

A guide for parents

Talking to children about cancer

Caring for people with cancer

Talking to children about cancer

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Contents

| Talking to children about cancer | 5 |
|--|----|
| | |
| Children's reactions to a cancer diagnosis | 29 |
| | |
| Treatment and other concerns | 49 |
| | |
| Living with metastatic (advanced) cancer | 69 |
| | |
| Support resources | 77 |

About this book

This booklet is about how to talk to children when an adult in their life has cancer. This adult will often be a parent/guardian and the booklet is written with this in mind. However, it can be used by any important adult in your child's life, such as a grandparent, aunt, uncle or other family member.

The booklet gives advice about how to talk to children of all ages about cancer. It also looks at how they might react to the news, including tricky questions they might ask.

One of our main messages of this booklet is that it is best to talk openly to children about cancer in an age-appropriate way. Being upfront about cancer and keeping children up to date will benefit them in many ways.

Our booklet covers different topics, such as:

- How to talk to children about your diagnosis
- Children's reactions
- Your concerns around practical and financial issues
- Support services and websites that you may find useful

You will probably find different parts of this booklet are helpful at different times, so keep it for reference.

Medical social workers, nurses, play therapists and other professionals can also help you to talk to your children about cancer.

Talking to children about cancer

| Why tell the children? | 7 |
|--------------------------------------|----|
| When is the best time? | 11 |
| Who should tell my children? | 12 |
| Who can help me talk to my children? | 15 |
| Single parents and separated parents | 18 |
| Where should I tell my children? | 19 |
| How can I tell my children? | 20 |
| What should I tell my children? | 21 |
| What words should I use? | 23 |



Talking to children about cancer

When you learn that you or someone close to you has cancer, it can be a shock. You are likely to have a wide range of emotions, anxieties and concerns. If you have children, thinking about their emotional needs and how to talk to them will be an extra worry.



Why tell the children?

Your first reaction might be to keep the news from your children or delay telling them. Your instinct is to protect your children, particularly when something sad, uncertain or unusual is happening.

It may be hard for you to even admit to yourself that you are ill, let alone say anything to your children. You may also be distracted by your illness, as you come and go from hospital. You may feel too tired or focused on getting through the treatment. As a result, it may not be easy to see what's going on with your children. It is normal to find this situation really hard.

It is also normal for you to feel overwhelmed by everything you are going through. However, being upfront and having an honest, age-appropriate discussion with your children can help them in many ways.



Children feel valued

You know your children best and will be guided by each child's personality and needs when telling them about your cancer. Being open and honest about the situation will build trust between you. They will feel valued as a trusted family member. You cannot stop children feeling sad, but you can help and support them to cope with their feelings.

Children sense change

Children are observant and sensitive to change, especially to family routines and schedules. They will also notice if you are getting more phone calls or having quiet conversations. They may be aware of your sadness.

When something is seriously wrong – such as a cancer diagnosis – it is very difficult to hide it from children. Whatever their age, keeping it from them does not necessarily spare them from anxiety or sensing something is wrong. Secrecy can make children worry and feel isolated.

You're in this together

Telling your children about your illness and getting everything out in the open can be a relief. You can explain that family life is changing and together you can learn to cope with these changes. Some people might find this easier than others.



Children might find out another way

If you don't tell the children about your illness, you run the risk of them finding out from someone else. This could come from overhearing a conversation at home or at school. If a child does not know the facts about your illness, they could get misleading information elsewhere — such as from the internet, social media or television. This could add to their worry.

Uncertainty is hard

If children overhear conversations or feel something is wrong, they may feel they cannot ask about it. Or they may worry or imagine that the situation is far worse than it really is, especially if they have previously experienced bereavement in the family. Living with uncertainty can be harder for children than knowing the truth.

Children benefit from talking

If children are encouraged to talk and ask questions about cancer in an open manner, they may be better able to cope in general. It may be a chance for them to learn about emotions and how to deal with difficult feelings. By sharing information and emotions, the bonds between parents and children can be made stronger as well. This can help children face other difficulties in the future. It may be a chance for the entire family to discover depths of love and strength that can bring family members closer together.



10

When is the best time?

Choosing the time to tell is not always easy. Often there is no right time. You may need time to come to terms with the news yourself before you are able to explain it to your children. It may be more manageable if you tell your children a little at a time. For example, 'I am going into hospital to have some tests. We're not sure yet what's wrong, but when we do know we will tell you.'

It may be better to start telling them during the early stages of the illness, so that your child feels included in the treatment plan.



Before a change occurs

A good time to talk about cancer is before some obvious change occurs. For example, if your hair is going to fall out due to your treatment, you may want to explain this beforehand so it does not come as a shock. Children can usually accept changes if told about them in advance.

Who should tell my children?

The ideal person would be you, the parent/guardian who has cancer, the other parent/guardian, or both of you together. But this may not always be possible.

If you plan to tell your children yourself, it is important to be prepared beforehand. Children can ask very direct questions — sometimes questions we do not have answers to. Take time to consider how best to approach the subject and allow yourself plenty of time to spend with your children afterwards. This gives them time to ask more questions, if they wish. Or just by spending some playtime together, you can give them the reassurance they may need.



Children may not ask questions right away, so don't be surprised if they come back to you later. They will sometimes feel more comfortable asking difficult questions in a setting where they do not have to maintain eye contact, for example, when out for a walk or during a car journey.

You and someone your child knows well

You may decide to break the news with the support of your partner, relative or family friend — someone your child knows well. In this way, you can comfort your child and you are not left alone to deal with their reaction.

Someone close to your child

If you are unwell or staying in a hospital far from home, someone your children are close to – the other parent, grandparent, aunt or uncle – might tell them the news. A child is likely to be more comfortable with someone they know and trust. Check with the person first that they are prepared for the conversation.



It is hard to be the one to break such news, especially if you are not feeling too sure about what is happening. Naturally you will want to protect children from the hurt and sadness surrounding an illness. But children are likely to be more hurt if they are not told or included.

If you are in hospital, keep up regular contact with your children. If you are in hospital for a long period of time, they may think things are not going well. By staying in touch, you can reassure them that the hospital is the best place for you at this time. It can take some time for your children to adjust to you being away.



Preparing to talk

Regardless of who tells your children, make sure the information is accurate and suitable for their age group. For more on speaking to children of different ages, see page 31.

Whoever explains the illness to your children should have a good understanding of the situation and be prepared to answer any questions. You may not have all the answers. That is OK. Don't be afraid to say things such as:

- 'I don't know but when I do, I'll tell you.'
- 'I can't remember why I need to have this drip. But next time I see
 the doctor I'll ask them and then I'll tell you. If we see the doctor
 while you're here, then you can ask them yourself if you want or
 we can ask them together.'

14

Who can help me talk to my children?



There are many health professionals ready to help you and your family throughout treatment and afterwards. It is fine to ask for advice on how to talk to your children, especially if you have any queries or special concerns. Ask your doctor or nurse to put you in contact with someone who has experience in advising parents how to talk to children about cancer. Some of the professionals who can help you talk to your children include:

Medical social workers

These are specially trained professionals who work with patients and their families in hospitals. They can help deal with any social issues or practical needs. They can speak on your behalf (advocate) if you and your family have any concerns. They can give advice on benefits, entitlements and services available when you go home. They can also help you support your child to cope with the emotional effects of cancer. They are skilled at giving emotional support to children, adolescents and their families at times of loss and change. You can ask your nurse about meeting a medical social worker.

Hospital consultant

An expert doctor. They are in charge of your treatment. They have a team of doctors working with them.

Clinical nurse specialist/oncology liaison nurse

A specially trained nurse who works in a cancer care unit. They give information and reassurance to you and your family from diagnosis and throughout your treatment journey.



Psycho-oncology team

These are specialists in psychological care and support for cancer patients. Usually the team includes psychiatrists, clinical psychologists and nurses.

Advanced nurse practitioner (ANP)

ANPs give expert information and support and are specially trained to carry out tests and help to review your treatment.

Counsellor

A person specially trained to give emotional support to you and your family. They can be based in either hospitals or in the community. Counselling can be made available to children and adults. For details about the Irish Cancer Society's free counselling service, see page 84.



Family doctor (GP)

Your family doctor may be able to help if you are having problems telling your children about cancer or coping with their behaviour and emotions. They can arrange professional help for you, such as counselling.

Community health services

This includes family doctors, public health nurses, community welfare officers and home-help organisers. They can visit you in your home and give advice and support. Your local health centre or the medical social worker in the hospital can advise you about these services.

16



Support groups

These groups can put you in touch with people in a similar situation to yours.
They can give you practical advice about living with cancer and talking to children. You may find it easier to share your thoughts and feelings with someone who has



had a similar experience to you. You can call our Support Line on 1800 200 700 to find your nearest support centre. Or go to www.cancer.ie/local-support

Irish Cancer Society

You can call our Support Line on 1800 200 700 and speak to one of our cancer nurses for confidential advice, support and information. This can include practical advice on talking to children about cancer. Our nurses can also let you know about support services and other practical supports in your area. You can also visit one of our Daffodil Centres, which are located in 13 hospitals nationwide. These are staffed by cancer nurses and trained volunteers. For more information on Daffodil Centres, see page 81.

Hints and tips: For parents/guardians

- · Decide together who will tell your child and what to say.
- · Work together and share the load.
- Ask someone in the healthcare team for advice on how to talk to children.
- Take up all offers of support from family and friends.
- · Ask for help if you need it.

Single parents and separated parents

If you are a single parent with cancer, the situation can be extra hard. You may have less support. In this case, you may need to rely more on your family, friends and relatives. During your treatment, you may need someone to help look after your children.

If you are a separated parent, your children may be used to changes in home routines already. They may also be used to living in 2 separate households for periods of time. Even so, it is best to keep things as stable as possible for them. Make sure familiar things are kept in each household, such as special toys, photos, clothes and bedding. Stick to daily routines so that the move from one home to the other is as smooth as possible.

If you are in hospital, the children should be brought to visit you regularly, if possible. Find a way to keep the 2 households up to date on any changes in your medical treatments. It is a good idea to have a second plan for any unexpected changes, such as a change in hospital visiting times or restricted access.

Where should I tell my children?

It can be hard to sit down with your child just to break difficult news. It may seem like a formal or embarrassing thing to do. Wherever you decide to have the chat, try to make sure it's a comfortable environment. Sometimes it can be easier to talk when you are doing something else together like walking, playing or colouring. It is best to allow plenty of time so that you are not interrupted or have to rush off without answering your child's questions.

Talking to a child in their bedroom may not be a good idea. This may be the safe place your child will escape to afterwards.

It may be best to talk early in the day, so that you can spend time together or talk again before bedtime.



19

Support Line Freephone 1800 200 700

How can I tell my children?

Finding a way to tell your children may take some time and thought. It can help to rehearse what you are going to say too. This can help you to foresee any questions your child might ask.

At the time of diagnosis, you may want to tell your children individually. You could talk to your oldest child first. Start by telling them a few basic facts about the situation. They may have worked some of it out already. Maybe ask them what they know, what they want to know and what their concerns are. Their worries may be different to yours.

Your child may appear distant and not ask anything as they try to process what they've been told. They may come back to you with questions later. Let your child know that they can come back to you with any questions or thoughts whenever they want to.



When speaking to younger children, give clear, simple explanations. Also, link your explanations to what your child may have already noticed. Young children often ask the same questions over and over. Each time they will take in a little more of what you tell them.

What should I tell my children?

There are some basic things that you should say:

- Explain what the illness is by using the word cancer.
- Explain how your health will be affected, for example, you might be more tired than usual or you might lose your hair.
- Give some details about the treatment in simple, clear language.
- Tell them you are not sure how things will work out, but you are meeting with the doctors to figure out a plan.
- Let your children know about any changes to their daily routine.

One way to start the conversation could be to find out what your child already understands about cancer. Bear in mind that children hear stories at school, from TV programmes or from the internet, so they may have their own ideas of what having cancer means.



It may be useful to talk through their thoughts and ideas with them. For example, your child may have heard that people do not recover from cancer. In this case, it is good to explain that there are many types of cancer which can affect people in different ways and people can recover. Explain too that cancer is not contagious and they cannot catch it.

It is best to give children information slowly. Take things a step at a time to avoid confusing them. Keep repeating the information so that the message is the same each time. For children, the amount of information you give them is usually less important than making them feel comfortable with what you say.

When talking about your treatment, your children might want to know what it will mean for them. If you are in the hospital, who will bring them to school, make dinner or take them to after-school activities? Let your children know these concerns are important to you too. Reassure them there will be a plan and that you will let them know about it.



Assure your children that you will continue to let them know what is happening, as things may change. Let them know they can come to you anytime with questions and that you will try to answer them as best you can. Above all, be willing to answer questions simply and honestly whenever they may arise. It is also important not to force children to talk about your illness.

What words should I use?

Choose your words carefully so that your children are clear about what is being said. Children need to hear information in words they can understand. For example, older children may be familiar with the exact names of parts of the body, but younger children may need to have them explained in more general terms.

The drawing exercise in Activity 1 in the centre of this booklet may be useful for explaining parts of the body. Be aware that children tend to be very concrete in their thinking, so they are likely to take what is said literally.

Do not overload them with information as it can be confusing for them. Avoid giving them too many details about cancer, finances or test results. But whatever you choose to tell them should be the truth.

Do not make promises that may have to be broken. This may affect your child's trust in you. If you are pressed to make plans, perhaps you could say 'I hope I will be able to...' or 'I'll make every effort to...'

Some cancer words explained

Cells Tiny building blocks in your body like Lego. Cells group together to make tissues and organs.

Cancer When cells in a part of your body start to grow out of control. Groups of these cells can sometimes spread to other parts of the body. Different types of cancer are treated in different ways.

Side-effects Unwanted effects caused by cancer treatments.

Chemotherapy Drugs to cure or control cancer.

Surgery An operation that removes the cancer cells.

Radiotherapy Special X-rays that can kill cancer cells.

See page 51 for more information on explaining cancer treatments.

Descriptions of cancer

Below are some descriptions of cancer that may be used, depending on the age of your child.

- 'There is something in my body called cancer. It is making me sick. The doctors are giving me medicine to try to make it go away.'
- 'Our bodies are made up of lots of cells. When someone has cancer, some cells change and they grow faster than normal cells. Treatment is needed to fight them'.
- 'Cancer is an illness of the body that can be in different places for different people.'

Keep information current

It may help to start with information about what is happening at the time. Explain simply and slowly what is happening and what you think may happen in the coming days or weeks. The following examples may be helpful in doing this. The drawing exercise in Activity 1 in the centre of the booklet may also be useful.

For example:

- 1 'As you may know, I am sick. I have something wrong with me and it's called cancer. I'm getting medicine to help me get better. The doctors and nurses tell me that sometimes I will be fine but there will be times I may feel sick or tired. The rest of the family will help out more around the house until I feel well again.'
- 2 'If you have any questions about cancer, you could ask me or someone else in the family like Dad/Mam/Granny/Grandad. Sometimes you may hear about other people's cancers. Everybody's cancer is different. I will tell you what we know about my cancer. No one caused me to get sick.'

24

Listen to children

Encourage your child to talk to you whenever they want and give them every chance to express what they are feeling and thinking. Also, listen carefully to what they have to say. They will ask what they really want to know.

If you are worried that your child continues to express sadness or anger – or any other emotion that troubles you – talk to the medical social worker or let your nurse arrange for them to talk to you. You could also speak to your GP or a counsellor. The Irish Cancer Society funds professional one-to-one counselling at some cancer support centres and by video or phone. Call our Support Line on Freephone 1800 200 700 to find out more.

You could also let the staff in your children's school or crèche know what is happening. These are other people who can keep an eye on your children and help support them if needed.



Drawing exercises

Drawing exercises can be used to help children express their thoughts and feelings. Drawing allows a parent and child to have some distance from the emotion but still offers a way to express it. It is another possible way for you and your child to communicate if you are finding words difficult. Some children love to draw and find it easier to communicate in this way. Other children may not be interested in drawing, especially very young children or older children and teenagers.

Sometimes drawing exercises can be a way for parents to begin talking about the impact of their illness and find out how their child is thinking and feeling. If your child has concerns or worries, you can then talk these over with them and reassure them. You can also explain any information they may not understand.

A drawing can express an emotion in a definite moment in time. So don't be alarmed if your child draws a picture that shows sadness or anger. Next time it might be very different. Emotions are not fixed but change all the time. Having mixed emotions when somebody in the family is ill is a very normal reaction for both adults and children.

There is an activity sheet at the centre of this booklet with suggested exercises to help children express feelings and emotions. Trust your child to decide what they would like to draw and don't force them if they have no interest. You know your children best, so you might decide that this is not a useful exercise. Trust your instincts.

Express your feelings too

It is helpful to express your feelings as well as share the facts. Let children know how the situation affects you too. For example, 'Mammy is sad because Daddy is sick' or 'I'm a little scared too, but I'm not going to get this cancer off Dad, nor are you.' If you are feeling sad, it is OK to cry and explain to your child that you are crying because you feel sad.

Reassure your children that they will still be loved and cared for, no matter what happens. They will always be cared for by another family member such as their mother, father, aunt, uncle or grandparent. When you talk about your illness, prepare children for certain changes to the family routine. This sends a powerful message that you or your partner are still in charge and your child's needs are not forgotten. Tell your children that you love them again and again and you will make sure they are cared for. Even though this is a difficult time, try to remain hopeful with your children. Hope is very important in helping people to cope.



Hints and tips: What to do and say

- Find out what your child understands about cancer.
- Let your child know what has happened and what will happen next.
- Use clear, simple, truthful and repeated explanations.
- Use simple everyday words, suitable for the age of your child.
- Tell older children and teenagers about cancer separately from younger children in the family.
- Say to your child 'I don't know' if you are unsure about anything, but reassure them that you will try to find out.
- Encourage your child to talk to you whenever they want.
- · Listen carefully to what your child has to say.
- Tell your child they are still loved and cared for.
- Reassure children that they will always be looked after even if you can't do it yourself.
- · Be honest.
- Share your own feelings to help show children that it is OK to feel strong emotions.
- · It is OK to cry in front of your children.
- $\boldsymbol{\cdot}$ Use books and activities to help you to explain cancer.

Hints and tips: What not to do

- · Don't lie.
- Don't make promises that you may be unable to keep.
- Don't take away all hope leave your children feeling there will be better times ahead.
- Avoid giving too many details about cancer, finances or test results.
- Don't force your children to talk if they don't want to.

Children's reactions to a cancer diagnosis

| Talking to children of different ages and stages | 31 |
|--|----|
| Understanding your child's feelings | 43 |
| Depression in children | 47 |
| Other issues in your child's life | 47 |
| Finding help for worrying behaviour | 48 |



Talking to children of different ages and stages

The following pages explain how children, at various ages and stages of development, might react when coping with a serious illness within the family.

Children are often better able to cope with change than adults. Remember that each child is different and will react in their own way when a parent is diagnosed with cancer.



Infants and toddlers

A parent's presence is very important to this age group. They may feel abandoned when a parent is in hospital, so make sure to give them lots of love, hugs and attention when you can.

They need a lot of support from adults to help them understand what is going on. Tell your child what is happening but keep it as simple as possible and repeat it often.

- 'Mammy is sick.'
- 'Daddy has cancer.'
- · 'Mammy needs to go to the hospital.'
- 'The doctors will give Daddy medicine to get better.'

How your child might react

- Babies and toddlers can become unsettled and clingy
- Their sleeping and eating patterns might change
- They might be cranky and have more temper tantrums



What you can do

- Keep the baby or toddler near you when you can and with someone they know well when you are away in hospital or at appointments.
- Cuddle and hug them often.
- Leave an item of yours to comfort them if you are going to be away from them.
- Tell your child often that you will soon be back.
- If you are in hospital, ask your baby's childminder to video call or phone you so the baby or toddler can see and hear you in real time.
- Try, as much as possible, to keep to the child's usual routine, such as mealtimes and bedtimes.
- If the hospital allows it and you are feeling up to it, let your child visit you.

Children aged 3-5

Like toddlers, children at this age have no sense of time and no understanding of how things happen and reasons why. They can feel insecure and anxious if left by a parent and may not understand why mammy or daddy must stay in hospital. If possible, arrange for someone they know well to stay with them. This may help reduce fears around separation and being left alone.

How your child might react

- More anxious about being away from you not wanting to go to bed or to preschool
- Regress in behaviour bedwetting, sucking their thumb or soother, needing their comfort blanket or toy
- Out of sorts crying and whinging for no obvious reason
- Lashing out at other children or their childminder
- Difficulty getting to sleep or waking in the night
- Not eating like they used to needing to be spoon-fed



What you can do

- Give simple explanations about your illness: 'I am sick and I have to go to hospital to get better.'
- Check that your child understands what you are saying. Use a
 doll or toy animal to talk about cancer. Or use the picture
 (Activity 1) in the centre of this book to help show them.
- Let them ask questions, even if it is the same question over and over.
- · Give them lots of hugs and cuddles.
- Stick to their usual routines, if possible. Tell them if there are going to be changes, such as 'Granny will bring you to football'.
- Reassure the child that they will be looked after and tell them who is going to be with them most while you are having treatment.
- Let them talk to you via video calls or phone calls if you are in hospital.
- · Let them visit you, if the hospital allows it.
- Encourage them to draw (see page 26), as this can help them to express themselves.
- Reassure them that they did not cause your cancer by anything they did or thought.
- Do not tolerate aggressive behaviour such as kicking or biting.
 Teach your child how to express their feelings in other ways, such as by talking or drawing.
- Talk to your doctor if you are worried about your child's behaviour.

Support Line Freephone 1800 200 700

Children at this age think logically, understand rules and gender and role differences. They like facts and need ongoing information and updates. They are able to take in more information than younger children and relate it to things they already know. For example, they may know someone else who has had cancer.



How your child might react

- Separation anxiety they don't want to be away from you
- Fearful and worrying about changes to daily routines
- Crying a lot
- Angry sometimes with aggressive outbursts
- Complaints of feeling unwell headaches and tummy aches
- Trouble sleeping
- Quiet and subdued
- Loss of interest in hobbies and activities

What you can do

- Tell your child in simple terms about your illness and keep them up to date on your treatment. Give them plenty of opportunity to ask questions.
- Answer their questions honestly, including, 'Are you going to die?' You can ask your social worker and cancer care team for help to explain things to your child.
- Suggest to them that you will let their teachers, coaches and other school staff know about your cancer situation.
- Repeatedly reassure your child that they did not cause your illness and that cancer is not contagious.
- Encourage your child to keep up hobbies and other activities, as much as possible.
- Encourage them to see their friends outside of school. Remind them that it's OK to still have fun.
- Talk to them about healthy ways to manage feelings such as anger and anxiety.
- Accept it if they don't want to talk to you about their feelings.
 You may be able to enlist a friend or family member who your child might confide in.
- Ask your child to video call or phone you when you are away or to send text messages or photos. That way you can be in touch constantly.
- Talk to your doctor if your child shows signs of severe anxiety, such as intense feelings of fear, withdrawal from social situations or problems concentrating.

Teenagers

Teenagers are able to understand more than they can handle emotionally. They also have to face the job of becoming an independent person.

Adolescence is a time of change and can be quite hard for some teenagers. On hearing your news, some will rebel and regress in behaviour, acting like younger children. Others will take on extra responsibilities. Some will adapt more easily to disruption in family life.



Explain to teenagers that talking about their feelings and worries is a helpful way of coping with stressful situations. They may not be used to expressing their feelings or may be afraid to ask questions in case it upsets you.

How your child might react

- Wanting to be more independent and responsible yet becoming more insecure and dependent
- Stressed showing physical symptoms such as headaches or minor ailments
- Critical of you and your partner's efforts to support them emotionally
- Blocking you out not engaging in conversations about your cancer
- Embarrassed to be seen with you
- · Guilty about being embarrassed to be seen with you
- Annoyed about being asked to do more around the house
- Hiding their feelings sometimes withdrawn and subdued
- Angry sometimes rebellious
- Trouble sleeping
- · Fear and worry about the future
- Loss of interest in hobbies and activities
- Change in school grades

What you can do

- Give them as much detail about your illness as they need –
 including information on your treatment plan, possible sideeffects and prognosis (if they ask).
- Keep them up to date about your cancer and treatment, even if they show little interest.
- Encourage them to ask questions and even to meet with some of the team looking after you, if possible.
- Encourage them to share their feelings with you, though they may prefer to talk to their friends.
- Encourage them to keep up activities and to see their friends.

38

Assure them that it's still OK to have fun.

- · Reassure them that cancer is not contagious.
- Assure them that nothing they did or said caused the cancer.
- Suggest they keep in touch regularly by sending you photos and messages if you are in hospital.
- Suggest that you tell their teachers, coaches and other school staff about the family situation.
- As far as possible, stick to the usual routines of daily life at home.
- Enlist them to help out with household jobs, but don't overdo it.
 Helping out gives them a sense of responsibility, as they move into adulthood. Encourage and thank them for their support.

Children with special needs

If your child has a developmental disability, you may worry even more about how your illness will affect them. You may worry about being away from them and leaving them in the care of people who may not fully understand their ways.



Sensitive to changes

It will take time and patience for your child to understand new situations because of your illness. Children with special needs are often very sensitive to change of any nature. They can notice small changes in your appearance or in their daily routines. These changes can bring new difficulties.

You know your child best and are likely to know the best way to explain new things to them. You will know what has worked best in the past and the need to stick to routines. You may need to repeat your explanation about your illness to your child again and again. Stick to the same words and keep it as simple as possible. It is important to stress what will be different in your child's day and what will be the same.

You could also let your child know how your appearance will change during your illness, especially before it happens.

Carers and childminders

It is helpful to have a small number of people around who know your child well. Let carers or childminders know what your child likes and dislikes.

You can also leave advice (by word or in a written note) in case any difficulties arise. Sometimes special needs teachers and care organisations can give advice and support for caring for your child at key times. Tell those caring for your child in your absence what you have told your child, especially the words you have used.

Involve other people

Relatives and family friends are often a good support to children and teenagers at this time. If teachers are informed about your illness, they will have a better understanding of any situation that might arise at school. They may also be able to offer useful suggestions. See page 57 for more details about school. There are also professionals experienced in supporting children, teenagers and their families to cope with a serious illness. For example, medical social workers.

40



Your child's questions

It is good to encourage your children to ask questions about your illness and treatment. Some questions you will find easy enough to answer, others you won't. Often there is no right way to answer, but it is good that your children are asking questions and talking about how they feel.

If you are unsure how to answer, you can tell them that you don't know but that you will find out. Be sure to go back to them when you have the answer. Also, it's best not to push children to ask you questions if they don't want to. Just let them know that they can ask questions any time they want and spend plenty of time with them if you can.

What they might ask...and what you might say

Are you going to die?

People do sometimes die from cancer, but lots of people don't. For me, we're hoping that won't happen. I will be having the treatment the doctors say is the best for me. My type of cancer usually goes away with treatment.

Was it my fault that you have cancer?

No, absolutely nothing you did or said made me get cancer. Scientists don't know exactly what causes cancer, but the evidence shows it was nothing you said or did!

Is cancer contagious?

No, you can't catch cancer. It's not like Covid 19 or a cold or flu. So it is safe to be near me or hug me.

Who should I tell?

You can tell your friends if you are comfortable with that. Or you don't have to tell anyone, if you prefer not to. I was thinking about talking to your principal or teachers, just so they know what's happening at home. (You can explain to your child the benefits of letting school staff or coaches know.)

Who will look after me?

For younger children, an example might be:

'Granny is going to bring you to and from school. She'll make dinner and help you with your homework. And she will leave when Dad comes home. Rob will take you to football with Ben and Tommy will take you to karate.'

Older children and teenagers can help to work out the arrangements for after school that they would prefer. But it is important to reassure them that you will help them make these arrangements if they are finding it difficult.

Understanding your child's feelings

Sometimes children imitate their parents and learn how to express feelings from the adults around them. If you rarely show how you feel, your children may not find it easy to do so either. Children may even become frightened of their own emotions. They may need time to talk about this to realise that these feelings are normal in this situation.

Like adults, children may feel some of the emotions listed below. However, they may not be able to talk about them. The drawing exercises in Activities 2 and 3 at the centre of this booklet can help children identify these feelings and express them. See also page 26 for more information about drawing exercises.



Fear

The uncertainty of cancer may be hard for children to understand. They may be afraid because you cannot control the cancer or make yourself well again. You may be able to help lessen this fear by giving them clear age-appropriate information. Your children may be less likely to feel worried or confused if you give them the chance to talk about their fears.

Feeling cross and angry

It is natural for children to feel angry about changes caused by your illness. But this does not mean that they do not love and care about you. Family life may now revolve around hospital visits. As a result, there may be some changes to their daily routine.

When children are asked to help out more, they might appear angry and unwilling to co-operate. Young children may be annoyed if they are asked to play quietly. They may also be disappointed or irritable if an outing has to be cancelled. Children may not understand if you cannot keep plans because you are unwell or have to attend hospital. Explain that you have to keep hospital appointments even though you would prefer to stay with them.



Behaviour

If you are unwell, your children may aim their anger at you, at the other parent or another adult. They are more likely to express fear in the form of anger and may be unwilling to co-operate. Children can pick fights at school, withdraw from friends or even refuse to go to school. These can be normal reactions resulting from strong and frightening feelings they may not understand.

Older children may also become upset and angry if they are not told enough information about your illness. They may feel shut out.

Love and support

You will need patience and time to comfort your children and help them feel more secure. They will need a great deal of love and support at this time. You could find ways for your children to vent their anger in a controlled way. This could involve physical activity like team sports or writing down their feelings. Their drawings or words about cancer could be stuck to a scrapbook or a noticeboard in the study or computer area at home. These actions can release their emotions and you can support and comfort them afterwards.



Feeling guilty

Guilt is a very strong emotion and can be overwhelming. Children can feel guilty for many reasons. They may feel guilty because they are well themselves and are glad not to be ill. They may feel guilty because they can go out and continue with their normal routines. To make up for these feelings children often try to be very 'good'. If this happens, they will need to know that while it is normal to be sad at times, it is alright to still laugh and have fun.

Feeling sad

It is not easy to be apart from someone you love. Children can feel very sad about this. A diagnosis of cancer can bring many changes to you if you are ill. Seeing physical changes and a parent becoming physically weak can cause children to be sad. It may mean that you can no longer do certain things with your children. Children generally expect an adult to be strong and they can be sad when they realise this is not always the case.

Envy

It is not unusual for children to be envious if they see that you are receiving all of the attention. They may also be envious of other children who seem to have no troubles in their families.

Hints and tips: How to recognise if your child is affected by your illness

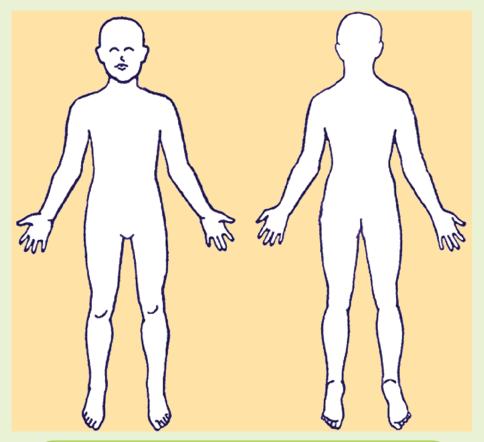
- Signs of depression not sleeping, eating, dressing or washing
- Difficulties at school skipping school, under- or overachieving
- General lack of interest in things
- Uncontrollable bouts of crying
- Regression to a younger stage. For example, thumb sucking or wetting the bed
- Being silent, withdrawn or self-critical
- Self-destructive behaviour using drink or drugs
- Premature sexual relationships
- Risk taking, such as reckless riding of e-scooters or reckless driving



Colour, write or draw any part of the body affected by the illness.

This exercise can help if your child is asking questions about where your body is affected by your cancer, your treatment or side-effects. Your child might also wish to draw the part to help them understand it more clearly.

It is best if you supervise or check in with your child once the drawing is done, so that you can discuss any of their feelings. See page 26 for more about drawing exercises.

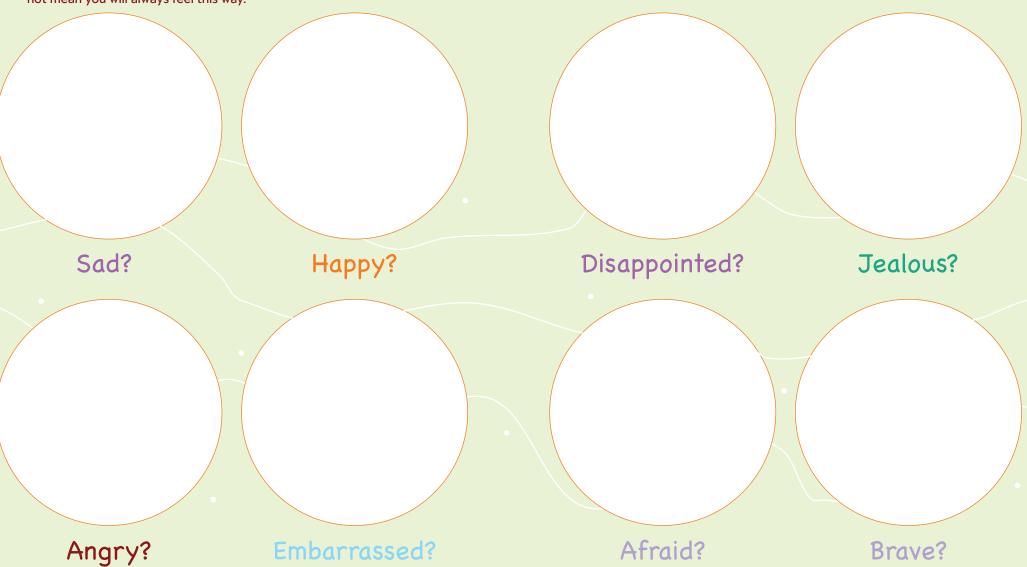


Visit our website www.cancer.ie for printable copies of these activity pages.



How do you feel today?

Draw some feeling faces. Remember that having a feeling right now does not mean you will always feel this way. This exercise might help you and your child to identify and explore some of the many feelings experienced when somebody in the family is sick. See page 26 for more about drawing exercises.

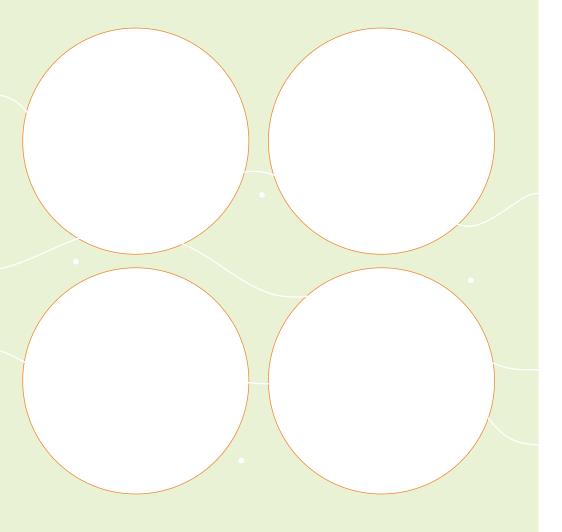




ACTIVITY 3

How do you feel today?

Your children might like to draw many different things on blank paper and enjoy the freedom to choose their own face or feelings. You might also like to explore your feelings too — they may even be the same as your child's! See page 26 for more about drawing exercises.



Depression in children

Depression in children is often not like depression in adults. A common sign of depression in a child is a change in behaviour. For example, suddenly getting poor grades in school or losing friends. Most children can cope if a parent has cancer. But for some children there may be times when it overwhelms them. If your child appears to be having trouble, it may mean a more serious problem than a normal, sad response to cancer.

Talk to your GP, medical social worker or nurse if your child is experiencing these difficulties.



Other issues in your child's life

It can often feel as if cancer has taken over a family's life. But remember that there may be other things going on in your child's life that could explain their behaviour. For example, your child may be having difficulty adjusting to a new teacher or they may be having problems with a friend.

Try to get your child to talk about what is troubling them. A simple statement such as 'You seem very thoughtful/sad/worried these days. Tell me what's going on' may give you a new understanding of your child's behaviour. It might also help to check with your child's teachers to see if they have noticed a change. Check out all of the possibilities before you decide what you need to do to help your child feel better.

Finding help for worrying behaviour

If you are concerned that your child's behaviour has become uncontrolled or dangerous, it is important to get help for them. Such behaviours could involve something out of character for them or potentially harmful to their wellbeing, such as:

- Excessive worry or stress affecting their focus or social interactions
- Becoming increasingly self-critical
- Self-harming
- Big changes in eating or sleeping patterns

You may also notice an increase in reckless behaviours in your teenage children, such as drinking alcohol, vaping, taking drugs, reckless driving or being sexually active at an early age.

To get advice and help, speak to your GP, medical social worker, nurse, psychologist or the psycho-oncology team if there is one at your hospital. You might also consider contacting a child and adolescent psychotherapist.

Treatment and other concerns

| How can I explain about treatments? | 5 |
|--|----|
| Should I let my children stay at home? | 55 |
| Should I let the school know? | 57 |
| How can I keep things as normal as possible? | 59 |
| When treatment ends | 64 |
| Things to remember | 66 |



How can I explain about treatments?

If your child shows an interest or is concerned with your treatment, it might be useful to explain how it works. This may help them feel more comfortable and secure about you being in hospital. It may be possible for your children to visit you in hospital. This can be discussed beforehand with the staff in the hospital, if you wish.

Try to explain your treatment in a way they will understand.



Surgery

Explain that this is an operation to remove cancer cells. Children may be curious or even frightened by the idea of surgery and scars. Explain to them what they may see after the surgery. For example, bandages, stitches, drips or drains. This will let them know what to expect. If you are attached to tubes and drips after surgery, it can help to tell your children what these are for. This might help them be more prepared when they visit.

Chemotherapy and targeted therapies

Chemotherapy and targeted therapies can be described to children as special medicines that treat cancer. Some of the medicines are tablets that can be taken at home or in hospital. Other medicines may be given by injections or through a drip. Usually chemotherapy is given regularly over a period of months. Targeted therapies are usually given for longer periods than chemotherapy and they have fewer side-effects. Reassure your children that it is safe for them to be around you while you are having these treatments.



Radiotherapy

Radiotherapy can be described as very strong X-rays that are used to kill the cancer cells. Machines will be used to give this treatment. These machines are large and can be moved around to allow different parts of your body to be treated. The treatment is painless and only takes a few minutes. Radiotherapy is usually given daily over a number of weeks, except at weekends. Reassure your children that it is safe for them to be around you after you have had your radiotherapy treatment.

Side-effects of treatment

It is helpful for children if they are prepared for the possible effects of your treatment. Find out from your doctor and nurse what side-effects you might get and discuss them with your children. Explain that these side-effects are normal and are caused by the treatment.

Side-effects may include the following:

Hair loss

Loss of hair can be caused by chemotherapy. It can also happen if you have radiotherapy to the head. This can happen gradually for some or more suddenly for others. Prepare and reassure your children that your hair will grow back after the treatment has finished. Let them become familiar with any head scarves and wigs that you choose to wear. If appropriate, some children may want to be involved in shaving your hair and/or in choosing wigs or head scarves.

Nausea and loss of appetite

Some people may have nausea (feeling sick) and loss of appetite when having treatment. These symptoms may be helped by medicine. Explain to your children that your doctor will choose the best anti-sickness medicine for you.

Tiredness

Tiredness or fatigue is another side-effect for those having treatment. Due to fatigue, you may become weaker and may need to rest more. Again, it is helpful to prepare children for this and make them aware that this is normal.

Pain

For some people, pain is a side-effect of treatment. Medicine to help with pain may make you feel sleepy or drowsy, so you may need to sleep or rest more often. Reassure your children that they can still talk to you even if you are needing to rest more because of pain.

What your children might ask ... and what you might say



Will the surgery hurt?

No, the doctors will give me an anaesthetic first, which means I will go into a deep sleep. So I won't feel anything during surgery.

Afterwards, I will have some pain but I will be able to take painkillers and make the pain go away.

Does a drip hurt?

When the medicine is going in through the drip, it doesn't hurt at all.

Will you be tired all the time?

Chemotherapy or radiotherapy can make you feel very tired for a while. But we can plan to do some things on the days I am not tired. When I am tired, maybe we can colour or watch a movie.

Will your hair grow back?

When I finish the treatment, the doctor says my hair will grow back. But until then, I can get a wig or wear nice scarves and hats. Maybe you could help me choose some. When my hair does grow back, it might look a little different. It might be a different colour or it might be curly even though it was straight before.

Will you be radioactive with radiotherapy?

Radiotherapy is like getting an X-ray, so I won't be radioactive. You can still hug me!



Should I let my children stay at home?

You may wonder if it is the right thing to send your children to school or playschool or to let them stay at home. It is true that children can become very anxious if they are separated from those closest to them at stressful times. They may feel abandoned or not important enough to be included. They are quite likely to feel unsettled and visualise what is going on at home if they are separated from parents or carers. But it is also important for children to take 'time off' from being sad and do normal things.

Talk to your children and explain why you need to be separated from them. It is important to keep up your normal routine as much as possible (see 'How can I keep things as normal as possible?' on page 59). Children cope best with routine and structure. If other arrangements must be made for their care, try to include them in these arrangements as far as possible.

Keeping in touch with friends

If you keep children from school, they might lose school contacts, friends and a familiar environment. This may only add to the pain of being separated from you if you are in hospital. It is best all round if they continue to go to school. Keeping up familiar and normal routines helps children to feel safe.

You may find that older children or adolescents may not want to be at home. They may prefer to spend more time with their friends and get involved in activities. This can be their way of avoiding your illness and distracting themselves. There is no right amount of time that they should spend at home. But let them know what times they are expected to be at home for family time. For example, meals or special events.



Should I let the school know?

Many parents wonder if they should let the school know about their illness or not. You may prefer to say nothing, especially if your children have no problems in school and are happy to be in a familiar environment. They may behave just as they did before your illness. However, the behaviour of some children may change at school.

If you do decide to tell the principal or teachers, talk this over with your children first. They may prefer that you don't tell the school, but explain that there are good reasons to do this. If the teachers are aware of the situation, it will allow them to react sensitively and find helpful ways of working with your child. A teacher can also let you know how your child is coping.

Hints and tips: Things you might tell the school

- · That you have cancer.
- Some basic information about your treatment: how long it will last and the likely side-effects.
- How you describe cancer to your child.
- · What your child understands about cancer.
- · Any fears or concerns your child has about cancer.
- · How your child copes or how they ask for help.

Changes in behaviour

Changes can become obvious in the classroom if your child shows poor concentration, loses interest in homework or falls behind in class. Some children may even skip school or look for excuses not to attend. They may have less interest in keeping contact with friends or in going to visit them in their homes. On the other hand, some children may focus on school and homework more than ever before. This can be their way of coping with the changes within the family.

Staying quiet

At school, your children may not tell their classmates or teachers about your illness. Often they do not want to be seen as different at school for fear of being rejected. They might also feel that if they did say something, no one would understand what they are going through. So don't be surprised if your child is keeping news of your illness to themselves.



How can I keep things as normal as possible?

One of the best ways to keep things as normal as possible is to stick to familiar routines and let your children be children. Another way is to try to involve your child in your day-to-day activities. This means sharing both good and bad experiences. This can increase the bond between you even more. Hospital visits don't have to be depressing for children but can be a chance to have some fun and adventure.

It is important that plans made with children about visiting the hospital are kept – check with your nurse that children may visit. If they don't want to visit you in hospital, don't force them. Instead try to talk through why they do not want to visit and help relieve any fears they might have.



You may feel that you don't want your illness to upset family life, feel guilty that you can't join in as much as before or that you're letting your children down. However, your illness and treatment will dictate your energy levels and your ability to participate in regular family life. Let your children know when you are not feeling so well and make the most of good days to involve them in fun activities.



Children often only see things from their own point of view and may express their disappointment if you are not able to do something. If this happens, it can be helpful to acknowledge their feelings ('I know that you are disappointed that we cannot go to the park today'). Then remind them of your feelings ('my body does not have the energy right now'). You could then offer connection and fun in a different way ('how about we colour/play cards/watch a TV show together after I rest').

Bring personal items to hospital

To keep them in touch with you in hospital, children can bring cards or pictures from home, flowers picked from the garden (if the hospital allows flowers) or a favourite toy that could 'mind' you in hospital. If this is not possible, children could send in these gifts with an adult, make phone calls, make video calls and send text messages.



Explain how the hospital works

Children may be curious about how a hospital 'works'. It may be possible for a member of staff to explain how different pieces of equipment work. It may also be helpful for your children to know who is caring for you. For example, the different doctors and nurses on the ward. Medical social workers and other professionals are also available to offer support to you and your family at this time.

Hints and tips: Sharing experiences in hospital

- · Let your children visit you on the ward or day room.
- · Let them see your bed or armchair and the call bell.
- Phone your child from hospital and let them ring or video call you from home.
- Exchange photographs and pictures.
- Exchange presents: wrap up a small gift to give your child.
 Or they could bring you some fruit wrapped up or a flower, if the hospital allows flowers.

Let children help out

At home your children could help bring you meals or get things for you like books, papers or personal items. If they feel they are helping you, it will make them feel better.

Draw pictures

Young children can be encouraged to draw pictures about the experience of having a parent who is ill. For example, a visit to the hospital, who they met or what they saw. This can be a good way to express emotions and a chance for you to talk about it together. See page 26 for more on drawing exercises.

Write about emotions

Encourage teenage children to keep a journal. This may help them to express their emotions and feelings. It may also make them feel like they are keeping some order in a world that seems full of chaos.

Have some fun

Though it is easier said than done, try not to let your illness take over. Family outings, such as trips to the zoo, cinema or school events, are still important. Let your children know that it is alright to joke and to have fun. Laughter can often relieve tension and help everyone relax.

62

Hints and tips: Sharing experiences at home

- · Let your child bring you a meal, book or paper.
- Let your child role play act out what is happening to you.
- Encourage your child to draw a picture about their experience of you being ill.
- · Read a book together.
- Watch a film together.
- Choose stories about a parent with cancer and read them together.
- Share songs and poems that mean a lot to you and your child.
- Get together with other parents or families who are coping with cancer.



When treatment ends

The end of treatment is a time when people often expect to feel relieved, happy and able to get on with life again, but it can take some time for your body and mind to recover and to adjust to life after cancer treatment.

Do what you can to celebrate the end of treatment – letting the children know how much you appreciated all they did to help you. Do something fun – like a day trip or short break away together, if you can. However, you may need to tell them you still need their support, especially if they expect more from you than you feel able to give. Explain that the treatment effects are likely to last for a while after treatment finishes, but that family life will return to 'normal' little by little.

Our cancer nurses can support you if you need help with talking to your children any time throughout your cancer journey.

Call 1800 200 700 or visit a Daffodil Centre.



What your children might ask ... and what you might say

Once the cancer goes away, can it come back?

For most people the cancer won't come back. If it does come back, the doctors will look at what is best for me.

So, are you not going to be tired anymore?

I'm still going to be tired for a while. The treatment took a lot of energy out of my body, so I need to get all that energy back and this might take some time. But we'll be able to do lots of things together and even if there are some days that I'm very tired, there will be lots of days where I'll be feeling good.

Do you have to go back to hospital?

I will go back for check-ups. I will probably be nervous going for check-ups, because I will still have to have some tests. But you can talk to me or tell me funny jokes to help me when I'm feeling nervous.

CLIMB programme for children

CLIMB is a 6-week programme designed especially for children of primary school age (5-12) who have a parent or significant adult with a diagnosis of cancer.

Each session covers an emotion and it is designed to be fun and involve discussion, art and play. It aims to assist children to understand and express the feelings they experience when a parent or significant adult has cancer.

CLIMB stands for Children's Lives Include Moments of Bravery. It is co-ordinated by the National Cancer Control Programme and is run through local cancer support centres and hospitals.

You can call our Support Line on Freephone 1800 200 700 to find your nearest cancer support centre. Or visit www.cancer.ie/local-support. There is also more about CLIMB on the HSE's website, www.hse.ie

Things to remember

Trust your instincts

As a parent, you know your children better than anyone else. Your instinct is likely to guide you on what is best to say to them. Try to give them information using your own words. Each family is unique. The way you share and experience what is happening may depend on how your family normally communicates.

Children's feelings

Ask your children how they feel. Children's experience of and reactions to serious illness in the family may be different from yours as an adult.

Listen well

This can be a time of very intense emotions. You can help your children to cope with these feelings by taking time to really listen to what they have to say.

Be honest

Be honest with children as early as possible. Children can sense tension within the family. This can lead them to imagine the situation to be far worse than it is.



Accurate information

It is important that children are given accurate information. They may overhear conversations or rumours from neighbours, another child in the playground or at school that might be exaggerated or incorrect. Perhaps you could include a doctor or nurse when giving information.

Ask questions

Ask questions to make sure they understand what you and others tell them. Information needs to be repeated, as children may reject some things at first or may not understand what they have been told. Give small amounts of information regularly, so children will feel included and know that they are being kept up to date. Try to give the information in simple terms that can be understood easily.

Give them time with you

Where possible try to encourage children to spend time with you even if you are very ill. Although this can appear difficult at the time, it may be valued in the future.

Not their fault

Let children know they are not to blame for anything that has happened and assure them that they will always be cared for.

Praise and encouragement

Praise them for being helpful or thoughtful. They have an enormous amount to contribute. Let them have the chance to do that.

Have fun

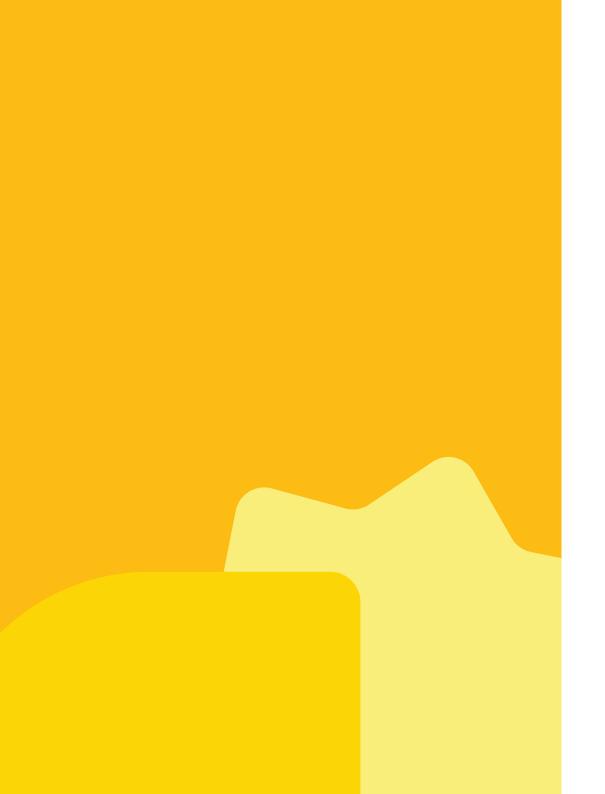
Try not to let your illness take over. Family outings are still important. Let them know it is alright to joke and to have fun. Remember, laughter can relieve tension.





Living with metastatic (advanced) cancer

| Living with metastatic (advanced) cancer | | |
|--|----|--|
| What if I don't get better? | 72 | |
| What you can do to help your children | 75 | |



Living with metastatic (advanced) cancer

Metastatic cancer is cancer that has spread to another part of your body. It is also known as secondary cancer or advanced cancer. Sometimes cancer has already spread when you are first diagnosed. Or, the cancer may come back (recur) after you have had treatment. If this happens, it is best to tell the children and keep them involved with your continuing cancer journey. This is a very difficult thing to do, particularly if there is a chance that you are not going to recover.

Your healthcare or palliative care team can support you and your family at this time. The medical social worker can help prepare you for difficult conversations with your family, including conversations with children.

How children will absorb and understand the information will depend mainly on their age. Most likely you will be able to adapt the information to their level and ability to understand.



What if I don't get better?

Balance hope with reality

If you have been given a diagnosis of metastatic cancer, it is still important to balance hope with reality. Many people with advanced cancer are living for longer and often even doctors cannot give a time frame. It is OK to say this to your children and to tell them that if there is any change, you will let them know.

By sharing your hopes with them – hoping to celebrate an event or go to a football match – while also acknowledging the reality, you will help prepare them for the loss when the time comes.

Be honest and open

Once children know the cancer is advanced, you will need to explain how your illness is expected to progress and a rough idea of time. In some cases, people live for years with metastatic cancer. In others, death may be much closer.

By helping children face death together as a family, you are likely to help them adjust and recover from their grief quicker. At this time, you will want to consider what is important for you, how you want to spend your time and how your children can be involved.



72

If your death is expected more quickly, try to be as honest with your children as you can. You can help lessen their fears by preparing them for what to expect. For example, you might explain that you may be more sleepy or need more medication. The palliative care team will be there to ensure that you are as symptom and pain free as possible. They will be able to support you and your family and discuss your care preferences with you.



What words should I use?

Try to use simple words such as "dying" and "died" when you are talking to children about death. Children can get confused if you use words and phrases such as "passed away", "lost" or "gone to sleep". For example, young children may become fearful of going to sleep. So, it's best to be clear and direct with your language.

Your social worker, palliative care nurse, doctor or counsellor may be able to help you to devise some age-appropriate ways to explain what's happening.

73

What your children might ask ... and what you might say

Who is going to look after me?

Dad/mam/granny/grandad is going to look after you the most. And your auntie Paula is going to help you a lot. You are loved so much and they will look after you and keep you safe.

Why are you going to die?

The treatment stopped working and the doctors can't really make me better. I don't know why it has happened – it is hard to understand. Sometimes sad things just happen.

When will you die?

The doctors say it might be in a year/6 months/a month. Nobody can tell for definite. But we'll have some special times together in the time that is left. (Your answer may change when death is near.)

Will I die too?

No. You can't catch cancer from me. You are safe and you are healthy and well, so you won't die.



What you can do to help your children

In the weeks before

- Create a memory box or scrapbook. Encourage your child to keep mementoes of you, such as photos or personal items like perfume, aftershave, scarves or bits of jewellery.
- Prepare children by explaining how your illness might affect you in the days ahead. For example, you might be sleepy and need a lot more medicine.
- Let them know that it is a time of uncertainty and that no one can know when death will happen.
- Prepare them by talking about what you think and believe death is like. Use simple words that they will understand.
- Listen carefully to what your child wants to say. If your child has any regrets in particular, let them express them at this time. That way, you can forgive them and say how much you love them. Let your child know you are not angry with them but pleased and proud of them.
- If you or the other parent cannot talk about death, others such as a trusted friend or family member, GP, medical social worker, oncology nurse, counsellor, priest or religious leader may be able to help.
- Support your children to express their feelings in a positive way, for example, talking to somebody they trust or listening to music.
- Try to maintain routine and boundaries as much as possible.

Do not worry that you will be too weak or not strong enough to involve your children all the time. What they will remember is the quality of time spent and not the quantity.

Email: supportline@irishcancer.ie

When the time is near

It is important that when the time comes that your child spends some time with you.

- Give your child the chance to say goodbye to you.
- Give yourself a chance to give a final blessing or last wish. This can bring a soothing closure to your relationship. Try not to be too prescriptive, for example, 'I hope you become a doctor, get married and have children of your own'.



Rather you might say, 'I hope that you have a very happy life whatever you choose to do'.

For after your death

There are some things you can do to help your children deal with their grief and prepare for the future. You might like to write letters for the future, especially for important occasions like birthdays. That way you can tell your child more about yourself and your feelings for them. You can also express your hopes and wishes for their future.

Let your children attend or be involved in the funeral or cremation service.

Support for your children

You may like to organise bereavement support for your children and teenagers. Talk to a cancer nurse on our Support Line 1800 200 700 and they can direct you to services that might help or to your local cancer support centre.

Support resources

| Irish Cancer Society services | 79 | |
|-------------------------------|----|--|
| Local cancer support services | 88 | |



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
- Welfare and Supports Team
- Telephone Interpreting Service
- Peer Support
- Patient education

- Counselling
- Support in your area
- Transport Service
- Night Nursing
- Publications and website information



Support Line Freephone 1800 200 700

Call our Support Line and speak to one of our cancer nurses 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, please go to https://www.cancer.ie/Support-Line-Video-Form

You can also email us at any time on supportline@irishcancer.ie.

Daffodil Centres

Visit our Daffodil Centres, located in 13 hospitals nationwide. The centres are staffed by cancer nurses and trained volunteers who 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 of your nearest Daffodil Centre, go to **www.cancer.ie** and search 'Daffodil Centres'.



Who can use the Daffodil Centres?

Daffodil Centres are open to everyone. Just call in if you want to talk or need information on any aspect of cancer including:

- Cancer treatments and side-effects
- Chemotherapy group education sessions
- Emotional support
- Practical entitlements and services
- · Living with and beyond cancer
- End-of-life services
- Lifestyle and cancer prevention
- Local cancer support groups and centres

Welfare and Supports Team

We provide appropriate supports and advice for people living with cancer. This includes:

- Understanding your welfare entitlements
- · Advice on accessing extra childcare
- Telling your boss about your diagnosis/returning to work
- Housing and homelessness issues

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 after a diagnosis. This might include having an Irish Cancer Society Welfare Officer present when discussing your diagnosis with your employer or at meetings with your financial provider to help them understand your diagnosis.

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 Welfare Officers or other supports might be of help.



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.

To be referred to a Peer Support volunteer, call Freephone 1800 200 700 or contact your nearest Daffodil Centre. For more information on Peer Support, search 'peer support' at www.cancer.ie

Patient education

At our free patient education workshops, our cancer nurses provide tailored information before and after cancer treatment.

The workshops take place in person in one of our 13 Daffodil Centres nationwide or online. To register for a place at one of our Patient Education Workshops, call our Support Line on Freephone 1800 200 700, contact your nearest Daffodil Centre or email patienteducation@irishcancer.ie



Counselling

The Society funds professional one-to-one counselling for those who have been affected by a cancer diagnosis. Counselling is available for the person who has been diagnosed, family members and close friends. The services we provide are:

- Remote counselling nationwide, by telephone or video call.
- In-person counselling sessions in cancer support centres around the country.

For more information, call our Support Line on 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, call our Support Line on 1800 200 700 700 or visit www.cancer.ie/local-support

Transport Service

We provide transport and financial grants for patients in need who are in cancer treatment.

- Transport is available to patients having chemotherapy treatments in our partner hospitals who are having difficulty getting to and from their local appointments.
- We have recently opened a pilot service for patients having radiotherapy treatment at University Hospital Cork and Bons Secours Hospital, Cork.
- Travel2Care is a fund for patients who are having difficulty getting to and from their appointments for diagnostic tests or cancer treatment. Patients can apply for this fund if they are travelling over 50 kilometres one way to a national designated cancer centre or satellite centre. Travel2Care is made available by the National Cancer Control Programme.

To access any of these supports, please contact your hospital healthcare professional, call our Support Line on Freephone 1800 200 700 or contact your nearest Daffodil Centre.

Email: supportline@irishcancer.ie

Night Nursing

We provide end-of-life care for cancer patients in their own home. We offer up to 10 nights of care for each patient. Our service allows patients to remain at home for the last days of their lives surrounded by their families and loved ones. This is a unique service in Ireland, providing night-time palliative nursing care to cancer patients, mostly between 11pm and 7am.

For more information, please contact the health professional who is looking after your loved one.

We were really lost when we brought
Mammy home from the hospital and the
night nurse's support was invaluable.
She provided such practical and
emotional support.

Our night nurse was so caring and yet totally professional. We are so grateful to her for being there for Dad and for us.

Support Line Freephone 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 call our Support Line on Freephone 1800 200 700 or contact your nearest Daffodil Centre for free copies of any of our publications.



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 us at supportline@irishcancer.ie
- · Contact your nearest Daffodil Centre
- Follow us on:
 - Facebook/IrishCancerSociety
 - X @IrishCancerSoc
 - Instagram @irishcancersociety
 - · Linkedin @irish-cancer-society

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 partners, families and carers, during and after treatment, many of which are free. For example:

- Professional counselling (the Irish Cancer Society funds oneto-one counselling remotely and 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 yoga, reflexology and acupuncture
- Specialist services such as prosthesis or wig fitting and lymphoedema services, such as education, exercise, selfmanagement 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/local-support

Your notes

Support Line Freephone 1800 200 700

| Your notes | | |
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Acknowledgments

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Join the Irish Cancer Society team

If you want to make a difference to people affected by cancer, join our team! Visit **www.cancer.ie** if you want to get involved.

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

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