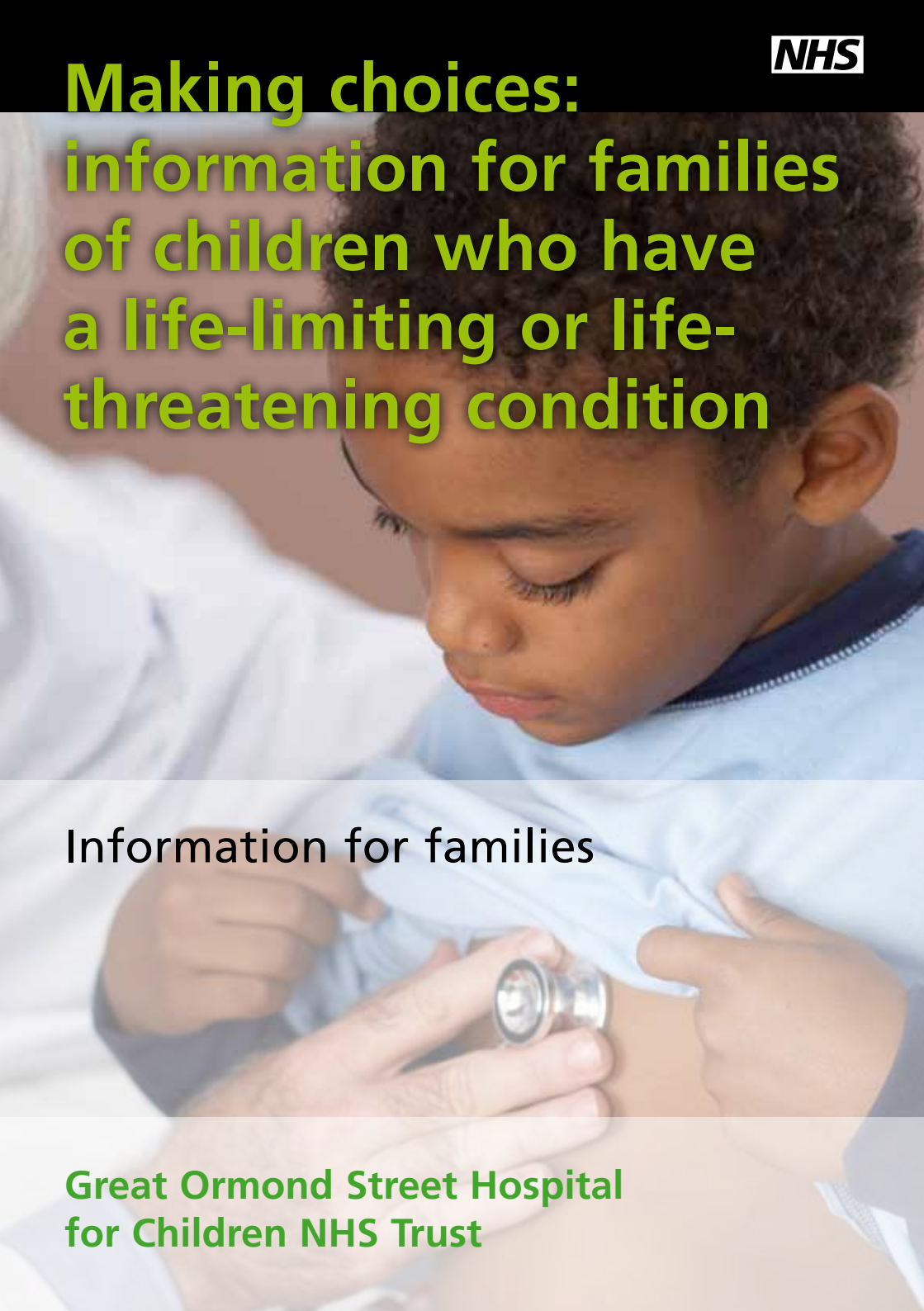


# Making choices: information for families of children who have a life-limiting or life- threatening condition

The background of the entire page is a photograph of a young child with dark, curly hair, wearing a light blue hospital gown. The child is looking down with a somber expression. A healthcare professional's hands are visible, one holding a stethoscope to the child's chest. The lighting is soft and clinical.

Information for families

Great Ormond Street Hospital  
for Children NHS Trust

**This guide has been written for families whose children have life-limiting or life-threatening conditions. Included here are professionals and organisations that may offer support to you and your family so that your choices are right for your child and family.**

**Over time, your child's condition may change and this guide may help you to prepare for making choices as you adapt to changing circumstances.**

**We hope that this guide will enable you to ask any questions you need answered. You may want to pick out the sections that are relevant to you at this time and also revisit it as often as you wish. Please discuss anything in this booklet with a member of staff.**

## Contents

page

### Diagnosis

Questions _____	4
Meetings _____	5
Named contact _____	5
Sharing information _____	6
Communicating _____	6

### Growing and developing

Play support _____	9
Hospital school support _____	10

### Health changes

Assessing needs _____	12
Who at GOSH can help? _____	12
Support in your local community _____	17

### End of life care planning

Decision making care plan _____	22
Choice of place of care _____	23
Organ and tissue donation _____	25
Memories _____	25
Who at GOSH can help? _____	26

### Bereavement

Funerals _____	27
Bereavement follow up from GOSH _____	27
Bereavement support in community _____	30

### Support and information

Organisations _____	31
Books _____	34
GOSH information sheets _____	34

# Diagnosis

When your child is receiving medical treatment or undergoing investigations you receive a lot of information from health professionals. This can be very stressful. We hope this section will provide you with some useful tips to help you make sense of the information you receive and help get answers to your questions.

## Questions

Often people who are anxious or worried forget things when they are given a lot of information at one time. It can be helpful to write down any questions you may have before meetings or you may want to discuss with family or friends before the meeting.





## Meetings

Parents, carers and other family or friends of your choosing are welcome to attend meetings with the healthcare team. They can help to support you during the meeting and take notes for you.

If English is not your first language an interpreter can be made available to you before, during and after the meeting. You may be given some written material to supplement the meeting you have with the doctor. Your child may be offered information that is appropriate to their age and understanding.

If you would like copies of letters from your meeting, please ask staff at the meeting. It may be helpful to check who is your contact following the meeting.

When meeting with health professionals to discuss your child's care we intend that:

- The meeting takes place face to face.
- The meeting is where possible, in a private space
- That you are introduced to all of the professionals who are present
- That you are given as much time as you need to absorb information and to ask the questions you have.
- Following the meeting, there are opportunities to ask any other questions that have arisen.

## Named contact

Also known as a key worker or lead professional.

As parents/carers you may want to decide who you regard as your child's key worker. This will

be the person you feel you can contact easily and who you feel can understand the wide range of care your child may be receiving within the hospital as well as within the community. This can be someone from GOSH, your local hospital or a member of your community team.

### Sharing information

Some families find it helpful to nominate another family member or friend to relay any significant news to family or friends. This saves you having to repeat the same information for each person. Some parents have also found setting up a website to update friends and family helpful.

### Communicating

#### Communicating with your child

Depending on their age and understanding, children may want to be involved in discussions around their care. We find this varies from family to family. Studies show children often know far more about their illness than is thought. Some children may also

hide what they know in order to protect their parents.

*On being told he had Friedreich's Ataxia he said "I'm glad you told me what is wrong with me, I thought I had a brain tumour" - Kathy, mother of a 13 year old boy.*

It can be helpful to listen to your child and find out what their understanding is. When they ask questions, you can give them the information they have requested. It is best to give out small amounts of information at a time and you may need to repeat some of the information.

If you create the opportunities your child will know that they can ask you more questions when they feel ready. Where possible it may be helpful for both parents, or another family member or close friend to be present to provide support. You may want to involve grandparents or someone else known well to the child.

If your child is in hospital or a hospice you can ask staff to help you have these discussions.



"During his long illness, we learned that our ten year old son would ask us direct questions when he was ready to hear the answer. We always answered his query fully and appropriately, as did the consultant and registrar, without adding unasked for information. Sometimes pictures were drawn to clarify the explanation and any further questions were answered straight away." - Maggie, mother of a ten year old boy.

### **Communicating with brothers and sisters**

Your other children will want to know what is happening to their brother or sister. Depending on your child's condition this may involve many years of them being part of their brother or sister's care. It will be helpful for you to find out from your other children what they understand about their sister or brother's illness. This can help them to feel included. Children with a very sick brother or sister can often feel left out. If you are unable to spend much time with them,

because your attention is taken up with caring for your sick child, try to identify family or friends who can spend time with them.

Being able to be open and honest with your other children's questions may enable the family to talk more openly with each other and help to provide support for each other.



*"I was advised by a member of staff at a children's hospice that it is impossible to give a younger child too much information as they will only take on board that which they are capable of understanding and accepting/dealing with."  
Heather, mother of an 11 month old daughter.*

There are some books and workbooks that can help to open up these conversations. With smaller children you will probably read them together, but with older children you may want to allow them to read these on their own and then find time to discuss this with them.

When visiting your sick child hospital Play Specialist staff may be available to give your other children some time (see play support).



# Growing and developing

## Play Support

Hospital play specialists work with children on the wards and in outpatients.

Your child may need help understanding and working through information about their diagnosis, condition, treatment and prognosis. Through play and other techniques your child can be helped to understand more about the different emotions that they

may be experiencing and learn how to cope with these and express themselves to others.

Your other children may benefit by spending time with a Play Specialist; their needs will vary due to individual circumstance, age and development. If they are older you may want the Play Specialist to explain what is happening and/or to do some activities which could help them.



## Hospital School support

The Children's Hospital School aims to provide an enriching and enjoyable experience for all its pupils, including those with life-threatening and life limiting conditions. The staff work hard to provide normality through education, to prevent anxiety about schoolwork and help children maintain relationships with their peers.

If your child is well enough to attend sessions at the school, encouraging them to do so will provide them with a break from

the ward and an opportunity to spend time with other children.

If your child is too unwell to attend the schoolroom or is required to stay in isolation they may be taught on the ward for about an hour a day between 10.00 and 3.00pm.

## Your other children and the hospital school

There are limited places at the Hospital School for brothers and sisters. If, due to the circumstances of your child's inpatient stay, your other child is unable to attend



their home school for more than two weeks, you can request that they are taught at The Children's Hospital School. You will need to meet the Assistant Head in Charge of Deployment to discuss this.

Siblings can also attend 'The Centre' which is next to the school. Children over four and at school can attend unaccompanied. Children under 4 years old can attend if accompanied by an adult. There is also an area called 'The Den' which is aimed at children aged over 10 years. The opening hours are set to complement school hours and are 10am to 1pm and 2pm to 4.30pm

### **Returning home**

When your child is discharged from hospital, the Children's Hospital School will advise their home school. The Pupil Liaison Officer will work with you and your child's home school to support your child returning to school, sometimes with a reduced agreed timetable. A report will also be sent to you and your child's home school detailing

the schoolwork covered and progress made while your child was in hospital.

### **Home Schooling**

If your child is unable to return to their home school and they are likely to miss school for three weeks or more due to medical reasons, you can request home tuition. You will need to contact the Education Department at your Local Authority as soon as possible to make the arrangements. You may require documentation from the hospital medical staff to support your request for home tuition. Your child is entitled to between five and ten hours tuition per week and this can be arranged to suit your child's needs.

# Health changes

Your child will be reviewed regularly by the health teams in the community, at your local hospital and at GOSH. The following information is intended to help you understand how the different health professionals can help. These health professionals form part of the multidisciplinary team looking after your child. They will, on occasion, communicate with each other through letters and phone calls to help in the coordination of your child's care.

Below are some of the staff groups with whom you may come into contact. They may be able to signpost you to other staff members at GOSH or in the community. You may wish to find out more about a service to help support you in caring for your child and aid any decision-making. Staff are available to help you and your family make choices.

## Medical team

Your child will be under the care of one or more consultants. Each consultant works in a team with other junior doctors known as registrars, specialist registrars or fellows. You may not always see the consultant, but the consultant is kept fully informed of the results of appointments and tests and is involved in decision making.



## Clinical Nurse Specialists (CNS)

Most teams at the hospital will include at least one clinical nurse specialist. You will hear them referred to as the CNS for a specific condition. They will act as a link between the multidisciplinary team (all the professionals caring for your child) and they are a point of contact for you should you require advice and information, while in hospital and when your child is discharged home.

## Palliative Care Team

'Palliative care for children and young people is an active and total approach to care, from the point of diagnosis or recognition, throughout the child's life, death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the child or young person and support for the family. It includes the management of distressing symptoms, provision of short

breaks and care through death and bereavement.'

ACT (Association for Children's Palliative Care) Quality Markers, Brunswick Court, Brunswick Square, Bristol, BS2 8PE

The support offered by the Palliative Care team will vary according to the needs of each child and family. The team understand that those needs may change with time and the nature of the child's illness. They will take into consideration the support available from your child's existing health care team and the stage of your child's illness when the team become involved.

Many children are already well known to at least one team at GOSH and a local hospital, children's community team or a hospice. The Palliative Care team aim to work together with the teams already involved. They are able to offer support and advice at times when difficult decisions are needed about symptom management and about the practical and emotional difficulties

of looking after a child with a life-threatening or life-limiting illness.

There is a team leaflet readily available; please ask for a copy.

You can ask your family doctor (GP), staff at GOSH, your local hospital or community staff to make a referral to the Palliative Care team.



## **Family Liaison Nurses**

If your child is being cared for on an intensive care ward, you will find Family Liaison nurses who are specialist nurses providing practical, emotional and educational support and advice. This may be during your child's stay in hospital or when your child is at home. The Family Liaison nurses can help you make contact with other professionals who may be better placed to provide certain information, such as family support workers, play staff, community children's nurses both in hospital and local to your home. The Family Liaison nurses will also provide help and support when considering choices in relation to children with life-limiting or life-threatening illness, as you feel appropriate to your family needs.

## **Pastoral and spiritual support**

The Chaplaincy and Spiritual Care Department operate a 24/7 on-call service that provides pastoral, spiritual and religious care. Spiritual care includes themes such as hope, meaning, and relationships.

The chaplaincy and spiritual care team can listen and talk with you about any of these issues, pray with you, light a candle or provide that which you would find most helpful. They are also available for blessings, baptism or other rituals that you may want for your child. Chaplaincy and spiritual care support is available throughout your child's illness and can provide a range of services, including specific rituals and referrals to other local professionals and agencies. Please ask for a copy of their leaflet.

Spiritual care givers from all faiths and philosophies can be contacted via the switchboard 24 hours a day, seven days a week. If you are in hospital you will regularly see spiritual care givers on the ward. Please do let them know if you want to speak to them or you can ask one of the team on the ward to contact them for you. You are welcome to visit the chapel, which is located on the ground floor opposite the pharmacy, or multi faith room, which is located in the same corridor as the school, at any time.

## Psychology team

Paediatric psychologists can help you and your child cope with the emotional and practical demands of your child's illness and the stresses involved in receiving hospital treatment. There may be a psychologist in clinic or on the ward who could talk to you about what they can offer or you can ask a member of the nursing or medical team to make a referral for you. When you meet with a member of the team, they will make an assessment and discuss with you what support would be appropriate and available to your child and family.



Information about the paediatric psychology team is available, please ask for a copy of their information sheet.



## Social Care team

GOSH has a team of social workers with a diverse range of skills and experience and there is a social work link to most wards. The social worker will undertake an assessment of the impact of your child's illness on your child and your family, should this be required. The social workers are able to offer wide-ranging support to suit the family's needs, providing practical help and advice as well as emotional support. They can also talk with staff at GOSH and with professionals in your local area so that everyone understands the needs of your child and family and help you in accessing appropriate additional support where available.

Three CLIC Sargent social workers offer the same service, specifically to all children who have a diagnosis of cancer.

A duty social worker is always available to offer advice and support between 9am and 5pm, Monday to Friday. They and the team can be contacted on 020 7829 8896 or internal extension 5320.



## Family Support Workers

Family Support Workers work within the Social Care Team and can provide practical support to you with the following:

- Financial assistance
- General welfare benefits advice
- Charity and social fund applications
- Liaising with your employers

## Citizens Advice Bureau

The Citizens Advice Bureau (CAB) service based at GOSH offers advice and advocacy in all areas of law and provides specialist case work in debt and welfare benefits. The CAB provides free, confidential and impartial advice. You will need to be referred to them by the social work department or the Pals office.

## PALS (Patient Advice and Liaison Service)

Pals provide a quiet and confidential space for you discuss any concerns about your child's current care and future treatment

plans. They can support you at meetings with health professionals, advocate on your behalf, or refer you to other agencies that may be able to help you with additional social needs such as money and employment issues.

Pals offer a drop in service and is available Monday to Friday 9am to 5pm and Saturdays 10am to 12.30pm. You can contact them on 020 7829 7862 or internal extension 7862 or email [pals@gosh.nhs.uk](mailto:pals@gosh.nhs.uk). PALS staff are able to visit you on the ward if you would prefer this.

## Support in your local community

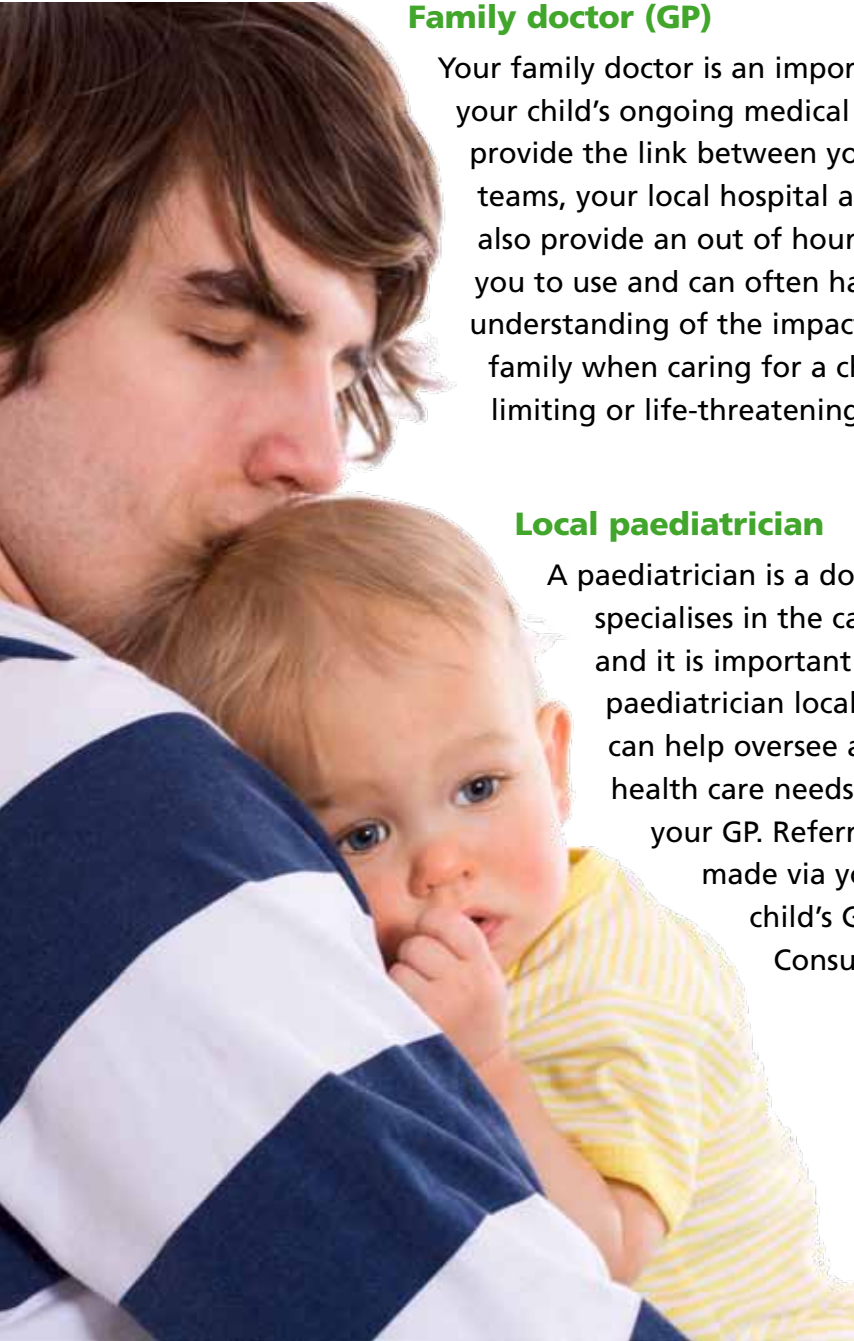
Your child may be spending a considerable time in hospital, but may also have long periods at home or in their local hospital or children's hospice. When your child is at home, they may need extra support both at home and school. The following teams are available to help you make the choices that are best for your child and family and support you in caring for your child.

## Family doctor (GP)

Your family doctor is an important part of your child's ongoing medical care. They can provide the link between your community teams, your local hospital and GOSH. They also provide an out of hours service for you to use and can often have a good understanding of the impact on the whole family when caring for a child with a life-limiting or life-threatening illness.

## Local paediatrician

A paediatrician is a doctor that specialises in the care of children and it is important to have a paediatrician local to you. They can help oversee all your child's health care needs together with your GP. Referrals can be made via your GP or your child's GOSH Paediatric Consultant.



## Health Visitors

Every family with a child under the age of five has a named health visitor. Your health visitor will work closely with your GP, offering you support, and working in partnership with you to monitor your child's growth and development. Your health visitor can be contacted during normal office hours, Monday to Friday.

## Social Care Team

You are entitled to have your child's needs assessed by the local authority children's social care service. Local authorities have a legal duty (Children Act 2004) to assess all children with a disability.

## Community Children's Nursing teams

Community Children's Nursing (CCN) Teams provide nursing support and care for children at home. If your child requires continued nursing care at home, and you do not know your CCN, the nursing team at GOSH can organise a referral. The community

team will work in partnership with you to help meet the specific needs of your child and family. If your child has been referred to the Palliative Care team they will also work closely with your CCN team to ensure all your child's nursing needs are met.



## Hospices

Children's hospices offer a wide range of specialist services for children with life-limiting and life-threatening conditions. These may include day care, hospice at home, respite breaks, telephone advice, emergency care, contact/key worker visits, end of life care and bereavement support. The focus is on quality of life and providing opportunities and life experiences for these young people. Hospice staff recognise

that the family are the experts in their child's care and will work alongside families to achieve the best care for their child. For more information about Children's Hospices, please contact Children Hospices UK (contact details at the back of the booklet).

*"The hospice was a beacon in our lives. We looked forward to our visits there. It was a place filled with warmth, a place to eat well, recharge and rest."-  
Nic, mother of a 7 year old girl.*



Notes

# End of life care planning

Many parents who come to accept that their child may die begin to make choices. Knowing their child and family, they will begin to think about preparing for their child's death.

*"After successful in-utero surgery we were full of hope and excitement for the birth of our baby girl. At no point were we told that she may not survive. When she died, just a few hours old, we were totally unprepared for our terrible loss." - Sharon, mother of a baby girl, a few hours old.*

## Decision-making care plan

One of the benefits of forward planning is giving yourself time to consider your options and to think about how you might want your child cared for as their condition changes and as goals of care change from active treatment to recognising that death may be

approaching. The needs of every child will be different and you and your family may want help and support to consider the options available to you as your child's condition changes.

An 'Emergency Care Plan' will help everyone caring for your child to be aware of the discussions you have had and the choices you and



your child have made. It will be given to you but also copied to your GP, CCN team, local hospital, hospice and ambulance service. The plan for guidance may be changed at any time that you feel it requires revision. It covers what might be done in the event of a sudden deterioration as well as slow changes in your child's condition; it also helps you to consider issues around resuscitation.

### Choice of place of care

Sometimes choice of place of care may not be possible, but the doctors and those caring for your child will always try to incorporate your wishes if where possible. You may change your mind at any time as circumstances change. For instance, if your child becomes acutely unwell and is admitted to hospital, you may then decide to stay in hospital for their end of life care.

You may want to discuss some of these choices with your child, depending on their age and understanding.

### Hospices

Families may decide that they want their child to receive their final care at a hospice. Others may decide to take their child to a hospice after death; the hospice can provide care after death and before the funeral. During this time families are also welcome to stay, so they can spend this time with their child, saying goodbye.

Hospices can provide bereavement support to the immediate and extended family. It is provided in many different ways, such as activity weekends, workshops, groups and one-to-one work. Support can also be offered before death. A lot of hospices have specific activities geared towards helping brothers and sisters.



## Dying at home

Many children feel most comfortable at home. If you feel supported by your CCN team and are able to receive telephone support from the Palliative Care team, then you may feel that home is the best place for your child. Being at home may enable all of the family to play a part in caring for your child at the end of his/her life. Your GP and local

hospital will need to be aware of your plan in order to help with the practicalities and to provide back up if something unexpected occurs.

*"Michael knew he was dying and when we had the 'conversation' all he wanted to know was "When will I know and how?" He was not frightened, and added, "you will look after Lara" (his puppy)"*  
*- Susie, mother of teenage boy*



## Organ and tissue donation

You may wish to consider organ or tissue donation after your child's death. Organ donation is a precious gift that may help to enhance the lives of others. You may want to think about organ donation during your child's life and to discuss this with your family. The transplant coordinator can provide information and answer any questions you may have, either during your child's life or after their death.

*"At a desperate time, donation gives a glimmer of comfort, knowing that a part of your child lives on, enabling others to return to a normal life." - John, Gill and Richard, parents and brother of a young girl who died in a road traffic accident.*

## Memories

You may want to think about creating memories for you and your family. These may include special family outings or other everyday activities enjoyed with your child. Taking photos and family videos can help to add to

those lasting memories.

You may also want to consider creating a memory box. Depending on your child's age and their understanding of death and dying you may want to create a memory box with them. You may choose to wait to do this after your child's death and it can be helpful to include all family members.

You may choose to create other memories of your child, such as handprints and footprints. Some parents also like to keep a lock of their child's hair.

*"Our daughter was coming up to three years old, when our baby son, Rishi, died at GOSH. Regardless of her age, we made sure that we included her at all times and only explained to her what she needed to know. When we went to see Rishi at the mortuary, our daughter was with us, she was pre-occupied playing with the toys whilst we were having a cuddle. She came in with her cups of tea and said she had made one for Rishi. For us, that*



*was as normal as it was going to get"- Ranj, mother of a 2 day old baby.*

### **Family Liaison nurses**

The family liaison nurses can provide help and support for you when you are making decisions around your child's end of life care whilst on the intensive care unit.

This support can continue through all aspects of bereavement care as required by each individual family.

### **End of Life Care**

Members of the Palliative Care team are available to help you talk about any choices you may wish to discuss relating to end of life care for your child and to offer support. If there is anything in relation to end of life care that you would like to discuss, please contact the Palliative Care team.

# Bereavement

## Funerals

This may or may not be something you want to plan before your child dies. Older children sometimes want to be involved in planning their own funeral. You may find it useful to talk to professionals caring for your child, whether this is in hospital, the community or the hospice. You may also want to access your spiritual or religious support when thinking about this. You can find further practical information about funerals in our booklet called *When a Child Dies*.

## Bereavement follow-up from GOSH

When your child dies it is likely that you will experience a range of emotions and at times these emotions may feel impossible to bear. The death of a child is the most devastating event a parent can experience, so it is entirely normal to feel emotional turmoil at this time.



"The first thing to try and understand is that to lose a child is probably the most devastating thing that could ever happen to you. Normal rules do not apply. There will be few parents who would not have given their own lives willingly to help save their child during those hours of need, and most other experiences we are ever likely to face as parents and adults pale into insignificance when compared."  
[www.naomihouse.org.uk](http://www.naomihouse.org.uk)

We recognise that families have to find their own way to begin to understand the enormous loss they have experienced. Some families find the support they get from family and friends is sufficient for them. Others welcome some extra support from their local community. Your GP can advise on access to additional support.

You may decide you need support soon after the death of your child or you may decide a few years later that you would value the opportunity to talk about what

happened to your child. This is particularly the time when other family and friends may not be aware of your continuing pain. The different services that we can offer you at GOSH to help you during this very difficult time are listed below.

### **If your child dies at GOSH**

You should be offered an appointment to meet with your consultant six to eight weeks following the death of your child. This meeting should provide an opportunity for you to ask any unanswered questions and to discuss post mortem results if this is applicable. If you do not feel able to have a meeting at this point, we can arrange a meeting when you feel ready. If you do not receive a letter offering you this appointment, please contact the Bereavement service who can organise this for you.

### **If your child dies on an intensive care unit at GOSH**

If your child dies in one of the intensive care units the Family Liaison nurses will keep in contact with you, providing advice, guidance, support and practical help as required. They will be a point of contact to help coordinate the bereavement follow-up meeting and can provide some bereavement support over the phone. They can also help with finding local support available to you.

### **If your child has been looked after by the GOSH Palliative Care Team**

If your child has been cared for by the palliative care team will you should receive a letter from the Bereavement Care team six months after your child dies. You will also receive birthday and anniversary cards for two years following the death of your child. For families who live within areas local to GOSH, the Bereavement Care team is able to offer bereavement support. We can also refer to local services.



## Annual Thanksgiving Memorial Service and Memorial Book

GOSH holds an annual Thanksgiving Memorial service for children that die who have been under the care of the hospital. Please do contact the chaplaincy office on 020 7813 8232 if you would like to attend. You are welcome to attend this as many times as you wish.

You should be offered the opportunity to have your child's name placed in the hospital's memorial book. The memorial book is available after the memorial service for families to view their child's name. You are welcome to visit the chapel at any time and to see the memorial book, however please let the Chaplains or the Bereavement service know in advance of your visit, so we can ensure someone is there to assist you.

## Bereavement support in your community

Other bereavement organisations are mentioned at the back of this booklet. Please ring the Bereavement Service on 020 7813 8551/ 8550 if you have problems locating a local service.

## Child Death Helpline 0800 282 986

This is a national freephone helpline that is underwritten by Great Ormond Street Hospital for Children NHS Trust and Alder Hey Children's NHS Foundation Trust. The Helpline is staffed by trained volunteers who are all bereaved parents themselves. You may find it helpful to talk to another bereaved parent. This service is available to you for as long as you choose to use it. The opening hours are listed at the back of this booklet.

**Acknowledgements:** This booklet has been compiled with help from bereaved parents, including volunteers from the Child Death Helpline. Our grateful thanks to them.

# Support and information

## ACT – The Association for Children’s Palliative Care

ACT is an organisation working nationally to achieve the best quality of life and care for all children and young people who have a life-limiting or life-threatening condition and their families.

Helpline: 0845 108 2201

Website: [www.act.org.uk](http://www.act.org.uk)

## Bliss

A national charity dedicated to improving the survival and long-term quality of life for babies born too soon, too small or too sick to cope on their own.

Helpline: 0500 618 140

RNID Typetalk: 018001 0500 618 140

Blisstext: 07800 00 810

Website: [www.bliss.org.uk](http://www.bliss.org.uk)

## Child Cancer Helpline from Clic Sargent

Helpline: 0800 197 0068 – Monday to Friday from 9am to 5pm

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

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

## Children’s Hospices UK

Children’s Hospices UK is the national charity that gives voice and support to all children’s hospice services.

Tel: 0117 989 7920

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

Website: [www.childhospice.org.uk](http://www.childhospice.org.uk)

## Contact a family

Contact a Family provides support, advice and information for families with disabled children, no matter what their condition or disability.

Helpline 0808 808 3555 – Monday to Friday from 10am to 4pm – also Monday evenings from 5.30pm to 7.30pm

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

Website: [www.cafamily.org.uk](http://www.cafamily.org.uk)

## Crossroads

Crossroads provides services through a network of local providers across England and Wales. Each offers a variety of support services for carers. Trained carer support workers can provide respite care.

Tel: 0845 450 0350

Website: [www.crossroads.org.uk](http://www.crossroads.org.uk)

## Child Death Helpline

Your call will be answered by a trained volunteer who is also a bereaved parent

Helpline: 0800 282 986 and 08088006019 for mobiles callers  
These are both Freephone numbers  
Monday to Sunday from 7pm to 10pm, Monday, Thursday and Friday mornings from 10am to 1pm; Tuesday and Wednesday 10am to 4pm.

Website:  
[www.childdeathhelpline.org.uk](http://www.childdeathhelpline.org.uk)

## Sands

Supporting anyone affected by the death of a baby

Helpline: 020 7436 5881  
Website: [www.uk-sands.org](http://www.uk-sands.org)

## Foundation for the Study into Infant Death (FSID)

Supporting families whose babies have died suddenly and unexpectedly;

Helpline: 0808 802 6868  
Email: [helpline@fsid.org.uk](mailto:helpline@fsid.org.uk)  
Website: [fsid.org.uk](http://fsid.org.uk) [note no www]

## Cruse Bereavement Care

Cruse provide free support to bereaved people

Helpline: 0844 477 9400  
Email: [helpline@cruse.org.uk](mailto:helpline@cruse.org.uk)  
Website:  
[www.crusebereavementcare.org.uk](http://www.crusebereavementcare.org.uk)

## Cruse Youth Helpline and RD4U

Cruse website especially for children and young people which can link you to support through email, and where you can read about the bereavement experiences of other young people.

Helpline: 0808 808 1677 – Monday to Friday from 9.30am to 5pm  
Website: [www.rd4u.org.uk](http://www.rd4u.org.uk) – includes separate sections for girls and boys

## Compassionate Friends

The Compassionate Friends (TCF) is an organisation of bereaved parents and their families offering understanding, support and encouragement to others after the death of a child or children.

Helpline: 0845 123 2304  
Email: [helpline@tcf.org.uk](mailto:helpline@tcf.org.uk)  
Website: [www.tcf.org.uk](http://www.tcf.org.uk)



## Winston's Wish

The charity for bereaved children

Helpline: 08452 03 04 05

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

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

## Childline

Free and confidential helpline for children & young adults in the UK

Helpline: 0800 1111

Website: [www.childline.org.uk](http://www.childline.org.uk)

## Child Bereavement Charity

Supporting families and educating professionals when a child dies and when a child is bereaved.

Tel: 01494 446648

Email: [support@childbereavement.org.uk](mailto:support@childbereavement.org.uk)

Website:

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

## St Christopher's Candle Project

Based at St Christopher's Hospice-Offering support to all children, young people and their families in the south east London area. They can also provide advice on books for children and young people

Tel: 020 8768 4586

Website: [www.stchristophers.org.uk](http://www.stchristophers.org.uk)

## Books

There is a lot of literature that you may find helpful. Your library is a good starting point. See some examples below.

### For parents

- Harriet Sarnoff Schiff (1979) *The bereaved parent*. Souvenir Press. ISBN 0285648918
- Celia Hindmarch (2009) *On the death of a child*. 3rd edition. Radcliffe. ISBN 1846194032

### For children and young people

- Earl A Grollman (1993) *Straight talk about death for teenagers*. Beacon Press. ISBN 0807025011
- Marge Heegaard (1991) *When someone very special dies*. Woodland Press. ISBN 0962050202
- Elizabeth Laird (2006) *Red sky in the morning*. Children's Books. ISBN 0330442902
- Doris Stickney (2004) *Waterbugs and dragonflies: explaining death to children*. Pilgrim Press. ISBN 0829816240

## Leaflets and information sheets from GOSH

These can all be obtained on our website at:

[www.gosh.nhs.uk/gosh\\_families/information\\_sheets/index.html](http://www.gosh.nhs.uk/gosh_families/information_sheets/index.html)

Visit our Children First for Health website for more information for children, young people and parents

[www.childrenfirst.nhs.uk](http://www.childrenfirst.nhs.uk)

Notes



© GOSH Trust July 2010

Ref: 2010F0840

Compiled by the End of Life Care Group with assistance from bereaved parents  
in collaboration with the Child and Family Information Group

Great Ormond Street Hospital for Children NHS Trust  
Great Ormond Street  
London WC1N 3JH

[www.goshfamilies.nhs.uk](http://www.goshfamilies.nhs.uk) [www.childrenfirst.nhs.uk](http://www.childrenfirst.nhs.uk)