

One day at a time

Living
without
your child



For parents and carers

One day at a time

Living without your child

Living without your child has been written using the real experiences of bereaved parents to support parents and carers after the death of their child from 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, 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

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

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Living without your child

Caring for your dying child can drain you of all your energy. When your child dies you may feel completely exhausted and empty. The thought of living without your child may seem impossible; you can suddenly feel very lost, vulnerable and alone. Many parents find it difficult to imagine anyone else experiencing what they are going through.

It may also feel as if it's the end of your world and that you will never be happy again. In this leaflet we touch on the experiences of parents after the death of a child or young person. Every experience is unique and different, but we hope that you will find words that will help you if you are living without your child.

"Try to be kind to yourself and do whatever helps you get through each hour, even if it's upsetting for others."

Jenny

1

Understanding your grief

Grief is an extremely powerful emotion. It can be painful beyond belief and may feel completely overwhelming. At first, simple things like going to the supermarket may seem impossible. Everyday events may trigger painful memories, feelings of

anxiety and surges of emotion. Just going about your everyday life may seem pointless and trivial. You may feel as if you will never smile again, let alone be happy.

It's important to be reassured that this is normal because you love your child and your life has changed forever.

"It varies day-to-day. Some days it's really hard, especially when you look at certain photos or hear a certain song on the radio, or on the telly."

Robert

Everybody grieves differently; grief is your personal response to death. There is no right or wrong way to grieve. Trust your instincts about the right way for you to express your grief.

If you have a partner, it can be hard to understand their feelings and how they are coping. Easing their distress may seem impossible and it may be difficult to reach out to them. At the same time, you may be feeling that no one understands what you are going through, not even your partner.

Try to give your partner the space and time that they need and to understand what will help them cope. If you can, help them to understand what you need. This may enable you both to move forward at a time when it's hard for you to cope with your own grief as well as supporting your partner. It's also important to accept that you may both want to turn to others, like family and friends, for support during this time. The death of a child may bring difficult times for a relationship, but it can be a time when couples grow together through their shared loss.

"I think it's brought Graeme and I closer together as we had to learn to communicate with each other a lot more than we ever had before."

Nicola

Taking each day as it comes may be easier than thinking about the years stretching ahead. Do what you need to help you get through each day and night; sleep, walk, cry, scream, go out, stay in, keep busy or do nothing. Do what is right for you and at your own pace.

"I would climb this hill and it would take me nearly three hours to go up and down. I would do it twice a day just because it made me come to life for a while and after I'd climbed it I would feel I could get on with things."

Katie

As the days go by, some will feel better than others. At other times your grief may overwhelm you. In time, you are likely to find yourself having days when you feel stronger and more peaceful. This will take time, and it may take many months and many changes as you adjust to a life without your child.

2

Dealing with other people

People may find it difficult to understand how your life has changed since your child died. They will try to be supportive but they may not know how to approach you, or how to talk to you about what you are going through.

"The grief is unspeakable...you are absolutely raw with pain and emotion. You're also trapped in a fairly individual world because everyone has a very different relationship with your child. My relationship as his father is unique and nobody can really empathise with that."

Jay

Facing others can be very painful and people will react to the death of your child in many ways.

"I think people are maybe a bit more careful about what they say but I'm quite determined that they have to talk about my daughter. I'd rather that they talked about her and the memories than just pretend that she never existed."

Nicola

You might find that people you had been close to drift away as they are not able to cope with painful emotions. Other people may surprise you and be supportive and helpful in ways that you would not have imagined.

Some people may share their own experiences of losing a loved one, or offer advice on how to cope. This might help, or you may find it unhelpful – some comments may even seem hurtful or insensitive, even if they aren't meant to be. It's not unusual for people to find it hard to know what to say, or what words to use, even when they mean well.

"Try and ignore people who tell you what you should be doing, or how you should be feeling, as only you know how you feel or what you can do each day. Try not to worry about other people's feelings, as just coping with yourself and your family is hard enough at this time."

Jenny

3

Supporting your other children

If you have other children, they will also be grieving and trying to come to terms with the death of their brother or sister.

To begin with, it can be difficult to find any emotional energy for anyone but yourself. It may seem impossible that you can find in yourself the strength to be a parent again. You might need to involve other family members or friends to care for and support your children, to help you through these difficult times.

“You have to give your other children a life and I think for me that’s what keeps me going.”

Nafissa

A child’s grief can appear to be very different from an adult’s grief. If you are concerned about any aspect of your children’s behaviour or feelings, you can talk to the team caring for your family. Initially, children may appear to be coping well following the death of their brother or sister. It may be many months or even years before they show any signs of needing support. Remembering that the death of your child has profoundly changed your life may help you to understand the impact on your other children long into the future.

Some multi-disciplinary teams arrange special support groups for siblings – your CLIC Sargent Social Worker will be able to tell you about groups where you live.

Your CLIC Sargent Social Worker, or someone else from the hospital team, may be able to visit your children’s school or college to offer advice if you think it would be helpful. Schools and colleges can be a place of normality for children and young people during difficult times, but teachers may need information and advice about the best way to support your family.

4

Family and friends

Your extended family and friends may be grieving, not only for your child but also for you and your immediate family. They may be finding it difficult to know how to help you and to offer support, particularly if it's difficult for you to face them.

It may help to explain simply to them how you are feeling and to ask them to be understanding. They will want to do what is right for you at the time and are likely to respect your wishes. Small acts of kindness, helping with the housework, offering meals or leaving flowers may be expressions of sympathy when it's hard for people to find the right words.

This can be a particularly difficult time for grandparents, grieving for a grandchild and feeling the terrible grief they see their own child facing. Your CLIC Sargent Social Worker may be able to give advice about local support groups for grandparents. Many of the useful organisations listed at the end of this leaflet also have resources or networks specifically for bereaved grandparents.

5

Your child's personal belongings

At some point, you will want to consider what to do with your child's personal belongings. However, it may be months, or even years, before you feel ready to make decisions about these possessions and all the memories that are attached to them. Do what is right for you, and at the time that is right for you.

Items can be left where they are, stored away safely or given away. You may like to ask siblings, grandparents and close friends if they would like something to remember your child. Perhaps your child has asked you to do something specific with their things.

Whatever you do with your child's belongings, be prepared for them to bring back very strong emotions. You may find comfort and happy memories in your child's precious belongings but also intense feelings of loss and pain as you live with their absence.

6

Your child's room

Deciding whether to make changes to your child's room may be difficult. Only you will know when the time feels right to make these decisions. You may take comfort in leaving your child's room untouched and familiar until you are ready for any change. Equally, you may find that leaving things untouched is unbearably painful. It's important that you are not rushed into any decision you are not ready to make.

You may want to redecorate or to leave things exactly as they are. You, or your child's siblings, may want to sleep in your child's bed or in their room. Brothers or sisters may want to play in your child's room as they try to make sense of things and adjust to their loss. All of this is fine if it feels right for you and your family.

Will I ever be happy again?

After your child dies you may find that you look back and relive over and over again what has happened, focusing on specific details. You may have a constant need to talk about your child and your feelings. You may also feel angry and have unanswered questions, including why your child had to die.

You may feel the need to return to the hospital or the hospice where your child died. You may have questions for the doctors or the team who cared for your child. Many parents find that support groups, counselling or complementary therapies help them to cope.

There could be practical challenges for you to face. You may need to consider how and when to return to work, or how to handle changes to your previous routine. Returning to work and to ordinary routines and daily activities may be helpful. It's important that you do whatever you need to do, and at your pace, to help you adjust to the changes in your life.

As time goes by moments of overwhelming grief may feel less intense or be less frequent. Some of the things that you may have found almost impossible to do since your child's death may become easier. For example, things like:

- ◉ Visiting places that you visited with your child

- ◉ Seeing other healthy children of a similar age to your child

- ◉ Making sense of the world and feeling yourself again

- ◉ Accepting that your child is with you but in a different way

- Accepting that the future has changed
- Coping with other people's reactions
- Remembering your child with a smile.

"In the early days you imagine you're never going to feel happy again. Everything was so depressing and life just didn't feel like worth living. However, the sun did come out again... My life turned around in lots of different ways. You get stronger. It goes up and down so it's not always a straight road... but seven years on I can guarantee that you do feel a lot better and that life really is worth living again."

Katie

Although your experience is unique, many parents have been through similar experiences. It's important to be reassured that you are not alone and others may be able to offer you comfort and support as you come to terms with the death of your child.

There may be times when you feel that you need professional help, the support of someone who has specialist skills and experience. You can talk to anyone from the specialist team who cared for you and your child, or a trusted professional such as your GP. There is also a list of other organisations you may like to contact at the back of this leaflet.

Useful organisations

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

A Child of Mine – Help for Bereaved Parents

A personal website started by a family following the death of a child from cancer. The website includes personal stories, poems, support, practical information and resources.

www.achildofmine.co.uk

Child Death Helpline

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

www.childdeathhelpline.org.uk
Tel: 0800 28 29 86

Cruse Bereavement Care

Provides support for those grieving for someone close who has died. They have a phone and email help service, websites for adults and young people, and local branches in England, Wales and Northern Ireland.

www.cruse.org.uk
www.rd4u.org.uk
Tel: 0844 477 9400

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

www.crusescotland.org.uk
Tel: 0845 600 2227

Child Bereavement UK

Supports families who have experienced the death of a child, as well as children who have lost someone important to them. Their website has a range of information and links to other resources, as well as an online forum. They also offer bereavement support and an information phone line.

www.childbereavementuk.org
Tel: 0800 02 888 40 (support line);
01494 568 900 (bereavement services)

The Compassionate Friends

Offers support to parents, grandparents and siblings following the death of a child. Their website has a range of information about bereavement, and an online forum where members can share experiences and support each other. They also have phone helplines that are answered by bereaved parents.

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 on our website by going to www.clicsargent.org.uk/bereavement

Other useful resources

CLIC Sargent

One day at a time – A film for people affected by the death of a child or young person from cancer.

In our own words – A booklet sharing the stories and experiences of families whose child has died of cancer.

Children's Cancer and Leukaemia Group

Bereavement: where to go for help – A booklet for people affected by the death of a child from cancer.

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

These can be ordered by going to www.clicsargent.org.uk/bereavement, or calling 0300 330 0803.

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.

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

