



My child has finished
cancer treatment

What happens next?

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About this book

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 your child or teen has completed their treatment, but you may also feel anxious 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.

When treatment finishes



What happens when your child finishes treatment?

Medical matters

- Your child's line or port will be removed as soon as possible, under general anaesthetic, 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 operation.
- 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.
- Your clinical nurse specialist will support you and your child through the early years after treatment has finished.
- Your child in time will transition to adult services and will be supported in the transition by doctors and nurses working with adolescent and young adult cancer patients.

Paperwork

- You will be given a treatment summary outlining all the treatments your child received, including the names of any chemotherapy drugs used, surgical procedures they had, and radiotherapy received. Keep this treatment summary somewhere safe as your child may need to know the details of their treatment sometime in the future. For example, if they are having medical treatments or as part of a pre-employment health check when starting a new job.
- A discharge summary is shared with your GP detailing treatment received, follow-up care and whether extra support is needed. This is updated if further follow-up treatment is needed.

What is follow-up care?

Once active treatment finishes, it can be reassuring to know your child will move onto a long-term follow-up plan designed to support your child as they grow and develop. They will still be seen in the clinic and the frequency will depend on how much time has passed.

At the beginning, this may be every 4-6 weeks. As time goes by, the length between visits usually increases to every 2-3 months, then every 6 months. By the time five years have passed, your child may only need to be seen once a year or even less.

At the beginning, the main focus of follow-up 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.



As time passes, the chance of cancer returning lessens. Clinic visits increasingly focus on making sure any long-term side-effects of treatment are found early and treated quickly if necessary. These are often called late effects and can happen some time after treatment has finished, which is why your child will probably continue to be seen in a follow-up clinic for many years – possibly for the rest of their life. While this may sound daunting at first, it is important to make sure your child is fully supported after treatment has finished so any concerns are flagged up straight away. Your child may need to be monitored with specific scans or occasional blood tests (see page 35 for more details).

Your child will have access to the hospital unit while they still have their Hickman line in. Once this is removed and their immune system has recovered, you will go to your GP first if your child needs medical care between hospital appointments.

Longer term issues can occur following cancer treatment. Your treating consultant, supported by the clinical nurse specialist, follows up on your child – dealing with any late effects that might occur – until they transition to adult services. The team has access to specialists in endocrinology and cardiology, and allied health professionals as needed.



Follow-up is an ideal chance to talk through any concerns you may have about your child – whether physically or emotionally – with the medical 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.

Parent FAQs

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 clinical nurse specialist (CNS) who you had contact with during treatment. They can advise you or arrange for someone else to contact you. You can also call our Support Line on 1800 200 700 and ask to talk to our Children's Cancer Nurse.

What do I do if my child is unwell 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 (low neutrophil white blood cell count), or still have a central line and will need to go 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 6 months after treatment. If they previously needed to take extra medicines when they came into contact with chicken pox or measles, they may still need to take these during this period. Talk to your medical team about this. See also 'Practical issues at school' on page 27.

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:

- A lot of bruises that can't be explained (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

Will my child need more immunisations?

Yes, most children will need to have their childhood immunisations (vaccinations) repeated about 6-12 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.*



Is there anything my child shouldn't do?

Generally, your child should be encouraged to return to normal activities as soon as they feel or are able to. 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. If your child has been left with a disability, returning to life as before can be difficult. You will be supported by your child's healthcare team in this case.

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. The school should help with your child's reintegration and support them to join in as many activities as possible. Each child is different, but in time most children get back to school full time and are able to join in with sports and other activities.

What about puberty and fertility?

Following treatment, most children go into puberty quite normally. 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 they were diagnosed. It is often very hard to remember everything that was said at the beginning. Ask the medical 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. This is called transition. There is no single right time for this to happen and a flexible approach is used, depending on the time since diagnosis, current health of the patient and their physical and emotional maturity. Sometimes transition can take place after the age of 18, if they are still on treatment, for example, for acute lymphatic leukaemia (ALL). Transition for this group would happen when the treatment is completed.

Transition does not happen immediately but is a planned, coordinated process where your child will be prepared over a period of time, given all the information they need and be introduced to their new adult team to make sure there is continuity of care.

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

- Talking to your child to help them understand more about their cancer and treatment
- Explaining the reasons for them going 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
- Give them healthcare advice



If you require any further information on transition, please discuss this with your medical team.

Dealing with emotions and feelings



Is it normal to have mixed emotions?

Most parents whose child is approaching the end of treatment feel relieved the 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 may also have time to think about practical matters such as work, their child's education and finances, which may have been put on hold during treatment. Families are often exhausted after months or years of treatment.

Parents sometimes feel they swap the worry about cancer and treatment 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.

"At the end of treatment, my husband and I thought '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."

The Irish Cancer Society provides information and support to people affected by a child or adolescent cancer diagnosis.

- Contact a Children's Cancer Nurse through the Support Line Freephone 1800 200 700
- Email supportline@irishcancer.ie



Why am I 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 diagnosis, 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.

Call our Support Line or visit a Daffodil Centre if you would like to talk to our cancer nurses. They can also refer you for free counselling, funded by the Irish Cancer Society.

Why don't I feel 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 chemo?" 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 if it feels right to you.

Where did everybody go?

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 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 parents have much less access to these sources of support, often at a time when they really need it.

Call our Support Line on Freephone 1800 200 700 if you would like to be put in touch with a parent volunteer who has had a child with cancer and understands how you are feeling.

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 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.

I am 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 the 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. They have received a very well calculated amount of treatment. There is no evidence any more treatment will help. If you are struggling with fears about relapse, it can be helpful to remember:

- Most childhood cancers never come back (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

Coping with anxiety about follow-up appointments

Going 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. 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 go back to hospital, so explaining in a way they can understand is important. Going 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 okay.

It is always important to remember that even when children have the same diagnosis, each child's illness is unique.

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 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.

I don't feel like I am coping

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 at some time in the future.

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 symptoms such as 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. Sometimes, the strongest thing to do is to ask for help (see page 26).

Getting advice

If you would like to get information and advice on coping with a child's cancer and your feelings after treatment, you could speak with our Children's Cancer Nurse by calling the Irish Cancer Society Support Line on 1800 200 700 – Monday to Friday, 9am to 5pm, or email supportline@irishcancer.ie.



You might also like to be put in touch with a trained parent volunteer whose child has had cancer.

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 unwell and it can be hard to be out of the 'spotlight'.

Also, 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 be hard to get things back to normal. 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.

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.



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.

Possible age-specific issues after treatment

You may experience some issues with your child after treatment – depending on their age.



Babies

Babies will have little understanding of their cancer treatment. They may, however, be quite clingy when visiting the clinic for follow-up appointments. You can help your baby by giving them lots of cuddles and reassurance during these visits.

Toddlers/Preschoolers

Very young children will have some understanding of their cancer treatment. However, you may find that they regress during treatment with their behaviour becoming more difficult, refusing to toilet train, having more temper tantrums and feeling anxious when separated from parents.

Sometimes role play can be helpful – by pretending to be doctors and nurses, you can help children work through their experiences.

Also, returning to the clinic may not always go smoothly at first but they may begin to look forward to visiting friends at the clinic over time.

While you may have constant worries about your child, try to allow them to be as independent as possible and explore the world. Also, try to be consistent with your parenting and discipline, as this will help them to adjust to normal life.

School-age children

For children going to school, body image issues such as hair loss and weight gain can make them feel insecure. In time, they will become more confident as things return to normal.

Friendships can also be a real issue at this age, and old friends may have stopped playing with your child. Encourage your child to participate in activities and try new things. This way they may make new friends.

Keep in regular contact with the school and discuss any concerns you may have.

Teenagers

Facing cancer and its aftermath can be difficult for teenagers, as they are also coping with the usual issues of being a teenager. They may become withdrawn or depressed. Or they may become angry or rebellious, although these are also normal teenage behaviours.

They can become very anxious about the possibility of relapse, or sometimes they will deny the seriousness of the illness by taking risks.

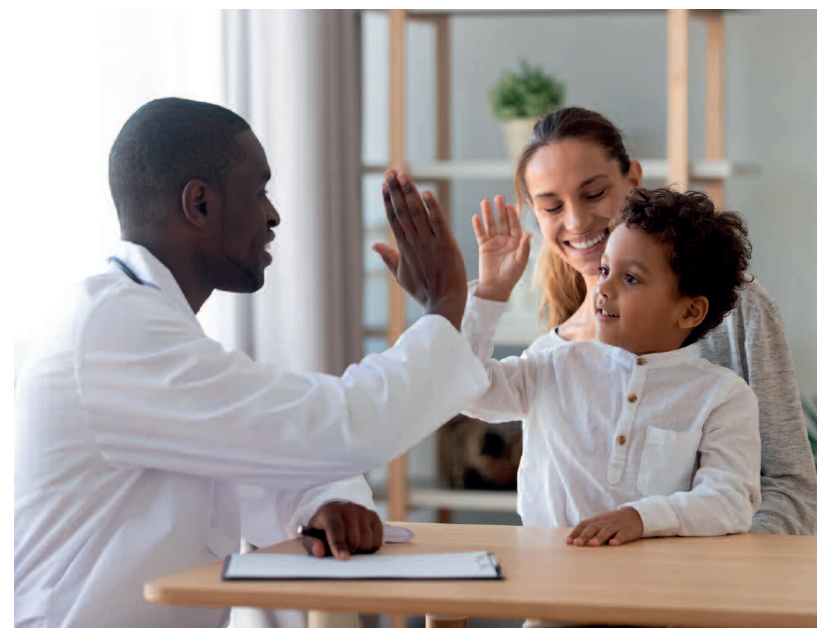
Encourage your teenager to talk to you about how they are feeling, be non-judgemental and open to listening to them. They may want to put the whole thing behind them and even try to delay or cancel follow-up appointments.

Help your teenager to work towards their future but also help them to understand their healthcare needs to continue and is not optional.

CanTeen Ireland is a nationwide support group for young people who have or have had cancer, see www.canteen.ie.



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 by 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.



Children will miss their doctors and nurses and the bonds they formed with the people who helped them through this time, and returning to the clinic means they can see them again. 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.

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 after treatment.
- 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. These can include clear rules of behaviour with lots of emphasis and rewards when goals are reached, and as little attention as possible to unwanted behaviours.

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. If you would like to talk to a professional counsellor, call our cancer nurses on 1800 200 700 and ask about free counselling.

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.

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 26). 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 a cancer diagnosis and treatment on brothers and sisters. They will probably have the same fears and concerns that you have, 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, which they can hide for fear of upsetting parents further. If you feel your other children are struggling, your child's GP or medical team can help by arranging appropriate support for siblings. Some cancer support centres offer professional counselling, while some children's charities offer specially designed supports for children with a serious illness and their families. See page 44 for more about cancer support services.

"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, 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 such as returning to work. For some parents, meeting other parents on school runs or going 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 workplace 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 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 may need to seek advice about insurance.

Sources of help and 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 open and honest about how you are feeling. Talking can help to make your own thoughts clearer. Some parents, however, find it is helpful to have some time to themselves.

You may find some of these people can be 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, the friends that have remained will hopefully continue to support you, even if it's just a friendly chat over coffee.

Your child's medical team: The staff you met during treatment will be aware of the difficulties parents and young people face at the end of treatment. The medical social worker and clinical nurse specialist will be there to offer you emotional support as your child's treatment finishes.

Local cancer support services: The Irish Cancer Society works with cancer support groups and centres across the country to ensure people affected by cancer have access to confidential support, including professional counselling. This includes parents of children diagnosed with cancer and some have services for children and siblings (see page 44).

Irish Cancer Society: The Irish Cancer Society cancer nurses can be contacted on our Support Line 1800 200 700 or by email on supportline@irishcancer.ie. Alternatively, you can drop into your local Daffodil Centre. Other support services include an online community and peer-to-peer support, see pages 40-44 for more details.

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.

Practical issues at school



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 information is given to the school relating to any medical issues still affecting your child. Your specialist nurse may 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 about 6 months* after treatment finishes, until their immune system has recovered. 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.

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

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. Your child should be encouraged to exercise for at least one hour per day as recommended by experts, unless there are any obvious reasons why they cannot be physically active. 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 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. Also, some cancers may have needed treatment to the brain and/or spinal cord, which can sometimes affect memory, learning abilities, and ability to concentrate. Some problems may not be noticed until years after treatment is finished. Informing teachers of the possible problems that may arise from this treatment means that children can be watched closely and given extra help if needed.

These can sometimes increase the risk of educational problems:

- Child's history of learning issues before the diagnosis of cancer
- Low energy levels and tiredness
- Lots of long school absences
- Hearing or vision affected by treatment
- Physical disabilities from treatment
- Treatment to the brain and spinal cord



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 problems or need help and support when your child goes back to school, please talk to a member of your child's medical team at the hospital.

Healthy living after treatment



Living a healthy lifestyle

It is important to help your child stay as healthy as possible and reach their full life potential. The effects of childhood cancer and treatment 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, needing extra supplements and high-calorie foods. Some treatments, like radiotherapy or high-dose steroids, are more associated with weight gain. This 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. This will be very reassuring to see. 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.

Choosing a healthy lifestyle 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 well-balanced diet, exercising regularly, avoiding an excessive alcohol intake and protecting children from sunburn using cover-up clothing and a high-factor (minimum SPF30) sunscreen.

Specific challenges



If your child has had a donor stem cell transplant

Following a donor cell stem transplant, it can take longer 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

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, mental 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 more information call our Support Line on 1800 200 700 and ask for a copy of our booklet *Understanding brain and spinal cord tumours in children*.

Summary of follow-up tests and scans



Most children won't have any long-term effects. If they 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:

- **Type of treatment**
- **Site of treatment**
- **Dose of treatment**
- **Your child's age during treatment**



Late effects may include problems 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

At the clinic your child will be regularly weighed and measured to check 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, for example, radiotherapy to the spine can mean your child will not grow as tall as expected or a limb treated with radiotherapy may be shorter than the limb that has not been treated.

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 so may be referred to an endocrinologist (a specialist doctor in growth and hormones).

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. 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 investigations will be done. If there are problems, your child 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.

Depending on how much they receive will determine if these are repeated. These scans will carry on for the rest of their lives and for young women they 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 special tests on the lungs (lung function tests). This is usually following some types of chemotherapy, radiotherapy to the lungs and total body irradiation (TBI). These tests involve measuring lung volumes and are easy for a child to do.



Kidney tests

Removing 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 important to have their 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 how treatment affects fertility will depend on the type of treatment your child had.

Some female survivors of cancer, who were treated in CHI, Crumlin and are aged between 18 and 24, can have fertility assessment and subsequent tests and treatment if suitable. 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. Your doctor or nurse specialist will be able to discuss any worries you have about this.



Irish Cancer Society services



Our Cancer Support Department provides a range of cancer support services for people with cancer, at home and in hospital, including:

- Support Line
- Daffodil Centres
- Survivor Support
- Support in your area
- Night nursing
- Website information

Support Line Freephone 1800 200 700

Our cancer nurses can help you if you need information and advice on coping with a child's cancer, looking after yourself and practical support. Contact us and ask to speak with our children's cancer nurse or be referred to one of our trained parent volunteers.

The Support Line is open Monday to Friday, 9am to 5pm. Or email us on supportline@irishcancer.ie or visit our online community at www.cancer.ie

For the deaf community, our Support Line is using the Sign Language Interpreting Service (SLIS) using IRIS. Contact IRIS by text 087 980 6996 or email: remote@slis.ie



Daffodil Centres

Visit our Daffodil Centres, located in 13 hospitals nationwide. The centres are staffed by cancer nurses and trained volunteers who provide confidential advice, support and information to anyone concerned about or affected by cancer.

Who can use the Daffodil Centres?

Daffodil Centres are open to everyone – you don't need an appointment. Just call in if you want to talk or need information on any aspect of cancer including:

- Cancer treatments and side-effects
- Emotional support
- Practical entitlements and services
- Living with and beyond cancer
- End-of-life services
- Local cancer support groups and centres

You can email daffodilcentreinfo@irishcancer.ie or visit www.cancer.ie to find your local Daffodil Centre.



Peer-to-peer support

All of our trained parent peer-to-peer volunteers have children who have been treated for cancer in the past. They can give you emotional and practical support. For a referral, contact the Irish Cancer Society Support Line on Freephone 1800 200 700.

Website

See www.cancer.ie/cancer-information/cancer-children-teenagers for information on children's cancers, how to cope and a list of helpful services, including an interactive map.

Community-based cancer support centres

The Irish Cancer Society works with community-based cancer support centres across the country. The centres can support adults affected by a child's cancer diagnosis and some have services for children with cancer or children affected by a family member's cancer.

Call our Support Line on 1800 200 700 or visit a Daffodil Centre and our nurses will tell you what's available in your area and can refer you to a centre. They can also organise free counselling for you, your child or others affected by your child's cancer. The Society partners with organisations to fund the cost of counselling.

Your own notes

Your own notes

Your own notes



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Irish Cancer Society

43/45 Northumberland Road, Dublin, D04 VX65

T: 01 231 0500

E: info@irishcancer.ie

W: www.cancer.ie

Support Line Freephone 1800 200 700

Email: supportline@irishcancer.ie

Find us on Facebook

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