



Valuing short lives

A parent's guide: Making critical care choices for your child



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

Who is this leaflet for?

ACT has developed this leaflet for parents, carers or legal guardians who care for a child with a life-limiting or life-threatening health condition. It has been written to support you whilst you are thinking about the critical care options for your child.

You will have been given this leaflet because the healthcare team responsible for your child's care is concerned that your child may be approaching the end of their life. Important discussions and decisions will now need to be made and the healthcare team will want to ensure you understand what is happening and to explore your views, values, beliefs and wishes.

This leaflet is designed to give you information, signposts and prompts to help you understand the challenges that everyone who is looking after your child faces and to help you make informed choices and decisions about treatment and critical care choices for your child.

When should I read this leaflet?

You might be reading this leaflet because:

- Your child's diagnosis has just been made or their prognosis may have changed.
- Your child's doctor has told you that there have been changes or a deterioration in your child's health.
- Your doctor might say that the treatment your child is receiving is no longer working, or that the treatment might be thought to cause more harm than benefit to your child.
- Your doctor may say that further treatment may be unbearable for your child.
- There may be no treatment available for your child's condition.



- Your doctor may have asked you to think about particular care choices, for example your thoughts on not continuing with specific life-sustaining treatment or whether you want the medical team to resuscitate your child if their heart stops beating.

These decisions will be very difficult for you and your family. We hope this leaflet will provide you with some tools and information to help you think about your child's care options.

Your child's best interests

Everyone involved in your child's care will be trying to act in their very best interests. While ultimately, the child's best interests may be to die peacefully, with respect and dignity, the challenge is to be sure that this is indeed in the child's best interests. Your personal views are an essential element to the provision of end of life care for your child. The doctors may be able to give you their own professionally informed opinion, but the value of your opinions cannot be over-emphasised.

How this leaflet is structured

ACT hopes that this leaflet gives you the information you need to start thinking about your choices, and to help you explore options with your child's doctor. We have included some of the key things that you need to think about and some of the questions that you can ask the professionals who are caring for your child.

We have written this leaflet in a question and answer format. We have tried to include some of the questions or concerns that you might have at this time. We have also included a glossary of terms at the end of the leaflet to help you make sense of some of the phrases or terms that doctors and other healthcare professionals may use. If you have further questions or would like to talk to someone from ACT, please call our Family Helpline on 0845 108 2201 (open weekdays 9am to 5pm) or visit the family help section on our website: www.act.org.uk/families

Everyone is different and will have their own personal beliefs about what is right for their child.

What are critical care choices?

Critical care choices are the choices that you and the medical team will make together towards the end of your child's life. Critical care choices will be different for every child.

You can ask your doctor to explain the specific options for your child. They may include your views on resuscitation if your child's heart stops beating, whether you want intensive care to continue, or whether you are ready for invasive treatment to stop. (By 'invasive' treatment we mean the types of treatment that may be administered using technical medical equipment, tubes or a cannula, or perhaps a ventilator to assist breathing.) If your child is on a ventilator or has a breathing tube, your doctor may talk to you about removing this and helping your child to breathe in a less intrusive way, or to allow a more natural death if this is the agreed choice.

What is an end of life care plan?

An end of life care plan is a document that outlines your and your child's wishes for their end of life care and death.

Although it will be painful to start thinking about this, many parents tell us that forward planning for end of life care can make them feel more in control of the situation, and make time to create positive memories during the last few days.

It can include what type of care you would like your child to receive, how pain and symptoms will be managed, where you would like your child to die, and your thoughts on organ donation. An end of life plan can also include your critical care choices to help ensure that your wishes are understood. Some families also like to think about wishes for how their child's body is cared for after their death or plans for their child's funeral or special ceremony.

ACT has developed an information sheet about end of life planning that you can download from our website: www.act.org.uk/familyfactsheets

The professionals that are supporting you and your child can help you to think about your options and writing your plan. Once you have written a plan it is best to share this with your doctor, so they can share it with all the professionals involved in your child's care. As time progresses you may change your mind about what is right for your family. You can do this at any time.

The professionals that are supporting you and your child can help you to think about your options.

Will my child carry on getting the care and support they need?

No matter what care options you and your doctor decide on, your child will receive the care and support they need from their doctor. This will not stop.

Comfort care and symptom control are of paramount importance. The doctors and nurses who care for them will want to ensure that they are comfortable, as pain free as possible and have the respect and dignity they deserve.

When doctors talk about palliative care, not continuing with treatment or allowing someone to die naturally, it can sound frightening. But none of these approaches mean abandoning your child's care, pain and symptom management or comfort.

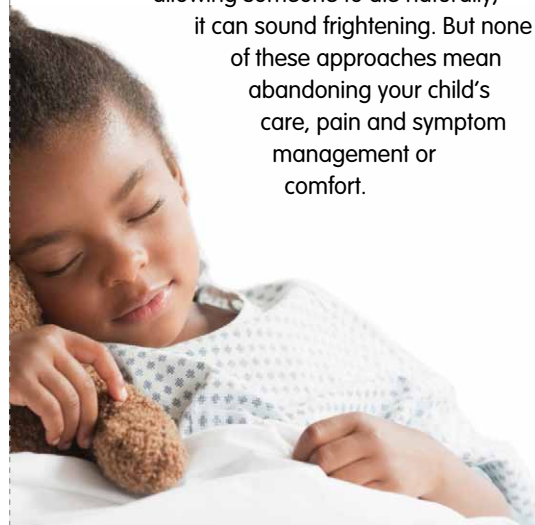
Making an informed choice

For you to make an informed choice you will need to understand all the different care options for your child.

Ask your doctor or consultant to explain all the options to you, and don't be afraid to ask them to repeat or explain anything that isn't clear. There may be other possibilities that you would like to explore with them. Your specific care options will be very personal to your child's particular condition and prognosis. Your doctor or consultant may suggest a specific care plan that they think will be in the best interests of your child, but it is your right to explore other options if you do not agree.

As well as having a say in the type of medical care your child receives, it might also be possible to explore where your child receives their care. For example if your child is in hospital, perhaps in a neonatal unit or intensive care/therapy unit, and depending on your care choices, you may be able to arrange for your child to be moved home, to a children's hospice, or to a quieter hospital ward or side-room. Talk to your doctor about your child's place of care if this is something that you think you would like to change. Not all doctors will think to explore different options for your child's place of care or place of death. Don't be afraid to raise this with your doctor and ask them to support your wishes and explore all the options.

Ask your doctor to explain how you can reach these decisions together. Don't feel rushed, and take time to seek other professionals' advice if you think this will help.



Do I have a choice in my child's critical care? ?

Parents and those with parental responsibility for young children have a right to be included in any decision-making process that will affect their child.

However, the decision-making process is complex. No single opinion should determine the final decisions about your child's care, and the scope of parental authority regarding healthcare decisions is not clear, although the senior clinician is ultimately responsible.

The healthcare professionals will guide you as to the range of choices available and want to work with you and accommodate your wishes as long as all the healthcare professionals are in agreement and the care plan is seen as beneficial to your child. Usually doctors and parents can reach consensus when considering what is best for the child, but sometimes, as a last resort when doctors and parents disagree, the case has to be resolved in Court.



Parents and those with parental responsibility for young children have a right to be included in any decision-making process that will affect their child.

Your child's doctor will also want to ensure that your child is involved in these decisions as much as possible, depending on their age and level of understanding. The legal authority of the child's opinion is extremely complex but the governing bodies of the medical profession recommend a child's involvement is in line with an assessment of their capacity to understand. The more they understand about their health, the greater authority of their views. However, the ability to understand has many influences and is extremely difficult to assess. The law says that a 'competent' patient over the age of 18 in England, Wales and Northern Ireland, or 16 in Scotland, is to be treated as an adult where their views are decisive. If you are worried about this or need to clarify matters, please ask your doctor for information and guidance. They should be able to guide you here.

You can also read the guidance used by doctors at the General Medical Council website www.gmc-uk.org/guidance/ethical_guidance/children_guidance_index.asp. (See 0-18 years: guidance for all doctors; General Medical Council.)

Making the most of precious time with your child i

As parents you will want to ensure that you spend as much quality time with your child as you can, especially if they are approaching their end of life.

It is sometimes difficult to do this when your child is in an intensive care setting, or has a lot of technical equipment surrounding them, such as a ventilator or a breathing tube. However, you should continue to help with your child's care: you may be able to help bathe your child, hold them or even lie next to them. The healthcare staff may be able to arrange for you to spend some personal family time together. Talk to your child and touch them; even if they appear unconscious, they may be able to hear and feel you.

You can ask your doctor or consultant if there are different ways to care for your child or if there are other treatment options that will enable you to be closer with your child. For example some treatments, such as antibiotics, could be given orally or via a tube rather than intravenously. This might make it easier for your child to come home.

Thinking about how you and your family can make the most of precious time with your child may help you to decide the best care plan for your son or daughter.

It is important that these decisions are made in your time – not in a time frame that suits your doctor.

Talk to your child and touch them; even if they appear unconscious, they may be able to hear and feel you.

I feel pressurised to make a quick decision about my child's care i

You should be given the time you need to think about such important issues. Sometimes it can feel pressurised, and there can be occasions when changes in your child's health will require a very quick decision.

You are not alone, and your doctor will want to work with you so you can make decisions together.

Ideally you should be given enough time to come to terms with what is happening and take in all the possible care choices. If you need more time, or more information, explain this to your doctor.

You may also want time to talk to your child and other family members about their wishes.

It is important that these decisions are made in your time – not in a time frame that suits your doctor.

How are critical care decisions made?



Critical care decisions are ideally made between the parents and the medical team. Your child may also want to be involved in making these choices.

Making critical care decisions that are right for your child will always be difficult. Usually the best decisions and best outcomes are those where the parents and professionals can reach agreement. This may not be possible, but your doctor will want to work towards this. The professionals who care for your child will base their advice on what they consider to be in the best interests of your child.

It's really important that you reach a decision together that you feel happy with. You should not feel rushed or pushed into a decision. The hope is that you feel supported and involved in the decision-making process, and understand the reasoning behind why such decisions have to be made and how they were achieved.

How do I talk to my child?



You may be anxious about telling your child what is happening, or wonder how you will ask your son or daughter what they want. Try not to worry about how to approach this.

Lots of parents say that this happens quite naturally. The best way is to spend time with your child; by being with them and talking to them you may easily sense

I feel very alone making these decisions



No one expects you to make these decisions alone. The professionals who care for your child will want to support you and work in partnership with you to make the best decisions.

If you need support, please tell your consultant, doctor or one of the nursing staff how you are feeling. You may also want to talk to those professionals who know you and your child the best. This might be someone at your local children's hospice or your family GP. But you should be aware that some professionals might have different views and this can be confusing.

You may also want to discuss your thoughts with other family members and friends, or with religious or spiritual leaders. You may also like to talk to your hospital chaplain.

how they are feeling and what they want to happen.

It may be that your child is unconscious and you might find it hard to communicate with them. Even if they appear unconscious your child may know that you are with them and hear what you are saying.

Making realistic choices and decisions



Every child's care needs will be unique. The choices about where, how and what kind of treatment or care your child receives will depend on your individual circumstances.

For example it may be hard for some children to go home or to a children's hospice for their care.

Some of the choices that you will want to think about will be very painful. You may reach very hard decisions about stopping intrusive treatment, such as ventilated breathing or for your child not to be resuscitated. Parents who have made similar choices often say that these are made out of love for their child, at a time when they know their son or daughter has been through enough intervention, and they want them to have a natural death.

The best starting place is to ask your doctor or consultant for as much information as possible about the realistic options and choices for your child.

We have included some prompts that you might find useful when you are talking to your doctor or healthcare team.



The best starting place is to ask your doctor or consultant for as much information as possible about the realistic options and choices for your child.

- Don't be afraid to ask doctors to explain things in more detail, or go through things several times. Tell them if you don't understand some medical terms or what different types of care mean.
- Does my child have to stay in hospital? What about going home, or staying at a children's hospice or finding a quieter ward?
- Will my choices for treatment impact on whether my child can come home?
- Ask your doctor to explain different options for managing symptoms such as pain and the different ways they can do this.
- If you do decide to care for your child at home, ask your doctor what to do if you decide you can't cope and need to come back to hospital.
- What are the treatment and critical care options?
- Whatever you choose – ask the doctor to explain the implications for all your family.
- What do I do if my child dies at home?

You may be asked to sign a consent form saying your child is not to be resuscitated (DNR), should their heart or breathing stop. This may seem a negative approach and that people are giving up, but in fact, it is a positive and active approach to your child's care. It will help to ensure that your care plan will be followed, and that your choices will be respected.

Your doctor may also ask you about taking your child off their ventilator and removing the breathing tube (this process is called 'extubation'). If you decide together that this is right for your child, your doctor can explain that it would be carefully planned and timed with you and your family. This may be able to be done at home or at another place of your choosing. You may be told that your child could die very soon after, but no one really knows. Some children may live for some time following this procedure – this could be minutes, hours, days or sometimes longer. Therefore, it is important that your doctor talks to you about what will happen after the ventilator and tube are removed – whatever happens to your child. Some doctors call this process 'parallel planning' – planning for both eventualities.

There may well be other questions or things you do not fully understand. Do not be afraid to ask. Now is the time to do this.

You may also want to write your questions down, so you do not forget.

How will all the professionals who care for our child know about our wishes?

When you have made decisions about your child's care options, or have written an end of life plan, it is important that you discuss this with your doctor.

When you and your child's doctor have agreed on a plan, your doctor should record this and share it with all the professionals that are involved in your child's care. It's a good idea to ask your doctor if they have done this. Make sure that you have your own signed copy that you can keep with you.

How can I tell friends and family about our choices?

It can help to share your choices and plans with close friends and family members so they can support you throughout your child's journey.

It helps to be aware that some people may not share your views, but you should remember that this might be because they have not had the same experiences as you. If your child has sisters and brothers you will want to help them to understand what is happening. Although talking to your children can be painful, it will help them to understand what is happening. Try to be as open and honest and to explain what is happening to their brother or sister. Keeping your children involved can help them to accept and understand things later on.

What if I change my mind?

We hope that you will make choices that are right for you, your child and all your family. But sometimes events can happen that make you change your mind about your child's care.

As time goes by you may feel differently about your child's treatment or about

where you would like your child to receive their end of life care.

If this happens to you, don't be afraid to talk to your child's doctor. They will want to ensure that you are still happy with your decisions, and can explore your thoughts on your child's care.

As time progresses you may change your mind about what is right for your child and your family. You can do this at any time.

What if my doctor and I do not agree?

Hopefully you and your doctor will be able to reach a decision that you are both happy with. The doctor and the healthcare team should be there to support your decision as long as they believe your care choices are in the best interests of your child.

However sometimes it is hard to reach agreement. If you and your doctor cannot decide on a care plan on which you both agree there are other ways in which you can resolve things and achieve consensus through mediation.

Your first option is to seek a second opinion. Your consultant should be able to arrange for an independent second opinion. They can arrange for all the medical files and information about your child's medical history to be shared with an

independent consultant. The independent consultant may wish to see you and your child, but this may not be necessary.

The independent consultant will assess your child's condition and prognosis and will look specifically at why you cannot agree on a care plan. It is their role to ensure that the care plan is in your child's best interests. They will want to help you all reach a decision that you can agree on.

On rare occasions parents and the medical team still fail to agree. Prior to asking the Court to resolve matters, the hospital may have an ethics committee, which comprises of a range of independent medical and ethical experts and lay personnel. Their role is to review your child's care options and make recommendations.

Don't be afraid to ask for help



There are lots of professionals and organisations that you can ask for help and support.

As well as the medical team, you might want to talk to friends, family or your spiritual or religious leaders. You may also find it helpful to talk to your hospital chaplain.

ACT's Family Companion



ACT has developed a dedicated book called the *Family Companion*.

It's been designed to support parents and family members who care for a child with a life-limiting or life-threatening condition throughout their child's journey, from diagnosis to their end of life. You can order a free copy by calling ACT on 0845 108 2201 or you can download it from our website: www.act.org.uk/companion



ACT wants families to have real choice in their child's care throughout their whole lifetime – no matter how short.

How ACT can help you



ACT is the UK wide charity working to achieve the best possible quality of life and care for every child who is not expected to reach adulthood, and their family.

ACT wants families to have real choice in their child's care throughout their whole lifetime – no matter how short.

ACT produces lots of resources and factsheets to provide you with information and support, including a regular family newsletter. To subscribe to the newsletter, or to download other helpful resources, visit www.act.org.uk/families. You can also email us at info@act.org.uk.

You can search our online database of services to help you find the support you need at www.act.org.uk/findhelp, and there's always our Family Helpline 0845 108 2201 if you have any questions, or don't know where to turn.

Who else can help?

We have included a small list of key organisations that may be able to help you. You can also download a comprehensive list of useful organisations at ACT's website: www.act.org.uk/findhelp

Bliss

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

www.bliss.org.uk

Tel: 0207 378 1122

Helpline: 0500 618140

Email: information@bliss.org.uk

Children's Hospices UK

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

www.childhospice.org.uk

Tel: 0117 989 7820

Email: info@childhospice.org.uk

Contact a Family

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

www.cafamily.org.uk

Helpline: 0808 808 3555

Email: info@cafamily.org.uk

The Child Bereavement Charity

The Child Bereavement Charity is a charity that supports families and educates professionals both when a child is dying or has died, and when a child is bereaved of someone important in their life.

www.childbereavement.org.uk

Tel: 01494 568900

Email: enquiries@childbereavement.org.uk

Childhood Bereavement Network

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

www.childhoodbereavementnetwork.org.uk

Tel: 0207 843 6309

Email: cbn@ncb.org.uk

The Child Death Helpline

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

www.childdeathhelpline.org

Helpline: 0800 282986

Email: contact@childdeathhelpline.org

The Compassionate Friends UK

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

www.tcf.org.uk

Helpline: 0845 123 2304

Email: info@tcf.org.uk

The Natural Death Centre

For independent funeral advice – dealing with death naturally.

www.naturaldeath.org.uk

Helpline: 01962 712 690

Organ Donation

National Tissue Donor Referral Centre (England and Wales).

Tel: 0800 432 0559

Scottish National Blood Transfusion Service Tissue Services (Scotland).

Tel: 0131 536 5751

Northern Ireland: Local organ donation team.

Tel: 0300 123 1208

Northern Ireland: Regional Transplant Coordinator.

Tel: 0289 032 9241

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

Helpline: 08457 909090

Email: jo@samaritans.org

Sands

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

www.uk-sands.org

Tel: 0207 436 7940

Helpline: 0207 436 5881

Email: support@uk-sands.org

Sibs

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

www.sibs.org.uk

Tel: 01535 645453

Email: By online form at:

www.sibs.org.uk/contact_us

SupportLine

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

www.supportline.org.uk

Tel: 0208 554 9004

Email: info@supportline.org.uk

TCF Sibling Support

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

www.tcfsiblingsupport.org.uk

Tel: 0845 123 2304

Email: info@tcfsiblingsupport.org.uk

Winston's Wish

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

www.winstonswish.org.uk

Helpline: 0845 203 0405

Email: info@winstonswish.org.uk



Glossary

Allowing a Natural Death (AND)

An Allowing a Natural Death (AND) order would ensure that only comfort measures are taken at end of life. This would include withholding or discontinuing resuscitation, artificial feedings, fluids, and other measures that would prolong a natural death. Allowing a natural death simply means not interfering with the natural dying process while providing care and pain and symptom management to keep the patient as comfortable as possible.

Cardiac arrest

This happens when the normal circulation of blood flow stops when the heart fails to contract (beat) properly.

Children's palliative care

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

Children's hospice services

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

Diagnosis

The process of determining the nature of a medical condition.

Do Not Resuscitate Order (DNR)

This is a document that outlines a patient's request saying that they do not want to be resuscitated should their heart or breathing stop.

End of life

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

End of life care

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

Extubation

This means removing the breathing tube and ventilator that has been assisting the child to breathe.

High dependency unit (HDU)

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

Hospice at home

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

Hospital ethics committee

It is not always easy to decide on the best course of action in providing medical care for a child, especially when there is uncertainty about how an illness might progress. Even when everything that can be known about the situation is known, it is possible to have several equally legitimate points of view that are quite different from one another.

In that situation it is increasingly common for a hospital ethics committee to be asked to consider the issues. They will not usually give a decision about the right way forward, but they will set out what the ethical issues are and how they are relevant to the discussions. They are advisory; that is, their recommendations do not have to be acted on. But if a decision did end up needing to go to Court, ethics committee advice would often be something the Court would expect the medical team to have considered and taken seriously.

Intensive care unit/Intensive therapy unit/critical care

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

Intravenous

This means the giving of substances directly into a vein, for example pain relieving drugs.

Prognosis

This will be your doctor's prediction of the chance of recovery or survival from a particular condition or disease.

Symptom management

Symptom management is the management of common symptoms. It is often used to refer to symptoms that are primarily physical, but in palliative care symptom management also includes attention to psychosocial and spiritual aspects of symptoms where appropriate. Symptoms may be treated with medication or other alternative methods.

Ventilator

A ventilator provides a mechanism of breathing for a patient who is physically unable to breathe, or is breathing insufficiently.

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

T: 0117 916 6422
F: 0117 916 6430
E: info@act.org.uk

www.act.org.uk

Helpline: 0845 108 2201

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Author: Myra Johnson, ACT

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Special thanks are due to parents Jackie and Martin for sharing their photographs of their daughter Emily on pages 3 and 6.

ACT has made every effort to ensure that the information contained in this leaflet is accurate and up to date at the time of publishing. However, please be aware that some of the information contained in this leaflet may change, especially that relating to the law and decision making. We suggest that you ask your consultant about any changes in the legal framework around decision making and seek legal advice.

ACT takes no responsibility for the contents of websites or documents referred to in this leaflet.

Notes Please use this space for your own notes and contacts



Valuing short lives

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

T: 0117 916 6422

F: 0117 916 6430

E: info@act.org.uk

www.act.org.uk

Helpline: 0845 108 2201

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

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

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