

# Compassionate communication, meaningful engagement

A best practice guide for supporting patients and families  
after a patient safety event



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## Background

Over the past year, several NHS Trusts have been working with Making Families Count<sup>1</sup> to develop a handbook to guide all healthcare staff in supporting and involving our patients and families after an unexpected patient event.

**When we refer to families throughout this handbook, we're referring to any loved one, carer or person closely involved in the patient's care.**

The project began with identifying a set of key principles (below). As a collective, we endorse that these principles should be applied when working with patients and families that have been significantly impacted or bereaved by an unexpected patient event or incident. These principles will help to ensure there is meaningful and consistent engagement which is always carried out with compassion.

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<sup>1</sup> Making Families Count is a unique training organisation made up of harmed and bereaved family members working in partnership with senior, experienced NHS professionals. They aim to improve outcomes for families and staff affected by serious harm and traumatic bereavements in health services. Their vision is that the NHS will make families count by ensuring that families are integral to healthcare reviews, leading to better reviews, better learning, safer services, and the right support for families. [Visit the Making Families Count website.](#)



## Key principles

Together we believe that we should always:

- Support patients and families with dignity and respect, treating everybody equitably
- Enable understanding through clear, plain language which is accessible to all – we will explain any jargon or abbreviations and avoid these where possible
- Strive to communicate in a way that works for everyone and listen to all views
- Encourage open conversation where people can share differing opinions and viewpoints in safe, supportive, and constructive discussions
- Be open, honest, and transparent. Wherever possible share what information we know, and give clear reasons about why we might not be able to do this
- Recognise the importance of the duty of candour<sup>2</sup> and the responsibility it places on the organisation to provide staff with the skills to deliver this
- Always say sorry (this is not an admission of liability) and recognise any hurt or trauma incurred
- Take proactive steps if we don't know the answer to a question and seek information to be able to respond. Where we have been unable to find the answer, we will explain the reason for this
- Identify a named person/clear point of contact who will have sufficient experience, seniority or importance to the person involved. This will include arrangements for when the named person is unavailable
- Provide access to learning, development and supervision to provide staff with skills and knowledge to work with families positively
- Ensure that support is readily available for staff wellbeing
- Have clear procedures and descriptions in place for the different types of patient safety reviews carried out by the organisation, their purpose and outcomes
- Ask how the patient or family would like to be involved in patient safety reviews. Provide options for how that could work while holding in mind the risk of re-traumatising families. We will strive to capture and answer everybody's views. Discussion with families will be key to informing the type of patient safety review we will undertake
- Follow a 'Just' and 'Restorative Learning Culture' which identifies learning without apportioning blame, keeps the focus on improvements in care and sets out to evidence change
- Ask families if they wish to be updated on the improvements we have made in response to the findings of a patient safety review
- Provide information to families about how they can raise concerns and the wellbeing support available

**We will always have in mind: 'How would you like to be treated if this were you?'**

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<sup>2</sup> Every health and care professional must be open and honest with patients and people in their care when something that goes wrong with their treatment or care causes, or has the potential to cause, harm or distress.



## Endorsements

### Making Families Count tell us...

We recognise how challenging and, in many cases, traumatising, the review procedure can be for families and staff. We're also very conscious that as the new Patient Safety Incident Response Framework comes in, there is an increased opportunity for people to learn from each other, and this handbook is part of that learning. Making Families Count brings the voices and experiences of family members to our training in this handbook.

One of the problems families often mention is a lack of status in the review, coupled with a lack of real involvement. It can feel as if they are passive recipients of the process, instead of being fully engaged and involved, sharing their vital evidence and potential solutions.

Staff don't always know how to engage effectively with families during reviews. There's a lot of fear around engaging with families. They can be afraid of upsetting the family more and making the situation worse or getting into trouble with their superiors. There are a lot of concerns about what they can and can't tell the family about confidentiality and information sharing.

Making Families Count wanted to co-create this handbook because we believe this will become a go-to guide to help staff feel more confident when working with families in a review. This will lead to a better patient safety response, which in turn will lead to a better outcome for families and more embedded learning for organisations.

## Thoughts from a Patient Safety Partner

As a Patient Safety Partner, I am impressed with the inclusivity, layout and content of this handbook. It's detailed in every aspect without being laborious and repetitive.

I find it reassuring to see the level of support that is advocated to be given to both families and staff so that there is clarity about knowing what to say and how to go about saying it.

Words that immediately stood out as reassuring from a family's perspective are: Compassion, Honesty, Dignity, Respect, Listening, Supportive, Apology, Proactive and Ownership. Put into actual practice, these letters become a whole lot more than just words. They help to soothe, support and assist those affected by unexpected and difficult events. When they occur, we would want to be a service/team that our families would look back on in years to come and remember us as a beacon of light offering assistance at such a dark moment in their lives. We always need to be seen as going the extra mile which this handbook will greatly assist with.

As staff, I can see how complex it may be to deal with such difficult situations and you may not always know how best to approach each situation. I believe this Handbook provides a clear outline and guidance on this. Furthermore, it provides practical support for staff in training and leadership.

Wouldn't it be fantastic for both our families and our staff, if all organisations had an impeccable reputation for really caring and going that extra distance in such difficult circumstances? I believe, through applying this handbook, this is totally achievable!





## Patient Safety Incident Response Framework

The Patient Safety Incident Response Framework (PSIRF) replaces the Serious Incident Framework. It's a whole system approach to incident management and focuses on learning and improvement.

PSIRF enables organisations to take responsibility for how they will review and learn from incidents based on a set of principles (compassionate engagement and involvement of patients, families, and staff; application of systems-based approaches to learning; proportionate responses to incidents; supportive oversight focused on system functioning and improvement).

Individual organisations will have their own Patient Safety Incident Policies and Plans on how to deliver national guidance. Unlike the Serious Incident Framework, decisions about patient safety incident responses will not be determined by the level of harm alone but rather by added value to learning and/or significant concerns about care. It's important to recognise that Patient Safety Incident Investigations (PSII) will only be one of a toolbox of methodologies that can be adopted to review incidents. The principles within this handbook apply to any type of incident response.

## Types of incident response review and investigation

There are some incident response types<sup>3</sup> (for learning) available to NHS Trusts including:

- Hot debrief / SWARM huddle
- Initial finding review
- After action review
- Tabular timeline
- Case notes /desktop review
- Mortality review / Structured Judgement Review
- Learning disabilities mortality review (LeDeR)
- Clinical audit
- Thematic review
- Patient Safety Incident Investigation (PSII)

### What does this mean?

A learning response aims to understand the circumstances that led to the incident and identify procedures, practices or areas in the system or organisation that might need to be changed or improved. It's not to determine the cause of death or to blame an individual or hold an organisation to account. There are other channels for these processes where necessary.

Some incidents will require a specific learning response, these will be identified in your organisation's Patient Safety Incident Response Plan.

### What does this mean for patients, carers and their families?

The Trust or organisation may not undertake a PSII following an incident resulting in moderate or severe harm or death, and instead use an alternative method to review and learn from the incident. This means there may not be a formal investigation report to share. Consideration of the views and perspectives of the patient or their family must always occur when deciding to undertake a review or investigation and they must be given the appropriate support to share their experience.

Patients and families must have the opportunity to ask any questions and all best efforts must be made to answer these whether a review or investigation is being undertaken or not. This is further explained in the 'Explaining the Engagement Lead Role' section of this handbook. More information is also available at Learn Together, a resource for anyone involved in an investigation.

**“I longed for better care and fewer deaths as proof of effective learning.  
Nothing can bring him back but knowing that his story is helping to prevent  
avoidable deaths brings me the greatest comfort”**

**Mother speaking to Making Families Count**

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<sup>3</sup> Details of these learning responses will be included in your organisation's Patient Safety Incident Response Policy and Plan





## Principles of Compassionate Engagement

Engagement with a patient's family needs to be handled with sensitivity, compassion and consideration of individual circumstances and needs. It will start with an initial contact and then engagement will continue (perhaps with a different member of staff) as the patient safety learning response progresses. Therefore, this section should be read in conjunction with the 'Duty of Candour' and the 'Explaining the Engagement Lead Role' sections. These are the key principles of any stage of communication with those affected<sup>4</sup> by a patient safety incident:

### Preparation

- Identify who the initial family contact(s) should be (being aware that other family members may feel that they wish to be involved and a different family member may be identified as being the main contact moving forward).
- Ensure that the contact details for the family, including details of the relationship to the patient are accurate e.g., check pronunciation, and spelling.
- Establish how the patient prefers, or preferred, to be known. Be aware that they may have preferred to be known by a name their family didn't use for them. Establish how you are going to manage this and be consistent.

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<sup>4</sup> We have referred to the subject in this section as 'the family' but these principles apply if it's the patient we are engaging in our review

- Ask if the Terms of Reference have been drafted and the type of review<sup>5</sup> being undertaken; have some understanding of different types of reviews and their implications (e.g., proposed timeframes).
- What is your understanding of the cultural and spiritual needs and dynamics of the family? You may need to seek more information.
- Try to find out known anniversaries e.g., birthdays, and religious days.
- Establish any communication needs, including the need for an interpreter (a requirement to understand the cultural context).
- Read case records and available documentation, and set aside time to know the facts of the situation in advance to prepare for all family contacts.
- Make sure you allow time following contacts to decompress and/or debrief.
- Acknowledge and be prepared for the grief of the family, in all of its manifestations.
- Always be prepared to flex and be responsive to the needs of the family.
- If necessary, seek support from your organisation, including your Caldicott Guardian, about what information can be shared with families.
- Carry out an appropriate risk assessment if you are planning face to face contact.
- Be mindful that families can be involved and their voices heard without necessarily disclosing confidential information.

## Key considerations for your interactions

- Be clear about the reason for your contact.
- Introduce yourself clearly, and your role; ask if this is a good time to speak and arrange a time to call back if this is not the case.
- Listen to what is said, as well as what is not being said; hear and listen to the distress of others in a measured and supportive way.
- Make a meaningful apology (saying sorry is not an admission of fault, you are showing empathy).
- Acknowledge the family's grief.
- Be careful with your use of language, no jargon, and use simple words.
- Know your limitations so that you can manage the family's expectations.
- Repeat yourself if necessary and summarise your discussion.
- Be aware of any parallel responses (e.g. police, local authority).
- Stay grounded, be compassionate, show interest, don't interrupt.
- If necessary, remember to arrange follow-up contact at a time and date suitable to the family.

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<sup>5</sup> Details of different learning responses will be included in your organisation's Patient Safety Incident Response Policy and Plan

## What you might expect or anticipate

- Families are likely to have questions e.g. what's going to happen next? What happened on the patient's last 'contact', when was the patient last seen, what were they like when you last saw them, what did the patient say?
- Anticipate that the family may tell you that the contact is not a convenient time for the family, and you may need to reschedule. Or they may not want contact – be respectful of this, and provide your details in case they change their mind.
- Be prepared that the family may need to ask for you to repeat yourself, it's difficult to retain information at times of great stress.
- Acknowledge that the family member might be grieving and the response to the contact may be unexpected and difficult.
- The family needs to be allowed to express their feelings without fear of being shut down. This can be challenging if they are angry, and they could be raising their voice. You should not, however, tolerate personal abuse.
- The family may share details about their loved one and any concerns they have. Refer to the 'Signposting' section of this handbook
- Acknowledge that the family may require support and signposting.

## Endings

- Endings can be difficult for everybody involved.
- It's helpful to be clear from the outset that your support is finite.
- It will be beneficial to you, your service, and for families to understand the timeframe for your support. For example, this may come to an end when the NHS organisation has completed their review.
- It can be helpful to draw your support to an end in writing.

**“It took a two-year fight to confirm what we already suspected;  
our son had been sent alone to the hospital without being  
accompanied by anyone he knew”**

**Mother speaking to Making Families Count**





## Duty of Candour

The vast majority of people who work in health and social care wish to provide the very best care they can. There is very rarely intent by staff to provide care that did not go as expected or planned.

When patient safety events<sup>6</sup> such as incidents<sup>7</sup> occur, they can have a real and deep impact on people's lives. Regardless of the level of harm incurred, those affected have a right to receive a meaningful apology and explanations for what happened as soon as possible.

We know this is not easy but being open and transparent with patients and/or their families when treatment or care goes wrong is always the right thing to do – this is often referred to as the 'duty of candour'.

There are two types of duty of candour, statutory and professional. Both have similar aims – to make sure that those providing care are open and transparent with the people using their services, whether or not something has gone wrong.

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<sup>6</sup> 'Patient Events' are unplanned or unintended events/circumstances that may have or could have caused harm to the patient. They include 'incidents', outcomes from an illness or unintended consequences of a treatment intervention. For example side-effects from medications or a known complication of a surgical intervention, not related to a care omission.

<sup>7</sup> 'Incident' is something unplanned, unexpected or unintended that has happened, or failed to happen, as a result of the care or treatment provided that could have or did lead to patient harm.

## Family perspective on duty of candour

If a family member has been harmed in the care of your organisation, the impact on the whole family can be enormous and potentially life-changing. This is particularly the case when someone dies. However, it can still be traumatic if someone experiences harm and survives, both for the individual who was harmed and their family. There may be significant changes in the quality of life of the patient and the family.

The impact on the family can be traumatic when professionals involved do not engage promptly with them and refuse to answer the questions they have, honestly. Without answers, families cannot move on with their lives. They can become trapped in chronic grief and become increasingly angry and mistrustful of all professionals.

A failure to be open, transparent, honest, and compassionate can lead to families being re-traumatised by the experiences they have had, as they find themselves in a constant battle to get answers and seek a truthful account of what happened. Families sometimes wait years to find out what has happened, often at the inquest, yet responding promptly, and openly, early on will spare families a great deal of suffering.

This was the experience of one family, whose son died in NHS care:

“I was first contacted by the Trust in November. They sent me an Easy Read cartoon-style version of a form ‘So you have a complaint.’ I wrote back with a formal complaint in December. Their CEO wrote back in May and their letter said...Although a Root Cause Analysis has now been completed, we made this decision not to inform you that this had taken place or share our findings, as we thought it would be too distressing for you.”

In marked contrast, the experience of another family was:

“The consultant met us as soon as he was back on duty... he was forensic in his analysis about his actions and about the actions of his team... He maintained contact with us throughout the process. It restored our trust in their service, even though the impact on our daughter had been severe.”

## What is the professional duty of candour?

This is a professional responsibility to be open and honest with patients and families when something that goes wrong with their treatment or care causes, or has the potential to cause, harm or distress.

This includes saying sorry and taking action to put things right where possible. It is always the right thing to do and is not an admission of liability.

## Fulfilling the professional duty of candour

As soon as you realise something has gone wrong with a patient's care, you should speak to them or their family.

- Where possible, speak to them face to face in a quiet, neutral space. If it's not possible to speak face to face, try and ascertain what their preferred approach would be, e.g. a virtual meeting or a telephone call.

- Ensure that you suggest that there is someone available to support them, such as a friend, relative or professional colleague.
- Provide a true account of what has happened including what is known. Provide the opportunity for questions to be asked.
- It's okay not to immediately know all the facts, but you should be clear about what has and has not yet been established.
- Be human. Saying sorry for what has happened is crucial, as well as offering condolences if that is relevant. You must apologise from the outset for the harm caused, regardless of the level of harm or fault. Saying sorry is always the right thing to do and is not an admission of liability.
- Depending on the circumstances, it may be more appropriate to promptly escalate the situation to a senior member of your team or organisation and request they speak to the patient (or family) on your behalf.
- Ensure the details of a single point of contact are provided. This should be someone who will be involved throughout the process and can regularly update them.
- Irrespective of the level of harm incurred, you should document and report the incident through your organisation's reporting process, and include the actions taken.

## What is the statutory duty of candour?

The statutory duty of candour is laid out in Regulation 20 of the Health and Social Care Act 2008 (Regulated Activities) Regulations 2014. It puts an overarching legal duty on health and social care providers to be open and transparent with people using services, and their families, in relation to their treatment or care and is overseen by the CQC. Those responsible for governance/patient safety within your organisation can advise you if you are unsure whether the statutory duty of candour applies.

The statutory duty of candour applies to notifiable safety incidents.

'Notifiable safety incident' is a specific term defined in the duty of candour regulation. It should not be confused with other types of safety incidents or notifications.

A notifiable safety incident must meet all 3 of the following criteria:

1. It must have been unintended or unexpected.
2. It must have occurred during the provision of an activity we regulate.
3. In the reasonable opinion of a healthcare professional, already has, or might, result in death, or severe or moderate harm to the person receiving care.

Remember, even if something does not qualify as a notifiable safety incident, there is always an overarching duty of candour to be open and transparent with people using services.



## Fulfilling the statutory duty of candour

When something qualifies as a 'notifiable safety incident', the specific steps laid out in Regulation 20 must be carried out 'as soon as reasonably practicable'.

- This means opening conversations with the 'relevant person' - The 'relevant person' is defined in the regulation as either the person who was harmed or someone acting lawfully on their behalf. This could be a family member. Please seek advice from your legal team or Caldicott Guardian if you feel unsure.
- Someone may act on behalf of the person who was harmed if the person:
  - has died
  - is under 16 and not competent to make decisions about their care or the consequences of the incident
  - is over 16 and lacking mental capacity. This is in accordance with the Mental Capacity Act 2005.

Once you have identified the 'relevant person' you must:

- Tell the relevant person, face-to-face, that a notifiable safety incident has taken place.
- Say sorry
- Provide a true account of what happened, explaining whatever is known at that point.
- Explain to the relevant person what further enquiries or investigations will take place
- Follow up by providing this information, and the apology, in writing, and providing an update on any enquiries.
- Keep a secure written record of all meetings and communications with the relevant person.

We recognise that people are sometimes uncertain about how to apologise when an incident is still being investigated. But from the start, simple straightforward expressions of sorrow and regret can and should be made for the harm the person has suffered.

Throughout the process, you must give 'reasonable support' to the relevant person, both about the incident itself and when communicating with them about the incident. This will vary with every situation, but could include, for example:

- Environmental adjustments for someone who has a physical disability.
- An interpreter for someone who does not speak English well; Information in accessible formats.
- Signposting to mental health services.
- The support of an advocate.
- Drawing their attention to other sources of independent help and advice, see the 'Signposting' section of this handbook. Your organisation should also have a list of relevant organisations.

## First impressions count (what our families are saying)

- Families seek early contact.
- Say sorry meaningfully – don't say "We are sorry if..." or "Sorry but ..."
- Make sure your initial letter says three things: you are sorry; you will look into what happened; tell them what has happened as fully as possible. Within the letter, ensure that you provide appropriate contact details in writing to the relevant person/family.

## Our key messages

- Being open and transparent with patients and their families when treatment or care goes wrong is key to good duty of candour compliance.
- Remember that saying sorry is always the right thing to do and is not an admission of liability.
- Always be compassionate towards the needs of the patient and their family.
- Ensure conversations are bespoke to their needs, consider the sensitivities of the situation, and always ensure that all communication is personalised and empathetic.

**“My wife and I spent four years blaming ourselves after the death of our baby daughter, for something we could never have foreseen nor done anything about. But no one took the time to involve us so we could understand this. It almost broke us.”**

**Family Member speaking to Making Families Count**

**“We believe that working well with families and carers from the start should be an ‘always event’ - it can make a real difference.”**

**Service Manager at a Mental Health NHS organisation**



## Confidentiality and information sharing

Confidentiality is often seen as a barrier to sharing information with a family, particularly if a patient has experienced harm, or after death. Managing confidentiality when working with families or significant others following incidents can be complex. Below are some key points to consider when faced with such challenging situations:

- Confidentiality issues should never stop us from listening to feedback and concerns from any family.
- If the family is requesting access to health records, ensure that you follow your organisation's Subject Access Request process and seek support from your colleagues who lead on subject access and information governance processes.
- It's important to consider their request to ensure that no further harm or further trauma is caused.
- Often coroners will share reports/information with the family in un-redacted form, as they will consider that is the correct way to approach the inquest. Coroners do not hold the same duties of confidentiality towards the deceased as a health care provider.
- Failing to disclose information can cause difficulties, particularly if the family's relationship with the healthcare provider is already strained.
- What information is disclosed should always be decided on a case by case using the relevant information. This can be complex. If you are unsure about what information you can share, discuss this with your line manager, patient safety team, information governance team, the Caldicott Guardian or legal services; you are not alone and support is available for you.



## Preventing Suicide

There is now clear guidance that information can now be shared with families and carers to prevent suicide. Some NHS Trusts have now developed policy guidance for staff in such situations.

The [National Consensus Statement on Information Sharing and Suicide Prevention](#) should be used alongside any relevant professional code of conduct.

In the context of this guide, there are two clear statements to be aware of:

“Data protection law does not prevent sharing personal data in an emergency situation, including to protect a person from serious harm, or to prevent the loss of human life. In an emergency, you should share data as is necessary and proportionate.”

“The duty of confidentiality is not a justification for not listening to the views of family members and friends, who may offer insight into the individual’s state of mind or predisposing conditions which can aid care and treatment. Good practice will also include providing families with non-person specific information in their own right, such as how to access services in a crisis, and support services for carers.”

The Zero Suicide Alliance have developed guidance from this Consensus Statement called: [SHARE: consent, confidentiality and information-sharing in mental healthcare and suicide prevention](#).

**“With status comes legitimate influence and access. Appropriate status can protect families from secondary trauma. It’s a myth that families only want to lay blame, yet this position is often used to give families less status in investigations”.**

**Family, Making Families Count member**



## Explaining the Engagement Lead Role

Meaningful learning and improvement following a patient safety incident can only be achieved if supportive systems and processes are in place. Within these systems, we should prioritise the compassionate engagement and involvement of those affected by a patient safety incident namely the patient and their family or loved ones. While we cannot change the fact that an incident has happened, it's always within our gift to compassionately engage with those affected, listen to, and answer their questions and try to meet their needs.

We must all recognise that engaging with those affected by a patient safety incident substantially improves our understanding of what happened, and potentially how to prevent a similar incident in future. Patients and their family may be the only people with insight into what occurred at every stage of a person's journey through the healthcare system. Not including those insights could mean an incomplete picture of what happened is created.

To facilitate this, NHS Trusts need a process whereby an 'engagement lead' is allocated to each learning response to a patient safety incident. This may be the individual who is leading or supporting the actual learning response and/or this may be a dedicated Family Liaison Officer (FLO).

Specific criteria and titles for staff members that fulfil a role to compassionately engage with patients and families after an event will differ from organisation to organisation. But overall, there needs to be someone who is supporting and available to the patient and their family following a patient safety event.

In addition, it's important that the patient and their family are aware of their engagement lead.

Whoever is fulfilling this role will:

- Act as a conduit between the patient or family and your organisation to provide a two-way flow of information. This information should be delivered in an empathetic, accessible format in a timely manner avoiding medical jargon and abbreviations (see other sections within this Handbook on 'Principles of Compassionate Engagement' and 'Accessible Information Standards').
- Establish a method of communication and agree on what information the patient/family wish to receive and share this information appropriately (for example with the patient safety team).
- Be in a unique position to capture information shared by the family.
- Answer any questions they have and if you cannot answer them explain that you don't know but will find out and agree on how you will let them know.
- Seek to understand family dynamics and background that is helpful in relation to the communication and response provided by the organisation.
- Explain that all levels of review or investigation use a 'systems and human factors<sup>8</sup>' based approach to better understand learning and don't focus on individuals or blame.
- Manage expectations around timescales and inform of usual timeframes.
- If there is not going to be a review or investigation, ensure the family has an opportunity to ask questions and plan to provide answers if the information is not immediately available.
- Be clear as to what format the patient and family can expect to receive the outcome of any review or investigation.
- Agree on a plan to keep in contact, how, when etc. and who they can contact if you are not available.
- Understand the duty of candour and be able to communicate this in a meaningful way.
- Always act with empathy, openness and honesty and offer an apology for what has gone wrong.
- Identify learning and themes and share these with the appropriate areas of the organisation to improve safety and experience.
- Signpost to other sources of independent help and advice - see the 'Signposting' section of this Handbook. In addition, your organisation should also have a list of relevant organisations that you can use.

If your organisation has a dedicated family liaison officer (FLO), that individual will *usually* be separate from the clinical care and patient safety team – this provides a level of impartiality inviting the patient/family to be involved and participate in the learning response, if they so wish.

A dedicated FLO will receive clinical supervision and debriefs to ensure their wellbeing and safety whilst working in an emotionally pressured environment.

For further information and support for staff involved in investigations of a patient safety incident, see the [Learn Together](#) website.

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<sup>8</sup> This means that the focus of the review or investigation is to understand the complex healthcare interactions that led to the incident rather than focusing on the interventions of an individual.



**“The role of a FLO requires the right training, skills, support and organisational framework for it to be effective and to help ensure that families are included appropriately in investigations.”**

**Head of Family Engagement, Healthcare Safety Investigation Branch**



## Accessible Information Standard

We all have a responsibility, by law, to make sure that we communicate with everybody in ways that they understand. This also applies to people who don't speak English, people who are deaf, hard of hearing, who have a visual sensory loss or other disability, such as a learning disability or autism. It's helpful to consider applying these principles also for people who are grieving. It can be very difficult for an individual in shock or significant distress to take in and recall information.

Don't assume anything; many of us have hidden needs that affect us in different ways. Be proactive. Be curious. Ask people what they need, and what will help them. Nobody should have to rely on friends or family to communicate for them.

The responsibility for good communication lies with us as professionals. Your organisation will have its own guidance about how we provide information to individuals, according to their needs. There are also national standards that we should follow:

1	<b>Identify</b>	Ask if people have any information or communication needs, and find out how to meet those needs
2	<b>Record</b>	Record those needs in a set way that is highly visible, using specific definitions
3	<b>Follow</b>	Use alerts or flags to make it clear on the person's file what their needs are, so prompt action can be taken
4	<b>Share</b>	Share information about the person's needs with other NHS and adult social care providers
5	<b>Act</b>	Make sure people get their information in an accessible way and have the communication support they need

## Who can help you?

If you don't already know, make a point of finding out who is the lead for the Accessible Information Standard in your organisation. There will be training and resources available to support you. Don't be afraid to ask for help if you need it.

## What is good communication?

Good communication is using clear, everyday language, using short sentences and avoiding acronyms and abbreviations. Sometimes we may need to repeat ourselves. It means providing written information to back up conversations and giving information in formats that the person can use, such as large print audio and Easy Read, email or text.

Good communication is about ensuring the receiver can understand your messages; this may be through using interpreters and other communication methods such as British Sign Language (BSL). It may also include giving people who cannot use voice phones other ways of making contact and accessing our services (e.g. text, email, BSL video relay).

The principles of good communication should apply to every method of communication, for example:

- what we write
- what we speak
- providing a professional interpreter for people who speak other languages, including BSL
- when we send a text
- when we write an email or letter.

## Tips for written communication with everybody

- Consider making all standard printed letters and documents easier to read – use plain English, highlight important information, and support text with diagrams, images, or photographs.



- Use a minimum font size of 12 point, preferably 14.
- Use a clear, uncluttered font such as Arial and add page numbers.
- Ensure plenty of white space on documents, especially between sections. Avoid squashing text onto a page and, if possible, include a double space between paragraphs.
- Keep track of the electronic originals of documents you print out so you can re-print in a larger font or convert to an alternative format when required.
- Print on matt and not gloss paper and if printing double-sided ensure that the paper is of sufficient thickness to avoid text showing through from the other side.

See Appendix 3 for more information.



## Just Culture

“A just culture considers wider systemic issues where things go wrong, enabling professionals and those operating the system to learn without fear of retribution...generally in a just culture inadvertent human error, freely admitted, is not normally subject to sanction to encourage reporting of safety issues. In a just culture, investigators principally attempt to understand why failings occurred and how the system led to sub-optimal behaviours. However, a just culture also holds people appropriately to account where there is evidence of gross negligence or deliberate acts”. [Professor Sir Norman Williams’s Review](#) into Gross Negligence Manslaughter in Healthcare, 2018.

Being involved in a patient safety event, such as the death of someone you have been supporting, can be incredibly stressful and difficult. These incidents can affect all those involved very personally. It may be the case that you question yourself and your decision making, that you become worried about something you have done or haven’t done.

NHS organisations are striving to focus reviews on learning from complex interactions within the healthcare system and its processes, rather than seeking an individual or team to blame. Your organisation would want to understand what happened, why and how it happened, and it would want to learn from the event to try to prevent it from happening again. You may have a role to play in this, as a contributor to the review. Your organisation should *not* be seeking to single out any one individual to be held responsible unless there is clear evidence of gross negligence or deliberate act.

Your manager may follow the guidance produced by NHS England - ‘[Just Culture Guide: Supporting consistent, constructive and fair evaluation of the actions of staff involved in patient safety incidents.](#)’ This will inform you how they can support you.

The guidance states that “singling out an individual is rarely appropriate - most patient safety issues have deeper causes and require wider action.”

If you are in contact with bereaved families, it may be the case that they feel strongly that one or more people are responsible for what has happened; it may be the case that they are very angry and, at those times, the premise of Just Culture and the Patient Safety review can be difficult to take on board: that is, understanding what learning the *organisation* needs to do, and how this learning will drive change. The review does not focus on individuals.

Your organisation may have developed its own local guidance to support families to understand their patient safety review processes.

Families are likely to have a lot of questions. For many families, NHS systems feel impenetrable and unnecessarily complicated. Please seek the support of your manager if you need to, and be reassured that, unless you have intentionally harmed someone in your care, your organisation will support you.

It may be the case that a family will only wish to deal with senior management in your organisation. This is not unusual, please don't take it personally. If this does happen, please raise it with your manager for wider discussion and planning. Sometimes a multi-disciplinary meeting can help to establish the best way to respond.

Your senior leaders and Patient Safety Team are ensuring that this culture is embedded in your organisation, and that you feel safe and confident to speak up and process difficult things that are an inevitable part of our work.

## Support for Staff

Your organisation recognises the impact these significant events may have on you and your colleagues. It's important that you know who to turn to if you need support.

Please consider using your organisation's wellbeing services, seeking support from your line manager or peers, and using supervision. Debriefs can also be a good way to start to make sense of difficult situations.

**If you need someone to talk to**, NHS England have introduced a **confidential text support service**, you can access support by texting **FRONTLINE to 85258** for support 24/7. This service is available to all NHS colleagues who have had a tough day, who are feeling worried or overwhelmed, or who have a lot on their mind and need to talk it through.

NHS England have also introduced a free and confidential self-check tool that can provide you with further information on the range of support offers that are available and help you to identify what option is the right one for you to access.

[If you are a member of a union, you may wish to contact them for support and advice.](#)

The Royal College of Psychiatrists have resources to support colleagues after a patient has died by suicide. [See the resources on their website.](#)

**“We need to be careful about buying into a ‘them and us’ culture regarding families. We're all family members and may all need treatment and support at some point in our lives”**

**Family Member, Making Families Count**





## Safeguarding: Our responsibilities

### Safeguarding is everybody's business

You will be working with people at incredibly vulnerable times in their lives and your safeguarding responsibilities apply to everything you do.

It may be the case that you become concerned about an adult, child, or young person following the death of, or serious harm to, someone they were close to. One example of this may be if the deceased was the carer for somebody else, or that a child or young person is at risk of neglect as those around them try to come to terms with what has happened.

We can become anxious about raising safeguarding concerns, for example, if we're worried about the impact it might have on the relationships with the people we're working with. However, to safeguard appropriately, we must be honest and open with everybody, including ourselves, about why we are worried and what we're going to do about it. We should always record the rationale for our decision making.

You will have your own safeguarding department and safeguarding training, guidance, and support processes in place. Please make sure you're familiar with these, and make sure you know how to contact your organisation and local authority safeguarding teams, where appropriate.

Discuss any concerns with your manager or a senior member of staff if there is an immediate risk. Seek advice if you are unsure. Your local authority will make the final decision as to whether the concerns meet the threshold for further enquiry; sometimes it's important to build a picture of repeated concerns to inform decision making.



## Medical examiner service

The medical examiner service has been introduced in England and Wales to increase understanding and peace of mind for families, as well as improve learning and patient safety by providing a review of care. There is a legal obligation for NHS organisations to work with the medical examiner's office.

### When will a medical examiner be involved?

Following all deaths that are not being reviewed through the coronial process. This mainly applies to expected deaths, for example an older adult receiving end of life care. Most unexpected deaths are reviewed through the coronial process.

This process can provide families with an additional opportunity to raise any concerns they may have and is independent of the health provider.

Families can raise concerns directly with the medical examiner in relation to their loved ones' death and/or care prior to any learning response process agreed by the organisation.

## Purpose of the medical examiner service

The medical examiner service provides independent scrutiny of deaths and gives bereaved people a voice. The purpose is to:

- Provide greater safeguards for the public by ensuring proper scrutiny of all non-coronial deaths.
- Ensure the appropriate direction of deaths to the coroner.
- Provide a better service for the bereaved and an opportunity for them to raise any concerns to a doctor not involved in the care of the deceased.
- Improve the quality of death certification.
- Improve the quality of mortality data which will support learning and improvement.

## Who are medical examiners and what is their role?

Medical examiners are independent senior doctors who have not been involved in the care of the person who has died. Their role is to objectively examine deaths to:

- Agree the proposed cause of death and the overall accuracy of the Medical Certificate of Cause of Death (MCCD) with the doctor completing it.
- Discuss the cause of death with the next of kin/informant and establish if they have questions or any concerns with care before death.
- Act as a medical advice resource for the local coroner.
- Identify the selection of cases for further review under local mortality arrangements and contribute to other clinical governance procedures.

## What does this mean for families?

- Increased transparency
- Offer families the opportunity to raise concerns, providing new levels of scrutiny to help deter criminal activity and poor practice.

## Tips when working with families

- Provide information details about the medical examiner role and local contact details (which will be known by your Patient Safety team)
- Explain the purpose of the medical examiner.
- Be clear the medical examiner review is completely separate from any patient safety learning response and is independent of the NHS organisation(s) where the patient received care.
- Offer to support families to consider any questions they may have for the medical examiner in advance of contact with the medical examiner.
- Let families know that contact from the medical examiner can be expected within approximately 3-5 working days.





## Inquests

\*Please be mindful that not all deaths will lead to an inquest process\*

### What happens at an inquest?

An inquest is held when a person has died in certain specific circumstances and an investigation is necessary to establish the facts concerning the cause of death. Usually this is when the person died unexpectedly or in circumstances that remain unexplained. For example, deaths that have occurred as a result of violence, due to unnatural means or as a result of sudden and unknown causes, would all necessitate an inquest taking place.

The coroner will aim to gather information from a range of sources, to find out the facts of the death and deliver a conclusion. It is not a trial and does not assign blame or liability.

### The role of the coroner

The coroner are independent judicial office holders. They are a type of specialist judge who investigates and explains certain kinds of deaths. Unlike the rest of the judiciary, are appointed by local authorities.

### The role of the coroner's officer

The coroner's officer works on behalf and at the direction of His Majesty's Coroner making enquiries into the circumstances of the death. The coroner's officer is a point of contact for families and significant others.



## What is the purpose of an inquest?

An inquest is an official, public enquiry, led by a coroner (and in some cases involving a jury) into the circumstances of a sudden, unexplained, or violent death.

The coroner, or a jury, can make findings on:

- Who was the person who died?
- When did they die?
- Where did they die?
- How they came by their death?

## Who can attend an inquest?

- Inquests are often held in public, which means that members of the public and the media may attend.
- The coroner may summon witnesses to attend the inquest, this will depend on the particular circumstances.
- The family and/or the organisation(s) may have legal representation.

## The findings of an inquest

The coroner's conclusion will be based on all the evidence heard. The most common conclusions available to the coroner are:

- Natural causes
- Accident or misadventure
- Unlawful killing
- Suicide
- Lawful killing
- Open (where there is insufficient evidence to reach any other conclusion)
- Narrative

This is not a definitive list of the conclusions that can be made at the end of an inquest.

## Prevention of future death (regulation 28)

Following the inquest, the coroner can write a report in cases where the evidence suggests that further avoidable deaths could occur and that, in the coroner's opinion, preventative action should be taken. The report will be sent to the person or authority which may have the power to take the appropriate steps to reduce the risk and they have a mandatory duty to respond in full within 56 days.

## What is the inquest experience?

It's recognised that an inquest can be a challenging and intimidating process for both the family and staff attending the Inquest. Appendix One has some personal stories of our families' and staff experiences.

It's important to remember that your organisation will have a process to support staff who may be involved, and the family engagement lead role/family liaison service should also seek advice to support the family as appropriate.



## Signposting

Signposting is important for families following a bereavement or traumatic event, particularly to obtain specialist advice and support. Referrals to peer support bereavement organisations can be especially valuable, to overcome a sense of isolation with the issues they face. These organisations can provide vital emotional support and may be available outside office hours in some cases.

### Providing options

It's important to consider options available, being mindful of the individual's needs. We should also provide families with choice, which will allow them to take back some control, when faced with some of the most challenging experiences of their lives.

### Top tips

- Ask what would really help the family and who is around to support them?
- Do they need something different e.g. independent listening service, advocacy support?
- Do we already offer a service that is appropriate to the needs of the family?
- Talk to local organisations to check what they can offer by way of support - some families have been referred to bereavement services that don't understand, for example, what it's like to be traumatically bereaved and may not be trauma-informed.
- Always check the details you provide to families before you signpost to relevant services to ensure website and contact details are up to date.

- Some organisations may have a formal referral process, so you may be able to facilitate that for the family.
- Check that any leaflets you give out are also up to date.
- Each organisation will probably have a network of local voluntary organisations that will be unique to your area.
- Mapping services and resources for families can save them valuable time and energy and may greatly assist you in your work.
- There may be local umbrella organisations for voluntary action, or volunteer bureau that have databases of local charities.
- Work with your experts by experience in your local organisation who may have excellent contacts to local organisations who can help.

## What if you are worried about a family member

It's important to gauge how the family member(s) is/are during contacts, if you pick up on concerns, be curious and ask.

There are a range of primary, internal, and external support options available, such as advocacy and bereavement support. You or the individual's GP may consider and onward referrals for example Talking Therapies.

## Signposting/support in a crisis

Each organisation will have its own arrangements for accessing services, this could be through the gateway, via GP referral for assessment, crisis services, NHS 111 or emergency services.

- ask for advice if you need support to determine the severity and immediacy of the risk presented.
- ensure that family are given clear and accurate information about the availability of support, who it could be provided by and contact arrangements.
- refer to the following pages for a list of support services following a bereavement for both emotional as well as practical support.

**“Whatever is thrown at you, never forget, there's a charity for everything  
– you just have to look for it”**

Making Families Count family member





## Bereavement and Support Agencies

### Bereavement support for adults

#### Age UK

[www.ageuk.org.uk](http://www.ageuk.org.uk)

Age UK provides services and support at a national and local level to older people. Useful information about bereavement can be found here:

[www.ageuk.org.uk/health-wellbeing/relationships-and-family/bereavement/emotional-effects-of-bereavement](http://www.ageuk.org.uk/health-wellbeing/relationships-and-family/bereavement/emotional-effects-of-bereavement)

#### Cruse Bereavement Care

[www.cruse.org.uk](http://www.cruse.org.uk)

Cruse supports people after the death of someone close. Their trained volunteers offer confidential face-to-face, telephone, email and website support, with both national and local services. They also have services specifically for children and young people.

#### Grief Encounters

[www.switchboard.org.uk/what-we-do/grief-encounters/](http://www.switchboard.org.uk/what-we-do/grief-encounters/)

Run by Switchboard, Grief Encounters supports LGBTQ people who have experienced a bereavement. They have a helpline and run monthly informal sessions. Some of these are creative, and a chance to meet other LGBTQ people who have been impacted by a death.

Telephone: 01273 204050

Email: [info@switchboard.org.uk](mailto:info@switchboard.org.uk)

### **Jewish Bereavement Counselling Service**

[www.jbcs.org.uk](http://www.jbcs.org.uk)

Support for any member of the Jewish community who has been bereaved.

Helpline: 020 8951 3881

Email: [enquiries@jbcs.org.uk](mailto:enquiries@jbcs.org.uk)

### **Muslim Community Helpline**

[www.muslimcommunityhelpline.org.uk](http://www.muslimcommunityhelpline.org.uk)

Confidential support for any members of the Muslim Community.

Helpline: 020 8904 8193 or 020 8908 6715 Monday – Wednesday 10.00 – 13.00, Thursday 13.00 – 15.00, Friday 10.00 – 16.00

### **Punjabi Speaking Women's Group**

Helpline: 07376 303 438

Email: [birmingham@uksobs.org](mailto:birmingham@uksobs.org)

(Of note this is also has a resource section for professionals)

### **The Good Grief Trust**

Email - [hello@thegoodgrieftrust.org](mailto:hello@thegoodgrieftrust.org)

(A useful database of support services)

### **WAY – Widowed and Young**

[www.widowedandyoung.org.uk](http://www.widowedandyoung.org.uk)

WAY is a membership organisation for anyone who has lost a partner and provides self-help support and guidance for widows and widowers under 50 through local groups, social activities and online forums.

Thursday 13.00 – 15.00 Friday 10.00 – 16.00

## **Bereavement support after a death by suicide for adults**

### **Amparo**

[amparo.org.uk](http://amparo.org.uk)

Amparo provides emotional and practical support for anyone affected by suicide. The service is completely confidential and can provide short-term or longer-term support, depending on what you feel you need.

Helpline: 0330 088 9255

## Support After Suicide Partnership

[www.supportaftersuicide.org.uk](http://www.supportaftersuicide.org.uk)

A website with details of organisations who offer support to people bereaved by suicide and information about relevant resources. The website is provided by the Suicide Bereavement Support Partnership, an alliance of organisations with a focus on providing timely and appropriate support to everyone bereaved or affected by suicide.

## Survivors of Bereavement by Suicide (SOBS)

[www.uk-sobs.org.uk](http://www.uk-sobs.org.uk)

SOBS offers support for those bereaved or affected by suicide through a helpline answered by trained volunteers who have been bereaved by suicide and a network of local support groups.

Helpline: 0300 111 5065 Every day 9.00 – 21.00

Email: [sobs.support@hotmail.com](mailto:sobs.support@hotmail.com)

## Bereavement advice and support for children and young adults

### Child Bereavement UK

[www.childbereavementuk.org](http://www.childbereavementuk.org)

Child Bereavement UK offers support to children, young people, parents and families when a child dies (at any age) and when children and young people up to 25 are bereaved; and support and training for professionals.

Helpline: 0800 02 888 40 Monday-Friday 09.00 – 17.00

Email: [support@childbereavementuk.org](mailto:support@childbereavementuk.org)

Live Chat: [www.childbereavementuk.org](http://www.childbereavementuk.org)

### Childhood Bereavement Network

[www.childhoodbereavementnetwork.org.uk/directory](http://www.childhoodbereavementnetwork.org.uk/directory)

Searchable directory of local child bereavement services and other helpful information. It offers a resource for professionals and support to children and young people up to the age of 25.

Helpline: 0800 02 888 40

### ChildLine

[www.childline.org.uk](http://www.childline.org.uk)

ChildLine offers free and confidential support for children and young people up to the age of nineteen. No problem is too big or too small. The website has links to message boards where young people talk to other young people: one topic area is about bereavement.

Helpline: 0800 1111 Every day, 24 hours

1-2-1 chat: [www.childline.org.uk/Talk/Chat](http://www.childline.org.uk/Talk/Chat)

## Cruse Bereavement Care

[www.cruse.org.uk](http://www.cruse.org.uk)

Cruse supports people after the death of someone close. Their trained volunteers offer confidential face-to-face, telephone, email and website support, with both national and local services. They also have services specifically for children and young people.

Helpline: 0844 477 9400 Monday to Friday 9.30 – 17.00 Tuesday, Wednesday and Thursday 09.30 – 20.00

Email: [helpline@cruse.org.uk](mailto:helpline@cruse.org.uk)

## Daisy's Dream

A charitable organisation which can provide support to a child and their family following a bereavement.

Email: [Daisy's Dream \(daisysdream.org.uk\)](mailto:Daisy's Dream (daisysdream.org.uk))

## Grief Encounter

Supporting bereaved children and young people

[www.griefencounter.org.uk](http://www.griefencounter.org.uk)

Contact Details :0800 802 0111

## Hope Again

[www.hopeagain.org.uk](http://www.hopeagain.org.uk)

Hope Again is a web-based resource for bereaved young people, created by young people who have been bereaved; it's part of Cruse.

National Helpline: 0808 808 1677

Email: [helpline@cruse.org.uk](mailto:helpline@cruse.org.uk)

## PAPYRUS-UK

[www.papyrus-uk.org](http://www.papyrus-uk.org)

Papyrus-UK offers support and advice to young people who may be at risk of suicide and to those concerned about a vulnerable young person.

Helpline: 0800 068 4141 Monday to Friday 10.00 – 22.00 Weekends 14.00 – 22.00 Bank holidays 09.00 – 17.00. SMS: 07860 039977 Email: [pat@papyrus-uk.org](mailto:pat@papyrus-uk.org)

## Winston's Wish

[www.winstonswish.org](http://www.winstonswish.org)

Winston's Wish offers support and guidance to bereaved children and families. They can help with finding the words to explain death and suicide to children, can talk about funerals, responses and reactions, and suggest ways and resources to support grieving children. They have produced *Beyond the Rough Rock*, a book on supporting a young person or child bereaved by suicide.

Helpline: 080 88 020 021 Monday to Friday 8am-8pm. Email: [ask@winstonswish.org](mailto:ask@winstonswish.org)



## Bereavement support for parents

### Child Death Helpline

[www.childdeathhelpline.org.uk](http://www.childdeathhelpline.org.uk)

The Child Death Helpline is answered by trained volunteers who have experienced a child's death. It offers support to anyone affected by the death of a child of any age, under any circumstances, however recent or long ago.

Helpline: 0800 282 986 Monday to Friday 10.00 – 13.00 and 19.00 – 22.00 Tuesday and Wednesday 13.00 – 16.00

### Muslim Bereavement Support Services

[www.mbss.org.uk](http://www.mbss.org.uk)

Support for Muslim parents after the death of a child: face to face, group, helpline support in several languages.

Helpline: 020 3468 7333

### The Compassionate Friends

[www.tcf.org.uk](http://www.tcf.org.uk)

The Compassionate Friends support people when a child of any age dies through any cause. They have local support groups and online message boards with special sections for those bereaved by suicide and childless parents.

Helpline: 0345 123 2304 Every day 10.00 – 16.00 and 19.00 – 22.00

## Specialist Services

### AAFDA- Advocacy after Fatal Domestic Abuse:

[aafda.org.uk](http://aafda.org.uk)

They are a Centre of Excellence for Reviews after Fatal Domestic Abuse and for Expert and Specialist Advocacy and Peer Support

### Hundred Families

[www.hundredfamilies.org](http://www.hundredfamilies.org)

Contact details: [info@hundredfamilies.org](mailto:info@hundredfamilies.org)

(Support after mental Health Homicide - aims to offer accurate information and practical advice for families. Offers evidence -based resources for mental health professionals and others interested in serious violence by those with severe mental illness).

### National Autistic Society

[www.autism.org.uk/advice-and-guidance/topics/mental-health/suicide](http://www.autism.org.uk/advice-and-guidance/topics/mental-health/suicide)

## Respond

Specialist support services to people (and families) with learning disabilities, autism or both who have experienced abuse, violence, or trauma.

[Supporting the lives of people with learning disabilities and autism / Respond](#)

Contact details – 020 7383 0700

## SSAFA – the Armed Forces Charity

Support for veterans, serving personnel and families [www.ssafa.org.uk](http://www.ssafa.org.uk)

## Practical Support

### Citizens Advice

Advice on financial matters if a family are on a low income.

[www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)

### Help with funeral costs

The UK Government website signposts people to financial help with funeral costs.

[www.gov.uk/funeral-payments](http://www.gov.uk/funeral-payments)

## Practical advice on registering the death and planning a funeral

There is comprehensive guidance about what to do when someone dies on the UK Government site:

[www.gov.uk/when-someone-dies](http://www.gov.uk/when-someone-dies)

If a coroner is involved, the registration of a death follows a slightly different process to the usual one for most deaths.

This link explains the steps. [www.gov.uk/after-a-death/when-a-death-is-reported-to-a-coroner](http://www.gov.uk/after-a-death/when-a-death-is-reported-to-a-coroner)

### Tell Us Once Service

Available in every area of England, Scotland, and Wales. Visit the Tell Us Once Service to inform all government departments of a death by completing a simple form. [www.gov.uk/tell-us-once](http://www.gov.uk/tell-us-once)

### Turn2Us

A national charity providing practical help to people who are struggling financially.

This is an organisation that supports individuals in financial need and can also signpost professionals to grant-making organisations on behalf of families they support.

<https://www.turn2us.org.uk>

## Appendix One: Experiences of an inquest

What our families and staff may think about inquests - extracts from their perspectives.

### The experience from Family A

Most people never have to experience one and it is not something you can easily prepare for. I think our solicitor was very clear from the outset in seeking to manage our expectations. There were no false promises or attempts to put a positive gloss on things, something we got to appreciate more and more. For example, our solicitor was very clear in suggesting that while we might feel the organisation had been negligent in their care of our daughter (otherwise how could she have died in their care?), the bar for establishing negligence is exceedingly high in legal terms and rarely met.

In our daughter's case, having given a short narrative verdict, the coroner made it clear she did not find grounds to establish that negligence was proven. Despite our solicitors 'coaching', I am sure any onlooker would have seen a collective slumping of shoulders from our family at this point, only to rise seconds later as she issued her four Rule 43 reports against the organisation for deficiencies in our daughter's care and/or failures in procedures or adhering to them.

Regarding professionals feeling intimidated, you will be only too aware of the support, legal and otherwise, available to them and funded at the taxpayers' expense. I suspect that much coaching is given, alongside support in preparing statements etc. It took the NHS organisation many months to produce any statements and they certainly were not contemporaneous, despite the internal investigation that took place. I was astonished that staff were not requested to provide their statements immediately following the incident that led to our daughter's death. More concerning for me is the fact that, from our experience and that of others we have talked to, inquests become adversarial with Trusts and other professional bodies seeking to cast themselves in as positive a light as possible and protect themselves from criticism.

In turn, I think this forces families at times to take an almost pugilistic approach. The danger in all this is that truth is too often the victim and yet that is all most families want.

The defensive approach from professionals and more precisely their barristers, also means that they are not supporting the coroner in establishing the answers to the four questions that are the focus of a coroner's remit and which all parties to an inquest are there to assist with. Of course, the majority of families do not employ legal teams to represent their loved one's interests before a coroner. As I am sure you know, legal aid is almost non-existent, and you need deep pockets to employ an appropriately experienced legal team. Sadly, this means that many professionals are rarely challenged. Indeed, we understand from our legal support that many families do not even attend their loved one's inquest. I could go on but my overriding concern in all this is that in seeking to protect their interests professionals are not supporting the process in the search for the truth."

### The experience of Family B

When our daughter died by suicide whilst in the care of the mental services we were, and still are, completely devastated. A detailed serious incident investigation into the circumstances took almost a year. The inquest was eventually held almost 2 years after her death.

We were completely unaware of the processes of courts and inquests before this nightmare began. We were fortunate to have the support of the charity INQUEST who intervened with the

coroner on our behalf to get the inquest, initially scheduled for a few months after her death, postponed pending the outcome of the organisation investigation. We were also helped by them to find kind and experienced inquest lawyers to represent us. They helped us to access exceptional circumstances funding, which would not have been automatic, as we were not granted an Article 2 inquest by the coroner.

The lead-up to the inquest was highly stressful, even aside from our grief and shock, and the issue of funding. Disclosure of some evidence was delayed, and the coroner eventually gave two later inquest dates, which were changed to pre inquest reviews at very short notice. We don't live in the area where the inquest was held. While working full time, we were having to arrange and then to rearrange two weeks of accommodation, as well as ensuring caring responsibilities could be covered while we were away.

We had assumed that inquests, in addition to confirming basic facts, were genuine attempts to uncover circumstances around unnatural deaths, to attempt to prevent future deaths. We learnt in advance that coroners are independent practitioners who vary considerably in their conduct of inquests. We had been warned that ours had a track record of being particularly uncritical of service failures and we thought we were prepared for this. However, what we found truly shocking and heart breaking was the adversarial nature of the process. It seemed that the death of our daughter was incidental. The priority of the state funded lawyers (for the NHS organisation, ambulance, and police) was attempting to limit lines of enquiry, to protect the interests of their clients. In our view the coroner enabled this, and the organisations involved were protected from having to acknowledge what went wrong.

In our opinion, if the organisations involved were genuinely as sorry as they professed to be about our loss, then they would instruct their legal teams not to attempt to limit the scope of inquests, so that maximum learning could be achieved. It is only through learning, that the numbers of tragic deaths can be reduced, and more families don't have to endure these horrendous events.

In our inquest, the potential for learning to increase future safety appeared secondary to protecting the reputations of the organisations involved. Despite a highly critical internal investigation by the organisation, there was no acknowledgement during the inquest of the impact of the numerous things that went wrong in the care of our daughter. The coroner found no neglect and issued no Rule 43 Prevention of Future Deaths reports.

The Parliamentary Justice Committee report on The Coroner's Service from 2021 recommended that bereaved families should be at the heart of the inquest process. Our experience was that we were peripheral to the process and where our enquiries could be limited, they were.

## Staff Experience A

Attending an inquest is anxiety-provoking and emotional. Anxiety provoking because you are conscious you will be speaking about the person who died in front of their family members, who are grieving and who may well have opposing views to you about the care their loved one received. Emotional because you are so aware of the family's loss and grief. I have also found myself feeling guilty for feeling emotional myself about the death of the individual concerned because who am I to feel emotional when the family are going through so much? That said, I have been able to address family members at an inquest and tell them how sorry I am about the death of their relative and I think it is important to be able to do that, even though condolences may not always be accepted.



I haven't experienced an intimidating coroner and I have been well supported by my organisation, but I think the whole experience is quite intimidating really, including the legal language, standing when the coroner enters the room and so on.

The few experiences I have had with inquests and the memories of the patients and their families haven't left me, nor would I expect or want them to.

## Staff Experience B

It's always a terrible day when you hear about the death of a patient by suicide. It has happened to me only a few times, but each time there is a sense of tremendous sadness as well as endless reflecting on what could have been done differently or better. We nearly always have to contribute almost immediately to a patient safety investigation in our own organisation. Increasingly these have become safer spaces to discuss honestly how care had gone well and what improvements could be made.

The coroner's process often comes months or sometimes years after the event and is always daunting. Nearly all doctors have patients that die under their care, but only psychiatrists almost always end up with a coroner's investigation which feels like an assumption that psychiatric diseases are different and all deaths should be preventable. It's still an unusual event to go to coroners as suicide remains rare, and we have a Trust legal team who will go through the process of how the system works if you haven't attended before. You don't always have a Trust lawyer, and even if there is one, they don't (and legally cannot) coach or tell you what to say.

We are always reassured that the process is inquisitorial, and not adversarial, but I have been subjected to aggressive, persistent cross-examination by lawyers and sometimes coroners who clearly don't understand psychiatric care, risk assessment or the nature of psychiatric conditions. I have had to comfort very junior doctors and nurses who have been berated by counsel during cross-examination and sometimes simply don't know what they are being asked and are too scared to say so. I always go into a coroner's court assuming that the family want to blame me for the death of a loved one, and this is not how the process should work. It would help if coroners were led less by lawyers on each side and could develop some expertise in mental health so that they could genuinely uncover what happened and why.

## Appendix Two: Additional resources

### Patient Safety Incident Response Framework

[Support for patient service users, carers and families](#) when a patient safety incident investigation (PSII) is being undertaken – LearnTogether.org

[Support for staff when a PSII is being undertaken](#) – LearnTogether.org

[Other helpful resources](#) - – LearnTogether.org

### Duty of candour

[Duty of candour animation - NHS Resolution](#)

[Regulation 20: duty of candour - Care Quality Commission \(cqc.org.uk\)](#)

### Accessible Information Standard

[NHS England » Accessible Information Standard](#)

[Meeting the Accessible Information Standard - Care Quality Commission \(cqc.org.uk\)](#)

Making meetings accessible for those with learning difficulties and autism: [NHS England » Making meetings accessible](#)

MENCAP on Accessible Information Standard, with an Easy Read Guide: [Accessible Information Standard | Mencap](#)

Royal National Institute for the Deaf: [RNID - National hearing loss charity](#)

Royal National Institute for the Blind: [RNIB | Home](#)

### Just Culture

[Just Culture - NHS MerseyCare Documentary on Vimeo](#)

NHS England have also introduced a free and confidential self-check tool that can provide you with further information on the range of support offers that are available and help you to identify what option is the right one for you to access. The self-check tool is now available at the following link: [self-check tool](#).

Please visit this website for further information from NHS England: [NHS England » Support available for our NHS people](#)

[Support after a patient has died by suicide: resource from the Royal College of Psychiatrists. Visit the Royal College of Psychiatrists website](#)

### Safeguarding

NSPCC, What is Child Abuse: [Types of Child Abuse & How to Prevent Them | NSPCC](#)

General Medical Council, Protecting Children and Young People: [Protecting children and young people: The responsibilities of all doctors - ethical guidance summary - GMC \(gmc-uk.org\)](#)

Royal College of Nursing, Safeguarding Children and Young People: [Safeguarding Children and Young People: Roles and Competencies for Healthcare Staff | Royal College of Nursing \(rcn.org.uk\)](#)

Working Together to Safeguard Children: [Working together to safeguard children - GOV.UK \(www.gov.uk\)](#)

MAPPA Guidance: [Multi-agency public protection arrangements \(MAPPA\): Guidance - GOV.UK \(www.gov.uk\)](#)

ADASS: [safeguarding.pdf \(adass.org.uk\)](#)

The Office of Public Guardian safeguarding information: [SD8: Office of the Public Guardian safeguarding policy \(web version\) - GOV.UK \(www.gov.uk\)](#)

Social Care Institute of Excellence: [The Care Act: Safeguarding adults \(scie.org.uk\)](#)

The Ann Craft organisation <https://www.anncrafttrust.org/>

DoLS <https://www.scie.org.uk/files/mca/directory/dols-single-page-overview.pdf?res=true>

[Mental Capacity Act Mental Capacity Act - Social care and support guide - NHS \(www.nhs.uk\)](#)

## Medical examiner

National information: <https://www.england.nhs.uk/establishing-medical-examiner-system-nhs/>

## Inquest

[A guide to Coroner Services for Bereaved People – Ministry of Justice](#)

[Inquest.org.uk](#): A charity providing free and independent advice following the death of a person in state care or detention.

## Appendix Three - Additional Tips for Accessible Information Standard

### Communication plan

By asking the right questions, you'll be able to create a clear communication plan. This can be shared with other people who will find it helpful. It will be a live document that might change over time and should be regularly reviewed.

You may like to use a template to create a communication plan, or whatever works for the individual:

I am [name here]. This is what I need you to know about me.	
I communicate using:	e.g. BSL, deafblind interpreter, language interpreter, written communication only
To help me communicate, I use:	e.g. hearing aid, talking mat, lip reading
I need information in:	e.g. braille, easy read
The best way to contact me is:	e.g. email, mobile, text

### What can I do to aid communication?

Here are some tips for communication with people with a range of difficulties that might make accessing services and support difficult. These approaches may also be helpful to those in a state of shock.

Not all profoundly deaf or hard of hearing people use British Sign Language (BSL). Some deaf people speak, some lip read, some use sign and some use both. Some have difficulties with written English – others don't. Not all deaf people will be able to use our written information.

People with hearing aids may still need assistance. They may also be lipreading. Even with hearing aids, a deaf person may not be able use a voice phone.

### Profoundly deaf/hard of hearing people who do not use BSL

- Make sure you have someone's full attention – using simple gestures such as pointing or waving can help.
- Identify yourself clearly. Say who you are and why you're there.
- Check that you are in the best position to communicate, usually this will be facing the person - at eye level is often easiest.
- Find a suitable place to talk, with good lighting and away from noise and distractions.
- Speak clearly and a little slower than you would do usually, but don't shout.
- Keep your face and lips visible. If you're concerned about religious expression or infection prevention (i.e., COVID-19, use of masks), please discuss this with your manager.
- Use gestures and facial expressions to support what you're saying.



- Check if the person has understood what you are saying. Look for visual clues as well as asking if they have understood. Rephrase what you said if someone doesn't understand you.

## A person who is blind or has some visual loss

- May need information which is usually written down or provided in standard print in an alternative format such as: large print, audio (CD, mp3 file), or braille.

## People who are blind, deafblind or have some visual loss

- May require information to be sent or shared with them electronically (via email) instead of in a written or printed format. Using email may enable the recipient to use their own assistive technology or software, for example a 'screen reader' which converts text to speech.
- Find out what format to send the information in, consistent with the individual's software or assistive technology.

## Support for people with a learning disability

- The level of a person's learning disability will have a significant impact on their ability to communicate and therefore level of support needed. They may already have a 'communication passport' showing their preferences.
- People with a mild or moderate learning disability may need information in Easy Read format and verbal information explained more slowly and simply.
- A person with a more severe or profound learning disability may be supported by one or more carers and may need additional support to communicate, including using communication tools or aids.
- A person who has a learning disability may need information in an alternative format such as easy read or explained using Makaton<sup>9</sup>.
- A person with a learning disability may require support from a communication professional, for example an advocate.
- A person with a learning disability may also use non-verbal communication including gestures, pointing or eye-pointing.

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<sup>9</sup> A simple and easy way of communicating using signs, symbols and speech.

For more information, contact your Patient Safety team



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**Bristol, North Somerset  
and South Gloucestershire**  
Integrated Care Board



**Nottinghamshire Healthcare**  
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