



A Family Companion

to the Together for Short Lives Core Care
Pathway for Children with Life-limiting and
Life-threatening Conditions

Third edition, 2014



www.togetherforshortlives.org.uk

A Family Companion to the Together for Short Lives Core Care Pathway for Children with Life-limiting and Life-threatening Conditions

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Together for Short Lives is the leading UK charity for all children with life-threatening and life-limiting conditions and all those who support, love and care for them – families, professionals, and services, including children's hospices. Our work helps to ensure that children can get the best possible care, wherever and whenever they need it. When children are unlikely to reach adulthood, we aim to make a lifetime of difference to them and their families.

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The Together for Short Lives Care Pathway diagram is adapted from the summary diagram, on p16, of the *Core Care Pathway for Children with Life-limiting and Life-threatening Conditions*, Together for Short Lives (2013), Bristol.

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This publication will be reviewed on an annual basis and amended as needed, at our discretion.

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Introduction

Together for Short Lives is the UK charity working to ensure that all children and young people unlikely to live to reach adulthood, and their families, get the best possible care and support whenever and wherever they need it.

We want families to have real choice in their child's care throughout their life – no matter how short. If your child has been diagnosed with a health condition which means their life will be shortened, you will be facing an extremely difficult time – trying to deal with the news about your child and how this will affect your whole family. At this very emotional and stressful time, you will be plunged into a whole new world of hospitals, terminology (medical speak), medicine, equipment and many different health professionals looking after various aspects of your child's care. If you have other children, they too are likely to need extra support to come to terms with the news of their brother or sister's condition and the impact it might have on family life.

In addition to this Companion, Together for Short Lives has developed a Charter which sets out what families should expect from their care provision. It states that every child and family should be treated with openness and honesty, provided with accurate information and listened to about their wishes and care choices.

The Together for Short Lives Charter can be found on page 43

The Together for Short Lives Core Care Pathway¹ has been developed as a tool for professionals to help them to maintain the standards set out in the Charter. It provides a framework and practical guidance for all professionals at key stages of a child's care journey and sets out six standards of care. It places the child and family at the centre, making sure care is planned and services work together so that families can access the appropriate support at the right time.

The Family Companion has been developed to help you to get the care and support that you are entitled to. It also signposts you to the services, agencies and professionals that can help you along the way.

The Family Companion is split into six sections that reflect the six key standards of the Core Care Pathway. You might not want to read the whole document at once if you don't feel you are ready, but having the information there to read when you do feel ready, can make facing these difficult issues a little less stressful.

Together for Short Lives has developed a range of Family Factsheets to be used alongside this Companion, which offer more detailed information about specific topics. These will be regularly updated and can be downloaded from our website.

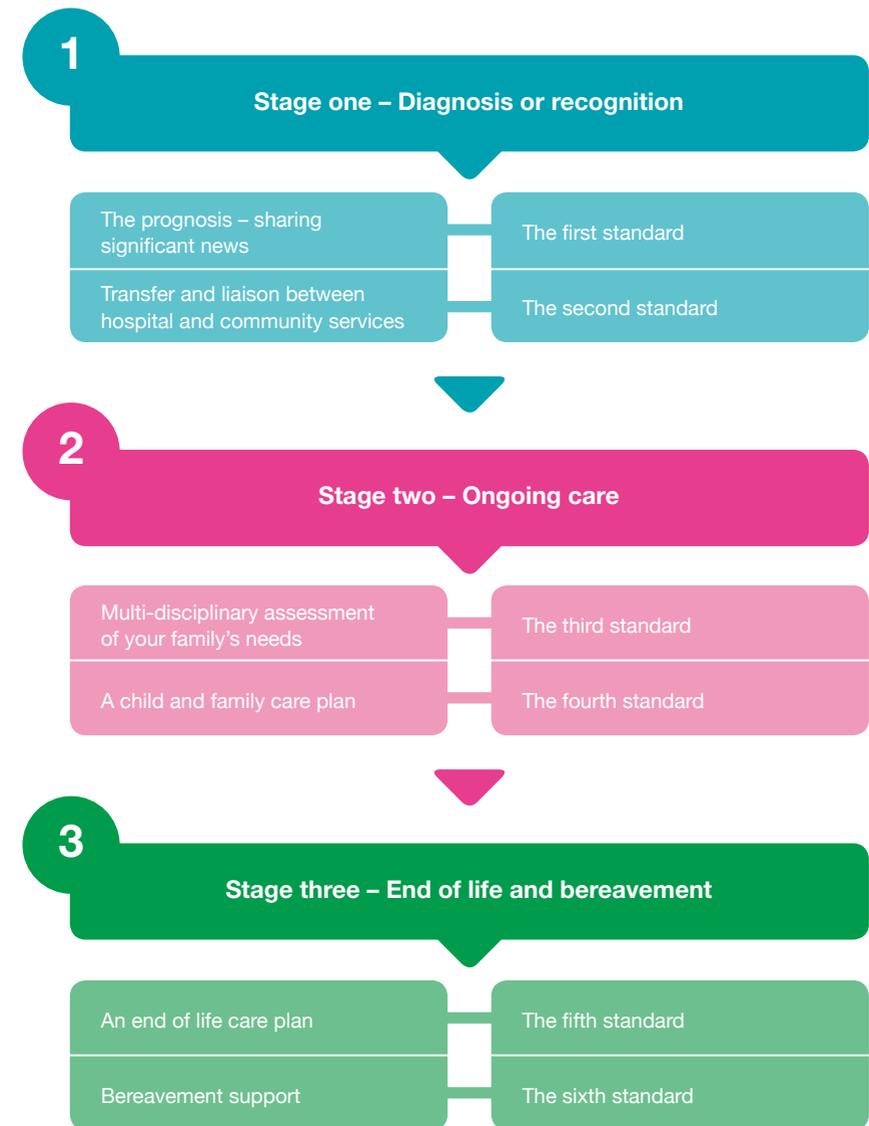
If there's something worrying you that we haven't included in this Companion, or if you need us to explain anything in more detail, call the Together for Families Helpline on

0808 8088 100

You can also talk to your care team or your GP about any of the issues raised in this Companion.



The diagram below shows the three key stages of the Together for Short Lives Core Care Pathway and highlights the six standards that set out the level and quality of care that every family should expect during their journey.



1. A Core Care Pathway for Children with Life-limiting and Life-threatening Conditions, Together for Short Lives (2013), Bristol.



Stage one: Diagnosis or recognition

We know that for many families reading this Companion, you may have already received a diagnosis or been told that your child has a life-limiting or life-threatening condition. Whether you are preparing for a key medical appointment or reflecting on a diagnosis that has already taken place, you might find it useful to consider the following key elements:

The first standard: The prognosis – sharing significant 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.

What does this mean for me?

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

As a parent, being told that your child has been diagnosed with a life-limiting or life-threatening condition is likely to be the most shocking and upsetting experience you will ever go through.

Emotional and psychological support can help you cope with the initial diagnosis as well as throughout your child's illness. Emotional support can come 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 listen. In some cases, however, professional support may be required to help you through this difficult time.

What should I expect?

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

After diagnosis, time with a nurse or other staff member should be offered to you before you leave the clinic or hospital – to provide support and to address your concerns. 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 exactly how your child's condition will progress – but they should be open and honest about this.

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.

i See our factsheet on [Understanding Siblings' Needs](#).

A room to ensure you have privacy

You should be told about your child's diagnosis and prognosis (what might happen in the future) in a private setting. 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. If your child is old enough to understand what is being said, they 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.

To 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. Perhaps your spouse or partner will already be with you, or you might want to arrange for a relative or friend to be with you to support you during the appointment when you learn about your child's diagnosis.

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

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

Write down 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 at them.

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 (PALS) at the hospital.
- School staff, including those involved with your other children.
- Children's hospices.

i See our factsheet on [Children's Hospice Services](#).

- Other charities and support groups.

The second standard: Transfer and liaison between hospital and community services

Every child diagnosed in the hospital setting and their family 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.

What does this mean for me?

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 and primary care team, social services, 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 (when 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 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.

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 a specialist community team 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 (respite), nursing care, housing adaptations 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.

A designated key worker or 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.

Aids, equipment and supplies

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.

i See our factsheet on [Aids and Equipment](#).

Your home

There may be issues about whether your housing meets your child's special care 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 your current housing will support your family's needs now and into the future.

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.

An initial needs assessment meeting

As part of the discharge planning process, an initial needs assessment meeting should take place, involving key staff supporting your child; for example hospital staff, community staff, social services, your GP and you and your family. Your child and family's immediate needs should be discussed and a care plan agreed to enable a smooth transfer home.

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

- 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 shared plan to meet your child's nursing and care 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 arrangements are made as appropriate so you have easy access to:
 - medication
 - aids and equipment
 - support for the whole family
 - spiritual support
 - psychological support
 - short breaks for your child
 - provision of training to meet your child's needs
 - transport

✓ Here's a checklist of what you should expect at this stage

- 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 with your child.
- Planning for the transfer home should begin as soon as possible. An initial needs assessment meeting should take place, during which a clear transfer plan will be agreed with you.
- A lead community children's nurse should be agreed before you go home and your GP should be invited to become involved. Clear plans should be in place for shared medical care.
- Equipment and supplies should be provided before your child is transferred home.
- Transport arrangements for your child should be in place.
- You should be provided with any necessary training to meet your child's care needs.
- You should know who to contact in different situations and have all the appropriate contact details you need.
- 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 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
- Health visitor



Stage two: Ongoing care

The third standard: Multi-disciplinary assessment of your family's needs

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

What does this mean for me?

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 have the very best family life possible.

What should I expect?

Assessment of your family's needs should be an ongoing process, with your child and family at the centre. Your needs are inevitably going to change over time and there should be a clear process for regular planned reviews and for enabling you to request a review of your needs as and when you feel this is necessary. If your child is a teenager, these reviews should also begin planning and preparing for their transition and support in to adulthood. 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 and family's needs will be discussed with you and assessed by a team working with you to ensure your child and family get the ongoing care that's needed. This is called a 'multi-agency needs assessment'. This should be a meeting of the small team of key people who work with you to 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. This process should cover the needs of your extended family and others who are important to you and your child. It should include assessment of your child's health and symptoms, needs for equipment and supplies, education and leisure as well as your whole family's emotional, practical, social, spiritual and cultural needs.

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

You should have an opportunity to talk about the hopes, wishes and concerns of your child and family and for these to be central to the planning process. You should be supported to be an equal partner in the care your child receives, and to have a choice about where they are cared for, with your child's interests kept central to this process. The aim of the needs assessment process should be to empower you to be able to lead the care that your child needs in partnership with professionals and services, so that you have control over your lives.

You and your family should be kept fully informed and involved and you should be given your own copy of the assessment information to keep. Professionals working with you should use easy to understand, non-jargon language.

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/ lead professional.

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.

A lead agency and lead professional

It is important that you know which agency is taking lead responsibility for co-ordinating your child's care. Often this will be the community children's nursing team. This team will become a vital support to you and your family. You should be allocated a keyworker or lead professional from within this lead agency to be your main point of contact and with whom you and your child can expect to develop a strong partnership.

✓ Here's a checklist of what you should expect at this stage

- A 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 central to the assessment process and expect to work in equal partnership with your professional team.
- Your child should be the central focus of the assessment 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 to share information with identified professionals should be discussed with you.
- You should be given your own copy of the assessment information to keep.
- It should be made clear who is taking the keyworker/lead professional role.
- Professionals involved in the multi-agency needs assessment should have appropriate skills and local knowledge of what is available.

Who can help?

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

It can be helpful to find someone for your child to talk to outside of the family, such as a trusted member of staff at your local children's hospice. Your care team will be able to put you in touch with a suitable individual or service.

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. If you have other children, it can also be helpful to inform their school so that they can provide emotional support as needed.

The fourth standard: A child and family care plan

Every child and family should have a multi-disciplinary, multi-agency care plan developed in partnership with them for the delivery of co-ordinated care to enhance family strengths and meet need. A multi-agency and multi-disciplinary team should be identified in agreement with the family and use key working principles.

Wherever possible this should involve all agencies involved in supporting the child and family, including the child's community nursing team, therapists, hospice, hospital services, school, social care and short break services.

What does this mean for me?

This stage of the care pathway involves the development of a care plan that reflects the needs and wishes of your whole family, including your other children, 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 that were identified in the multi-agency needs assessment process described earlier in this document. It should include details of what will be provided by each service.

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 share the document with.

You should be given 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.

What should I expect?

Co-ordinated care

You should have a lead professional who acts as your dedicated key worker to take the lead in co-ordinating services and who should act as a single point of contact for you, your child and your family. This should be 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. They may be someone from the community children's nursing team that is allocated to your child or they may come from another service involved in your care.

Information you can understand

You will find huge amounts of information on the internet, in 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 understand what is happening. If you need help talking to them about their brother or sister, ask a member of your care team if they can help explain things in a child-friendly way.

i See our factsheet about **Understanding Sibling's Needs**.

i See our factsheet about **Parent Support Groups**.



Support with 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.

It can help to keep a diary of your child's symptoms so that you can share this with members of the care team.

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

You might be experiencing a whole range of feelings: numbness, anger, sadness or disbelief, to name just a few. 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 could be difficult or even 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.

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.

Call the Together for Families Helpline on

0808 8088 100

for further information.

i See our factsheet on **Emotional Support and Counselling**.

Access to benefits and financial assistance

Because of the extra costs involved in looking after a child with a life-limiting condition and the possibility that you may have to change your hours of work or employment, it is really important to obtain advice about benefits. There may be money you can claim for both your child and yourself as a carer. You may also be entitled to discounts on existing bills or one-off payments for specific items. You may well be entitled to a range of benefits, so do seek advice as early as possible as many cannot be backdated.

i See our factsheet on **Benefits**.

As well as state benefits, there are also a wide range of charities and organisations that provide funds or equipment for families in difficult circumstances or grant special wishes for ill children.

i See our factsheet on **Grants and Wishes**.

Access to flexible short breaks and holidays

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 (often called respite care) enable your child to have fun and enjoy new experiences and allow you to rest, catch up on sleep, go out with friends and have time away from the many professionals involved in your care. Short breaks should be flexible and can be provided for your child in your own home, in a children's hospice 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. Holidays and short breaks away from home can be organised through children's hospices or other specialised charities with appropriate nursing and other support provided. Further information about short breaks and supported holidays can be obtained from your care team.

i See our factsheet on **Short Breaks and Holidays**.

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.

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 an 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. 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.

Help with 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. As a carer, you are entitled to an assessment of your own health needs.

Access to aids and equipment

As mentioned in stage one, 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, for your care plan.

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.

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 your current housing will support your family's needs.

i See our factsheet on **Aids and Equipment**.

Transport

Your transport needs should be a key part of your care plan as this can make a real practical difference to how well you can manage daily life with your family. Ask your care team about help with any transport issues, such as learning to drive, accessing specially adapted car seats, transport being provided if you have bulky equipment, help with accessing the 'Blue Badge' scheme for disabled parking.

You might also be able to join the Motability Scheme which enables disabled people to lease a new car, scooter or powered wheelchair by exchanging their Government funded mobility allowance.

i See our factsheet on [Transport](#).

Emergency Healthcare Plan/Advance Care Plan

It can often bring comfort to have your wishes documented about how you would want your child cared for in an emergency or if they deteriorate suddenly. Although this can be hard to think about in advance, it can put your mind at rest to know that you have discussed these issues with your family and that your wishes are documented and shared with key agencies. Such plans are sometimes called Advance Care Plans and have the status of a medical care plan. They can, but do not have to, include your wishes about your child's end of life. You can ask your care team about how to go about developing an Emergency Healthcare Plan or Advance Care Plan.

i See our factsheet on [Care Planning in Advance](#).



A smooth transition for your child to adult services

It is important to begin planning for your child's transition from children's to adult services at an early stage – ideally at 14. Many families find it helpful to think about 'parallel planning' whereby you plan both for your child's future in adult services alongside planning in case of deterioration. It is likely that you will feel reluctant to begin the process of moving your child on to adult services, especially if they are unwell at the time, but it can help to make the transition easier if you and your child begin to discuss their hopes for their future and meet and start to plan how these can be achieved with the new professionals and services in the adult sector. Although services are different in the adult world, there is growing awareness of the needs of young adults with complex health needs and many adult services, such as hospices, are beginning to extend their services for younger adults. Most young adults, once they have made the move to adult services, find that they enjoy the greater freedom and independence that the move brings.

The Mental Capacity Act

As your child approaches adulthood you will need to think about the shift towards their legal status as decision-makers and your role as parent carers in supporting them to make decisions. For many young people with life-limiting conditions, their capacity to make decisions will be affected by their condition. Mental capacity is the ability to make an informed decision based on understanding a given situation, the options available and the consequences of the decision.

i See our factsheet on the [Mental Capacity Act](#).

Continuous review of needs

During this stage of the pathway it is likely that your needs will fluctuate. At some times, things will be quite stable and you will feel in control and at others there may be events that make it difficult for you, whether these are deteriorations in your child's health or other events that can impact on your life. Your care team should be able to provide you with sensitive, timely and appropriate support at times of change so that you can re-establish control.

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.

✓ **Here's a checklist of what you should expect at this stage**

- ❑ A key worker should be identified to co-ordinate the care plan.
- ❑ Information to be provided for you, your child and your family.
- ❑ Regular reviews of your needs.

✓ **Here's a checklist of what your child and family care plan should take account of and include**

- ❑ Your child's symptoms and personal care.
- ❑ Emotional/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.
- ❑ Transport.
- ❑ Emergency Healthcare Planning or Advance Care Planning.
- ❑ Transition to adult services.

Who can help?

- Key worker
- Community Children's Nurse
- GP
- Consultant
- Nurse specialist
- School staff including special educational needs co-ordinator (SENCO)
- Support groups
- Children's hospices





Stage three: End of life and bereavement

The fifth standard: An end of life care plan

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

What does this mean for me?

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, your child and your family may want time to consider, instead of being forced to make difficult decisions in a rush at a time of crisis.

This stage of the 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 the care and support to achieve your wishes.

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.

To work together on developing 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, sometimes called an Advance Care Plan (ACP), 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.

Choice about your child's place of death

Your care team should discuss with you your preferred place of care for your child at the time of death. Depending on your local service availability, you might wish your child to die at home, in hospital or in a children's hospice. This will be a personal choice and you should be supported to achieve this as far as possible, with appropriate access to 24 hour support. You may change your mind about where you would like your child to die and, where possible, this should be accommodated.

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 the 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 it.

i See our factsheet on [Emotional and Counselling Support](#).

Being spiritual does not mean that you have to belong to, or even agree with, any organised religion. Whether or not you belong to an organised religion, you may consider yourself to be spiritual, with your own 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 child's life and human life in general.

Health care chaplains and spiritual care teams are trained to give spiritual support to everyone, no matter what their religious beliefs. Chaplains will work with you, your child and family to address worries, doubts and questions.

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

i See our factsheet on [Spiritual, Religious and Cultural Issues](#).

✓ Here's a checklist of what you should expect at this stage

- Professionals should be open and honest when the approach to end of life is recognised.
- Joint planning should take place as soon as possible with your family and the care team 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 should be available, including access to medication and suitably qualified and experienced practitioners.
- Emotional and spiritual support should be provided for you and your family.
- Support should be provided for your child and family in their choices regarding end of life.

What should I consider when thinking about my child's end of life plan?

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 this is what you choose.

A natural death is where invasive treatments and equipment are withdrawn so that your child can die peacefully and without pain.

Withholding treatment

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 your 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.

What will happen at the time of death?

It will help if you and your family can discuss what you want to happen at the time of your child's death. You can use the questions below to help you to think together 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
- brush your child's hair and maybe 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.

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. 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.

It can be helpful to reflect on what kind of ceremony you want, for example:

- a chance to draw everyone together whose life was touched by your child, to say good bye 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

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 other children as they work their way through their grief.

i See our factsheet on [Emotional and Counselling Support](#).

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.

The child death review process (England only)

Government legislation 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 prior 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, 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.

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.

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

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. This type of 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.

The sixth standard: Bereavement support

Bereavement support should be provided along the care pathway and continue throughout the child's death and beyond.

What does this mean for me?

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.

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.

You may find it helpful just to talk to a friend, a befriending organisation or a professional such as your GP.

Who can help?

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

i See our factsheet on **Emotional and Counselling Support**.

There are many sources of help and support available, and Together for Short Lives has a national freephone helpline and information service – Together for Families – that can signpost you to the services that are most appropriate for you:

0808 8088 100

What to do if you feel the standards have not been met

Making a complaint

We hope that this Family Companion has provided you with an overview of the care and support that you can expect to receive from your local services. If, however, you feel that you have not received the standard of support or care to which you are entitled, you may wish to make a complaint. There are processes in place as well as agencies that can provide you with support.

There are three levels of complaint if you are not satisfied with your health or social care provision:

1. In the first instance you will need to follow the complaints procedure of the service provider about which you wish to make a complaint. You are encouraged to obtain details of the individual complaints procedure and make your complaint as early as possible if you have concerns. There are a number of organisations that can support you through this process, including:
 - PALS (Patient Advice and Liaison Services) in all NHS trust areas in England, www.nhs.uk/service-search/patient-advice-and-liaison-services-%28pals%29/locationsearch/363
 - PASS (Patient Advice and Support Services) in Scotland www.patientadvicescotland.org.uk
 - The Community Health Council in Wales www.wales.nhs.uk/sitesplus/899/home
 - The Patient and Client Council in Northern Ireland www.patientclientcouncil.hscni.net/making-a-complaint
 - Citizens Advice Bureau (CAB). To find your local CAB visit www.citizensadvice.org.uk

2. If you have gone through the entire complaints procedure and are not satisfied with the outcome you can take your complaint to the relevant Ombudsman.
3. As a final stage, you have the option of seeking a Judicial Review in the High Court, where a judge will consider whether an NHS or local authority's decision was lawful. The judge will evaluate the process used to reach the decision rather than the decision itself. It is necessary to seek the High Court's permission to apply for judicial review. It is advisable that you have exhausted the complaints and ombudsman procedures first. However, it is possible to seek an urgent Judicial Review in some circumstances.

Judicial review can be quite a complicated and lengthy process. Also the courts can make a costs award against the claimant, meaning you may be ordered to pay the legal costs of the opposing party, which could be thousands of pounds. For this reason, you are encouraged to seek legal advice and, if possible, apply for Legal Aid.

For full information on Judicial Review please see www.justice.gov.uk/courts/rcj-rolls-building/administrative-court/applying-for-judicial-review

Making a complaint about education provision

If you have issues with your child's education provision and live in England or Wales, you can seek advice from IPSEA, which is a registered charity offering free and independent advice to parents of children with special educational needs www.ipsea.org.uk.

Legal clinics

A legal clinic is a free service which provides initial legal advice for families. Each clinic varies in what areas of law they offer advice in. There are clinics operating throughout the UK. You can find details of legal clinics in your area at the following website www.lawworks.org.uk/clinics.

 See our factsheets on **Making a Complaint**.



The Together for Short Lives Charter for Children and Young People with Life-limiting and Life-threatening Conditions and their Families

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

1. Every child* and family member should be treated with respect and dignity.
2. The child and family should be offered an individual care and support package that is built around their unique needs.
3. A multi-disciplinary team should work together to support the family, and communicate with the child and family in an open and honest manner.
4. Children and families should always be listened to, and be encouraged to talk through their wishes and care choices.
5. At all stages of care, from diagnosis to death and bereavement, families should be provided with accurate and relevant information that they can understand.
6. Where possible, children should be cared for in the family's place of choice – in hospital, a hospice, or at home.
7. Emotional, psychological and spiritual support should be offered to the child, and those close to him or her.
8. Children and young people should be given the opportunity to access education and employment that is right for them.
9. The child and family's wishes concerning end of life care should be discussed and planned for well in advance.
10. Support and care should extend to all family members, friends and all those involved with the child.

* When the term 'child' is used, it refers to any baby, child or young person with a life-limiting or life-threatening condition.

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, from health, social care, education and from the statutory and voluntary sectors.

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: Provide nursing and supportive care at home and often act as your child's key worker. 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 medication.

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 medications your child will require. Lots of 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 you 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 the rarity of your child's condition this specialist may be based a long way away 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 have an adult palliative care service. They can provide advice and support to you and the multi-disciplinary 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 Bureaus and independent advice centres. They can help you claim all the benefits that you may be entitled to.

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.

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.

Patient Advice and Liaison Services (PALS): PALS 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 PALS either phone your local clinic, GP surgery, health centre or hospital and ask for details of the PALS service.

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 provides a home visiting educational service for pre-school children with additional support needs. 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

Care pathway/journey

The Together for Short Lives care pathway approach 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, throughout their care journey.

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 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:

- support for the entire family (including siblings, grandparents and the extended family)
- 24 hour telephone support
- practical help, advice and information
- specialist short break care

- provision of specialist therapies, including physiotherapy as well as play and music therapy
- 24 hour access to emergency care
- 24 hour end of life care
- bereavement support
- provision of information, support, education and training where needed to carers

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

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.

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 that 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. (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 rendering 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 children with 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

Needs-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.

Post-mortem

A post-mortem is the examination of a body after death. It is also known as an autopsy. Post-mortems are carried out by a pathologist, who is a doctor who specialises in the diagnosis of disease and the identification of the cause of 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 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 so as to provide a break (respite) from caring.
- 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 provides additional care in an appropriate setting or programme 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, which 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 prepare for and move from children's services to adult services.

Technology dependent children

Technology dependent children are those who depend on a medical device to compensate for the loss of a vital bodily function and substantial and ongoing nursing care to avert deterioration of their condition.

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.



A Family Companion to the Together for Short Lives Core Care Pathway for Children with Life-limiting and Life-threatening Conditions

This Family Companion is designed especially for parents/carers and family members of children and young people who have been diagnosed with a life-limiting or life-threatening condition.

At a time when things can seem overwhelming, this Companion acts as a step by step guide through the complex and often confusing processes that take place following diagnosis. It is designed to help parents think important things through, as well as provide information about what can be expected – explaining 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.

Together for Families Helpline
7am-Midnight, 7 days a week

0808 8088 100

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W: www.togetherforshortlives.org.uk

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Together for Short Lives is the leading UK charity for all children with life-threatening and life-limiting conditions and all those who support, love and care for them.