Information booklet

East and North Hertfordshire NHS Trust

Additional information for families following a bereavement

This information has been prepared with the support of families, NHS trusts and other stakeholders

Contents

Introduction

If you have been directed to this booklet, you have experienced the death of someone close to you. We are very sorry for your loss, and we know that this can be a very difficult and distressing time. We hope this booklet will help you understand what you can expect from East and North Hertfordshire NHS Trust. This booklet also aims to explain what happens next – including information about how to comment on the care your loved one received and what happens if a death will be looked into by a Coroner. It also provides details of the processes involved if you have any significant concerns about the care we provided and gives you practical advice, support and information.

Contacting us

In addition to this booklet, you should also have received a bereavement folder containing a booklet called 'Following a Bereavement – A practical guide for family and friends' and details of how to make initial contact with the Bereavement Office so that we can advise you of the process that will take place and discuss any questions or concerns you may have.

Understanding what happened

As a family member, partner, friend or carer of someone who has died while in the care of East and North Hertfordshire NHS Trust, you may have comments, questions or concerns about the care and treatment they received. You may also want to find out more information about the reasons for their death. Your questions or concerns can be discussed with the Bereavement Assistant during your initial contact, which will be passed to the assigned Medical Examiner Officer (MEO) to discuss with the Medical Examiner (ME) and qualifying doctor. However, please do not worry if you are not ready to ask these questions straight away, or if you think of questions later – you will still have the opportunity to raise these with us when you are ready through the Medical Examiner Office or Bereavement Assistant (see bereavement pack) or our Patient Advice and Liaison Service (PALS).

Telephone: 01438 285811 or email: pals.enh-tr@nhs.net.

It is also important for us to know if you do not understand any of the information we provide. Please tell us if we need to explain things more fully.

Practical information, support arrangements and counselling

We will provide you with information about bereavement support services and practical advice about the things you may need to do following a bereavement. This information is included in the separate booklet called 'Following a Bereavement – A practical guide for family and friends'. This includes:

- Details of how to contact the Bereavement Office, Chaplaincy and Support Services
- A step-by-step guide on what must be done following a death
- Issuing and distributing the Medical Certificate of Cause of Death (MCCD)
- How to arrange an appointment to register the death
- What happens when a death is referred to the Coroner and why this would be required.

Please let us know if we can be of any help regarding these or other issues. The Gov.uk website (www.gov.uk/after-a-death) also provides practical information on what to do following a death.

We know that the death of a loved one is traumatic for families. This can be even more so when concerns have been raised, or when a family is involved in an investigation process. Some families have found that counselling or having someone else to talk to can be very beneficial. You may want to discuss this with your GP, who can refer you to local support. Alternatively, there may be other local or voluntary organisations that provide counselling support that you would

prefer to access. Some examples of organisations that may be able to help you are included in the 'Following a Bereavement' booklet and later in this booklet.

Reviews of deaths in our care

It is important to us that families feel able to raise concerns, as they may highlight issues that may not otherwise have been identified.

Case note reviews (structured judgement reviews) are carried out in a number of circumstances.

The Medical Examiner Service was established by the Government with the intended requirement for Medical Examiners (ME) to provide independent scrutiny of all deaths not taken for investigation by the Coroner.

Within East and North Hertfordshire, all deaths that occur will be reviewed by an ME based at East and North Hertfordshire NHS Trust. The ME is an independent, senior doctor who has not been involved in the care of your relative. Medical Examiner Officers (MEO) will also work closely with the ME and will co-ordinate the process of ensuring the required certificate of cause of death can be issued. You will have a named MEO who will be your main point of contact throughout the process. If the Medical Examiner is concerned that harm may have been caused to a patient, the death will immediately be referred for further local review as detailed below. If they do not feel that harm was done but consider that further review would provide valuable learning for the Trust, the death will be referred for a structured judgement review.

Structured judgement reviews are routinely carried out in NHS trusts on a proportion of all their deaths to learn, develop and improve healthcare, both from examples of excellent care and where it is recognised that care could have been better.

A clinician (usually a doctor), who was not directly involved in the care your loved one received, will look carefully at their case notes. They will look at each aspect of their care and how well it was provided. When a routine review raises a concern that poor care may have resulted in harm to your loved one the case is referred for further local review under our patient safety incident management process detailed below.

We may also carry out a structured judgement review when a significant concern is raised with us about the care we provided to a patient, but this does not appear to relate to a patient safety incident, and where the concerns are not being raised as a formal complaint. We consider a 'significant concern' to mean:

(a) any concerns raised by the family that cannot be answered at the time; or

(b) anything that is not answered to the family's satisfaction, or which does not reassure them.

In such situations we will undertake a structured judgement review for your loved one, to provide an independent perspective to that of the team who cared for your loved one. This review will be used to inform continuing discussions with you.

Aside from structured judgement reviews, there are specific processes and procedures that N H S trusts need to follow if your loved one had a learning disability or autism, is a child, died in a maternity setting or as a result of a mental health-related homicide.

Patient Safety Learning Review

In a small percentage of cases, there may be concerns that the death could be related to a patient safety incident. A patient safety incident is any unintended or unexpected incident, which could have, or did, lead to harm for one or more patients receiving healthcare. Where there is a concern that a patient safety incident may have contributed to a patient's death, a further local review will be undertaken. The purpose of this is to find out what happened and why and identify any potential learning. Whilst it is recognised that this cannot change what has happened to your loved one, the Trust is committed to learning and to reduce the risk of something similar happening to any other patients in the future.

If it is agreed that a learning response is required, we will inform you and explain the process to you. We will also ask you about how, and when, you would like to be involved. We will explain how we will include you in setting the terms of reference (the topics that will be looked at) for the investigation.

In some cases, an investigation may involve more care providers than just East and North Hertfordshire NHS Trust. For example, your loved one may have received care from several organisations (that have raised potential concerns). In these circumstances, this will be explained to you, and you will be told which organisation is acting as the lead.

You will be kept up to date on the progress of the investigation and be invited to contribute. This may include commenting on any draft learning response and sharing your insight both as to what happened and the learning. The Trust recognises the valuable insight that service users can bring to a learning review and will work with you to ensure that this is captured through the process.

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 advocate to accompany them to meetings, etc. Please see details of independent organisations that may be able to help, later in this booklet. You are welcome to bring a friend, relative or advocate with you to any meeting.

Where the death of a patient is associated with an unexpected or unintended incident during a patient's care, staff must follow the Duty of Candour Regulation/Policy (www.cqc.org.uk/guidance-providers/regulations-enforcement/regulation-20-duty-candour). The charity AvMA (Action Against Medical Accidents) has produced information for families on Duty of Candour (www.avma.org.uk/policy-campaigns/duty-of-candour), which is endorsed by the Care Quality Commission.

Coroners' inquests

When a death is referred to the Coroner, the Coroner will use the information provided by the Medical Examiner Office to determine whether a post-mortem is required to establish the cause of death. Dependant on the circumstances of the death, the Coroner may also open an inquest. A Coroner investigates unnatural or violent deaths, where the cause of death is unknown, or because the death took place in prison, police custody or another type of state detention, such as a mental health hospital. An inquest is a fact-finding exercise led by the Coroner to determine the medical cause of death, the circumstances of someone's death and the conclusion of the Coroner as to the death The investigation may also include an inquest hearing.

We will inform you of the decision to refer the death to the Coroner and the reason for this decision. If we do not refer a death to the Coroner, but you do not agree with the cause of death as agreed by the Medical Examiner and qualifying doctor, we will make a referral to the Coroner for a post-mortem to take place.

We can provide you with contact details for Hertfordshire Coroner's Office should you have any queries. Please contact the Bereavement Assistant: Telephone 01438 284634

If you are seeking or involved in an inquest, you may wish to find further independent information, advice or support. There are details of organisations that can advise on the process, including how you can obtain legal representation, at the end of this booklet.

At the end of the inquest, the Coroner will register the death with the registrar for the district where the death happened. The family may then apply for a death certificate through the registrar by completing an application form provided at the conclusion of the inquest.

Providing feedback, raising concerns and/or making a complaint

Providing feedback: We want to hear your thoughts about your loved one's care. Receiving feedback from families helps us to understand the things we are doing right and need to continue, and the things we need to improve.

Raising concerns: It is very important to us that you feel able to ask any questions or raise any concerns regarding the care your loved one received. In the first instance, the team that cared for your loved one should be able to respond to these. After this, your named contact at East and North Hertfordshire NHS Trust is the best person to answer your questions and concerns. Also, as already mentioned, when you are contacted by the Medical Examiner you can raise any concerns you have with them. An important part of their role is to provide you with an opportunity to raise any concerns with a doctor who was not involved in the care of your loved one. Additionally, in the first instance, you may prefer to speak to our Patient Advice and Liaison Service (PALS) team who are here to help you (contact details provided on page 3).

Making a complaint: We will do our best to respond to any questions or concerns that you have. Additionally, you can raise concerns as a complaint, at any point. If you do this, we will ensure that we respond, in an accessible format (followed by a response in writing where appropriate to your needs), to the issues you have raised.

If you wish to make a formal complaint, please write to:
Chief Executive, East and North Hertfordshire NHS Trust, Lister Hospital (L66), Coreys Mill Lane, Stevenage, Herts SG1 4AB or call the Complaints Team on 01438 284387, or email: patcomplaints.enh-tr@nhs.net.

Our complaints procedure is available on our Trust website (www.enherts-tr.nhs.uk) or you can request a copy by contacting our Patient Advice and Liaison Service (PALS) team.

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 we decide not to investigate in these circumstances, you can contact the Parliamentary and Health Service Ombudsman (PHSO).

Please note you do not have to wait until an investigation is complete before you complain – both processes can be carried out at the same time. For example, a complaint can trigger an investigation if it brings to light problems in the care that were not previously known about. However, if both the complaint and investigation are looking at similar issues, we may not be able to respond to the complaint until the associated investigation is complete.

If you are not happy with the response to a complaint, you have the right to refer the case to the

Parliamentary and Health Service Ombudsman (PHSO). PHSO has produced 'My expectations for raising concerns and complaints for users of health services'. It sets out what you should expect from the complaints process. A report and a summary can be read on the PHSO's website: www.ombudsman.org.uk/publications/my-expectations-raising-concerns-and-complaints

Please see the frequently asked questions at the end of this booklet for more information on what to do if you are not happy with the responses you receive from us.

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 of 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.

Some of the independent organisations may be able to find you an 'advocate' if you need support when attending meetings. They may also direct you to other advocacy organisations that have more experience of working with certain groups of people, such as people with learning disabilities, mental health issues, or other specialist needs.

The list below does not include every organisation, but the ones listed should either be able to help you themselves or refer you to other specialist organisations best suited to addressing your needs.

In addition, all local authorities (councils) should provide an independent health complaints advocacy service, which is independent of NHS trusts, that people can access free of charge. If you would like to use this service, please contact Healthwatch Hertfordshire on 01707 275978.

We may also be able to provide you with details of other organisations and services that provide local support, and if relevant, we would be happy to talk these through with you.

Local/regional organisations

- **Healthwatch Hertfordshire:** The consumer champion for health and social care. Healthwatch Hertfordshire, Kings Court, London Road, Stevenage, Hertfordshire, SG1 2NG.

  Email: info@healthwatchherfordshire.co.uk.
  Tel: 01707 275978
  Website: www.healthwatchhertfordshire.co.uk
- **POhWER:** Offers general advocacy services in many areas across the country. In Central and East of England services are provided in Buckinghamshire, Hertfordshire, Luton, Norfolk and Suffolk.

  www.pohwer.net/central-and-east-of-england
- **VoiceAbility:** Provides NHS complaints advocacy giving telephone/advocacy support to make a complaint about the NHS, signposting different options and providing information and contact details or one to one support to make a complaint. It provides this service in Birmingham, Cambridgeshire, London, Northamptonshire, Peterborough and Suffolk.

  www.nhscomplaintsadvocacy.org – 0300 303 1660.

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. 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.

  www.avma.org.uk – 0845 123 2352.

- **Advocacy after Fatal Domestic Abuse:** Specialises in guiding families through Inquiries including domestic homicide reviews and mental health reviews, and assists with and represents on inquests, Independent Police Complaints Commission (IPCC) inquiries and other reviews.

  www.aafda.org.uk – 07887 488 464.

- **Child Bereavement UK:** Supports families and educates professionals when a baby or child of any age dies or is dying, or when a child or young person (up to age 25) is facing bereavement. This includes supporting adults to support a bereaved child or young person. All support is free, confidential, has no time limit, and includes face to face sessions and booked telephone support.

  www.childbereavementuk.org – 0800 028 8840.

- **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.

  www.childdeathhelpline.org.uk – 0800 282 986.

- **Cruse Bereavement Care:** Offers free confidential support for adults and children when someone dies, by telephone, email or face-to-face.

  www.cruse.org.uk – 0808 808 1677.

- Guide for bereaved families: offers a guide for families and information on Coroner Services.

  https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/859076/guide-to-coroner-services-bereaved-people-jan-2020.pdf

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

  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'.

  www.inquest.org.uk– 020 7263 1111 option 1.

- **National Survivor User Network:** Is developing a network of mental health service user 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.

  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.

  www.patients-association.org.uk – 0800 345 7115.

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

  www.respond.org.uk – 020 7383 0700.

- **Sands:** Supports those affected by the death of a baby before, during and shortly after birth, providing a bereavement support helpline, a network of support groups, an online forum and message board.

  www.sands.org.uk – 0808 164 3332.

- **Support after Suicide Partnership:** Provides helpful resources for those bereaved by suicide and signposting to local support groups and organisations.

  www.supportaftersuicide.org.uk

- **The Law Society:** Can help you to locate a firm in your area with appropriate experience should you require any legal representation or legal advice.

  https://solicitors.lawsociety.org.uk/

Acknowledgement and thanks

The NHS is very grateful to everyone who has contributed to the development of this information. In particular, we would like to thank all of the families who very kindly shared their experiences, expertise and feedback to help develop this resource.

This information has been produced in parallel with 'Learning from Deaths – Guidance for NHS trusts on working with bereaved families and carers', which can be found at www.england.nhs.uk/publication/learning-from-deaths-guidance-for-nhs-trusts-on-working-with-bereaved-families-and-carers

Future updates to this information

Please note that this information will be updated in the future as a result of expected new guidance and processes. These include:

- The outcome of the consultation on the Serious Incident Framework
- Guidance on Child Death Reviews
- The ambition in the original CQC report 'Learning from Deaths' to include **all** providers of NHS commissioned care, including primary care
- Further policy developments that may be of relevance.

Frequently asked questions (FAQs)

What should I do if I have concerns about the treatment my relative/friend received prior to their death?

Please speak to your named contact at the Trust, the staff involved in the treatment of your loved one, or the Patient Advice and Liaison Service (PALS). You can also raise your concern with the Medical Examiner when you are contacted by them. If necessary, you can ask for an investigation. You can also make a formal complaint, either to the Trust directly or to the relevant Integrated Care Board (ICB) – please see below for more information.

Who orders a post-mortem or inquest?

In some cases, we refer deaths to the Coroner and in some cases the Coroner may then order a post-mortem to find out how the person died. Legally, a post-mortem must be carried out if the cause of death is potentially unnatural or unknown. The Coroner knows this can be a very difficult situation for families and will only carry out a post-mortem after careful consideration. A family can appeal this in writing to the Coroner, giving their reasons, and should let the Coroner know they intend to do this as soon as possible. However, the Coroner makes the final decision, and if necessary, can order a post-mortem even when a family does not agree. Please note that the body of your loved one will not be released for burial until any post-mortem is completed, although the Coroner will do their best to minimise any delay to funeral arrangements. You can speak directly to the local Coroner's office about having a post-mortem and/or inquest.

What should I do if I think the treatment was negligent and deserving of compensation?

Neither patient safety investigations nor complaints will determine liability or deal with compensation, but they can help you decide what to do next. You may wish to seek independent advice, for instance from Action against Medical Accidents (see the section on 'Independent information, advice and advocacy'). They can put you in touch with a specialist lawyer if appropriate. Please note, there is a three-year limitation period for taking legal action, unless the deceased was under 18 or did not have capacity, in which case the usual limitation rules do not apply. A family can make a claim of clinical negligence either before or after the inquest. The inquest is a separate process, and the Coroner does not decide whether there has been negligence, although the findings of the Coroner might help inform an approach to a claim.

What should I do if I think individual health professionals' poor practice contributed to the death and remains a risk to other patients?

Lapses in patient safety are almost always due to system failures rather than individuals. However, you may be concerned that individual health professionals contributed to the death of your loved one and remain a risk. If this is the case, you can raise your concerns with the Trust or go directly to one of the independent health professional regulators listed below.

Where can I get independent advice and support about raising concerns? Please see the section on independent information, advice and advocacy, which details a range of organisations. Other local organisations may also be able to help.

Other organisations that may be of help:

- **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 'Feedback on care' link on their website.
  Visit: www.cqc.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:
  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). Visit
  www.hsib.org.uk

- **Integrated Care Board (ICB)**
  ICBs are responsible for managing the NHS budget and arranging for the provision of health services within the local Integrated Care System area. Complaints can be made to the relevant ICB instead of us, if you prefer. Please ask us for contact details of the relevant ICB(s) or visit
  www.england.nhs.uk/integratedcare/ics-leadership

- **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.
  Visit: www.england.nhs.uk/contact-us or telephone 0300 311 22 33

- **Nursing and Midwifery Council (NMC)**
  The NMC is the nursing and midwifery regulator for England, Wales, Scotland and Northern Ireland. From autumn 2018 it 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 website 'concerns' section:
  www.nmc.org.uk

- **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. www.ombudsman.org.uk – 0345 015 4033

The information in this booklet can be made available in alternative formats, such as easy read or large print, and may be available in alternative languages, upon request.

To request this please contact East and North Hertfordshire NHS Trust:
Telephone: 01438 284387 or email: ais.enh-tr@nhs.net

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