

One day at a time

When  
**your child**  
isn't going to get  
**better**

For parents and carers



One day at a time

## When your child isn't going to get better

*When your child isn't going to get better* has been written using the real experiences of bereaved parents to support parents and carers when they are told that their child will die of cancer.

It's part of a series called *One day at a time*.

The leaflets in the series include:

- When your child isn't going to get better
- When your child dies
- Living without your child.

There is also a film called *One day at a time* which can be ordered from our website by going to [www.clicsargent.org.uk/bereavement](http://www.clicsargent.org.uk/bereavement), or by calling 0300 330 0803.

CLIC Sargent would like to thank the parents who told us their stories and played a huge part in making this series possible.

CLIC Sargent is the UK's leading cancer charity for children and young people, and their families. As part of our service we work with families coming to terms with the death of a child or young person from cancer, and also provide a range of practical support.

For further details, please speak to your CLIC Sargent care professional, call us on 0300 330 0803 or visit [www.clicsargent.org.uk/bereavement](http://www.clicsargent.org.uk/bereavement)

At the back of this leaflet there is a list of other specialist organisations you could contact for additional help and support.

## Contents

Coping with your emotions	4
Making informed choices	5
Nearing the end of your child's life	12

# Coping with your emotions

There may come a time when you are told that your child isn't going to get better and that they are going to die. This is one of the hardest things you will ever have to deal with and it's impossible to say how you will react.

You are likely to experience powerful emotions with this news and you may have lots of questions. It's important to know that there is no right or wrong way to grieve, only your way. You also need to know that you don't need to cope with this alone. If you need support, or if you just need to talk, ask your CLIC Sargent Social Worker, speak to someone in the team caring for your child or contact a specialist organisation – you can find details at the end of this leaflet.

*"You go through stages of just being numb. And then the anger kicks in. Blaming other people. What did she do to deserve that? Why? Why?"*

Jennie

## 2

# Making informed choices

It's likely you will have many questions. Some will come straight away and others when you have had time to think, to talk to close family and friends and consider your personal situation.

You may feel overwhelmed and helpless. The team caring for you and your child can support you and help you to understand more about the decisions and choices ahead of you. Having a good understanding will help you to make decisions that are right for you and for your family.

Here are some common questions parents and carers ask and some suggestions and options for you to think about.

### How much longer will my child live?

One of the first questions you may ask is how long your child has left to live. The consultant looking after your child can advise you and may be able to give you an approximate time. But nobody can tell you exactly when as every situation is different.

## Can I continue to talk to the consultant?

Your consultant will want to help you with all the information and advice that you need. You may find it helpful to make a list of any questions that you want to ask your consultant, or another professional in the team caring for your child, as it can be difficult to remember all the things you want to ask about. Having the right information will help you to have a better understanding of what lies ahead.

## Where can I get support?

CLIC Sargent care professionals are there to help you cope both emotionally and practically. Talk to your CLIC Sargent Social Worker to find out what support is available.

You can also get help and support from the team caring for your child in hospital, in a hospice or at home; your GP; spiritual leaders and communities; family and friends; and support groups or helplines. You will find a list of specialist organisations you can contact at the back of this leaflet.

This is your personal choice; don't feel pressured into accepting help if you don't want it. People will understand if you do not feel able to accept the help they are offering at this time.

## What do I say to my child?

What you decide to say to your child is your choice, and it's important to do what feels right for you and your child. You may find it helps to be guided by your child's questions and understanding.

Your child may be aware that things are changing. They may realise they are not getting better or overhear something that makes them worry. It can be difficult to talk to your child about dying, but some families find that being open helps.

If you do decide to talk to your child about what is happening, it can be hard to know where to start. You may find it helpful to talk things through with the team caring for your child.

There is also a booklet, called *Facing the death of your child*, that includes some advice about how to talk about death and dying with your child. The details are at the back of this leaflet.

## What do I say to family and friends?

It's only natural that family and friends will be worried and want to know about your child. You can decide how much you want to share with others about your situation and when to share it. You may want to be very private as you adjust to your situation. Equally, you may feel it's important to talk to or share information with others.

You may feel able to pass on this information yourself, or you could ask someone else in the family to let people know on your behalf.

This can be a very difficult time for relationships as you and your family come to terms with your situation. It's important to be as open and honest as possible about your feelings and fears so that you can support each other and make decisions that are right for you.

*"Your friends are always your friends. They see you on good days then see you on bad days. But it doesn't matter – it's still you."*

Jessica

### What do I say to my other children?

What you decide to tell your other children is up to you. You know your children best so be guided by your instincts and your experience. Try to take the lead from your children and be as honest as you feel able. Remember that children may overhear conversations and can be very sensitive to the strong emotions and atmosphere around them.

You may find it helpful to talk to your CLIC Sargent Social Worker, or to another trusted professional, about the best way to approach the subject with your children. There are also books that can help explain death and grief to children.

### What do I say to close family?

Sometimes people close to you may worry they are going to upset you even more by asking you questions.

They may find it easier to talk to a member of the team in the hospital looking after your child. Medical staff or CLIC Sargent Social Workers are happy to talk to grandparents, family members or friends if this would help.

They will always ask your permission and clarify with you the extent of any information to be given before meeting with any of your family members.



## How to deal with people wanting to help

You may be inundated with offers from people who want to help you but are not sure what they can do.

*“You know your family best – try not to be swayed by other people who want to tell you what to do for the best – listen to the advice but trust your instincts.”*

Jenny

You might like to consider a list of tasks that you can give to other people, leaving you with more time and energy to devote to the things that are important to you right now. Shopping, laundry, ironing and cooking are often practical tasks that others can do. If you have other children, you could consider asking somebody to take them to and from school if you do not feel up to facing other parents at the school gate.

On the other hand, you may want to continue doing these everyday tasks yourself. Everyone is different and you might want to keep family life as normal as possible.

## Should schools or colleges be informed?

It's always a good idea to try to keep your child's school or college informed of the situation. Our social workers and specialist nurses are happy to contact and visit them if you and your child wish.

If you have other children, remember to contact their schools or colleges too. Siblings can find it reassuring to know that there is a trusted teacher or tutor who understands what they may be experiencing, and can offer them support if needed in the months ahead.

## What about work?

If you are employed you will need to consider how you are going to keep employers informed of the situation, and whether or not you will feel able to work during this period.

Some possible options for you to think about are:

- ▶ Talking to your GP about a Statement of Fitness for Work (or 'fit note') to recommend reduced hours or flexible working, or to exempt you from work

---

- ▶ Talking directly to your employer about reduced hours or flexible working – many employers will be sympathetic and may be able to accommodate a change of your work arrangements

---

- ▶ Talking to your employer about special leave or compassionate leave. However, you need to be aware that this leave may be unpaid

---

- ▶ Talking to your employer about unpaid leave if you can afford to and wish to have time away from work. It's important to take advice about the implications of unpaid leave for your national insurance, pension and continuity of service.

If it helps, your CLIC Sargent Social Worker can contact your workplace on your behalf to discuss your options with your manager or HR department. You will need to give your permission to allow your personal circumstances to be discussed.

Most employers will try to support you during this difficult time but it's important that you keep in touch and talk to them as openly as you can about arrangements that will help you and your family. Problems can arise because an employer isn't fully aware of the circumstances and how a parent could be supported.

If you receive benefits, you can get advice from our welfare advisers about the best way for you to proceed.

If you are self-employed, you may need specialist advice. This might involve making a claim for benefits. Our welfare advisers can help advise you on the best way to obtain correct, up-to-date advice and support.

You can contact the CLIC Sargent welfare advice service on 0800 915 4439 or [welfareadvice@clicsargent.org.uk](mailto:welfareadvice@clicsargent.org.uk)

### How do I carry on with everyday life?

Try to make the most of the time when your child is feeling well as this time is very precious. Choose very carefully how you use this time and be cautious about accepting too many holidays and treats. Be guided by your child as they may be happier with short outings to favourite places, or just doing simple and familiar things at home.

Although you will want to make this time as special as possible, if you are able to, it's important to try to maintain the routines and the behaviour you normally expect. Children and young people respond well to consistency and it may help your child and their siblings to feel more secure. You may also want to talk to brothers and sisters about allowances they need to make.

You may be concerned about looking after your child at home. Remember that there will always be medical advice available from the team caring for your child any time you need it. There is also a useful booklet called *Managing symptoms at home* mentioned at the back of this leaflet.

# Nearing the end of your child's life

## Where will my child die?

You will need to think about where you would like your child to be cared for towards the end of their life.

Many children and young people are happiest at home surrounded by familiar faces and belongings. However, this may not feel right for you as a family, or it may not be possible for your child to have the level of medical care that they need at home.

You have choices so try to discuss the views and opinions of all the family members. These choices may well alter with changes in your child's health.

You can ask the team caring for your child, or your CLIC Sargent Social Worker, for advice about hospice care for children and young people. It may be possible to arrange a visit to a local hospice, to help you decide if this would be a good choice for your child. Your hospice may also be able to accommodate short family stays.

Brothers and sisters may appear to be managing well and to be carrying on as normal. However, they could be feeling very vulnerable and just trying to be brave and strong. They might need extra reassurance and comfort, and to feel that they understand things that are happening and are being included in any decisions.

Children and young people react in many different ways. You can discuss any concerns you might have with the staff caring for you and your family. They will be happy to listen to any worries and to offer you advice and support.

## How will my child die?

You may have lots of questions and anxieties about how your child will die, and it may not be possible for anyone to know exactly how this will happen. What you can expect is that everyone involved in your child's care will talk with you honestly and with respect for your fears, your wishes and feelings.

You will be surrounded by very experienced people who will listen carefully to you and help you understand what is happening and any choices that you may have.

## Will my child suffer?

The team looking after your child are highly skilled and experienced. They will do everything that they can to ensure that your child is peaceful and comfortable at all times.

## What can I do to help?

Doctors and nurses can help you be closely involved in the care of your child, if this is what you want. They know that you are the expert when it comes to looking after your child and will listen to your views.

If you are thinking about complementary therapies to help to manage your child's symptoms, it's advisable to discuss your plans with the staff looking after your child. They can advise you on the best way to introduce and use these therapies. It's always best to take advice from medical staff if you are considering introducing any medicines or therapies other than those prescribed by the specialist team.

## How will I cope?

It's normal to feel that you are facing an impossible and overwhelming task. You may be wondering how you can possibly cope with the pain of your situation. You may find support through family, friends and your community, and you will have the skills and knowledge of an experienced team who will help you and guide you through the choices ahead of you.

*"This time is very precious – use it to make good memories."*

John

*The quotes in this publication are from parents and carers. These are personal views and should not necessarily be taken as the view of CLIC Sargent. Please note that everyone's experience will be different and may not follow the order outlined in this publication. Services will differ across the UK. CLIC Sargent does not accept any responsibility for information and services provided by third parties, including those referred to or signposted to in this publication.*

*While we endeavour to ensure that the information provided is accurate and up-to-date at time of printing, CLIC Sargent cannot accept liability for any loss or damage resulting from any inaccuracy or omission in this publication. Information should not be relied on in place of appropriate professional or other advice specific to your circumstances.*

# Useful organisations

As well as your CLIC Sargent care team, the following specialist organisations could also be a good source of help and support:

## A Child of Mine – Help for Bereaved Parents

A personal website with stories, poems, practical information and other resources.

[www.achildofmine.co.uk](http://www.achildofmine.co.uk)

## Child Bereavement UK

Supports families when a child dies or is dying, or when a child is facing bereavement. Offers bereavement support and an information phone line, online resources and a forum.

[www.childbereavementuk.org](http://www.childbereavementuk.org)

Tel: 0800 02 888 40 (support line);

01494 568 900 (bereavement services)

## Child Death Helpline

A phone helpline for anyone who has been affected by the death of a child. It's staffed by volunteers, who are all bereaved parents.

[www.childdeathhelpline.org.uk](http://www.childdeathhelpline.org.uk)

Tel: 0800 28 29 86

## The Compassionate Friends

Offers support to parents, grandparents and siblings following the death of a child. Their website has bereavement information and a forum for members to share experiences. Their helplines are answered by bereaved parents.

[www.tcf.org.uk](http://www.tcf.org.uk)

Tel: 0845 123 2304 (England, Scotland,

Wales); 0288 77 88 016 (Northern Ireland)

Links to other organisations you may find helpful can be found at

[www.clicsargent.org.uk/bereavement](http://www.clicsargent.org.uk/bereavement)

## Cruse Bereavement Care

Supports people after someone close has died. Offers phone and email help services, websites for adults and young people and local branches in England, Wales and Northern Ireland.

[www.cruse.org.uk](http://www.cruse.org.uk)

[www.rd4u.org.uk](http://www.rd4u.org.uk)

Tel: 0844 477 9400

A similar service is also provided by Cruse Bereavement Care Scotland.

[www.crusescotland.org.uk](http://www.crusescotland.org.uk)

Tel: 0845 600 2227

## Together for Short Lives

Offers a helpline for anyone who looks after or knows a child with a life-limiting condition. Their website has information for families and details of local support services and hospices.

[www.togetherforshortlives.org.uk](http://www.togetherforshortlives.org.uk)

Tel: 0808 8088 100

## GOV.UK (England and Wales)

[www.gov.uk](http://www.gov.uk)

## The Scottish Government (Scotland)

[www.scotland.gov.uk](http://www.scotland.gov.uk)

## nidirect (Northern Ireland)

[www.nidirect.gov.uk](http://www.nidirect.gov.uk)

Practical and up-to-date information about what to do following a death.

## Other useful reading

### Children's Cancer and Leukaemia Group

#### *Managing symptoms at home*

*Choices* – a booklet for parents when curative treatment for children is no longer an option

*Facing the death of your child* – a booklet for parents covering all aspects of bereavement.

[www.cclg.org.uk](http://www.cclg.org.uk)

One day at a time

When  
**your child**  
isn't going to get  
**better**

REF: SER066\_14068a

Version 3, July 2014

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 CLIC Sargent on 0300 330 0803 and ask to speak to the Information Manager.



Registered charity number 1107328 and registered in Scotland (SC039857)

