



redkite

One day at a  
time series

# *when your child isn't going to get better*

For parents and carers

One day at a  
time series

## *when your child isn't going to get better*

Adapted from the publication 'One day at a time: When your child isn't going to get better', produced by CLIC Sargent, the UK's leading cancer charity for children and young people, and their families.  
[www.clicsargent.org.uk](http://www.clicsargent.org.uk).

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 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 charity that supports children and young people with cancer aged up to 24, and the family and friends that 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](http://www.redkite.org.au)

**1800 REDKITE (1800 733 548)**  
**[support@redkite.org.au](mailto:support@redkite.org.au)**

### Additional support

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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## ***1. new 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 is 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 is 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, speak to someone in the team caring for your child or contact a specialist organisation such as Redkite. You can find contact 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 is likely you will have many questions. Some will come straightaway 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?***

Talk to your hospital-based social worker to find out what support is available. You can get help and support from the team caring for you and your child in hospital, in a hospice or at home, your GP, community organisations such as Redkite, 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.

***“What has helped me is being in touch with other people that have lost children, because you can feel isolated.”***

Beverly

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 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 is important to talk to or to 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 challenging time for relationships as you and your family come to terms with your new situation. It is 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?***

If you have other children, it is important to communicate with them. 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 hospital-based or Redkite 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. Redkite has a book collection for families to access; please speak to your social worker if you feel this would be helpful, or contact Redkite directly.

## ***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. If you feel comfortable, have your treating team talk to your family about what is happening for your child. Medical staff or social workers are willing to talk to grandparents, family members or friends if this would help.

The staff 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 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. For instance, shopping, laundry, ironing and cooking are often practical tasks that others can do. If you have other children, you might also like to consider asking somebody to take or collect your children 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 is always a good idea to try to keep your child's school or college informed of the situation. If you would like support with this, please speak to your treating team or Redkite about making contact 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 medical certificate to exempt you from work or to recommend reduced hours or flexible working
- ▶ 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
- ▶ Consider the options of accessing your superannuation or income protection if these options are available to you.

If it helps, your child's treating team can provide written information to your employer to support any change in your working arrangements.

Most employers will try to support you during this difficult time but it is 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 are in receipt of benefits from Centrelink, you can obtain advice from them to ensure you are receiving the most appropriate benefits for your current situation.

If you are self-employed, you may need specialist advice. This might involve making a claim for benefits.

## ***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 most happy 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 is important to try and maintain the routines and the good behaviour you normally expect. Children and teenagers respond well to consistency and it may help your child and their siblings to feel more safe and 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 at any time that you need it.

## ***3. dealing with the hardest steps***

### ***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.

Most children and teenagers 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 your treating team for advice about hospice care for children and young people. If there are appropriate options in your local area, it may be possible to arrange a visit to a hospice to help you decide if this would be a good choice for you. 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 for you. 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 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. Be aware that 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 to understand what is happening and any choices that you may have.

## ***Will my child suffer?***

The team looking after your child is 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 is 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 is 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 is 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 are likely to have the love and support of your family, friends and community. And you will also have the support, skills and knowledge of an experienced team who will help you and guide you through the choices ahead of you. If these options are not available to you or you would like to talk to a support person, please contact Redkite who are here to help at any stage.

***“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 Redkite or 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 Australia. Redkite and CLIC Sargent do 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, Redkite and 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**

### **Redkite**

Redkite supports anyone aged up to 24 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 expenses for face to face counselling and funeral arrangements and essential household expenses.

[www.redkite.org.au](http://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](http://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](http://www.grief.org.au)  
Tel: 1300 664 786

### **Cancer Council Australia**

Resources and information about options when cancer cannot be cured.

[www.cancerCouncil.com.au/cancer-information/advanced-cancer](http://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](http://www.canteen.org.au)  
Tel: 1800 226 833

### **Bear Cottage** (Sydney)

Affiliated with The Children's Hospital at Westmead, Bear Cottage is a children's hospice dedicated to caring for children with life-limiting conditions and their families.

[www.bearcottage.chw.edu.au](http://www.bearcottage.chw.edu.au)  
Tel: 02 9976 8300

### **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](http://www.vsk.org.au)  
Tel: 1800 888 875

### **Palliative Care Helpline** (Queensland)

The Palliative Care Helpline is a Queensland statewide telephone service that provides information, emotional support and counselling to individuals affected by life-limiting or terminal illness.

[www.palliativecarehelpline.org.au](http://www.palliativecarehelpline.org.au)  
Tel: 1800 772 273

### **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](http://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](http://www.childhoodcancer.asn.au)  
Tel: 08 8239 1444

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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