

End of life planning

If your child has had a life-limiting diagnosis, you have probably thought at some point, about their death. You might have already made arrangements for when this happens. However, it is likely that you will find the reality of your child dying very difficult, and may not want to think about making plans for their death until it approaches.

If you can, you should try and plan for your child's end of life and death, as soon as possible after you are told that your child is approaching the end of their life. This will help you and the professionals working with you to achieve your wishes for your child's end of life, as closely as possible.

Planning ahead will mean you don't have to think about so many practical things at the time of your child's death, when you will want to spend as much time as possible with your child, and when you will probably be feeling emotional, exhausted and confused. Families have told Together for Short Lives that forward planning for their child's end of life can make them feel more in control of the situation, and can give them more time to create positive memories during the last few days.

Make sure you take your time and think about your child's end of life only when you are ready; perhaps after speaking to your GP, your child's doctor or someone from your care team or hospice.

An end of life care plan

Your care team should work together with you, your child and the rest of your family to develop a written end of life care plan. Make sure everyone working with your child has a copy of the plan, so they can act in accordance with your wishes. It is important that the care plan is reviewed regularly – you can change your mind at any point about any aspect of the plan.

We've suggested a few things you might want to think about as a starting point:

■ Allowing a natural death

You may want to think about whether you want to withdraw invasive treatments and equipment at the end of your child's life.

■ Planning for the time of death

Think about who you want to be present, who will look after your other children, who will call family and friends.

■ Looking after your child's body after death

There are a number of choices you can make here. You can take your child to a special suite at a children's hospice, or even take them home.

■ Organising ceremonies

Think about whether you want a traditional funeral or whether you would like to remember your child in another way.

■ Organ donation

Even if your child has had a long-term illness, it is still possible to donate tissues such as heart valves and corneas.

■ A will for your child

Your child may find it comforting to write a 'will', choosing to give various toys and other items to specific friends or family members.

Siblings often need extra support and are easily forgotten at such an emotional time when so much focus is on your sick child.

When it becomes apparent that your child is approaching his or her end of life, you may want to talk to someone to help you come to terms with the reality of this difficult time, and what it will mean for you and the rest of your family.

There are lots of people who can help – remember you're not alone

If you feel you or any member of your family needs to talk to someone outside your direct care team, you can ask your GP or a member of the care team to help find a professional for you to talk to.

There are also support groups and organisations that can help both emotionally and practically.

How Together for Short Lives can help

Together for Short Lives runs a helpline for families: 0845 108 2201. We can provide you with support and signpost you to information, help and the services you need. We're also there for you if you just need to talk.

Together for Short Lives has produced a booklet called *A Family Companion* which is designed to help all parents and carers who have a child with a life-limiting health condition. It acts as a guide through the processes that follow diagnosis, up to end of life and into bereavement.

For your free copy just call Together for Short Lives on 0845 108 2201 or email info@togetherforshortlives.org.uk

We also produce a family newsletter, *together for families*, which is published four times a year. To subscribe, contact us.

Together for Short Lives also has a special family website area: www.togetherforshortlives.org.uk/families

Who can help?

There are many organisations that can help you at this time. You can find many of these organisations on the Together for Short Lives website at: www.togetherforshortlives.org.uk/support

The Child Bereavement UK

The Child Bereavement Charity supports families and educates professionals when a child is dying or has died, and when a child is bereaved of someone important in their life. The charity provides a national support and information helpline for families and professionals, publications and resources, a website with online forums, and a family bereavement support service.

Web: www.childbereavement.org.uk
Tel: 01494 568900
Email: support@childbereavementuk.org

Childhood Bereavement Network

Childhood Bereavement Network seeks to ensure that all children and young people in the UK, together with their families and other care givers, including professional carers, can easily access a choice of high-quality local and national information, guidance and support to enable them to manage the impact of death on their lives.

Web: www.childhoodbereavementnetwork.org.uk
Tel: 0207 843 6309
Email: cbn@ncb.org.uk

Winston's Wish

Winston's Wish is the childhood bereavement charity that provides services to bereaved children, young people and their families.

Web: www.winstonswish.org.uk
Tel: 0845 203 0405
Email: info@winstonswish.org.uk