

Talking to Children about Cancer

A guide for parents

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This booklet has been produced by Nursing Services in 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.

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Published by the Irish Cancer Society.
© Irish Cancer Society 2007, revised 2008, 2011, 2013
Next revision: 2015

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ISBN 0-95323-690-1

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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.

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.

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.

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.



National Cancer Helpline Freephone 1800 200 700

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. When speaking to professionals, ask that they 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 in learning 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 and throughout treatment.

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.
Cancer counsellors	These are specially trained people who give psychological support to patients with a cancer diagnosis and to their families. They can be based in either hospitals or in the community. For details about the Irish Cancer Society's cancer counselling service, see page 52.
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. He or she can arrange professional help for you.

National Cancer Helpline Freefone 1800 200 700

Community health services	These are services available from your local health centre. They include family doctors, public health nurses, registered nurses, welfare officers and home-help organisers. They can visit you in your home and give advice and support.
Community welfare officer	This person can help with practical issues, such as financial worries. They were formerly employed by the Health Service Executive (HSE) but now come under the Department of Social Protection (DSP). They are based in health centres or DSP offices and manage the Supplementary Welfare Allowance scheme.
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. See pages 43–48 for a list of cancer support groups. You can also download the Irish Cancer Society's <i>Directory of Cancer Support Services</i> from www.cancer.ie
Irish Cancer Society	The staff of the National Cancer Helpline will be happy to discuss any concerns you or your family may have at any stage of your illness. This can include practical advice on talking to children about cancer. They can also let you know about support services and other practical supports in your area. The Helpline freefone number is 1800 200 700. You can also visit a Daffodil Centre if one is located in your hospital. For more information on Daffodil Centres, see page 52.



Preparing the way

Impact of a cancer diagnosis

When you learn that either you or someone close to you has cancer, it can be a shock. At the time you are likely to have a wide range of emotions, anxieties and concerns. At first, it can be hard coming to terms with your own worries about the diagnosis and treatment. If you have children, thinking about their emotional needs and how to talk to them will be an extra concern. You may worry over 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, excluded 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. Remember too that some things just cannot be made better in a short space of time.

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.

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 from the pretence for parents. 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.

>>> 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.

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. Protecting 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. Nowadays 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.

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.

>>> A good time to talk about cancer is before some obvious change occurs.

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 him or her.

A child is likely to be more comfortable with and trust someone who is known to him or her. 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 supports than are usually found in a two-parent family. 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.



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.



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.

>>> Young children need clear, simple explanations.

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.

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.'

What words should I use?

Choose your words carefully so that your children are clear about what is being said. Children need to be given information in words they can understand. For example, older children may be familiar with the exact names of parts of the body, whereas 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 too 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	Problems 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 31 for more tips on explaining cancer treatments.

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 occur 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/Granddad, etc.]. 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.'

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 5–7 for more information.

>>> 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.

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, 'Mummy 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.

>>> 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.

- Be honest.
- Let children know how the situation affects you.
- It is okay to cry in front of your children.
- Use books and activities to help you explain about cancer.

>>> 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 his or her 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 much 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.

>>> 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 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, especially if one has been admitted to hospital, 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 children 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. Invite them to visit you if this is allowed by the hospital. Hospitals are loud busy places and can be very scary for children. So your children might feel more comfortable if they bring a special toy or plaything with them.

Non-verbal behaviour

If young children are upset, it can be hard for them to express it in words. It may be seen in behaviour changes such as 'clinging', bedwetting, thumb sucking, trouble sleeping, or being quiet and withdrawn. Encourage your child to talk about what they are feeling.

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's illness. 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 or are aware that other families are experiencing.

As with younger children, you may notice some changes in the behaviour of children in this age group. These may include changed eating habits and sleeping patterns. Their attitude to schoolwork and friendships may be different from before. They may become withdrawn and quiet. Encourage them to talk or express their feelings in another way.

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 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 and counselling young people and their families in living with the impact of 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 18 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.

»» Clear information that is suitable for the age of your child may help to reduce their fear.

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 be even 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.

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.

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.



Tips & Hints – 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 – thumb sucking.
- Being silent, withdrawn or self-critical.
- Self-destructive behaviour – using drink or drugs.
- Premature sexual relationships.
- Risk taking – reckless driving.

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.

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

Cancer may not be the only problem

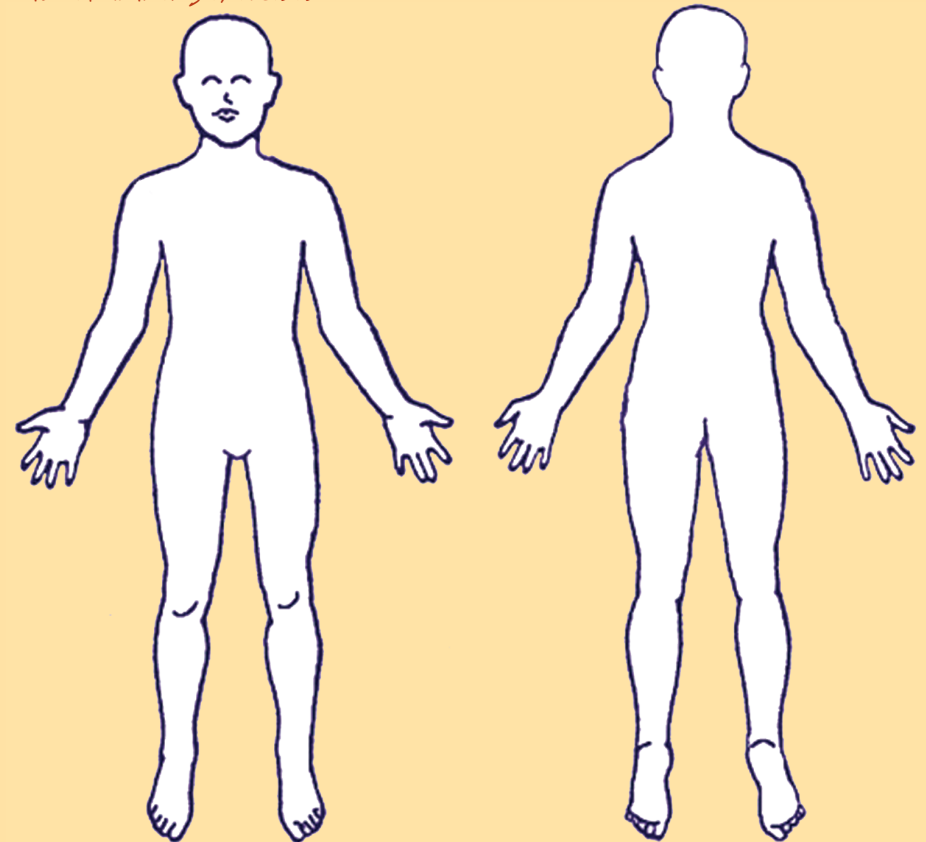
It can often feel as if cancer has taken over a family's life. But remember that there may be other things going on in your child's life that could explain their behaviour. For example, your child may be having difficulty adjusting to a new teacher or they may be having problems with a friend.

ACTIVITY 1

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 18 for more about drawing exercises.



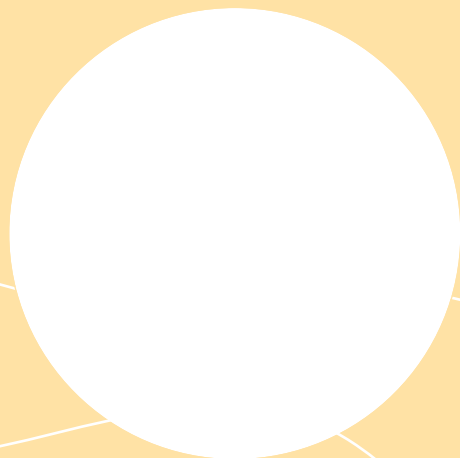
Phone 1 800 200 700 for more copies of this leaflet.



ACTIVITY 2

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.

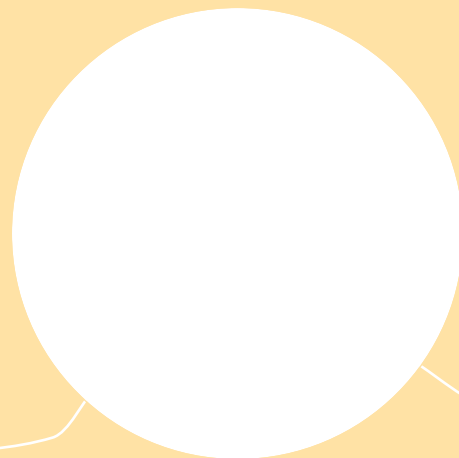
This exercise might help you and your child to identify and explore some of the many feelings experienced when somebody in the family is sick. See page 18 for more about drawing exercises.



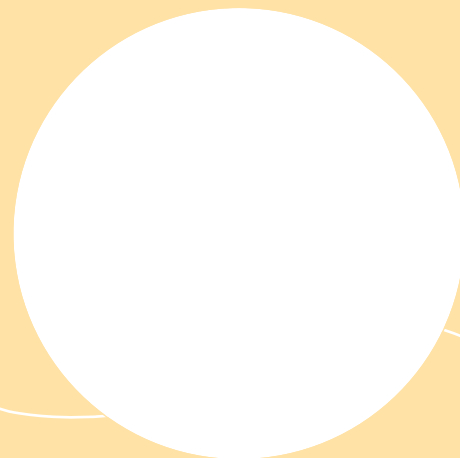
Sad?



Happy?



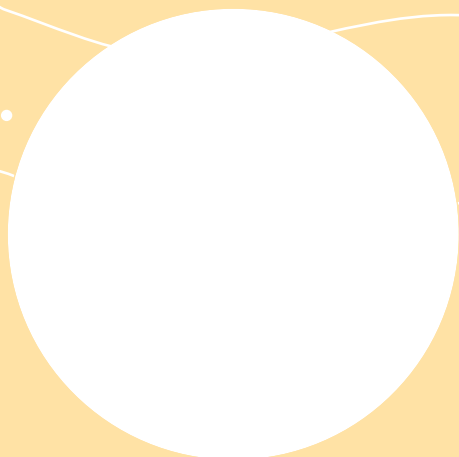
Disappointed?



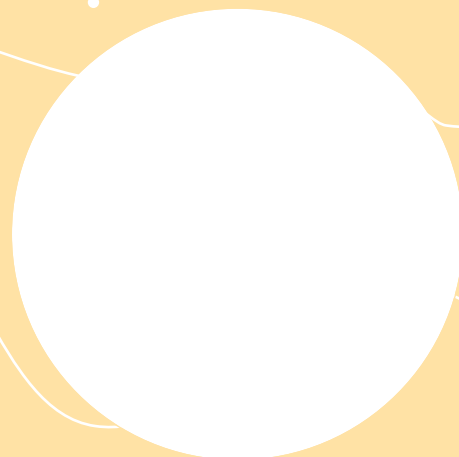
Jealous?



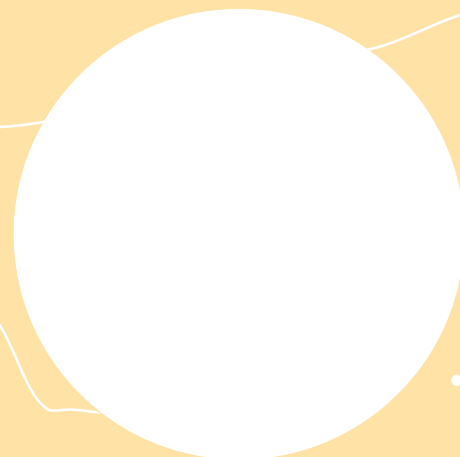
Angry?



Embarrassed?



Afraid?



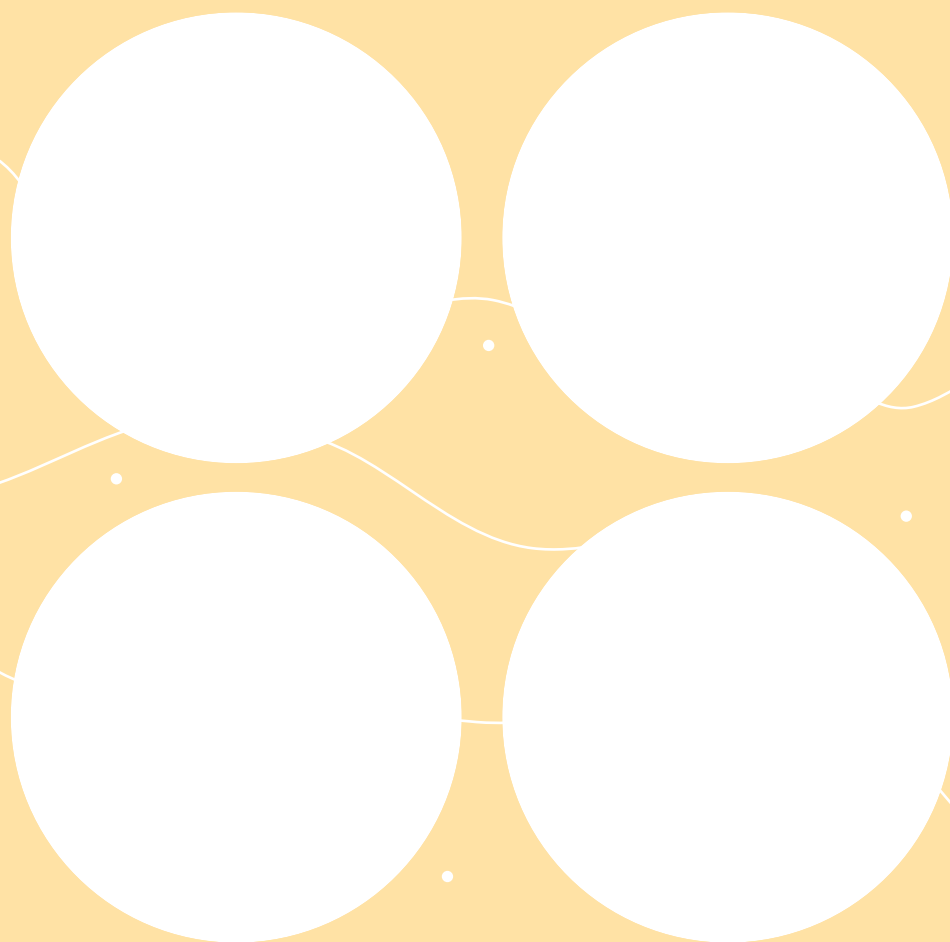
Brave?

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 18 for more about drawing exercises.



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 have changes in their behaviour such as 'clinging', bedwetting, thumb sucking, being quiet and withdrawn or having trouble sleeping.

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.



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.



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 him or her feel more comfortable and secure about you in hospital. It may be possible for your children to visit you while in hospital having treatment. This can be discussed beforehand with the staff in the hospital, if you wish.

»»» If your child shows an interest or is concerned with your treatment, it might be useful to explain how it works.

The following are some ways to explain how treatment works.

Surgery

Surgery may be needed 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

Chemotherapy can be described to children as the drug treatment that is used 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. Sometimes you may be given chemotherapy through an infusion pump over a varied period of time, depending on the treatment. This could involve a small bottle placed in a bag that can be worn over your shoulder even at home. Usually chemotherapy is given regularly over a period of months, where you are admitted to hospital or come in as a day patient.

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.

Targeted therapies

These are special drugs used in the treatment of cancer. They are also known as biological therapies. They target certain proteins on the surface of cancer cells to prevent the cells from growing and to kill them. The therapies are usually given for longer periods than chemotherapy. There are less side-effects to them than chemotherapy but they may be more long term.

>>> It is helpful for children if they are prepared for the possible effects of the treatment.

Side-effects of treatment

It is helpful for children if they are prepared for the possible effects of the treatment. Find out from your doctor and nurse what side-effects you might get and discuss them with your children. Remember that each person is individual and reacts to treatment in their own way. Side-effects may include the following:

- **Hair loss:** Loss of hair can be caused by chemotherapy. It can also occur when receiving radiotherapy to the head. This can happen gradually for some or more suddenly for others. Do prepare and reassure your children that your hair will grow back after the treatment has finished. Let them become familiar with any scarves and wigs that you choose to wear.
- **Nausea and loss of appetite:** Some people may have nausea and loss of appetite when having treatment. These symptoms may be helped by medicine. Explain to your children that these side-effects are normal and due to chemotherapy.

- **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. Because of taking regular medicine, explain to your children that you are likely to sleep more often and need more rest.



To sum up: what to do

- Surgery may be needed to remove cancer cells.
- Chemotherapy is a drug treatment used to fight cancer.
- Targeted therapy is a drug treatment used to fight cancer.
- Radiotherapy is very strong X-rays used to kill the cancer cells.
- Side-effects of treatment can include hair loss, nausea and loss of appetite, and tiredness.

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.

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.



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.

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.

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, send text messages or use a camcorder.

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.



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.'

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.
- 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. For example, 'I hope you become a doctor!'

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.



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.



Support resources

Useful organisations

Irish Cancer Society

43/45 Northumberland Road
Dublin 4
Tel: 01 231 0500
National Cancer Helpline:
1800 200 700
Email: helpline@irishcancer.ie
Website: www.cancer.ie

The Carers Association

[Includes information and support for young carers]
Market Square
Tullamore
Co Offaly
Tel: 057 932 2920
Freefone: 1800 240 724
Email: info@carersireland.com

Children in Hospital in Ireland

Carmichael Centre
Coleraine House
Dublin 7
LoCall: 1890 252 682
Email: info@childreninhospital.ie
Website: www.childreninhospital.ie

Citizens Information

Citizen Information Phone Service:
0761 07 4000
Email: information@citizensinformation.ie
Website: www.citizensinformation.ie

Irish Oncology and Haematology Social Workers Group

Website: <http://socialworkandcancer.com>

Money Advice and Budgeting Service (MABS)

Commercial House
Westend Commercial Village
Blanchardstown
Dublin 15
Tel: 01 812 9350
Helpline: 0761 07 2000
Email: helpline@mabs.ie
Website: www.mabs.ie

Health insurers

AVIVA Health

(formerly VIVAS Health)
PO Box 764
Togher
Cork
Tel: 1850 717 717
Email: info@avivahealth.ie
Website: www.avivahealth.ie

GloHealth

PO Box 12218
Dublin 18
Tel: 1890 781 781
Email: findoutmore@glohealth.ie
Website: www.glohealth.ie

Laya Healthcare (formerly Quinn)

Eastgate Road
Eastgate Business Park
Little Island
Co Cork
Tel: 021 202 2000
LoCall: 1890 700 890
Email: info@layahealthcare.ie
Website: www.layahealthcare.ie

Voluntary Health Insurance (VHI)

IDA Business Park
Purcellsinch
Dublin Road
Kilkenny
CallSave: 1850 44 44 44
Email: info@vhi.ie
Website: www.vhi.ie

National support groups

ARC Cancer Support Centres

Dublin and Cork (see pages 45 and 46).

Brain Tumour Support Group

Medical Social Work Department
St Luke's Hospital
Highfield Road
Rathgar
Dublin 6
Tel: 01 406 5163

CanTeen Ireland

Young Peoples' Cancer Support Group
Carmichael Centre
North Brunswick Street
Dublin 7
Tel: 01 872 2012
Freefone: 1800 200 700
Email: info@canteen.ie
Website: www.canteen.net

Lakelands Area Retreat & Cancer Centre

[Includes specialist support for children]
Multyfarnham
Mullingar
Co Westmeath
Tel: 044 937 1971
CallSave: 1850 719 719
Email: info@larcc.ie
Website: www.larcc.ie

Thyroid Cancer Support Ireland

Cooksgrove
Killynan Cooke
Cloghan
Mullingar
Co Westmeath
Tel: 087 909 0836
Email: info@thyroidcancersupport.ie
Website: www.thyroidcancersupport.ie

Connaught support groups & centres**Athenry Cancer Care**

Social Service Centre
New Line
Athenry
Co Galway
Tel: 091 844 319 / 087 412 8080

Ballinasloe Cancer Support Centre

Society Street
Ballinasloe
Co Galway
Tel: 090 964 5574 / 087 945 2300
Email: ballinasloecancer@yahoo.co.uk

Cara Iorrais Cancer Support Centre

2 Church Street
Belmullet
Co Mayo
Tel: 097 20590
Email: caraiorrais@gmail.com

East Galway Cancer Support Centre

The Family Centre
John Dunne Avenue
Ballinasloe
Co Galway
Tel: 087 984 5574 / 087 945 2300
Website: www.eastgalwaycancersupport.com

Gort Cancer Support Group

The Hawthorn
Ennis Road
Gort
Co Galway
Tel: 086 312 4220
Email: gcsupport@eircom.net
Website: www.gortcs.ie

Mayo Cancer Support Association

Rock Rose House
32 St Patrick's Avenue
Castlebar
Co Mayo
Tel: 094 903 8407
Email: info@mayocancer.ie
Website: www.mayocancer.ie

Roscommon Cancer Support Group

Vita House Family Centre
Abbey Street
Roscommon
Tel: 090 662 5898
Email: vitahouse@eircom.net

Sligo Cancer Support Centre

[Includes support group for children and young adults]
44 Wine Street
Sligo
Tel: 071 917 0399
Email: scsc@eircom.net
Website: www.sligocancersupportcentre.ie

Tuam Cancer Care Centre

[Includes a programme for children affected by cancer in the family]
Cricket Court
Dunmore Road
Tuam
Co Galway
Tel: 093 28522
Email: support@tuamcancercare.ie
Website: www.tuamcancercare.ie

Leinster support groups & centres**ARC Cancer Support Centre**

ARC House
65 Eccles Street
Dublin 7
Tel: 01 830 7333
Email: info@arccancersupport.ie
Website: www.arccancersupport.ie

ARC Cancer Support Centre

ARC House
559 South Circular Road
Dublin 8
Tel: 01 707 8880
Email: info@arccancersupport.ie
Website: www.arccancersupport.ie

Arklow Cancer Support Group

25 Kingshill
Arklow
Co Wicklow
Tel: 085 110 0066
Email: arklowcancersupport@gmail.com

Balbriggan Cancer Support Group

Unit 23, Balbriggan Business Park
Balbriggan
Co Dublin
Tel: 087 353 2872

The Bella Rose Foundation

[Women with cancer]
Merry Maid House
West Park Campus
Garter Lane
Citywest
Dublin 24
Tel: 086 879 3242
Email: thebellarosefoundation@gmail.com

Bray Cancer Support & Information Centre

[Includes specialist support for children]
36B Main Street
Bray
Co Wicklow
Tel: 01 286 6966
Email: info@braycancersupport.ie
Website: www.braycancersupport.ie

Cuisle Centre

Cancer Support Group
Block Road
Portlaoise
Co Laois
Tel: 057 868 1492
Email: info@cuislecentre.com
Website: www.cuislecentre.com

Dóchas: Offaly Cancer Support

Teach Dóchas
Offaly Street
Tullamore
Co Offaly
Tel: 057 932 8268
Email: info@dochasoffaly.ie
Website: www.dochasoffaly.ie

Éist Cancer Support Centre Carlow

The Waterfront
Mill Lane
Carlow
Tel: 059 913 9684
Mobile: 085 144 0510
Email: info@eistcarlowcancersupport.ie
Website: www.eistcarlowcancersupport.ie

Gary Kelly Support Centre

George's Street
Drogheda
Co Louth
Tel: 041 980 5100 / 086 817 2473
Email: services@gkcancersupport.com
Website: www.gkcancersupport.com

Greystones Cancer Support

La Touche Place
Greystones
Co Wicklow
Tel: 01 287 1601
Email: info@greystonescancersupport.com
Website: www.greystonescancersupport.com

Haven Cancer Support and Therapy Group

Haven House
68 Hazelwood
Gorey
Co Wexford
Tel: 053 942 0707 / 086 250 1452
Email: info@thehavengroup.ie
Website: www.thehavengroup.ie

HOPE Cancer Support Centre

22 Upper Weafer Street
Enniscorthy
Co Wexford
Tel: 053 923 8555
Email: mary@hopesupportcentre.ie
Website: www.hopesupportcentre.ie

Kilkenny Cancer Support Services

Walkin Street
Kilkenny City
Tel: 085 721 9280
Email: info@kilkennycancersupport.com
Website: www.kilkennycancersupport.com

Lakelands Area Retreat & Cancer Centre

Ballinalack
Mullingar
Co Westmeath
Tel: 044 937 1971
CallSave: 1850 719 719
Email: info@larcc.ie
Website: www.larcc.ie

Newbridge Cancer Support Group

144 Allenvue Heights
Newbridge
Co Kildare
Tel: 083 360 9898
Email: newbridgecancerhealinghelp@gmail.com

Rathdrum Cancer Support Centre

34 Main Street
Rathdrum
Co Wicklow
Tel: 087 292 8660
Email: rathcan@gmail.com

Tallaght Cancer Support Group

Millbrook Lawns
Tallaght
Dublin 24
Tel: 087 217 6486
Email: ctallaght@yahoo.ie

Wicklow Cancer Support Centre

1 Morton's Lane
Wicklow
Tel: 0404 32696
Email: wicklowcancersupport@gmail.com

Munster support groups & centres**Cancer Information & Support Centre**

Mid-Western Regional Hospital
Dooradoyle
Co Limerick
Tel: 061 485 163
Website: www.midwesterncancercentre.ie

CARE Cancer Support Centre

14 Wellington Street
Clonmel
Co Tipperary
Tel: 052 618 2667
Email: cancersupport@eircom.net
Website: www.cancercare.ie

Cork ARC Cancer Support House

Cliffdale
5 O'Donovan Rossa Road
Cork
Tel: 021 427 6688
Email: karen@corkcancersupport.ie
Website: www.corkcancersupport.ie

Kerry Cancer Support Group

124 Tralee Town House Apartments
Maine Street
Tralee
Co Kerry
Tel: 066 719 5560 / 087 230 8734
Email: kerrycancersupport@eircom.net
Website: www.kerrycancersupport.com

Recovery Haven

5 Haig's Terrace
Tralee
Co Kerry
Tel: 066 719 2122
Email: recoveryhaven@gmail.com
Website: www.recoveryhavenkerry.org

Sláinte an Chláir: Clare Cancer Support

Tír Mhuire
Kilnamona
Ennis
Co Clare
Tel: 1850 211 630 / 087 691 2396
Email: admin@clarecancersupport.com
Website: www.clarecancersupport.com

South Eastern Cancer Foundation

Solas Centre
7 Sealy Close
Earlscourt
Waterford
Tel: 051 876 629
Email: infosecf@eircom.net
Website: www.secf.ie

Suimhneas Cancer Support Centre

2 Clonaslee
Gortland Roe
Nenagh
Co Tipperary
Tel: 067 37403
Email: suaimhneascancersupport@eircom.net

Suir Haven Cancer Support Centre

Clongour Road
Thurles
Co Tipperary
Tel: 0504 21197
Email: suirhaven@gmail.com

Youghal Cancer Support Group

161 North Main Street
Youghal
Co Cork
Tel: 024 92353 / 087 273 1121

Ulster support groups & centres**Cancer Support and Social Club**

Tiernaleague
Carndonagh
Co Donegal
Tel: 086 602 8993 / 087 763 4596

Coiste Scaoil Saor ó Ailse

Knockastoller
Bunbeg
Letterkenny
Co Donegal
Tel: 087 121 7857
Email: scaoilsaor@hotmail.com

Crocus: Monaghan Cancer Support Centre

The Wellness Centre
19 The Grange
Plantation Walk
Monaghan
Tel: 087 368 0965

Cuan Cancer Social Support and Wellness Group

Cootehill Credit Union
22-24 Market Street
Cootehill
Co Cavan
Tel: 086 455 6632

The Forge Cancer Support Group

The Forge Family Resource Centre
Pettigo
Co Donegal
Tel: 071 986 1924

Living Beyond Cancer

Oncology Day Services
Letterkenny General Hospital
Letterkenny
Co Donegal
Tel: 074 912 5888 (Bleep 674/734) / 074 910 4477

Support group & centres unaffiliated to Irish Cancer Society

Cancer Care West

Inis Aoibhinn
University Hospital Galway
Costello Road
Galway
Tel: 091 545 000
Email: info@cancercarewest.ie
Website: www.cancercarewest.ie

Cúnamh: Bons Secours Cancer Support Group

Bon Secours Hospital
College Road
Cork
Tel: 021 480 1676
Website: www.cunamh.ie

Dundalk Cancer Support Group

Philipstown
Hackballscross
Dundalk
Co Louth
Tel: 086 107 4257

Good and New Cancer Drop In Centre

Unit 1, Portlink Business Park
Port Road
Letterkenny
Co Donegal
Tel: 074 911 3437

Killybegs Cancer Support Group

Kille
Kilcar
Co Donegal
Tel: 074 973 1292
Email: riverbankdunne@eircom.net

Solace: Donegal Cancer Support Centre

St Joseph's Avenue
Donegal Town
Tel: 074 974 0837
Email: solacedonegal@eircom.net

Support for children experiencing loss

Barnardos Bereavement Counselling for Children

Christchurch Square
Dublin 8
Tel: 01 453 0355
Helpline: 01 473 2110
(Mon–Fri 10am–12 noon)
Email: bereavement@barnardos.ie
Website: www.barnardos.ie

Barnardos Cork

The Bowling Green
White Street
Cork
Tel: 021 431 0591
Email: bereavement@cork.barnardos.ie
Website: www.barnardos.ie

Barretstown

The Barretstown Camp Fund Ltd
Barretstown Castle
Ballymore Eustace
Co Kildare
Tel: 045 864 115
Email: info@barretstown.org
Website: www.barretstown.org

Rainbows Ireland Ltd

National Office
Loreto Centre
Crumlin Road
Dublin 12
Tel: 01 473 4175
Email: ask@rainbowsireland.com
Website: www.rainbowsireland.com

Useful websites for children

NICaN Kids

Website for children run by the Northern Ireland Cancer Network.
www.cancerni.net/kids

NICaN Teens

Website for teenagers run by the Northern Ireland Cancer Network.
www.cancerni.net/teens

Kids Connected

A US website for children with a parent with cancer or who have lost a parent to cancer.
www.kidsconnected.org

Riprap

A UK website for children aged 12 to 16 to help them cope when a parent has cancer.
www.riprap.org.uk

Siblinks

A UK network for young people aged 13 to 25 who have a family member affected by cancer.
www.siblinks.org

Useful contacts outside Republic of Ireland

Action Cancer

Action Cancer House
1 Marlborough Park
Belfast BT9 6XS
Tel: 028 9080 3344
Email: info@actioncancer.org
Website: www.actioncancer.org

American Cancer Society

Website: www.cancer.org

Cancer Focus Northern Ireland

40–44 Eglantine Avenue
Belfast BT9 6DX
Tel: 048 9066 3281
Email: hello@cancerfocusni.org
Website: www.cancerfocusni.org

Cancer Research UK

Tel: 0044 20 7242 0200
Website: www.cancerhelp.org.uk

Macmillan Cancer Support (UK)

Tel: 0044 20 7840 7840
Email: cancerline@macmillan.org.uk
Website: www.macmillan.org.uk

Macmillan Support & Information Centre

Belfast City Hospital Trust
77–81 Lisburn Road
Belfast BT9 7AB
Tel: 028 9069 9202
Email: cancerinfo@belfasttrust.hscni.net

National Cancer Institute (US)

Website: www.nci.nih.gov



Helpful books



Free booklets available from the Irish Cancer Society:

- *Understanding the Emotional Effects of Cancer*
- *Lost for Words: How to Talk to Someone with Cancer*
- *Who Can Ever Understand? Taking About Your Cancer*
- *A Time to Care: Caring for Someone Seriously Ill at Home*
- *Managing the Financial Impact of Cancer: A Guide for Patients and their Families*
- *Journey Journal: Keeping Track of Your Cancer Treatment*

Storybooks for young children

Badger's Parting Gifts

Susan Varley
HarperCollins, 2002
ISBN 0006643175
[About bereavement]

Muddles, Puddles and Sunshine: Your Activity Book to Help When Someone Has Died

Diana Crossley
Winston's Wish, 2000
ISBN 1869890582

The Secret C: Straight Talking about Cancer

Julie A Stokes
Winston's Wish, 2000
ISBN 0953912302

Talking to Children When Someone Close is Ill

Marie Curie Cancer Care, 2008
[www.mariecurie.org.uk]

When Someone Has a Very Serious Illness: Children Can Learn to Cope with Loss and Change

Marge Heegaard
Woodland Press, 1992
ISBN 0962050245

Why Mum? A Small Child with a Big Problem

Catherine Thornton
Veritas, 2005
ISBN 1853908916

For adolescents

When Your Parent Has Cancer: A Guide for Teens

National Cancer Institute, 2005
[PDF available at www.cancer.gov/cancertopics]

Special needs

Getting on with Cancer

Sheila Hollin, Veronica Donaghy, Jane Bernal & Irene Tuffrey-Wijne
Royal College of Psychiatrists, 2002
ISBN 1901242846
[For those with Down syndrome]

For parents

As Big as It Gets: Supporting a Child When a Parent is Seriously Ill

Julie Stokes & Diana Crossley
Winston's Wish, 2007
ISBN 9780953912391

Raising an Emotionally Healthy Child When a Parent is Sick

Paula K Rauch & Anna C Muriel
McGraw-Hill, 2006
ISBN 0071446818

Irish Cancer Society services

The Irish Cancer Society funds a range of support services that provide care and support for people with cancer at home and in hospital.

- Cancer Information Service (CIS)
- Daffodil Centres
- Cancer support groups
- Survivors Supporting Survivors
- Counselling
- Night nursing
- Oncology liaison nurses
- Cancer information booklets and factsheets
- Financial support
- Care to Drive transport project

Cancer Information Service (CIS)

The Society provides a Cancer Information Service with a wide range of services. The **National Cancer Helpline 1800 200 700** is a freefone service that gives confidential information, support and guidance to people concerned about cancer. It is staffed by specialist cancer nurses who have access to the most up-to-date facts on cancer-related issues. These include prevention of cancer, risk factors, screening, dealing with a cancer diagnosis, different treatments, counselling and other support services. The helpline can also put you in contact with the various support groups that are available. The helpline is open Monday to Thursday from 9am to 7pm, and every Friday from 9am to 5pm.

- The website **www.cancer.ie** provides information on all aspects of cancer.
- All queries or concerns about cancer can be emailed to the CIS at **helpline@irishcancer.ie**
- **Message Board** is a discussion space on our website to share your stories and experiences with others.
- The **CancerChat** service is a live chatroom with a link to a CIS nurse.
- The **walk-in caller service** allows anyone with concerns about cancer to freely visit the Society to discuss them in private.
- Find us on **Facebook** and follow us on **Twitter** (@IrishCancerSoc).

Daffodil Centres

Daffodil Centres are located in a number of Irish hospitals. They have been set up by the Irish Cancer Society in partnership with each hospital and are an extension of the Cancer Information Service. They are generally found near the main entrance of the hospital and are open during the day. Staffed by a specialist nurse and trained volunteers, they provide a range of information, advice, help and support on all aspects of cancer, free of charge.

Daffodil Centres give you a chance to talk in confidence and be listened to and heard. If you are concerned about cancer, diagnosed with cancer or caring for someone with cancer, you are welcome to visit the centre. Do check to see if there is a Daffodil Centre in your hospital.

Cancer support groups

The Irish Cancer Society funds a range of support groups set up to support you and your family at time of diagnosis, throughout treatment and afterwards. See pages 43–47 for more details.

Survivors Supporting Survivors

Being diagnosed with cancer can be one of the hardest situations to face in your lifetime. Survivors Supporting Survivors is a one-to-one support programme run by the Irish Cancer Society. It provides emotional and practical support to newly diagnosed patients. It can provide you and your relatives with information, advice and emotional support from time of diagnosis and for as long as is needed. All the volunteers have had a personal experience of cancer and understand the emotional and physical impacts of the disease. They are carefully selected after recovery and are trained to provide information and reassurance on the phone. The service is provided on a one-to-one basis and is confidential. If you would like to make contact with a volunteer, call the National Cancer Helpline on 1800 200 700.

Counselling

Coping with a diagnosis of cancer can be very stressful at times. Sometimes it can be hard for you and your family to come to terms with your illness. You might also find it difficult to talk to a close friend

or relative. In this case, counselling can give you emotional support in a safe and confidential environment. Call the National Cancer Helpline on 1800 200 700 to find out about counselling services provided by the Irish Cancer Society and services available in your area.

Night nursing

The Society can provide a night nurse, free of charge, for up to 10 nights if you need end-of-life care at home. The night nurse can also give practical support and reassurance to your family. You can find out more about this service from your GP, local public health nurse, a member of the homecare team or the palliative care services at the hospital. Homecare nurses can offer advice on pain control and managing other symptoms.

Oncology liaison nurses

The Society funds some oncology liaison nurses who can give you and your family information as well as emotional and practical support. Oncology liaison nurses work as part of the hospital team in specialist cancer centres.

Cancer information booklets and factsheets

These booklets provide information on all aspects of cancer and its treatment, while the factsheets deal with very specific topics. The booklets also offer practical advice on learning how to cope with your illness. These booklets and factsheets are available free of charge from the Irish Cancer Society by calling 1800 200 700. They can also be downloaded from www.cancer.ie or picked up at a Daffodil Centre.

Financial support

A diagnosis of cancer can bring with it the added burden of financial worries. In certain circumstances, the Irish Cancer Society may be able to provide limited financial help to patients in great need. You may be suitable for schemes such as Travel2Care or Financial Aid.

Travel2Care is funded by the National Cancer Control Programme (NCCP) and managed by the Irish Cancer Society. The scheme can help with your travel costs if you have genuine financial hardship due

to travelling to a designated cancer centre or approved satellite centre. It will help with the costs of public transport, such as trains or buses, private transport costs, or petrol and parking. If you are travelling to a Rapid Access Diagnostic Clinic, you may qualify for the Travel2Care scheme.

Travel2Care: If you would like to request this kind of help, contact your oncology nurse or the Irish Cancer Society at (01) 231 6643 / 231 6619 or email travel2care@irishcancer.ie

Financial Aid: A special fund has been created to help families in financial hardship when faced with a cancer diagnosis. If this applies to you, contact the medical social work department in your hospital. You can also speak to your oncology nurse or contact the Irish Cancer Society at (01) 231 6619.

Care to Drive transport project

Care to Drive is a scheme operated by the Irish Cancer Society. It provides free transport for patients to and from their chemotherapy using volunteer drivers. All of the volunteers are carefully selected, vetted and trained. You are collected from your home, driven to your appointment and brought back home again. Call (01) 231 0522 for more information.



If you would like more information on any of the above services, call the National Cancer Helpline on 1800 200 700. You can also visit the website www.cancer.ie or a Daffodil Centre.



Notes

Acknowledgements

We would like to extend a special word of thanks to the following for their invaluable contributions to this booklet and/or previous editions:

Ursula Bates, Principal Psychologist

Valerie Keane, Senior Medical Social Worker

Patients and their families

Would you like more information?

We hope this booklet has been of help to you. After reading it or at any time in the future, if you feel you would like more information or someone to talk to, please call the National Cancer Helpline on 1800 200 700.

Would you like to be a patient reviewer?



If you have any suggestions as to how this booklet could be improved, we would be delighted to hear from you. The views of patients, relatives, carers and friends are all welcome. Your comments would help us greatly in the preparation of future information booklets for people with cancer and their carers.

If you wish to email your comments, have an idea for a new booklet or would like to review any of our booklets, please contact us at **reviewers@irishcancer.ie**

If you would prefer to phone or write to us, see contact details below.

Would you like to help us?

The Irish Cancer Society relies entirely on voluntary contributions from the public to fund its programmes of patient care, education and research. This includes our patient booklets. If you would like to support our work in any way – perhaps by making a donation or by organising a local fundraising event – please contact us at CallSave 1850 60 60 60 or email **fundraising@irishcancer.ie**

Irish Cancer Society, 43/45 Northumberland Road, Dublin 4

Tel: 01 231 0500 **Email:** info@irishcancer.ie **Website:** www.cancer.ie

Irish Cancer Society

43/45 Northumberland Road, Dublin 4

T: 01 231 0500

E: info@irishcancer.ie

W: www.cancer.ie

National Cancer Helpline Freephone 1800 200 700

Open Monday to Thursday 9am to 7pm

Friday 9am to 5pm

Find us on Facebook

Follow us on Twitter: @IrishCancerSoc

