Irish Cancer Society

My child has finished treatment

What happens next?

My child has finished cancer treatment

What happens next?

Reading this booklet

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. 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.

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.

Contents

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 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 move (transition) to adult services and will be supported in this move 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 them 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 to make 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, or 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 59 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.

Follow-up is an ideal chance to talk through any concerns you may have about your child – whether physical or emotional – 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 completely normal 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 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 45.

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
- Feeling unwell for 2-3 weeks without a known cause

Will my child need more immunisations?

Depending on the treatment your child had and where they were in their vaccination schedule when they were diagnosed will determine if they need to be re-vaccinated. Your oncology consultant will discuss this in more detail and may require your child to have a blood test to see if they have kept their immunity during treatment.

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 ready and 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 or they may need to learn new ways to adapt. 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 sometimes called transitioning. 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.

The idea of moving to adult services should be introduced in the early teen years (up to around 14 years). This will give the child and their parents/guardians plenty of time to get used to the idea. The planning and preparing stage should happen when the young person is around 14-16. The actual move will probably take place between the ages of 16 and 18.

Sometimes, the move to adult services can take place after the age of 18, if they are still on treatment, for example for acute lymphatic leukaemia (ALL). The move for this group would happen when the treatment is completed.

The move does not happen immediately but is a planned, coordinated process where your child will be prepared over a period of time. They will be given all the information they need and be introduced to their new adult team to make sure there is continuity of care. For more information, speak with your medical team or see **www.steppingup.ie**

Moving to adult services can be a stressful time for both young people and their parents/guardians. You all probably know the oncology team very well and are nervous about having a new oncology team in a new setting. Your child will also become the main person the medical team communicates with, which might be difficult for everyone to get used to.

Adult services are very aware of the challenges and changes in the dynamics of how care is delivered and will be very supportive.

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. These thoughts and reactions are all normal.

> “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.”

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 they're finished their 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.

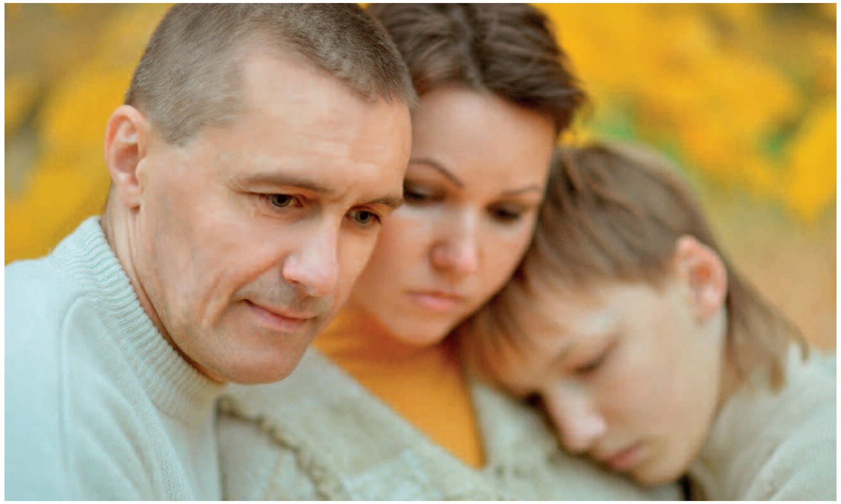
Others find planning a holiday or some other enjoyable event gives them something positive to focus on. Whatever you and your child choose will be right if it feels right to you.

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 Peer Support 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.

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 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 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 42).

Your child and their feelings

Behaviour

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 while 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.

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.

A child's behaviour can also be a reflection of what is going on in the wider family. 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 handling it with success.

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/pre-schoolers

- 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 healthcare to continue

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. 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.

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

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 pages 42 and 43 for more about cancer support services, including cancer support centres.

> “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!”

A ‘new normal’

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:** While 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 for 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 78).
- **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 support for parents. See page 73 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

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 to give the school information about 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.

What happens if my child is in contact with measles?

For the first 6 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.

Some patients, depending on their treatment plan, will need a blood test to see if they still have immunity. If their immunity has been lowered by treatment, they will need to get re-vaccinated with the MMR. Your child's consultant will be able to tell you if your child needs a blood test to have their immunity levels confirmed.

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

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 1 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.

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.

When it comes to Junior Cycle exams, Leaving Certificate exams and applying for third level education (college), your child may be eligible for extra supports, such as:

- **Reasonable Accommodations at Certificate Examinations (RACE):** This is aimed at students with disabilities, such as a hearing impairment, mobility issues or learning difficulties, who are doing the Junior Cycle or Leaving Certificate. This may apply to children if their cancer or cancer treatment has left them with a disability. Reasonable accommodations can include taking your exam in a hospital bed or having a scribe (someone else to do the writing) during an examination.
- **Disability Access Route to Education (DARE):** This is an alternative admissions route to third level for students whose disability or ongoing illness has had a negative impact on their education in secondary school. DARE offers reduced points places to school leavers who have experienced additional challenges in secondary school as a result of their disability or ongoing illness. Childhood, adolescent and young adult cancer has been included in the scheme since 2023.

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 behaviours, such as smoking, drinking alcohol, taking drugs and underage 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. Setting SMART goals can help with this:

- **Specific:** Set a clear goal such as 'I will walk outside every day'
- **Measureable:** Make it measureable 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 well-balanced diet, exercising regularly, avoiding excessive alcohol intake and protecting yourself from sunburn using cover-up clothing and a high-factor (minimum SPF30) sunscreen.

Good dental hygiene and regular visits to the dentist are also important. Cancer treatments like chemotherapy and radiotherapy can affect a child's developing teeth.

It is also important that your child has any vaccines recommended to them, such as the HPV vaccine and the flu vaccine. Cancer can weaken your child's immune system so some vaccines may not be suitable for them. Check with the doctor about which vaccinations are recommended for your child and make sure to get them.

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 cord 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 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.

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

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. Around 2 out of 3 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

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).

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 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.

- **Boys** – 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.
- **Girls** – 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.

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. For those who become pregnant later on, scans 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 type 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 are treated differently and how treatment affects fertility will depend on the type of treatment your child had.

Your child's medical team can speak to you about how cancer or cancer treatment may impact their fertility, as well as any options that may be open to them.

Your child may be able to avail of the Childhood Cancer Fertility Project, which is a partnership between the Irish Cancer Society and Merrion Fertility Clinic. It offers free fertility preservation and other services to young people with a cancer diagnosis, including:

- Children who have yet to reach adolescence
- Female survivors of childhood cancers aged between 18 and 27

For more information, speak to your child's medical team who can discuss this further with you, or contact our Support Line on 1800 200 700. You can also read more about the background and aims of the Childhood Cancer Fertility Project on our website, **www.cancer.ie**

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

Money matters

- If your child had cancer, you may not have been able to work for a time. You may also have had extra expenses.
- You might be entitled to certain social welfare payments.
- There are services to help you if you're finding it hard to manage.

A diagnosis of cancer in the family often means that you have extra expenses, such as medication, travel, heating and childcare costs.

Practical and financial advice from the Irish Cancer Society

We provide individualised financial and practical advice for people living with cancer. This includes:

- **Understanding your welfare entitlements**
- **Advice on accessing extra childcare**
- **Telling your boss about your child's diagnosis**

We can tell you about the public services, community supports and legal entitlements that might help you and your family. We can also act as advocates for patients and their families who may need extra support. This might include having a Practical and Financial Officer present when discussing your child's diagnosis with your employer or financial provider.

To be referred, call our Support Line on Freephone 1800 200 700 or contact your nearest Daffodil Centre. Our nurses will chat with you and confirm if a discussion with one of our Practical and Financial Officers might help.

Medical expenses

How much people pay towards their medical expenses depends on whether they qualify for a medical card or not and what type of health insurance they have, if any.

All children who have been diagnosed with cancer within the last 5 years can get a medical card. This is not means tested. In other words, the parents' income will not be taken into account. A medical report from the child's GP or hospital doctor is required.

More information on this is available on **www.hse.ie**

A medical card will cover the costs of care in the public health system. If you opt for private healthcare for your child and you have health insurance for them, your insurance company will pay some of the costs, but the amount will depend on your insurance plan. You should check with your insurance company to see what your child is covered for.

Benefits and allowances

There are benefits that you may be entitled to, such as Carer's Allowance, Carer's Benefit and Carer's Leave.

If you want more information on benefits and allowances, contact:

- The medical social worker in the hospital your child attends
- Citizens Information – Tel: 0818 074 000
- Department of Employment Affairs and Social Protection – Tel: 0818 662 244 or ask to speak to a DSP representative at your local health centre or DSP office.

Always have your child's PPS number to hand when you are asking about entitlements and benefits. It's also a good idea to photocopy completed forms before posting them.

If you have money problems

If you are getting into debt or you are in debt, the Money Advice and Budgeting Service (MABS) can help you. MABS can look at your situation, work out your budget, help you to deal with your debts and manage your payments. The service is free and confidential.

Call the MABS Helpline 0818 072 000 for information.

If you are finding it hard to cope financially, contact your medical social worker in the hospital or your local health centre for advice.

You can also call our Support Line 1800 200 700 or visit a Daffodil Centre and the nurse will suggest ways to help you manage.

Money and finances

Go to **www.cancer.ie** and see our **Managing money** page for information on:

- Medical costs and help available
- Benefits and allowances that your family may qualify for
- Ways to cope with the cost of cancer

Our Benefits Hub on our website has lots of information on government supports for people who are unwell and their carers. It also has advice on how to apply.

Irish Cancer Society services

We provide a range of cancer support services for people with cancer, at home and in hospital, including:

- Support Line
- Creative Arts Therapy
- Daffodil Centres
- Telephone Interpreting Services
- Peer Support
- Counselling
- Support in your area
- Publications and website information
- Practical support and financial solution services

Support Line Freephone 1800 200 700

Call our Support Line and speak to one of our cancer nurses or our children's cancer nurse for confidential advice, support and information for anyone affected by cancer.
Our Support Line is open Monday to Friday, 9am-5pm.

The Support Line service also offers video calls for those who want a face-to-face chat with one of our cancer nurses. From the comfort of your own home, you can meet a cancer nurse online and receive confidential advice, support and information on any aspect of cancer.

Our cancer nurses are available Monday to Friday to take video calls on the Microsoft Teams platform. To avail of this service, visit **https://www.cancer.ie/Support-Line-Video-Form**

One of our nursing team will then email you with the time for your video call. The email will also have instructions on how to use Microsoft Teams on your phone, tablet or computer.

Creative Arts Therapy

The Irish Cancer Society offers free Creative Arts Therapy support for children, adolescents and young adults (0-24 years) who have, or have had, cancer. Their siblings can also take part. Creative Arts Therapy includes art therapy, dramatherapy and music therapy. These can help children with things like emotional expression and social interaction, as well as physical and cognitive goals.

Sessions can take place:

- In-person or online.
- One-to-one or in a group.
- In your home or nearby.

If you're interested in availing of Creative Arts Therapy support sessions for your child and/or their siblings, please email creativeartstherapy@irishcancer.ie and one of our team will be in touch.

Daffodil Centres

Visit our Daffodil Centres, located in 13 adult hospitals nationwide. The centres are staffed by cancer nurses and trained volunteers. They provide face-to-face advice, support and information to anyone affected by cancer. The service is free and confidential.

This is a walk-in service. You do not need an appointment. For opening hours and contact details for each of the Daffodil Centres, go to cancer.ie and search 'Daffodil Centres'.

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
- Local cancer support groups and centres

Telephone Interpreting Service

We make every effort to ensure that you can speak to our Support Line and Daffodil Centre nurses in your own language through our Telephone Interpreting Service.

If you would like to speak to us using the Telephone Interpreting Service, call our Support Line on Freephone 1800 200 700, Monday to Friday 9am-5pm, or contact your nearest Daffodil Centre.

- Tell us, in English, the language you would like.
- You will be put on hold while we connect with an interpreter. You may be on hold for a few minutes. Don't worry, we will come back to you.
- We will connect you to an interpreter.
- The interpreter will help you to speak to us in your own language.

Peer Support

Peer Support is a free and confidential telephone service connecting people with similar cancer experiences. Peer Support volunteers are fully trained to provide emotional and practical cancer support in a safe, responsible and kind way.

Parent Peer Support is also available for the parents of children and young people diagnosed with cancer. Parents can speak to a parent of a child who has gone through a cancer diagnosis.

Our trained volunteers are available to provide emotional and practical support to anyone whose child is going through or finished their treatment. This service is also available to other adult family members, like grandparents, aunts and uncles. This programme is in partnership with Childhood Cancer Ireland and CanTeen Ireland.

To be referred to a Peer Support volunteer, call our Support Line on Freephone 1800 200 700 or contact your nearest Daffodil Centre.

Counselling

The Society funds professional one-to-one counselling. The services we provide are:

- Remote counselling nationwide, by telephone or video call.
- In-person counselling sessions in Cancer Support Centres around the country.

Counselling is available for the patient, family members and close friends.

For more information, call Freephone 1800 200 700 or contact your nearest Daffodil Centre.

Support in your area

We work with local cancer support centres and the National Cancer Control Programme to ensure patients and their families have access to high-quality confidential support in a location that's convenient to them.

For more information about what's available near you, contact your nearest Daffodil Centre or call our Support Line on 1800 200 700.

Publications and website information

We provide information on a range of topics including cancer types, treatments and side-effects, and coping with cancer. Visit our website **www.cancer.ie** to see our full range of information and download copies. You can also Freephone our Support Line or call into your nearest Daffodil Centre for a free copy of any of our publications.

Local cancer support services

The Irish Cancer Society works with cancer support services all over Ireland. They have a range of services for cancer patients, their families and carers, during and after treatment. Many of these are free. For example:

- **Professional counselling** (the Irish Cancer Society funds free one-to-one counselling through many local support services)
- **Support groups,** often led by professionals like social workers, counsellors, psychologists or cancer nurses
- **Special exercise programmes**
- **Stress management and relaxation techniques,** such as mindfulness and meditation
- **Complementary therapies** like massage, reflexology and acupuncture
- **Specialist services** such as prosthesis or wig fitting and lymphoedema services, such as education, exercise, self-management and manual lymph drainage
- **Mind and body sessions,** for example, yoga and tai chi
- **Expressive therapies** such as creative writing and art
- **Free Irish Cancer Society publications** and other high-quality, trustworthy information on a range of topics

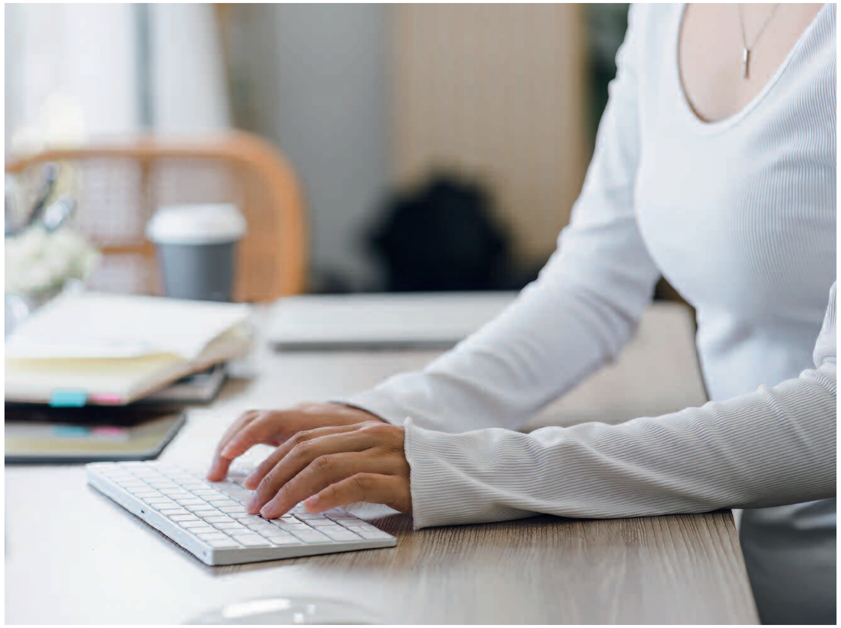
Cancer support services usually have a drop-in service where you can call in for a cup of tea and find out what's available.

You can call our Support Line on Freephone 1800 200 700 to find your nearest cancer support centre. Or go to **www.cancer.ie** and search 'Find support'.

To find out more about the Irish Cancer Society's services and programmes:

- **Visit us at www.cancer.ie**
- **Call our Support Line on Freephone 1800 200 700**
- **Email our Support Line at supportline@irishcancer.ie**
- **Contact your nearest Daffodil Centre**
- **Follow us on:**

  Facebook
  X
  Instagram
  LinkedIn



Notes/questions

Notes/questions

Notes/questions

Adapted with permission from the publication ***A parent's guide to finishing treatment***, produced by the Children's Cancer and Leukaemia Group (CCLG) – the UK's leading provider of accredited cancer information for children and young adults, and their families www.cclg.org.uk. CCLG accepts no responsibility for the accuracy of this adaptation.

The original publication was reviewed and edited by the CCLG Late Effects Group and the CCLG Publications Committee, comprising multiprofessional experts in the field of children's cancers.

CCLG acknowledgments

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.

Publication of the original booklet was funded by CCLG.

Irish Cancer Society acknowledgements

CAYA CONTRIBUTOR
Claire McCall, CAYA Cancer Nurse Coordinator at the Irish Cancer Society

EDITOR
Deborah Colgan

Published in Ireland by the Irish Cancer Society.

Join the Irish Cancer Society team

If you want to make a difference to people affected by cancer, join our team!

Support people affected by cancer

Reaching out directly to people with cancer is one of the most rewarding ways to help:

- Help people needing lifts to hospital by becoming a volunteer driver
- Give one-on-one support to someone newly diagnosed with cancer as part of our Peer Support programme
- Give information and support to people concerned about or affected by cancer at one of our hospital-based Daffodil Centres

Share your experiences

Use your voice to bring reassurance to cancer patients and their families, help people to connect with our services or inspire them to get involved as a volunteer:

- Share your cancer story
- Tell people about our services
- Describe what it's like to organise or take part in a fundraising event

Raise money

All our services are funded by the public's generosity:

- Donate direct
- Take part in one of our fundraising events or challenges
- Organise your own event

Contact our Support Line on Freephone 1800 200 700 if you want to get involved!

Did you like this booklet?

We would love to hear your comments or suggestions. Please email reviewers@irishcancer.ie

Our cancer nurses are here for you:

- Support Line Freephone **1800 200 700**
- Email **supportline@irishcancer.ie**
- Contact your nearest Daffodil Centre

Irish Cancer Society

www.cancer.ie