



redkite

One day at a
time series

living without your child

For parents and carers

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time series

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Adapted from the publication “One day at a time: Living without your child”, produced by CLIC Sargent, the UK’s leading cancer charity for children and young people, and their families.
www.clicsargent.org.uk.

“Living without your child” 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 is 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

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

Redkite is a national organisation that supports children and young people with cancer (24 and under), and the family and friends who care for them. From diagnosis, through treatment, and beyond into survivorship or bereavement, we’re there with essential support from hospital to home.

As part of our service we work with families dealing with the death of a child or young person from cancer, and also provide a range of practical support. Find out more at www.redkite.org.au



1800 REDKITE (1800 733 548)

support@redkite.org.au

additional support

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

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1. 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 is upsetting for others.”

Jenny

2. 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 is important to be reassured that this is normal because you love your child so much and because 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 to cope. If you can, help them to understand what you need. This may enable you both to move forward at a time when it is difficult for you to cope with your own grief as well as supporting your partner. It is also important to accept that you may both want to turn to others, like family and friends, for support during the difficult times. The death of a child may bring very 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 times your grief may overwhelm you. In time, you are likely to find yourself having days when you feel stronger and more peaceful. This may take many months and many changes as you adjust to a life without your child.

3. 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. You might also find other people’s comments seem hurtful and insensitive, even if they don’t mean to be.

4. 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 or contact Redkite for support. 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.

Schools and colleges may also be a place of support, sanctuary and normality for children and teenagers at difficult times, but teachers may need information and advice about the best way to support your family. The team caring for your family or the support team at Redkite are available to talk through ways to provide information and advice to teachers and schools.

5. 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 is difficult for you to face them and their sadness.

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 is 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. The Redkite support team offers specialist support for grandparents. There are details at the end of this leaflet on how to access other resources and networks.

6. 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.

7. 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 is 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.

8. *will I ever be happy again?*

As time goes by moments of overwhelming grief are likely to become fewer. How long this takes will vary from person to person. During this time 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.

“In the early days you imagine you’re never going to feel happy again. Everything was so depressing and life just didn’t feel 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

In the months after your child’s death 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. Others find that returning to work and to ordinary routines and daily activities is helpful. It is important that you do whatever you need to do and at your pace to help you to adjust to the changes in your life.

Over time, 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

Although your experience is unique, many parents have been through similar experiences. It is 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, Redkite, 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

Redkite

Redkite supports anyone 24 and under with cancer, and the family and friends that care for them. Through palliative care, death and bereavement, Redkite's professional social workers are available for counselling sessions or informal emotional support. We can also help cover costs for face to face counselling, funeral arrangements and essential household expenses.

www.redkite.org.au

Tel: 1800 REDKITE (1800 733 548)

Bereavement Care Centre

Provides counselling and support services for terminally ill people and their families, and for those recently bereaved.

www.bereavementcare.com.au

Tel: 1300 654 556

The Australian Centre for Grief and Bereavement

The Australian Centre for Grief and Bereavement provides a range of education, counselling, research and clinical services for those working in and affected by experiences of grief and bereavement.

www.grief.org.au

Tel: 1300 664 786

National Centre for Childhood Grief

The National Centre for Childhood Grief provides loving support in a safe place where children grieving a death can share their experience as they learn to live with its impact on their lives.

www.childhoodgrief.org.au

Tel: 1300 654 556

Cancer Council Australia

Resources and information about options when cancer cannot be cured.

www.cancercouncil.com.au/cancer-information/advanced-cancer

Tel: 13 11 20

CanTeen

CanTeen provides information and support for 12-24 year olds experiencing grief and loss due to the death of a sibling.

www.canteen.org.au

Tel: 1800 835 932

Very Special Kids (Victoria)

Very Special Kids provides flexible family support programs, planned and emergency respite, end-of-life care for families caring for a child with a life-threatening condition, and bereavement support.

www.vsk.org.au

Tel: 1800 888 875

The Compassionate Friends (ACT, NSW, QLD, VIC, SA, WA)

The mission of TCFA is to offer and provide friendship and support to bereaved parents and their families following the death of a child at any age.

www.tcfaustralia.org.au

Paradise Kids (Gold Coast)

Paradise Kids is a charity founded in 1996 to help children learn life skills to deal with grief through death, loss or illness.

www.paradisekids.org.au

Tel: (07) 5574 6853

Childhood Cancer Association (South Australia)

The Childhood Cancer Association provides financial assistance to help with counselling, support groups, respite accommodation and funeral costs.

www.childhoodcancer.asn.au

Tel: (08) 8239 1444

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 and Redkite. Please note that everyone's experience will be different and may not follow the order outlined in this publication. Services will differ across Australia. CLIC Sargent and Redkite do 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 us:

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