

National Quality Board

First edition, July 2018



Learning from deaths

Guidance for NHS trusts on working with bereaved families and carers

This document was developed by NHS England on behalf of the National Quality Board (NQB).

The NQB provides coordinated clinical leadership for care quality across the NHS on behalf of the national bodies:

- NHS England
- Care Quality Commission
- NHS Improvement
- Health Education England
- Public Health England
- National Institute for Health and Care Excellence
- NHS Digital
- Department of Health

For further information about the NQB, please see:

<https://www.england.nhs.uk/ourwork/part-rel/nqb/>

A variety of stakeholders has been involved in the development of this guidance including:

- bereaved families,
- advocacy organisations,
- NHS trusts,

Along with the national bodies listed above.

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Forewords

Foreword from National Quality Board members

The NHS is there to provide expert care and to do this with compassion. We are committed to creating a learning culture, where we listen to experiences and use what we hear to drive improvements. Every day we hear stories from patients, and from families of patients, about the care they have received from the NHS. In the main these stories are overwhelmingly positive: they are about lives being saved or transformed; truly dedicated and inspirational staff; and cutting edge healthcare.

However, we also hear about the experiences of families and carers of those who were harmed or died due to errors in NHS healthcare. These events are tragic and terrible, and have long-lasting consequences for the families and carers involved. When someone dies we should minimise the suffering and distress for families.

This new guidance, issued by the National Quality Board (NQB), is about improving how we engage with families and how we learn when things go wrong. It consolidates existing guidance and provides a perspective from many family members, who have experienced a bereavement within the NHS.

The guidance advises trusts on how they should support, communicate and engage with families following a death of someone in their care. We have not mandated a 'one size fits all' approach in recognition that each family and each trust is different. We hope that trusts will use the good practice it sets out to complement and improve work they are already doing to support families.

Families' insights and experiences have shaped the guidance. Some have spoken of not being treated with respect, sensitivity and honesty at the worst point of their lives. This is especially the case in circumstances where there may have been or were issues with the care provided.

We know that some trusts have already made significant progress on how they engage with families. Change is happening and there are already good examples to learn from and implement in other areas. However, we must continue to move forward and involve families and carers in this change - we will fall at the first hurdle if we do not value, respect and work with them.

We believe that the principles set out in this guidance will help trusts and commissioners to identify where they can make improvements in how they engage with families; and how they involve families in improving systems and processes.

The guidance will also be a source of information for families so they know what they can expect following the loss of their loved one. It will send a clear message that they will be listened to and their experiences will be taken seriously. We are grateful to the families that worked with NHS England to develop this guidance and thank them for their support.

We call on trust boards and commissioners to review and respond to this guidance, to champion an ethic of learning in the NHS and commit to the culture change



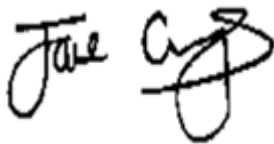
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Foreword from families on the Learning from Deaths

Steering Group

Under any circumstances, losing a loved one can be traumatic, and the level of support provided to families by the NHS at this time can make a considerable difference. However, there are families whose loved ones have died in untoward circumstances and whose subsequent experience has been deeply at odds with what we expect from our highly valued NHS. It is the voice of these families that we are part of, and which we have tried to represent. Over 70 such families have supported this guidance's development, with more involved either through email updates or social media.

Families like ours have experienced significant harm and have struggled to get the answers we need from the NHS. Our traumatic experiences have included the deaths of children in acute care; disabled children in NHS commissioned care; adult suicides in the care of mental health trusts; and preventable deaths of elderly relatives. In this, the NHS has failed us. Firstly, trusts have not supported us after the avoidable loss of a much-loved family member. Secondly, we have had to fight our way through a defensive system to try to get to the answers we need.

Many of the families involved have experienced trauma as a consequence of this experience – and some have experienced breakdowns of mental and physical health, or the fracturing of their own relationships. Families have also been placed into financial hardship as a result of fighting to understand what really happened. This simply cannot be right. We need to know how and why our loved ones died. Yet the culture has often worked against this, especially when families have had limited, if any, involvement.

Families understand that the systems NHS staff work in are often under strain; and that as a result, mistakes are made. However, when families have to fight a system, often for years, this benefits no one. In some circumstances, trusts have overlooked the essential information a family brings to an investigation, thereby missing opportunities for invaluable learning. Families would much rather work with trusts to understand what happened. We want to be part of the process to identify the things that went well; and the things that went wrong, to ensure these errors are never repeated.

We saw the acceptance of the CQC's report 'Learning, Candour and Accountability' as a milestone. It marked a clear recognition that there were problems in the way the NHS has engaged with families after the death of a loved one; and the need to ensure investigations into the care provided are robust when things go wrong. We are therefore encouraged to see that some good practice is emerging, demonstrating that change for the better is achievable.

This guidance will benefit all those involved following a death. In particular, we believe it will support staff and families after an unexpected, avoidable or traumatic death in NHS care. It has the potential to break down the 'them and us' culture that we have experienced. Used well, this guidance will support staff in knowing what to

do and how to do it; and families will better know what to expect and what will happen; making it easier for all to negotiate their way through this difficult time.

We urge you to embrace this guidance. It has the potential to produce the dramatic change the CQC proposed; reducing trauma to the bereaved; and giving real meaning to the term 'learning from deaths'.

Families involved in the Learning from Deaths Steering Group

Introduction

This guidance is for NHS trusts, NHS foundation trusts and for services provided through NHS England specialised commissioning. It consolidates existing guidance and provides perspectives from family members who have experienced a bereavement within the NHS. It details how trusts should support and engage families after a loved one's death in their organisation's care.

The information in this guidance can also be used by families following a bereavement. Therefore it includes explanations of some terms and processes that will be familiar to NHS staff and board members. Clinical commissioning groups (CCGs) should familiarise themselves with this guidance, as they are responsible for commissioning services from trusts and have a monitoring and assurance role.

We use the term 'families' in the broadest sense; it covers people closest to the person who has died, including friends, partners and carers. Similarly, the term 'trusts' covers all types of trusts and NHS England specialised commissioning services.

Other care providers such as primary care, hospices and private providers could use the document as a best practice guide to involving families.

Although the guidance highlights general good practice for engaging families following a death, it particularly focuses on engagement when a death is subject to an investigation, or where concern arises that problems occurred in care related to the death. Families can use it to find out what to expect when a loved one dies while in a trust's care.

This guidance is complemented by *Information for families following a bereavement* (Annex 1). This is additionally available as an editable PDF, an easy-read version, and a plain text version. This information should supplement trusts' own information and resources for bereavement support for families. Both the guidance for trusts and information for families have been developed by NHS England in collaboration with families who have experienced the death of someone in NHS care and been involved in NHS investigations, as well as with voluntary sector organisations. It has also been informed by feedback from trusts and other NHS organisations.

Context

The Care Quality Commission (CQC) report [*Learning, candour and accountability: a review of the way NHS trusts review and investigate the deaths of patients in England*](#) emphasised that the way trusts engage with families had to improve significantly.

Following the CQC report, in March 2017 the National Quality Board (NQB) published [*Learning from Deaths guidance*](#), which directed NHS England to:

“develop guidance for bereaved families and carers, identifying good practice for local services on the information that families say they would find helpful. It will cover what families can expect by way of local support in relation to investigations and what to expect when services have identified the death as complex or needing an independent investigation so potentially involving longer timeframes and multiple agency involvement.”

NQB’s guidance of March 2017 sets clear expectations for how trusts should engage meaningfully and compassionately with bereaved families and carers at all stages of responding to a death. It also described trust boards’ responsibilities for ensuring effective implementation of all aspects of learning from deaths, including timely and compassionate engagement with bereaved families.

Boards are responsible for embedding a culture of learning and transparency across their organisations, and for ensuring that the needs and views of patients, families and carers are considered in everything the trust does. Boards should be committed to changing the balance of power and have regard to the need to promote equality, in line with the Public Sector Equality Duty {Equality Act 2010}. They should ensure that family involvement focuses on inclusivity, representation, non-discrimination and empowerment.

This guidance aims to align with CQC’s new approach to assessing the [‘well-led’ domain within its inspection framework](#), which includes assessing how trusts have implemented NQB’s Learning from Deaths guidance of March 2017.

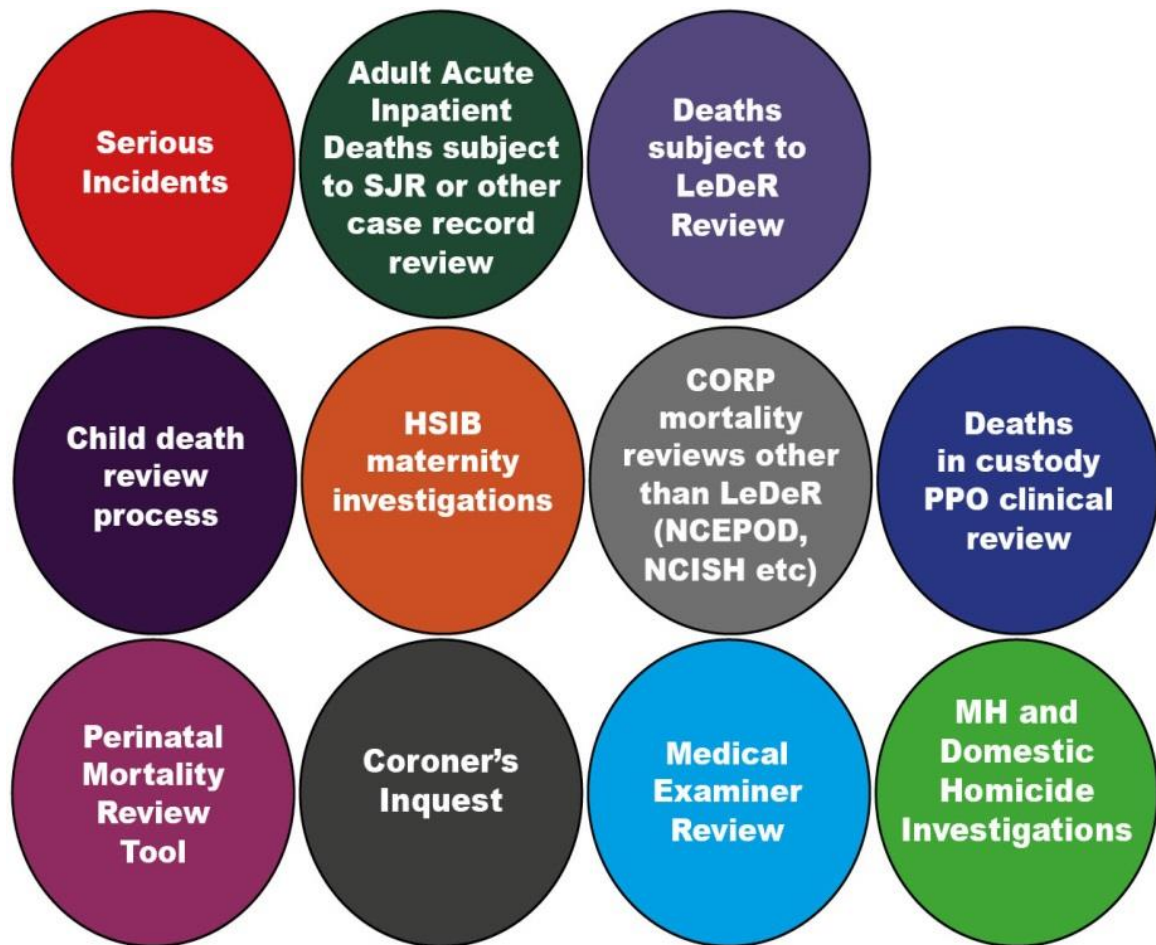
Other relevant guidance

This guidance complements and should be read in conjunction with:

- [Duty of Candour](#)
- [Serious Incident Framework](#)¹
- [NHS complaints procedure](#)
- where appropriate, [Safer Maternity Care](#).

This guidance also complements other parts of the Learning from Deaths programme (see diagram on page 10). Trusts should be familiar with their specific requirements.

¹ The Serious Incident Framework is currently under review, and an updated version will be published by the end of 2018.



Key:
CORP: Clinical Outcome Review Programme
LeDeR: Learning Disabilities Mortality Review
MH: Mental Health
NCEPOD: National Confidential Enquiry into Patient Outcome and Death
NCISH: National Confidential Inquiry into Suicide and Homicide by People with Mental Illness
PPO: Prisons and Probation Ombudsman
SJR: Structured Judgement Review
HSIB: Healthcare Safety Investigation Branch

This guidance should be used alongside the complaints process, as an investigation and a complaint can take place at the same time. For example, a complaint can trigger an investigation, if it brings to light previously unknown problems in care. However, if both the complaint and investigation are looking at similar issues, a complaint could be paused until the investigation is complete.

This guidance complements specific guidance on child death reviews which trusts and other providers are expected to follow when it is published. It also complements *When a child dies – a guide for families and carers*.

This guidance also complements guidance on independent investigations. NHS England is responsible for commissioning independent investigations of mental healthcare related homicides if the perpetrator is, or has been, under the care of specialist mental health services or received a package of care for their mental health problems (care programme approach) in the six months before the homicide. These investigations are for learning and to prevent recurrence.

Family involvement in developing the guidance

Some trusts already demonstrate good practice in involving families in learning from deaths, and examples are emerging across the system in response to NQB's guidance. Families welcome this as a positive step.

It is important to acknowledge however that some families' experiences of the NHS have been challenging and distressing. In helping to develop this guidance, families spoke of traumatic experiences and cover-ups, which led to a lack of trust in the NHS and amplified their grief.

Over 70 families shared their experiences to highlight where improvements can be made. They attended events in November 2017 with staff from trusts and voluntary organisations, and they had ongoing input through email updates and the Learning from Deaths Steering Group. We include quotes from the November 2017 events, and some practice examples which families identified.

Families explained they want to be involved when things go wrong because they wish to:

- know the truth about their loved one's death,
- highlight opportunities for learning,
- be reassured that others will not face similar problems.

Families said legal action was usually a last resort and a final attempt to find out what happened. They preferred to work with a trust as equal partners from the start.

The families showed great commitment to developing this guidance and a desire to help improve the way trusts and families work together. They are driven by a need to shift relationships between staff and families, and encourage true learning from deaths through openness and honesty.

Scope

This guidance does not mandate a 'one size fits all' approach to how trusts should support bereaved families, as every family has its own needs and wishes and will grieve in its own way. Many trusts have their own approaches to supporting bereaved families, developed with family involvement, and review them regularly.

Trusts should be aware of local and national support for bereaved families. This includes organisations offering specialist support – for example, following the death of:

- a child,
- someone with mental health problems,
- someone with a learning disability,
- someone who died in a maternity setting.

We will update this guidance as new processes are implemented and other related guidance is published. These include:

- any update to the Serious Incident Framework following the current consultation,
- implementation of the medical examiner's role,
- guidance on child death reviews,
- the ambition in *Learning, candour and accountability* to include all providers of NHS commissioned care, including primary care and ambulance trusts, within the scope of this programme,
- further relevant policy developments.

Trusts should review and update their policies when the expected new guidance is published.

The Learning from Deaths Programme Board will continue its work and oversee developments across the NHS. It will continue to consider issues faced by families and by NHS organisations and staff, as well as further opportunities for learning and improvement.

1. Guiding principles

NQB's guidance set the principles that families can expect trusts to follow after the death of someone in NHS care – see below. Families who helped develop this guidance asked that these principles be expanded; and for more detail to be included, to reflect their feedback and experiences. This is shown in blue text.

Key principles that bereaved families can expect will be followed

1. Bereaved families and carers should be treated as equal partners following a bereavement

- a. Trusts should be mindful of the imbalance of power represented by the finances, resources, information and knowledge available to them compared to families.
- b. Trusts should try to lessen this inequality by ensuring families are listened to. They should use plain, understandable language to engage families. And they should provide information on how to apply for access to medical and other records.
- c. Trusts should have a clear policy for engaging with bereaved families and carers. This should include a commitment to welcoming their questions or sharing concerns about the quality of care their loved one received.

2. Bereaved families and carers must always receive a clear, honest, compassionate and sensitive response in a sympathetic environment

- a. Families only receive the news of a loved one's death once. A human rather than clinical approach to communication is important at this time.
- b. They should be treated with respect, kindness, care and compassion.
- c. It is important to recognise that families are grieving; all communications with families should be person-centred. Challenge from families should be received positively.
- d. Trusts should make it a priority to support bereaved families and carers. They should ensure a consistent level of timely, meaningful and compassionate engagement at every stage, including notification of the death (and of the instigation of an investigation, lessons learned and actions taken, where relevant).

3. Bereaved families and carers should receive a high standard of bereavement care which respects confidentiality, values, culture and beliefs, including being offered appropriate support. This includes providing, offering or directing people to specialist suicide bereavement support

- a. Some families that helped develop this guidance never received information about services that could support them, including how to gain access to counselling inside or outside the trust.
- b. The investigation or complaints process is stressful and damaging for families on top of their grieving. They should be offered counselling services appropriate to their needs, or directed to organisations that may help them through these processes.
- c. All families should receive a letter from the trust following the death of a family member in its care. They should also receive information about bereavement support, including points of contact for questions or concerns.

- 4. Bereaved families and carers should be informed of their right to raise concerns about the quality of care provided to their loved one**
 - a. Families should be told about the different ways they can raise concerns, and the processes involved should be explained.
 - b. Trusts should adopt a learning culture that encourages families to raise concerns, as they may highlight issues that may not otherwise be identified.
- 5. Bereaved families' and carers' views should help to inform decisions about whether a review or investigation is needed**
 - a. Families felt they were a lone voice when seeking to have a death investigated and that organisational culture placed corporate defensiveness above concern for the truth.
 - b. Families often have useful information the trust may not be aware of.
 - c. Where an investigation may not be pursued despite a family's concerns, the family should be involved in discussions about why, before the trust reaches a final decision. Families should be told about their options to appeal the decision or raise the issue elsewhere.
- 6. Bereaved families and carers should receive timely, responsive contact and support in all aspects of an investigation process, with a single point of contact and liaison**
 - a. Families need consistent and clear communication from a senior representative with authority to take decisions on the trust's behalf. The communication should be transparent, open and honest.
 - b. Timescales should be agreed with families and kept to, with any missed deadlines explained, where possible in advance.
 - c. Trusts should provide families with easy-to-understand guides and checklists to explain processes and procedures.
 - d. Families should be given contact details for organisations providing advocacy, advice, information and support, in addition to support available within the trust.
- 7. Bereaved families and carers should be partners in an investigation to the extent, and at whichever stages, that they wish to be involved, as they offer a unique and equally valid source of information and evidence that can better inform investigations**
 - a. Some families said they had to become detectives, seeking information through their own initiative and determination, and learning how processes work.
 - b. Families should be central in investigations and treated as equals. This includes being involved in setting the terms of reference and agreeing from the outset how they can be actively involved in any investigation(s).
 - c. Families' views should be welcomed and received positively. The trust should aim to respond fully to points raised; where it cannot, it should explain why.

8. Bereaved families and carers who have experienced the investigation process should be supported to work in partnership with trusts in delivering training for staff in supporting family and carer involvement where they want to.

- a. Trusts should use families' experiences in developing training programmes and materials. This gives staff an opportunity to hear families' voices and experiences first hand.
- b. Trusts should aim to involve families in staff training. Families can tell staff about the impact of poor engagement. This can help staff interact positively with families in future.
- c. Families can help share learning from one trust to another, particularly when they belong to networks of other families in similar situations.
- d. Trusts should recognise that reviewing and investigating deaths offers an opportunity for learning and a key way to improve the quality of care for all patients.
- e. Where trusts receive feedback, including positive and negative comments from bereaved families about the care and support they provide, they are encouraged to share this so others can learn from it.

2. Family involvement before a death

“Death is inevitable and a natural event for all of us, and not all deaths will represent a medical failing or problem in the way the person has been supported during their life.” (CQC: Learning, candour and accountability, 2016).

Many deaths that occur in the NHS are anticipated or expected. When clinicians recognise that a patient may be in the final stage of their illness, or that death is imminent, it is important they meet and talk openly with the patient and their family (if that is what the patient would like). Openness, transparency and listening to patient and family concerns and expectations at this stage are all important. This helps in what many will find frightening and difficult circumstances that they may never, or rarely, have faced before – unlike clinicians. Good communication and relationships when a death is expected or is imminent, are likely to lead to good communication and compassionate care of family members after death. The importance of this cannot be emphasised too strongly.

Trusts should be aware of the guidance on end of life care, including the [Ambitions Framework](#) and the [government's commitment to choice in end of life care](#), both of which emphasise the importance of families and carers.

Trusts should have regard to the [guidance on 'Last Offices'](#) as part of care for the dying patient and the immediate period after death.

3. Immediate actions following a death

Informing families about a death

Families can expect that:

- The trust will engage them in a sensitive and transparent manner and offer sincere condolences for their loss.
- They will be informed immediately or as soon as possible after a death; where possible this should be done in person in a private space.
- The staff member conveying this news will give as much information as they can about the circumstances of the death and answer any questions raised by the family that they can.
- They will be told at the first point of notification that they can comment on the care of the person who has died, and raise any concerns. This should include information on the ways they can comment or complain – for example, by speaking to staff, contacting the Patient Advice and Liaison Service (PALS) and through the NHS complaints process.
- All families should receive a letter from the trust following the death of a family member in its care. They should also receive information about bereavement support, including points of contact for any questions or concerns.
- This information should be supplemented by *Information for families following a bereavement* (Annex 1). This is also available as an editable PDF, an easy-read version, and a plain text version.
- Where relevant, trusts will support staff members to fulfil any responsibilities they have under the Duty of Candour. This includes apologising when the trust is aware that a 'notifiable patient safety incident' has occurred connected to the death.

Good practice: Protocol for informing families of a death

How trusts communicate with families following a death is critically important. It is recommended that trusts develop an easy-to-understand protocol for staff to follow in the event of a death.

Trusts should ensure staff can act sensitively and consistently, confident that they are giving accurate information. Telling families that a person has died in NHS care can be challenging for staff, and trusts need to take into account staff welfare, support and wellbeing.

Trusts should ensure their staff (including family liaison officers, where available) have the necessary skills, expertise and knowledge to work with bereaved families. Staff should have specific training and support in following the protocol. This could include mandatory training, induction sessions and regular access to online and offline training.

Bereavement services and support

Families should be offered access to bereavement services. These should include practical advice and support on:

- collecting death certificates,
- how to register a death,
- collecting personal belongings,
- where to find local bereavement support or counselling.

Where the deceased person received care in a community setting, or from different trusts, normally the lead care provider will be families' key point of contact. It should offer bereavement support, and expect co-operation and collaboration from all the providers involved. Where there is disagreement about which organisation should take the lead in supporting the family, CCGs should take this decision in consultation with the providers involved.

Trusts should be aware of emerging work on developing bereavement pathways; for example, the [National Bereavement Care Pathway](#) helps professionals support families after pregnancy or baby loss. Eleven sites across England are piloting this pathway, and aim to ensure all bereaved parents are offered equal, high quality, individualised, safe and sensitive care.

Good practice: Bereavement pathway

Great Ormond Street Hospital has a clear bereavement pathway stating staff roles and responsibilities at various stages. It covers the process to follow when expected and unexpected deaths occur, including timescales for contact with the family and the information to share with them.

Where there is a bereavement service, all staff should support it by providing timely information and documenting key details. This can speed up processes such as collecting personal belongings and death certificates, and reduce the impact on grieving families.

Trusts should give families clear written information on how to contact support services such as the chaplaincy and PALS, or local and national charities providing advocacy, counselling or legal advice.

If a trust has not already done so, it should produce a localised information sheet to accompany *Information for families following a bereavement* (Annex 1). A list of useful organisations providing support, advocacy or advice can also be found in this document.

Good practice: Information for families

Basildon and Thurrock University Hospitals NHS Foundation Trust gives families practical advice and details of organisations that could support them, such as local charities and helplines. The information covers collecting death certificates, registering a death, how to view a loved one's body, chaplaincy services and the local coroner's contact details. This information is reviewed regularly, with dates set for the next review. A copy can be found on the trust's [website](#).

A loved one's death can be particularly traumatic when concerns have been raised or it is under investigation. Trusts should be aware of this and the importance of telling families about where to get counselling support, including through their GP and voluntary organisations.

Good practice: Family liaison service

Developing a well-trained, supported and motivated family liaison service is an effective way to provide a compassionate service to bereaved families. This should be a distinct service within a trust, with dedicated staff time to provide effective family support.

Examples of trusts that have successfully implemented this type of service are available on the [NHS Improvement website](#).

Raising concerns

Families and carers should be told when notified of a death that they can comment on the care of the person who has died and raise any concerns.

The staff member who tells the family about the death should ask if they have comments, questions or concerns about the care their loved one received or the circumstances of their death. This may not always be appropriate immediately after the death, but should be done at a suitable point.

When a family raises 'significant concerns', this automatically triggers a case note review. 'Significant' means:

- any concerns raised by the family that cannot be answered at the time or
- anything not answered to the family's satisfaction, or which does not reassure them.

Section four contains more details on case note reviews.

Good practice: Encouraging feedback

Gateshead NHS Foundation Trust has developed a letter to encourage families to give their feedback on the care provided to their loved one before they died. The letter refers to how routine reviews help the trust learn and make improvements. The trust follows up the letter with a questionnaire for families.

Families should also receive a written communication from the trust offering condolences and providing a point of contact where families can raise concerns. As previously mentioned, this should be accompanied by *Information for families following a bereavement* (Annex 1).

When communicating with families, trusts should demonstrate their commitment to learning from deaths and using learning to drive improvements. This includes explaining that the trust will review a percentage of deaths to identify both areas for improvement and good practice. The trust should communicate specific details if it has a standardised approach to reviewing certain types of death – for example, when someone with a learning disability has died.

It is important to recognise that families may not feel able to raise concerns, or to discuss their loved one's care, immediately after becoming aware or being informed of their death. They may think of questions or issues they would like to discuss once they have had time to reflect.

It is important to let families know they can provide feedback whenever they are ready, but also tell them about time limits for certain processes – for example, when making a complaint or seeking an inquest.

Whenever families are engaged, repeat the request for their comments, questions or concerns – in subsequent meetings and conversations, and in all relevant written communications.

“Recognise that, in grief, families may change their mind over time about how to engage.”

Family feedback from November 2017 event

Duty of Candour

The [Duty of Candour](#) is a statutory duty to be open and honest with patients (or 'service users'), or their families, when something goes wrong that appears to have caused, or could lead in the future, to significant harm.

The regulations define a 'notifiable safety incident' as "an unintended or unexpected incident... that could result in, or appears to have resulted in the death of a service user... or severe or moderate harm or prolonged psychological harm to the service user".

Families should be told what happened as fully as possible, and in a sensitive way, in person. This should be done as soon as possible after the incident is known about, and it should include an apology. The trust should then write confirming the agreed plans for an investigation and the agreed method and timescales for communication. The written notification must contain all the information provided in person, including the apology, as well as the results of any enquiries since the notification in person. The results of further enquiries and investigations must also be provided in writing to the relevant person, if they wish to receive them.

Trusts should tell families where they can get support, such as counselling if appropriate, or independent advice.

The charity [AvMA \(Action Against Medical Accidents\)](#) has [produced information for families on Duty of Candour](#), which is endorsed by the Care Quality Commission. Trusts are encouraged to share this with families.

Good practice: Condolences and apologies

Offering condolences and expressing sympathy shows compassion and concern for the bereaved family. The most important thing to communicate is that you care and that you are available to provide, or direct them to, the necessary support. This should be offered to everyone.

Trusts should support staff to fulfil their responsibilities under the Duty of Candour, where relevant. This includes making an apology where the trust is aware that a 'notifiable patient safety incident' has occurred connected to the death.

The family engagement that supported the CQC's *Learning, candour and accountability* review showed that some staff often fear saying the wrong thing and making a situation worse. This can lead to them saying nothing. Saying sorry is always the right thing to do. NHS Resolution has produced [a leaflet for NHS staff, called 'Saying sorry'](#).

“Families should be told clearly what’s happened, how it happened and what will happen next.”

Family feedback from November 2017 event

4. Case note reviews

A case note review (also referred to as a case record review) is a structured desktop review of a case record/note, carried out by clinicians, to judge the quality of care provided to someone before their death. Trusts routinely carry out case note reviews on a proportion of all their deaths to learn, develop and improve healthcare, as well as when a problem in care may be suspected.

NQB’s [Learning from Deaths guidance](#) provides a comprehensive list of the circumstances in which a case note review must be undertaken. This includes deaths where bereaved families and carers, or staff, have raised a significant concern about the quality of care.

NOTE: Specific, recognised processes and programmes focus on the deaths of children, people with learning disabilities, maternal deaths and mental health homicides (independent investigations). These deaths are covered by other approaches and governance arrangements. The programmes set out the exact review processes involved when someone from a specific patient group dies, and information about these is publicly available to families. Families should be directed to this information where appropriate, as these processes take precedence over the guidance in this document.

Trusts should explain to the families of all deceased patients that they routinely carry out case note reviews on a proportion of all deaths to learn about the quality of care they provide. They should make clear to families that if the trust reviews the care of their loved one and finds significant problems in that care, they will contact the family to tell them what they have found and what they are doing about it.

A review should be automatically triggered where a family raises a significant concern (as defined on page 18). Once the review is complete, the trust should tell the family about its findings and any next steps.

If a review cannot be carried out because the deceased person’s medical records cannot be found, the loss should be investigated in line with the organisation’s procedures. Every effort should be made to locate the missing records, and details of those efforts should be shared with the family.

If manual hospital records about someone who has died are still within the retention period but are missing, and the data is not available in electronic format, families should be told they can make a complaint. Families may also approach the GP to see if they hold copies of any hospital letters.

Trusts should consider developing a letter or information for families that explains the purpose of reviews and the next steps if any problems in care are identified. This could be part of other written information given to the family, including *Information for families following a bereavement* (Annex 1). This letter could include:

- condolences for the death,
- information that every month the trust review a number of records of patients who die in its care, and that the family's loved one's case may be reviewed as part of this,
- information about case note reviews and how they help the trust take every opportunity to learn from the care it provides – both where care has been good and where there are opportunities to improve,
- an explanation of how families can comment, ask questions or raise concerns about their loved one's care; and that if they raise significant concerns, this would automatically prompt a case note review,,
- a statement that, where a case note review identifies potential problems with the care provided, the trust will share the findings with the family
- information about local and/or national bereavement support available to families.

If a case note review identifies problems in care that the trust was previously unaware of, and which could have contributed to the death, an investigation will be triggered (see section five). Families should be told about the investigation and offered an opportunity to be involved.

Similarly, families should be told if a case note review identifies issues that mean the death should be referred to the coroner. They should be offered support and directed to the coroner's office and to sources of independent advice and support.

Learning Disability Mortality Review

All deaths of people with a learning disability should be subject to structured judgement review. In addition, they should be notified to the Learning Disability Mortality Review Programme ([LeDeR](#)) for allocation to a LeDeR reviewer.

If the person who died was a child, the child death review process must be followed and its findings shared with the learning disability review process.

As all learning disability deaths will be reviewed, we expect these reviews will highlight good practice as well as instances where care should have been improved.

5. Information and participation in an investigation

An investigation is a systematic analysis of what happened, how it happened and why, usually following an adverse event when there are significant concerns about the care provided.

Investigations draw on evidence (including physical evidence, witness accounts, organisational policies, procedures, guidance, good practice and observation) to identify problems in care or how services are delivered, and to understand how and why those problems occurred. The process aims to identify changes needed to the care being provided, to reduce the risk of similar events happening in future.

[The Serious Incident Framework](#) defines a serious incident as an adverse event where the consequences for patients, families and carers, staff and organisations are so significant or the potential for learning is so great, that a heightened level of response is justified. By declaring a serious incident, an organisation is automatically committing to carry out an investigation, and by carrying out an investigation it is identifying that what occurred was a serious incident. We will update this guidance to reflect the revision of the framework currently being undertaken.

Organisations may also carry out other investigations – for example, human resources investigations, but these should be undertaken separately from the safety investigations carried out under the Serious Incident Framework.

If the trust thinks an investigation should be carried out, it should ask the family for their views. When it is agreed that an investigation will be undertaken, families should be fully involved, including in setting the terms of reference for the investigation. Some families will find it difficult to participate in investigations and may need access to independent information advice and/or advocacy. If this is the case trusts should give families details of independent advocacy services that can help (see section six).

“Investigative process shouldn’t feel like ‘them’ and ‘us’ – it should not feel combative.”

Family feedback from November 2017 event

At the start of the investigation, the trust should obtain any comments, concerns or questions the family wants to share about their loved one’s care. The trust should recognise however that some families may need time before they feel ready to be involved. It should also answer any of the family’s questions about the investigation process. Both should agree on when the family will receive copies of reports

(including drafts) and when trust staff will be available to consider and respond to questions about the reports.

Good practice: Family meetings

After deciding an investigation will take place, meetings with the family should be held at agreed times that work for everyone involved and take account of other commitments such as work and childcare. Trusts should liaise with families to understand their preferences: do meetings need to be held face to face or would telephone conversations, video calls or other options be more suitable?

Meetings should be held in settings that are sensitive to the circumstances of the bereavement: for example, a family may not want to meet in a room close to where their loved one died. Trusts are advised to speak with families in advance to check that a venue is satisfactory.

Families should always receive written minutes of meetings with the opportunity to clarify or correct them. It is good practice to seek agreement from all parties that the minutes are an accurate reflection of the meeting.

Families should be given clear written information about:

- the investigators
- timescales for completing the investigation
- details of the process and how it will be carried out in line with the Serious Incident Framework and good practice
- how updates on the investigation's progress, including any delays, will be communicated to the family
- the agreed arrangements for how the family wish to receive the investigation report (including drafts).

The trust should ask the family how and when they would like to contribute to the investigation; and how they would like to be kept informed of progress. There should be ongoing, sensitive communications with the family, and the trust should recognise that families' preferences may change over time. Trusts should ensure families know who to contact in the trust to discuss their involvement. It may be appropriate to give families examples of how they might like to be involved. It is important to bear in mind that most families will not be familiar with the investigation process.

At the start of the investigation the trust will provide families with a named point of contact (and a named deputy to cover leave or absences). This person will provide regular updates, key findings to date and information on how the findings will be used to change practice. They will also explain any delays.

The trust should ensure all phone calls and other communications such as emails and letters are noted, recorded and responded to in a timely manner.

As equal partners, families should be kept up to date (if they wish to be) with the investigation's progress, have access to relevant information and see draft reports while they can influence them. It may be necessary at the draft stage to remove some information (for example, personal information) due to information governance requirements. If so, it should be explained. Arrangements should be made for families' comments to be received, reviewed and included in draft reports.

“Families and carers must be shown the same respect as others.”

Family feedback from November 2017 event

Good practice: Meaningful involvement in investigations

Trusts will achieve better quality investigations by involving families effectively. Families are a valuable and sometimes alternative source of information about a person's care and treatment. Where there is disagreement with the family's account, the report should acknowledge all the differing versions of events.

When an investigation is linked to care in a community setting or care provided at more than one trust, the same principles of family involvement apply. Normally the lead care provider would lead the investigation, while all providers involved would be expected to co-operate and collaborate to identify learning. Where there is disagreement about who leads the investigation, the relevant CCGs should decide which organisation leads.

Good practice: Patient safety investigations

A patient safety investigation is a systematic analysis of what happened, how it happened and why from a systems and human factors perspective. It usually follows a patient safety incident or a poor outcome of care (including death) when there are significant concerns about the care provided. The purpose of a patient safety investigation (as stated in the Serious Incident Framework) is to identify what changes can be made from a systems and human factors perspective, to reduce risk and prevent recurrence. It is not to establish blame or liability. It should neither seek to assign blame or seek to avoid blame. The patient safety investigation should simply seek to understand what happened; how it happened; and why; in order to recommend effective systemic improvements.

A patient safety investigation should not be affected by any legal action. The family should be fully involved in the investigation (as outlined in the Serious Incident Framework, Duty of Candour and [Being Open](#)). Their involvement should include helping to scope the terms of reference and the investigation, being listened to and having their account of what happened included, sharing information about gaps/problems in care with them, analysis of these gaps/problem during the investigation, sharing evidence gathered relevant to the treatment/incident relating to

the deceased, and sharing the draft report with them ahead of the sign-off/completion process.

Care needs to be taken if there is a police or other statutory investigations taking place. A multi-agency discussion should establish any running-order issues. There is a [protocol for liaison and effective communications between the National Health Service, Association of Chief Police Officers and the Health and Safety Executive](#).

Information after the investigation is completed

Families can expect the trust to provide them with the final report, in writing, with no undue delay following its completion. They should be asked how they would like to receive the report findings. This should include an offer to meet so the trust can explain any issues the family raised that were not accepted, and why. A meeting is also a good opportunity to provide information or explanations on the report's technical or medical aspects. Families may want support at the meeting and to bring an advocate, friend or relative with them.

Good practice: Letters and written communications

Letters containing unexpected information should not be sent without a preceding meeting or telephone call with the family. When unplanned letters are sent and arrive at the end of the week, a family can be left all weekend with no one to contact if they have questions, which should be avoided if possible. Calling before a letter is sent can be of great benefit to families.

All letters and written communications should be in plain English, free of jargon; and any technical terms should be explained. For families who are unable to read (or understand) written English, or have other accessibility needs, all communications should be adapted accordingly; this could include information in Easy Read or translation into another language.

Where a meeting with the family is held to share the report's findings, written minutes should be available to all attendees detailing:

- if identified, details of care not delivered to the expected standard,
- lessons identified and changes in practice,
- details of care processes already changed or to be further reviewed, and how,
- issues outside the trust's scope to remedy and where they have been referred – for example: commissioners, NHS England, CQC,
- the plan and timescales to address the identified issues.

Good practice: Confidentiality and investigations

Investigation findings may need to disclose or manage confidential personal information, perhaps including information which a patient did not want or expect to be shared with members of their family.

This should be considered by the organisation's [Caldicott guardian](#) and information governance lead, with the final decision being made by the Caldicott guardian. They may on occasion also need to liaise with colleagues with a legal speciality. Trusts should consider the seventh Caldicott principle, that sharing information can be as important as protecting confidentiality, to positively share information wherever possible. Consideration should be given to existing policies and procedures and information sharing should take place in accordance with data protection law/the law of confidence. Families will be given clear explanations on decisions made regarding these issues.

6. Access to independent advice, information and advocacy

Families needing extra help should be given details of independent advocacy services used to support people who have experienced a loved one's death in NHS care. These could be local or national organisations, depending on the circumstances of the bereavement and locally available advocacy services. All local authority areas should provide an independent health complaints advocacy service, independent of the trust, which people can access free of charge.

Annex 1 contains a list of such organisations. Trusts' PALS and bereavement services may also have links to providers of these services.

The Learning from Deaths programme board is reviewing how advocacy services might be commissioned in future.

Where a family appoints an advocate, their role should be clear to both the family and the trust. This is to help ensure all involved share expectations of their role and the trust understands how the advocate should be involved.

Trusts should provide families with local information on what happens when a death is referred to the coroner, including the coroner's contact details.

If a case is going to be dealt with through an inquest, the coroner's office is responsible for telling families about the inquest process and should direct them to further information and support. Trusts should make clear to families that the trust has no control over how the coroner's office operates.

When preparing for an inquest, trusts and their legal representatives should note that their purpose is to assist the coroner to establish the facts. They are not there to defend the trust's actions but to provide details of what happened and action taken to prevent a recurrence.

7. Family and carer participation in trust training

Skills for Health and Health Education England have developed an [online learning package](#) to encourage a learning and quality improvement culture in the health and care sectors.

At a time that is right, families who have experienced an investigation could be invited to work with the trust on training staff to improve patient safety and how they involve families.

Using positive and negative family experiences can help staff understand the impact on families and strengthen how they and the organisation learn from deaths.

Both new and long-standing staff can benefit from ongoing training, and it is an important part of setting an organisation's standards and culture.

Good practice: Family participation in training

Many trusts are working with families to deliver joint training. This may be speaking at a training event, making a short film to be shown at staff training or individuals giving structured training sessions. Groups such as Making Families Count hold powerful workshops that change the practice of those attending. Like all training, it is more effective when regularly available, to allow staff to learn on an ongoing, rather than a one-off basis.

8. Involving families in action planning and assurance processes

Trusts should offer families the opportunity to take part in evaluating recommendations and action plans following an investigation, and then regularly update them on progress until action is completed.

Families are well placed to comment on how trust policies and procedures work in practice, enabling trusts to understand more about which systems work well and which may need improvement. Trusts should also seek feedback on their resources for bereaved families, including post-bereavement information.

Good practice: Bereavement survey

The end of life care team at UCLPartners, an academic health science network, has developed a bereavement survey with the palliative care team at Cicely Saunders Institute, King's College Hospital. It is given to friends and relatives, and helps trusts assess quality of care in the last few days of life. The survey includes a recommended cover letter and spreadsheet, which automatically generates graphs when survey data is entered. It is available free and used in several London trusts. For more information and contact details, see the [UCLPartners' website](#).

9. Action if a family is dissatisfied with an investigation or their involvement

Every effort should be made to address families' concerns, however if a family is unhappy with the way they have been involved, or with the outcome of a review or investigation, you should direct them to the most appropriate organisation(s) for support and provide information about the trust's complaint procedures. This could include organisations that provide advocacy or advice (see the list in annex 1), healthcare commissioners, regulators or the ombudsman.

Information for families following a bereavement (Annex 1) contains frequently asked questions to help families decide next steps to take if they are dissatisfied with the outcome of a review, complaint or investigation.

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Annex 1: Information for families following a bereavement

Information for families following a bereavement

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

July 2018

This information can be made available in alternative formats, such as easy read or large print, and may be available in alternative languages, upon request. Please contact: [insert name of trust] on [insert contact details].

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Introduction

If you have been given this leaflet, 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 leaflet will help you understand what you can expect from [insert name of 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 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 leaflet, you should also have received a letter from us, either in advance, or accompanying this information. The letter should have included 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 [insert details].

[Note: Trusts to amend the above information in line with their local arrangements. For example, trusts might phone people, rather than (or in addition to) sending a letter, and taking into account the circumstances of the death, such as community settings]

Understanding what happened

As a family member, partner, friend or carer of someone who has died while in the care of [insert name of 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. The staff who were involved in treating your loved one should be able to answer your initial questions. 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 (the trust) when you are ready through your named contact at the trust (see above).

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 could include:

- collecting any personal items belonging to the person who has died,
- making arrangements to see the person who has died,
- collecting the death certificate,
- how to register the death.

Please let us know if we can be of any help regarding these or other issues. The Gov.uk website (<https://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 later in this leaflet.

[Insert contact details for the Bereavement Office (if you have one), chaplaincy, and local support services, such as the voluntary sector]

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 in NHS trusts on a proportion of all their deaths to learn, develop and improve healthcare, as well as 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 specific processes and procedures that trusts need to follow if your loved one had a learning disability, is a child, died in a maternity setting or as a result of a mental health related homicide. If this is the case, we will provide you with the relevant details on these processes.

Investigations

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 safety investigation will be 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 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.

In some cases, an investigation may involve more care providers than just **[insert name of 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 acting as the lead investigator.

You will be kept up to date on the progress of the investigation and be invited to contribute. This includes commenting on the draft investigation reports before they are signed off. Your comments should be incorporated in the report. After the report has been signed off, the trust will make arrangements to meet you to further 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 advocate to accompany them to meetings, etc. Please see details of independent organisations that may be able to help, later in this leaflet. You are welcome to bring a friend, relative or advocate with you to any meetings.

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](#). The charity [AvMA \(Action Against Medical Accidents\)](#) has [produced information for families on Duty of Candour](#) which is endorsed by the Care Quality Commission.

Coroners' inquests

Some deaths are referred to the coroner, for example where the cause of death is unknown, or the death occurred in violent or unnatural circumstances. When a death is referred to the coroner they may request a post mortem examination. The coroner will decide whether an inquest is 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 inform you 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 important to do this as soon as possible after your loved one has died, as delays in requesting an inquest may mean that opportunities for the coroner to hold a post mortem are lost.

We can provide you with contact details for the appropriate coroner's office. **[Alternatively, trust to insert appropriate coroner details here; and to amend the sentence accordingly]**

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 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.

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 the **[insert name of trust]** is the best person to answer your 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 and Liaison Service (PALS) team will be able to help.

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. 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 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 <https://www.ombudsman.org.uk/publications/my-expectations-raising-concerns-and-complaints>

Please see the frequently asked questions 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 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 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 the trust, that people can access free of charge. If you would like to use this service, please contact them on [\[trust to insert relevant local authority complaints advocacy contact details here\]](#).

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

[Trust to insert relevant local/regional advocacy contact details here. Some examples have been included below. Please delete if not relevant to your area].

- **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 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 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 represent on nquests, Independent Police Complaints Commission (IPCC) inquiries and other reviews. www.aafda.org.uk - 07768 386 922.
- **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 282 986/0808 800 6017
- **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 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 - 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.uk
- **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/

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/LfDinvolvingfamilies.

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.
- The implementation of the role of the Medical Examiner.
- 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). 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. 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, 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 any post mortem is completed, although a 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 establish 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.

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 us 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:

- **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/ccg-details
- **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
- **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. Visit: 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 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. It has introduced a new public support service that puts patients, families and the public at the centre of their 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 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). www.hsib.org.uk

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