

FACING DEATH AND TALKING ABOUT IT

A booklet to help young people

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FINDING OUT YOU ARE GOING TO DIE

Being told that you're not going to recover from your cancer is probably the most difficult thing you'll ever hear. Facing death, particularly when you're young, understandably causes a range of raw emotions and feelings, including rage, despair and disbelief.

You may feel angry, shocked, upset or afraid – or all these things at the same time. You might find it hard to believe what you've been told, and feel that it's unfair and wrong.

At times you may feel envious of people around you that do not have to think about dying. This can be hard to deal with, and you may feel disappointed with yourself or guilty for feeling this way. You may also feel bad, or not yourself, if you take your feelings out on those you love.

All these emotions are natural and understandable. There are professionals and organisations that can help you along the way.

This booklet is designed to help you talk to your family, partner and friends – how to tell them what's happening, what you're feeling and what you need from them. It's not meant to be your only source of help and information. You can call on a variety of professionals, including CLIC Sargent care professionals, nurses, counsellors, psychologists and others. They can discuss any of the issues raised in this booklet, or listen to anything else that's on your mind.

It's entirely up to you who you tell and when you tell them, but this will always be a difficult conversation. There is no 'right' thing to say, and it may take a few goes. People can react to bad news in surprising ways, so be prepared for this, even if you know them well. If you want some help telling people, talk to a member of the team caring for you. They could help you to practise what you want to say.



TALKING TO THE PEOPLE YOU'RE CLOSE TO

"It's actually made my mum and me much closer. We haven't talked like this since I left home."

"I've only talked about it with my best mate once. It was really tough - we don't usually talk about 'big' stuff."

"It took me three weeks before I could bear to tell anyone apart from my mum and dad. I had to practise with my social worker what I was going to say."

How it can help

Those closest to you will want to support you at this time, even though it's hard for all of you. They are the people who know you best, and talking to them can make you feel comforted, supported and reassured. Sharing your thoughts and fears can help you deal with difficult emotions. It may also strengthen your relationship.

Talking can also give you a sense of control. Family and friends will usually want to make sure your needs and wishes are met. It can help you and them to talk about what you want in terms of the 'practicalities' of dying - such as pain control, where you would like to die and what kind of funeral you would like. You can find more information about these questions on pages 10-15.

There are ideas on how to talk to different people in your life on pages 23-26.

What can get in the way

Talking about the fact you're going to die soon is naturally difficult, but there may be reasons why you find it particularly hard.

Perhaps you prefer to keep your feelings private. However, bottling things up can be hard and can make you feel very alone. If you can talk to a few people, it could help you cope better. There are some suggestions for starting conversations in the 'Tips for talking' section on page 16.

You may find that the emotions you're experiencing are too overwhelming to talk about just yet. You may find that talking about dying makes it too real and unbearable. Take your time - maybe later on you'll feel more comfortable about talking. In the meantime, it might help to write down the things that you find difficult to talk about so you can come back to them when you feel ready. You might want to consider discussing them with a member of the team caring for you or contacting one of the organisations listed on pages 28-29.

Some people may be reluctant to talk with you, maybe because they're struggling to deal with the situation themselves. Or they're afraid of upsetting you, or that they'll get upset in front of you.

In some cultures people don't talk about dying, because they believe it shows you have lost hope and may make it happen sooner. If this is what it is like for you, you'll need to consider carefully what will help you most.

If someone really doesn't want to talk it can be frustrating. Maybe they can show you they care in other ways, such as hugs or making you cups of tea. Or they may be able to help in practical ways - such as getting some shopping or picking up a DVD you want to watch.

WHAT TO TALK ABOUT

Despite what you're going through, you're still living your life and you'll probably want to talk about everyday things a lot of the time - what music you're into, what to have for dinner, news about friends. Talking about normal things can help. However, you may also have many thoughts and questions related to dying. Here are some topics that you might like to talk to someone about.

Faith, spirituality and beliefs

It is natural to think about what happens when you die. Some people have a very strong faith, while others have different beliefs, or may be unsure what they believe. It is common to think about and question your beliefs at this time. Sharing your thoughts and feelings about faith and spirituality with a friend or relative can comfort you and bring you closer together.

You may find that you're so angry about what's happening to you that you've lost your faith. If this is something you feel unable to talk about with someone close, you may find it helpful to talk to a religious leader. You could also talk through any religious or non-religious thoughts with a psychologist or counsellor, or with your CLIC Sargent care professional or another member of your hospital care team.

The things you won't get to do

It's natural to feel angry and resentful about the things you won't get to do in your lifetime. These are huge emotions, and while sharing them won't stop you feeling sad, it can help you feel less isolated.

Young people sometimes talk about feeling more willing to take greater risks or try new things for the first time. Talk with your CLIC Sargent care professional or someone you trust if you feel like this, as it's important to stay safe.

You may feel that there are some things you'd like to do in the time you have left, such as visiting a place you've always wanted to go to or trying something you've never done before. Your family or friends might be able to help arrange these things, or if you're well enough, there are organisations that arrange special days for seriously ill young adults. Or you might simply want to watch a film you really enjoy with those close to you or share a favourite meal.

"I've talked to my mum about who I want to get all my DVDs and the money in my savings account. Making plans has taken my mind off things a bit."

Practical matters

Sometimes sorting out practical and financial matters can leave you more able to concentrate on other things.

You may have clear areas of responsibility that you need to discuss, for example financial matters, deciding who will look after your children, or what will happen to your pets. If you have children, it's a good idea to think about who will care for them as early as possible, as you may need to draw up a legal document about this. You may want to talk about making a Will or something less formal, like a letter outlining who you want to get your belongings when you die. Writing a Will can feel like a daunting task so you might want to discuss your options with someone beforehand. Your CLIC Sargent care professional can answer any questions you have, put you in touch with our welfare rights team or contact a solicitor on your behalf.

Some people choose to leave money and possessions to family, friends, or to a charitable cause that's important to them. You may want to discuss with close friends or family whether there's something personal that you'd like to leave to them or that they would like to remember you by.

Looking back over your life

It can be easy to forget how much you have achieved and what a difference you have made to others in your life. It can be helpful to think about – and celebrate – this.

What about the memories you share with loved ones, friends and family? They are as important to those who share your life as they are to you. Recording some of your memorable and special moments can help you realise how significant your life has been. It can also offer a connection with you later – when your loved ones want to remember you.

Making amends or 'completing unfinished business'

It's only natural to have some regrets about things you may have said or done in the past. Settling old arguments and helping to heal old wounds can be a very positive experience both for you and the other person. If this feels important, you may want to get in touch and say you'd like to sort things out. You may or may not want to tell them about your illness.

It may be that the other person, for whatever reason, is not interested in sorting things out. If this is the case, try to remember that you tried your best and move on.

You could also leave cards for people if you would like to give them a message after you have died. It could be for a special birthday or anniversary, or a date personal to you both.

THE VERY END OF YOUR LIFE

Thinking about what the end of your life might be like can be very difficult. Although no one can predict exactly what will happen, your care team will be able to give you a clearer idea of what to expect and answer any questions you have, so it's important to feel you can ask them anything you want.

You might have clear ideas about what you want to happen, where you want to be and the kind of care you want to receive. If so, it's important to tell people while you are well enough. On the other hand, you may struggle to think clearly or find the right time when you are able to make decisions. You might also not feel well enough to think about it or know how to put it into words. It can be very helpful to talk to your care team and those close to you so that you know all the options available to you before you make decisions.

Starting the conversation

Your care team might bring this conversation up with you first or it may come up naturally. It may not be something that you're ready to talk about when it is first mentioned and that's fine. You can come back to it another time. If you do feel ready, some of the things you may like to consider could include:

- What kind of medication you'd like for pain control and to relieve symptoms
- If there are any treatments you don't want to receive
- Where you would like to be cared for
- The people who you want to be with you
- Who will make decisions about your care if you're unable to communicate your wishes
- What information you want or don't want to be told about your condition
- Any special things you'd like, such as spiritual or religious beliefs.

Some people find it easier to express themselves in writing when certain things can be too hard to say out loud.

You can write down your wishes and preferences in a document called an advance care plan – this is also known as The Preferred Priorities for Care (PPC) document or advance statement in England and Wales (or Anticipatory Care Plan in Scotland, and Advance Care Plan in Northern Ireland). These aren't legal documents but should be taken into consideration if a time comes when you're unable to make a decision or communicate your wishes.

Your care team can help you to fill out your advance care plan. Once you have filled in the form, a copy will be kept with your GP as well as any other medical professionals who are involved in your care. You will be able to keep the form and if your wishes change you can make changes to it.

You also have the option of giving someone Lasting Power of Attorney (LPA), which means they have the legal authority to make decisions about your care and treatment on your behalf, if the time comes when you are not able to do so yourself. You can find more information about how to set this up from the Citizens Advice Bureau, or ask your CLIC Sargent care professional.

Discussing your wishes with loved ones

You might find it hard to talk to your family or friends about what will happen in your final weeks. Some people might avoid the subject as they don't want to acknowledge what's happening. Telling loved ones about the kind of care you want or don't want to receive can be very difficult, especially if they don't understand what will happen or disagree with you. However, talking about this in advance means that they will know what to expect and can support you better.

Managing symptoms

Managing your symptoms can be an important part of what goes into your plan. You will be offered medication to manage

your symptoms and for pain control. You may want to discuss how your medication will be given, whether it's orally or by an injection, if it is something you are worried about.

You may also want to discuss with your care team any complementary therapies which may benefit you, such as massage, reflexology, meditation or physiotherapy. These can often be done from your home, hospital or hospice.

Advance decision to refuse treatment

Under the terms of the Mental Capacity Act, if you are over the age of 18 and living in England and Wales you can state any specific treatments you may want to refuse in the future with a legal document known as an advance decision (also called a 'living will'). In Scotland this is referred to as an advance directive (for anyone over the age of 16).

In Northern Ireland and Scotland there is currently no legislation on advance decisions - this means that they are governed under common law. However, medical professionals must still take advance decisions into account and it is likely that a court would consider it legally binding, providing the decision was made by an adult with capacity and is clear and unambiguous.

The information about what you can put in an advance decision can be complicated, so it's a good idea to talk with a doctor or nurse who fully understands your medical history. They can explain what is and isn't possible before you sign it.

Where you would like to die

Choosing where to die can be really difficult, and it's important that you know what your options are. They could include being at home, at a hospice for young people (if there is one in your community near to where you live), in hospital or a combination. Ask your doctor or palliative care team to talk through the options available to you.

Although people will want to respect your wishes, it may not be possible for you to be cared for where you want. For example, if you want to stay at home, there may not be space downstairs for you to have a bed or washing facilities. There may not be a young person's hospice in your area, or your care needs may mean you need to be in hospital.

Discussing your care in advance will mean that you know which choices are available to you and can decide on the best option for your situation. Deciding on where you will die isn't an easy thing to think about, but remember that anything you decide isn't set in stone. You can always change your mind, but knowing your options can help.

Hospital

Palliative care teams will be there to help hospital staff give you the best care possible, whether it's offering emotional support to you and your family or helping you cope with pain or other symptoms. Some people find it reassuring to be in a place with so many skilled doctors, nurses and care professionals on hand 24-hours a day.

Young people's hospice

Hospices provide free care to young people and their families when they are first diagnosed as having a terminal illness, through to the end of their life. Hospices may offer various activities and therapies. It may also be possible for family members or partners to stay overnight. You can ask the hospice staff for more information about visitors and any other questions you have.

Home

Some people prefer to be in an environment that is familiar and it can help to feel part of family life. If you choose to be at home when you die, you may receive palliative care from nurses who come to your home. This could include help with any pain or symptoms, day-to-day nursing, or emotional support. They may also be able to provide specialist equipment to make you more comfortable. Not every local authority will offer the same community support, so you may want to speak to your care team, or ask someone close to you to help find out what options are available if you want to carry on living at home.

Combination of care

Some people choose a combination of options in their final months. For example, you may want to visit a hospice as an outpatient and then go back home at night-time. Some hospices will provide transport to take you home if this is something that you and your family would benefit from.

The people you want to be with you

Deciding who you want to be with you when you die is a very personal choice and you might want to talk it through with a member of your care team. Some people want to be surrounded by a lot of family and friends, while others prefer to have only a partner or close family member with them. If you are in a hospital or hospice, there may be restrictions on the number of people who can visit at once, so it's worth checking this with your care team.

Some people might be unsure whether you want them to be there and might not want to raise the subject. Some may be worried about how they'll cope if they are in the room, while others may feel strongly that they want to be with you to say goodbye. Talking about your wishes beforehand means your loved ones know what to expect and can prepare themselves.

If you have children who may not want to be in the room with you, you might also want to ask a family member or friend to come and look after them.

Any special things you'd like

You might want to think about things you'd like to happen in your last few days. This could be a religious or cultural ceremony, listening to music that holds a special place in your heart, or a meditation session. You may also have readings or prayers, or a poem or story that you'd like to hear while surrounded by your close friends and family. Your care team can contact a chaplain, religious leader or a non-religious celebrant to lead this, or you can have a more informal time when you invite

loved ones to share stories or photographs. Often instead of being a sad occasion it can be an opportunity to share your love and special moments and memories in your life.

Funeral arrangements

Thinking and talking about your funeral may be hard, but you may find it helps to tell someone what you would like. This can be reassuring to you and them.

There are lots of things you might want to discuss, such as: whether you want to be buried or cremated, what readings you'd like (or whether you'd prefer people to say some words of their own) and what music you'd like played. You could also say whether you'd like people to bring flowers, or make a donation to charity.

You can choose to have a religious funeral, in a church or place of worship, or you can choose to have a non-religious funeral instead. The British Humanist Association can help you to arrange a non-religious ceremony. Their website, www.humanism.org.uk, has more information.

If you would like to be involved in planning your funeral, your CLIC Sargent care professional can support you in this. They can contact a funeral director on your behalf and ask them to meet with you to plan the ceremony.

It can be scary to think about the process of dying, and the actual weeks and days towards the end of your life. This is completely natural. Speak with your CLIC Sargent care professional or nurse about such fears, or another member of your hospital care team. They can listen to your worries and, where possible, answer your questions.

TIPS FOR TALKING

Be yourself

You may feel that people expect you to act or talk in a certain way, or that you need to put on a 'brave face'. Why should you? Dying doesn't make you a different person, so don't be afraid to go on behaving or talking in the way that's natural to you. If you come from a family of arguers, carry on arguing! If you've always used humour to defuse difficult situations, don't suddenly feel you need to get serious.

Some people might be surprised if you argue, joke or are light-hearted. If so, you may want to explain that it's your way of handling the situation.

"I've always been known as a bit of a joker, and I'm not about to change now. I know I'm in a bad way, but I'm not going to change things by suddenly acting gloomy and serious."

You don't need to tell people everything at once

With most people, you won't need to cover everything in one conversation or make every conversation meaningful. Don't panic if you feel you haven't said everything you want to in a particular conversation - just come back to it later.

Make a note of the things you want to say to special people

Write a list of the important things you want to say to the people you love so you can tell them when the time feels right. Or you could put your thoughts and feelings in a letter for them.

Let people know when you're ready to talk about dying

If you say something like, "I'd like to talk to you about something difficult", it can help prepare your friend or relative, and reassure them that you're ready to talk about what's happening.

Try to be clear and specific

Making your needs and preferences clear can help you and the people close to you. Saying "I feel scared" and sitting quietly with someone for a few minutes can be helpful. But if you are able to give more details, like "I feel scared because I don't know what the last few days will be like" they may be able to give you more specific support. If something has been worrying you, try to say so. This will let them know what's important to you and will help them to help you deal with it.

Tell people about important conversations in advance

If a topic is very important to you, it may be worth telling the other person in advance that you'd like to talk about it, and set up a time to do so. This will help both of you prepare for the conversation, so you're more likely to feel listened to and the other person can make sure they've understood your feelings and wishes.

Choose the right time and place

For important conversations, choose a time when you're both feeling relaxed and at ease. Don't pick a moment when one of you is in a hurry, distracted or worrying about something else. If things become difficult or upsetting, try to stay with it if you can. If this is too hard, make another time to come back to it.

Think of somewhere you'll be comfortable. You may be able to talk at home, or be able to go for a walk or find a quiet spot in the park. If you're in hospital, ask if there's a quiet room you could use, or tell staff if you'd like to not be disturbed for a while.

Try to think of something to do after an important conversation, like watching a DVD or getting something to eat. It can help to have a focus afterwards.

Acknowledge how hard it is

Admitting that it's difficult to talk about dying will help you and the person you're talking to feel more at ease. If one of you is distressed, angry or embarrassed, don't be afraid to talk about it. And try not to be put off by silence. Big conversations need silence so you can take in what is being said.

Check that the other person understands what you're saying

Every now and then ask: "Do you see what I mean?", or "Does that make sense to you?", or "Do you understand?".

Sometimes it's easier to talk to people you're not close to

You may feel you'll never want to talk in depth about dying to your family or friends, but you might feel okay to talk to someone outside your immediate circle. If so, your CLIC Sargent care professional or a member of the team caring for you are all there for you to talk to. They can also explore options such as counselling with you, if you like.

Alternatively, there are several organisations listed at the back of this booklet where you can talk to someone in confidence.

Use books to help you

There are other books and leaflets which can help you start conversations about dying, tell children what's going to happen, or explain what you need and how you feel. Some of these are listed at the back of this booklet. Or ask a member of the team caring for you if they can recommend one.

Practise with a professional

If you are feeling anxious and not sure how to talk to people about something important to you, ask a member of the team caring for you to help. You can 'role play' with them, trying different ways of broaching the subject, to see which works best for you.

IF YOU DON'T WANT TO TALK

Don't feel obliged to get into a conversation that you don't want to have. It's fine not to want to talk about dying.

If someone tries to start a conversation you don't want, acknowledge what they're trying to say, but explain that you don't feel like talking about it right now. You could suggest another time when you might feel ready to return to the subject. You may feel angry - if so, try to remember they are most probably doing it because they care.

Remember, talking isn't the only way to feel connected: sometimes a hug, holding hands or even just sitting with someone for a while can be very comforting.

You might not feel like talking, but it can help to open up about how you're feeling. This could be with someone close to you, or you might prefer to talk with someone in your care team.

"One of my friends just kept going on about it. In the end I had to tell her I didn't want to talk about dying any more. I just want to talk about Big Brother and stuff like that."

Using this book to let people know what you need

You might want to use this book to help communicate some of your thoughts. You could show particular sections

to your parents, partner, extended family and friends, or highlight the sections that you relate to in particular. When you feel ready, you could use them to start a conversation about how you are feeling and what you need.

COMMUNICATING ONLINE

Social media

Social media can be a great way to keep in touch with friends and family, especially if you aren't able to go out and see people as much. It can feel overwhelming if you need to let a lot of people know updates about your situation, so you might find it helpful to use social networking sites to communicate with many people at once. You could set up a group conversation on Facebook or WhatsApp, or send out group emails to tell friends or family how you're getting on so that you don't have to contact them all individually.

You may not always want to talk about your illness and sometimes you might want to remind people that you have other things in your life than cancer. Looking at friends' social media activities can help you to feel connected and know what's going on in their lives. You could ask them about things you've seen that they're doing, or keep up with shared interests like music or sports.

Blogging

Writing a blog, either under your own name or anonymously, can be a really therapeutic experience. You may find it a good way of reaching out to friends and family, without having to directly speak to one person in particular. It can also allow you to connect with people you may never have met before who can offer support or advice.

Blogs allow people to leave comments underneath individual posts. This means there's less pressure to reply

to individual comments and you can read and digest them in your own time. People won't always expect a reply, but they know you will be reading them.

If you don't feel like writing something, you can also post pictures and upload audio, graphics or videos. Sites like Pinterest, Instagram and YouTube can give you a chance to be creative and focus on things you enjoy.

You could also ask a close friend or family member to write a blog on your behalf, if you aren't feeling well enough.

Online discussion forums

Joining the CLIC Sargent online community or other discussion forums can give you the opportunity to talk to others who are in a similar situation. Many people use forums to ask questions, tell their story, or as a safe space to express things that they're finding frustrating. They can provide a very positive environment where young people can support each other.

The responses you receive won't necessarily be the 'right answers' and it's important to remember that some may be misleading. Contributors on unmoderated forums may make unproven medical claims about 'miracle cures', so always check any information you see with an accredited organisation, like a charity or public body.

You might want to join CLIC Sargent's online community, which is for 16-24 year olds who have, or have had, cancer. The discussion boards are moderated to make sure that harmful posts are removed, and you can choose to post anonymously. You can also search through hashtags to find the topics that are relevant to you. You can find details about how to join on page 28.

Memorialised accounts

You might also want to think about what will happen to your social networking accounts after you die.

Facebook now allows you to choose a legacy contact to manage your account after you die. They'll be able to do things like pin a post on your Timeline, respond to new friend requests and update your profile picture but they won't post as you or see your messages.

Or you may want your social networking and email accounts to be closed down after you die. If you don't want a Facebook account, you can request to have your account permanently deleted. You can manage this and legacy contacts in the security settings.

You could also write down any passwords for a trusted friend or family member, or set up password managers on your computer or an online space and leave details of this in your Will.

Protecting yourself online

Some people use social media in the same way they would a diary, but it's worth always remembering that once you say something in a public setting, it's there for all to see. Being honest and open isn't a bad thing, but in moments where you're feeling vulnerable and upset you may find more comfort in talking privately to friends and family.

It's important to understand the privacy settings on your social media account or to speak to someone who knows how to set them so that you are happy with who can see what. This can help protect you from online trolls who sometimes leave nasty comments just to get a reaction. Think about who you want to see your updates – your friends, the general public or a select group of people?

TALKING TO DIFFERENT PEOPLE

Your partner

You may want to 'protect' your partner by denying that anything bad is happening or avoiding it. Or they might want to do the same for you. This is quite natural. But it's important to be as open and honest as you can. Try to keep your relationship as normal as possible and don't feel that you have to behave any differently than you would have before. If you feel angry, or full of despair, talk about it.

There will be times when you find it hard to get on. There are bound to be stresses and strains. Treatment, an uncertain future, feeling like problems are hard to resolve because there is less time or simply feeling tired and unwell can all take their toll on a relationship - and just at a time when you need each other most.

Taking short breaks from each other may help to relieve anger or stress and can be a real boost. Talking to others may also help.

The situation can affect both yours and your partner's interest in sex. Whatever the issues, try to be as honest as possible. You may be able to find a way to cope with the situation or you might decide to make more time for sex. You may decide to show each other you care in different ways (giving each other a massage, for example). Or together you might decide that right now you and your body have other needs and priorities.

"At first my partner kept crying all the time. I had to tell him that it wasn't helping me. We had a huge row, but afterwards he said he was glad I'd told him how I feel."

Your parents

Everyone's relationship with their parents is different. You may be very close to one or both of your parents, or you might have a difficult relationship or no contact with them. You might find that your relationship with your parents has changed since your diagnosis, bringing you closer together or causing tension.

Having a child die before them is the worst thing that most parents could ever expect to happen. It goes against the 'natural order' of things. Your parents will probably be experiencing some very strong emotions. Their natural inclination will be to want to look after you and they may find it difficult at this time to remember that you are grown up with your own ideas. At times this might feel stifling, but try to remember that they mean well. It may help to explain that you appreciate their love and support and talk to them about what kind of help you need from them.

Your children

Talking to your children about your illness can be daunting, and you may want to ask for professional help.

When you're ready to tell your children that you're going to die, it is important that you do so in a way they understand. Specialist books can be useful as you can link what's happening in the story to what you're going through. The younger a child is, the longer it will take them to understand what's happening, so you may have to repeat things several times.

Giving children information in 'bite-sized chunks' as your illness progresses can help them adjust. However, once they realise that you really are going to die soon, children can sometimes think that it must be their fault, and will need to be reassured that this is not the case.

Here are some ideas that may help you explain what's happening:

- Try to use simple language. Phrases like 'pass away' or 'go to sleep' can confuse or distress children, especially when they are very young and do not fully understand what dying means.
- Be as honest and open as you can. Even very young children can sense when things are difficult, so explaining and answering their questions can help.
- Although it can be hard, try to introduce what's happening to your children as early as you can. This will give them the chance to process the news gradually.
- Make the most of opportunities to explain what's happening. If your children mention something that's related to your cancer, it could be a good chance to talk about what may happen.

You might not always know the answers to your children's questions, and that's okay. Try asking your CLIC Sargent care professional or a member of your care team for some help if you aren't sure what to say. Reassure your children that although you don't know the answer, you will try to find out.

You might like to put together a memory box with your children, which you could fill with special things that are personal to you. This could be your favourite aftershave or perfume, or a book that you read to them when they were young. You could include photographs too, and cards from special occasions, like birthdays or anniversaries.

Your siblings

How your brother or sister reacts will depend on your relationship with them, their age, and what they're like. For some people, their siblings can be a source of support, love or distraction.

It can help to be open and honest about how you're feeling and what's happening. This may help you both feel less afraid. You could also discuss with your brother or sister practical ways

they can help. For example, you could discuss them caring for your pets, or just ask them to watch some films with you.

Sometimes, though, siblings may struggle with your diagnosis, or be unsure what to do. This can make them react in unexpected ways, and they might not feel like talking. You could recommend they speak to a member of your care team about what's happening. They could also contact one of the organisations listed in this book.

Extended family

Your grandparents, cousins, aunts and uncles may feel overwhelmed and unsure of how to be with you. They may not know as much about your illness as your parents or partner and you might want to suggest they contact one of the organisations at the back of this book for more information and support. Try to explain to them the things they can do to help you practically and emotionally. It can be very difficult to tell a large number of people about your illness and keep them up to date with what's happening. You might want to consider communicating by email or through a social networking site like Facebook. Or you could ask a close relative to pass on information to the wider family on your behalf.

Friends

Like your extended family, your friends may not be sure of the best way to be with you. Again, talk to them about what they can do to help you practically and emotionally. You might want to discuss the ways you would like them to keep in touch, the kind of things you'd like to talk about, how you want them to treat you and what you still feel able to do and not do.

Remember that it is up to you who you talk to, what you tell them, and how you do it.



ORGANISATIONS THAT CAN HELP YOU

CLIC Sargent

CLIC Sargent provides clinical, practical, financial and emotional support to help children and young people cope with cancer.

Our care professionals, including young people's social workers, young people's community workers and nurses, understand what you're going through. We also provide financial help to meet extra costs, free 'Home from Home' accommodation close to a number of specialist cancer centres for families, and short breaks in the UK. Your CLIC Sargent care professional can discuss any of the issues raised in this booklet – as well as anything else that's on your mind. Or call us on **0300 330 0803** and we'll put you in touch with someone who can help.

You can also visit our website at **www.clicsargent.org.uk** or email us on **info@clicsargent.org.uk**.

To join the online community for 16–24 year olds, visit **community.clicsargent.org.uk**. Or you can download the CLIC Sargent online community app on your mobile or tablet.

Other organisations

Below are details of some organisations that other people have found useful. Your CLIC Sargent care professional will be happy to talk through your options if you would like to contact anyone else.

British Association for Counselling and Psychotherapy's therapist directory

Provides details of local counsellors and psychotherapists, so you can find one who's right for you.

T: **01455 883300**

W: **www.itsgoodtotalk.org.uk/therapists**

Samaritans

Provides 24-hour confidential emotional support for anyone in distress or despair.

T: **08457 909090 (UK) or
1850 609090 (ROI)**

E: **jo@samaritans.org**

W: **www.samaritans.org**

Child Bereavement UK

Provides information and support to bereaved children and those supporting them.

T: 01494 568900

E: support@childbereavementuk.org

W: www.childbereavementuk.org

jtvancersupport.com

Hosts video diaries, animations and other creative recordings, made by young cancer patients about their cancer journeys. Includes some videos by patients who are palliative.

W: www.jtvancersupport.com

Macmillan Cancer Support

Practical, medical, emotional and financial support for people of all ages affected by cancer. The organisation produces the following booklets that might be particularly useful at this time:

Caring for someone with advanced cancer, Coping with advanced cancer, Talking to children and teenagers when an adult has cancer, End of life.

T: 0808 808 00 00

W: www.macmillan.org.uk

Cruse Bereavement Care

Helps bereaved people to understand their grief and cope with their loss.

T: 0844 477 9400

E: helpline@cruse.org.uk

W: www.cruse.org.uk

Cruse Bereavement Care Scotland

T: 0845 600 2227

W: www.crusescotland.org.uk

Hope Again

Website designed to support young people after someone close to them dies. Includes advice and a message board. Developed by Cruse's Youth Involvement Project.

T: 0808 808 1677

E: hopeagain@cruse.org.uk

W: www.hopeagain.org.uk

WAY Widowed & Young

A membership organisation which supports young widowed men and women following the death of their partner.

T: 0300 012 4929

E: enquiries@widowedandyoung.org.uk

W: www.widowedandyoung.org.uk

Willow Foundation

Organises special days for seriously ill young adults.

T: 01707 259777

E: info@willowfoundation.org.uk

W: www.willowfoundation.org.uk

Winston's Wish

Offers support and guidance to families supporting a grieving child.

T: 08452 030405

E: info@winstonswish.org.uk

W: www.winstonswish.org.uk

PUBLICATIONS FOR CHILDREN

Below are some publications which can help you start a discussion with your children about illness, death and dying. Others are available - speak to a member of the team caring for you for more information.

This is about me and you

Jenni Thomas and Lynda Weiss

Download from the Angus Lawson Memorial Trust or Jenni Thomas' website:

www.almt.org/grief-counselling-resources

www.jennithomas.com/resources/downloads

This is a workbook designed to help parents with a terminal illness communicate with their children about loss and death. It is written in a way that enables adults to be open and share some of their feelings with children.

When someone has a very serious illness

Marge Heegaard (1991)

Woodland Press

ISBN-13: 978-0962050244

This book is designed to help families communicate with a child about illness, to evaluate their child's understanding and feelings and help them find ways to cope.

When dinosaurs die: a guide to understanding death

Laurene Krasny Brown and Marc Brown (2004)

Little, Brown and Company

ISBN-13: 978-0316119559

This storybook is designed to help children grasp the concept of death and understand grieving.

As big as it gets: supporting a child when a parent is seriously ill

Julie A. Stokes, Diana Crossley and Di Stubbs

Winston's Wish

ISBN-13: 978-0953912391

This booklet provides ideas and suggestions for terminally ill parents and carers, so they feel able to involve their children in what is happening.

SUPPORTING CHILDREN AND YOUNG PEOPLE WITH CANCER

Ref: SER061_15162

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Next planned review: 2017

For information about the sources used to put this publication together, or if you have any comments or queries about it, please contact us on 0300 330 0803 and ask to speak to the Information Manager.

 The Information Standard	This organisation has been certified as a producer of reliable health and social care information. www.theinformationstandard.org
Certified member	

www.clicsargent.org.uk

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