face at the end of treatment. Do let them know if you feel you need some extra support at this time.

### Support groups and counsellors

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 (see contact details at back of booklet).

The organisations listed at the back of this booklet will also be able to guide you to what counselling services are available in your area. Your GP may also be able to provide support and advice.



## Coping with coming back to the hospital

Coming back to the hospital for check ups can be stressful. Some parents say that they feel increasingly anxious as the day of the appointment gets closer. Similarly, many parents feel much more relaxed afterwards 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 your child is well.

Your child may not understand why they need to come back to hospital. Coming back to the hospital brings 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 that parents hear news of children that 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 that their own child is ok. It is always important to remember that even when children have the same diagnosis, each child's illness is unique. Do ask to speak to someone about your concerns if you feel this would be helpful.

## Coping with special occasions

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 that they can reach a balance between being grateful that their child is free from cancer and the sadness over the inevitable losses that the experience has brought.

## Talking to your child about the illness

As your child grows up the amount of information they need about their illness and its treatment increases. 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. Many children will learn about their illness from comments from older siblings, cousins or 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.

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

It is also important that your child knows about their illness so that they understand why they still need to come to clinic for appointments even when they are well. The section on transition on page 22 explains more about this.

## Brothers and sisters

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

## Finding a 'new normal'

Although life will never 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 this involves returning to nursery or school and, as much as possible to a full range of leisure activities.

For parents this may be getting back to normal activities, be that at work or home. For some parents returning to work 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 involve 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 very positive message to all children that things are better now. 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.

“ It's not about finding normal, it's about making a new normal. ”

(Clare, mother of Mason, diagnosed with Hepatoblastoma)





## Practical issues at school

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### What about returning to school?

School plays an important role in helping a child maintain a normal routine and stay in touch with friends during and after treatment.

Attending school provides 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 their attendance may have been interrupted, and 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 that 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 that 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 that appropriate action can be taken. After that there is no need to worry about any measles contact.

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

## Can my child join in PE and swimming?

Yes. Your child should be encouraged to join in physical activity at school. Exercise is important for healthy living and unless there are any obvious reasons why your child cannot be physically active, a daily amount of exercise should be encouraged.

Once your child's central line has been removed and the wound has healed there is no restriction on swimming.

You may find the CCLG booklet 'Sport and Exercise for Children and Young People with Cancer: A Parent's Guide' helpful.

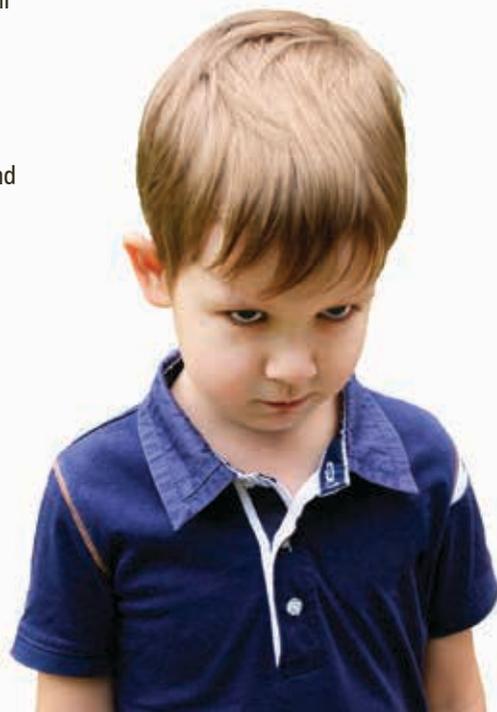
## What about discipline/behaviour?

After treatment, some children may take a little time to adjust and occasionally feel anxious or worried about school. They may become more tearful or express their frustrations in anti-social 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.

## Educational issues

Most children who have had cancer treatment will have no educational problems at all. For some children, intellectual development may be affected by their cancer or their treatment. One reason may be due to reduced energy levels experienced during treatment and their prolonged absences from school. In addition, some cancers may have required treatment to control or prevent spread of the disease to the brain and/or spinal cord. This treatment can sometimes affect memory and learning abilities. Some parents and teachers report issues to do with lack of concentration. Informing teachers of the possible problems that may arise from this treatment means that where this is a possibility, children can be watched closely and given extra help if needed.



## What increases the risk of educational problems?

The following can sometimes increase the risk of educational problems:

- a history of learning problems before the diagnosis of cancer,
- frequent or prolonged school absences,
- treatment that has affected hearing or vision,
- treatment that results in physical disabilities,
- treatment that includes the brain and spinal cord.

Children who have had a brain tumour are more likely to find that learning and memory may be affected. The brain is a very complex structure that continues to grow and develop throughout childhood and adolescence. Some problems may not become noticeable until years after treatment is finished. Ensuring teachers are aware of this and carefully watching your child's progress at school will mean that extra support can be put in place if necessary. This extra help and support will help make sure your child reaches their full educational potential.

As your child moves further into the follow-up period, it will be important for teachers to keep a close eye on their progress and to assess if any specific testing is required.

Children with cancer have had experiences and knowledge that most children of their age will not have had. They can have developed early maturity in some areas.

If you have any problems or need help and support when your child goes back to school, please ask your Macmillan/CLIC Sargent or other specialist nurse, or another member of the hospital team.

“ The thought of returning to school after 3 months of treatment was one of the most difficult things for Olivia. The School and Oncology Nurse helped enormously by speaking to the students, giving them advice on how to handle her return. Within a week of being back, Olivia said she felt as if she'd never been away! ”

(Jo, mother of Olivia, diagnosed with Hodgkin's Lymphoma)

## Moving on

### Healthy living after treatment

Now that your child is off treatment and is in the 'follow-up' phase, the aim is to help your child stay as healthy as possible and reach their full potential.

The effects of childhood cancer and treatment on appetite and physical activity are different for each child. If your child experienced problems with nutrition and maintaining a healthy weight during treatment, you may have given them food supplements and been encouraged to give them calorific foods. On the other hand some children being treated for leukaemia may have gained a lot of weight during treatment.

Now that treatment is completed, it is a good time to look at your child's diet, to ensure it's healthy, and their physical activity. 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 very reassuring to see. However, in order for them to maintain a healthy body in the future, returning to a healthy diet and physical activity is very important. These choices can have a positive effect on your child's health for many years to come.

A good diet and physical activity will have many benefits for children who have had treatment for cancer. These include:

- helping to heal tissues and organs that have been 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 well-being.

A balanced healthy diet is based on the five commonly accepted food groups which are:

- bread, cereals and potatoes,
- fruit and vegetables,
- milk and dairy,
- meat, fish, pulses and nuts,
- foods containing fat, and food and drinks containing sugar. (Foods in this fifth group are not essential to a healthy diet).

### What about vitamin supplements?

Vitamin supplements are not a replacement for good eating habits. Encouraging your child to have a variety of foods from the first four groups of food every day will help ensure they have the wide range of nutrients and vitamins their bodies need to remain healthy and function properly.

### What about exercise and physical activity?

Children and adolescents should be encouraged to try to fit some physical activity into their daily routine.



It is important to combine healthy eating with physical exercise.

In general, a healthy lifestyle includes: not smoking; eating a low fat, high fibre diet; exercising regularly and avoiding an excessive alcohol intake.

Protect children from sunburn using cover-up clothing and a high factor sunscreen.

### What happens when my child reaches 18?

All children who complete their treatment for cancer need to attend follow-up clinics regularly in order to identify, assess and treat problems that may arise. Some children will have few problems in the follow-up period; others may need more help including both physical and psychological support.

Problems related to cancer treatment that occur or persist when treatment is finished are known as 'late effects'. Follow-up care will continue well into your child's adult life.

If your child is very young when they finish treatment, adolescence and adulthood may seem a long way off. However, as adolescence approaches, your child will grow physically and emotionally. They need to be supported in developing as much independence as possible in order for them to be able to make choices about their own healthcare.

### What is transition?

In some cancer centres, young adults who were treated for cancer as a child and have been off treatment for over five years, are now having their follow up visits in an adult hospital. The process of helping these young people as they move from the familiarity of the child and family environment of paediatrics to being cared for in an adult hospital clinic is called 'transition'.

You can help this process when your child is young by:

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

So they feel ready to move on they will also be supported by doctors and nurses in clinic:

- in understanding their cancer, treatment and follow up,
- in gaining more independence and starting to make their own decisions,
- by giving them health care advice.

Adolescent and adult long-term follow-up care will vary in each cancer centre. If you require any further information on 'transition', your own doctors/nurses will be able to inform you.

The CCLG publication 'Aftercure' provides additional useful information.

## Specific challenges

### If your child has had a donor stem cell transplant

The contents of this booklet will hopefully be helpful to you whatever form of childhood cancer your child has been treated for. However, for children who have had a donor stem cell transplant, some aspects of their recovery will be different.

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:

- the 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/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 has had a brain or spinal tumour

For some children the damage caused by their cancer causes more problems than the treatment. Where a child's tumour has affected their physical activity, their mental abilities or personality, the end of treatment may not feel like an important milestone.

Of course parents of these children still have fears about relapse and the challenge of adjusting to a new normal life. However, they also have to adjust to the limitations their child faces. For children who have had radiotherapy to their brain, it may be hard to know how treatment will have affected the child until several years later.

Parents in this situation need emotional support and practical help to ensure their child enjoys life and achieves as much as possible. The organisations listed at the back of this booklet can give extra guidance if you are in this position.



## Follow-up

The majority of children won't have any long-term effects. Where these do occur, they happen because of the damage cancer treatment can cause to healthy cells in the body. These effects can occur as a result of surgery, radiotherapy, some chemotherapy drugs and bone marrow transplants. Most problems result from chemotherapy or radiotherapy. They depend on four things:

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

The long-term effects may include problems with growth and development, heart, lung and kidney function, and fertility.

### Growth

At the clinic your child will be regularly weighed and measured to check that they are growing normally. Decreased growth during treatment is common. There is usually a period of 'catch up' growth when treatment finishes. Radiotherapy may have important effects on growth and development. It may affect growing bones, e.g. radiotherapy to the spine can mean your child will not grow as tall as expected or, if given to an arm, it might be shorter than expected.

Radiotherapy to the brain may affect the pituitary gland which produces many hormones, including growth hormone. If your child does not produce enough growth hormone they will not grow properly and

may need to have some special tests. If there is a problem they will be referred to an Endocrinologist (specialist in growth and development). Sometimes a daily injection of man-made growth hormone is needed to help your child grow. Sometimes other hormones are affected, for example thyroid hormone and cortisol. These can be replaced with tablets.

### Puberty (sexual development)

Certain treatments may affect your child's sexual development (puberty). These include:

- radiotherapy to the brain,
- radiotherapy to the lower abdomen or pelvis, including the ovaries and testicles,
- total body irradiation (TBI) for a bone marrow transplant,
- certain chemotherapy drugs,
- surgery to the ovaries, womb or testicles.

All children are monitored carefully at the follow-up clinic for signs of puberty, especially if they had any of the treatments mentioned above. If there appears to be any delay going into puberty some investigations will be done. Sometimes sex hormone therapy may be needed to help to start sexual development. If there are problems they will be referred to an Endocrinologist.



## Heart and lungs

Some chemotherapy drugs and radiotherapy can affect the heart and lungs. If your child had these they will have had heart ultrasound scans (echocardiograms) during treatment and these will continue occasionally, about every three to five years, after treatment ends. 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 special tests on the lungs (lung function tests). This is usually following radiotherapy to the lungs or total body irradiation (TBI). These tests involve measuring lung volumes and are easy for a child to do.

## Kidney tests

Removal of 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 special 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 important to have their blood pressure checked; this is usually done routinely at the clinic visit. If your child's kidneys are working well at the end of treatment they should not develop problems in the future.

## 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 that 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 each child had 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 special risk of developing certain cancers. This is very rare. Your doctor or nurse specialist will be able to discuss any worries you have about this.

## Useful information

The following may be useful sources of information and support for childhood cancer survivors.

### Organisations

#### Children's Cancer and Leukaemia Group

[www.cclg.org.uk](http://www.cclg.org.uk)

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

#### Childhood Cancer Parents Alliance

[www.ccpa.org](http://www.ccpa.org)

#### CLIC Sargent

[www.clicsargent.org.uk](http://www.clicsargent.org.uk)

#### Macmillan Cancer Support

[www.macmillan.org.uk](http://www.macmillan.org.uk)

#### Teenage Cancer Trust

[www.teenagercancertrust.org](http://www.teenagercancertrust.org)

### Websites

#### Aftercure

[www.aftercure.org](http://www.aftercure.org)

Includes useful links and online factsheets on late effects.

#### Beyond the cure (US site)

[www.beyondthecure.org](http://www.beyondthecure.org)

### Booklets

**Aftercure:** A guide for teenage & young adult survivors of childhood cancer (CCLG, 2014)

#### Childhood Cancer Survivors

Nancy Keene, Wendy Hobbie & Kathy Ruccione (US Childhood Cancer Guides, 2012)

**Relationships, sex and fertility for young people affected by cancer** (Macmillan, 2012)





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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If you have any comments on this booklet, please contact us at the address above.

CCLG booklets are available to download from our website.