



redkite

One day at a
time series

when your child dies

For parents and carers

One day at a
time series

when your child dies

Adapted from the publication “One day at a time: When your child dies”, produced by CLIC Sargent, the UK’s leading cancer charity for children and young people, and their families.

www.clicsargent.org.uk

“When your child dies” has been written using the real experiences of bereaved parents to support parents and carers when their child dies 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.

contents

When your child dies	6
If your child dies in hospital	7
If your child dies at home or at a hospice	8
Planning the funeral	10
Coping with the funeral	13
After the funeral	14

1. when your child dies

Being with your child during death and after death is intensely personal, and you are likely to experience very powerful emotions in the hours and days that follow.

Try not to be worried about what is normal or what is expected. It is important for you to be as comfortable as possible and to make choices that are right for you. You may feel calm and have a sense of relief, you may feel very shocked and your emotions may feel out of control. You may feel distress and panic about how you will manage now that your child has died.

You will have choices about how you wish to spend time with your child after death. After your child dies you may feel that you need to be by yourself with your child or with your partner. You may want to involve family members or others such as a minister of your faith. Making decisions after your child dies may be very difficult for you. If you have the opportunity, and feel able, it may help to talk to your family and to your care team about your wishes before your child dies.

After death your child may feel cold but look calm and peaceful. You are likely to feel protective towards your child in death as in life; take an extra blanket for them if you want to or you may want to take a cushion for their head, a toy, a cuddly animal or any other special object that is important for your child or for you. These simple steps can help you to feel more comfortable and peaceful, so do whatever feels right for you at the time.

Brothers and sisters may wish to see their sibling after death. You know your children best so be guided by what you know as a parent and by what your children tell you. Children and teenagers may be frightened about death and may need a great deal of support and reassurance if they choose to see their sibling to say goodbye. If they do not wish to see their sibling you may like to consider a photograph to keep for the future.

2. if your child dies in hospital

If your child dies in hospital a member of the medical staff will normally issue a medical certificate of death. The team that is supporting you in hospital will help to guide you through this process and ensure the correct paperwork and process is completed.

The ward staff may be able to arrange for you to have as much time as you need with your child after death. Hospital facilities vary, but your child can normally stay on the ward should you wish other family members to come to say goodbye. Most hospitals will also have a side ward or a special room which is more private.

At some point your child may need to be moved from the ward to the hospital mortuary while funeral arrangements are made. Or the funeral directors of your choice will make arrangements to collect your child from the ward and take them to the funeral home.

You may wish to ask for a lock of your child's hair, a photograph, a hand or a foot print. You can ask the ward staff to help you with any of your wishes. You can choose how your child is dressed after death, you can wash and dress your child and ask for someone to help. Remember, nothing has to happen in a hurry. The most important thing is that you feel as comfortable as possible with the care of your child after their death.

3. if your child dies at home or at a hospice

If you are on your own and your child dies at home you should contact your treating team or palliative care team.

You will have a number of choices:

- Your child can be taken to a funeral home when you are ready and remain there until the funeral
- Your child can be taken to a funeral home and then return home at any point before the funeral
- Your child can remain at home with you until the funeral

If your child is at home, at some point they will need to be moved. This can be arranged through your funeral directors. The point when your child is taken away from your home is likely to be very emotional and you may prefer to remain in another part of the house or choose not to be at your home at the time. You can carry your child from your house or you may ask for help from your family or the funeral director. A stretcher on wheels may be recommended.

“It’s important not to be rushed after your child has died as you will be left with the memories. Thinking about and listening to guidance before this time can be helpful but try not to let anybody talk you into doing anything that does not feel right to you. However you and your family choose to manage this time is absolutely OK. You do have choices.”

Jenny

4. planning the funeral

You may have begun to think about your child's funeral before the death of your child.

If you have religious or other requirements that may affect the timing of your child's funeral it's important to talk to the team caring for your child. Try to make some time to think and to talk to your family and others (for example a minister of your faith or your funeral director) about the funeral. It is important that you are not rushed and that the plans for the funeral are right for you.

“Organising the funeral did probably keep me going because I knew exactly what I wanted.”

Karen

Funeral services can be arranged in a number of different settings, for example, in a place of worship or at a cemetery or crematorium. Your funeral director can give you advice.

- You can have a religious service
- You can have a non-religious or humanist service
- You can decide not to have any service at all and to arrange your own ceremony or special occasion

“We wanted the funeral to be a celebration of our granddaughter's life. We knew that there were going to be lots of young people there and it may well have been the first funeral they had been to. So we wanted to make it something they would like. We put a lot of thought into it and asked her friends what music they thought we should have.”

Jennie

You can choose whoever you want to lead a service or ceremony and also how much you want to be involved in planning the details. You will need to think about how the service or ceremony will be conducted so that it feels right for you. Many parents prefer to be led by a minister of their faith and others want to involve family and friends. You may want to choose music or readings to remember and celebrate your child's life. If you have other children you will also need to think carefully about the best way to involve them in the funeral.

burial

If you decide on a burial for your child you will be able to discuss available options with your funeral director and choose the one that is most suitable for you. Funeral directors and cemetery officials will give you information and advice. You will need to pay for both the plot and the headstone. It's also worth checking cemetery rules about the type of headstones that are accepted and about planting and ornamentation. Some cemeteries will allow you to buy a family plot for future burials. If your child is to be buried, you have some choices:

- A burial can form a part of the service with everybody attending
- You can arrange for this part of the service to be private or for close family only

The grave where your child is buried will be filled in after you have left the graveside.

cremation

If your child is to be cremated, you can plan the service in a number of ways:

- You can ask for the committal (the transfer of the coffin) to be during the service
- You can ask for the coffin to remain in view until after you have left the service
- You can ask for the coffin to be out of sight for the entire service.

You will be able to choose what will happen to your child's ashes:

- You can arrange to have the ashes buried at the crematorium
- You can arrange to have the ashes scattered in the garden of rest
- You can arrange to collect the ashes to bury or scatter yourself

Some parents like to scatter their child's ashes in a place that is special to

them. Others choose to keep the ashes with them at home. Whatever you choose has to be right for you and your family. All of these decisions can be discussed with your funeral director.

You will have to wait for a period of time after the burial or burial of ashes before a headstone can be erected. Funeral directors will give you advice about these details.

funeral costs

Some funeral directors may not charge for all of their services for a child or young person. It is worth discussing your requirements with them and asking for an idea of cost before you proceed with any arrangements. You should also ask how much a burial plot and headstone will cost if you are considering a burial. Redkite and other organisations have financial support programs you may be able to access for support with the cost of the funeral. Please contact Redkite for further information or speak to your treating team.

flowers

If you have flowers at your child's funeral you have various choices:

- You can leave the flowers at the church or crematorium with instructions for them to be placed by your child's grave later in the day
- You can take them home with you
- You can arrange for them to be given away

If you do choose to leave the flowers, consider removing the personal cards so that they are not lost or damaged.

6. coping with the funeral

Here are some thoughts to help you with planning the day of the funeral, dealing with practicalities and looking after yourself and your family:

- If you decide that you want an order of service for the funeral you may want to include photographs of your child on the service sheet. Don't be afraid to ask other people to help out with the order of service and other practical tasks
- As there may be a lot of people at the service you might want to ask a friend or the funeral director to arrange to take a list of names as people enter the service so that you know who attended
- It may be possible to relay the service outside the church or crematorium in case there are more people attending than can be accommodated. Again, this is something that you can ask the funeral director, a friend or family member to check for you before the day of the funeral
- If you have other children who want to attend the funeral they may need some explanations and preparation so that they will know what to expect. You could ask a trusted adult to keep a watchful eye over them and reassure them that there is someone to turn to during the day if you are not available to them at any time
- The day of your child's funeral is likely to be both physically and emotionally exhausting. If you are worried about how you will manage think about talking to your GP

7. after the funeral

You may want to get together after the funeral with family, friends and people from your child's community. This might just be taking some time to talk to people following the funeral. You could also:

- Make arrangements to meet at a local hotel, a place of worship or community venue and invite people to attend following the funeral. You can then choose whether or not you wish to go
- Arrange for people to come back to your home. You may like to think about asking a friend or family member to be responsible for asking people to leave when you want to have time alone

Your family and friends will understand that you need to do what is right for you, even if this means that you prefer to have time for yourself without making any special arrangements for others.

“The thing that you’ve got to remember is all your memories are going stay there for ever and that’s a good thing. Tomorrow’s going to be a bad day because they’re not going to be there but you’ve always got their memories.”

Paul

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: 1800 642 066

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.

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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comments or queries about it, please contact us:
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