A lifetime of specialist care

Royal Brompton & Harefield NHS
NHS Foundation Trust

Information for families following a bereavement

April 2019

Contents

This information has been adapted from a document produced by the National Quality Board and was developed with the support of families and healthcare organisations.

Introduction

This leaflet has been given to you because of the recent death in hospital 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 leaflet will help you understand what you can expect from Royal Brompton & Harefield NHS Foundation Trust. This leaflet 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 has been referred to a coroner. It also provides details of practical advice, support and information that is available to you.

Contacting us

In addition to this leaflet, you should also have received a bereavement pack from us, either in advance, or accompanying this leaflet. The pack should include the details of someone in the Trust who you can contact for support and if you have any questions. Please do get in touch with them if you want to provide comments, ask questions or raise any concerns.

If you need to speak to someone immediately and have not yet received a letter from us, please contact the bereavement team on **01895 828 638** for Harefield Hospital and **0330 12 88121 ext 82268** for Royal Brompton Hospital, or email **pals@rbht.nhs.uk**.

Understanding what happened

It is not unusual following the death of a loved one to have questions, now or in the future, about the care or treatment your loved one received while under the care of Royal Brompton & Harefield NHS Foundation Trust – please do raise these with the bereavement team. Do not worry if you are not ready to ask these questions straight away, or if you think of questions later – you will still be able to raise these with us when you are ready, again through the bereavement team.

It is also important for us to make sure that you have understood any information given to you.

Please tell us if we need to explain things more fully or if you would like to have a meeting with those who cared for your loved one.

Practical information, support arrangements and counselling

Our bereavement team will provide you with information about bereavement support services and practical advice about the things you may need to do following a bereavement. This could include:

- collecting any personal items belonging to the person who has died
- making arrangements to see the person who has died
- the collection of the Medical Cause of Death certificate
- how to register the death.

The gov.uk website (**www.gov.uk/after-a-death**) also provides practical information on what to do following a death.

Bereavement team on **01895 828 638** for Harefield Hospital and **0330 128 8121 ext 82268** for Royal Brompton Hospital.

Multi-faith Chaplaincy Team **0330 128 8121 ext 88060**.

Counselling support

We know that the death of a loved one can be very traumatic for families. This can be even greater 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 use. Some examples of organisations that may be able to help you are included later in this leaflet.

Reviews of deaths in our care

Case note reviews (or case record reviews) are carried out in different circumstances. Firstly, case note reviews are routinely carried out by NHS trusts on a proportion of all patient deaths to learn, develop and improve healthcare. They are also carried out when a problem in care may be suspected.

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 finds any issues with a patient's care, we contact their family to discuss this further.

Secondly, we also carry out case note reviews when a significant concern is raised with us about the care we provided to a patient. 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.

This may happen when a death is sudden, unexpected, untoward or accidental. When a significant concern has been raised, we will undertake a case note review for your loved one and share our findings with you.

Aside from case note reviews, there are special processes and procedures that trusts need to follow if your loved one had a learning disability. If this is the case, we will provide you with the relevant information on these processes.

Investigations

In a small percentage of cases, there may be concerns that the death could be, or is 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 safety investigation is undertaken. The purpose of a safety 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 any other patients in the future.

If an investigation is to be held, 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 the investigation if you wish. Investigations may be carried out internally or by external investigators, depending on the circumstances.

In some cases, an investigation may involve more care providers than just Royal Brompton & Harefield NHS Foundation Trust. For example, your loved one may have received care from several organisations (that have raised potential concern). In these circumstances, this will be explained to you, and you will be told which organisation is leading the investigation.

You will be kept up to date on the progress of the investigation and be invited to contribute if you wish. After the report has been signed off, the Trust will make arrangements to meet you to discuss the findings of the investigation further.

You may find it helpful to get independent advice about taking part in investigations and other choices open to you. Some people also find it helpful to have an independent advocate to accompany them to meetings etc. You are welcome to bring a friend, relative or other advocate with you to any meeting. Please see details of independent organisations that may be able to help, later in this leaflet.

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-dutycandour**). The charity Action Against Medical Accidents (AvMA – **www. avma.org.uk**) has produced information for families on Duty of Candour which is supported by the Care Quality Commission.

Coroners' inquests

Some deaths are referred to the coroner, for example where the cause of death is unknown. When a death is referred to the coroner they may require a post mortem examination. The coroner will then decide whether an investigation and inquest are required to establish the cause of the death. An inquest is a 'fact finding' exercise which normally aims to determine the circumstances of someone's death.

We will let you know if we have referred the death to the coroner. If we do not refer a death to the coroner, but you have concerns about the treatment we provided, you can ask the coroner to consider holding an inquest. It is a good idea to do this as soon as possible after your loved one has died. Delays in requesting an inquest may mean that opportunities for the coroner to hold a post mortem are missed.

We can provide you with contact details for the appropriate coroner's office:

- For deaths that have taken place at Royal Brompton Hospital – Westminster Coroner **020 7802 4750**.

- For deaths that have taken place at Harefield Hospital – West London Coroners **020 8753 1164**.

If you are involved in, or hoping to have 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 leaflet.

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 (i) the things we are doing right and need to continue, and (ii) the things we need to improve upon. A feedback form can be found in the bereavement pack.

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, a member of the bereavement team at Royal Brompton & Harefield NHS Foundation Trust is the best person to help you find answers to questions and concerns. However, if you would prefer to speak to someone who was not directly involved in your loved one's care, our Patient Advice Liaison Service (PALS) team will be able to help. PALS can be contacted on **020 7349 7715** (Royal Brompton Hospital) or **01895 826 572** (Harefield Hospital) or **pals@rbht.nhs.uk**.

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 make sure that we respond to the issues you have raised. You may raise a complaint by contacting PALS (see above) or by writing to the chief executive. 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 sooner we will review your complaint and decide whether it would still be possible to fairly and reasonably investigate.

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, a complaint response could be paused until the investigation is complete.

If you are not happy with the response to a complaint or a decision has been made not to investigate your complaint because it is over the 12 month cut-off, 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. You can access this at **www.ombudsman.org.uk/publications/my-expectations-raising-concernsand-complaints**.

Please see the frequently asked questions section at the end of this leaflet 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 regarding 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 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 special needs.

The lists on the following pages do 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.

The NHS Complaints Advocacy Service is independent and free of charge. It provides practical support and information for those who want to complain about an NHS service. It can be contacted on **0300 330 5454** / **07860 022 939** (Textphone) or emailed **nhscomplaints@voiceability.org**. Further information is available at **www.nhscomplaints advocacy.org**.

In addition all local authorities (councils) should provide an independent health complaints advocacy service, which is independent of the Trust, that people can access free of charge. If you would like to use this service, please contact your local authority service or your local health advocacy provider. 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

South East Advocacy Projects

Provides a range of general advocacy services across the south of England.

www.seap.org.uk

Swan Advocacy

Provides advocacy services in north Somerset and south Gloucestershire, Somerset and Wiltshire, including generic advocacy and independent health complaints advocacy to support people to complain about NHS services and has expertise where bereavement or end of life care are a factor.

www.swanadvocacy.org.uk

POhWER

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

www.pohwer.net

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 for one to one support to make a complaint. It provides this service in Birmingham, Cambridgeshire, London, Northamptonshire, Peterborough and Suffolk.

www.nhscomplaintsadvocacy.org / 0300 330 5454

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 23 45

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 / 07768 386 922

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

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 / 020 726 3111 option 1

National Survivor User Network

Is 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.

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 Care Quality Commission.

www.patients-association.org.uk / 020 8423 8999

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

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

Other organisations that may be of help

Clinical commissioning groups (CCGs)

Clinical commissioning groups pay for and monitor services provided by NHS Trusts. Complaints can be made to the relevant CCG instead of us, if you prefer. Please ask us for contact details of the relevant CCG(s) or visit:

www.england.nhs.uk/ccgdetails

Parliamentary and Health Service Ombudsman (PHSO)

The PHSO makes final decisions on complaints that have not been resolved by the NHS in England and UK government departments. It shares findings from its casework to help parliament scrutinise public service providers. It also shares 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

Care Quality Commission (CQC)

The CQC is the regulator for health and social care in England. The CQC is interested in hearing about concerns as general intelligence on the quality of services, but please note that it does not investigate individual complaints.

www.cqc.org.uk

National Reporting and Learning System (NRLS)

Members of the public can report patient safety incidents to the NRLS. This is a database of incidents administered by NHS Improvement, which is used to identify patient safety issues that need to be addressed. Please note though that reports are not investigated or responded to.

www.improvement.nhs.uk/resources/report-patient-safety-incident

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.

Email: **england.contactus@nhs.net / 0300 311 22 33**

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 its work. The service is already providing support and a full service will be up and running by autumn 2018. More information can be found within the 'Concerns about nurses or midwives' section on its website:

www.nmc.org.uk

General Medical Council (GMC)

The GMC maintains the official register of medical practitioners within the United Kingdom. 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 at:

www.gmc-uk.org

Healthcare Safety Investigations Branch (HSIB)

HSIB's purpose is to improve safety through effective and independent investigations that don't 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).

www.hsib.org.uk

Frequently asked questions (FAQs)

What should I do if I have concerns about my relative/friend's treatment contributing to their death?

Please speak to a member of the bereavement team on **01895 828 638** for Harefield Hospital and **0330 12 88121 ext 82268** for Royal Brompton Hospital and they will arrange for you to speak to the staff involved in the treatment of your loved one, or the Patient Advice and Liaison Service (PALS). If necessary, you can ask for an investigation. You can also make a formal complaint, either to the Trust directly or to the relevant clinical commissioning group (CCG) – 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. Families 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, a 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 it is completed, although a coroner will do his/her best to minimise any delay to funeral arrangements. You 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 establish liability or deal with compensation, but they can help you decide what to do next. You may wish to seek independent advice from Action against Medical Accidents (see the section

on 'Independent information, advice and advocacy' on page 9). It can put you in touch with a specialist lawyer if appropriate. Please note that there is a three-year limitation period for taking legal action.

What should I do if I think an individual's 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 us or go directly to one of the independent health professional regulators.

Where can I get independent advice and support about raising concerns?

Please see the section on independent information, advice and advocacy (page 9), which details a range of organisations.

Acknowledgement and thanks

The NHS is very grateful to everyone who has contributed to the development of this information. In particular, they 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**.

If you have any concerns about any aspect of the service you have received in hospital and feel unable to talk to those people responsible for your care, call Patient Advice and Liaison Service (PALS):

- Royal Brompton Hospital – 020 7349 7715
- Harefield Hospital – 01895 826 572

Alternatively email pals@rbht.nhs.uk. This is a confidential service.

Royal Brompton Hospital
Sydney Street
London
SW3 6NP
tel: 0330 12 88121

Harefield Hospital
Hill End Road
Harefield
Middlesex
UB9 6JH
tel: 0330 12 88121

Website: www.rbht.nhs.uk

إذا كنت ترغب في الحصول على ترجمة فورية لمضمون هذه الوثيقة إلى اللغة العربية، يرجى منك الاتصال بأحد مستخدمينا بجناح المصلحة التي يتم فيها استشفائك. أحد موظفينا سيسعى لترتيب إجراءات الترجمة وإتمامها في الوقت المناسب لك.

Brosurteki bilginin Turkçe tercumesi için tedavi goruyor oldugunuz bolume bas vurunuz. Bolum personeli tercumenin gerçeklesmesini en kisa zamanda ayarlacaktir.

 April 2019