



Southern Health
and Social Care Trust

Quality Care - for you, with you

When a child dies



***Information to support parents, families and
carers in bereavement***

April 2024

We would like to express our deepest condolences to you and your family on the death of your child.

We hope this booklet may help guide you through some of the practical and necessary formalities that need to be undertaken at this sad and difficult time. Healthcare professionals are also available to support and guide you.

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Section 1: Practical Matters

Taking time

Coping with the death of a child is very overwhelming therefore, it is important to take some time to gather your thoughts, to cry, to talk or to have some time alone. You will have to make some practical decisions and it is important that you are fully informed of all the options available.

It is often helpful to have the support of family members and friends at this time. If you wish, the staff can contact your faith representative or the hospital chaplain for support.

The staff who cared for your child will do all they can to help and support you at this time. If, in the days or weeks ahead you wish to speak to the healthcare professionals who cared for your child at the time of their death, please contact the ward manager/community nursing team manager or medical team to arrange an appointment.

When your child has died in hospital

After your child has died, staff will support you to make decisions about what happens next and explain how you can bring your child home. You may wish to wash and dress your child and the staff will be happy to assist you.

Depending on the circumstances and where the death occurred, at an appropriate time your child may be brought respectfully to a mortuary or room of repose. This is a special facility where your child can remain until you have had time to choose a funeral director, make your own arrangements or until the formal arrangements for release or post mortem are completed.

If you wish you can accompany your child when they are transferred to the mortuary and the staff there will assist you to see and spend time with your child when possible.

When the Trust is legally able to do so i.e. when the medical certificate of cause of death has been completed, your child will be released to your chosen funeral director and you can take them home.

It may be possible for a child to be taken home directly from the ward without going to the Mortuary. If this option is possible and appropriate, staff will discuss this with you and following completion of the necessary forms you can take your child home in a private or funeral directors car.

Return of belongings (when your child has died in hospital)

The staff will confirm your wishes as they prepare to gather your child's personal belongings together. You can take the belongings immediately or if preferred, they can be collected later. Please confirm with the staff what you would like to do.

Organ and Tissue Donation

In some hospital areas, for example, Intensive Care or Emergency Department, you may be specifically asked about your wishes on organ or tissue donation and specialist staff will support you.

In some circumstances, the person with parental responsibility can consent to organs/tissues being donated when their child dies. Sometimes a medical condition or the cause of death will mean a child cannot be a donor.

When your child has died at home

If your child has died at home, you or a family member should report the death to the GP or out of hour's doctor. If another healthcare professional is present in the home at the time of death e.g. a community nurse, they will support you to do this.

The doctor will visit you as soon as possible to confirm your child's death and explain the next steps e.g. completing the medical certificate of cause of death. You can contact a funeral director who will help you care for your child at home and make decisions about the funeral.

The Medical Certificate of Cause of Death

If the cause of your child's death is known, the doctor will forward the medical certificate of cause of death (MCCD) to the General Registrar's Office (GRO). The GRO will then distribute the MCCD to your local registry office.

The Coroner's Office and Postmortem examinations

If your child died suddenly or unexpectedly, or had not been seen by a doctor within the 28 days before the death occurred, the doctor has a duty in law to contact the Coroner who investigates sudden or unexplained deaths.

If the Coroner decides to determine the cause of death, he may order a post mortem examination (sometimes called an autopsy) which is carried out by a pathologist after death. The Coroner does not need the deceased's family's consent for this post mortem examination which will be carried out in Belfast Forensic Mortuary. The doctor will talk you through this process and you will have a contact from the Coroner's Office (Family Liaison

Officer) to keep you informed throughout the post mortem examination process. When the post mortem examination is complete the Coroner's Service will provide a certificate to allow a funeral to take place. The doctor or general practitioner who cared for your child will discuss this carefully with you and provide you with written information on this process if you require it.

A hospital consented post mortem

You may be asked by a doctor for permission to carry out this post mortem. This is an examination carried out with the consent of relatives, in order to more fully understand the illness, the cause of death and to enhance future medical care. It is your decision to grant permission for this. All babies and children undergoing a hospital consented post mortem examination will be transferred from the Belfast Trust Mortuary to Alder Hey Children's NHS Foundation Trust in Liverpool.

The doctor or general practitioner who cared for your child may discuss the options with you and provide you with further written information on this process to make sure you are fully informed before making a decision.

Registering your child's death

Once the medical certificate of cause of death (MCCD) has been completed, the death will need to be registered with the Registrar of Births and Deaths. All deaths that occur in Northern Ireland must be registered in the council district in which the death occurred or in which the child or parents normally/usually resided. A list of district registrar's offices is included at the end of this booklet. Your funeral director will be able to advise you if you are unsure.

A General Registrar's Office (GRO 73) "Details Required for Registration of Death" form must be completed by the named person with parental responsibility and forwarded to the local registry office. Your funeral director will assist you with the completion of this form. The local registry office will then contact the named person with parental responsibility to complete the registration process. There is no cost for registering a death, but it can be useful to purchase additional copies of the death certificate.

After the death has been registered, the registrar will issue a certificate for burial or cremation to the funeral director so they can proceed.

If the Coroner has ordered a post mortem examination, they will contact the registrar of death after the examination. If you as parents are not married, either of you may register the child's death.

Making Funeral Arrangements

Unless there is a special religious or cultural reason for holding the funeral immediately, you can take some time to say goodbye and to plan your child's funeral. Your family, friends, or faith representative will be able to assist you with your decisions and planning.

- While it is possible to make all the arrangements yourself, you may find the support of a funeral director invaluable as they know all the issues that need to be considered. Friends, family or your spiritual leader may be able to help you choose a funeral director.
- Advice on burial options can be obtained through your funeral director, whether or not you are planning a formal funeral

service. He/she will also help you organise the purchase of a grave if necessary. Your faith representative will provide guidance regarding Church and council owned cemeteries

- Cremations in Northern Ireland are undertaken in Roselawn Crematorium in Belfast. Further information on cremation can be obtained through your funeral director or by contacting the crematorium directly on Tel: (028) 90448288. The funeral director will be able to help you with the additional forms required to allow a cremation to take place. Cremations cannot take place until the cause of death is confirmed.
- Many people are concerned that funerals are expensive, it is advisable to contact the Department of Communities Bereavement Service team to report the death. They will be able to discuss the Child Funeral Fund with you on free phone number: **0800 085 2463**.

Repatriation of Deceased

You may wish to have the body or cremated remains of your child repatriated to another country. To remove a body from Northern Ireland, permission needs to be obtained from the Coroner. Arrangements for the reception and burial/cremation of the body in the country of destination need to be made prior to departure. The funeral director you choose will guide you through these arrangements.

If your child died here while on vacation, the cost of repatriation may be included in their travel insurance policy. Otherwise, it is worthwhile checking the cost of repatriation before choosing this option. The relevant consulate or embassy of the country to which the body is to be repatriated can also provide you with advice and information.

The mortuary staff and funeral directors have experience of repatriation in these circumstances and they will also support you at this time.

People to tell

Your family General Practitioner will be contacted when your child has died in hospital. In these circumstances, every possible step will also be taken to cancel future hospital/community appointments to avoid further distress. Please advise staff if you have been involved with other agencies that should be made aware of your child's death.

There are a number of other organisations or people to tell when someone dies e.g. Child benefit office. The NI Direct website has good guidance and advice on who needs to be informed that your child has died (see section 3).

Collection of nursing or care equipment

Your child might have been receiving nursing, health visiting or other specialist community services before they died. It is likely that the community team will contact you to offer their condolences. If there is equipment in your home, the community nurse will advise the community store to arrange a suitable time for it to be collected. You can also contact the person or service who supplied the equipment or Community Equipment Store, Manor Drive, Lurgan. Tel: (028) 38341316

Section 2: Coping With Bereavement

Grieving

Everyone will experience bereavement at some time in their life; however the death of a child is a profound and devastating loss for parents and their family circle.

Grief is what we feel following a death, whether it is expected or unexpected. While it is a painful and emotional time, grieving is a very natural process and response to a death. Everyone's reaction to a death is individual and will vary, but there are some common experiences that people share;

- Many people describe shock soon after the death of a child, especially when the death has been sudden
- feelings of numbness, panic, disbelief, anger, guilt, crying or being unable to cry, emptiness, anxiety, agitation and depression are often present
- For some, sleeping or eating might be difficult

Everyone grieves differently and there is no set way in which to get through this time. It can be hard to accept your child has died and it can put a tremendous strain on family relationships. All these reactions are natural. Mixed emotions and complicated feelings are understandable at this difficult time.

It is common to have feelings of sadness and depression. These should lessen with time. If however, the feelings get stronger and you are unable to carry out normal tasks or you experience suicidal thoughts, then it is important for you to seek specialist help. The best way to access support is through your GP. You can also access help through Lifeline, which provides 24-hour support for those in distress. Telephone Freephone 0808 808 8000 or access at www.lifelinehelpline.info

Physical and Behavioural Changes

You may feel tired but cannot sleep; hungry but unable to eat. Often people have difficulty concentrating and are easily distracted or forgetful and some people find themselves in a state of panic and view things out of proportion. You may feel run down and lethargic or have aches and pains that you do not normally have. This can be a normal part of the grieving process. Friends and neighbours sometimes avoid you, because they do not know what to say or they are finding it difficult to cope with their own feelings of grief. It may help if you take the first step by letting them know that you would appreciate their friendship and support.

It might seem that life would be more bearable if you made drastic changes to avoid painful memories, such as moving house or disposing of your Child's belongings. Try to avoid doing this at an early stage after the death. There will come a time when it is right for you to make such important decisions.

Special dates, such as birthdays and anniversaries can be particularly emotional times. Deciding in advance how you will mark these occasions can be helpful.

Talking to Someone

It is important to take care of yourself. One of the most helpful things can be to talk about your child who has died. Only you can decide who you would like to share that with. It could be:

- A family member
- A friend
- Your faith/belief representative
- Your GP
- Someone from a support organisation. Further details of support organisations can be found at the back of this booklet

Try to:

- Talk about the baby who has died using their name
- Look after yourself.
- Eat properly and try to rest even if you can't sleep
- Give yourself time and permission to grieve
- Seek help and support if you feel you need it
- Tell people what you need

Try not to:

- Isolate yourself or keep emotions bottled up
- Think you are weak for needing help
- Feel guilty if you are struggling to cope
- Turn to drugs or alcohol as the relief will only be temporary

Helping bereaved children

Adults often feel the need to protect children from death and their own grief, as they think the children will find it too upsetting. However, children are often more frightened when they are not sure what is going on around them than when they are allowed to be a part of it. When you tell children that a loved one has died, use simple but clear language and answer any questions as honestly as you can. Use words such as 'dead' and 'death' rather

than 'lost' or 'sleeping' which can be confusing for them. Pre-school children generally don't understand that death is permanent and may repeatedly ask questions.' Children of primary school age usually have an understanding of the finality of death and often ask direct questions about it.

Signs of Grief in Children

Children may display symptoms such as becoming quiet and withdrawn, clingy towards a parent, bed-wetting, fearing the dark, or displaying sleep or behavioural problems at home or school. These are all normal reactions for young children, and for most, they will pass in time. Teenagers are already going through physical and emotional changes, and communication can often be difficult for this age group. They often feel a sense of injustice and question why their sibling or family member had to die. They may 'test the boundaries' by, for example, staying out late or losing interest in school. It can be helpful for them to talk about their feelings. It is important that they feel someone is listening to them and acknowledging how they feel.

Supporting children after the death

Sometimes it helps to allow children to decide for themselves whether they wish to see the child after death. However, to enable them to make their decision, you will need to prepare them by explaining what they will see. For young children you may need to explain that the body no longer eats, talks, cries, laughs or sleeps and that it may feel cold to touch.

It may be helpful to encourage the child to write a letter, draw a picture or put a small gift or toy in the coffin (take care that this does not include batteries or electrical items if the child is going to be cremated). This can be a positive way for the child to say

goodbye. You can also encourage children to keep a memory box or book containing special things or thoughts of the deceased child. Staff will provide you with resources to assist you to explain the death of your child to other children. As with adults, sometimes individual children will benefit from specialist bereavement support. If you think this is the case for a child in your care, contact your GP or one of the organisations listed in the Support Organisations section of this booklet.

The Trust has a booklet called “When someone close to you dies - a guide for talking with and supporting children” which you may find helpful. If you would like a copy ask the staff who cared for your child. It is also available to read on the Trust website:

<https://southerntrust.hscni.net/service/bereavement/>

Section 3: Information and Local Support

Annual Special Services of Remembrance

Each year the Trust holds special services to remember babies and children who have died. They are advertised in the local press and on the bereavement information page under “Our Services” on the Southern Trust website: <https://southerntrust.hscni.net/services/>

Books of Remembrance

Books of remembrance hold the names of babies and children who have died in our hospitals or our wider community. Their names are entered on their parents' request. There is no time limit for when names can be added and parents can also write some words to be included alongside their baby or child's name. The books are rededicated at our services of remembrance each year.

Southern Trust Support Services

Bereavement Co-ordinator

The Bereavement Co-ordinator can be contacted for advice on bereavement support in the Southern area. Information on bereavement support is available on the Trust Website

Tel: (028) 37560085

Email: Bereavement.Coordinator@southerntrust.hscni.net

Web: <https://southerntrust.hscni.net/service/bereavement/>

Practical Support

NI Direct Website - <https://www.nidirect.gov.uk/>

Provides helpful advice for families dealing with the death of a relative eg funeral arrangements, registration of death etc.

District Registrars Offices :

Armagh	The Palace Demesne, Armagh, BT60 4EL	03300 561130
Banbridge	Downshire Road, Banbridge BT32 3JY	03300 561133
Craigavon	Civic Centre, PO Box 66, Lakeview Road, Craigavon BT64 1AL	03300 561131/ 03300 561132
Dungannon	15 Circular Road, Dungannon BT71 6DT	0300 0132132
Newry and Mourn	Newry Town Hall, Bank Parade, Newry BT35 6HR	0330 1374041

Department of Communities:

Bereavement Service Team	Freephone 0800 085 2463
Benefits	Freephone 0800 022 4250

Bereavement Register: Web: <https://www.thebereavementregister.org.uk/>

Registering a relative's details with this site will stop unwanted direct mail being sent to those who have died.

Kevin Bell Repatriation Trust: Web: <http://www.kevinbellrepatriationtrust.com/>

Aims to relieve the financial hardship of bereaved families repatriating the body of loved ones who have died abroad in sudden or traumatic circumstances back to Ireland.

Organisations Providing Bereavement Support and Information

The list below is intended to act as a guide to the range of support and information available both locally and regionally. Inclusion in this list does not necessarily constitute or imply any endorsement or recommendation by the Southern Health and Social Care Trust of that organisation or services.



Bereaved NI <https://bereaved.hscni.net/> provides a range of accessible resources for people who are experiencing bereavement and ensure that they have the required information and support for their bereavement journey.

Supporting Bereaved Parents

Anam Cara

An organisation that supports bereaved parents.

Tel: 353 (0)1 4045378 / Northern Ireland Tel: (028) 95213120
Web: www.anamcara.ie Email: info@anamcara.ie

Child Death Helpline

A Free phone service for all those affected by the death of a child.

Helpline: 0800 282986 / 0808 800 6019 Web: www.childdeathhelpline.org.uk

Compassionate Friends NI

Support and friendship after the death of a child at any age:

Local Helpline: (028) 87788016 National Helpline: 0345 1232304 Web: www.tcf.org.uk

Cruse Bereavement Care

Provide a range of bereavement services for children and adults regardless of how and when the death occurs.

NI Regional Office: 10 College Green, Belfast BT7 1LN Tel: (028) 90434600
Email: northern.ireland@cruse.org.uk Web: www.cruse.org.uk

Armagh/Dungannon: Merrion House, 46 The Square Moy BT71 7SG Tel: (028) 87784004

Newry/Mourne: 9 Enterprise House, WIN Business Park, Canal Quay, Newry BT35 6PH
Tel: (028) 30252322

Life After Loss

Provide support and information to anyone affected by the loss of a baby.

Web: www.lifeafterloss.org.uk

The Lullaby Trust

Provides specialist support for bereaved families and anyone affected by sudden infant death.

Helpline: 0808 8026868 Email: support@lullabytrust.org.uk Web: www.lullabytrust.org.uk

SANDS (Stillbirth and Neonatal Death Charity)

Support anyone affected by the death of a baby and promote research to reduce the loss of babies' lives. They provide a helpline and hold support group meetings across NI.

Regional Office: Magharee House, 82 Thomas Street, Portadown BT62 3NU
Tel: (028) 38392509 NI Helpline 07740993450 Web: www.sandsni.org

A Little Lifetime Foundation (formally ISANDS)

A charity based in Dublin providing information and support to bereaved parents and families in Ireland.

Web: www.isands.ie

Twins Trust

Support all parents and carers of twins, triplets or more who have died whether it was during or after pregnancy.

Web: <https://twinstrust.org/bereavement.html>

Supporting Children

Barnardos Child Bereavement Support Service

Provides advice and support to adult children, young people, their families and carers who have been bereaved

Advice Line: (028) 90668333 Web: www.barnardos.org.uk/childbereavementservice

Barnardos Nova

Nova is a Barnardos NI trauma support service providing therapeutic support for children and families affected by psychological trauma

Tel: (028) 40628758 Email: ni.nova@barnardos.org.uk Web: www.barnardos.org.uk/nova

Childhood Bereavement UK

Supports families and educates professionals when a baby or child is dying or when a child is facing bereavement

Helpline: 0800 02 888 40 Web: www.childhoodbereavementnetwork.org.uk

Winston's Wish

Childhood bereavement charity offering practical support and guidance for bereaved children, their families and professionals

Helpline 0845 2030405 Email: info@winstonswish.org.uk Web: www.winstonswish.org.uk

Bereavement Support Organisations

Brake

Provides support for people bereaved by road crashes

Helpline : 0808 8000401 Email: help@brake.org.uk Website: <https://www.brake.org.uk/>

Cancer Focus NI

Provides counselling service to patient and relatives pre and post bereavement.

40-44 Eglantine Avenue, Belfast BT9 6DX Tel: (028) 90663281 Email: care@cancerfocusni.org
Web: www.cancerfocusni.org

Family Trauma Centre – Belfast Trust

Regional service providing specialist treatment of children, young people and families following severe trauma. Referral to the service from General Practitioner, Health Visitor, School, Social Work etc.

Tel: (028) 90204700

LIFELINE 0808 808 8000

Counsellors available 24 hours a day, 7 days a week who are experienced in dealing with issues such as depression, anxiety etc to give you help and support, in confidence.

Tel: 0808 808 8000 Text phone: 18001 0808 808 8000 Web: www.lifelinehelpline.info

Links Counselling Service

Confidential counselling service for bereavement provided in Armagh and Lurgan

23a Castle Lane, Lurgan BT67 9BD Tel: (028) 38342825
Email: info@linkscounselling.com Web: <https://www.linkscounselling.com>

Marie Curie

Bereavement support for those bereaved by a terminal illness

Helpline: 0800 090 2309 Website: www.mariecurie.org.uk/help/support/bereavement

Southern Area Hospice

Provide bereavement support for those whose loved one received hospice care.

Courtenay Hill, Newry BT34 2EB

Tel: (028) 30287711 Web: www.southernareahospiceservices.org/

STEP (South Tyrone Empowerment Programme)

STEP is a community development and training organisation. It offers migrant support including advice and guidance through face to face appointments with bi-lingual staff

The Junction, 12 Beechvalley Way, Dungannon BT70 1BS

Tel: (028) 87750211 Email: info@stepni.org Web: www.stepni.org

The Samaritans

Provides confidential emotional support 24 hours per day. They are there for you if you are worried about something, feel upset or confused, or you just want to talk to someone.

Craigavon: Tel: (028) 38333555 Newry: Tel: (028) 30266366

National Helpline Tel: 116123 Web: www.samaritans.org

WAY Widowed and Young

Self help social and support network for those widowed up to the age of 50, and their children

Web: <https://www.widowedandyoung.org.uk/bereavement-support/>

Supporting People bereaved through suicide

Southern Trust Protect Life Co-ordinator

Support for families bereaved through suicide

Tel: (028) 37564461 Mobile: 07825 627133

The Niamh Louise Foundation

Provides peer support for people bereaved through suicide.

32 Coalisland Road, Killybrackey, Dungannon, Co. Tyrone BT71 6LA Tel: (028) 8775 3327

Email: info@niamhlouisefoundation.com Web: www.niamhlouisefoundation.com

PIPS Hope and Support

Provides bereavement support services in the Southern Trust area.

Newry: 50 Mill Street, Newry BT34 1AG Tel: (028) 30266195

Lurgan: 41 Union Street, Lurgan, BT66 8EB Tel: (028) 3831 0151

Email: info@pipshopeandsupport.org Web: www.pipshopeandsupport.org

Supporting People with Learning Disability or Dementia

Alzheimer's Society

Works to improve the quality of life of people affected by Dementia.

30 Skegoneill Street, Belfast BT15 3JL

Telephone: 028 90664100 **Email:** nir@alzheimers.org.uk **Web:** www.alzheimers.org.uk

Mencap

Supports people with a learning disability and their families in Northern Ireland.

Web: www.mencap.org.uk

Mencap NI Telephone: (028) 90691351 / NI Learning Disability Helpline: 0808 808 1111

Macmillan "Easy Read" Resources

Provides accessible information in simple language and pictures about dying, death and bereavement.

Web: <https://be.macmillan.org.uk/Downloads/CancerInformation/Easyread/MAC16345What-can-help-you-feel-better-when-someone-dies.pdf>

Contact Us

We welcome your comments, suggestions, compliments or complaints and we will use them to assist us in improving our services. To make your views known, please contact:

Service User Feedback Team

Southern Health and Social Care Trust
First Floor
Finance Building
Lurgan Hospital
100 Sloan Street
Lurgan
BT66 3NX

Tel: (028) 37564600

Email: serviceuserfeedback@southerntrust.hscni.net

Have Your Say

The Trust is committed to involving service users, carers and other stakeholders in the planning, development and evaluation of its services. There will be times when the Trust will have opportunities for you to become involved. Register your interest with the Personal and Public Involvement Team on

Tel: (028) 37564471

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