

# Family Factsheets

Together for Short Lives has developed a series of factsheets to support families and provide information on a range of issues. These factsheets can be found on our website or hard copies can be requested by emailing [info@togetherforshortlives.org.uk](mailto:info@togetherforshortlives.org.uk).

## Factsheet 1 - Parent Support Groups

Contains key contact information for some of the main charities and support groups for families.

## Factsheet 2 - Children's Hospice Services

Describes support that hospices can provide, including a list of 53 children's hospices.

## Factsheets 3-6 - Making a Complaint

These factsheets provide information on how to make a complaint about NHS services, local authorities and education provision. They also offer guidance on how to find local legal clinics.

Factsheet 3 - England

Factsheet 4 - Scotland

Factsheet 5 - Northern Ireland

Factsheet 6 - Wales

## Factsheet 7 - Grants and Wishes

Advice on sources of charitable funding and other forms of support from grant-giving and wish-giving organisations.

## Factsheet 8 - Short Breaks and Holidays

Details about organisations that arrange short breaks for young people and their families.

## Factsheet 9 - Emotional support and Counselling

Contact details for some of the key charities that are experienced at providing emotional and bereavement support for families.

## Factsheet 10 - Care Planning in Advance

Explains the purpose of an Advance Care Plan and offers guidance on details that could be included.

## Factsheet 11 - Transport

Details of organisations that provide information about travel and transport for those with disabilities or mobility problems.

## Factsheet 12 - Aids and Equipment

Details of organisations that can provide information about suitable aids and equipment.

## Factsheet 13 - Spiritual, Religious and Cultural Wishes

Explains how spirituality, religion and cultural backgrounds can play a part in shaping families' wishes. It aims to help give families the confidence to ask professionals to care for their child in accordance with their beliefs.

### Factsheet 14 - Benefits

Advice on how parents can access benefits that could be available for their child. These include tax credits, disability living allowance and carer's allowance.

### Factsheet 15 - Understanding Siblings' Needs

Guidance for parents about how to talk to their children about their brother or sister's diagnosis. It includes contact details for charities that can provide support to siblings.

### Factsheet 16 - The Child Death Review Process (England)

Explains the purpose and processes of the Child Death Review. The review was made mandatory in 2008 to understand why children die and to put in place interventions to protect other children and prevent future deaths.

### <Factsheet 17 - Discontinued>

### Factsheet 18 - Charities for Children with Cancer

Provides information and contact details for some charities that support children with cancer and their families. It includes national and regional charities.

### <Factsheet 19 - Discontinued>

### Factsheet 20 - The Mental Capacity Act

Explains what the term mental capacity means and outlines the five main principles of the Mental Capacity Act. It also provides details about where the Mental Capacity Act and a guide for families can be found online.

### Factsheet 21 - Talking with your Child about their Life-limiting Condition

Aims to offer practical advice and address some common concerns parents have when talking to their child about their condition.

### Factsheet 22 - When a child dies

Supports families and carers preparing for the death of a child.

### Factsheet 23 - Transition to adult services

Supports young people and their families through the move to adult services.



Together for Families Helpline & Live Chat: 10am-4pm, Monday-Friday

0808 8088 100

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[www.togetherforshortlives.org.uk](http://www.togetherforshortlives.org.uk)



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# Family Factsheets

## Factsheet 1

# Parent Support Groups

At Together for Short Lives, we know families often appreciate support from professionals and other families who understand their situation. This factsheet provides information and contact details for some helpful charities and support groups for families with experience of looking after a seriously ill child. We've grouped them into general support groups and those supporting families with specific conditions.

## General support groups

There are groups that support families regardless of their child's condition.

### Together for Short Lives' Facebook support group

The Together for Short Lives' family Facebook group is a supportive community where people with experience of caring for a seriously ill child can connect with other families.

<https://www.facebook.com/groups/1270199326332286>

### Contact - local and national groups

Contact, a charity for families with disabled children, runs a number of local and national support groups. Some professionals and organisations, particularly children centres, run their own groups.

Find your nearest one on their website.

<https://contact.org.uk/help-for-families/information-advice-services/local-support/parent-support-groups/>

### Family Lives - local groups

Family Lives' vision is that all families should have access to active support and understanding. They offer parenting and relationship support groups.

<https://www.familylives.org.uk/how-we-can-help/in-your-area/>

### Rare Connect - online platform

A safe, easy to use platform where individuals, families and patient organisations can develop online communities and have conversations across continents and languages. RareConnect partners with the world's leading rare disease patient groups to offer global online communities.

<https://www.rareconnect.org/en>

## SWAN - Support network

SWAN (Syndromes Without A Name) is the only dedicated support network available for families of children and young adults with undiagnosed genetic conditions in the UK. Find out more about becoming a member by emailing SWAN on the address below.

[joinus@undiagnosed.org.uk](mailto:joinus@undiagnosed.org.uk)  
[www.undiagnosed.org.uk](http://www.undiagnosed.org.uk)

## Kinship

Kinship provides support for all kinship carers. In addition to their peer support groups they also have a scheme called "Someone Like Me" – a volunteer delivered peer support service.

[www.kinship.org.uk/peer-support-for-kinship-carers/](http://www.kinship.org.uk/peer-support-for-kinship-carers/)

## Camp Simcha - parent support

Camp Simcha exists to make a difference to all Jewish children and their families across the spectrum of Jewish observance. They offer counselling for parents and siblings who are struggling to cope emotionally with their child or sibling being seriously ill. To find out more about what they offer, email their team or head to their website.

[office@campsimcha.org.uk](mailto:office@campsimcha.org.uk)

<https://www.campsimcha.org.uk/get-support/how-we-support/groups/parents/>

## Children of Jannah - for bereaved parents of Muslim faith

Private online groups: Children of Jannah runs private Facebook groups, allowing bereaved parents to share their feelings and fears in a safe, online environment.

Life after Loss meetings: Facilitated by specially trained Life After Loss staff, bringing bereaved parents together through mutual support. The facilitators work through five areas of bereavement over the course of five two-hour sessions in a safe, secure environment.

[info@ChildrenofJannah.com](mailto:info@ChildrenofJannah.com)

<https://www.childrenofjannah.com/>

## Children's Hospice Services and other charities

Children's Hospices and other children's palliative care charities across the UK offer support groups for families looking after a seriously ill child, and for those who are bereaved. Find details of these in the Together for Short Lives service directory.

<https://www2.togetherforshortlives.org.uk/portal/public/volunteer/>

## Condition-specific support groups

These are groups that support families whose child has a specific condition.

## Batten Disease Family Association - online support group

The Batten Disease Family Association (BDFA) is a national charity supporting families affected by Batten Disease. They run a private online support group for families, which can be accessed by calling their support line.

0800 046 9832

[www.bdfa-uk.org.uk](http://www.bdfa-uk.org.uk)

## Young Lives vs Cancer- online support group

Young Lives vs Cancer have different groups for young adults, parents and carers, bereaved families and dads:

<https://www.younglivesvscancer.org.uk/what-we-do/day-to-day-support/join-our-facebook-groups/>

They also have a helpline and live chat if you have a question about support groups in your area:

You can either message on Live Chat, call on 0300 303 5220 or email at [getsupport@younglivesvscancer.org.uk](mailto:getsupport@younglivesvscancer.org.uk).

## Cystic Fibrosis Trust - Peer to peer support

The Cystic Fibrosis Trust is a national charity dealing with all aspects of Cystic Fibrosis (CF). Their service, CF Connect will put you in touch with a trained parent volunteer who you can talk to in confidence about having a child with Cystic Fibrosis.

0300 373 1000  
[helpline@cysticfibrosis.org.uk](mailto:helpline@cysticfibrosis.org.uk)  
[www.cysticfibrosis.org.uk](http://www.cysticfibrosis.org.uk)

## Epilepsy Action - peer to peer support

Epilepsy Action is a charity supporting individuals and families impacted by epilepsy and seizures. They have a parents supporting parents programme where you can link up with other families affected by epilepsy. See also "West Syndrome support group" and "UK Infantile Spasms Trust" on this factsheet.

<https://www.epilepsy.com/living-epilepsy/parents-and-caregivers/parents-helping-parents>

## Metabolic Support UK - Metabolic Connect

Metabolic Support UK is the leading umbrella patient organisation for all inherited metabolic disorders. Their service Metabolic Connect brings patients and families together to share experiences, provide support and friendship.

[www.metabolicsupportuk.org/metabolic-connect](http://www.metabolicsupportuk.org/metabolic-connect)

## Muscular Dystrophy UK - Local muscle groups

Muscular Dystrophy UK is the charity for the 70,000 people living with muscle-wasting conditions in the UK. Their Muscle Groups give young people and their families the opportunity to meet regularly to talk about the things that matter to them.

<https://www.musculardystrophyuk.org/get-support/muscle-groups>

## Sands

Sands is the leading stillbirth and neonatal death charity in the UK. They have a countrywide network of over 104 local support Groups, usually run by bereaved parents and family members, offering parents the chance to meet others, gain support and share experiences.

<https://www.sands.org.uk/support-you/how-we-offer-support/sands-groups>

## Spinal Muscular Atrophy UK - online communities & sharing experiences

Spinal Muscular Atrophy UK gives support and information to those living with SMA and their families. Their website lists a series of support groups set up by people in the SMA Community.

<https://smauk.org.uk/connect-with-others>

## UK Infantile Spasms Trust - Online support group (UKIST)

The UK Infantile Spasms Trust (UKIST) provides a network of support to families with children affected by the rare seizure disorder infantile spasms, also known as West syndrome. They run a Facebook support group for affected families which you can access via the link below. See also "Epilepsy Action" and "West Syndrome Support Group" on this factsheet.

<https://ukinfantilespasmstrust.org/contact/>

## West Syndrome - Support Group

The West Syndrome Support Group is run by parents and offers support and a sympathetic ear to families of children affected by West Syndrome. See also "Epilepsy Action" and "UK Infantile Spasms Trust" on this factsheet.

01252 654 057



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## Call our helpline or chat via live chat

[www.togetherforshortlives.org.uk](http://www.togetherforshortlives.org.uk)

[helpline@togetherforshortlives.org.uk](mailto:helpline@togetherforshortlives.org.uk)

Helpline: 0808 8088 100

Live chat:

[www.togetherforshortlives.org.uk](http://www.togetherforshortlives.org.uk)

Our helpline and live chat provides information and listening support for families with experience of caring for a seriously ill child. We're open 10am-4pm Mon-Fri. Outside these hours, you can leave a message or email [helpline@togetherforshortlives.org.uk](mailto:helpline@togetherforshortlives.org.uk).





# Family Factsheets

## Factsheet 2

# Children's Hospice Services

Children's hospice services help children and young people with life-limiting conditions who are not expected to reach adulthood, and their families, to deal with the emotional and physical challenges they face and to make the most of life. This care can be provided throughout the course of a child or young person's life.

Children's hospice services aim to meet the physical, emotional, social and spiritual needs of children, young people and their families. Care is provided by a multi-disciplinary team of specialist staff, all working closely together to ensure seamless support to the entire family (including siblings and grandparents).

Children's hospices provide a wide range of support, including:

- 24 hour telephone support
- practical help, advice and information
- specialist short break care
- specialist therapies, including physiotherapy, complementary therapies, play and music therapy
- 24 hour access to emergency care
- 24 hour end of life care
- care for a child's body after death

- bereavement support
- information, support and training for parent carers

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

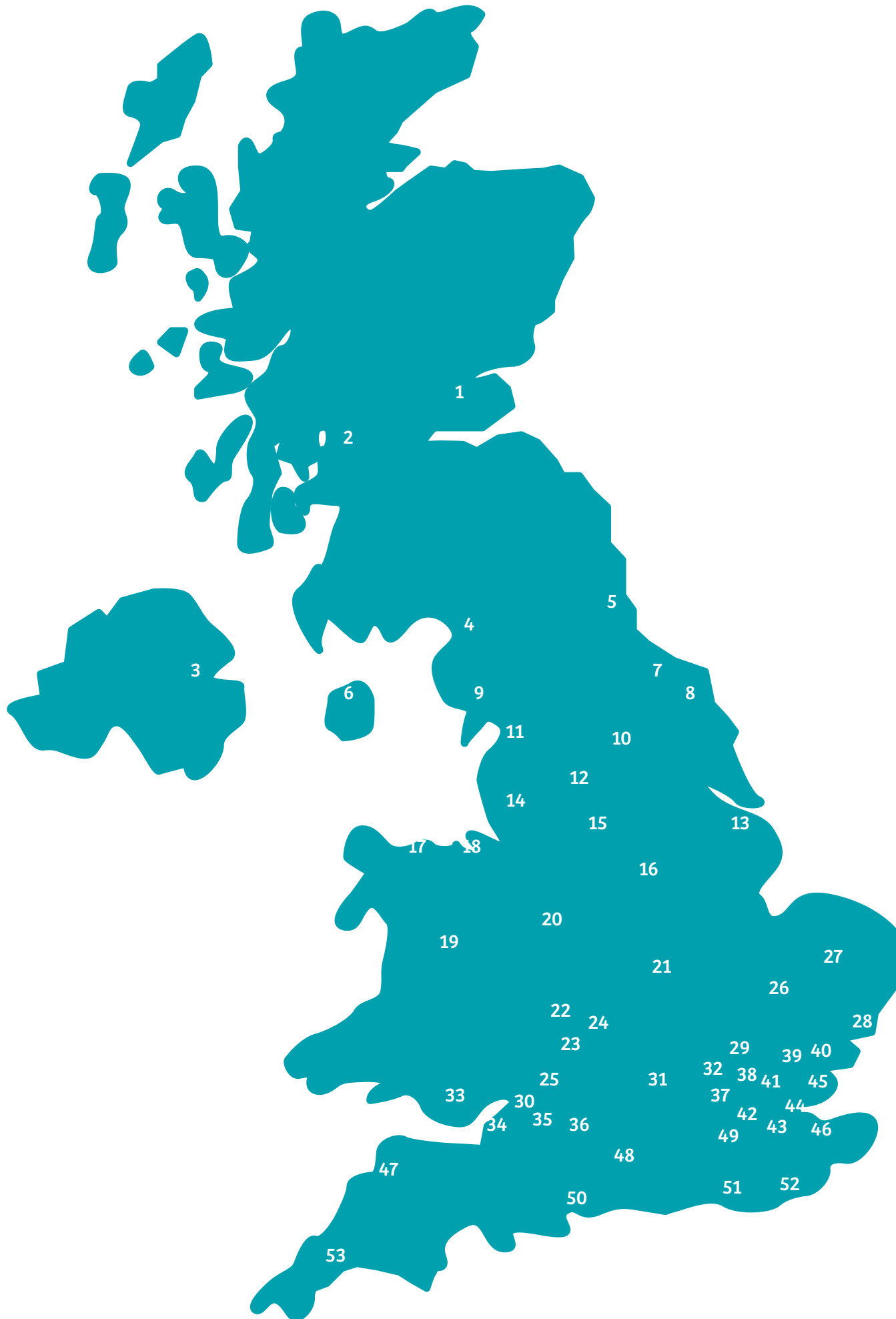
For more information about the work of children's hospices or to find your nearest service, please see the map of children's hospice services overleaf.

You can find further information on our website [www.togetherforshortlives.org.uk](http://www.togetherforshortlives.org.uk) or you can call our helpline: 0808 8088 100

## Find your nearest children's hospice service

1	Rachel House Children's Hospice (CHAS)	31	Helen & Douglas House
2	Robin House Children's Hospice (CHAS)	32	Rennie Grove Hospice Care
3	Northern Ireland Children's Hospice	33	Tŷ Hafan
4	Jigsaw, Cumbria's Children's Hospice	34	Charlton Farm (CHSW)
5	St Oswald's Hospice	35	Jessie May's Children's Hospice at Home
6	Hospice Isle of Man – Rebecca House	36	Julia's House – Wiltshire
7	Butterwick House Children's Hospice	37	Alexander Devine Children's Hospice Service
8	Zoe's Place – Middlesbrough	38	Noah's Ark Children's Hospice
9	Brian House Children's Hospice (Trinity Hospice and Palliative Care Services)	39	Haven House Children's Hospice
10	Martin House Children's Hospice	40	The J's Hospice
11	Derian House Children's Hospice	41	Richard House Children's Hospice
12	Forget Me Not Children's Hospice	42	Shooting Star Children's Hospices (Shooting Star House)
13	St Andrew's Children's Hospice	43	Demelza South East London
14	Zoe's Place – Liverpool	44	ellenor
15	Francis House Children's Hospice	45	Little Havens Children's Hospice
16	Bluebell Wood Children's Hospice	46	Demelza Kent
17	Ty Gobaith	47	Little Bridge House (CHSW)
18	Claire House Children's Hospice	48	Naomi House and Jacksplace
19	Hope House	49	Shooting Star Children's Hospices (Christopher's)
20	Douglas Macmillan Hospice (Dougie Mac)	50	Julia's House - Dorset
21	Rainbows Hospice for Children and Young People	51	Chestnut Tree House
22	Acorns Children's Hospice – Acorns in the Black Country	52	Demelza Community
23	Acorns Children's Hospice – Acorns in Birmingham	53	Little Harbour (CHSW)
24	Zoe's Place – Coventry		
25	Acorns Children's Hospice – Acorns for the Three Counties		
26	EACH Milton		
27	EACH Quidenham		
28	EACH Ipswich		
29	Keech Hospice Care		
30	James Hopkins Trust		







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# Family Factsheets

## Factsheet 3

# Making a Complaint – England

We hope the vast majority of families will be provided with the range of care and support that they need from local services. If, however, you feel that you have not received the standard of support or care that you are entitled to, you may wish to make a complaint.

## Making a complaint about NHS services in England

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

1. Complaints procedure of the individual service
2. Health Services Ombudsman
3. Judicial Review

### 1. Complaints procedure of the individual service

You are encouraged to complain as early as possible when an issue arises or you have a concern. You have a year from the date of the event occurring or you being made aware of the concern to lodge your complaint.

Request a copy of the complaints procedure of the service provider you wish to make a complaint about. There will be either a complaints manager or a designated person to oversee the

procedure. Follow the steps outlined in the complaints procedure provided. Most complaints can be resolved at this level. NB: You cannot appeal the outcome of your complaint investigation.

If you would like help with the NHS complaints process you can access a PALS (Patient Advice and Liaison Services) office in all NHS trust areas. You can find your local PALS office by visiting [www.nhs.uk](http://www.nhs.uk). You can also receive assistance from an NHS Complaints Independent Advocacy Service. To find your local service you should either ask the PALS office, speak to your local authority, visit <http://nhscomplaintsadvocacy.org> or contact VoiceAbility's NHS Complaints Advocacy helpline on 0300 330 5454. Additionally you can receive assistance from your Local Citizens Advice Bureau (CAB). To find your local CAB visit [www.citizensadvice.org.uk](http://www.citizensadvice.org.uk).

If you wish to complain about a private health service that you have paid for, you must request and follow their complaints procedure. If the private service is being paid for by the NHS you should use the NHS complaints procedure.

## 2. Taking your complaint to the Health Services Ombudsman in England

If, having gone through the entire complaints procedure, you are unhappy with the results you can escalate your concerns to the Parliamentary and Health Service Ombudsman.

To complain to the Ombudsman you will need to complete a form that can be found at [www.ombudsman.org.uk/make-a-complaint/how-to-complain/what-can-we-help-with](http://www.ombudsman.org.uk/make-a-complaint/how-to-complain/what-can-we-help-with). If you require assistance through this process you can speak with the NHS Complaints Advocacy Services <http://nhscomplaintsadvocacy.org>.

## 3. Judicial Review of Decisions

Additionally, you have the option of seeking a Judicial Review. Judicial Review (JR) is held in the high court and can be used to evaluate the processes that led to the decision and whether these were lawful. If you file for JR following a decision by the NHS, the review will be on their decision, however; if you file for JR after an Ombudsman decision, the JR will review the Ombudsman decision and not the original decision of the NHS.

1. To file for a JR it is advisable that you exhaust the complaints and Ombudsman procedures first, however; it is possible to file for urgent Judicial Reviews in some circumstances.

2. It is important to note that you must file for JR as soon as practicable or a

maximum of three months from the date you were aware of a decision or should have been aware.

3. For full information on Judicial Review please see [www.justice.gov.uk/courts/rcj-rolls-building/administrative-court/applying-for-judicial-review](http://www.justice.gov.uk/courts/rcj-rolls-building/administrative-court/applying-for-judicial-review).

Judicial Review can be quite a complicated and expensive process and it is recommended that you seek legal advice regarding any JR proceeding. It is also very important to note that the courts can make a costs award against the claimant, meaning you may be ordered to pay for the legal cost 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. You can check your eligibility for legal aid and get information about how to apply at [www.gov.uk/check-legal-aid](http://www.gov.uk/check-legal-aid). You may be able to access legal advice through a local law centre [www.lawcentres.org.uk](http://www.lawcentres.org.uk).

## Making a complaint about a local authority

If you are complaining about the actions or decision of a local authority it is important to request the complaints procedure for your local authority directly. Each local authority has its own policy, but there are a number of common elements, which are explained in this document.

### Local Authority Complaints Procedure – Possible three stages of complaint procedure

Stage one: Local Resolution

A complaint is raised with the manager of the team or unit providing the service that you wish to complain about. The manager should respond to the complaint within

10 working days. The timescale may be extended by an additional 10 days in extenuating circumstances.

### Stage two: Formal Investigation

If you are not satisfied with the response at Stage one, you may request a Stage two investigation. The request must be received within 20 days of receiving the Stage one outcome.

At Stage two, complaints are investigated by an external investigating officer and by an independent person (if the complaint relates to a child). The investigating officer and independent person will interview you and the staff members involved. The investigation will be concluded within 25 working days, or 65 working days if an extension is agreed with the complainant.

The investigating officer's report may uphold, partially uphold or not uphold your complaint, and may include recommendations. The role of the independent person is to oversee the investigation of your complaint and produce a separate report. Both reports go forward to the Director of Children's Social Care, who will adjudicate at Stage two and will write to you indicating whether or not the investigating officer's findings are accepted by the Director and any action which will be taken.

The Government have issued clear guidelines about who is able to access this stage of the procedure. If you wish to consider this option please contact the Customer Relations Team in the local authority, who will be able to advise you on the best way forward.

### Stage three: Review Panel

If you are not satisfied with the outcome at Stage two you can request a review by a panel. To do this you must write

to the Customer Relations Team within 20 working days of receiving your letter informing you of the outcome of the Stage two investigation. The panel must be held within 30 working days of receiving your request to hold a review.

The panel comprising three independent people will meet to consider the complaint and how it was dealt with. You will be invited to attend the panel and you can bring a friend or advocate with you if you wish. The panel must send their report to the Director of Services for Children and Young People within five working days of the date of the panel, and you will receive a copy of this report at the same time. The Director will consider the panel's report and recommendations and will write to you with their findings within 15 working days of receiving the review panel's report.

If you require assistance with making your complaint you can speak with someone at the Citizens Advice Bureau (CAB). To find your local CAB check [www.citizensadvice.org.uk](http://www.citizensadvice.org.uk). Additionally, you can ask your local authority if there is an advocacy support program available in your area.

### Local Government Ombudsman

You have the right to approach the Local Government Ombudsman at any time if you are dissatisfied with the investigation of your complaint. However, the Ombudsman would not normally get involved until the local authority has concluded its investigation and produced a response. If you contact the Ombudsman after the third stage of the complaint procedure (the review panel), you must do so within one year of the decision being made. To complain to the Ombudsman you need

to complete a form that can be found at [www.lgo.org.uk](http://www.lgo.org.uk).

If you require assistance through this process you can speak with the Local Government Ombudsman directly at 0300 061 0614.

## Making a complaint about education provision in England

If you have issues with your child's education provision and live in England or Wales, you can seek advice from IPSEA.

IPSEA can be contacted on 0800 018 4016. Their website is [www.ipsea.org.uk](http://www.ipsea.org.uk).

## Legal clinics

One way to find a legal clinic is to check the LawWorks website [www.lawworks.org.uk/clinics](http://www.lawworks.org.uk/clinics). LawWorks is the pro bono charity for solicitors.

Some clinics offer set appointment times while others operate on a drop-in basis, a small number of clinics also offer advice over the phone. Contact the clinic you intend to visit or view their website to find out how they operate. Some clinics offer

a general advice service and will provide brief advice on a wide range of issues and help you decide what to do next. Other clinics offer specialist advice in particular areas of law.

Some clinics can help you to complete simple forms, or draft a letter for you to send or make a telephone call on your behalf. Very occasionally and only after receiving your express permission, a clinic may agree to undertake a limited amount of additional work on your behalf.

Remember that legal advisers may have 30 minutes or less to hear your story and provide advice. Being clear about your query will help you get the most out of your session.

You should take any critical documents pertaining to your query with you to an appointment. This might include letters, assessments, contracts or court documents.

We are grateful to LawWorks, the pro bono charity for solicitors for their help in preparing this fact sheet.

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# Family Factsheets

## Factsheet 4

# Making a Complaint – Scotland

We hope the vast majority of families will be provided with the range of care and support that they need from local services. If, however, you feel that you have not received the standard of support or care that you are entitled to, you may wish to make a complaint.

This factsheet looks at the processes in place as well as agencies that can provide you with support if you wish to complain about health, social care or education provision.

## Making a complaint about NHS services in Scotland

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

1. Complaints procedure of the individual service
2. Health Services Ombudsman
3. Taking legal action

### 1. Complaints procedure of the individual service

You are encouraged to complain as early as possible when an issue arises or you have a concern. You have a year from the date of the event occurring or you being made aware of the concern to lodge your complaint.

Request a copy of the complaints procedure of the service provider for whom you wish to make a complaint about. In larger centres there is usually a complaints manager that will deal with your complaint. In smaller centres, such as family practices, there is not likely to be a complaints manager; rather, there will be a designated person to oversee the procedure. Follow the steps outlined in the complaints procedure provided. Most complaints can be resolved at this level.

If you would like help with the complaints process with the NHS you can access a PASS (Patient Advice and Support Services) which is operated through the Citizens Advice Bureaus in Scotland. You can find your local PASS office by visiting [www.patientadvicescotland.org.uk](http://www.patientadvicescotland.org.uk).

If you wish to complain about a private health service that you have paid for you must request and follow their complaints procedure. If the private service is being paid for by the NHS you should use the NHS complaints procedure.

## 2. Taking your complaint to the Health Services Ombudsman in Scotland

If you are unhappy with the results of the local complaint procedure you should escalate your concerns to the Scottish Public Services Ombudsman. To complain to the Ombudsman you need to complete a form that can be found at [www.spso.org.uk](http://www.spso.org.uk) or you can ring 0800 377 7330.

The Ombudsman will be able to help if you have already gone through the entire complaints procedure through the NHS and are not satisfied with the outcome.

## 3. Taking legal action against the NHS in Scotland

Taking legal action against the NHS can be quite a complicated and expensive process and it is recommended that you seek legal advice regarding any legal proceeding. If possible, apply for Legal Aid. You can check your eligibility for legal aid and get additional information about how to apply at [www.slab.org.uk/public/advice/index.html](http://www.slab.org.uk/public/advice/index.html). You may be able to access legal advice through a local law centre [www.lawcentres.org.uk](http://www.lawcentres.org.uk).

## Making a complaint about social services in Scotland

For information regarding a complaint about social service provision in Scotland please contact Citizens Advice Scotland at [www.cas.org.uk](http://www.cas.org.uk).

## Legal Clinics

A legal clinic is a free legal service which is intended to provide initial advice. Each clinic varies as to what areas of law they offer advice in. Typically, clinics are staffed by volunteer solicitors and barristers and law students often help with the administration of the clinic.

There are clinics operating throughout the UK. These clinics may operate out of Law Centres, GP surgeries, Citizen's Advice Bureaus or universities. These might be advertised locally or on the internet. One way to find a legal clinic is to check the LawWorks website [www.lawworks.org.uk/clinics](http://www.lawworks.org.uk/clinics). LawWorks is the pro bono charity for solicitors.

Some clinics offer set appointment times while others operate on a drop-in basis, a small number of clinics also offer advice over the phone. Contact the clinic you intend to visit or view their website to find out how they operate. Some clinics offer a general advice service and will provide brief advice on a wide range of issues and help you decide what to do next. Other clinics offer specialist advice in particular areas of law, such as housing or employment, for example.

Some clinics can help you to complete simple forms, or draft a letter for you to send or make a telephone call on your behalf. Very occasionally and only after receiving your express permission, a clinic may agree to undertake a limited amount of additional work on your behalf.

It is important to remember that sometimes legal advisers may have 30 minutes or less to hear your story and provide advice. Being clear about your query will help you to get the most out of your session.

You should take any documents pertaining to your query with you to an appointment. This might include letters, assessments, contracts or court documents. Any documents that are critical to the query should be taken. It is important to remember that advisers have limited time to spend with you so limiting documents to only the most necessary is the best way to get the most from your appointment.

We are grateful to LawWorks, the pro bono charity for solicitors for their help in preparing this fact sheet.





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# Family Factsheets

## Making a Complaint – Northern Ireland

We hope the vast majority of families will be provided with the range of care and support that they need from local services. If, however, you feel that you have not received the standard of support or care that you are entitled to, you may wish to make a complaint.

This factsheet looks at the processes in place as well as agencies that can provide you with support if you wish to complain about health or social care provision.

### Making a complaint about NHS services in Northern Ireland

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

1. Complaint to the Health and Social Care Services (HSC)
2. Health Services Ombudsman
3. Judicial Review

#### 1. Complaints to the Health and Social Care Services

In Northern Ireland complaints regarding social care and health care are made to the Health and Social Care Services (HSC).

You are encouraged to complain as early as possible when an issue arises or you have a concern. You have one year from the date of the event occurring or you being made aware of the concern to lodge your complaint. You should report your complaint within six months but you do have up to 12 months.

Find the contact details for your local HSC trust here [www.nidirect.gov.uk/make-a-complaint-against-the-health-service](http://www.nidirect.gov.uk/make-a-complaint-against-the-health-service).

If you require assistance lodging a complaint about the HSC you can contact Patient and Client Council at [www.patientclientcouncil.hscni.net/making-a-complaint](http://www.patientclientcouncil.hscni.net/making-a-complaint) or 0800 917 0222.



## 2. Taking your complaint to the Health Services Ombudsman in Northern Ireland

If you are unhappy with the results of the local complaint procedure you should escalate your concerns to the Commissioner for Complaints at the Northern Ireland Ombudsman. To complain to the Ombudsman you must complete a form that can be found at [www.ni-ombudsman.org.uk/How-to-Complain-.aspx](http://www.ni-ombudsman.org.uk/How-to-Complain-.aspx).

The Ombudsman will be able to help if you have already gone through the entire complaints procedure through the HSC and are not satisfied with the outcome.

## 3. Judicial Review of Decisions in Northern Ireland

Additionally you have the option of seeking a Judicial Review. Judicial Review (JR) is held in the high court and can be used to evaluate whether the decision made were lawful. This means that a judge will evaluate the processes used to reach the decision rather than the decision itself. If you file for JR following a decision by the HSC, the review will be on the HSC decision, however; if you file for JR after an Ombudsman decision, the JR will review the Ombudsman decision and not the original decision of the HSC.

To file for a JR it is advisable that you have exhausted the complaints and ombudsman procedures first, however; it is possible to file for urgent Judicial Reviews in some circumstances.

It is important to note that you must file for JR as soon as practicable or a maximum of three months following you being made aware of the decision (or time that you should have been aware). The time starts running from the date you are made aware of the decision or should have been aware.

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

Judicial Review can be quite a complicated and expensive process and it is recommended that you seek legal advice regarding any JR proceeding. It is also very important to note that the courts can make a costs award against the claimant, meaning you may be ordered to pay for the legal cost 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. You can check your eligibility for legal aid and get additional information about how to apply at [www.dojni.gov.uk/index/legalservices/legal-services-members-of-the-public.htm](http://www.dojni.gov.uk/index/legalservices/legal-services-members-of-the-public.htm). You may be able to access legal advice through a local law centre [www.lawcentres.org.uk](http://www.lawcentres.org.uk).

For information and support please contact your local Citizen's Advice Bureau or look at their website [www.citizensadvice.co.uk](http://www.citizensadvice.co.uk).



## Legal clinics

A legal clinic is a free legal service which is intended to provide initial advice. Each clinic varies in what areas of law they offer advice in. Typically, clinics are staffed by volunteer solicitors and barristers and law students often help with the administration of the clinic.

There are clinics operating throughout the UK. These clinics may operate out of Law Centres, GP surgeries, Citizen's Advice Bureaus or universities. These might be advertised locally or on the internet. One way to find a legal clinic is to check the LawWorks website [www.lawworks.org.uk/clinics](http://www.lawworks.org.uk/clinics). LawWorks is the pro bono charity for solicitors.

Some clinics offer set appointment times while others operate on a drop-in basis, a small number of clinics also offer advice over the phone. Contact the clinic you intend to visit or view their website to find out how they operate. Some clinics offer a general advice service and will provide brief advice on a wide range of issues and help you decide what to do next. Other clinics offer specialist advice in particular areas of law, such as housing or employment, for example.

Some clinics can help you to complete simple forms, or draft a letter for you to send or make a telephone call on your behalf. Very occasionally and only after receiving your express permission, a clinic may agree to undertake a limited amount of additional work on your behalf.

It is important to remember that sometimes legal advisers may have 30 minutes or less to hear your story and provide advice. Being clear about your query will help you to get the most out of your session.

You should take any documents pertaining to your query with you to an appointment. This might include letters, assessments, contracts or court documents. Any documents that are critical to the query should be taken. It is important to remember that advisers have limited time to spend with you so limiting documents to only the most necessary is the best way to get the most from your appointment.

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# Family Factsheets

## Factsheet 6

# Making a Complaint – Wales

We hope the vast majority of families will be provided with the range of care and support that they need from local services. If, however, you feel that you have not received the standard of support or care that you are entitled to, you may wish to make a complaint.

## Making a complaint about NHS services in Wales

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

1. Complaints procedure of the individual service
2. Health Services Ombudsman
3. Judicial Review

### 1. Complaints procedure of the individual service

You are encouraged to complain as early as possible when an issue arises or you have a concern. You have one year from the date of the event occurring or you being made aware of the concern to lodge your complaint.

You can request a copy of the NHS complaints procedure or from your Local Health Board: [www.wales.nhs.uk/ourservices/directory/localhealthboards](http://www.wales.nhs.uk/ourservices/directory/localhealthboards).

For more information about the NHS Wales complaints procedure visit [www.wales.nhs.uk](http://www.wales.nhs.uk).

For help lodging a complaint about the NHS Wales you can contact The Community Health Council at 0845 644 7814 or 02920 235 558 or at [www.wales.nhs.uk/sitesplus/899/home](http://www.wales.nhs.uk/sitesplus/899/home).

You can also receive assistance with your complaint through the Citizens Advice Bureau (CAB): [www.citizensadvice.org.uk](http://www.citizensadvice.org.uk).

If you wish to complain about a private health service that you have paid for you must request and follow their complaints procedure. If the private service is being paid for by the NHS you should use the NHS complaints procedure.

### 2. Taking your complaint to the Health Services Ombudsman in Wales

If, having gone through the entire complaints procedure, you are unhappy with the results you can escalate

your concerns to the Public Services Ombudsman. To complain to the Ombudsman you must complete a form that can be found at [www.ombudsman-wales.org.uk](http://www.ombudsman-wales.org.uk).

### 3. Judicial Review of Decisions

Additionally you have the option of seeking a Judicial Review. Judicial Review (JR) is held in the high court and can be used to evaluate the processes that led to the decision and whether these were lawful. If you file for JR following a decision by the NHS, the review will be on their decision, however; if you file for JR after an Ombudsman decision, the JR will review the Ombudsman decision and not the original decision of the NHS.

To file for a JR it is advisable that you have exhausted the complaints and Ombudsman procedures first, however; it is possible to file for urgent Judicial Reviews in some circumstances.

It is important to note that you must file for JR as soon as practicable or a maximum of three months you are made aware of the decision or should have been aware.

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

Judicial Review can be quite a complicated and expensive process and it is recommended that you seek legal advice regarding any judicial review proceeding. It is also very important to note that the courts can make a costs award against the claimant, meaning you may be ordered to pay for the legal cost 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. You can check your eligibility for legal aid and get information about how to apply at [www.gov.uk/check-legal-aid](http://www.gov.uk/check-legal-aid). You may be able to access legal advice through a local law centre [www.lawcentres.org.uk](http://www.lawcentres.org.uk).

### Making a complaint about a local authority

If you are complaining about the actions or decision of a local authority it is important to request the complaints procedure for your local authority directly. Each local authority has its own policy, but there are a number of common elements, which are explained in this document.

#### Local Authority Complaints Procedure –Possible three stages of complaint procedure

##### Stage one: Local Resolution

A complaint is raised with the manager of the team or unit providing the service that you wish to complain about. The manager should respond to the complaint within 10 working days. The timescale may be extended by an additional 10 days in extenuating circumstances.

##### Stage two: Formal Investigation

If you are not satisfied with the response at Stage one, you may request a Stage two investigation. The request must be received within 20 days of receiving the Stage one outcome.

At Stage two, complaints are investigated by an external investigating officer and by an independent person (if the complaint relates to a child). The investigating officer and independent person will interview you and the staff members involved. The investigation will be concluded within 25

working days, or 65 working days if an extension is agreed with the complainant.

The investigating officer's report may uphold, partially uphold or not uphold your complaint, and may include recommendations. The role of the independent person is to oversee the investigation of your complaint and produce a separate report. Both reports go forward to the Director of Children's Social Care, who will adjudicate at Stage two and will write to you indicating whether or not the investigating officer's findings are accepted by the Director and any action which will be taken.

The Government have issued clear guidelines about who is able to access this stage of the procedure. If you wish to consider this option please contact the Customer Relations Team in the local authority, who will be able to advise you on the best way forward.

### Stage three: Review Panel

If you are not satisfied with the outcome at Stage two you can request a review by a panel. To do this you must write to the Customer Relations Team within 20 working days of receiving your letter informing you of the outcome of the Stage two investigation. The panel must be held within 30 working days of receiving your request to hold a review.

The panel comprising three independent people will meet to consider the complaint and how it was dealt with. You will be invited to attend the panel and you can bring a friend or advocate with you if you wish. The panel must send their report to the Director of Services for Children and Young People within five working days of the date of the panel, and you will receive a copy of

this report at the same time. The Director will consider the panel's report and recommendations and will write to you with their findings within 15 working days of receiving the review panel's report.

If you require assistance with making your complaint you can speak with someone at the Citizens Advice Bureau (CAB). To find your local CAB check [www.citizensadvice.org.uk](http://www.citizensadvice.org.uk). Additionally, you can ask your local authority if there is an advocacy support program available in your area.

### Local Government Ombudsman

You have the right to approach the Local Government Ombudsman at any time if you are dissatisfied with the investigation of your complaint. However, the Ombudsman would not normally get involved until the local authority has concluded its investigation and produced a response.

If you contact the Ombudsman after the third stage of the complaint procedure (the review panel), you must do so within one year of the decision being made. To complain to the Ombudsman you need to complete a form that can be found at [www.lgo.org.uk/forms/ShowForm.asp?fm\\_fid=62](http://www.lgo.org.uk/forms/ShowForm.asp?fm_fid=62).

If you require assistance through this process you can speak with the Local Government Ombudsman directly at 0300 061 0614.



## Making a complaint about education provision in England or Wales

If you have issues with your child's education provision and live in England or Wales, you can seek advice from IPSEA.

IPSEA can be contacted on 0800 018 4016. Their website is [www.ipsea.org.uk](http://www.ipsea.org.uk).

## Legal clinics

One way to find a legal clinic is to check the LawWorks website [www.lawworks.org.uk/clinics](http://www.lawworks.org.uk/clinics). LawWorks is the pro bono charity for solicitors.

Some clinics offer set appointment times while others operate on a drop-in basis, a small number of clinics also offer advice over the phone. Contact the clinic you intend to visit or view their website to find out how they operate. Some clinics offer a general advice service and will provide brief advice on a wide range of issues. Other clinics offer specialist advice in particular areas of law, such as housing or employment, for example.

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# Family Factsheets

## Factsheet 7

# Grants and Wishes

This family factsheet offers advice on sources of charitable funding and other forms of support from grant-giving/wish-granting organisations.

We all have special wishes and dreams. For children and young people with a life-limiting condition there is often a sense of urgency to make those dreams a reality. There are a range of charities that provide support to help children and families achieve their dreams and ensure that their families have an opportunity to build important memories of happy times together.

There are other charitable funds which give grants to people in financial need who meet their eligibility criteria, using a sum of money that the grant-giving charity has set aside for this purpose. Although some grant-giving charities have only one fund, others run several funds that give money for different purposes. We have provided a list of some of the key organisations in the UK that provide grants for families or enable dreams or wishes for disabled or life-limited children. You will need to check the individual criteria of each of these organisations and establish whether they are currently open for applications.

Please note that this is not an exhaustive list and you can call our Together for Families Helpline on 0808 8088 100 for details of other organisations that can help.

### [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](http://www.dctc.org.uk)

Tel: 01428 726 6330

Email: [info@dreamscometrue.uk.com](mailto:info@dreamscometrue.uk.com)

### [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](http://www.familyfund.org.uk)

Tel: 0845 130 4542

Email: [info@familyfund.org.uk](mailto: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](http://www.fhaonline.org.uk)

Tel: 020 3117 0650

Email: [info@fhaonline.org.uk](mailto: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](http://www.make-a-wish.org.uk)

Tel: 01276 405060

Email: [info@makeawish.org.uk](mailto:info@makeawish.org.uk)

### The Muscle Help Foundation: Muscle Dreams

The Muscle Help Foundation's specialised team deliver amazing and once in a lifetime experiences for children and young people with Muscular Dystrophy.

[www.musclehelp.com](http://www.musclehelp.com)

Tel: 01763 274658

Email: [info@musclehelp.com](mailto:info@musclehelp.com)

### Rays of Sunshine

Rays of Sunshine brightens the lives of seriously ill young people and their families by granting wishes and providing ongoing support within hospitals.

[www.raysofsunshine.org.uk](http://www.raysofsunshine.org.uk)

Tel: 0208 782 1171

Email: [info@raysofsunshine.org.uk](mailto:info@raysofsunshine.org.uk)

### REACT (Rapid Effective Assistance for Children with Potentially Terminal Illness)

A charity working to improve the quality of life for financially disadvantaged children with life-limiting illnesses living in the UK. The charity provides grants and holidays.

[www.reactcharity.org](http://www.reactcharity.org)

Tel: 0208 940 2575

Email: [react@reactcharity.org](mailto:react@reactcharity.org)

### Round Table Children's Wish

Round Table Children's Wish is a charity dedicated to granting 'handcrafted' wishes for children and young people with life-threatening illnesses.

[www.rtcw.org](http://www.rtcw.org)

Tel: 01202 514515

Email: [info@rtcw.org](mailto:info@rtcw.org)

### 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](http://www.starlight.org.uk)

Tel: 0207 262 2881

Email: [talktous@starlight.org.uk](mailto:talktous@starlight.org.uk)

### Promise Dreams

Promise Dreams helps to make dreams come true for seriously and terminally ill children aged 0-18, and their families, across the UK, this might include family holidays, specialist equipment or meeting favourite celebrities.

[www.promisedreams.co.uk](http://www.promisedreams.co.uk)

Tel: 01902 212451

Email: [info@promisedreams.co.uk](mailto:info@promisedreams.co.uk)

### When You Wish Upon a Star

A national organisation set up to grant wishes for seriously ill children between the ages of 2 and 16.

[www.whenyouwishuponastar.org.uk](http://www.whenyouwishuponastar.org.uk)

Tel: 0115 979 1720

Email: [head.office@whenyouwish.org.uk](mailto:head.office@whenyouwish.org.uk)

### Willow Foundation

The Willow Foundation provides special days for 16-40 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](http://www.willowfoundation.org.uk)

Tel: 01707 259777

Email: [info@willowfoundation.org.uk](mailto:info@willowfoundation.org.uk)





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# Family Factsheets

## Factsheet 8

# Short Breaks and Holidays

For many families caring for a child with complex disabilities or health needs it can be extremely difficult to contemplate being able to afford or organise a holiday with appropriate care in place. However a short activity break for your child or a holiday together can be immensely rewarding and can enable your child and your family to build some amazing memories to treasure.

There are several charities which organise special holidays for a seriously ill child, either with their family or on their own with a group of other children/young people. These are provided in the UK or overseas, and different criteria may apply depending on the scheme.

For some, families can apply directly, whereas others may need a referral from a doctor or a recognised charity.

Many of the schemes are open all year round and can be applied for online. These holidays are generally free of charge, fully insured and a medical team with carers is provided to ensure the individual's medical needs are met during the holiday.

Please note that this is not an exhaustive list and Together for Short Lives does not take responsibility for ensuring that these suggestions will be appropriate for everyone.

You are advised to conduct your own research to ensure that the venue and accommodation is suitable for your own family requirements.

You can call our helpline on 0808 8088 100 for details of other organisations that can help.

Our Grants and Wishes factsheet also includes details of organisations that provide grants for holidays.



### Birchington Convalescent Benefit Fund

The fund is used to help disadvantaged children under the age of 18 to have a 'change of air' whilst they are recovering from an illness or suffering from a long-term illness. The grants are modest and rarely given for expensive overseas holidays. An application must be supported by a recognised body, such as social services, a doctor or a charity. Grant decisions are made in February, April and June.

Tel: 01923 235 111

Email: [enquiries@churchsociety.org](mailto:enquiries@churchsociety.org)

### The Children's Hope Foundation

The Children's Hope Foundation offers holidays and short breaks for families with children aged 3-17 with special needs for a nominal charge. The charity's caravan houses up to eight people and is in Camber Sands, East Sussex.

[www.childrenshopefoundation.org.uk](http://www.childrenshopefoundation.org.uk)

Tel: 020 7700 6855

Email: [info@childrenshopefoundation.org.uk](mailto:info@childrenshopefoundation.org.uk)

### Donna's Dream House

A Blackpool-based charity that provides holidays for terminally ill children in a specially adapted house.

[www.donnasdreamhouse.co.uk](http://www.donnasdreamhouse.co.uk)

Tel: 01253 752222

Email: [len@donnasdreamhouse.co.uk](mailto:len@donnasdreamhouse.co.uk)

### Heswall Disabled Children's Holiday Fund

The fund hosts a free week-long summer camp each August for up to 30 boys aged 9-15, from North West England, who have physical disabilities. In addition to the Camp the fund also sponsors children with disabilities for whom their camp is not suitable on other specialist holidays.

[www.heswallcamp.org.uk](http://www.heswallcamp.org.uk)

Email: [boys@heswallcamp.org.uk](mailto:boys@heswallcamp.org.uk) or  
[committee@heswallcamp.org.uk](mailto:committee@heswallcamp.org.uk)

### Kids Cancer Charity

(formerly Christian Lewis Trust)

The charity provides a holiday programme for children/ young people with cancer and their families. This ranges from luxury static caravans on specially chosen sites situated on the coast in Wales, where the family can get away from the pressures of hospital and treatment, to resort holidays in both Walt Disney World in Florida and Disneyland Paris where we have partners able to provide a unique programme of supervised and special facilities.

[www.kidscancercharity.org](http://www.kidscancercharity.org)

Tel: 01792 480500

Email: [enquiries@kidscancercharity.org](mailto:enquiries@kidscancercharity.org)

### Whiteleys Retreat

Situated in South Ayrshire, Whiteleys Retreat provides therapeutic short breaks for children, young people and their families with cancer and life altering illnesses in Scotland.

[www.whiteleysretreat.com](http://www.whiteleysretreat.com)

Email: [info@whiteleysretreat.com](mailto:info@whiteleysretreat.com)



### The Oliver Curd Trust

The Oliver Curd Trust provides free holidays for families with children who have a life-limiting or life-threatening illness. The charity also provides breaks to bereaved families. The charity has two caravans in East Sussex, one in Battle and the other in St. Leonards-on-Sea. Both caravans sleep up to six people and families can take a week's holiday or an extended weekend at one of them. Do contact the Trust to discuss any access requirement you have.

[www.theolivercurdtrust.co.uk](http://www.theolivercurdtrust.co.uk)

Tel: 07856 119151

Email: [enquiries@theolivercurdtrust.co.uk](mailto:enquiries@theolivercurdtrust.co.uk)

### Sebastian's Action Trust

Sebastian's Action Trust offers respite holidays to seriously ill children and their families, enabling precious time to be spent together. They provide spaces and places where families can access time together, away from the stresses of hospital and home at The Bluebells, Hampshire and The Woodlands, Berkshire.

[www.sebastiansactiontrust.org](http://www.sebastiansactiontrust.org)

Tel: 01256 391854

Email: [info@sebastiansactiontrust.org](mailto:info@sebastiansactiontrust.org)

### Youth Cancer Trust

Provides free, fun activity based holidays at the Tracy Ann House in Bournemouth for young people (aged 14 -30) suffering with cancer or any malignant disease, from anywhere in the UK and the Irish Republic, or who are patients of any UK hospital. Holidays may also be granted for people in remission for up to five years or for those living with the effects of having had cancer as a teenager.

[www.youthcancertrust.org](http://www.youthcancertrust.org)

Tel: 01202 763 591

Email: [admin@yct.org.uk](mailto:admin@yct.org.uk)

### The Calvert Trust

Enables people with disabilities, together with their families and friends to achieve their potential through the challenge of outside activities. Activities include canoeing, abseiling, swimming or sliding down a zip wire. The Calvert Trust does not charge a fee for their holidays. For a full price list and more information on their centres in Exmoor, Kielder and the Lake District, please do visit their website.

[www.calvert-trust.org.uk](http://www.calvert-trust.org.uk)

### Sandcastle Trust

The Sandcastle Trust provides grants to families affected by a rare genetic condition for short breaks, special days and annual attraction passes. They also offer support to families who have suffered a bereavement as a result of a rare genetic condition.

[www.sandcastletrust.org](http://www.sandcastletrust.org)

Tel: 0207 1998 261

Email: [info@ssandcastletrust.org](mailto:info@ssandcastletrust.org)

### Hannah's Holiday Appeal

Hannah's Holiday Appeal provides free breaks away for families of children with cancer and life-limiting illnesses at one of their holiday homes located on Hayling Island and the New Forest. The sites have indoor and outdoor pools, restaurants, arcades, and club houses with great entertainment teams to entertain the whole family. Most importantly, all homes are within a half hour drive from hospital for peace of mind for everyone.

[www.hannahsappeal.org](http://www.hannahsappeal.org)

Tel: 023 9226 7899

Email: [pam@hannahsappeal.org](mailto:pam@hannahsappeal.org)

### Barretstown

Barretstown offers free specially designed camps and programmes for children and their families in Ireland and the UK living with a serious illness. Supported behind

the scenes by 24-hour on-site medical and nursing care, everything, including accommodation, food and medical assistance are provided at no cost to the family.

[www.barretstown.org](http://www.barretstown.org)

Tel: +353 45 864 115

Email: [info@barretstown.org](mailto:info@barretstown.org)

### After Umbrage

After Umbrage offer free breaks for carers in their holiday cottages outside Bath. This offer is extended to carers within their first year of bereavement too.

[www.afterumbrage.org.uk](http://www.afterumbrage.org.uk)

Contact information is available through a form on their website.

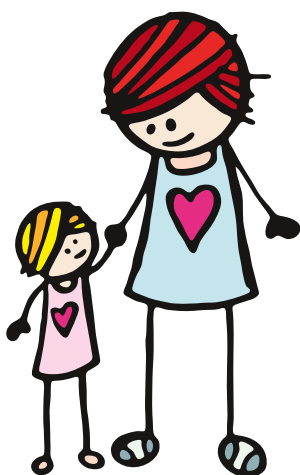
### Tourism for All UK

Tourism for All UK provides information on travel and leisure for people with disabilities, providing details of where their specific need can be met. Tourism for All UK is a membership organisation (annual subscription £25) that helps people with disabilities find the best holiday to suit them.

[www.tourismforall.org.uk](http://www.tourismforall.org.uk)

Tel: 0845 124 9971

Email: [info@tourismforall.org](mailto:info@tourismforall.org)



Together for Families Helpline & Live Chat: 10am-4pm, Monday-Friday

0808 8088 100

[helpline@togetherforshortlives.org.uk](mailto:helpline@togetherforshortlives.org.uk)

[www.togetherforshortlives.org.uk](http://www.togetherforshortlives.org.uk)



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# Family Factsheets

## Factsheet 9

# Emotional Support and Counselling

Emotional and psychological support can help you cope with the initial diagnosis as well as throughout your child's illness and in bereavement. 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. This factsheet provides contact details for some of the key charities and organisations that are experienced at providing support emotional/bereavement support or counselling for families.

If you think you or your child would benefit from talking to a counsellor you can find a local qualified counsellor using [www.counselling-directory.org.uk](http://www.counselling-directory.org.uk). Children's hospices and local children's palliative care teams can also provide emotional support for you and your family.

If you feel you would benefit from a listening ear or want to make contact with others going through similar experiences, do call

our confidential helpline on 0808 8088 100 or via LiveChat on our website: [www.togetherforshortlives.org.uk/get-support](http://www.togetherforshortlives.org.uk/get-support)

### Child Bereavement UK

Child Bereavement UK aims to ensure that all families have access to the support and information they need when a child grieves or when a child dies. They provide confidential support, information and guidance to families and professionals, with professionally trained bereavement support workers available to take calls 9am-5pm Monday - Friday.

[www.childbereavementuk.org](http://www.childbereavementuk.org)

Tel: 0800 02 888 40

Email: [support@childbereavementuk.org](mailto:support@childbereavementuk.org)

### 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](http://www.childhoodbereavementnetwork.org.uk)  
Tel: 020 7843 6309  
Email: [cbn@ncb.org.uk](mailto: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](http://www.childdeathhelpline.org)  
Helpline: 0800 282 986  
If phoning from a mobile: 0808 800 6019  
Email: [contact@childdeathhelpline.org](mailto: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](http://www.tcf.org.uk)  
Helpline: 0345 123 2304  
Email: [info@tcf.org.uk](mailto:info@tcf.org.uk)

### Family Lives

Family Lives provides professional, non-judgmental support and advice in a way that all members of the family can freely access through a 24 hour helpline, extensive online advice, email and live chat services, befriending services, and parenting/relationship support groups.

[www.familylives.org.uk](http://www.familylives.org.uk)  
Helpline: 0808 800 2222  
Email: [askus@familylives.org.uk](mailto:askus@familylives.org.uk)

### 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](http://www.samaritans.org)  
Helpline: 116 123  
Email: [jo@samaritans.org](mailto:jo@samaritans.org)

### Support Line

Offers confidential emotional support to children, young adults and adults by telephone, email and post. They work with callers to develop healthy positive coping strategies, an inner feeling of strength and increased self esteem.

[www.supportline.org.uk](http://www.supportline.org.uk)  
Helpline: 01708 765200  
Email: [info@supportline.org.uk](mailto:info@supportline.org.uk)

### Winston's Wish

Winston's Wish was the UK's first childhood bereavement charity. They lead the way in providing emotional and practical bereavement support to children, young people and those who care for them.

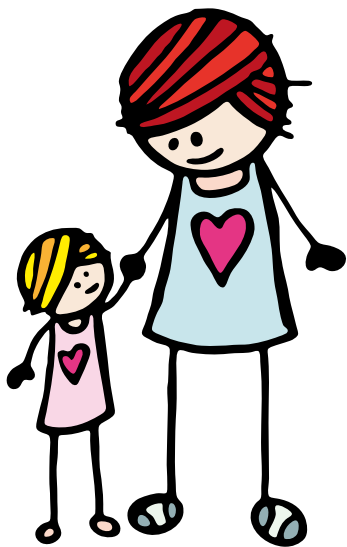
[www.winstonswish.org.uk](http://www.winstonswish.org.uk)

Helpline: 0845 20 30 40 5

Email: [info@winstonswish.org.uk](mailto:info@winstonswish.org.uk)

Many parent support groups also provide emotional support and an opportunity to be put in touch with families going through a similar experience to you. Please ask for a copy of our factsheet on Parent Support Groups.





Together for Families Helpline & Live Chat  
10am-4pm, Monday to Friday

0808 8088 100

[info@togetherforshortlives.org.uk](mailto:info@togetherforshortlives.org.uk)

[www.togetherforshortlives.org.uk](http://www.togetherforshortlives.org.uk)



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# Family Factsheets

## Care Planning in Advance

Throughout your child's care, you will have been developing plans for their care based on assessments made by the team caring for them. As your child's condition becomes more unstable or starts to deteriorate, the professionals may want to develop other plans to deal with that deterioration or instability. These plans are called by different names by different teams.

### Anticipatory Care Planning

An Anticipatory Care Plan (ACP) sets out what actions should be taken when your child's condition becomes unstable or deteriorates or they develop potentially life-threatening complications of their illness. The actions should be discussed and agreed by you and your child (when appropriate). It is important that someone explains to you the choices you have in the care your child receives.

If your child is approaching the end of their life, this planning is particularly important and these plans are sometimes called Advance Care Plans or End of Life Plans. The purpose of these plans is to try to ensure that your child's care runs smoothly and in accordance with your wishes. This may, for example, ensure the care happens in a place that you choose or prevent inappropriate admissions to

hospitals. Planning ahead will mean that you don't have to think about so many practical things at the time of your child's death, when you will want to spend as much time as possible being with your child and when you are likely to feel exhausted and confused.

### How will I cope?

It is natural to have lots of questions, concerns and fears about this stage of your child's care, and you will need lots of information about your child's condition and what to expect. You may wonder:

How will I tell my other children, family and friends?

How will we care for our very sick child?

What is going to happen?

What are the practical steps I need to take?

Don't be afraid to ask for help. Families have told us that forward planning for their child's end of life, although really difficult, can make them feel more in control of the situation and can give them more time to create positive memories during the last few days.

### What will an ACP include?

The team caring for your child will be there to support you and will be able to answer the questions you have. Before you meet them you might want to think about what questions you want to ask. You might find it easier to write a list of all the things you are worried about or want to know.

Here are some of the questions you might want to discuss:

- What care is available and where can it be provided?
- Is it available 24hrs a day, 7 days a week?
- Who will be there out of ours to care for your child?
- What sort of steps do you want the team to take if your child needs resuscitating or if they suddenly deteriorate? Will it be possible to withdraw invasive treatments and equipment and allow a more natural death?

- Do you have any views on organ and tissue donation? Do you need more information about this? Even if your child has had a long-term illness, it is still possible to donate tissues such as heart valves and corneas.
- A plan for managing your child's symptoms should be in place, who will manage this?
- Who do you want to be there at the time of your child's death? Who will look after your other children? Who will call family and friends?
- Where do you want your child to be cared for, at the time of death, and after death? There are a number of choices you can make, including taking your child to a special suite at a children's hospice or taking them home.
- What kind of ceremony (ies) would you like? You may want to have a special naming ceremony, an informal celebration or a traditional funeral; you may want to plan more than one, or you may not wish to have any.
- Does your child wish to make a will? Your child may find it comforting to write a will, choosing to give their toys or possessions to specific friends or family members.

Think about who else you would like to be with you at the discussions. It's always best to have a friend or other family member with you.

Don't be afraid to ask for time to think about these important choices you are making, or to ask for more discussions with the staff involved in your child's care.

### Keeping and reviewing the plan

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

### Keep a list of useful contacts close by

It's good to keep a list of all the professionals involved in your child's care. Make sure you are given out-of-hours contact numbers so you have peace of mind day and night. If you are worried about anything and can't wait to see your child's specialist – talk to your GP. In a medical emergency call 999.



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0808 8088 100

[helpline@togetherforshortlives.org.uk](mailto:helpline@togetherforshortlives.org.uk)  
[www.togetherforshortlives.org.uk](http://www.togetherforshortlives.org.uk)



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# Family Factsheets

## Getting around

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.

### Disability Living Allowance; Mobility Allowance.

When applying for Disability Living Allowance (DLA) you will be asked questions on your child's ability and safety to walk

to assess their eligibility for a mobility allowance. The mobility allowance is paid in with the DLA payments every four weeks. Children over the age of 16 can apply for Personal Independence Payments instead.

<https://www.gov.uk/dla-disability-living-allowance-benefit/DLA-rates>

### Motability Scheme

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.

This useful web page entitled "How the scheme works" gives information about travel and transport for those with disabilities and/or mobility problems:  
<https://www.motability.co.uk/about/how-the-scheme-works/>

Children under three years old may also be able to access the scheme the scheme, more details can be obtained from Family Fund: <https://www.familyfund.org.uk/mobilitysupport>

### Blue Badge Scheme

The Blue Badge Scheme is an arrangement that gives a range of parking concessions to disabled motorists and to parents of disabled children over the age of three, although it is available to younger children with specific medical conditions. You may also be eligible for discounts on Road Tax.

Details on how to apply: <https://www.gov.uk/apply-blue-badge>

## Home to school journeys

Your Local Authority have responsibility for supporting eligible families with help for home to school journeys. Do contact your Local Authority in the first instance if your child's school is not supporting you with this. For advice and information on home to school transport see the Independent Parental Special Education Advice (IPSEA) website: [www.ipsea.org.uk](http://www.ipsea.org.uk)

## Hospital transport

Some children are eligible for transport to and from medical appointments if they have an eligible medical need. For example, for children who need to travel in an ambulance. Check on your appointment letter for contact details to book this or ask the Hospital Department directly.

## Car parking at hospital

Most hospital car parking charges were abolished in Wales in 2008 and Scotland in 2009. Hospitals in England and Northern Ireland now provide free car parking to groups that may be frequent hospital visitors, or those disproportionately impacted by daily or hourly charges for parking, including: Blue Badge holders and frequent outpatients who have to attend regular appointments to manage long-term conditions.

Free parking will also be offered at specific times of the day to certain groups, including: parents of sick children staying in hospital overnight. Check with your hospital if they are using Automatic Number Plate Recognition (ANPR) systems, which use camera technology to scan car number plates or ticket or token systems where eligible people can then redeem free parking or receive a refund.

## Public transport

All public transport providers must provide an accessible service. In practice, you may not be able to use their service at all times or without a staff member to help you. You have different rights depending on whether you're on a train, taxi, bus or coach. Some areas also publish a guide to accessible transport services. Scope has a handy guide on finding accessible public transport:

<https://www.scope.org.uk/advice-and-support/finding-accessible-transport/>



## Charities that may support you getting around

### Whizz-Kidz

They provide disabled children with customised mobility equipment, training, advice and life skills and gives them the independence to be themselves.

[www.whizz-kidz.org.uk](http://www.whizz-kidz.org.uk)

Tel: 0207 233 6600

Email: [info@whizz-kids.org.uk](mailto:info@whizz-kids.org.uk)

### Evie's Gift

They provide short term support to families when their child is in hospital including help with transport costs. Contact your Hospital support worker or nurse to apply:

<https://www.eviesgift.org.uk/>

### React Childrens Charity

They help families caring for a child with an illness which is life-threatening or has the potential to shorten their lifespan. Their purpose is to provide assistance in situations where none is available elsewhere:

<https://reactcharity.org/applications>



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# Family Factsheets

## Factsheet 12

# Aids & equipment

If your child would benefit from specialist equipment or other aids, these should be identified at their assessment meeting. These may be led by health, social services or another children's services team who can inform you about the options available to meet your child's need. In some areas, you may have a multi-agency assessment. In each case it is important that you are told who has responsibility to provide it and details of who to contact should any problems arise.

While some aids and equipment may be provided by statutory services, this factsheet provides details of some organisations that provide information about different models/types that are on the market. In some cases, these organisations may also provide the equipment directly.

Assistive technologies are products and services that empower disabled people to become more independent. Under the Equality Act 2010, assistive technology is recognised as a 'reasonable adjustment' which should be made available to prevent discrimination in a wide variety of contexts. The term covers a diverse range of technologies from wheelchairs and walking sticks to environmental controls which enable users to operate door openers, computers and other household appliances with a single accessible device.

## Navigating the specialist equipment and technology market

Specialist aids and equipment and assistive technology can be purchased directly from suppliers. However, it can be difficult to choose between products or even know what is available. The following websites have been designed to provide buyers with a starting place in their search for suitable products.

### Independent Living

Independent Living provides a website and a catalogue containing a full range of aids to support daily living, mobility and independence. It also offers a free weekly newsletter on the latest developments in independent living.

[www.independentliving.co.uk](http://www.independentliving.co.uk)

## **Living Made Easy**

Living Made Easy is an advice and information website maintained by the Disabled Living Foundation. The website aims to provide comprehensive and impartial information about daily living equipment.

[www.livingmadeeasy.org.uk](http://www.livingmadeeasy.org.uk)  
Helpline: 0300 999 0004

## **Useful charities**

### **Newlife**

Newlife helps disabled and terminally ill children in the UK by providing equipment to help individual children as well as providing nurse led information, service and funding research. They have a special 'Just Can't Wait' equipment service for families of terminally ill children.

[www.newlifecharity.co.uk](http://www.newlifecharity.co.uk)  
Helpline: 0800 902 0095

### **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](http://www.whizz-kidz.org.uk)  
Tel: 020 7233 6600  
Email: [info@whizz-kidz.org.uk](mailto:info@whizz-kidz.org.uk)

### **AbilityNet**

AbilityNet is a charity dedicated to helping disabled people access digital technology at home and in education and the workplace. It provides a range of free services to disabled people and their families, friends, carers and employers.

[www.abilitynet.org.uk](http://www.abilitynet.org.uk)  
Helpline: 0800 269 545  
Email: [enquiries@abilitynet.org.uk](mailto:enquiries@abilitynet.org.uk)

## **The Aidis Trust**

The Aidis Trust is a charity that provides free and impartial support on technology to disabled people living across the UK.

[www.aidis.org](http://www.aidis.org)  
Tel: 0808 800 0009  
Email: [info@aidis.org](mailto:info@aidis.org)

## **Disabled Living**

Disabled Living is a charity which provides impartial information about equipment (assistive technology) and services for disabled adults, children, older people and the professionals who support them.

[www.disabledliving.co.uk](http://www.disabledliving.co.uk)  
Tel: 0161 607 8200  
Email: [info@disabledliving.co.uk](mailto:info@disabledliving.co.uk)

## **The Disabled Living Foundation**

The Disabled Living Foundation is a national charity that provides impartial advice, information and training on independent living. Its website hosts a range of factsheets on different types of equipment, assistive technology suppliers and sources of funding.

[www.dlf.org.uk](http://www.dlf.org.uk)  
Helpline: 0300 999 0003  
Email: [helpline@dlf.org.uk](mailto:helpline@dlf.org.uk)

## **ERIC (Education and Resources for Improving Childhood Continence)**

ERIC's Helpline service provides support for children, parents and professionals who deal with childhood continence issues.

[www.eric.org.uk](http://www.eric.org.uk)  
Helpline: 0845 370 8008 on a Monday and Wednesday (9.30am-4.30pm)  
Email: [helpline@eric.org.uk](mailto:helpline@eric.org.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](http://www.thesequaltrust.org.uk)

Tel: 01691 624222

Email: [info@thesequaltrust.org.uk](mailto:info@thesequaltrust.org.uk)

## **Useful commercial providers**

### **The British Healthcare Trade Association (BHTA)**

The BHTA is the UK's largest association of companies that manufacture and sell assistive technology. Its members work in a wide variety of assistive technology fields including wheelchairs, stairlifts, orthotics and communication aids. Companies registered with the association can be found on the 'Find Member' section of its website, which can be a useful way of locating reputable suppliers.

[www.bhta.net](http://www.bhta.net)

Tel: 0207 702 2141

Email: [bhta@bhta.com](mailto:bhta@bhta.com)

### **Inclusive Technology**

Inclusive Technology is an online retailer that specialises in providing computer access equipment and software for disabled users. Its catalogue includes switches and other computer access devices, communication aids, eyegaze, and educational assistive technology for people with physical, sensory and learning impairments.

[www.inclusive.co.uk](http://www.inclusive.co.uk)

Tel: 01457 819 790

Email: [inclusive@inclusive.co.uk](mailto:inclusive@inclusive.co.uk)

## **Government schemes that are there to support you**

The government runs a number of services and programmes to assist those needing housing adaptations or specialist equipment. In most cases they provide access to expert assessors and finance both the acquisition and maintenance of the equipment supplied.

### **Disabled Facilities Grant (DFG)**

Disabled Facilities Grants (DFG) are administered by local councils and aim to finance changes to a disabled person's home to make the residence more accessible. You must be assessed for these grants by a trusted assessor. For children under 18 this is likely to be their physiotherapist or occupational therapist. This can include widening doors and improving access to rooms, installing ramps and adapting heating or lighting controls to make them easier to operate. The DFG is means-tested, based on household income and savings for adults. Children under 18 can get a grant without their parents' income being taken into account. The maximum amount of funding available varies by region. It is not available in Scotland.

### **Further information:**

England and Wales: [www.gov.uk/disabled-facilities-grants/overview](http://www.gov.uk/disabled-facilities-grants/overview)

Northern Ireland:

[www.nidirect.gov.uk/articles/disabled-facilities-grants](http://www.nidirect.gov.uk/articles/disabled-facilities-grants)

## Access to Work

The Access to Work Programme provides grants to finance any additional support or equipment that may be needed to help disabled people access employment.

[www.gov.uk/access-to-work/overview](http://www.gov.uk/access-to-work/overview)

Tel: 0345 268 8489

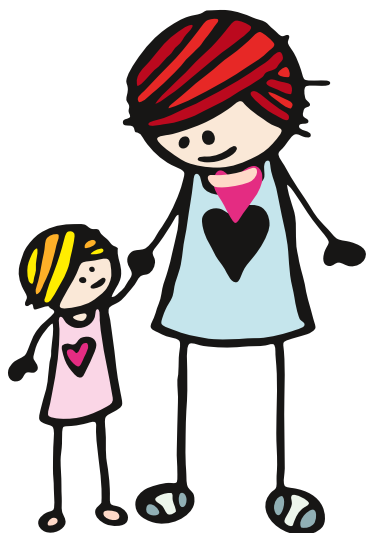
Textphone: 0345 608 8753

Email: [atwosu.london@dwp.gsi.gov.uk](mailto:atwosu.london@dwp.gsi.gov.uk)

## Disabled Students' Allowance (DSA)

The Disabled Students' Allowance (DSA) covers the extra disability-related costs students with disabilities or specific learning difficulties incur while studying in higher education. Students can access the DSA by applying to the relevant student financing agency, depending on whether they live in England, Wales, Scotland or Northern Ireland.

[www.yourdsa.com](http://www.yourdsa.com)



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Monday-Friday

0808 8088 100

[helpline@togetherforshortlives.org.uk](mailto:helpline@togetherforshortlives.org.uk)

[www.togetherforshortlives.org.uk](http://www.togetherforshortlives.org.uk)



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# Family Factsheets

Factsheet 13

## Spiritual, Religious and Cultural Wishes

Finding out that your child may not live the life you had planned for them, and especially that they may die before they reach adulthood, is devastating and life changing. It can make you question everything you thought you believed, and leave you wondering, “why me?”

This factsheet explains how spirituality, religion and cultural backgrounds can play a big part in shaping families’ wishes, and aims to help give you the confidence to ask professionals to care for your child in accordance with your values or beliefs, whatever they may be.

[Is it possible to be spiritual without being religious?](#)

Learning that your child is very ill is distressing, and it is often a deeply spiritual time, no matter whether or not you are a religious person.

Spirituality refers to what it is to be human – to the things that give life meaning and value, and as such is a deeply personal and subjective thing. It can involve questions and concerns about life, meaning, morals and values, and can encompass our relationship with ourselves, other people, the world around us, and sometimes but by no means always, a god or deity.

Spirituality is an integral part of any religion, but it can also be a meaningful part of a person’s life if they do not belong to a religion or have faith in a god.

Spirituality is a deeply personal part of a person’s life and is entirely unique to each individual.

[How can I be sure my religious preferences will be respected?](#)

If you are a member of a religious faith, there are often specific rituals surrounding end of life and what happens after a death.

Even if you are not a practicing or devout member of a faith, you still may feel these rituals are important for you and your family. People often draw much comfort from rituals, as well as readings from religious texts, or having various religious items such as holy books, prayer beads or icons with your child during their final days or hours.

If it is something you want, you should feel confident to ask a religious leader to come visit you in your home, or at the hospital or hospice where your child is being cared for, to talk to you about any questions you might have, to guide you in your decisions, or just to comfort you or lead you in prayer or meditation.

### How can I be sure my cultural preferences will be respected?

Different cultures often have specific attitudes towards illness and death, and may have different practices according to the age or sex of the person being cared for. This cultural diversity leads to many varying beliefs about medical treatment, and the sort of care a child should receive.

Professionals will often be aware of different cultural attitudes, and should be able to help accommodate your wishes. Sometimes, however, professionals may not know about certain cultural practices, but they should be open to learning about your culture and how this has an impact on the way you would like your child to be cared for. Make sure you talk to someone in your child's care team to help them understand your culture, and exactly what you would like to happen.

If English is not your first language, and you need support to help you articulate your cultural values or to help clarify your wishes, an interpreter should be made available to you if you ask a member of your child's care team.

You could also ask a community leader to come talk to the professionals looking after your child, to help explain your cultural background and how this affects your wishes for your child's care.

### Will my wishes for my child's care be fulfilled?

Every family is unique in their spirituality, religion, culture, beliefs and values. Whatever your wishes for your child's care, these should be respected by the team supporting you and your child, and they should all work to accommodate your wishes as closely as possible.

Professionals should not assume anything. Just because you belong to a particular religion or culture, they should understand that each individual will have different values and beliefs and will interpret their own spirituality differently. If you are not a practicing member of a faith community, professionals should not assume that you do not want to perform any rituals, say any prayers, or speak to a religious leader.

Spirituality, religion and culture are very intertwined and very fluid in today's society. Many families are multi-cultural and/or multi-faith, and many families may have moved to the UK midway through life which means they hold or respect the values of two cultures and societies. Some, although they may belong to a non-Christian religion, may still see some value in 'British' rituals or practices which are based historically in Christian values – so may draw upon two religious backgrounds when deciding what they want to happen.

Whatever your wishes, whether they reflect the typical values of one faith, of two or more faiths or cultures, or of none at all – you are entitled to your beliefs, and should feel comfortable articulating those beliefs and values to anyone working with your child. All professionals should be



able to assist you in meeting your wishes as closely as possible.

### What support is there for me?

Throughout your child's illness, end of life stage, and after their death, you will no doubt want to talk to someone about how you feel.

It's a good idea to talk to family members and friends about what you are going through, but sometimes you might feel like they just don't "get it", as they have not experienced the same as you. You may also want to talk to someone who is emotionally detached from the situation, and who you can be confident won't judge you.

A spiritual care team or chaplaincy service should be available at most hospitals and hospices, and should also be able to help you link with local services if you are caring for your child at home.

### What is a spiritual care team or chaplaincy service?

These professionals are specially trained to talk to you about emotional and personal issues, and can help you to try and make sense of what is happening through a spiritual or religious context, regardless of your faith.

They will help you to explore your feelings, attitudes and beliefs and discuss with you any questions or concerns you might have. At all times, any conversation you have with a member of the spiritual care team or chaplaincy service will be completely confidential, and you should feel confident that they will not judge you. The spiritual care team or chaplain can be called upon at any time throughout your

child's care. Depending on the hospital or hospice you are using, they may require you to make an appointment, but often, they are available 24/7 upon request.

Many services have these professionals available on an on-call basis in case of emergencies.

As well as being there to talk, spiritual care and chaplaincy professionals can help organise religious services, especially in situations when there has been little to time to plan or contact your usual religious leader.

Hospitals and hospices usually have a quiet room or multi-faith prayer room where you can go at any time during the day or night to pray, meditate, or just have some quiet time to reflect.

Some hospitals and hospices keep religious artefacts, symbols or sacred books for families to use, so if you are not very religious or do not have the objects yourself, you can access them at times of need. This service is not available in all areas, and may not extend to all religions, especially those less common in the UK.

If a chaplain or member of the spiritual care team is associated with one faith, it doesn't mean they won't be able to help you if you belong to another religious community, or have no faith. Often they can help by talking with you more generally about how you are feeling and what it all means. In many cases, spiritual care professionals have a great deal of knowledge about many faiths, and contacts within the religious community as a whole, and can call upon members of other faiths when required.

Just because a chaplain or member of the spiritual care team is affiliated with or representative of a certain religion, this

does not mean they will not be able to meet your individual needs. They will be happy to talk to anyone, including those of no faith or spiritual inclination, and it is not their role to “convert” you to their religion. If you are non-religious, you can still talk to your chaplain about spiritual concerns, emotional well-being and the big questions without being concerned that they will want to discuss religion.

### What if I don't understand something?

If English is not your first language, it might be hard to tell the care team about what you want for your child. You might find it difficult to understand what your doctor or nurse is telling you about your child's illness. It is your right to ask for an interpreter to help you.

Even if English is your first language, you may not always understand all the medical terms and jargon professionals use. It is important that you understand

everything they are saying, and the implications and risks associated with any treatment that is being planned for your child. If you are unsure about any terms, ask questions and make sure you ask your doctor to explain the terms in a way that you can understand. You can also ask them to write down what they have said, so you can reflect upon it later.

If you find it difficult to understand written or verbal information about your child's condition or their care, make sure you ask for this information in a way that is clear to you. If you have a visual or hearing impairment you can ask for a signer, or for information to be provided to you in Braille. The team will not want to administer any treatment to your child, unless they know you are absolutely clear about what will happen, and are happy to go ahead.

Many thanks to Erica Brown for contributing her time and expertise to this resource.

Together for Families Helpline & Live Chat: 10am-4pm, Monday-Friday



0808 8088 100

[helpline@togetherforshortlives.org.uk](mailto:helpline@togetherforshortlives.org.uk)  
[www.togetherforshortlives.org.uk](http://www.togetherforshortlives.org.uk)



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# Family Factsheets

## Benefits

There are a number of benefits and tax credits that you may be entitled to. Some benefits can be paid because your child is disabled while others may be paid to you for other reasons. For example, you may be getting disability living allowance (DLA) for your child and carer's allowance as their carer. However depending on your income and certain other factors you may also be able to claim benefits such as income support, child tax credit and housing benefit.

Personal Independence Payment (PIP) is the the disability benefit for disabled people aged 16 or above. Like DLA, PIP has two types of payment - a mobility component and a daily living component. However, the decision about whether someone qualifies for PIP is based on different rules than DLA and depends on the number of points you score following a medical assessment.

There are a number of organisations that can provide you with information about all the benefits that you may be entitled to:

- The national charity for families with disabled children, Contact, has a freephone national helpline on 0808 808

3555 and can provide you with a free benefits check service and have a wealth of information and factsheets on their website:

[www.contact.org.uk](http://www.contact.org.uk)

- Your Local Citizens Advice Bureau or welfare rights unit can carry out a full benefits check for you. A range of useful information about benefits is available from their country-specific website pages:

- England: [www.citizensadvice.org.uk/benefits/](http://www.citizensadvice.org.uk/benefits/)
- Northern Ireland: [www.citizensadvice.org.uk/about-us/northern-ireland](http://www.citizensadvice.org.uk/about-us/northern-ireland)
- Scotland: [www.citizensadvice.org.uk/scotland/benefits/](http://www.citizensadvice.org.uk/scotland/benefits/)
- Wales: [www.citizensadvice.org.uk/wales/benefits](http://www.citizensadvice.org.uk/wales/benefits)

- The Gov.UK website signposts to independent online benefits calculator to help you to work out what benefits you may be entitled to claim: [www.gov.uk/benefits-calculators](http://www.gov.uk/benefits-calculators).

- Together for Short Lives has developed a resource about personal budgets which can be accessed from our website: [www.togetherforshortlives.org.uk/young-persons-budget](http://www.togetherforshortlives.org.uk/young-persons-budget)

A personal budget is a sum of money that is made available to someone who needs support. The money comes from their local authority social care or education department or NHS and is allocated to the individual or family to spend on help and support to meet their assessed eligible needs and to achieve agreed outcomes.

Children and young people with an Education, Health and Care Plan (EHCP)

and/or with a continuing care package are able to access a personal budget. When the money comes from the NHS it is referred to as a Personal Health Budget.

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0808 8088 100

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[www.togetherforshortlives.org.uk](http://www.togetherforshortlives.org.uk)



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# Family Factsheets

## Factsheet 15

# Understanding Siblings' Needs

This family factsheet has been written for parents and carers of a child who has been diagnosed with a life-threatening health condition or a condition that will shorten their life. It has been designed to help parents who are worried about talking to siblings about their brother or sister's diagnosis and how this will affect them. We hope that this factsheet will provide reassurance around worries or anxieties about broaching this difficult conversation with siblings.

### Coming to terms with your child's diagnosis

Hearing the news that that your child has a health condition that is life-threatening or will shorten their life is devastating. Dealing with your own feelings, as well as coping with new and challenging practical matters can be hard to bear. The thought of sharing this news with your children can be overwhelming. Some parents think it's better for siblings not to know or be told, and extended family and friends often encourage this approach. Talking to children early on will help them to cope better in the long term.

### Building trust

Sometimes children who aren't sure what is going on, or who feel that something is being kept from them, may try and find out the truth in some other way. They may have overheard you talking and picked up a little bit of information. They may go searching for their own answers – talking with friends or looking on the internet. It's easy for children to fill in the gaps for themselves and possibly get things wrong. It's always best if your children hear things from you as parents, the people they love and trust. Children cope much better when this happens.

## How do siblings feel about their brother or sister?

As parents you instinctively know when something is bothering or worrying your children. Similarly, your children can easily pick up on how you are feeling. Even if they don't know what is going on, they can pick up on the signs and know when you are not happy or when something just doesn't feel "right". Siblings may experience all kinds of emotions and feelings when they hear about their brother or sister's health. They may feel sad, angry, confused, guilty or fearful about the future. They may feel protection or loyalty towards their sibling. They may worry about how it will change things, or worry that they may get ill too.

It's important to help children express their feelings. They will need lots of support in coming to terms with the news. Talking with them and finding special time for them will help. Often children, especially older ones, will understand that you have new demands and that time is precious. Some children will not want to bother you, or feel bad about taking your attention when they know you are busy. They can sometimes feel guilty about getting on with their own lives.

## Worrying about talking to your children

Many parents worry about how they can share their child's diagnosis with siblings. Perhaps you are worried about how they will react. You may want to protect them from the truth. You might not feel emotionally strong enough to say the words you need to, or worry about crying in front of your children. You may be concerned about using the right words to describe what is happening to their brother or sister.

Often there is so much happening at this time. You may have constant hospital appointments and lots of meetings with professionals involved with supporting your child. Balancing this with family life and work is hard and finding time to talk to your children is hard as well. But giving as much attention as you can to all your children will help to reassure them. If they know what's going on, it's easier for them to adjust to changes in family life.

These are all normal feelings. You might find some of your fears start to fade when you have started opening up to your children.

## Finding the right words

Being truthful may be painful, but it can save a lot of pain and misunderstanding in the future. It also builds the trust between you and your children. Some siblings' worries can be easy to address. They might worry that they could "catch" the same health condition or worry unnecessarily about dying.

If you are worried about how to start the conversation or what words to use, then there are lots of people you can talk to (we have included some key contacts at the end of this factsheet). If you are in touch with your local children's hospice, you could talk to them about explaining things to your children. You can also talk to your GP or another professional who is supporting you. You might find it helpful to talk to your spiritual advisor or religious leader, or to other parents who have had similar experiences.

You might not always know the answers to questions your children ask. But it's ok to be honest and say you don't know. Some parents find it easier to talk



to siblings in the presence of a trusted professional, such as a palliative care nurse, who is available to answer difficult questions and who can offer emotional support. Other parents will want to do this in the privacy of their own home, without anyone else present.

### Finding the right time

Try and find a time that is right for you and your children. A moment when you know you have time and space, and nothing will disturb you or when you know that you won't be distracted by other commitments. You might choose a regular time when you would normally talk to your family about important things.

If you have a partner, husband, wife, friend or relative who is supporting you, take time to talk things through together. This may help you to find the right words and think through some of the issues that could come up. It also helps if you both know what you are going to say; that way there will be no mixed messages.

### Finding the right approach

All children deal with things in different ways. Go at their pace and allow time for them to get used to the news. Keep things really open so they know they can ask you questions when they are ready. Be open and honest and encourage them to talk. Talking to very small children and toddlers can be tricky. Maybe explain things as they happen. For example when your child asks questions such as: "why can't my brother have dinner like me?" or "why is my sister always ill"? Reassure them that although there are new things to get used to, family life will carry on, and there are lots of special family things that won't change.

Siblings will have their own unique journey with their brother or sister. Having a disabled or seriously ill sister or brother can help to build strong sibling relationships. There are lots of ways of involving your children in caring for their brother or sister. Having a special role can make them feel included. Maybe there are games they can play with their sibling, or perhaps they can help you care for their brother or sister. Try and involve all your children along their brother or sister's care journey, talking to them about changes and explaining the care or treatment that they need.

Give siblings choice about how much they want to be involved and acknowledge the things they do to support their brother or sister. It will help your children if you make sure that key people in their life know what is going on at home. Talk to your children's teachers, nursery staff and close family friends. It's a good idea to have regular meetings at nursery, school or college so that siblings' teachers and support staff understand any changes that might affect them.

### How siblings may respond

On hearing the news or having their suspicions confirmed about their brother or sister's health, siblings react in different ways depending on their age and personality. Some become quiet and want to be by themselves, some ask if they can go out to play, others get very upset and cry or get angry. Negative changes in behaviour may make parents feel that they have done the wrong thing, however it is normal for things to get worse in the short term and then get better.

## Remember that you are not alone

There are lots of organisations and support available.

### Sibs

Sibs supports siblings who are growing up with a brother or sister with any disability, long term chronic illness, or life-limiting condition. They can provide parents with phone support on talking to siblings about diagnosis, as well as activities for explaining disability or illness to siblings.

[www.sibs.org.uk](http://www.sibs.org.uk)  
Tel: 01535 645453  
Email: [info@sibs.org.uk](mailto:info@sibs.org.uk)

### Young Carers

YCNet is a UK-wide interactive site dedicated to young carers, offering information, advice, email support and supervised message boards and chat sessions.

[www.youngcarers.net](http://www.youngcarers.net)  
Tel: 0844 800 4361  
Email: [youngcarers@carers.org](mailto:youngcarers@carers.org)

### Winston's Wish

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

[www.winstonswish.org.uk](http://www.winstonswish.org.uk)  
Tel: 0845 203 0405  
Email: [info@winstonswish.org.uk](mailto:info@winstonswish.org.uk)

### Child Bereavement UK

Child Bereavement UK 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.

[www.childbereavementuk.org](http://www.childbereavementuk.org)  
Tel: 01494 568900  
Email: [support@childbereavementuk.org](mailto:support@childbereavementuk.org)

Many children's hospices also offer specialist sibling support sessions and activities. Contact our Together for Families Helpline Service on 0808 8088 100 for further details.

Thanks are due to the UK charity Sibs for all their help and support in developing this family factsheet.

Together for Families Helpline & Live Chat: 10am-4pm, Monday-Friday

0808 8088 100

[helpline@togetherforshortlives.org.uk](mailto:helpline@togetherforshortlives.org.uk)  
[www.togetherforshortlives.org.uk](http://www.togetherforshortlives.org.uk)



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# Family Factsheets

## The Child Death Review Process (England)

From 1 April 2008 Child Death Review (CDR) processes were made mandatory for Local Safeguarding Children Boards (LSCBs) in England for all child deaths up to the age of 18 years.

The overall purpose of the child death review process is to understand why children die and put in place interventions to protect other children and prevent future deaths.

Following the death of a child, information about the circumstances of their death is collected and summarised from records held by ambulance services, hospitals, community health services, schools, police, children's services and other agencies. A Child Death Overview Panel (CDOP) of doctors, other health specialists and child care professionals consider the anonymous information, to try to ascertain what caused the death, what support and treatment was offered to the child and their family up until the death, and what support was offered to the family after the child died. It is required to consider whether there were any preventable factors that contributed to the death. It decides whether there are any recommendations and actions needed to help prevent similar child deaths in the future.

These recommendations are shared with local health trusts, public health departments, children's services and the police, as well as specialist agencies such as the fire service or traffic authorities in order to influence and improve services and life chances for children and families.

Another part of this process is the rapid response team who may be called upon to support families after a sudden unexpected death. For some families this may involve a home visit by a police officer and health professional, with the aim of gathering information to help understand the cause of death, and to ensure the family are provided with support.

All sudden, unexpected deaths of children must by law be reported to the coroner, who liaises with the police, health care professionals and social care teams in order to assess the situation and decide if a thorough investigation is necessary. Where death is expected, this rapid response will not occur. Some children

will die unexpectedly, but in the context of their illness, this will not be surprising. The rapid response team will need to consider these deaths, but will not need to investigate the circumstances. Where a death is unexpected, but not surprising, a home visit will usually not be necessary.

All the professionals involved in this process should ensure that children will be cared for with respect and dignity at all times. Key aims of the CDOP and Rapid Response team are to ensure that services for families are provided, families are supported and lessons for the future are learnt.

When it is anticipated that a child might die, for example a child discharged from hospital to home or children's hospice for end of life care, it can be helpful for all agencies to be notified in advance so that when the child dies, there is no confusion about the nature of the death.

As a family, you should be made aware of who to contact, so that appropriate support from the CDOP and Rapid Response Team is in place.

If you would like more information about the Child Death Review Process you can call our Together for Families Helpline on 0808 8088 100.



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0808 8088 100

[helpline@togetherforshortlives.org.uk](mailto:helpline@togetherforshortlives.org.uk)  
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# Family Factsheets

Factsheet 18

## Charities for Children with Cancer

This family factsheet provides information about cancer charities that offer support to children who have been diagnosed with cancer, and their families. Thankfully, the majority of childhood cancers respond well to treatment. However for some, curative treatment does not work and palliative care support options will be explored with you to make sure your child can live life to the full.

The following charities offer a number of services including financial and emotional support, practical help and comfort to children living with cancer. Some of these charities also offer respite breaks and accommodation for families during treatment, help dealing with life after cancer and bereavement support.

Please note that this is not an exhaustive list and you can call our Together for Families helpline on 0808 8088 100 for details of charities in your local area or for charities that support children with specific types of cancer.

### The Brain Tumour Charity

The Brain Tumour Charity supports children, young people and their families affected by a brain tumour diagnosis. As well as providing information and support; they also put on Family Fun Days for families to have relaxing days out together, and operate a Family Facebook Group so families can meet other

parents of under 18s with brain tumours. The charity also have a specific dedicated service for teenagers and young adults, which helps connect them with others who are going through similar experiences, as well as offering support and information tailored to them.

<https://www.thebraintumourcharity.org/>

Tel: 0808 800 0004

Email: [enquiries@thebraintumourcharity.org](mailto:enquiries@thebraintumourcharity.org)

### Children's Cancer and Leukaemia Group

Children's Cancer and Leukaemia Group is a leading children's cancer charity hub for childhood cancer through the specialist expertise of their members. They bring together childhood cancer professionals to ensure all children, teenagers and young adults receive the best possible treatment and care. They help young patients and their families with their information resources which are written by experts.

[www.cclg.org.uk](http://www.cclg.org.uk)

Tel: 0333 050 7654

Email: [info@cclg.org.uk](mailto:info@cclg.org.uk)

### CLIC Sargent

CLIC Sargent specialists work in hospitals around the UK offering practical support and advice to children and young people with cancer, and their families. Their website provides avenues of support including a wide range of resources for children, young people, families and professionals, developed in line with the Information Standard quality assurance framework. CLIC Sargent also offer one-off grants to 16 - 24 year olds who have been diagnosed with cancer, to help with the unexpected costs that a cancer diagnosis brings.

[www.clicsargent.org.uk](http://www.clicsargent.org.uk)

Tel: 0300 330 0803

Email: [info@clicsargent.org.uk](mailto:info@clicsargent.org.uk)

### Kids Cancer Charity

Kids Cancer Charity offers a range of support services for children and teenagers affected by cancer which includes those who have cancer themselves, their siblings and those bereaved by cancer. Their support services include play therapy for children and counselling for teenagers to help them communicate their feelings and experiences, thus helping them come to terms with their situation. Befriending support provides someone to talk to face to face, on the phone or via email. Their holiday programme includes: Disneyland Paris, Florida and luxury caravans on Holiday Parks in Wales.

[www.kidscancercharity.org](http://www.kidscancercharity.org)

Tel: 01792 480500

Email: [enquiries@kidscancercharity.org](mailto:enquiries@kidscancercharity.org)

### Lennox Children's Cancer Fund

Lennox Children's Cancer Fund offers support through two main projects – respite breaks in the UK and financial care grants. They also can provide emotional support over the phone or via email.

[www.lennoxccf.org.uk](http://www.lennoxccf.org.uk)

Tel: 01708 734366

Email: [info@lennoxccf.org.uk](mailto:info@lennoxccf.org.uk)

### Teenage Cancer Trust

Teenage Cancer Trust is the only UK charity dedicated to improving the quality of life and chances of survival for young people with cancer aged between 13 and 24. Teenage Cancer Trust funds and builds specialist units in NHS hospitals and provides dedicated staff, bringing young people together so they can be treated by teenage cancer experts in the best place for them.

Teenage Cancer Trust also educates young people in schools about cancer to help improve the speed and quality of diagnosis.

[www.teenagecancertrust.org](http://www.teenagecancertrust.org)

Tel: 020 7612 0370

Email: [hello@teenagecancertrust.org](mailto:hello@teenagecancertrust.org)

### Macmillan

Macmillan Cancer Charity provide information and support from diagnosis, through treatment and beyond. They provide support and information for those with cancer, and their families.

[www.macmillan.org.uk](http://www.macmillan.org.uk)

Tel: 0808 808 00 00

Email: [contact@macmillan.org.uk](mailto:contact@macmillan.org.uk)



### Cancer Research UK

Cancer Research UK fund scientists, doctors and nurses to help beat cancer sooner as well as provide cancer information to the public. They carry out world-class research and develop evidence-based policy to inform Government decision related to cancer and research.

[www.cancerresearchuk.org](http://www.cancerresearchuk.org)

Tel: 0300 123 1022

Email:

[supporter.services@cancer.org.uk](mailto:supporter.services@cancer.org.uk)

### Cancer charities across UK nations

#### Cancer Fund for Children – Northern Ireland

Cancer Fund for Children supports children and young people up to age 24 across the island of Ireland who are living with cancer. It also supports children whose parents have been diagnosed with cancer, siblings and bereaved families. The charity provides practical, emotional and financial support. It also offers residential stays and free therapeutic breaks for families affected by cancer.

[www.cancerfundforchildren.com](http://www.cancerfundforchildren.com)

Tel: 028 9080 5599

Email: [info@cancerfundforchildren.com](mailto:info@cancerfundforchildren.com)

### Children with Cancer and Leukaemia – Scotland

Children with Cancer and Leukaemia is an Edinburgh based charity that runs a drop in centre for children and young people with cancer and parents, providing somewhere to meet and talk with others who have had similar experiences. They also provide other services including a helpline and short breaks.

[www.cclasp.co.uk](http://www.cclasp.co.uk)

Tel: 0131 370 3170

Email: [info@cclasp.co.uk](mailto:info@cclasp.co.uk)

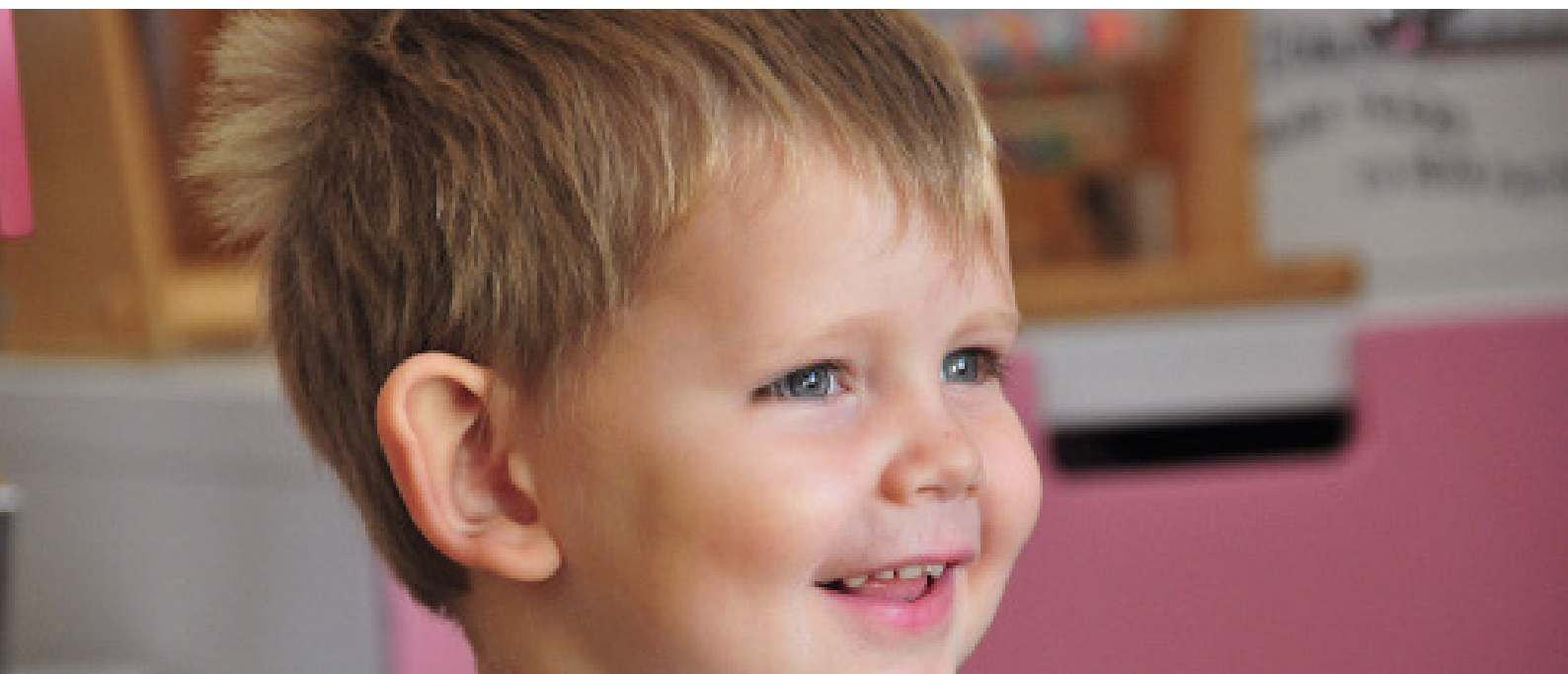
### LATCH – Wales

LATCH Welsh Children's Cancer Charity is a charity based at the Children's Hospital for Wales in Cardiff that provides support for children who are receiving treatment at the hospital. LATCH provides family on-site accommodation free of charge to keep families together during their child's stay in hospital. LATCH funds three dedicated social workers who ensure families receive practical, emotional and financial support.

[www.latchwales.org](http://www.latchwales.org)

Tel: 02920 748 859

Email: [info@latchwales.org](mailto:info@latchwales.org)



Special thanks to Children with Cancer UK for supporting the development of this resource.



Unfortunately, cancer and associated treatments continue to leave many children with life-threatening conditions. There are many organisations that support families at these times, offering support in the home, respite and/or wish or memory making activities. Call our Helpline for more information.

### Children with Cancer UK

Children with Cancer UK is the leading national children's charity dedicated to the fight against childhood cancer. The charity's aim is to determine the causes, find cures and provide care for children with cancer.

The charity funds life-saving research into the causes, prevention and treatment of childhood cancer, as well as innovative welfare projects to provide better care for young cancer patients, and their families. Children with Cancer UK campaigns to raise awareness of childhood cancer to protect more children and to improve the lives of young cancer patients, today and for future generations.

[www.childrenwithcancer.org.uk](http://www.childrenwithcancer.org.uk)

Tel: 020 7404 0808

Email: [info@childrenwithcancer.org.uk](mailto:info@childrenwithcancer.org.uk)

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# Family Factsheets

Factsheet 20

## 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

### In England and Wales

As your son or daughter approaches adulthood, you will need to know about the Mental Capacity Act. This will affect you if you live in England and Wales and are the family carer of someone aged 16 or older who is unable to make some decisions. As your child's nearest relative you know them really well, their likes and dislikes and how they communicate their wishes. However the law says that every adult has the right to make their own decisions wherever possible. Through the Mental Capacity Act every adult is supported to take as much control over their own lives as possible.

The Mental Capacity Act came into force in 2007 – it says important things about how to decide if your son or daughter is able to make their own decisions (described as having capacity). The Act encourages everyone to assume a person has capacity. If they are found to lack capacity the person most

directly involved in their care, such as a family member, will continue to make the decisions in that person's best interests and involve their relative when doing so. Best interests decisions should take into account all the things that the person who lacks capacity would consider important, if they were able to make the decisions themselves.

If your relative lacks capacity to make decisions about their healthcare, the responsibility for making best interests decisions sits with the health care team looking after them unless you have been appointed as a personal welfare deputy. The appointed decision-maker from the health care team must involve your son or daughter in the decision-making process and you can support this by sharing what you know about their preferences and wishes. You will always have a vital role in keeping your son or daughter involved in all the decisions made in their life.

At all times, the five principles of the Mental Capacity Act must be observed:

1. Everyone is believed to have capacity to make decisions unless it can be proved that they do not.
2. All appropriate help and support must be given to a person to help them make a decision before it is decided that they are unable to.
3. A person should not be treated as unable to make a decision just because the decision they make is unwise or unusual.
4. Any act or decision made on behalf of a person who lacks capacity must be done or made in their best interests.
5. Before any act or decision is made, regard must be given as to whether it could be achieved any other way which maintains their basic rights and freedom of action.

It is important to think about these changes in the law as your son or daughter approaches adulthood and in good time so that plans can be made in good time.

A useful guide for families and carers on the Mental Capacity Act is available at [www.gov.uk/make-decisions-for-someone](http://www.gov.uk/make-decisions-for-someone).

### In Scotland

The Adults with Incapacity (Scotland) Act 2000, provides the statutory framework for the medical treatment of incapacitated adults, from the age of 16. You can read a short guide to this Act at [www.gov.scot/Resource/Doc/217194/0058194.pdf](http://www.gov.scot/Resource/Doc/217194/0058194.pdf).

### In Northern Ireland

Decision-making is governed by the common law and the Northern Ireland Assembly is working towards statutory provisions for treating adults lacking mental capacity.

If you have concerns about how the Mental Capacity Act will impact on you as a family and your future decisions, do speak with a member of your care team.



Together for Families Helpline & Live Chat: 10am-4pm, Monday-Friday

0808 8088 100

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# Family Factsheets

## Talking with your child about their life-limiting condition

Coming to terms with the news that your child has a life-limiting or life-threatening medical condition is extraordinarily difficult. If the diagnosis was made recently you may find that things feel overwhelming at the moment. You may be worried about what the future holds for your child and how you can help them to live as happy and “normal” a life as possible. Many parents wish to hold off from telling their child about the prognosis/diagnosis for as long as possible, as they feel that by doing so they are protecting their child. This leaflet offers some suggestions about why it is likely to be useful to begin having these conversations early with your child and how you might go about doing so. It aims to offer you some practical advice about how to do this and address some common worries and concerns parents have.

Why should I talk to my child about their condition?

We know from research that children cope best with the realities of their condition when they are given honest, age appropriate information about their condition and the chance to ask questions. Children have an amazing capacity to understand and cope with their condition, as long as they are told in ways that they can understand and are supported to identify and learn strategies to help them manage.

“Why are they not telling me what’s going on?”

Even toddlers and pre-schoolers can sense when parents and other family members are upset or something is wrong.

“Why am I different?”

As they grow older children will be aware of changes in their condition and make comparisons between what they can do and what their peers/siblings can do. They may also be aware that they look different to other children. If they are not given an explanation they are more likely to worry about these changes and develop their own explanations about what is happening and why people are upset.

## Using the internet

Increasingly, children have access to the internet from an early age. This can lead to problems as they may search for information online which may or may not be accurate. This often leads to them developing worries that they would not have if they could talk to someone and get a clearer understanding about their concerns/questions.

### Why can't I wait until they bring it up?

Children will generally take their cue from you about whether they can talk about their worries. If as parents you avoid the topic, your child is likely to follow your lead. In this situation, children may conclude that it is "naughty" to talk about their condition because such talk upsets adults. Children are also often very sensitive and may feel the need to "protect" their parents and for this reason will not bring the subject up. Unfortunately, this means that they are forced to bottle up their worries and difficult feelings.

As your child gets older there will be an increasing expectation that they are going to play an active role in managing and making choices about their own medical care. If they are not informed about their condition it makes this impossible. By talking with them openly about their condition you are giving them the vocabulary they will need to talk not only with their healthcare providers but also with their peers. This in turn empowers them to manage and address any worries or concerns they have and to develop a growing independence to care for themselves.

## So how do I talk about this with my child?

Children like to learn information from their parents. Generally children do best if they have these conversations with adults they are close to. For this reason, your child's medical team may typically look to you to have these conversations with your child.

Any information shared with your child should be appropriate to their age, level of understanding and experience. Children's understanding of illness may develop as a result of maturity, experience and education. When thinking about talking to your child it is useful to remember that you do not need to tell them everything in one go and in fact doing so is likely to be overwhelming.

### In general, it is likely to be beneficial to think about:

- What do they already know?

Start the conversation by asking children what they already know about their condition. Ask questions to check that they truly understand.

- Do they really understand what they have been told?

Look out for misunderstandings – sometimes it can be hard to judge how much your child understands. Asking them to explain back to you what you have just told them will give you a clearer idea of their understanding.

- Explaining it's okay to talk

Tell them explicitly that they can ask you questions about their condition whenever they want. Do not presume that they know this.



- Being truthful

Answer truthfully any questions they have. If you do not know the answer, then say so. Often children just want to know that you are there and happy to listen.

- Giving the condition its name

Try and use the correct name for the condition your child has. Even for very young children having a name for something is helpful. They will become familiar with the condition over time and bit by bit, understand more about what it means.

- Telling them it's not their fault

When you first start to talk with your child about their condition make sure you explain that their illness is not the result of something anyone did, and that it isn't the type of illness that can be spread to other people. Young children are prone to misunderstandings and children under the age of five or six think in very concrete terms. This means that they can end up thinking that their condition is a result of being naughty or something they did.

- Keeping it in the present

Keep the focus on the day-to-day information they need to know now, particularly when talking with younger children.

- They don't need to know everything at once

Children will quickly feel overwhelmed if you give them too much information. When thinking about discussing your child's condition with them, it can be helpful to remember this is just the beginning of a conversation that you will repeat and expand on over time.

- Increasing information with age

As your child reaches new stages in development and new milestones (both positive ones such as entering secondary school and those associated with the progression of their condition) your child's information needs are likely to increase. If things have changed with their condition or they have upcoming hospital appointments then use these times to check in with them about how they are doing and whether they have any questions.

- Questions for the doctor - giving your child a voice

As your child gets older, ask them if they have any questions for the doctors before an appointment and check if they have any questions afterwards.

- Preparing them well for the future

As your child gets older, it is likely that they will be expected to become more actively involved in their treatment and treatment decisions. It is really important that they are prepared for this and know enough about their condition and its prognosis to make well informed decisions. In adult services, the young person may be asked specific questions about their wishes with regards to treatment in the future and it may be distressing for them if they are not already fully informed about their condition and prognosis. If you have any questions about your child's decision making capacity, do refer to our Factsheet on the Mental Capacity Act.



## What about brothers and sisters?

Brothers and sisters are likely to have questions (and often worries) about their sibling. It can be difficult to judge how much to tell them, particularly if there is a large age gap. Generally speaking, it is important to ensure brothers and sisters do not know more about the condition than the affected child. It is a big responsibility to expect a child to hold on to this sort of information and it is rarely helpful for children to be asked to keep secrets. In general, when thinking about talking to siblings, the guidance above is still relevant. Further information is available on our Understanding Siblings Needs Factsheet.

## Can anyone help me with this?

This is often a really difficult area for parents to think about. You may still feel unsure about how to go about it or when. If you would like further help thinking about this or specific advice for your family's situation, your child's consultant paediatrician (or community children's nurse, if you have one) can assist you with this. Some teams also have access to specialist psychological support that may help too. Children's hospices also offer this support to families. If you want to find out where your local

hospice is, please refer to our Children's Hospice Factsheet or call our Helpline on 0808 8088 100.

## Glossary

Prognosis – the likely course of a medical condition

The Family Factsheets mentioned above can be found at [togetherforshortlives.org.uk/familyresources](https://togetherforshortlives.org.uk/familyresources)

With grateful thanks to Dr. Linda Deeley, Consultant Clinical Psychologist, Compass Team, Musgrove Park Hospital, Somerset and Dr. Sadie Thomas-Unsworth, Specialist Clinical Psychologist, Psychological Health Services, Bristol Children's Hospital for writing this factsheet.



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# Family Factsheets

## When a child dies – questions parents ask

This factsheet has been developed to support families and carers preparing for the death of a child. The death of a child is devastating, and every experience is unique. There may never be a good time to approach this and talk about a child's end of life. But having information about what to expect and knowing where to go to for support can help families prepare and ensure that they are able to spend time together as a family. Families will need time to explore their wishes and access good support from health and social care professionals caring for their child.

Here are some responses to some questions often asked by parents. It's not intended to replace any face-to-face support offered by a child's care team, but may act as a useful prompt to inform families.

### **How will I know that my child is facing the end of their life?**

When a child with a life-limiting or life-threatening condition is dying, it can be difficult to recognise when they are moving towards their end of life. Their symptoms can fluctuate and it can be difficult to know when a deterioration in their condition will result in the child's death. This is a very distressing time for families and means that end of life care for children can be complex for the care team around the child and for the family to manage. It's very difficult to predict what will happen next. Even if a child is thought to be at their end of life, it's important to have multiple plans in place – an end of life plan and a plan to ensure the ongoing care of the child or young person in cases where they survive. Doctors and nurses often refer to this as parallel planning. Honest, open and sensitive communication between the family and their child's care team is vital. Ideally, there should have been open communication over time, before the last weeks, days or hours of the child's life. These conversations should enable plans to be made in advance so that families have realistic expectations of what may happen.



### **What about our wishes for our child's end of life?**

Professionals caring for seriously ill children often talk about an Advance Care Plan or an end of life plan. Sometimes these plans have other names, for example an end of life wishes document.

An end of life plan captures the discussions between families and professionals about a child's care and brings together a family's wishes and the needs of their child into a practical plan relating to care at the time of death. Having this plan in place ensures the best quality of life for the child, and the best possible death. If you are not sure about what plans are in place, do talk to those professionals who are caring for your child.

### **Do we have a say on where our child dies?**

Every child's needs will be unique, and choices about where end of life care will be provided depends on many factors

including the child's individual care needs, the family's preferences and doctor and medical team's opinion about treatment, and where the care can be delivered safely. At all times professionals will ensure that decisions taken are in the child's best interests and that the child's welfare is central to all considerations. However, the family's preferred choice of the place of their child's end of life care may be limited by local resources and the child's condition.

It's important that when the time comes, loved ones are close by, with privacy and space, whether the death occurs in hospital, at home or in a children's hospice.

Options for where end of life care may take place should be discussed as part of the end of life planning. It is important that families discuss their wishes with the team caring for their child. Every effort should be made to support the family (parents, siblings, grandparents and other extended family) to spend time together, caring for

their child and building memories that they can cherish in the months and years to come.

### **What happens after their death?**

Families need to have time and privacy with their child in the hours and days following their death. They need to know that almost anything they decide is possible, including moving the child's body to another place. There are special cooling mattresses that can be used to enable a child's body to be taken home. Some families may choose to use the 'cool room' at a children's hospice. It's important for families to explore what's possible with the team caring for their child. It can be helpful for families to care for their child's body during the hours or days after their death. This may be the only time when they feel that they can truly 'parent' their child, free from medical equipment, tubes and monitors. Some families may wish to take a lock of their child's hair, make hand or footprints and some like to take photographs of their child at peace.

Some families will want to carry out cultural rituals or have spiritual wishes which are individual to them. These needs should be discussed and the family supported to achieve these important rituals which can help to bring healing and closure.

Whether a child's death was expected or not, it is important to understand why children die. Following the death of a child, a Child Death Review is undertaken when information about the circumstances of their death is collected and summarised from records held by ambulance services, hospitals, community health services, schools, police, children's services and other agencies.

Discussions about post-mortem may need to take place and families will need sensitive and clear information to help them with any decisions about this. There are a number of reasons for a post mortem to be carried out, whether this is the choice of the family, a coroner's request or a request from professionals caring for the child.

### **What support will be available for bereaved families?**

Bereavement is unique to every individual. Families start to grieve from the moment they find out their child is likely to die young and they will need bereavement support throughout their child's life, death and beyond.

No one knows how they will feel or react after the death of a child. People describe a 'rollercoaster' of emotions, ranging from numbness to furious anger, profound sadness to perhaps a certain relief. Some parents may wonder if they will ever feel positive or happy again. It is important for families to trust their own instincts about what is right for them as individuals. Other family members and friends may experience or express grief differently, which can be difficult. Children grieve in different ways to adults and the bereavement needs of brothers and sisters and other children should be recognised and supported.

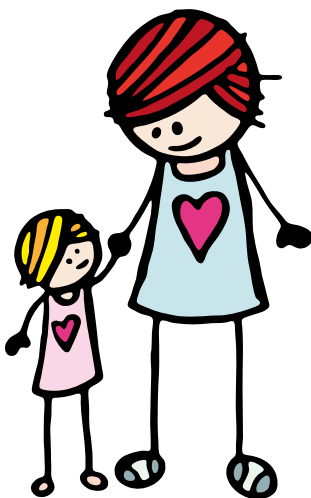
Children's hospices offer bereavement support to families and there are lots of specialist bereavement charities. Visit Together for Short Lives' website or call the Helpline to explore what support is available locally.



## Where can I find more information?

Together for Short Lives has produced a booklet for families called "Caring for your child at end of life".

There is further information to support families and carers, including a Family Companion and a range of factsheets. You can find them on the family section of our website.



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# Family Factsheets

## Factsheet 23

# Transition to adult services

Advances in medicine and technology mean that more children with life-limiting or life-threatening conditions are living into adulthood, often with complex and unpredictable health needs.

It can be a very worrying time for parents and carers as their child moves from familiar children's services to new adult services and is expected to take on decision-making responsibility for themselves. This factsheet aims to help parents to think about the different elements of transition that need to be planned for and to provide tips to help the process feel as smooth as possible.

## When does transition start?

Transition is not a single event, but is a gradual process of supporting a young person and their family through their teenage years and into adulthood, building up their confidence and ability to manage the care and support they need. The process should ideally begin around the age of 14 years, in England tying in with the Year 9 school annual review. A good transition should build on the young person's strengths and wherever possible work with the young person themselves to plan for how they can meet their aspirations in life.

It should also involve you as parents/ carers and support you to understand the changes in your rights as your child reaches

the legal age of adulthood. The legal age of becoming an adult is 16 years in Scotland but 18 years across England, Northern Ireland and Wales. Transition is a long process and young people often still want the support of their parents in making decisions. The age at which your child enters adult services is likely to vary depending on where you live and your circumstances.

Each service may have a different age when they transfer care from children's to adults. Some children will access aspects of adult health care before they are 18, while others may still be supported by paediatric services after their 18th birthday. Ask each service what age the transfer will take place, who is taking over and how they are going to introduce you to the new service.

## Making decisions and the Mental Capacity Act 2005

When your child reaches the age of adulthood, statutory agencies will consider them as an adult, regardless of their mental capacity. If your child has the capacity to make decisions for themselves, it is crucial that as parents, you encourage them to become more independent, so that there is a move from parent-led to individual-led decision making. It is important that you are aware of the changes to your role in decision-making for your adult child. For decisions about health and welfare, the Mental Capacity Act 2005 (England and Wales) applies to everyone over the age of 16 years. For further information, read our factsheet on the Mental Capacity Act.

[www.togetherforshortlives.org.uk/families/information\\_for\\_families/4980\\_the\\_mental\\_capacity\\_act](http://www.togetherforshortlives.org.uk/families/information_for_families/4980_the_mental_capacity_act)

## Making plans

During transition, young people should be supported by staff working across agencies so that they can plan for the care that they will need from health, social, education, housing and employment services. Many young people living in England will already have an Education, Health and Care Plan (EHCP) in place that sets out the support that they will need across these agencies. The EHCP assessment process gathers information from all those supporting your child to inform how the desired outcomes can be best met. The EHCP should be agreed in partnership with yourselves and should detail costs and timescales. This plan follows your child as they change services and should be reviewed should your circumstances change.

## Standards in transition

Throughout the transition process, five key standards should be met to ensure that all young people are supported to achieve a good transition.

<b>Standard 1</b>	Every young person from age 14 should be supported to be at the centre of preparing for approaching adulthood and the move to adult services. Their families should be supported to prepare for their changing role.
<b>Standard 2</b>	Every young person is supported to plan proactively for their future. They are involved in ongoing assessments and developing a comprehensive, holistic plan that reflects their wishes for the future.
<b>Standard 3</b>	Every young person has an end of life plan which is developed in parallel to planning for ongoing care and support in adult services.
<b>Standard 4</b>	Children's and adult services are actively working together to ensure a smooth transition.
<b>Standard 5</b>	Every young person is supported in adult services with a multi-agency team fully engaged in facilitating care and support. The young person and their family are equipped with realistic expectations and knowledge to ensure confidence in their care and support needs are being met in the future.

Scotland has The Principles of Good Transitions 3, a framework to inform, structure and encourage the continual improvement of support for young people with additional needs between the ages of 14 and 25 who are making the transition to young adult life.

<https://scottishtransitions.org.uk/summary-download/>

## Health

For young people with complex and life-threatening health conditions, their transition to adulthood will need to be underpinned by strong partnership working between children's and adult health services. This may involve community, hospital and hospice care teams. From the age of 14 years, healthcare professionals should begin to discuss with you and your child the plans for transferring to adult healthcare. It is helpful if your general practitioner (GP) is involved as they can be a key point of contact even if they have not had much contact with your child up to this point.

Healthcare professionals will also change; with your GP, Continuing Health Care or District Nursing teams playing an increasingly significant role. Your child should be introduced to new staff and agencies as part of the transition process and you should have opportunities to discuss what changes to expect with them.

People aged 14 and over who have been assessed as having moderate, severe or profound learning disabilities, or people with a mild learning disability who have other complex health needs, are entitled to a free annual health check which can be arranged through your GP practice.

There are likely to be some services that have supported you throughout your child's life that may not be available to you as they become an adult. For example, if you have used a children's hospice, this may not be available once your child reaches 18. Every children's hospice is different and will have a different upper age limit – so do check. Whilst more and more adult hospices are beginning to play a role in supporting young people, it is important

to remember that while they can offer a great range of support, not all of them are able to offer the range of services such as short breaks or some of the therapies for young people with very complex health needs that you may be used to.

It is really important to have plans in place which enable the transition process to remain focussed on your child's wishes. Having parallel plans will help meet the needs and wishes of your child should their health remain stable but also for times when their condition may deteriorate. These should be reviewed regularly. It is also important to check that any documented wishes for your child's treatment are in a format that is accepted by adult services and that copies are given to the GP and uploaded to the local ambulance service. This is important in any emergency as the ambulance service will actively treat unless written and signed instructions are seen.

## Social care

For many young people, their social life and relationships with friends are very important and they will need support to enable them to lead the social life that they want. Your local adult social care team are responsible for ensuring that a care package is in place. The care plan defines exactly what your child needs in the way of care, services or equipment to live their life in a dignified and comfortable manner.

You may also find that there will be changes to the grants or benefits that you receive. It is possible that income coming into your household and other non-finance benefits (such as housing and transport) will be

affected. However, you will have new rights under the Care Act which may entitle you and your child to new benefits.

## Education

There are various choices available to young adults after 16 years of age and your son or daughter may want to consider one of the following routes:

- Full-time education, such as school, college or home education
- Work-based learning, such as an apprenticeship
- Part-time education or training, if they are employed, self-employed or volunteering for more than 20 hours a week.

Specialist colleges offer tailored curricula for young adults with profound and multiple learning difficulties (PMLD). Further information is available on the Natspec website. <https://natspec.org.uk>

## Housing

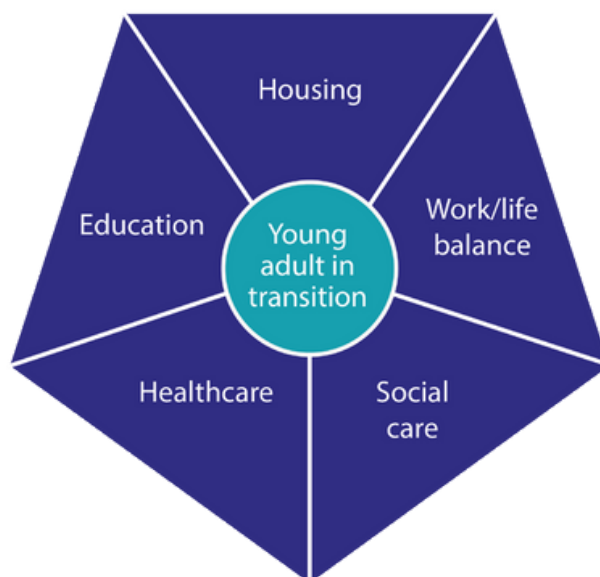
There are a range of options to enable your son or daughter to live in the setting that best suits them and with the right kind of care package. This might be at home with you, at university, in residential/supported living or living independently.

If you live in England, your local authority will publish its Local Offer which should contain information about different housing options. It should also detail where to get financial and other support (such as a personal assistant, assistive technology or modifications to a home) and more detailed advice on accommodation and support.

## Employment

As your child moves into adulthood they may want to enter work or find other opportunities such as volunteering or mentoring. There are a range of courses at colleges and work-based learning providers who can offer opportunities to develop work and vocational skills. For further information about supported employment visit the British Association for Supported Employment website. [www.base-uk.org](http://www.base-uk.org)

What is important is that all these services, in the children's and adult sector work together to ensure that there is a smooth handover process.



## Settling into adult services

You should have confidence that your child has a care package that allows them to live their life to their maximum potential and which meets their physical, emotional and social needs. Their needs will change over time, so it's important that you work closely with professionals to adapt the package to best meet their needs and enable them to reach their full potential as adults.

## National variations

### England and Wales

Eligibility for adult continuing health care and adult social care funding must be established by the appropriate adult team. This can be from age 17 years upwards, but transfer will only happen at 18 years.

Preparing for Adulthood is a programme funded by the Department for Education to provide expertise and support to local authorities and their partners to improve the transition of young people with special educational needs and disability (SEND) as they move into adulthood. The Preparing for Adulthood website hosts a wealth of information and resources.  
[www.preparingforadulthood.org.uk](http://www.preparingforadulthood.org.uk)

Each local authority in England and Wales has a legal requirement to provide a local resource for children and young people from birth to 25 years, with special needs. To find out more about the services available to support you, search for 'Local Offer' on your local authority website.

The Council for Disabled Children has produced a factsheet which explains the two pieces of legislation which impact on disabled young people – The Children and Families Act and the Care Act.  
<https://councilfordisabledchildren.org.uk/help-resources/resources/children-and-families-act-and-care-act-factsheet>

### Scotland

The Additional Support for Learning (ASL) Act should be followed as this sets out the processes and timescales for transition. In Scotland, the legal age of an adult is 16 and at this point it is important to assess a young person's capacity to make decisions about their life, including their care and treatment. The Adults with Incapacity Act (Scotland)

gives another person the legal power to make decisions on the adult's behalf.

[www.gov.scot/Topics/Education/Schools/welfare/ASL](http://www.gov.scot/Topics/Education/Schools/welfare/ASL)

The Scottish Transitions Forum hosts information for those living in Scotland and houses the Principles of Good Transition 3 document.

<https://scottishtransitions.org.uk/>

[http://scottishtransitions.org.uk/blank/wp-content/uploads/2017/01/complete-POGT3\\_A4-version.pdf](http://scottishtransitions.org.uk/blank/wp-content/uploads/2017/01/complete-POGT3_A4-version.pdf)

### Northern Ireland

In Northern Ireland, 'A Strategy for Children's Palliative and End of Life Care 2016-26' (Department of Health 2016), recommends that every child with palliative care needs should have an agreed comprehensive transition/discharge plan involving the hospital, community services and the family as set out in 'The Integrated Care Pathway for Children with Complex Physical Healthcare Needs', (DHSSPS 2009). A transition plan should be agreed at least six months prior to the planned transition.

## Helpful resources

Below are a number of resources and organisations that can help you plan for your child's transition but if you have further questions, please email:

[info@togetherforshortlives.org.uk](mailto:info@togetherforshortlives.org.uk)

or call 0808 808 100.

### Moving to Adult Services: What to Expect

An interactive guide for young people making the move to adult services.

[http://www.togetherforshortlives.org.uk/assets/0001/5480/TfSL\\_Moving\\_to\\_Adult\\_Services\\_Guide\\_\\_FINAL\\_.pdf](http://www.togetherforshortlives.org.uk/assets/0001/5480/TfSL_Moving_to_Adult_Services_Guide__FINAL_.pdf)

### Stepping Up

A guide for professionals aiming to ensure that all young people have a positive experience of growing up and making a good transition to adult services.

[http://www.togetherforshortlives.org.uk/assets/0001/0439/TfSL\\_Stepping\\_Up\\_-\\_Transition\\_Care\\_Pathway\\_6.pdf](http://www.togetherforshortlives.org.uk/assets/0001/0439/TfSL_Stepping_Up_-_Transition_Care_Pathway_6.pdf)

### My Adult, Still my Child

Outlines the legal implications of the Mental Capacity Act 2005 (England and Wales) and the changing role that parents have in decision making.

<http://myadultstillmychild.co.uk>

### Decision Making Toolkit

A resource designed to be used in partnership with young people to support them to make their own decisions and to participate in decisions made on their behalf.

<https://councilfordisabledchildren.org.uk/help-resources/resources/decision-making-toolkit-0>

### Carer's assessments

Carers UK provide factsheets and information on caring for either children or adults across each nation of the UK.

<http://www.carersuk.org/help-and-advice/practical-support/getting-care-and-support>

### Benefits

The following organisations provide up to date advice on benefits:

### Scope

[www.scope.org.uk](http://www.scope.org.uk)

### Turn2us

[www.turn2us.org.uk](http://www.turn2us.org.uk)

If your child would like you to act on their behalf on matters concerning their future care, this overview of Deputyships and Lasting Power of Attorney may be helpful.  
[www.gov.uk/power-of-attorney](http://www.gov.uk/power-of-attorney)

We would love to hear your feedback on this factsheet. Your comments will help us improve our offer to families caring for children with life-limiting or life-threatening conditions. Please complete this survey.  
<https://www.surveymonkey.co.uk/r/transitionFF>

Together for Families Helpline & Live Chat: 10am-4pm, Monday-Friday

0808 8088 100

[helpline@togetherforshortlives.org.uk](mailto:helpline@togetherforshortlives.org.uk)  
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