

Suitable for young adults aged 17+

Facing Death and Talking About It

A booklet to help young adults

www.clicsargent.org.uk



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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 difficult to believe what you've been told, and feel that it's unfair and wrong. "This can't be happening" you think.

All these emotions are normal and understandable.

You will find your own way of coping, and there are many people and organisations that can help you along the way. Some people manage over time to reach some sense of peace.

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 Social Workers and youth support workers, 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.

Telling people that you're going to die

“

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.

”

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. If you want some help telling people, talk to a member of the team caring for you. People can react to bad news in surprising ways, so be prepared for this, even if you know them well.

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.

”

How it can help

Your family and friends 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 relief, where you would like to die and what kind of funeral you would like.

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, if you can talk to a few people, it can help you cope better. Bottling things up can be hard and can make you feel very alone. There are some suggestions for starting conversations in the 'Tips for talking' section on page 10.

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 page 19.

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.

Faith and spirituality

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 normal 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 might want to consider talking to a religious leader, psychologist or counsellor.

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.

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 you may simply want to watch a film you really enjoy with them or share a favourite meal.

Practical matters

Sometimes sorting out practical and financial matters can help you feel better and can leave you free to concentrate on other things.

You may have clear areas of responsibility that you need to discuss, for example financial matters, or childcare. 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.

“

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.

”

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. Filming or taping some of your memories 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.

The very end of your life

Talking about what the very end of your life might be like can help you feel prepared. You might have clear ideas about what you want to happen at the very end of your life. If so, it's important to tell people while you are still well enough. These are some of the things you might want to discuss:

- ▶ What pain control you would like
- ▶ Any special things you'd like, to do with your beliefs
- ▶ Where you would like to die
- ▶ The people who you want to be there.

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.

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 diffuse difficult situations, don't suddenly feel you need to get serious.

“

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.

”

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.

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.

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?".

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 publication. 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 you don't want. 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.

“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.”

Some people use networking sites such as Bebo and Facebook to keep in touch. This way you can 'talk' to several people at once, when you feel like it. You can also deal with tricky questions more easily, responding only to those you want to answer.

And 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.

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 Social Worker, youth support worker 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 book where you can talk to someone in confidence.

Using this book to let people know what you need

You might want to use this book to start a discussion. You could leave it out for your parents, partner, extended family and friends to see, or highlight the sections that you relate to in particular and use them to start a conversation about how you are feeling and what you need.

Talking to specific 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.

“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.”

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 might decide to make more time for sex. You might decide to show each other you care in different ways, (giving each other a massage, for example). Or together you might accept that right now you and your body have other needs and priorities.

Your parents

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. The 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. If so, it may help to explain that you need and appreciate their love and support and talk to them about what kind of help and support 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.

Extended family

Your grandparents, cousins, aunts and uncles may feel bewildered and unsure of how to be with you. They may not know as much about your illness as your parents and 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. You might want to consider communicating by e-mail or through a social networking site like Facebook.

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 has been working with young people for over 20 years, and we understand what you're going through. Our care professionals include social workers, youth support workers, nurses and play specialists, who provide clinical, practical and emotional support. We also provide financial help to meet extra costs, free 'Home from Home' accommodation close to 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.

Other organisations

On the following page are details of some organisations that other people have found useful. Your CLIC Sargent care professional will be happy to talk through your options before you contact anyone else.

British Association for Counselling and Psychotherapy (BACP)

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

T: **01455 883300**

W: www.bacp.co.uk

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 Charity

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

T: **01494 568900**

E: **support@bereavement.org.uk**

W: **www.childbereavement.org.uk**

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*, *Dying with cancer*, *Talking to children about cancer*, *End of Life. The facts*.

T: **0808 808 0800**

W: **www.macmillian.org.uk**

CRUSE

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

T: **0844 477 9400**

E: **helpline@cruse.org.uk**

W: **www.crusebereavementcare.org.uk**

WAY Foundation

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

T: **0300 012 4929**

E: **info@wayfoundation.org.uk**

W: **www.wayfoundation.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

Jenni Thomas and Lynda Weiss for The Child Bereavement Charity

ISBN: 095233285

Order from the The Child Bereavement Charity:

01494 568900 / www.childbereavement.org.uk

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: 0962050245

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: 0316119555

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

Your notes and questions

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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.

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