

Helpful information for families and friends following a death in hospital



On behalf of Leicestershire Partnership NHS Trust, we extend our sincere sympathy to you and your family at this sad time. We appreciate that this can be a difficult and confusing time and there is a lot to think about. We hope this booklet will help you during the early days of your bereavement as well as something you can refer back to over time.

The booklet offers practical information (section 1), talks about grief and where you can access support (section 2), and explains our review of care processes (section 3).

We aim to meet the needs of all members of our community when someone close to them has died. If you have any religious, cultural, or other needs, please tell the nursing staff. This includes requests for urgent certification where there are specific religious or cultural requirements. Please ask us if you have any questions:

Named ward nurse/
ward sister:

Name of doctor on
the ward:

Ward name:

Hospital name:

Ward telephone
number:

Or you can contact the bereavement support nurse. We are here to help (see page 24 for contact details).

Name and contact
details of funeral
directors to be used:

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Section 1 - Practical advice

1.1 What to do first

After a death in hospital, there are certain things that will need to be done. What happens next will depend on the circumstances of the death.

Our hospitals do not have mortuary facilities and it is important to us that your loved one continues to receive the timely care they will need.

Where a death was expected, and transfer into the care of the coroner is not required, we will ask if you have a preferred funeral director and arrange for your loved one to be transferred into their care. Ideally, this transfer will be within four hours, but we know that this may not always be possible.

We appreciate that sometimes a decision about which funeral director to use may not have been made and further time is needed (see section 1.2 for advice). In this situation, we will make transfer arrangements with the funeral director who works with our hospitals. Your nurse will provide their contact details.

You may continue to use their services or choose to arrange transfer to another funeral director later.

It would be helpful to know as soon as possible if a cremation is being planned, as additional paperwork needs to be completed by the doctor.

Before arranging a funeral, you should find out if a Will had been made and locate it or talk to the solicitor who holds it. Check if the Will gives information about the deceased person's wishes for their funeral. They may have a funeral plan in place. A Will also gives the names of the "executors". Executors are the people legally entitled to deal with a deceased person's 'estate' (i.e. things they own and financial affairs). A firm of solicitors can help with managing this and any questions relating to tax issues that may arise.

Whilst we recommend speaking with the funeral director to talk about the type of service to be held, a firm date for the funeral should not be set until you have spoken with the registrar, and they have issued the death certificate. This is because sometimes a coroner needs to be involved.

Helpful information can also be found here:

What to do when someone dies: step by step - GOV.UK

<https://www.gov.uk/when-someone-dies>

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

Free helpline- 0800 082 1203 9am to 5pm Mon – Fri (excluding bank holidays)

If it was your loved one's wish to be a **tissue donor**, please inform your nurse as soon as possible and they will discuss this with you and contact the National Referral Centre on 0800 432 0559. Everything will be done to facilitate this request, but is dependent upon the timing of the death and certification process.

1.2 Choosing a funeral director

A funeral director (also called an undertaker) is a professional who cares for and prepares the body for a cremation or burial and arranges and manages funerals. The choice of a funeral director is important. You should feel comfortable and confident with them.

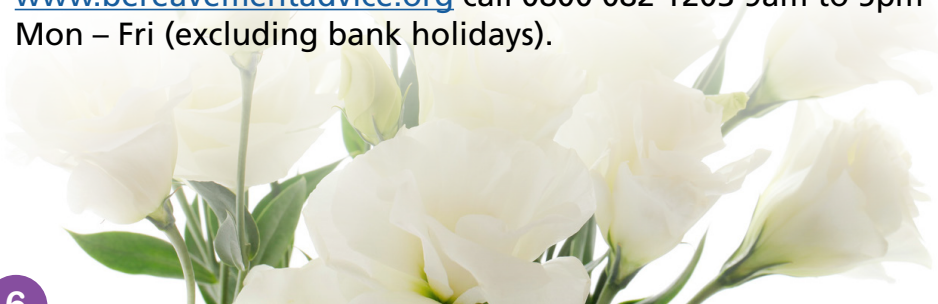
Before making your decision, you may wish to ask two or more companies for quotes, as charges vary. It is advisable that your chosen funeral director is a member of the National Association of Funeral Directors (<https://nafd.org.uk/>) or the National Society of Allied and Independent Funeral Directors (<https://saif.org.uk/members-search/>) who have codes of practice.

Funerals can be religious or non-religious and can be personalised to reflect the beliefs, background or wishes of your loved one.

You may choose a burial or cremation service; a direct (unattended) cremation with a memorial service or family and friends gathering afterwards; a natural burial or another type of personalised service.

If you are considering planning a funeral without a funeral director, you will need to contact your local council for more information. Also see: <https://www.leicester.gov.uk/media/183607/advice-on-arranging-a-funeral-without-a-funeral-director.pdf>.

For more advice, contact the Bereavement Advice Centre www.bereavementadvice.org call 0800 082 1203 9am to 5pm Mon – Fri (excluding bank holidays).



1.3 Your phone call from the medical examiner (ME)

A medical examiner (ME) is a senior doctor (consultant or general practitioner) trained in the clinical and legal parts of the death certification process. The MEs are based at the University Hospitals of Leicester NHS Trust.

All deaths in our hospitals undergo proportionate scrutiny by an ME, which involves the following:

The ME will firstly consider the cause of death given by the certifying doctor (where a cause is known) and decide whether the paperwork for registering the death can be completed or if a referral to the coroner is needed.

As part of the certification process and the national 'Learning from Death's' process, the ME will look at ("screen") a deceased patient's medical records. Where a direct referral to the coroner is not required, the ME will also telephone the family's preferred contact person usually within the next 2-3 working days (Monday – Friday excluding bank holidays 9am- 5pm). The ME will explain the proposed cause of death, answer any questions, and ask for feedback about the care - good and bad.

The ME will then inform the family and the doctor that either:

- the paperwork can be completed to register the death (see section 1.4).
- a referral to the coroner is needed. (see section 1.5).

Sometimes conversations with families or 'screening' of notes may lead to the ME requesting a fuller review of care or an investigation.

Where compliments are received, or feedback has led to areas for learning being identified, these are shared within our hospitals and sometimes with other organisations (e.g. trusts, community or GP services). This helps us to improve processes and the care we all provide.

The views of the bereaved are an important part of this process and the outcomes from a review or investigation can be shared with the next of kin (or their chosen person) by a bereavement support service nurse or the patient safety team (see “Reviews after deaths” section 3.1).

If the ME has been unable to contact you or you have further questions, concerns, or feedback you’d like to talk about sooner, please call the bereavement support service nurse (see page 24).

1.4 Paperwork completed by the hospital (where coroner referral is not required)

You do not need to collect any paperwork from the hospital – this is all sent electronically.

The Medical Certificate of Cause of Death (MCCD)

This is an official document completed by a doctor involved in caring for your loved one, which states the date, place and cause of death. This will be emailed to the Registrar of Births, Deaths and Marriages along with your family’s preferred contact person’s details.

This is done as quickly as possible, but the timing is dependent on the availability of a doctor, so sometimes this can take a little longer than we would like, and we ask for your understanding.

Once they have received the MCCD, the registrar’s officer will telephone the family’s preferred contact person to explain the next steps (see registering a death).

Cremation

Where a cremation is planned, the doctor will complete additional paperwork. The funeral director will receive this electronically and will send it to the crematorium.

1.5 When a death is referred to the coroner

If following discussion with the medical examiner (ME) it is agreed that the death needs to be referred to the coroner, an ME Officer will phone to let you know.

You do not need to contact the coroner – they will call you.

A coroner is a special type of judge appointed by the local authorities, who investigates the cause and circumstances of a death.

The police who work on behalf of the coroner will routinely be contacted by the hospital if an unexplained or unusual death occurs. They talk with ward staff and sometimes need to speak with family members to gather information.

The coroner may decide that no action is required and a doctor can then complete the paperwork for the death to be registered. You will be kept informed either by the coroner's officer or ME officer.

The coroner will investigate deaths that have been reported to them if it appears that:

- the death was violent or unnatural
- the cause of death is unknown, or
- the person died in prison, police custody, or another type of state detention (e.g. detained under Mental Health Act 1983)

For a short guide to coroner investigations, please visit: https://www.coronersociety.org.uk/img/pics/pdf_1503323567.pdf

Where the coroner decides to investigate the death, they may order a post-mortem (also called an autopsy). This is a medical examination of the body to determine the exact cause of death. It is carried out by a pathologist (a doctor who specialises in the nature and causes of disease). The coroner will discuss this with the next of kin, but they do not need to

ask permission, because they have a legal duty to investigate the death.

Sometimes the coroner may decide that a body scan (CT scan) will provide the necessary information and order this instead of a full post-mortem examination.

Post-mortems are carried out in an examination room similar to an operating theatre, where the pathologist will respectfully examine the inside and outside of the body.

The coroner will also decide whether an inquest is needed, which is a “fact finding” exercise to find out the reasons for someone’s death.

Prior to an inquest, the coroner may release a patient’s body into the care of the family and their chosen funeral director and provide an ‘interim certificate’ which allows a funeral to take place and is accepted by some organisation. This is sent to the registrar.

When the inquest has been concluded, the coroner will provide the registrar with the necessary forms to finally register the death and issue a death certificate.

The staff at the Coroner’s Office are very helpful and will answer any questions you may have.

HM Coroner for Leicester City and South Leicester District:

The Coroner’s Office

Town Hall

Town Hall Square

Leicester LE1 9BG

Call: 0116 454 1030 - lines open Monday to Friday 10.30am - 3.30pm (excluding bank holidays).

Email: leicester.coroner@leicester.gov.uk

HM Coroner for Rutland and North Leicester District:

HM Coroner’s Office

Leicestershire County Council

County Hall, Glenfield

Leicestershire LE3 8RA

Call : 0116 305 7732 - lines open Monday to Friday 9am - 3pm (excluding bank holidays).

Email: hmcroner@leics.gov.uk

A leaflet explaining the work of the coroner can be downloaded from www.gov.uk/government/publications/guide-to-coroner-services-and-coroner-investigations-a-short-guide.

1.6 Hospital (consent) post-mortems

This is different to a coroner post-mortem.

Occasionally, whilst we know the death was disease related (i.e. natural) we do not know the exact cause (e.g. primary site of cancer is unknown). In this situation either the hospital team or the family may wish for a further examination of a deceased person's body. For this to happen, the next of kin must give permission. For some families, having more information can be helpful, but others may feel that consenting to more investigations feels difficult. The doctor or medical examiner will help you understand the reasons for the request and support you in making a decision.

You do not have to agree if you do not want to.

If a post-mortem goes ahead, you can request a copy of the post-mortem report in "lay-person's" language, which will explain any medical terms. The bereavement support nurse can arrange for this report to be shared with you during a bereavement meeting with the doctor or medical examiner.

It is helpful to let your funeral director know if a post-mortem is taking place.

The doctor will still issue a Medical Certificate of Cause of Death to enable you to register the death. However, the funeral will not be able to go ahead until the post mortem has been carried out.

1.7 Your phone call from the Registry Office.

You do not need to contact the registry office - they will call the family's designated contact person, using the details provided by the hospital/GP.

A registrar is an official person who records births, marriages, and deaths.

Once they have received the relevant death certification forms, the registrar's assistant will telephone the family's preferred contact person. They will explain what happens next, arrange an appointment to register the death within the "registration district" where the death happened, and explain how to obtain 'official' copies of the death certificate.

Deaths should be registered within five days of the death, although this is frequently extended. This does not apply if the death has been referred to the coroner.

If the death occurred in a hospital within the city of Leicester, you will be contacted by the:

City of Leicester Register Office

City Hall Square

Leicester LE1 9BG

Call: 0116 454 1000. Open 9am – 5pm Monday to Friday
(excluding bank holidays).

If the death occurred in a Leicestershire hospital, you will be contacted by the:

Leicestershire Register Office

Anstey Frith House

Leicester Road

Glenfield LE3 8RN

Call: 0116 305 6565. Open Monday to Friday 9am - 5pm
(excluding bank holidays).

On weekends and bank holidays a registrar is only contactable for a limited time by the hospital, to issue paperwork for any urgent burials to take place.

1.8 Documents produced by the registrar

Death Certificate

This is the official certified copy of what is written in the death register. The executor (i.e. the person who is dealing with the financial affairs / estate) may need several copies, for private pension claims, insurance policies and financial matters. Many organisations will not accept photocopies. The registrar will explain the cost of buying copies of this document when registering the death and the increased cost if bought later.

Certificate for Burial or Cremation

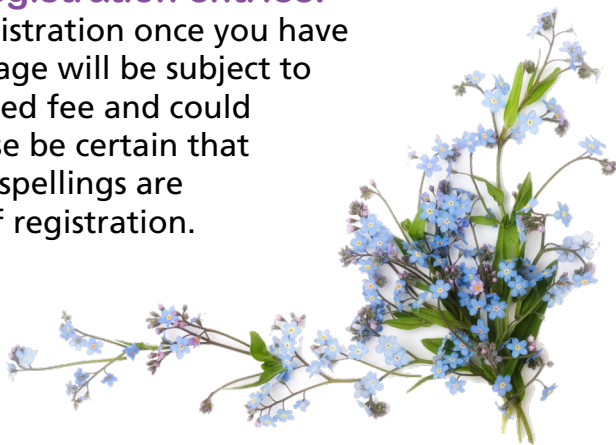
This form allows a funeral to take place, and is free of charge. The registrar will complete this form which is sent directly to the cemetery or crematorium where the funeral will take place.

Once the registration process is completed, the funeral date can be arranged.

Tell us Once 'code'. The registrar will explain how you can use the "Tell Us Once" service to inform most central and local government departments, in one go, about a death, and will provide a registration code. The registrar will advise you which government departments can be notified.

Fees to correct registration entries:

Any changes to a registration once you have signed the register page will be subject to a government enforced fee and could delay a funeral. Please be certain that the information and spellings are correct at the time of registration.



1.9 Who can register a death:

The following people are legally allowed to register a death:

- a relative (this is preferred)
- a person present at the death
- the occupier of the house or institution where the death took place (e.g. hospital representative, where there are no family members)
- the person who is instructing the funeral director



1.10 Information required to register a death

The registrar will need the following information:

- date and place of death
- name, address, date of birth and place of birth
- maiden name, in the case of a woman who has been married or formed a civil partnership
- occupation, and the name and occupation of their husband/wife/civil partner
- if the deceased was still married or in a civil partnership, the date of birth of their spouse
- the medical card or NHS number, if readily available
- whether the deceased was in receipt of a pension or benefits

Further information is available at: <https://www.leicester.gov.uk/your-community/births-marriages-and-deaths/>

The registrar will also ask you to bring the following documents of the deceased to your appointment if they are available. However, don't worry, if you cannot provide the following, they will still be able to process the registration.

- a passport, driving licence or birth certificate
- marriage certificate if applicable
- a document with an NHS number (prescription/doctors letter)

In readiness for your appointment, we recommend you complete the answers to the questions on the following page and have the list available during the appointment with the registrar.

The deceased person's full name:

Any other names that they used throughout their lifetime:

The date of their death:

Place of their death:

Their date of birth:

Their place (town) of birth:

Their most recent job (occupation):

Their most recent usual address:

Were they receiving a pension or benefits?

If they were married, or a widower, what was the full name, date of birth and occupation of their husband or wife (spouse)?

If the deceased person was married what is the date of birth of the surviving partner?

1.11 Cremation

A deceased person cannot be cremated until the cause of death is known. If we are made aware that cremation is planned, the certifying doctor will also complete additional paperwork needed for cremation. Your funeral director will receive this information electronically.

The local authorities set the costs of the cremation and the funeral director will arrange for this to be paid.

Ashes can be scattered in a garden of remembrance or in a special or favourite place, although you will need permission from the landlord or person responsible for the land before doing this. Ashes can be buried in a churchyard or cemetery, natural burial grounds or they can be kept. Your funeral director can organise this with you.

1.12 Burial

The cost of a grave space can vary. The costs will normally be higher for the burial of someone who lives outside the Council or Parish boundary for the chosen cemetery. If a grave space has been paid for in a cemetery, there will be a Deed of Grant, which is the legal document confirming who owns the Right of Burial in the grave.

Your funeral director can advise you of the fees for a burial.

You may choose a natural burial site. For information, see <http://www.naturaldeath.org.uk/> or call 01962 712 690

1.13 Financial help

If you receive certain benefits (e.g. Universal Credit) you can apply to the government for a Funeral Expenses Payment to help pay for the costs of the funeral. You will need to apply within 6 months of the funeral.

You may be eligible to claim a Bereavement Support Payment even if you do not normally claim benefits. This benefit provides a one-off payment to people under pensionable age. This is followed by up to 18 monthly payments after the death of a husband, wife or civil partner. You can also claim if you are unmarried and lived together and either have a child together or are pregnant with their child. To receive the full amount, you should apply within three months of the death.

For further information, see <https://www.gov.uk> or call the Bereavement Service helpline: 0800 151 2012. Their advisors will help you claim these benefits and help you complete the forms over the phone.

Advice on other benefits and financial support is available on the government website or you can contact your local Citizens Advice Bureau. For contact details for your local office, see <https://www.citizensadvice.org.uk/>

There are many other possible sources of financial help. Information about charitable grants can be found online. For example you can search the following sites:

- www.funeralguide.co.uk
- www.turn2us.org.uk
- www.yourfuneralchoice.com

If there is no executor and no family members who can arrange or pay for a funeral. Please discuss this with the hospital ward manager.

1.14 People to tell, managing mail and social media accounts.

There are various people and organisations that need to be told about the death. Tell Us Once is a service that lets you report a death to most government organisations in one go.

See: www.gov.uk/after-a-death/organisations-you-need-to-contact-and-tell-us-once

You will be given a code and invited to register with this by the Register Office.

Other people you could inform include:

- Solicitor - if there are any difficulties with legal issues or questions about the estate you may contact a solicitor or the Citizen's Advice Bureau.
- Local social services - if they provide services such as home care, meals or transport to day centres.
- Suppliers of equipment or mobility aids - whether NHS or another organisation such as the British Red Cross as these may need returning.
- GP and any other hospitals.
- Banks and Building Society - if it is a joint account the partner can continue to draw money. The Probate Office will advise on whether it is necessary to obtain Probate or Letters of Administration (see the "Help and support" section).
- A child's or young person's teacher, employer or college - should be informed if a parent, brother, sister, grandparent or other close relative or friend has died.
- Car insurance company - the policy held by the person that has died is no longer valid and other people driving under this policy are not legally insured.

- Home insurance company if applicable.
- Any clubs or subscriptions this person had.
- Gas, electricity, telephone and internet companies, local newsagent and milk deliveries (if applicable).
- If living in rented accommodation the council or private landlord should be told.

Junk mail can be stopped free of charge by registering with: The Bereavement Register <https://www.thebereavementregister.org.uk/> or the Mailing Preference Service <https://www.mpsonline.org.uk/>

Or you can call the Bereavement Advice Centre ,
Tel: 0330 045 0214. Open Mon- Fri 9am- 5pm (excluding bank holidays) see <https://www.bereavementadvice.org/>

Social media accounts can be deleted or 'memorialised' (left open, with restrictions) by contacting the account provider. They will usually require the following information:

- their social media username and email address
- their full name
- proof of death
- proof of your identity – driver's licence or passport
- proof of your relationship with the deceased

1.15 Probate

This is the legal right given to the executor of a Will (or closest living relative where there is no Will) to deal with someone's, money, property and possessions (their 'estate').

You may not need probate if the person who died only had savings, or had joint ownership of land, property or money with others (as these pass to the surviving other).

Applying for probate can be done online or by post. It can be a very involved process and many people choose to use a solicitor.

For information see <https://www.gov.uk/applying-for-probate>

Or contact the Courts and Tribunals Service Centre.

Tel: 0300 303 0648 open Monday to Friday, 9am to 1pm.

Closed on bank holidays

Email: contactprobate@justice.gov.uk



Section 2 - Help and support

2.1 What grief may feel like

Grief is a very personal experience. There are no rules or a “correct” way to grieve. However, there are some feelings that many people have. These notes do not give a complete list and you may not feel every one of these emotions.

Grief can be a very frightening experience. You may have periods of confusion and/or forgetfulness. Some people feel numb or that they have low energy and don’t feel like doing normal daily activities. Please be kind to yourself; maybe reduce the number or size of the tasks which you expect of yourself and allow yourself a little more time to complete jobs. Make sure you look after yourself; it is good to eat regularly and take some gentle exercise.

You may feel anger; maybe towards the person who has died for leaving you or at others, such as family members, health care professionals or God, for not being able to prevent the person from dying. Some people feel relief that their loved one is no longer struggling in pain and others have difficulty accepting the loss and so have a sense of denial at the events surrounding the illness and/or death.

There are often feelings of guilt for many different things said, done or left undone. Many people report that they feel an intense feeling of injustice and unfairness at their loss. Sometimes people feel guilt if they don’t experience strong emotions of grief initially. Shock, being busy, or when a person’s death has been expected for a long time can all play a part in this. Emotions can be triggered at any time.

There is also no particular order to these feelings and you may not experience them all. It is important to know that there is no set time-frame for feelings of grief, nor a time-limit.

The deep feelings of missing your loved one may continue for

a very long time. Some people say that they continue to “see” or “hear” the one they have lost for a long time, and can have vivid dreams, which can be upsetting.

It can feel like the world has moved on and forgotten you in your grief. It might provide comfort to recall happy memories and to talk to others who knew the person who died. It may be wise not to make important decisions whilst your grief still feels strong.

If you are struggling with your grief and you would like someone to talk to, there are a number of organisations which may be able to offer support. Some may offer counselling, others information and a few provide support groups. You can also talk to our Bereavement Support Nurses or your GP.



2.2 Advice, support and how to raise concerns.

It can sometimes be easier to talk to a stranger about things that you are going through than it is to talk to a person who is close to you.

The bereavement support nurses are here to talk confidentially with any member of your family about their bereavement. They can provide a listening ear and details of organisations that can offer further help, support or counselling.

A bereavement support nurse will routinely call the next of kin or preferred family contact within 6 to 8 weeks after the death, but any family member can make contact with them at any time.

If your family would like to provide feedback about the experience or have questions or concerns about the end of life care your loved one received, the bereavement support nurse can help to find the answers, request a review of care, or arrange for you to meet senior members of the clinical team involved in their care as part of the 'Learning from Deaths' Process. Next of kin consent will be required to share any information.

Email: bereavementsupportservice@uhl-tr.nhs.uk

Tel: 0116 258 4380 or 0116 258 6776

Mobile/text: 07950 868337 or 07811 024811

Open Monday to Friday 9am - 5pm (excluding bank holidays)

The chaplaincy team are also available to provide a "listening ear". They come from a variety of religions and beliefs, including non-religious chaplains. Please let your ward nurse know if you would like to speak with a chaplain.

The Patient Advice and Liaison Service (PALS) provides confidential advice and support. Please contact them to raise compliments, comments, concerns or if you wish to make a formal complaint about care. Their contact details are:

Email: lpt.pals@nhs.net or lpt.complaints@nhs.net

Tel: 0116 295 0830

Write to: Freepost LPT PATIENT EXPERIENCE

The NHS Complaints Regulations state a complaint must be made within 12 months of the incident happening or within 12 months of you realising you have something to complain about. However, if you have a reason for not complaining to us sooner we will review your complaint and decide whether it would still be possible to fairly and reasonably investigate. If you are not satisfied with our response to a complaint you can contact the Parliamentary and Health Service Ombudsman (PHSO): www.ombudsman.org.uk/publications/my-expectations-raising-concerns-and-complaints.

Access to hospital medical records. To request access, please contact the Data Privacy Team, who will advise how to raise a 'Subject Access Request' (SAR).

Email: lpt.sarrequests@nhs.net

Tel: 0116 295 5296

2.3 A lasting way to celebrate a life - making a charitable donation

If you would like to make a donation in memory of your loved one, to help a particular ward, hospital or medical condition that is personal to you, please contact the 'Raising Health' team:

Raising Health

Leicester Partnership NHS Trust

Unit 2

Bridge Plaza

Bridge Park Road

Thurmaston

Leicester LE4 8PQ

Email: lpt.raisinghealth@nhs.net

Tel: 0116 295 0889

Mobile: 07769 248620

See website: <https://www.raisinghealth.org.uk/>

2.4 Bereavement support organisations:

Age UK Leicestershire and Rutland

Offers information, advice and support available within the local community to older people (55+) and their carers.

Tel: 0116 299 2233

National helpline: 0800 009966

Website: www.ageuk.org.uk

Al-Anon Family Groups UK and Eire

Provides help and support for families and friends of those who have died of alcohol related illness.

Tel: 020 7403 0888

Website: www.al-anonuk.org.uk

Alliance of Hope

Provides support to survivors of suicide loss and can offer phone/skype counselling.

Website: www.allianceofhope.org

At a Loss

Signposting and bereavement resources. Search function to find local and national bereavement support.

Website: www.ataloss.org

Bereavement Advice Centre

Offers support and advice on the practical issues when someone dies.

Tel: 0800 634 9494.

Website: www.bereavementadvice.org

Care For The Family

Online resources and links to befriending and bereavement support events for the family.

Website: www.careforthefamily.org.uk/support-for-you/family-life/bereavement-support/

Child Bereavement UK

Support for parents who have lost a child (of any age, including adults) and also for children and young people who are bereaved, their family and carers who are supporting the child.

Tel: 01494 568 900

Freephone: 0800 02 888 40

Email: enquiries@childbereavementuk.org

Website: www.childbereavementuk.org

Child Bereavement Network

List of services throughout the UK that offer support to bereaved children and young people as well as other information and resources.

Website: www.childhoodbereavementnetwork.org.uk

Child Death Helpline

Provides a freephone helpline for anyone affected by a child's death, from pre-birth to the death of an adult child, however recently or long ago and whatever the circumstances of the death and uses a translation service to support those for whom English is not a first language. Volunteers who staff the helpline are all bereaved parents, although supported and trained by professionals.

Tel: 0800 282 986 or 0808 800 6017

Website: www.childdeathhelpline.org.uk

Childline

For when a child just needs to talk in confidence.

Tel: 0800 1111

Website: <https://www.childline.org.uk/>

Christian Counselling Service – Market Harborough and surrounding area

Counselling and bereavement group support. Therapy available irrespective of ability to pay. Charitable donations welcomed.

Website: <http://www.bowerhouse.btck.co.uk/>

Compassionate Friends

A network of bereaved parents provide support for other parents and siblings after the death of a child (of any age, including adults).

Helpline: 0345 123 2304

Website: www.tcf.org.uk

Coping With Cancer

Offers counselling, befriending services, disease specific support groups and complementary therapies to anyone affected by cancer within Leicester, Leicestershire and Rutland. They also run a solicitor's surgery for those struggling with any legal issues or would like some advice. You may refer yourself, a friend or ask your GP to make a referral.

Tel: 0116 223 0055

Website: www.c-w-c.org.uk

Counselling Directory

Helps people to find a private counsellor.

Website: www.counselling-directory.org.uk

Crisis Helpline

Offers access to support and guidance if they experience a mental health crisis.

Tel: 0808 800 3302 (2pm to 9pm weekdays)

Email: Leicestershire.Helpline@RichmondFellowship.org.uk

Cruse Bereavement Care

UK's leading bereavement support charity. Acts as a listening service for those or someone they know who have been affected by a death. They provide extensive information on practical, emotional and financial matters and details of online and face to face support groups they hold and counselling available.

National helpline: 0808 808 1677

Monday to Friday: 9.30am - 3pm

Website: www.cruse.org.uk

Dying Matters

Aims to help people talk more openly about dying, death and bereavement and to make plans for end of life.

Website: www.dyingmatters.org

(The) Good Grief Trust

Provides useful information, helplines, advice and encouraging stories from others to help the bereaved in this most difficult of times and to find a way forward.

Website: www.thegoodgrieftrust.org

Grief Chat

'Chat' live online anonymously to a trained grief counsellor. Using Grief Chat is free of charge and is open Monday-Friday, 9am-9pm. Also provides access to private counselling sessions.

Website: www.griefchat.co.uk or
www.ataloss.org/live-chat

Grief Encounters (Children)

Supporting bereaved children and young people and their families. Offering support, grief chat helpline, and counselling up to the age of 25 years which can be online if not local.

Tel: 08088020111

Website: www.griefencounter.org.uk

(The) Haven Counselling Centre

Counselling in Loughborough, arranged via office in Ashby-de-la-Zouch. Registered charity supported by contributions from clients and others.

Tel: 01530 560921

Website: www.thehavenashby

Hope Again

Run by Cruse Bereavement Care and is a website for young people to share stories and receive support.

Website: www.hopeagain.org.uk

Jolly Dollies

Social network for bereaved widows, to gain support and connect with others who understand. Opportunity for social meets.

Website: <https://thejollydollies.co.uk>

(The) Laura Centre

Offers counselling for parents and carers of children (of any age) who have died as well as offering counselling to children who have lost a parent. Their website also gives information relating to needs which may be specific to bereaved children and teenagers.

Tel: 0116 254 4341

Website: www.thelauracentre.org.uk

Leicester Counselling Centre

Private professional counselling available to the communities of Leicester, Leicestershire & Rutland.

Tel: 0116 255 8801

Website: www.leicestercounsellingcentre.co.uk

Leicester Womens Counselling Centre

Private professional counselling service available in Leicester.

Tel: 0116 255 8801 or 0333 344 4304

No website

LOROS

Hospice offers a counselling service to those bereaved where the deceased had a long term illness. Please ask your GP to refer you.

Website: www.loros.co.uk

(The) Loss Foundation

The Loss Foundation is a UK national charity dedicated solely to providing bereavement support following the loss of a loved one to cancer. They are also currently supporting Covid-19 bereavement. They offer online resources and run supportive events including peer support groups, therapy groups, workshops, social events, and weekend retreats.

Tel: 03002004112

Website: www.thelossfoundation.org

Macmillan Cancer Support

Provides physical, financial and emotional support and information, plus an online support community.

Website: www.macmillan.org.uk

MIND

Information and signposting for mental health concerns.

Tel: 0300 123 3393 (9am-6pm Monday-Friday, except bank holidays)

Website: www.mind.org.uk

National Association Of Funeral Directors

Supports its members in arranging meaningful funerals, and caring for bereaved people, providing advice, advocacy and support.

Website: <https://nafd.org.uk/>

Papyrus Hopeline Uk

For anyone under the age of 35 experiencing thoughts of suicide or for anyone concerned that a young person is thinking about suicide.

Tel: 0800 068 4141

Text: 07860 039967
(lines open every day 9am-midnight)

Website: www.papyrus-uk.org

RIP-RAP

Provides online advice and support service for young people (12-16 years) who have lost a parent through cancer.

Website: www.riprap.org.uk

Rutland House

Private counselling in Leicester.

Tel: 0116 416 1626

Website: www.rhcp.org.uk/

The Samaritans

Available 24 hours a day to provide confidential emotional support for people who are experiencing feelings of distress or despair, including those that may lead to suicide.

Tel: 0116 270 0007

National helpline: 116 123 (free to call)

Email: jo@samaritans.org

Shama Women's Centre

Offers free bereavement counselling support to men, women and children with special emphasis on minority ethnic communities. They have multi-lingual staff.

Tel: 0116 262 5876 (to book a confidential counselling session)

Tel: 0116 251 4747 (for general enquiries)

Silverline

A 24/7 call line for those in need of someone to talk to and offers information, friendship and advice for older people over 50. "There is no need to be alone".

Tel: 0800 4 70 80 90 (confidential and free)

Website: www.thesilverline.org.uk

Sue Ryder

National charity providing bereavement support, online resources and counselling (group, video or text).

Website: www.sueryder.org

Survivors of Bereavement by Suicide

A self-help group that offers support to families and friends of those who have committed suicide.

National helpline: 0300 111 5065

Website: www.uksobs.org

The Tomorrow Project

Supports those bereaved by suicide. Within 72 hours they will contact you to provide information and a named support worker.

Tel: 0115 880 0280

Email: bereavement@tomorrowproject.org.uk

Website: www.tomorrowproject.org.uk

The Victim Support Group

Offers emotional and practical support to those who have been bereaved due to a crime that has been committed.

Website: www.victimsupport.org.uk/

Vita Health Group

Provides talking therapies, in partnership with the NHS, for adults and those over 16 years who are registered with a GP in Leicestershire and Rutland. Self-refer online.

Website: www.vitahealthgroup.co.uk

Widowed & young – way (up to 51yrs) and Way up (51yrs +)

Offers a peer support network for anyone who's lost a partner - married or not, with or without children, whatever their sexual orientation. National organisation - Local in Leicester/ Leicestershire. Online community offering support and local meets in Leicestershire.

Website: www.widowedandyoung.org.uk

Website: www.way-up.co.uk

Winston's Wish

A childhood bereavement charity in the UK offering practical support and guidance to bereaved children, their families and professionals. The Winston's website has extensive resources for parents, carers and schools as well as many areas for children and young people.

Tel: 01242 515 157 (general enquiries)

Helpline: 0845 203 0405

Email: info@winstonswish.org.uk

Website: www.winstonswish.org.uk

Section 3 - Reviews and investigations after deaths

3.1 Learning from deaths

As an organisation we are very keen to learn how we can improve our care. Where we feel there is an opportunity for learning (or you have expressed to us that you do), we will routinely review our care to identify any learning.

Hospital reviews are also routinely carried out if a patient who has died was known to have a severe mental health illness or learning disability.

A review may also be requested if the medical examiner and/or the next of kin (when speaking with the medical examiner or bereavement support nurse) raises a question or concern about the patient's care that has not been fully answered or resolved.

If potential areas for learning are identified, these are discussed within the speciality by senior multi-disciplinary team members.

Part of the bereavement support nurses' role is to feedback to families (if requested) the outcome of any reviews undertaken and details of any learning or actions being taken.

Patient safety investigations are requested in a very small number of cases, if there was a problem in care which was thought to have led to harm or a patient's death.

The purpose of the investigation is to find out what happened and why. This is to identify any potential learning and to reduce the risk of something similar happening to another patient in the future.

If an investigation is to be held, we will inform the next of kin and explain the process. We will also ask about how, and when, the next of kin would like to be involved and keep

them up to date with the progress. We will explain how we will include them in setting the terms of reference (the topics that will be looked at) for the investigation. Investigations may be carried out internally or by external investigators, depending on the circumstances.

The next of kin's comments should be taken into account in the report. After the report has been completed the patient safety team will make arrangements to meet the next of kin, or their chosen family contact to discuss the findings of the investigation.

You may find it helpful to get independent advice about taking part in investigations and other options open to you. Some people will also benefit from having an independent person to accompany them to meetings etc. There are details of independent organisations that may be able to help later in this leaflet. Families are welcome to bring a friend, relative or advocate with them to any meetings.

If a patient dies following an unexpected or unintended incident that led to harm, staff must follow the Duty of Candour Regulation/ Policy. The charity AvMA (Action Against Medical Accidents. See section 3.2) has produced information for families on duty of candour which is supported by the Care Quality Commission.

Website link: <https://www.avma.org.uk/wp-content/uploads/Duty-of-candour.pdf>

The aim of our investigation will also be to address your concerns. Although families do not have to wait until an investigation is complete if they wish to make a complaint, if both the complaint and investigation are looking at similar issues, we may not be able to respond to the complaint until the investigation is complete.

3.2 Independent information, advice and advocacy

If you raise any concerns about the treatment we gave your loved one, we will provide you with information and support; and do our best to answer the questions you have. However, we understand that it can be very helpful for you to have independent advice. We have included details below of some of the organisations where you can find independent specialist advice to support an investigation into your concerns. These organisations can also help ensure that medical or legal terms are explained to you.

Local/regional organisations

POhWER

Offers general advocacy services in the south and midlands and independent health complaints advocacy to support people to complain about NHS services.

Tel: 0300 456 2370

Website: www.pohwer.net

National organisations

Action Against Medical Accidents (AvMA)

An independent national charity that specialises in advising people who have been affected by lapses in patient safety ("medical accidents"). It offers free advice on NHS investigations, complaints, inquests, health professional regulation and legal action regarding clinical negligence. Please note that there is a three year limitation period for taking legal action. Most advice is provided via its helpline or in writing but individual advocacy may also be arranged. It can also refer to other specialist sources of advice, support and advocacy or specialist solicitors where appropriate.

Tel: 0345 123 2352

Website: www.avma.org.uk

Advocacy After Fatal Domestic Abuse

Specialises in guiding families through inquiries including domestic homicide reviews and mental health reviews, and assists with and represent on inquests, Independent Police Complaints Commission (IPCC) inquiries and other reviews.

Tel: 07887 488 464

Website: www.aafda.org.uk

Website: www.childdeathhelpline.org.uk

Hundred Families

Offers support, information and practical advice for families bereaved by people with mental health problems, including information on health service investigations.

Website: www.hundredfamilies.org

Inquest

Provides free and independent advice to bereaved families on investigations, inquests and other legal processes following a death in custody and detention. This includes deaths in mental health settings. Further information is available on its website including a link to "The INQUEST Handbook: A Guide For Bereaved Families, Friends and Advisors".

Tel: 020 726 31111 (option 1)

Website: www.inquest.org.uk

National Survivor User Network

Developing a network of mental health service users and survivors to strengthen user voice and campaign for improvements. It also has a useful page of links to user groups and organisations that offer counselling and support.

Website: www.nsun.org.uk

Patients Association

Provides advice, support and guidance to family members with a national helpline providing specialist information, advice and signposting. This does not include medical or legal advice. It can also help you make a complaint to the CQC.

Tel: 0800 345 7115

Website: www.patients-association.org.uk

Respond

Supports people with learning disabilities and their families and supporters to lessen the effect of trauma and abuse, through psychotherapy, advocacy and campaigning.

Website: www.respond.org.uk

Support After Suicide Partnership

Provides helpful resources for those bereaved by suicide and signposting to local support groups and organisations.

Website: www.supportaftersuicide.org.uk

Acknowledgement

The information in this section incorporates information from the “Information for families following a bereavement” booklet and in parallel with “Learning from Deaths - Guidance for NHS Trusts on working with bereaved families and carers”, which can be found here: www.england.nhs.uk/publication/learning-from-deaths-information-for-families

3.3 Other organisations that may be of help

Integrated Care Boards (ICB)

The ICB are commissioners who manage and monitor NHS services provided within a local area. Complaints can be made direct to the ICB if you prefer not to raise a complaint directly with us or the appropriate health care provider.

Website: www.nhs.uk/nhs-services/find-your-local-integrated-care-board/

Parliamentary and Health Service Ombudsman (PHSO)

The PHSO make final decisions on complaints that have not been resolved by the NHS in England and UK government departments. They share findings from their casework to help parliament scrutinise public service providers. They also share their findings more widely to help drive improvements in public services and complaint handling. If you are not satisfied with the response to a complaint, you can ask the PHSO to investigate.

Tel: 0345 015 4033

Website: www.ombudsman.org.uk

Care Quality Commission (CQC)

The CQC is the independent regulator for health and adult social care in England. The CQC is interested in general intelligence on the quality of services, but please note that they do not investigate or resolve individual complaints. Feedback can be reported on the "My Experience" page of their website.

Website: www.cqc.org.uk

Learn from Patient Safety Events (LFPSE)

This is a national NHS service for the recording and analysis of patient safety events that occur in healthcare.

The public can report patient safety incidents to the LFPSE. Please note though that reports are not investigated or responded to.

Tel: 0300 311 22 33

Website: www.england.nhs.uk/patient-safety/patient-safety-insight/learning-from-patient-safety-events/report-patient-safety-incident/#public

NHS England – specialised services

Specialised services support people with a range of rare and complex conditions. They often involve treatments provided to patients with rare cancers, genetic disorders or complex medical or surgical conditions. Unlike most healthcare, which is planned and arranged locally, specialised services are planned nationally and regionally by NHS England. If you wish to raise a concern regarding any specialised services commissioned in your area, please contact NHS England's contact centre in the first instance.

Tel: 0300 311 22 33

Email: england.contactus@nhs.net

By post to: NHS England
PO Box 16738
Redditch
B97 9PT

Nursing and Midwifery Council (NMC)

The NMC is the nursing and midwifery regulator for England, Wales, Scotland and Northern Ireland. It has introduced a new public support service that puts patients, families and the public at the centre of their work. More information can be found within the "concerns about nurses or midwives" section on its website.

Website: www.nmc.org.uk

General Medical Council (GMC)

The GMC maintains the official register of medical practitioners within the UK. Its statutory purpose is to protect, promote and maintain the health and safety of the public. It controls entry to the register, and suspends or removes members when necessary. Its website includes “guides for patients and the public”, which will help you decide which organisation is best placed to help you. More information can be found within the “concerns” section of its website.

Website: www.gmc-uk.org

Healthcare Safety Investigations Branch (HSIB)

HSIB’s purpose is to improve safety through effective and independent investigations that do not apportion blame or liability. HSIB’s investigations are for patient safety learning purposes. Anyone can share cases with HSIB for potential investigation (but an investigation is not guaranteed).

Website: www.hsib.org.uk

The Trust makes every effort to ensure that the information in this booklet is accurate and up to date, but cannot guarantee that it is so.

We wish to thank the University Hospitals of Leicester for their support in producing this booklet.

SWAN model of End of Life Care



Promoting dignity, respect and compassion.

Sign, Words, Actions, Needs.

If you
need help to
understand this
leaflet or would like it
in a different language
or format such as
large print, Braille or
audio, please ask a
member of
staff.

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