



A Family Companion

to the ACT Care Pathway
for children with
life-limiting and life-
threatening conditions



A Family Companion to the ACT Care Pathway for children with life-limiting and life-threatening conditions is published by ACT in England.

ACT Brunswick Court, Brunswick Square, Bristol, BS2 8PE

T: 0117 916 6422

F: 0117 916 6430

E: info@act.org.uk

www.act.org.uk

Helpline: 0845 108 2201

ISBN: 1 898447 10 1

© ACT (Association for Children's Palliative Care) 2010.

First published 2009.

Second edition 2010.

Authors: Lizzie Chambers and Katrina McNamara-Goodger

Editor: Susannah Woodhead

Working Party: Lizzie Chambers, Louise Derbyshire, Wendy Dodds, Anna Gill, Katrina McNamara-Goodger, Julia Shirtliffe and David Vickers.

Design: Qube Design Associates Ltd

Print: Doveton Press Ltd

Photography: Front cover, page 21: With kind permission from Francis.

Page 7: With kind permission from Andy Newbold, Rainbow Trust Children's Charity.

Page 11: With kind permission from Anna Gill.

Page 17: With kind permission from East Anglia's Children's Hospices.

The ACT Care Pathway diagram (opposite): Adapted from the 'Integrated Care Pathway', pp. 15, 19, 25, *A Framework for the Development of Integrated Multi-agency Care Pathways for Children with Life-threatening and Life-limiting Conditions*, ACT (2004), Bristol.

ACT would like to thank all the organisations and individuals who contributed material and expertise to this Companion.

This project is supported by the Department of Health.



Valuing short lives

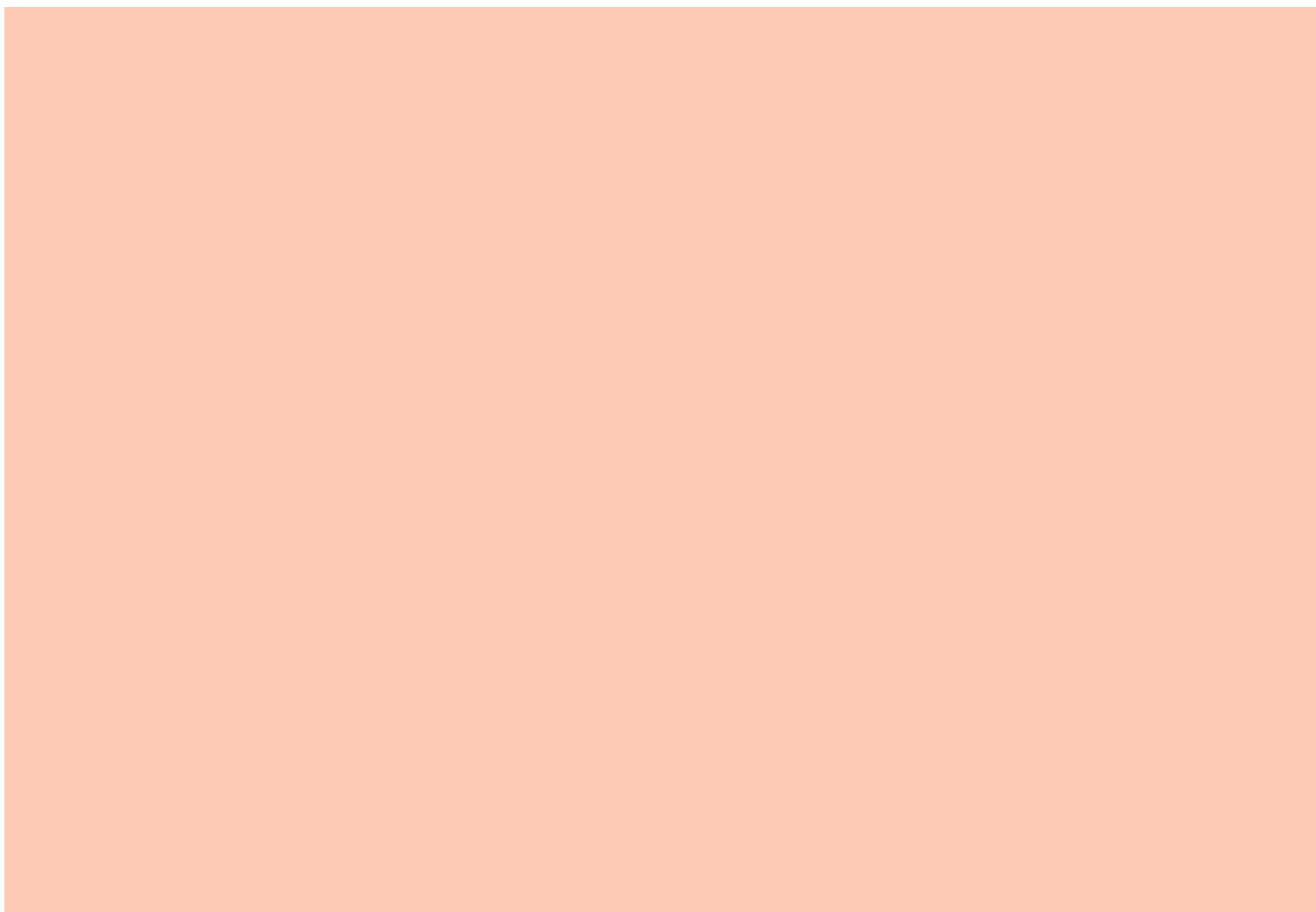
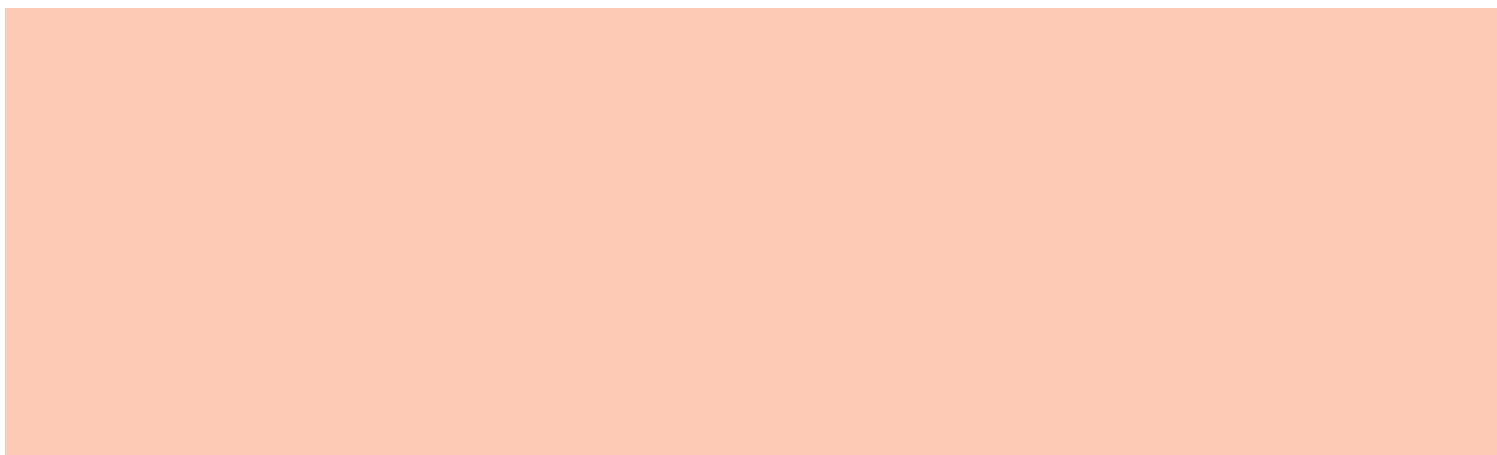
ACT is the only organisation working across the UK to achieve a better quality of life and care for every life-limited child and their family.

ACT is a registered charity and a company limited by guarantee. Registered Charity No: 1075541 Company Registration No. 3734710 England

ACT for children **ACT** for families **ACT** together **ACT** now!

The diagram below shows each stage of the *ACT Care Pathway* and highlights the five 'standards' that will be explained in the colour coded chapters throughout this Companion. The pathway diagram also acts as a table of contents, indicating page numbers for easy reference.





Introduction

If your child has been diagnosed with a life-limiting or life-threatening condition, you will be facing a difficult and traumatic time. You will be likely to encounter many professionals and services, all playing a vital role in your child's care.

Every child's care journey is unique – and the journey that each family takes alongside their child will be different, lasting different lengths of time and taking the child and family to different places. However, all families have many needs in common and the *ACT Care Pathway*¹ is a representation of what all families should expect to receive in response to those needs. We hope that *A Family Companion to the ACT Care Pathway* will provide you with an overview of the many services that are available and outline what you can expect at each stage of your journey.

The ACT Charter sets out what families should expect from their child's care. It states that parents should be treated with openness and honesty, and that they should be acknowledged as experts in the care of their child. It aims to ensure that the needs of every life-limited and life-threatened child and young person are addressed and planned for well in advance.

Directory

The ACT Charter can be found in the directory section of this Companion.

The *ACT Care Pathway* was produced by ACT in 2004 as a tool to help maintain the standards set out in the charter, by assisting professionals in planning appropriate care and co-ordinating the various services and individuals that will play a part in a child's care.

It presents a pathway which professionals can use to engage with the child and family's needs and make sure everything is in place for families to access the appropriate support at the right time.

The *ACT Care Pathway* sets five main 'standards' for care along the pathway, which provide a focus for professionals caring for your child.

A Family Companion to the ACT Care Pathway has been developed by ACT to help explain what these five standards will mean to you – the family – so that you know why these standards are in place, and how they can ensure that your child gets the care and support they are entitled to at different stages along their journey.

This Companion also aims to identify which services, agencies and professionals can provide support at various points along the pathway.

If there's something worrying you that we haven't included in this Companion, or you need us to explain anything in more detail, call the ACT Helpline on 0845 108 2201. You can also talk to your care team about any of the issues raised in this Companion.

Information

1. *A Framework for the Development of Integrated Multi-agency Care Pathways for Children with Life-threatening and Life-limiting Conditions*, ACT (2004), Bristol.



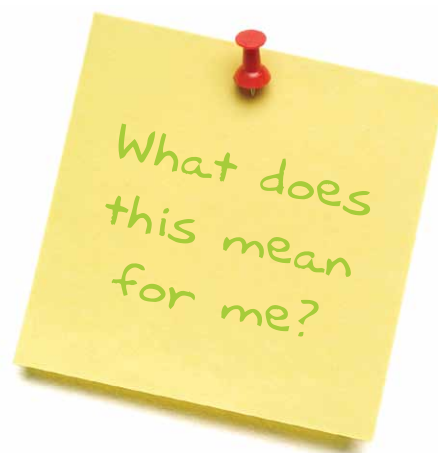
Breaking news

Every family should receive the news of their child's prognosis in a face-to-face discussion in privacy and should be treated with respect, honesty and sensitivity. Information should be provided for the child and the family in language that they can understand.

As a parent, being told that your child has been diagnosed with a life-limiting or life-threatening condition is probably one of the most shocking and upsetting experiences you will ever go through.

Emotional and psychological support can help you cope with the initial diagnosis, support you during your child's life, and can help you to prepare for their death, as well as provide bereavement support in the weeks, months and years afterwards. Psychological support comes from different people at different times and can take many forms; sometimes the best support can be someone's practical help, a friendly gesture or just someone being there to provide a listening ear or quiet company. In some cases, however, professional support may be required to help you through this difficult time.

At this stage of the pathway you should receive the news about your child's condition and the implications of what this will mean for you and your child.



What should I expect?

Time for face-to-face discussions and the opportunity to ask questions

Time with a nurse or other staff member should be offered to you before you leave the clinic or hospital, to give you support and to address your concerns. If your child is with you at the appointment where you are told the news, you should be given a chance to talk through what you have just discussed whilst another member of staff minds your child.

Write down the questions you want to ask your doctor in advance, so you don't forget. Ask your doctor to write down the answers so you can look back over them.

If your child is old enough to understand what is being said, he or she should be offered suitable support before you leave. You should also be offered support to help you talk to your other children and family members about your child's condition and what this means for them and for the whole family.

A room to ensure you have complete privacy

You should be told about your child's diagnosis and prognosis (what might happen in the future) in a private setting. Doctors and nurses will be able to talk with you about what *might* happen, but it is unlikely that they will know for certain. Sometimes it is difficult for them to know what the progress of your child's condition will be, especially as technology develops and new treatments are found, but they should be honest about this.

Have someone with you when you receive the news

It is important that you have the support you need at the point when you hear the news for the first time. This might mean that your spouse or partner will be with you, or a relative or friend will support you during the appointment when you learn about your child's diagnosis.

Make sure siblings' needs are not forgotten during this stressful time. They will no doubt have lots of questions and will need time and support to understand and come to terms with their brother or sister's condition, and the impact it will have on their lives.

Helpful written material to supplement your discussion

Written information should be given to you and to your child, to back up what your child's consultant has said. If English is not your first language and you need an interpreter to help you communicate, this should be available at all times.

Ask for copies of any letters written by the medical team about your child, so you always know what's going on.



Here's a checklist of what you should expect at this stage of the Care Pathway

- ☐ Time available for face-to-face discussions and the opportunity to ask questions.
- ☐ A private room to talk in.
- ☐ Make sure you are not alone at the appointment. A partner, relative or friend should come with you to offer support.
- ☐ Helpful written material to supplement your discussion.
- ☐ Information conveyed in a language you can easily understand, with interpreters provided if necessary.

Who can help?

- Friends and family members.
- Your child's consultant, specialist nurse, GP, community children's nurse (CCN) or health visitor.
- Social workers from local authority children's services.
- The Patient Advice and Liaison Service.
- School staff, including those involved with your other children.
- Children's hospices – you can find out where your nearest children's hospice is from Children's Hospices UK (website: www.childhospice.org.uk, tel: 0117 989 7820).
- Voluntary groups and services such as ACT.

Call the ACT
Helpline: 0845
108 2201

Information

Talking to other parents

www.makingcontact.org helps you to get in touch with other families who are affected by the same or similar conditions.

Information

Directory

Sibs is the UK charity for people who grow up with a disabled brother or sister. Contact Sibs for information about how they can support your other children (website: www.sibs.org.uk, tel: 01535 645453).

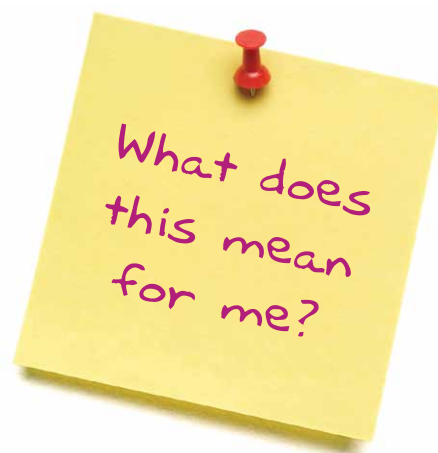




Planning for going home

Every child diagnosed in the hospital setting should have an agreed transfer plan involving the hospital, community services and the family, and should be provided with the resources they require before leaving hospital.

This stage of the Care Pathway is about preparing for your child to return home from hospital, and ensuring that this journey is carefully planned and assessed to enable a smooth transfer home. The planning process should involve all the key individuals involved in your child's care, including the hospital team, your GP, primary care team and social services as well as you and your family.



If your child is in hospital when diagnosed with a life-limiting condition, hospital staff should work with their colleagues in your local community to arrange a plan for your child to go home (where possible), ensuring that you have the right equipment, transport and immediate support in place before you leave hospital.

The point when a child leaves the hospital will be different for each family, depending on the nature of the child's condition and their health. Some may require immediate medical attention in hospital, and others may be able to go straight home after diagnosis.

You should be given an opportunity to go over all your concerns in detail and to make sure you have everything you need before you leave the hospital.

Information

What should I expect?

Communication with community services

You should have contact from community services while you are still in the hospital. This will give you time to plan before you leave hospital, making the transfer home easier and more comfortable for you, your child and your family.

Your GP should be told about your child's diagnosis and the plans that are in place for their discharge home. Where appropriate you may also have special carers involved to support you when you take your child home.

You and your child are likely to have a number of individual assessments for various types of services, such as short breaks, nursing care, housing and equipment. These may include assessments by children's continuing care, local healthcare provision, local authority services and other providers of services for children and young people.

Take the time to explain to siblings how changes in the home will affect them. Lots of health professionals coming and going, new equipment around and changes to the family routine may unsettle them.

Your key worker/lead professional

Ideally, you will be allocated an identified key worker, sometimes called a lead professional, whose role is to co-ordinate your child's care and liaise with the many professionals who will be involved. This individual will become your key contact concerning all aspects of your child's care.

A discharge planning meeting

A discharge planning meeting should take place, involving professionals providing medical and nursing support and therapies for your child as well as social, practical, emotional, psychological and spiritual support for you and your family.

The box below highlights the kinds of issues that will need to be discussed at this discharge planning meeting to enable your child to go home safely with appropriate support in place.

Add these contacts to your address book at the back of this Companion.

- Identifying a key worker or lead professional to co-ordinate your child's care.
- Arranging a needs assessment involving all the appropriate services.
- Making sure you know who to contact in different situations and how to contact them.
- Making sure professionals involved with your child know how and when to contact you.
- Deciding where you want your child to be cared for.
- Carrying out a risk assessment of your family home.
- Developing a plan to meet your child's nursing needs on a daily, 24 hour and emergency basis.
- Developing a plan to make sure you have access to medical advice (symptom control) on a daily, 24 hour and emergency basis.
- Making sure you have easy access to:
 - Medication
 - Aids and equipment
 - Support for the whole family
 - Spiritual support
 - Psychological support
 - Short breaks for your child

Aids, equipment and supplies

Once you are home, you may need some specialised equipment to enable you to care for your child. You will be assessed for this equipment by either your local authority or health services and a member of your care team should be able to provide you with information about this process.

Directory

There are lots of charities that can provide information and advice about aids and equipment. See the directory for details.

Your home

If your child has special care needs, there may be issues about whether your housing meets your child's needs. For example, there may not be enough space for storing equipment, or you may need specially adapted rooms. There may be funding available from your local authority to adapt your home or you may need a housing assessment to decide whether it might be necessary for you to move.

The services that will be supporting you when you get home need to be aware of your needs and it is important that you know how and when to get in touch with the various professionals involved. The key people who will be supporting you should visit you within three days of your return home and there should be someone for you to call for help on a 24 hour basis.

Use this space to think about your child's needs, and what adaptations you might have to make to your home.



Our home:



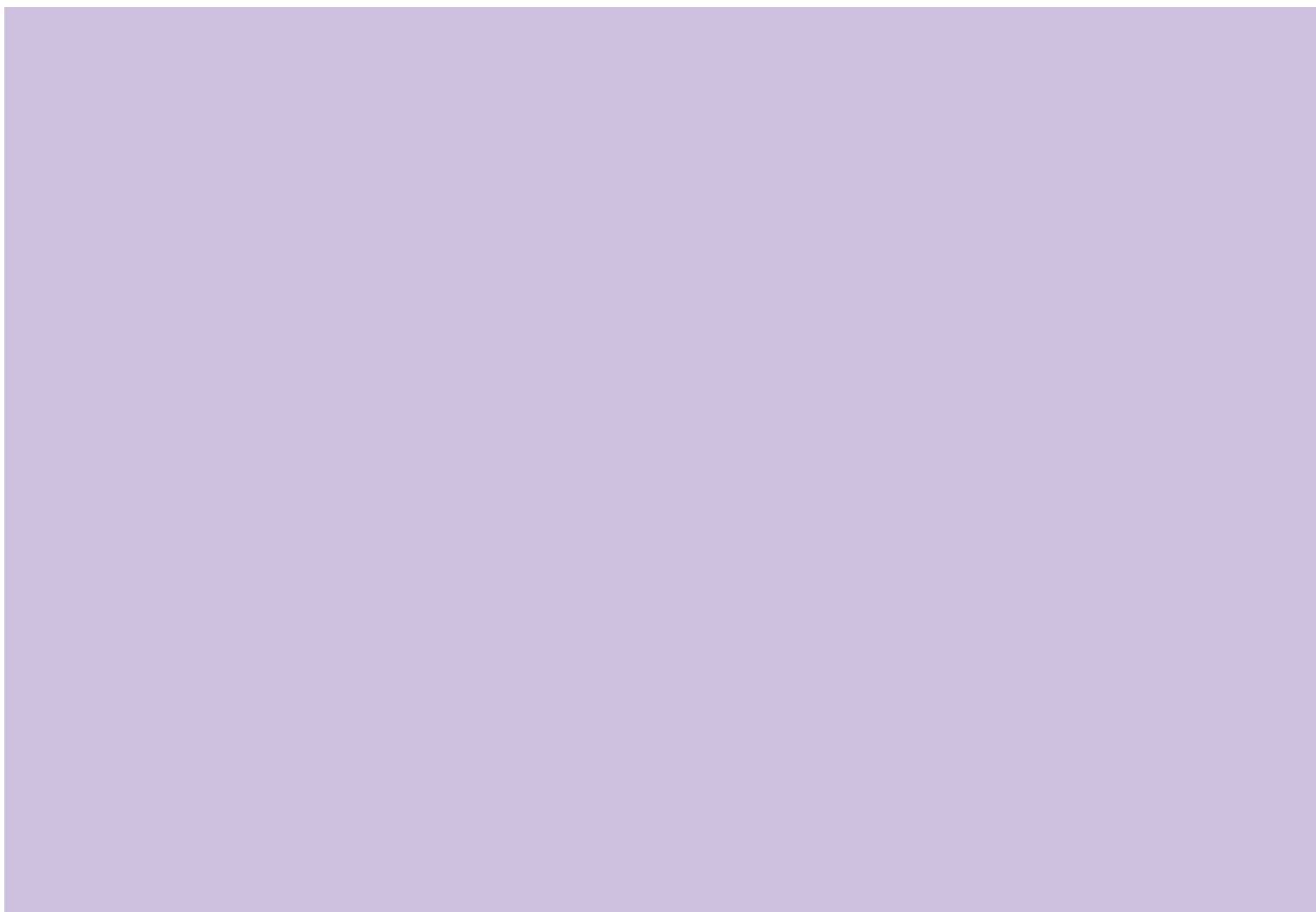
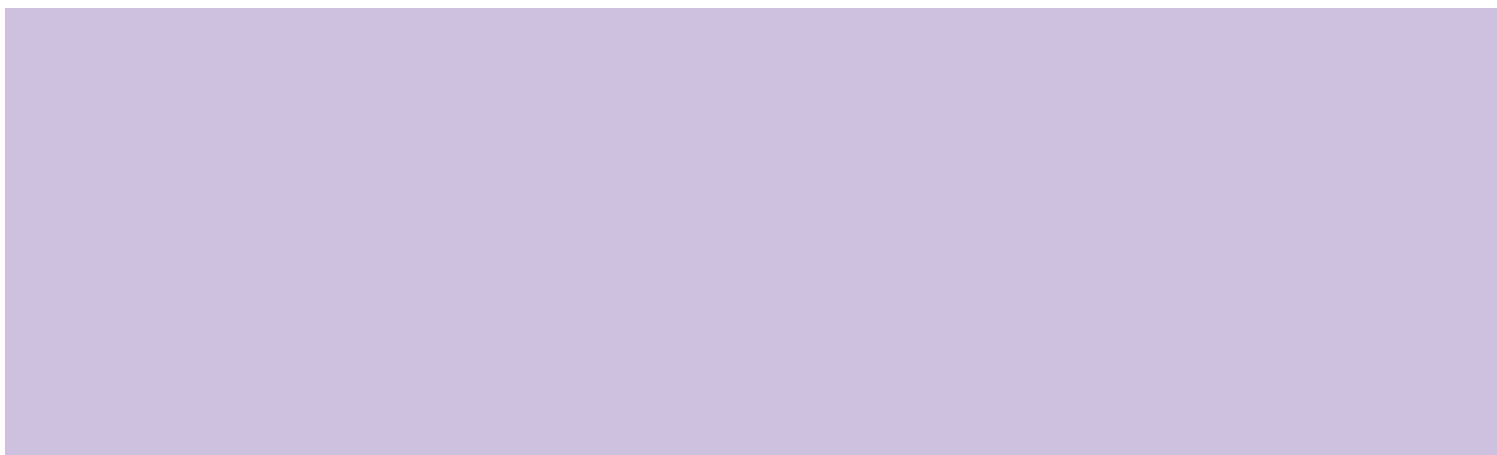
Here's a checklist of what you should expect at this stage of the Care Pathway

- ☐ Services in the community should be informed about your child as soon as possible and staff from community services should make contact with you while you are in hospital.
- ☐ Planning for the transfer home should begin as soon as possible. A discharge planning meeting should take place where a clear transfer plan will be agreed.
- ☐ A lead community nurse should be agreed before you go home and your GP should be invited to become involved.
- ☐ Equipment and supplies should be provided before your child is transferred home.
- ☐ You should know who to contact in different situations. You need to make sure you have the appropriate contact details.
- ☐ A home visit should take place within three days of getting home.
- ☐ You should be provided with a 24 hour contact number for emergencies.
- ☐ Where possible you should have an identified key worker or lead professional who will co-ordinate all aspects of your child's care.

Who can help?

- Community children's nurse (CCN)
- Hospital outreach nurse
- Social worker
- Occupational therapist
- Discharge planning co-ordinator (usually hospital based)
- Physiotherapist

Information

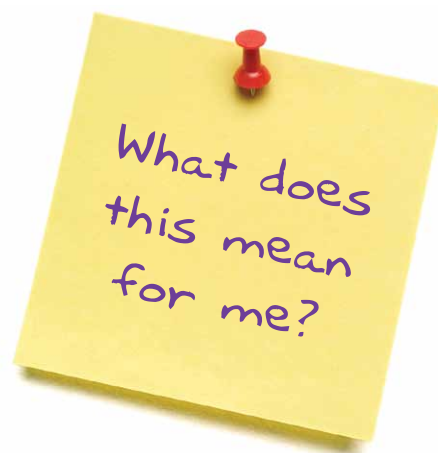




Multi-agency assessment of your family's needs

Every family should receive a multi-agency assessment of their needs as soon as possible after diagnosis or recognition, and should have their needs reviewed at appropriate intervals.

This stage of the Care Pathway is vital as it provides you with an opportunity to explain what is important to you, your child and your family so that written plans can be drawn up to enable you to live as normal a family life as possible.



What should I expect?

Your child and family's needs are inevitably going to change over time and there should be a clear process for regular planned reviews as well as a process for enabling you to request a review of your needs as and when you feel this is necessary. Your key worker or lead professional should be a named individual from one of the services involved in your child's care who will lead on your needs assessment and ensure that reviews take place as appropriate.

Multi-agency needs assessment

As soon as possible following your return home, your child's needs will be discussed with you and assessed by a team working with you to ensure that your child gets the ongoing care they need and that your choices are taken into account. This is called a 'multi-agency needs assessment'. This assessment process should be co-ordinated and involve all agencies and providers so that you do not have to repeat your needs to the various different services and organisations.

Make sure siblings' needs are considered as part of the multi-agency assessment.

You, your child and your family should be fully informed and involved

You should be supported to have a choice in the care your child receives, and to have a choice about where they receive that care. It is important that your needs are reviewed regularly. It is likely that local services will have set intervals when reviews are carried out, and you should be informed of these. However, if you would like an earlier or later review, you should be able to negotiate this with the local staff through your key worker or lead professional.

Your child's interests should be kept central to this process and you and your family should be kept fully informed and involved. Professionals working with you should use easy to understand non-jargon language.

Confidentiality and consent

You should be confident that your family's personal details will be kept confidential and your records held securely. You should also be in charge of deciding what information is shared, who it is shared with, and when it is shared. It is useful to remember that your child's interests are generally best served by sharing information widely, although your care team will advise you about confidentiality issues relating to certain personal details.

List all the key people you want to keep informed. Make sure you note them down in the address book at the back of this Companion.



During the assessment you can have whoever you wish present to help you make decisions, or just to support you. This may be your spiritual or community leader, friends and/or family members.

Here's a checklist of what you should expect at this stage of the Care Pathway

- ☐ The multi-agency needs assessment should take place as soon as possible following diagnosis.
- ☐ The assessment process should involve all agencies and providers so that you do not have to repeat your needs to different services and organisations.
- ☐ You should be involved in the assessment process.
- ☐ Your child should be kept informed and be involved in the process.
- ☐ Care should be taken to include the needs of the whole family.
- ☐ Your culture and personal beliefs should be respected.
- ☐ Straightforward, non-jargon language should be used.
- ☐ Issues of confidentiality and consent should be discussed with you.
- ☐ You should have access to any assessment information that is gathered.
- ☐ It should be made clear who is taking the lead role in your child's care.
- ☐ Professionals involved in the multi-agency needs assessment should have appropriate skills and local knowledge of what is available.

Who can help?

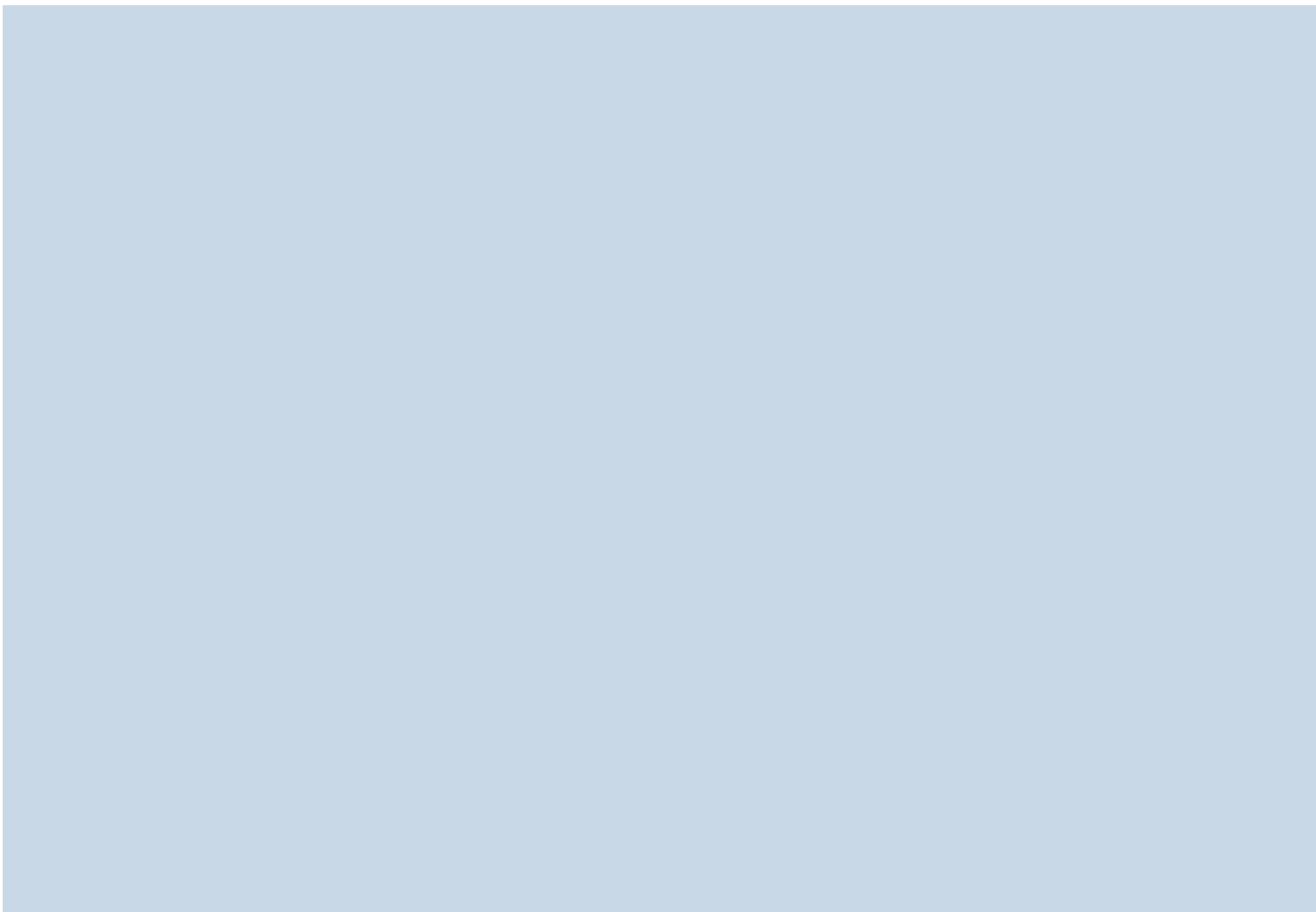
To find out more about who these people are, see the directory.

- Key worker/lead professional
- Family link worker
- Social worker
- GP
- Community children's nurse (CCN)
- Special educational needs co-ordinator
- School staff
- Education welfare services
- Children's hospice/hospice at home service
- Specialist nurse
- Specialist doctor

Information

It is usually a good idea to keep your child's school informed about the progress of their condition, to enable them to keep up with school work and maintain links with school friends. Siblings' schools should also be aware of what is happening, so that staff can deal appropriately with any emotional issues that may arise.

Information





4

A multi-agency care plan

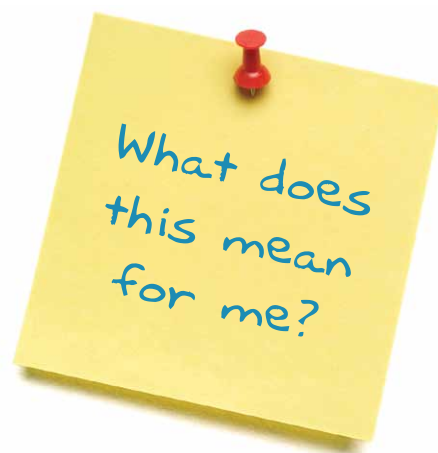
Every child and family should have a multi-agency care plan agreed with them for the delivery of co-ordinated care and support to meet their individual needs. A key worker or lead professional to assist with this should be identified and agreed with the family.

This stage of the Care Pathway involves the development of a care plan that takes into account the needs and wishes of your whole family, including your other children and other relatives and friends who are important to your child.

The care plan should be a working document that is shared, providing details of all the professionals and services required to meet the needs identified in the multi-agency needs assessment.

You should be given a copy of your child's care plan and be consulted about which services you want included in the plan, as well as which services you want to have a copy.

Use this space to jot down ideas of what you would like your child's care plan to include, or to make sure you remember any special wishes or requests your child might have.

A spiral-bound notebook is shown, open to a blank page. The spiral binding is on the left. At the top of the page, the words "child's care plan:" are written in blue ink. The rest of the page is blank, intended for notes.

Add these contacts to your address book at the back of this Companion.

You should have details of how to contact important people and out of hours services.

It should be clear when your child's next review of needs will be carried out and you should also be aware of how you can ask for a review to take place earlier than this if you want to draw up a revised care plan.

Review information

Use the diary below to record your reviews and appointments.

Date:	Time:
Where:	
Who:	
Date:	Time:
Where:	
Who:	
Date:	Time:
Where:	
Who:	
Date:	Time:
Where:	
Who:	
Date:	Time:
Where:	
Who:	
Date:	Time:
Where:	
Who:	

What should I expect?

Your key worker/lead professional

A key worker or lead professional is a named individual who will help your family find its way through what may be a complex network of services, acting as a single point of reference when you need to ask questions about many different things. You should also have a community children's nurse (CCN) allocated to your child.

Understanding information

You will find huge amounts of information on the internet, from books, from contact with other families, and from the many professionals that you encounter. This information can be overwhelming and you should ask your care team if you need help understanding or prioritising the information that you have received. All information that you are provided with by the care team should be in language that you can understand and interpreters should be available if required. Your child and their siblings should also be given information appropriate to their age and level of understanding.

Make sure your other children fully understand what is happening. If you need help talking to them about their brother or sister, ask a member of your care team. They will probably have experience of explaining things in a child-friendly way.

Your child's symptoms and personal care

You will no doubt be concerned about managing your child's symptoms and about how to look after them and keep them comfortable. You may find that you will have to provide a lot of personal care for your child, such as administering medications, giving them special treatments or using specialised medical equipment. For many families, the management of their child's symptoms and their personal care is a major worry. It is very difficult to live with the fact or the fear that your child is in pain or suffering with distressing symptoms. Your child's care plan should outline how you can access 24 hour nursing or medical support if you have concerns about your child's symptoms or care.

Psychological and emotional care for you, your child and your family

You may be experiencing a whole range of feelings: numbness, anger, sadness or disbelief. You may find it difficult to talk to those people who are closest to you, or they may find it hard to talk to you about their feelings. It may be difficult or frightening for you to initiate a discussion about things that are bothering you, either with your child, other family members or with members of the care team.

If you need to chat, call the ACT helpline on 0845 108 2201.

Information

Your child and other family members may also be finding it difficult to talk with you. It can help them to open up if they feel that they have a choice of people they can turn to.

Remember that even though you might need to talk, others may not be ready to put their thoughts and feelings into words. You may find it helpful to talk to other people in similar situations, or professionals who are aware of what you might be going through.

You might need extra, or more specialised support at certain times. For example, it may be appropriate for you to be referred to psychological support services. Your GP can refer your family to services where you can receive support individually, as a couple, or as a family.

It can be helpful to find someone for your child to talk to outside the family. Your care team will be able to put you in touch with a suitable individual or service.

Information

If you are a single parent, try not to keep your worries to yourself. Make sure you have someone to talk to, whether it be a family member or a friend. You could also talk to your GP.

Directory

Children's hospices and many local and national charities also provide emotional support. Call Children's Hospices UK for information about your local hospice on 0117 989 7820. See the directory for details.

Disability Living Allowance (DLA)

This is the main benefit for parents caring for a child with a disability. There are two components, the **care component** and the **mobility component**.

There is usually a three month qualifying period for DLA, but if your child is diagnosed as terminally ill and is not expected to live longer than six months, there are special rules which mean this qualifying period does not apply, and that your application will be prioritised.

To receive the mobility component of DLA, your child must be at least three years old.

Directory

Contact a family can provide details of benefits you may be entitled to. Call them on 0808 808 3555, email helpline@cafamilly.org.uk, or visit www.cafamilly.org.uk.

Carers Allowance

If your child is severely disabled, you may not be able to work as a result of caring for your child. You may be entitled to Carers Allowance, providing you are over 16, provide regular and substantial care for 35 hours or more per week and your earnings do not exceed a certain threshold.

Information

Find out more about the benefits you could be entitled to. Call the Benefits Enquiry Line on 0800 88 2200, or Contact a Family on 0808 808 3555. There is also useful information on the Citizen's Advice Bureau online service www.adviceguide.org.uk.

Blue Badge

The Blue Badge scheme entitles certain groups of disabled people to park in parking restricted areas. It is available in most areas, but some city centres do not operate the scheme. The online Blue Badge parking map can help you find Blue Badge parking bays in 64 towns and cities across the UK. www.direct.gov.uk/bluebadgemap.

The Blue Badge scheme does not normally apply to children under two, but in England, Scotland and Northern Ireland, exceptions are made when children have certain medical requirements.

For more details, contact the Blue Badge Helpline on 0207 944 2914 or 0161 367 0009.

Access to flexible short breaks

It can be a real boost for you, your child and your family to spend time together, or separately, on a holiday or supported break. Short breaks enable your child to have new experiences and allow you to have a break from caring. These should be flexible and available in your own home, in a hospice, hospital or other community setting, such as a playgroup. There are a number of organisations that can provide holiday accommodation for families caring for a child with complex health needs. Short breaks specifically for siblings are also available. Holidays and short breaks can be organised through children's hospices with appropriate nursing and other support provided. Further information can be obtained from your health visitor, key worker or lead professional..

See the holidays, short breaks and wishes section in the directory.

Directory

Access to education

For many children and young people, school remains the focus of their lives, providing opportunities to learn, develop, play and experience as normal a daily life as possible. You may find it useful to make sure that your care team communicates with your child's school to keep them informed about your child's absences and to ensure that your child is able to keep up with school work, if they are well enough to do so.

As a result of their condition, some children will have additional or special educational needs, or may have a condition which means they require special access to education.

There should be a dedicated professional at your child's school who deals with additional or special educational needs, who will assess and co-ordinate the different aspects of your child's educational needs.

This professional, along with the case officer at your education department, educational psychologist and others, will assess the possibility of mainstream education for your child, and if they consider this impractical, will identify an appropriate special school.

Children under the age of two who have complex needs are entitled to an assessment from the local education authority (LEA). This early identification of a child's needs can help them to access specialist support or home-based teaching.

School aged children should be able to attend their usual school for as long as possible, so that they can benefit from playing and interacting with their friends as well as receiving education. In addition to providing stimulation for the child, many parents report that school can be an immense source of support, providing a break during the day as well as other practical help for them. Where it is no longer possible for a child to attend school, his or her education will continue through the hospital school or the home tuition service, for as long as the child is well enough and enjoying the learning experience. Around the time of your child's 14th birthday, transition planning will begin for transfer into college or employment and other adult services.

Protecting your own health and emotional well-being

You may find that your caring responsibilities last for many years and that you become increasingly stressed and exhausted. For example, constant lifting of children as they become heavier young adults can take its toll.

Talk to your GP if you have concerns about your own health or well-being.

Access to aids and equipment

You may need specific pieces of equipment to help you care for your child and you should be assessed by someone from your local authority, primary care trust or children's team who can inform you about the options and services available to you.

You may need specialist bedding or clothing, particularly if your child experiences difficulties with continence. Your local health service may provide continence aids including nappies, but the age of qualification for this varies from service to service. Your health visitor or another member of the care team should be able to give you advice about this. You might find it helpful to contact your local disabled living centre for further information on special clothing and other products that might be helpful.

Your child's transition to adult services

It is important to begin planning for your child's transition to adult services at an early stage – ideally at 14. It is common for parents to feel reluctant to face the prospect of moving on to adult services, where it may seem that there is little expertise in particular childhood conditions, but it can help to make the transition easier if you meet with the new professionals and services in the adult sector and begin to make the emotional adjustment to a different, more adult-centred system of care.

You can request a review of your child's care plan if they have to go into hospital, if there is a change in your child's condition or if something happens within the family that affects your ability to cope.


 Information


Here's a checklist of what you should expect at this stage of the Care Pathway

- ☐ A key worker or lead professional should be identified to co-ordinate the care plan.
- ☐ Information should be provided for you, your child and your family.

The plan should include the whole family and take account of:

- ☐ Your child's symptoms and personal care.
- ☐ Psychological care for you, your child and your family.
- ☐ Access to benefits and financial assistance.
- ☐ Access to flexible short breaks.
- ☐ Access to education.
- ☐ Protection of your health and emotional wellbeing.
- ☐ Access to aids and equipment.
- ☐ Transition to adult services.



End of life plan

Every child and family should be helped to decide on an end of life plan and should be provided with care and support to achieve this as closely as possible.

This stage of the Care Pathway is about preparing for your child's end of life phase and helping to ensure that you, your child, and other family members are provided with care and support to achieve your wishes as closely as possible.

At some point since your child's diagnosis, you have probably thought about their eventual death. Perhaps you have already made arrangements and found good support through your local care team, hospital staff or hospice carers. If you haven't already done this, you should try to start planning what you will want to happen at this difficult time. There are practical issues to deal with and choices to be discussed, which you and your family may want time to consider, instead of being forced to make difficult decisions immediately after the death.



What should I expect?

Openness and honesty from professionals

You can expect professionals to be open and honest with you when they believe the end of your child's life is approaching. This is obviously a very difficult time for both you and the professionals to judge, but you should have a supportive team who you can trust to always have you and your child's interests at heart.

Working together to develop a care plan

Your care team should work with you to develop a care plan for this stage of your child's care. This plan will be shared with all those who you wish to have access to it. This plan should be reviewed regularly and it should be made very clear that you can change your mind on any aspect of the plan at any time. A copy of the plan should be kept with your child, with other copies made available to those working with you and your child, such as your child's GP or hospice.

24 hour access to pain and symptom control

Symptom control advice, including access to medication should be available 24 hours a day from qualified, experienced and skilled staff. You should know who to contact and how to contact them at different times of day.

Emotional and spiritual support

Your care team should be able to offer you advice and support on how to talk about these difficult decisions with other members of your family. Difficulties can sometimes arise when you are feeling fragile and vulnerable, and disagreements or differences of opinion can take on a heightened significance. It is always important to try to be honest about your feelings and ask for help if you need to.

Being spiritual does not mean that you have to belong to, or even agree with, any organised religion. Even if you are not religious, you may consider yourself to be spiritual, with thoughts and ideas about your relationship with the world. You may have formed beliefs about life and death.

Facing difficult decisions, thinking about death and dying, and dealing with loss, can all be deeply spiritual. These experiences can make you question your beliefs and values, as well as the meaning of your life, your child's life, and human life in general.

It is likely that your other children will have lots of concerns at this time, and questions about death and what happens afterwards. If you need help explaining these complex issues to your children, you can ask the hospital or hospice spiritual care team for assistance.

Health care chaplains and spiritual care teams are trained to give spiritual support to everyone, no matter what their spiritual or religious beliefs, which is centred around the individual and their specific needs. Chaplains will work with you, your child and the rest of your family to address worries, doubts and questions surrounding your child's condition and their death.

Your care team should be able to provide you with a list of people who can help support your spiritual and emotional needs.



Here's a checklist of what you should expect at this stage of the Care Pathway

- ☐ Professionals should be open and honest when the approach to end of life is recognised.
- ☐ Joint planning with the family and care team should take place as soon as possible and a written care plan should be agreed.
- ☐ Reviews of the care plan should occur to take account of changes.
- ☐ 24 hour access to pain and symptom control including access to medication and suitably qualified and experienced practitioners.
- ☐ Emotional and spiritual support for you and your family.
- ☐ Support for you, your child and family in their choices regarding end of life.

What should I consider when planning for my child's end of life?

A natural death is where invasive treatments and equipment are withdrawn.

Withholding treatment

A member of your child's care team may approach you to have a discussion with you about what you would like to happen if your child becomes seriously ill. They will discuss your wishes regarding allowing your child to have a more natural death, if that is what you choose.

You should have the chance to discuss what treatment and care you want to be given to your child and what should be withheld. You will have the chance to change your mind about this if you want to.

Organ donation

Many families and their children would like to have information about organ or tissue donation. If your child is in hospital, especially in a high dependency unit (HDU) or intensive therapy unit (ITU) it may be that a transplant co-ordinator or other specialist member of staff may approach you to discuss you or your child's views on organ donation. If your child has had a long-term illness, it may not be possible to consider major organ donation, but it could well be appropriate to discuss donation of tissues, such as heart valves or corneas (part of the eye). Many families have learned too late that such tissue donation would have been possible, and have been saddened by what they see as a wasted positive opportunity. It is likely that you may need to raise this issue with a member of the care team, especially if your child is not in hospital.

Planning for the last days

You will want to make the most of the last weeks and days of your child's life and to spend as much quality time with them as possible.

Your child may want to fulfil his or her own special wishes or goals, perhaps creating a memory box or planning their own funeral or memorial service.

Looking after your child's body after death

You should expect to be told in advance about the various options that your care team can offer regarding your child's body immediately after their death.

Practice and custom has often dictated that families are advised when and where they can 'see' their child after death and how they should behave. Sometimes other family members have strong (perhaps conflicting) views about these matters, and some professional advice or information may be helpful at this time. Don't feel under any pressure to do what you think you 'ought' to. You can arrange to take your child home in the period between the issue of the death certificate and the funeral if you want, or use a special suite within a children's hospice.

Organising ceremonies

You may choose to have one ceremony, more than one, or none.

Including your other children and your child's friends in a ceremony can help them with their sadness. There are a number of organisations who can help you support your children as they work their way through their grief.

Directory

See the bereavement section of the directory to find details of sibling support.

Ceremony:

Use this space to reflect on what you hope a ceremony will achieve.

It may provide:

- A chance to draw everyone together whose life was touched by your child, to say goodbye and draw comfort from each other.
- An occasion to hold as a memory that you can look back on.
- An opportunity to share the joy that your child brought to your lives and to the lives of others.
- A religious ritual.

What will happen at the time of death?

Make sure to include these people in your address book at the back of this Companion.

It will help if you and your family can discuss what you want to happen at the time of your child's death. Use these questions to think about what you want to happen.

- Who wants to be present?
- Who will take care of your other children? What backup do you have if you can't reach them?
- Which health professional will you call if you want a professional with you? What will you do if you cannot reach them?
- Who will make the calls to other people?

Take the time you need to say goodbye.

To help you say goodbye, you might want to:

- Bathe your child and dress them in special clothes.
- While brushing your child's hair, cut a lock of hair to keep.
- Make a handprint or a footprint.
- Take a final photograph.
- Bring in some flowers.
- Play their favourite music.
- Light a candle.

You can hold your child and spend as long as you wish together. You may want other people to be with you, or you may want to be alone.

Following the death of your child

The legal issues: what should I expect?

Many families worry about what they 'have to do' when their child dies. There are only two legal requirements to fulfil:

- Obtaining the death certificate.
- Registering the death.

The death certificate must be signed by a doctor and will then be given to you shortly after, as you will need it to register the death. (In England, Wales and Northern Ireland, the death has to be registered at the registration office closest to where the child has died.) If you aren't sure where the registration office is, ask a member of your care team. You must register the death within five days.

A coroner (or a procurator fiscal) is a doctor or lawyer responsible for investigating deaths and can arrange for a post-mortem examination if necessary.

Information

The child death review process (England only)

Government legislation now means that all local areas in England have to review the death of every child up to the age of 18. This is because the government believes that it may help other children and families in the future. This process is called the child death review process.

Information about each child and the circumstances of their death must be collected and summarised into a short report from records held by hospitals, local health services, schools, police, children's services and other agencies involved with the child. A panel of doctors and other child care professionals will consider this information to make sure they are clear about what caused the child's death, what support and treatment was offered to

the child and their family leading up to the death, and also what support was offered to the family after the child's death. Sometimes families are visited at home by the team of professionals, although this will not happen in most cases where a child dies as a consequence of a life-limiting or life-threatening condition.

If you are worried about the child death review process, or what happens when a child dies at home, talk to a professional that you already have a good relationship with. This might be your child's GP, community nurse, palliative care team or key worker/lead professional.



Information

Will my child be required to have a post-mortem?

If your child had a life-limiting or life-threatening condition, and death was expected, it is unlikely that a post-mortem will be considered necessary. Your GP, hospice or hospital doctor will probably be able to confirm this and issue a death certificate (an immediate legal requirement) straight away.

There are three types of post-mortem:

1. Coroner's (procurator fiscal's) post-mortem

There are some circumstances where a doctor cannot be sure of the cause of death and/or is obliged to refer to the coroner (procurator fiscal), who will ask for a post-mortem to be carried out. A coroner's (procurator fiscal's) post-mortem is a procedure carried out solely to establish the cause of death.

If a coroner's (procurator fiscal's) post-mortem is required, your care team will advise you about the process. Your written consent is required for the retention of any organ or tissue.

2. Hospital post-mortem

Sometimes, usually in hospital, a doctor may ask if you would consent to a post-mortem because such an examination may help to provide more information about your child's condition or treatment for the future. You may also be asked if you would consent to the retention, for research or teaching purposes, of a particular organ or tissue sample.

In this instance, you can choose whether you want to consent to or refuse the post-mortem itself, or any retention of organs or tissue. Remember, you can say no.

3. Post-mortem on request

You may also request a hospital post-mortem if you feel that it would be helpful for your understanding of your child's condition and cause of death. If you think this is something you might want to do, it's probably best to discuss it with your child's consultant prior to the death.

In Scotland, the procurator fiscal is responsible for investigating sudden or unexplained deaths.

Bereavement support

No one can anticipate quite how they will feel or react after the death of their child; most people describe a 'rollercoaster' of emotions, ranging from numbness to furious anger, profound sadness to perhaps a certain relief. Seemingly irrational behaviour and reactions are also very common, as well as overwhelming physical exhaustion or 'manic' energy and compulsive activity. Many people wonder how they will ever cope with the demands of everyday living; it may not seem worth carrying on; partners, relatives and friends may experience or express grief differently and may seem unsympathetic. Some parents may wonder if they will ever feel positive or happy again.

Make sure you talk to someone about your feelings – a partner going through the same as you is often comforting. If you are a single parent or living alone, make sure you talk to a friend or other family member. Don't keep your feelings to yourself. If you want, your GP can arrange for you to talk to a professional.

People find their own ways of getting through the early days. Some people value talking with a trusted person about their child and their feelings, finding it hard to concentrate on other activities; others experience difficulty in openly expressing their feelings and prefer, if they can, to immerse themselves in work, hobbies or physical activity.

Whatever you feel or do will probably be 'normal', and it is important to try and respect your own instincts and those of others also grieving, about what is right for you and for them as individuals. Try to resist being rushed into decisions or activities that you don't feel ready for.

A 'listening ear' from a friend, a befriending organisation or a professional such as your GP, may be very helpful.

Who can help?

- Community children's nurses (CCNs)
- Consultant
- GP
- Specialist nurses such as Macmillan nurses or CLIC Sargent nurses
- Children's Hospice staff
- Spiritual and pastoral advisers
- Bereavement support workers



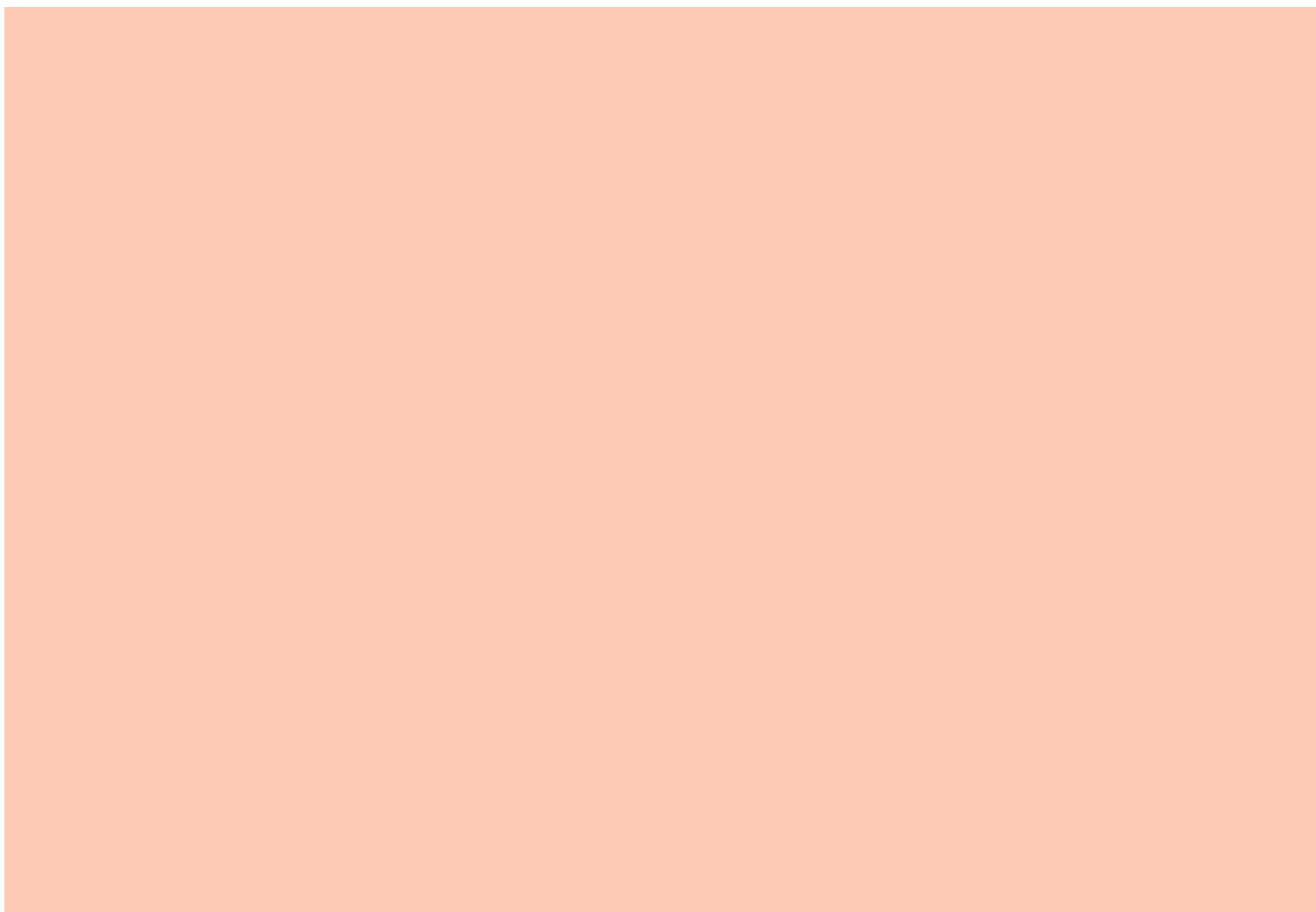
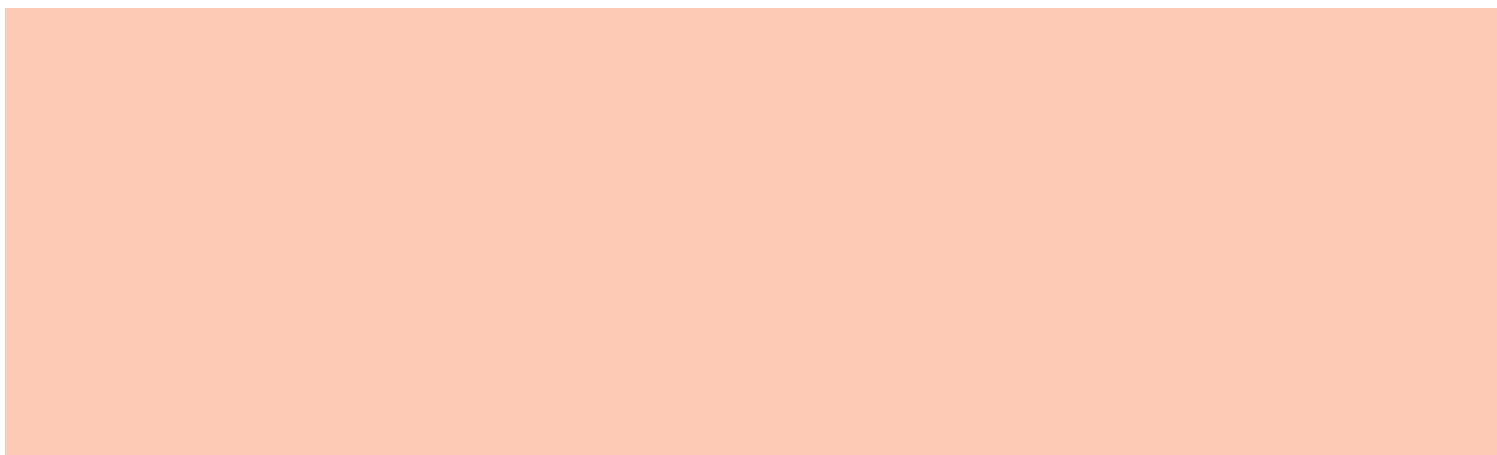
Information

Directory

Bereavement support is offered by a number of organisations. See the directory for details.

Every child and family's experience is different and you will need different levels and aspects of care during your journey. There are many sources of help and support available, and ACT has a national helpline and information service that can signpost you to the services that are most appropriate for you.

ACT Helpline: 0845 108 2201



Directory

This section of the Companion lists useful organisations and key professionals who might be able to support you at the various stages along the Care Pathway. It also includes a glossary of terms to help you understand your child's care journey as well as what people around you are talking about.

The ACT Charter for children and young people with life-limiting and life-threatening conditions and their families

ACT's Charter sets out what children with life-limiting and life-threatening conditions and their families should expect from services.

1. Every child shall be treated with dignity and respect whatever their physical or intellectual ability.
2. Parents shall be acknowledged as the primary carers and involved as partners in all care and decisions involving their child.
3. Every child shall be given the opportunity to participate in decisions affecting his or her care, according to age and understanding.
4. An honest and open approach shall be the basis of all communication.
5. Information shall be provided for the parent, the child, the siblings and other relatives, appropriate to age and understanding.
6. The family home shall remain the centre of caring wherever possible with appropriate support provided to all the family. Care away from the home shall be provided in a child-centred environment by staff trained in the care of children, young people and families.
7. Every family shall have access to a 24 hour multi-disciplinary children's palliative care team for flexible support in the home, and be in the care of a local paediatrician.
8. Every child and family shall receive emotional, psychological and spiritual support to meet their needs. This shall begin at diagnosis and continue throughout the child's lifetime, death and in bereavement.
9. Every family shall be entitled to a named key worker or lead professional who will enable the family to build up and maintain access to an appropriate network of support.
10. Every family shall be given the opportunity of regular consultations with a paediatric specialist who has particular knowledge of the child's condition.
11. Every family shall have access to suitable flexible short term breaks (respite care) both in their own home and away from home, with appropriate children's nursing and medical support.
12. Every child shall have access to education, extended school opportunities and other appropriate childhood activities.
13. The needs of adolescents and young people shall be addressed and planned for well in advance using a young person-centred approach.
14. Every family shall have timely access to practical support, including clinical equipment, financial grants, suitable housing and domestic help.

Useful organisations for families of life-limited or life-threatened children and young people

Listed below are some of the national organisations that provide support for children and young people with life-limiting and life-threatening conditions and their families. There are many others and this is by no means an exhaustive list. Please call ACT's helpline on 0845 108 2201 for details of other sources of support.

Information & Support

General

Benefits Enquiry Line

General advice about benefits and what you may be entitled to.

Tel: 0800 882200

Carers UK

Carers UK campaign to urge people to recognise the true value of carers' contribution to society and to ensure carers get the practical, financial and emotional support they need.

www.carersuk.org

Tel: 0808 808 7777

Email: info@carersuk.org

Children's Hospices UK

A national charity that can provide information on local children's hospice services.

www.childhospice.org.uk

Tel: 0117 989 7820

Email: info@childhospice.org.uk

Contact a Family

Contact a Family are a national charity providing advice, information and support for any family with a disabled child, whatever the child's condition.

www.cafamily.org.uk

Helpline: 0808 808 3555

Email: info@cafamily.org.uk

DIAL UK

A national organisation for a network of around 120 local disability and advice line services (DIALs) run by and for disabled people.

www.dialuk.info

Tel: 01302 310123

Email: infoenquiries@dialuk.org.uk

Directgov

A website providing information about benefits and entitlements.

www.direct.gov.uk

The Disability Alliance

Information and fact sheets about benefits, rights and what you can claim.

www.disabilityalliance.org

Tel: 0207 247 8776

The National Association of Citizens Advice Bureaux

Can provide you with contact details for your local Citizens Advice Bureau. Online advice available through: www.adviceguide.org.uk

www.citizensadvice.org.uk

Tel: 0207 833 2181

Organ Donation

National Tissue Donor Deferral Centre (England and Wales)

Tel: 0800 432 0559

Scottish National Blood Transfusion Service Tissue Services (Scotland)

Tel: 0131 536 5751

Rainbow Trust Children's Charity

Rainbow Trust Children's Charity provides practical and emotional support to families who have a child with a life threatening or terminal illness.

www.rainbowtrust.org.uk

Helpline South: 01372 453309

Helpline North: 01434 602961

REACT

REACT (Rapid Effective Assistance for Children with Potentially Terminal illness) is a dynamic charity working to improve the quality of life for financially disadvantaged children with life-limiting illnesses living in the UK.

www.reactcharity.org

Tel: 0208 940 2575

Email: react@reactcharity.org

Sibs

Sibs is the UK charity for people who grow up with a disabled brother or sister. They support siblings who are growing up with or who have grown up with a brother or sister with any disability, long term chronic illness, or life limiting condition.

www.sibs.org.uk

Tel: 01535 645453

Email – by online form at: www.sibs.org.uk/contact_us

Information & Support

Condition specific

Below are support organisations for some common conditions; if you are looking for information about a more rare condition, please get in touch with Contact a Family on 0808 808 3555 who can signpost you to the relevant organisation.

Batten Disease Family Association (BDFA)

The BDFA is the only UK patient organisation supporting families and professionals, and facilitating research into Batten Disease.

www.bdfa-uk.org.uk
Tel: 01233 639526
Email: support@bdfa-uk.org.uk

Cerebra

Cerebra is a unique charity set up to help improve the lives of children with brain related conditions through researching, educating and directly supporting children and their carers. Parent Support is the Cerebra information and support service for parents, carers and others involved with any child with a brain related condition (brain injuries, neurological disorders, mental disabilities and developmental problems).

www.cerebra.org.uk
Tel: 01267 244229
Email: info@cerebra.org.uk

Christian Lewis Trust: Children's Cancer Charity

The Trust helps families by providing emotional and practical support for the whole family, such as holidays, play therapy, befriending and bereavement support.

www.christianlewistrust.org
Tel: 01792 480500
Email: enquiries@christianlewistrust.org

CLIC Sargent

CLIC Sargent cares for children and young people with cancer and their families – in hospital and in the community. It provides specialist nurses and doctors, play specialists and home from home services, family support in the community, holidays, information and grants. It also helps survivors and supports the bereaved after treatment.

www.clicsargent.org.uk
Child Cancer Helpline: 0800 197 0068
Email: helpline@clicsargent.org.uk

Climb (Children Living with Inherited Metabolic Diseases)

Climb is committed to fighting metabolic diseases through research, awareness and support. For diagnosed and undiagnosed families with metabolic disease, they can supply long term support for all issues to do with diagnosis, treatment, benefit advice, small grants, family issues, bereavement and more.

www.climb.org.uk
Helpline: 0800 652 3181
Email: info.svcs@climb.org.uk

Cystic Fibrosis Trust

The Cystic Fibrosis Trust is the UK's only national charity dealing with all aspects of Cystic Fibrosis (CF). It funds research to treat and cure CF and aims to ensure appropriate clinical care and support for people with Cystic Fibrosis.

www.cftrust.org.uk
Helpline: 0845 859 1000
Email: enquiries@cftrust.org.uk

ERIC (Education & Resources for Improving Childhood Continence)

National charity dealing with bedwetting, daytime wetting, constipation and soiling in children and young people. ERIC provides information, support and resources to families and health professionals on bladder and bowel problems and also sells a range of useful products

www.eric.org.uk
Helpline: 0845 370 8008
Email: info@eric.org.uk
SMS (texting): 07624 811636

GIG (Genetic Interest Group)

The Genetic Interest Group (GIG) is a national alliance of patient organisations which support children, families and individuals affected by genetic disorders.

www.gig.org.uk
Tel: 0207 704 3141
Email: mail@gig.org.uk

Muscular Dystrophy Campaign

The Muscular Dystrophy Campaign is the leading UK charity dedicated to improving the lives of children and adults affected by muscle disease. It provides free care and support, funds world-class research to find treatments and cures, campaigns to bring about change and awards grants towards the cost of equipment such as wheelchairs.

www.muscular-dystrophy.org
Information Line: 0800 652 6352 (freephone)
Email: info@muscular-dystrophy.org

SENSE

Sense is the leading national charity that supports and campaigns for children and adults who are deaf blind. The charity provides expert advice and information as well as specialist services to deaf blind people, their families, carers and the professionals who work with them. It also supports people who have sensory impairments with additional disabilities.

www.sense.org.uk
Telephone: 0845 127 0060
Textphone: 0845 127 0062
Email: info@sense.org.uk

Teenage Cancer Trust

The Teenage Cancer Trust is devoted to improving the lives of teenagers and young adults with cancer.

www.teenagecancertrust.org
Tel: 0207 162 0370
Email: tct@teenagecancertrust.org

Education & Employment

Connexions Direct

Offers advice on education, careers, housing, money, health and relationships for 13-19 year olds in England. Includes web chat, telephone and call-back options.

www.connexions-direct.com
Tel: 0800 00 13219

Enquire

Enquire is the Scottish advice and information service for additional support for learning.

www.enquire.org.uk
Helpline: 0845 123 2303
Email: info@enquire.org.uk

National Portage Association

Portage is a home visiting educational service for pre-school children with additional support needs and their families.

www.portage.org.uk
Tel: 0121 244 1807
Email: info@portage.org.uk

Remploy

One of the leading UK providers of employment services and employment to people with disabilities and complex barriers to work.

www.remploy.co.uk
Tel: 0845 155 2700
Email: info@remploy.co.uk

The Shaw Trust

National charity which supports disabled and disadvantaged people to prepare for work, find jobs and live more independently.

www.shaw-trust.org.uk
Tel: 01225 716300

Skill – National Bureau for Students with Disabilities

Skill offers a UK wide service giving information and advice about access to education after the age of 16, training at work, entry to employment and volunteering.

www.skill.org.uk
Tel: 0800 328 5050 (Open Tuesdays 11.30am-1.30pm and Thursdays 1.30-3.30pm)
Email: info@skill.org.uk

Equipment & Technology

AbilityNet

A national charity providing free information and advice on all aspects of computing for people with a disability and their carers.

www.abilitynet.org.uk
Helpline: 0800 269545
Email: enquiries@abilitynet.org.uk

The ACT Foundation

The ACT Foundation helps fund equipment for disabled people and modifications to homes, schools, hospices etc.

www.theactfoundation.co.uk
Tel: 01753 753900
Email: info@theactfoundation.co.uk

The Aidis Trust

The Aidis Trust aims to help disabled people make best use of information and communication technology by giving information, help and support on all aspects of disability computing.

www.aidis.org
Helpline: 0845 120 3719
Email: info@aidis.org

Assist UK

Leads a UK wide network of locally-situated Disabled Living Centres. Each centre includes a permanent exhibition of products and equipment that provide people with opportunities to see and try products and equipment and get information and advice from professional staff about what might suit them best.

www.assist-uk.org
Tel: 0870 770 2866
Email: general.info@assist-uk.org

Disabled Living Foundation

A national charity that provides free, impartial advice about all types of equipment for disabled people. It can help you find products and suppliers and also has an equipment demonstration centre. They also produce factsheets and other information resources.

www.dlf.org.uk
Helpline: 0845 130 9177
Email: advice@dlf.org.uk

Family Action

Family Action gives grants for equipment to people of all ages who are on low incomes throughout the UK.

www.family-action.org.uk
Tel: 0207 254 6251

Independence at Home

Independence at Home provides small grants to people who live at home and are affected by chronic illness or neurological problems. The grants are only given where the balance left to raise is under £2,000.

www.independenceathome.org.uk
Tel: 0208 427 7929
Email: iah@independenceathome.org.uk

Newlife Foundation for Disabled Children

Newlife Foundation helps disabled and terminally ill children in the UK. It provides equipment to help individual children, nurse led support services, pioneering medical research, awareness and campaigning.

www.newlifecharity.co.uk
Tel: 01543 462777
Nurse Helpline: 0800 902 0095
Email: info@newlifecharity.co.uk

The Sequal Trust

The Sequal Trust fundraises on behalf of its members to provide communication aids, which can be in the form of a specialised computer system, voice synthesiser to relay pre-recorded messages, and many other items of communication equipment. They also maintain, repair and update equipment as necessary.

www.thesequaltrust.org.uk
Tel: 01691 624222
Email: info@thesequaltrust.org.uk

Whizz-Kidz

Whizz-Kids provides disabled children with customised mobility equipment, training, advice and life skills and gives them the independence to be themselves.

www.whizz-kidz.org.uk
Tel: 0207 233 6600
Email: info@whizz-kidz.org.uk

Grants, short breaks and wishes

Crossroads Caring for Carers

Crossroads service is about giving time – improving the lives of carers by giving them a break from their caring responsibilities.

www.crossroads.org.uk
Tel: 0845 450 0350
Email: information@crossroads.org.uk

Dreams Come True Charity

Dreams Come True is a national charity which makes the dreams of terminally or seriously ill children become a reality.

www.dctc.org.uk
Tel: 0800 018 6013
Email: info@dctc.org.uk

Family Fund

The Family Fund helps families with severely disabled children to have choices and the opportunity to enjoy everyday life. They give grants for things such as washing machines, driving lessons, hospital visiting costs, computers and holidays.

www.familyfund.org.uk
Tel: 0845 130 4542
Email: info@familyfund.org.uk

Family Holiday Association

The Family Holiday Association provides grants towards a one week holiday of the family's choice. Referral needed from a health visitor or social worker.

www.fhaonline.org.uk
Tel: 0207 436 3304
Email: info@fhaonline.org.uk

Make-A-Wish Foundation UK

Make-A-Wish grants magical wishes to children and young people aged 3-17 who are fighting life-threatening illnesses.

www.make-a-wish.org.uk
Tel: 01276 405060
Email: info@make-a-wish.org.uk

Starlight Foundation

Starlight Children's Foundation brightens the lives of seriously and terminally ill children by granting their wishes and providing hospital entertainment to help take their minds off the pain, fear and isolation of their illness.

www.starlight.org.uk
Tel: 0207 262 2881
Email: info@starlight.org.uk

Tourism for All UK

Tourism for All provides information on travel and leisure for people with disabilities, providing details of where their specific needs can be met.

www.tourismforall.org.uk
Tel: 0845 124 9971
Email: info@tourismforall.org.uk

Willow Foundation

The Willow Foundation provides special days for 16 to 40 year olds. Special days aim to provide young adults living with life-threatening conditions with a chance to escape the pressures of their daily routine and share quality time with family and/or friends.

www.willowfoundation.org.uk
Tel: 01707 259777
Email: info@willowfoundation.org.uk

Emotional, relationship and bereavement support

Brook

Provides free and confidential sexual health advice and contraception to young people and those that care for them. Can give advice on sexual relationships and disability.

www.brook.org.uk
Tel: 0808 802 1234

The Child Bereavement Charity

The Child Bereavement Charity is a charity that supports families and educates professionals both 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 both families and professionals, award-winning publications and resources, an interactive website with online forums, and a Buckinghamshire-based family bereavement support service.

www.childbereavement.org.uk
Tel: 01494 568900
Email: enquiries@childbereavement.org.uk

Childhood Bereavement Network

The 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.

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

The Child Death Helpline

The Child Death Helpline is a helpline for anyone affected by the death of a child of any age, from pre-birth to adult, under any circumstances, however recently or long ago.

www.childdeathhelpline.org

Helpline: 0800 282986

Email: contact@childdeathhelpline.org

The Compassionate Friends UK

The Compassionate Friends is an organisation of bereaved parents and their families offering understanding, support and encouragement to others after the death of a child or children. They also offer support, advice and information to other relatives, friends and professionals who are helping the family.

www.tcf.org.uk

Helpline: 0845 123 2304

Email: info@tcf.org.uk

The Outsiders Club

Befriending service and helpline for disabled young adults.

www.outsiders.org.uk

Helpline: 0707 499 3527 (Monday - Friday, 11.00am to 7.00pm)

Samaritans

Samaritans provides confidential non-judgmental emotional support, 24 hours a day for people who are experiencing feelings of distress or despair, including those which could lead to suicide.

www.samaritans.org.uk

Helpline: 08457 909090

Email: jo@samaritans.org

SupportLine

SupportLine provides confidential emotional support for children and adults. Staff help callers to develop healthy and positive coping strategies and provide details of counsellors, agencies and support groups across the UK.

www.supportline.org.uk

Tel: 0208 554 9004

Email: info@supportline.org.uk

TCF Sibling Support

Sibling Support is a project run by The Compassionate Friends which provides nationwide self-help support for people who have suffered the loss of a brother or sister.

www.tcfsiblingsupport.org.uk

Tel: 0845 123 2304

Email: info@tcfsiblingsupport.org.uk

Winston's Wish

Winston's Wish is the leading childhood bereavement charity and the largest provider of services to bereaved children, young people and their families.

www.winstonswish.org.uk

Helpline: 0845 20 30 40 5

Email: info@winstonswish.org.uk

Neonatal and birth specialists

Bliss

Bliss is the special care baby charity which provides vital support and care to premature and sick babies across the UK. Bliss offers guidance and information, funds ground-breaking research and campaigns for babies to receive the best possible level of care regardless of when and where they are born.

www.bliss.org.uk

Tel: 0207 378 1122

Helpline: 0500 618140

Email: information@bliss.org.uk

Sands

Sands is an organisation which can offer parents support when their baby dies during pregnancy or after birth.

www.uk-sands.org

Helpline: 0207 436 5881

Email: support@uk-sands.org

The Twins and Multiple Births Association (Tamba)

Tamba is a UK wide organisation helping parents of twins, triplets and more and professionals to meet the unique challenges that multiple birth families face. Their Bereavement Support Group (www.tamba-bsg.org.uk) provides support for families who have lost one or more children from a multiple birth, during pregnancy or at any stage afterwards.

www.tamba.org.uk

Tel: 01483 304442

Helpline: 0800 138 0509

Email: enquiries@tamba.org.uk

Directory of professionals

As a family you will come into contact with a large number of professionals who will be involved in your child's care journey, from health, social care, education and from the statutory and voluntary sector. They all have different roles depending on their respective professions. Their common goal is to provide a service to your child and family that best meets your needs. This directory gives a brief description of what each one does.

Healthcare professionals

Community based

Chaplaincy: Chaplaincy services are available in the community as well as in the hospital.

Children's hospices: Provide needs-led support and friendship to all family members including brothers and sisters. This may include short-term breaks (respite care), outreach services and visits to you at home as well as emotional and bereavement support.

Children's palliative care service: You may have a team in your area that provides multi-disciplinary care for children with life-limiting illnesses from the time of diagnosis. This type of service is not available in all areas.

Community children's nurses (CCNs): Provide nursing and supportive care at home and often act as your child's key worker or lead professional. They will liaise with other agencies. Some will provide short breaks in your home.

Community paediatrician: A senior children's doctor, usually a consultant working in the community. They work closely with the other doctors and specialists involved with your child, ensuring that your family's needs are managed and supported at a local level.

Dentist: Your child will be entitled to free dental care on the NHS.

Dietician: Will advise you on your child's dietary intake. If your child has difficulty with eating and drinking they can advise on supplements and special nutritious foods.

District nurses: May provide nursing care at home to your child, although they usually nurse adults. They can help with nursing supplies that your child requires.

Family doctor (GP): Provides medical and supportive care. They are able to refer your child to other services that may be needed, and they will also write prescriptions for medications. A list of family doctors will be available from your local primary care trust or from the NHS website (www.nhs.uk).

Health visitors: Provide health education and health promotion advice. They can also provide supportive care to you and your family. Some areas have specialist health visitors who have particular experience and expertise supporting families with very young children with an identified condition or disability, or who need extra help.

Occupational therapists: Work with children using play and other activities to maximise their abilities in all aspects of daily living, including education. They will help and advise you on managing everyday life for your child. They will assess your child for any equipment required such as wheelchairs, bathing aids and adaptations to your child's environment.

Pharmacist (local chemist): Able to supply most of the drugs your child will require. Many families find it helpful to use the same pharmacist who will then become familiar with your child's medication. Many provide a home delivery service, especially for large bulky items.

Physiotherapists: Help and support your child if he or she has difficulties with mobility, movement or breathing, caused by illness or surgery. They will assess your child's needs and abilities, set achievable goals and help you to carry out a physical management programme for your child. They can also provide advice on equipment that may be needed.

School nurse: Every school will have a named school nurse. They provide health promotion and education to school aged children. If your child attends a special school the school may have its own nurse. These nurses are able to give medication and nursing care to your child whilst at school.

Speech and language therapists: They will assess your child's communication ability and advise you on how to offer support. They can also help and advise if your child has difficulty with swallowing.

Healthcare professionals

Hospital based

Clinical nurse specialist: These nurses work closely with the specialist paediatrician in providing nursing care and support to your child and family. They are usually based within a hospital, but provide outreach services in your own home. They will have expertise in the type of condition your child has. They work closely with the other community health care professionals.

Consultant paediatrician (local general hospital): This doctor at your local hospital will be a children's doctor but may not have expert knowledge about your child's condition.

Consultant paediatrician (specialist hospital): This will be a children's doctor with an expert knowledge of the type of condition your child has. Depending on to the rarity of your child's condition this specialist may be based a long way from where you live.

Both of these doctors will work very closely with your family doctor and community paediatrician to provide medical services for your child.

Therapists: You may also meet speech and language therapists, physiotherapists and occupational therapists in the hospital. They work closely with their community-based colleagues.

Other Services

Adult palliative care service: Most areas of the UK have an adult palliative care service. They can provide advice and support to you and the team working with you. Your child may transfer to their care when he or she reaches adulthood.

Benefits advisor or welfare rights advisor: Welfare rights advisors work in welfare rights units, Citizens Advice Bureaux and independent advice centres. They can help you claim Disabled Living Allowance (DLA) and other benefits to which you may be entitled.

Child and adolescent mental health team: This team provides psychological and psychiatric services for children and their families. The team includes psychiatrists, psychologists, nurse specialists and social workers. Services for children with learning disabilities are often part of this service.

Coroner, Procurator Fiscal: The coroner is a doctor or lawyer responsible for investigating deaths in particular situations and can also arrange for a post-mortem examination of the body, if necessary. An inquest is a legal inquiry into the causes and circumstances of a death.

Independent parental supporter (IPS): An independent parental Supporter is someone trained by the Parent Partnership Service (PPS) to support parents and help them understand special educational needs and the SEN code of practice. Your local Parent Partnership Service should be able to put you in touch with one, if your local education authority (LEA) is considering issuing a statement of special educational needs. They help by providing information and sometimes, by coming with you to meetings.

Key worker/lead professional/link worker/care co-ordinator: A key worker, sometimes known as a lead professional, link worker or care co-ordinator, maintains regular contact with your family and takes responsibility for checking that you have all the information you need, that services are well co-ordinated and that information about your child is shared efficiently with everyone working with your family. Key worker services are not currently available in all areas.

Music therapist: A music therapist uses music and sound to help improve a child/young person's emotional wellbeing, relieve stress and improve confidence. They encourage patients to try different instruments and use their voices to explore sound and communicate through music, to help them express themselves, become aware of their feelings and interact with other people more confidently.

Nursery nurse: A nursery nurse is someone trained in, and able to support, the early stages of child development. They usually work in nurseries and schools. They are not medical nurses.

Parent support groups: These groups can provide invaluable support from other parents who have had similar experiences.

Play specialist: A play specialist helps children to make sense of difficult life experiences through the activity of play. Play is a child's natural way of communicating and with a play specialist they can explore various issues they might find difficult to express in other ways.

Portage home visitor/Portage worker: A portage home visitor, sometimes known as a portage worker, is someone who has received training from the National Portage Association to work with you and your child. Portage home visitors come from a wide range of professional backgrounds and may be teachers, speech and language therapists or occupational therapists, nursery nurses, health visitors, social workers or parents or volunteers with relevant experience.

Social services: Social services staff will carry out an assessment of your child's needs and you as parents are also entitled to a carer's assessment. The role of social services is to provide support for people to live as independently as possible – this may include care within the home, services that give you a break from caring and benefits advice.

Special educational needs co-ordinator (SENCO): A SENCO is a teacher in a school or early years setting who has responsibility for identifying children with special educational needs and making sure they receive appropriate support. This may involve working directly with the child, supporting mainstream staff in assessing a child's needs or a combination of both of these. SENCOs also work with external support services at Early Years Action or Early Years Action Plus.

Voluntary organisations: There are many types of voluntary organisations that provide a wide range of services and opportunities. These may include short breaks, bereavement support or holidays. Some also provide financial assistance in the form of care grants. Some are national organisations and some local, serving a specific community or condition. A member of your child's care team will be able to advise you on what is available for your family.

Glossary of terms

Blue Badge scheme

The Blue Badge scheme provides a range of parking concessions for people with severe mobility problems who have difficulty using public transport. The scheme operates throughout the UK.

There are small variations in its application in each UK country.

Care Pathway/journey

ACT's description of a Care Pathway approach to working with children who have life-limiting or life-threatening conditions is a way of engaging with a child and their family's needs, which can be used to ensure that everything is in place so that families have access to the appropriate support they need at the appropriate time.

Carer's Allowance

Carer's Allowance is a taxable benefit to help people who look after someone who is disabled. You do not have to be related to, or live with, the person that you care for. You may be able to get Carer's Allowance if you are aged 16 or over and spend at least 35 hours a week caring for a person getting Attendance Allowance, Disability Living Allowance (at the middle or highest rate for personal care) or Constant Attendance Allowance (at or above the normal maximum rate with an Industrial Injuries Disablement Benefit, or basic (full day) rate with a War Disablement Pension).

Children's palliative care

Palliative care for children and young people with life-limiting conditions is an active and total approach to care, from the point of diagnosis or recognition, embracing physical, emotional, social and spiritual elements through to death and beyond. It focuses on enhancement of quality of life for the child/young person and support for the family and includes the management of distressing symptoms, provision of short breaks and care through death and bereavement (ACT, 2008).

Care of the dying

Care of the dying is the care of the patient and family in the last hours and days of life. It incorporates four main types of care: physical, psychological, social and spiritual, and supports the family at that time and into bereavement.

Child

A child is defined as a young person up until their 19th birthday.

Children's hospice services

Children's hospice services provide palliative care for children and young people with life-limiting conditions and their families. Delivered by a multi-disciplinary team and in partnership with other agencies, children's hospice services aim to meet the needs of both child and family – physical, emotional, social and spiritual – through a range of services. These include:

- 24 hour end of life care.
- Support for the entire family (including siblings, grandparents and the extended family).
- Bereavement support.
- 24 hour access to emergency care.
- Specialist short break care.
- 24 hour telephone support.
- Practical help, advice and information.

- Provision of specialist therapies, including physiotherapy, play and music therapy.
- Provision of information, support, education and training where needed to carers.

Children's hospice services deliver this care in the home (commonly termed 'hospice at home service') and/or in a purpose built building.

Clinic

A clinic (or an outpatient clinic) is usually a public health facility that is devoted to the care of outpatients. A clinic can be in a range of different health agencies such as within a hospital or at your GP's practice.

Commissioner

A commissioner is a person with responsibility for commissioning services.

Commissioning

Commissioning is the process of improving outcomes and meeting the needs of the population within the local health community with the resources available.

Complex care/continuing care

Complex care, sometimes known as continuing care, is an individualised package of care beyond what is available through standard health services. It is provided to children with highly complex health care needs or intense nursing care needs.

Community services

Community services refer to a service that an individual or organisation performs within the local community. This might include community children's nurses who deliver nursing care and support within the local community including visiting a patient's home. Community services may also include some of the local services delivered by your council.

Continence

The ability to control one's bowel or bladder. Incontinence is the lack of control of either bowel or bladder, or both.

Death certificate

A death certificate, sometimes called medical certificate of the cause of death (MCCD), is a document issued by a government official such as a registrar of vital statistics that declares the date, location and cause of a person's death.

All deaths need to be registered between five and eight days following the person's death (the time period and procedures vary depending on where you live in the UK). You will need to register the death at your local Register Office and can find details of your nearest office from your council.

Diagnosis

The process of determining the nature of a medical condition.

Disability Living Allowance

Disability Living Allowance – sometimes referred to as DLA – is a tax-free benefit for children and adults who need help with personal care or have walking difficulties because they are physically or mentally disabled.

Disabled Living Centres

Disabled Living Centres provide information about a range of equipment and aids to support people who have disabilities. You should be able to see products and equipment that might help you and get information and advice from staff about what equipment might suit you best.

Discharge from hospital

After treatment in hospital your child will be discharged when the consultant or health professional who is in charge of your child's care decides that they are well enough to leave. Your healthcare professionals will often involve you in planning your child's discharge and should discuss you and your child's needs, and how they will be met, in order to ensure that you and your child have everything you need for your return home.

If your child's care needs are more complicated, their discharge procedure is referred to as a 'complex discharge'. For example, your child may have ongoing health and social care needs that require complex planning, or need community care services when they leave hospital.

Education Welfare Service

The Education Welfare Service (EWS) acts on behalf of the local authority in enforcing a parent's duty to provide appropriate education. Education welfare officers (EWOs) sometimes known as education social workers or attendance advisors work closely with schools and families to resolve attendance issues. They support children and families when pupils are experiencing difficulties in school or welfare issues are disrupting a child's education.

End of life

The end of life phase begins when a judgement is made that death is imminent. It may be the judgement of the health or social care team responsible for the care of the patient, but it is often the child/young person or their family who first recognises its beginning.

End of life care

End of life care is care that helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It focuses on preparing for an anticipated death and managing the end stage of a terminal medical condition; this includes care during and around the time of death, and immediately afterwards. It enables the supportive and palliative care needs of both child/young person and their family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support and support for the family into bereavement.

End of life care services

End of life care services are services to support those with advanced, progressive, incurable illness to live as well as possible until they die. These are services that enable the supportive and end of life care needs of both child/young person and their family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support. This is not confined to specialist services but includes those services provided by any health or social care professional in any setting.

Family

The term 'family' includes parents, other family members involved in the care of the young person, or other carers who are acting in the role of parents. Family includes informal carers and all those who matter to the child/young person.

High dependency unit (HDU)

A high dependency unit (HDU) is a hospital ward for patients who require more intensive observation, treatment and nursing care than is usually provided on a general ward. It is a standard of care between the general ward and full intensive care.

Hospice at home

Hospice at home is a term commonly used to describe a service which brings children's palliative care into the home environment. Hospice at home works in partnership with parents, families and other carers.

Intensive care unit/intensive therapy unit/critical care

Intensive care units, sometimes known as intensive therapy units, look after patients whose conditions are life-threatening and need constant, close monitoring and support from equipment and medication to keep normal body functions going. Critical care is the provision of this intensive level of support by a team of doctors, nurses, physiotherapists and other professionals working in an intensive care unit.

Key working

Key working or care co-ordination is a service, involving two or more co-ordinated agencies. It encompasses individual tailoring of services based on assessment of need, inter-agency collaboration at strategic and practice levels and a named key worker for the child and their family. Families with disabled children should only have a key worker if they want one. (Care Co-ordination Network UK, 2006).

Life-limiting/life-shortening conditions

Life-limiting conditions, sometimes known as life-shortening conditions, are those for which there is no reasonable hope of cure and from which children or young people will die. Some of these conditions cause progressive deterioration leaving the child increasingly dependent on parents and carers.

Life-threatening conditions

Life-threatening conditions are those for which curative treatment may be possible but can fail, such as cancer. Children in long-term remission or following successful curative treatment are not included.

Multi-agency assessment

This should be a meeting of a team of key people who all play a role in the care of your child and family. The multi-agency assessment should: gather information about the child and family's needs; assess the full range of medical, nursing, practical, social, educational, psychological and spiritual needs; explore the concerns and feelings of the family members; explore options within local provision and culminate in an agreed plan of action. The assessment should ensure your choices are taken into account as the assessment takes place. This assessment process should be co-ordinated and involve all agencies and providers, so that you do not have to repeat your needs to the various different services and organisations.

Needs-led

Need-led is the term used to describe services provided on the basis of the needs of the patient and family, rather than as a result of assessing the resources that are available.

Outpatients

An outpatient is a patient who is not hospitalised overnight but who visits a hospital clinic. The term is also used to describe a facility for diagnosis or treatment for such patients.

Parents

The term 'parents' is used to mean any carer for a child whether that is a married or unmarried couple, a single parent, guardian or foster parent.

Patient Advice and Liaison Services

Patient advice and liaison services provide confidential advice and support to families and their carers, information on the NHS and health-related matters, confidential assistance in resolving problems and concerns quickly, explanations of complaints procedures and how to get in touch with someone who can help, and information on how you can get more involved in your own healthcare.

To contact your local patient advice and liaison services, either phone your local clinic, GP surgery, health centre or hospital and ask for details, or phone NHS Direct on 0845 46 47.

A post-mortem

There are three types of post-mortem:

1. Coroner's (procurator fiscal's) post-mortem

There are some circumstances where a doctor cannot be sure of the cause of death and/or is obliged to refer to the coroner (procurator fiscal's), who will ask for a post-mortem to be carried out. A coroner's (procurator fiscal's) post-mortem is a procedure carried out solely to establish the cause of death.

If a coroner's (procurator fiscal's) post-mortem is required, your care team will advise you about the process. Your written consent is required for the retention of any organ or tissue.

2. Hospital post-mortem

Sometimes, usually in hospital, a doctor may ask if you would consent to a post-mortem because such an examination may help to provide more information about your child's condition or treatment for the future. You may also be asked if you would consent to the retention, for research or teaching purposes, of a particular organ or tissue sample.

In this instance, you can choose whether you want to consent to or refuse the post-mortem itself, or any retention of organs or tissue. Remember, you can say no.

3. Post-mortem on request

You may also request a hospital post-mortem if you feel that it would be helpful for your understanding of your child's condition and cause of death. If you think this is something you might want to do, it's probably best to discuss it with your child's consultant prior to the death.

Primary care organisation

A primary care organisation is the NHS body responsible for providing primary health services and improving health within their local community through commissioning. Primary care

organisations have taken on many of the responsibilities of planning and purchasing health services that were formerly undertaken by health authorities.

Primary healthcare team

A primary healthcare team comprises the general practitioner (GP), practice nurse and community staff (such as community children's nurses or physiotherapists) who work with the practice staff.

Short breaks

Short breaks have three main functions:

- To provide the child or young person with an opportunity to enjoy social interaction and leisure facilities.
- To support the family in the care of their child in the home or an alternative community environment such as a children's hospice.
- To provide opportunities for siblings to have fun and receive support in their own right.

Short breaks may offer the whole family an opportunity to be together and to be supported in the care of their child or it may offer care solely for the child or young person.

Specialist short break care

Specialist short break care refers to a setting of care, a programme of care or a service that provides additional care for highly complex or technology dependent children who may otherwise be excluded from short breaks. Specialist short break care may take place in the child's home or in a setting outside of the home such as a hospital, long-term care facility or hospice. Specialist short breaks will often address some aspects of symptom management. They should also meet the functions described under general short breaks.

Supportive care

Supportive care is an 'umbrella' term for all services, both general and specialist, that may be required to improve the quality of life for people with life-threatening illnesses. It recognises that people need some forms of care that are not directed towards cure.

Symptom management

Symptom management is the management of common symptoms associated with life-limiting conditions. It is often used to refer to symptoms that are primarily physical, but in palliative care symptom management also includes attention to psychosocial and spiritual aspects of symptoms where appropriate.

Transition

Transition is the process that children and young people go through as they move from children's services to adult services.

Technology dependent children

Technology dependent children are those who need both a medical device to compensate for the loss of a vital bodily function and substantial and on-going nursing care to avert death or further disability (Kirk and Glendinning 1999; Glendinning et al 2001).

Young adult

The term young adult describes a person from their 19th birthday.

Young person

The term young person describes a person from their 13th - 19th birthday.

Address book

Name:		Name:	
Position:		Position:	
Address:		Address:	
Tel:		Tel:	
Email:		Email:	
Name:		Name:	
Position:		Position:	
Address:		Address:	
Tel:		Tel:	
Email:		Email:	
Name:		Name:	
Position:		Position:	
Address:		Address:	
Tel:		Tel:	
Email:		Email:	
Name:		Name:	
Position:		Position:	
Address:		Address:	
Tel:		Tel:	
Email:		Email:	
Name:		Name:	
Position:		Position:	
Address:		Address:	
Tel:		Tel:	
Email:		Email:	
Name:		Name:	
Position:		Position:	
Address:		Address:	
Tel:		Tel:	
Email:		Email:	

Name:	
Position:	
Address:	
Tel:	
Email:	

Name:	
Position:	
Address:	
Tel:	
Email:	

Name:	
Position:	
Address:	
Tel:	
Email:	

Name:	
Position:	
Address:	
Tel:	
Email:	

Name:	
Position:	
Address:	
Tel:	
Email:	

Name:	
Position:	
Address:	
Tel:	
Email:	

Name:	
Position:	
Address:	
Tel:	
Email:	

Name:	
Position:	
Address:	
Tel:	
Email:	

Name:	
Position:	
Address:	
Tel:	
Email:	

Name:	
Position:	
Address:	
Tel:	
Email:	

Name:	
Position:	
Address:	
Tel:	
Email:	

Name:	
Position:	
Address:	
Tel:	
Email:	

Name:	
Position:	
Address:	
Tel:	
Email:	

Name:	
Position:	
Address:	
Tel:	
Email:	

Name:	
Position:	
Address:	
Tel:	
Email:	

Name:	
Position:	
Address:	
Tel:	
Email:	

Name:	
Position:	
Address:	
Tel:	
Email:	

Name:	
Position:	
Address:	
Tel:	
Email:	

A Family Companion to the ACT Care Pathway for children with life-limiting and life-threatening conditions

This Family Companion is designed especially for parents, family members and carers of children and young people that have been diagnosed with life-limiting or life-threatening conditions.

At a time when things can seem overwhelming, this Family Companion acts as a step by step guide through the complex and often confusing processes that take place following diagnosis. With interactive elements to help parents think important things through, as well as comprehensive lists of unfamiliar glossary terms and useful organisations, this Companion explains what should happen, why it should happen as well as making it clear what support should be made available, and where that support can be found.



Valuing short lives

ACT Brunswick Court, Brunswick Square, Bristol, BS2 8PE

T: 0117 916 6422

F: 0117 916 6430

E: info@act.org.uk

www.act.org.uk

Helpline: 0845 108 2201

ACT is the only organisation working across the UK to achieve a better quality of life and care for every life-limited child and their family.

ACT is a registered charity and a company limited by guarantee. Registered Charity No: 1075541 Company Registration No. 3734710 England

