Talking to Children about Cancer

A guide for parents
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This booklet has been produced by the Irish Cancer Society to meet the need for improved communication, information and support for cancer patients and their families throughout diagnosis and treatment. We would like to thank all those patients, families and professionals whose support and advice made this publication possible. We would particularly like to acknowledge the contribution of the many consultants, nurses and other healthcare professionals who so kindly gave up their time and expertise to contribute to previous editions of this booklet.

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Introduction
This booklet has been written to help parents, families and carers explain a diagnosis of cancer to children. It also looks at how a cancer diagnosis is likely to affect them. It focuses on the parent with cancer and gives some advice and suggestions to help children of all ages understand a serious illness.

Reading this booklet
The booklet is divided into four sections. The first part deals with talking to children about the diagnosis of cancer. It gives advice on who should tell the child, why, when and how. It also looks at activities that can help children express feelings and emotions.

The next section discusses how children may react to a cancer diagnosis both physically and emotionally. It gives advice on what to say and do, depending on the age of the child.

The third section looks at other concerns that you as a parent may have, such as school or if you do not get better. It also describes the various treatment options and how you can explain these to children.

The final section gives lists of useful organisations, helpful books and websites where you can get more information.

Talk openly
Though you may find it hard to do, it is important to tell your children if you or a relative has cancer. It is best to talk openly to your children and involve them as much as possible in family events. Children who are included in what’s going on are less likely to have problems adjusting to the illness. Even so, it will still be hard learning to adjust.

Help
We hope that you find this booklet helpful. Remember medical social workers, nurses, play therapists and other professionals can help you talk to your children too.

Who can help me talk to my children?
There are many health professionals ready to help you and your family throughout treatment and afterwards. Do 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. All of the people listed below can help. Some are based in hospitals while others work in the community.

Medical social workers: These are specially trained people who work with patients and their families in hospitals. They deal with all social issues and practical needs of you and your family. 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 counselling and giving emotional support to children, adolescents and their families at times of loss and change. You can ask your nurse to put you in contact with one.

Cancer nurse specialists: These are specially trained nurses who are based in large hospitals. They work together with other members of your medical team. They give information and emotional support to patients and their families from diagnosis, treatment and recovery by a team of experts. The team can include psychiatrists, clinical psychologists and specialist nurses working closely together.

Hospital consultant: This is a highly trained doctor who is head of a medical team in the hospital and in charge of your treatment plan. You can discuss any of your concerns with him or her.

Psycho-oncology services: Some larger hospitals have specialists that give extra psychological support to cancer patients who may need it. Care and support is given to these patients during diagnosis, treatment and recovery by a team of experts. The team can include psychiatrists, clinical psychologists and specialist nurses working closely together.

Advanced nurse practitioners: These are specially educated nurses who are highly trained in the diagnosis and management of some medical conditions, including cancer care.
Preparing the way

Impact of a cancer diagnosis

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 concern. You may worry about telling them that you have cancer.

Why should I tell my children about cancer?

Your first reaction might be to keep the news from your children or delay telling them. The natural instinct of adults is to protect children, particularly when something sad, uncertain or unusual is happening. But it is important to include them in what is happening so that they will not feel left out, or imagine things are a lot worse than they really are.

It may be hard for you to even admit that you are ill let alone say anything to your children. You may be distracted by your illness too, coming and going from hospital. You may feel too tired and be focused on getting through the treatment yourself. As a result, it may not be easy to see what’s going on with your children. All parents find this situation hard.

Deciding to share information

There is no doubt that deciding to share information is a big step. Even though you know your children best, you may be surprised at how well they deal with the truth, even if it seems sad or frightening to an adult. We cannot stop children feeling sad but if we share our feelings and give them information about what is happening, we can offer them help and support in their sadness.
Talking to children about cancer

Children may feel isolated if they are not told. They might feel they are not important enough to be included in a family matter. By telling them, it can be a relief for parents to have everything out in the open. It is also a way of admitting that family life is different now. As a family, you will all be learning to change together. Some people might find this easier than others.

The effects of not talking

Cancer is impossible to keep secret. Whatever their age, not telling children does not necessarily spare them from anxiety or prevent them from knowing something is wrong. Trying to protect your children can sometimes make things worse. Cancer affects the feelings and emotions of the whole family. Children, even very young ones, quickly pick up on changes in family life such as tension or unusual comings and goings and changes in your physical appearance.

There is also a chance that children may find out the truth from someone else or may discover it by accident. This could come from overhearing a private conversation at home or at school. If a child does not know the true facts, they could get misleading information elsewhere. Information about cancer can come from many places: the internet, watching television or reading magazines.

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 what it really is, especially if they have ever experienced bereavement in the family. So living with uncertainty can be even harder for children.

Benefits of talking to children

If children are encouraged to talk 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.
Talking to children about cancer

When should I tell my children?
Choosing the time to tell is not always easy. Often there may be 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, ‘Daddy is in hospital to have some tests. We’re not sure yet what’s wrong, but when we do know we will tell you.’ If your children are allowed into the hospital, perhaps Dad can even tell them himself if he feels up to it.

It may be better to do this 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 the treatment, you may want to explain this beforehand so it does not come as a shock. Children can accept changes if told about them in advance.

Who should tell my children?
Choosing the person who will tell may be another concern. In general it is easier if the information comes from someone who is close to your child. The ideal person would be you, the parent who has cancer, or the other parent 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.

Someone close to your child
If you are unwell or staying in a hospital far from home, a person familiar to your child, perhaps a parent, grandparent, aunt or uncle, may wish to tell your children. Do check with that person first that they are prepared and ready to be involved in this conversation and will continue to support your child.

A child is likely to be more comfortable with and trust someone who is known to them. It is of course 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 your children from the hurt and sadness surrounding an illness. But children are likely to be more hurt if they are not told or included.

Do keep in touch with your children. If you are in hospital for any long period of time, your children may think that things are going badly. By staying in touch, you can reassure them that the hospital is the best place for you at this time. Remember it takes a lot for your children to adjust to you being away.

Seek support
You may decide to break the news with the support of a doctor, nurse or a medical social worker. In this way you can comfort your children and you are not left alone to deal with their reactions.

Regardless of who tells your children, make sure the information is accurate and suitable for their age group. This will be explained in more detail on page 21. But do bear in mind that children can sometimes understand more for their age.

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 okay. Don’t be afraid to say such things 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 him and then I’ll tell you. If we see him while you’re here, then you can ask him yourself.’

**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 to find someone to help look after your child.

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

The ill parent should be visited regularly. Find a way to keep the two 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 as well. If times for visiting you in hospital change, let your children know why and for how long the change in routine will happen.

Where should I tell my children?

The place where you tell your child about cancer is another matter. It may be easier for all if it is discussed in a comfortable environment. This could be perhaps at home, at mealtimes, playtime or when out for a walk. It may be best to do it early in the day, so that you can spend time together or talk again before bedtime.

It can be hard to sit down just to break difficult news. It may seem like a formal or embarrassing thing to do. Think about what worked when you have had to tell children important news in the past. Sometimes it can be easier to talk when doing something normal like walking, playing or doing something else together. 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 his or her bedroom may not be a good idea. This may be the only comfortable and safe place your child can escape to afterwards.

How can I tell my children?

Finding a way to tell may take some time and thought. At the time of diagnosis, you may want to tell your children individually. You could tell the eldest first and possibly little ones together. How the eldest is told and copes afterwards can have a big impact on how the younger ones respond. Children often differ a lot in what they can understand at a particular age. It can help to give information at the level of your child’s understanding and not just their age. Young children need clear, simple explanations. Avoid confusing explanations. Also, link explanations to what your child may have already noticed.

It can help to rehearse what you are going to say too. That way it might help you to foresee any questions your child might ask.

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**Tips & Hints – for parents**

- Decide together who will tell your child and what to say.
- Work together and share the burden.
- 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.
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.
- Give some details about the treatment in simple, clear language.
- Tell them you are not sure how things will work out.
- 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 the internet, and so may have their own ideas of what having cancer means.

It may be useful to talk through their thoughts and ideas with them. It is possible that your child has 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. Do explain 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. 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 the 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...’

Descriptions of cancer

Below are some descriptions of cancer that may be used. Again this will depend on the age of your child.

1 ‘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.’
2 ‘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.’
3 ‘Cancer is an illness of the body that can be in different places for different people.’
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 about what they really want to know.

Using 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. As you know, 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. Even so, they may be able to talk to adults about their thoughts and feelings.

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 expresses concerns or worries, you can then talk these over with them and reassure them. You can also explain any information that your child 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.

At the centre of this booklet is a pull-out activity sheet with suggested exercises to help children express feelings and emotions, if that is what your child would like to do. Trust your child to decide what he or she 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. Please trust your own instincts.

If you are worried that your child continues to express sadness or anger – or any other emotion that troubles you – do talk to the medical social worker or let your nurse arrange for them to talk to you. Or you could also talk to your GP or a counsellor. See pages xx for more information.
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 okay to cry and explain to your child that you are crying because you feel sad.

Assure 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 or grandmother. When you talk about your illness, do 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.

If you are worried that your child continues to express sadness or anger – or any other emotion that troubles you – do talk to the medical social worker or your GP.

Tips & Hints – 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.
- Treat older children and teenagers separately to younger children in the family when telling them about cancer.
- Say to your child ‘I don’t know’ if you are unsure about anything.
- Encourage your child to talk to you whenever they want.
- Listen carefully to what your child has to say.
- Tell your child he or she is still loved and cared for.

Tips & Hints – 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.

To sum up

- Children feel isolated if not told about cancer.
- Not telling children does not always spare them from anxiety.
- Telling children can help them learn about emotions and feelings, which can help them in the future.
- Tell children a little at a time in the early stages of the illness and before a change occurs.
- Whoever tells your children should be someone close or familiar to them.
- Tell children in a comfortable environment.
- Explain to them in language they will understand, using words suitable for their age.
- Explain what the illness is. Use the word cancer.
- Explain how your health or the other parent’s will be affected by cancer.
- Give some details about the treatment.
- Tell them if you are not sure how things will work out, but that you will still keep them up-to-date.
Children reacting to a cancer diagnosis

Talking to children of different ages and stages

The following pages explain how children, at various ages and stages of development, are likely to 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.

Children under 3 years

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 and hugs and attention during this time.

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.’

At this age children are very sensitive to change. Explain any changes in routine to your child in terms of how it will affect them. This explanation should come before the change if possible. The time when children are most likely to be upset is when you are not there. For this reason, keep to normal routines, where possible, especially at bedtime and feeding. Children will feel safe when there is little or no change to their daily routines.

If you are in hospital and cannot be with your child, let those who your child knows well care for them. This might be a grandparent,
an aunt, the childminder or a family friend. Be sure they know your child’s routines, favourite foods, books and toys, as familiar things will bring comfort.

Children will feel safe when there is little or no change to their daily routines.

Children between 3 and 5 years
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 to stay with them. This may help reduce fears around separation and being left alone.

If you are in hospital, it may be helpful for your child if you can talk to them on the phone. You can then reassure them that it is hard being apart from them at this time. Let them visit you if this is allowed by the hospital. Hospitals are loud busy places and can be scary for children. So your child might feel more comfortable if they bring a special toy with them.

Non-verbal behaviour
If young children are upset, it can be hard for them to express it in words. Instead they may become clingy or quiet and withdrawn. They may also start to do things they’ve outgrown, like bedwetting, thumb sucking or waking at night. Encourage your child to talk about what they are feeling. If symptoms persist, do talk to your doctor.

Reassurance
Sometimes children at this age believe that they have caused the illness because of something they have done or thought. Assure them that this is not the case. Nothing anyone can say or think can cause another person to be sick. Even though this age group can have feelings of guilt, they do not last long. They need reassurance that they are loved, valued and will always be cared for.

Children between 6 and 12 years
Children at this age think logically, understand rules and gender/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.

As with younger children, you may notice some changes in their behaviour. This may include changes in eating habits and sleeping patterns. Their attitude to schoolwork and friendships may change. They may become withdrawn and quiet. Encourage them to talk or express their feelings.

At this stage, children may go back to behaving as if they were younger. This is quite natural and is their way of showing their upset and distress. In some children it may be a way of trying to get attention from adults. They may appear angry at the person who is sick or for the changes in the home.

Older children may become more anxious or worried about a parent’s health. This is because they are gaining a better knowledge and understanding of what a serious illness means.

Teenagers
Children at this age 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. Some will rebel and regress in behaviour, acting like younger children. Others will take on extra responsibilities and 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.
More responsibilities
If you are ill your teenage children may be asked to take on more responsibilities. They may have to mind your other children at home and cook meals. You can help teenagers during this difficult time by making them feel appreciated for doing the extra work. Encourage and thank them for their support. On the other hand, if the extra jobs leave them feeling overburdened, they may believe that their needs are not being met. In this case, it is a good idea to take up all offers of help from your relatives and friends.

Isolation
Teenagers may feel isolated from their friends due to the changes in family routine. They may be slow to invite friends home and may prefer to spend more time in their friends’ houses. As far as possible, continue with family routines that were in place before your illness. Routine is important and teenagers need to know that the same rules apply.

Most teenagers want to be treated as adults. However, due to the impact of your illness and the changes it may bring, they may not know what to do. Guidance and reassurance from you can help them at this time. Allow them their time to visit you in hospital.

Children with special needs
If your child has a developmental disability, you may worry even more over 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. As you know, 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. You are likely to know the best way to explain new things to your child. 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

Phone 1800 200 700 for more copies of this leaflet.
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.

Sad? Happy? Disappointed? Jealous?

Angry? Embarrassed? Afraid? Brave?

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 17 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 17 for more about drawing exercises.

day and what will be the same. You could 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 34 for more details about school. Whatever the age of your child, professionals such as medical social workers are experienced in supporting young people and their families in coping with a serious illness.
What emotional reactions can I expect?

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. Indeed children can 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 the booklet can help children identify these feelings and express them. See page 17 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. Clear information that is suitable for the age of your child may help to reduce fear. 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. In fact, 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 may be unwell or have to attend the hospital. Explain that you have to keep hospital appointments even though you would prefer to stay with them.

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**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 that they may not understand.

Older children may also become upset and angry if they are not told enough information about your illness and 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 poetry. 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.
Talking to children about cancer

Try to get your child to talk about what is troubling them. A simple question such as ‘You seem very thoughtful [sad, worried, etc.] these days. Can you tell me what’s happening?’ 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 behaviour could include reckless driving, taking drink and drugs or having sex at a very early age. Or it could involve any behaviour out of character for them. To get advice and help, speak to your GP, medical social worker, nurse, psychologist or the psycho-oncology unit, if there is one at your hospital.

What physical reactions can I expect?

As well as emotional reactions, children just like adults can have some physical reactions too. For example, upset tummies, difficulty in sleeping and so on. Some children may complain of symptoms like your cancer symptoms. This can be another way of showing that they are upset.

Very young children may become clingy or quiet and withdrawn. They may also start to do things they’ve outgrown, like bedwetting, thumb sucking or waking at night. If symptoms persist, do talk to your doctor. It is also best to tell your children that cancer is not an infection so they will not ‘catch’ it.
Talking to children about cancer

Other concerns

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 in hospital. It may be possible for your child to visit you in hospital. This can be discussed beforehand with the staff in the hospital, if you wish.

The following are some ways to explain how treatment works.

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. By doing so, your children will be prepared when they visit.

Chemotherapy and targeted therapies

Chemotherapy and targeted therapies can be described to children as special medicines to fight the 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 less side-effects.

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.

To sum up: ages and stages

- Expect your child’s behaviour to reflect what they’re feeling.
- A child can experience emotions such as fear, anger, guilt, loneliness, sadness and envy during a parent’s serious illness.
- A child can experience physical reactions such as upset tummies, bedwetting, thumb sucking, trouble sleeping or being very quiet.
- Children under 3 may feel abandoned when a parent is in hospital. They will need lots of love, hugs and attention during this time.
- Children between 3 and 5 may also feel abandoned when a parent is in hospital. This age group needs lots of reassurance that they are loved and cared for.
- Children between 6 and 12 may have changes in behaviour in their eating habits and sleep patterns. They may act younger than their age.
- Teenagers may have to take on extra responsibilities. Involve friends and relatives so that teenagers are not overburdened.
- Children with special needs will need extra help adjusting to new routines or changes in your appearance.

To sum up: what to do

- Listen to and respect your child’s feelings.
- Let your child visit you in hospital.
- Stick to normal routines as much as possible.
- Calm your child with love and security.
- Remind them that although there will be changes, other things will remain the same, for example, school and friends.

Cancer Nurseline Freephone 1800 200 700
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 fantasise about 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. 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 do let teenagers know what times they are clearly expected to be at home for family time. For example, meals, special events, and so on.

Email: cancernurseline@irishcancer.ie
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. In fact, they may behave just as they did before your illness. However, the behaviour of some children may change at school.

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.

Let the teacher know

It is best to let your children’s teachers know about your illness. This will allow the teachers to react sensitively and find helpful ways of working with your child. A teacher can also let you know how your child is coping. It is important to discuss this with your child before letting the school know.

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. Then again, they may 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 him or herself.

To sum up

- Explain to children why they have to go to school during your illness.
- Keep up familiar and normal routines as it helps children feel secure.
- Some children will experience no problems at school while others may have behaviour problems.
- Let the teacher or school principal know about your illness.

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 bonds 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, especially if you are living some distance which may not allow for daily visits. If your children do not want to visit you in hospital, don’t force them to come. Instead try to talk through why they do not want to visit and so relieve any fears they might have.

Tips & Hints – things to consider telling the teacher or school principal

- 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 cancer to mean.
- Any fears or concerns your child has about cancer.
- How your child copes or how they ask for help.
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 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, use Skype/FaceTime 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 and counselling to you and your family at this time.

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 your children feel they are being of help, it will make them feel better.

Draw images
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, what they saw. This can be a good way to express emotions and a chance for you to talk about it together.

Write about emotions
You can encourage your teenage children to keep a journal or diary. This may help them to express their emotions and feelings.

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 plays, are still important. You could let your children know that it is alright to joke and to have fun. Laughter can often relieve tension and make everyone relax.

Tips & Hints – sharing experiences in hospital
- Let your children visit you on the ward or day room.
- Let them see your bed or armchair, the call bell, etc.
- Phone your child from hospital and let them ring 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.

Tips & Hints – 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 DVD 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.
What if I don’t get better?

Most parents dread to hear the question ‘Are you going to die?’ Because your natural reaction is to protect your children, you may be tempted to say that everything will be fine. But in the long run, it is best not to give children false hope.

If there is a chance that you are not going to recover, it is still important to balance hope with reality. 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 the time, and how your children can be involved.

The weeks before

1. Create a memory box or scrapbook. Encourage your child to keep mementoes of you – pictures, photos, personal items like perfume, scarves, bits of jewellery, etc.
2. 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.
3. Let them know that it is a time of uncertainty and that no one can know when death will happen.

Ways to respond to the question ‘Are you going to die?’

- ‘Sometimes people die from cancer. I’m not expecting this to happen because the doctors told me they have very good treatments these days. My type of cancer usually goes away with treatment.’
- ‘There is no way to know right now what’s going to happen. I’ll know more after the first treatments are finished. When I know more, I’ll be sure to tell you.’
- ‘Right now there is not a lot known about the kind of cancer I have. But I’m going to give it my best shot and do everything I can to get well. I will always be honest with you about what is going on.’

4. Prepare them by talking about what you think and believe death is like. Again use simple words that they will understand.
5. Avoid euphemisms like ‘going to sleep’ or ‘going away’. This may confuse or frighten your child. Use exact words like ‘when I die…’
6. 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.
7. 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.

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 its quantity.

When the time comes

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

1. Give your child the chance to say goodbye to you.
2. Give yourself a chance to give a final blessing or last wish. This can bring a soothing closure to your relationship. Don’t express a wish for them that could become a burden to fulfil.

Afterwards

There are some things you can do to help your children in the months ahead as they deal with grief. These things will help prepare them for the future.

1. Continue adding to the memory box. You could include school reports, swimming certs or medals won for sports or any kind of achievement.
2. 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. It can also express your hopes and wishes for their future.
3. Let your children attend or be involved in the funeral or cremation service.
Support resources

Coping with the financial impact of cancer

A diagnosis of cancer often means that you will have extra expenses, like car parking during hospital visits, medication, travel, heating and childcare costs. If you can’t work or you are unemployed, this may cause even more stress. It may be harder for you to deal with cancer if you are worried about money.

Medical expenses

Medical expenses that you might have to pay include:

- Visits to your family doctor (GP)
- Visits to hospital
- Overnight stays in hospital
- Medicines
- Appliances, like wigs

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

If you have a medical card, you will probably have very little to pay for hospital and GP (family doctor) care or your medication.

Medical cards are usually for people on low incomes, but sometimes a card can be given even if your income is above the limit. For example, if you have a large amount of medical expenses. This is known as a discretionary medical card.

An emergency medical card may be issued if you are terminally ill and in palliative care, irrespective of your income.

If you do not have a medical card you will have to pay some of the cost of your care and medication.

If you have health insurance the insurance company will pay some of the costs, but the amount will depend on your insurance plan. It’s important to contact your insurance company before starting treatment.

Things to remember

- **Trust your instincts**: If you are a parent, you know your children better than anyone else. Your instinct is likely to tell you what is best to say to them. Try to give them information using your own words. Each family is unique and 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 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 what it actually is.
- **Accurate information**: It is important that children are given accurate information. They may overhear conversations or rumours from neighbours or neighbour’s children or in the playground that might be exaggerated or incorrect. Perhaps you could include a doctor or nurse when giving information.
- **Ask questions**: Ask questions to make sure that 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.
- **Spend time with the ill parent**: 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. Laughter can relieve tension.
**Benefits and allowances**

There are benefits available from the Department of Social Protection that can help people who are ill and their family. For example, Illness Benefit, Disability Allowance, Invalidity Pension, Partial Capacity Benefit, 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 you are attending
- Citizens Information – Tel: 0761 074 000
- Department of Social Protection (DSP) – Tel: 1890 662 244 or ask to speak to a DSP representative at your local health centre or DSP office.

Always have your 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 financial difficulties**

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 0761 07 2000 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. The Irish Cancer Society can also give some help towards travel costs in certain cases. See page 44 for more details of our Volunteer Driving Service and the Travel2Care fund.

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

**More information**

For more information please see our booklet, *Managing the Financial Impact of Cancer – A Guide for Patients and their Families*. This explains:
- Medical costs and help available
- Benefits and allowances that you or your family may qualify for

**Travel services**

- Ways to cope with the cost of cancer

The booklet also has lots of other information to help you manage the cost of cancer. For example, disability and mobility supports, help for people in financial difficulty, help for carers and living at home and nursing home supports.

The booklet is available on our website: [www.cancer.ie/publications](http://www.cancer.ie/publications)

**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:

- Cancer Nurseline
- Daffodil Centres
- Survivor Support
- Support in your area

- Patient travel and financial support services
- Night nursing
- Publications and website information

**Our Cancer Nurseline Freephone 1800 200 700.** Call our Cancer Nurseline and speak to one of our cancer nurses for confidential advice, support and information. You can also email us on cancernurseline@irishcancer.ie or visit our Online Community at [www.cancer.ie](http://www.cancer.ie)

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

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

**Our Survivor Support.** Speak to someone who has been through a cancer diagnosis. Our trained volunteers are available to provide emotional and practical support to anyone going through or finished with their treatment.
- **Support in your area.** We work with cancer support groups and centres across the country to ensure cancer patients have access to confidential support including counselling. See page 45 for more information.

- **Patient travel and financial support services.** We provide practical and financial support for patients in need, travelling to and from their cancer appointments. There are two services available through the Society:
  - **Travel2Care** is a limited fund, made available by the National Cancer Control Programme, for patients who are having difficulty getting to and from their treatments while attending one of the national centres of excellence or their approved satellite centres.
  - **Irish Cancer Society Volunteer Driving Service** is for patients undergoing chemotherapy treatments who are having difficulty getting to and from their local appointments in our partner hospitals.

To access either of these services please contact your hospital healthcare professional.

- **Irish Cancer Society 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 the only service of its kind in the Republic, providing palliative nursing care at night to cancer patients.

- **Our publications and website information.** We provide information on a range of topics including cancer types, treatments and side-effects, coping with cancer, children and cancer, and financial concerns. Visit our website www.cancer.ie or call our Cancer Nurseline for a free copy of our publications.

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**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 and their families, during and after treatment, many of which are free. For example:

- **Professional counselling** (the Irish Cancer Society funds up to 8 sessions of free counselling in many affiliated support services)
- **Support groups**, often led by professionals like social workers, counsellors, psychologists, or cancer nurses
- **Special exercise programmes**, like the Irish Cancer Society’s *Strides for Life* walking group programme
- **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 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 Cancer Nurseline on Freephone 1800 200 700 to find your nearest cancer support centre. Or see our online directory at [http://www.cancer.ie/support/support-in-your-area/directory](http://www.cancer.ie/support/support-in-your-area/directory)

Email: cancernurseline@irishcancer.ie
Helpful books

The Irish Cancer Society has a wide range of information on reducing your risk of cancer, different types of cancer, treatments, and coping. For free copies call the Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can also download or order the booklets on our website: www.cancer.ie.

You may find the following helpful:

Understanding the Emotional Effects of Cancer
Who Can Ever Understand? Taking About Your Cancer
Coping with Fatigue
Understanding Cancer and Complementary Therapies
A Time to Care: Caring for Someone Seriously Ill at Home
Lost for Words: How to Talk to Someone with Cancer
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 Survivor 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 Cancer Nurseline on Freephone 1800 200 700 if you want to get involved!

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**Did you like this booklet?**
We would love to hear your comments or suggestions.
Please email reviewers@irishcancer.ie

**More information and support**
If you would like more information or someone to talk to, now or at any time in the future, please call our Cancer Nurseline on 1800 200 700.