dimensions

Dying to Matter

A guide for families following the death of someone with a learning disability

Foreword

There is considerable evidence that people labelled with learning disabilities die earlier than their peers. Sometimes these deaths may be unexpected and families will want to understand what has happened and why. I know from experience that getting answers can be an uphill battle at a time in which you can barely stand.

This resource is designed to support families when someone dies unexpectedly and provide details of what to expect, what to do and the questions that could be asked. We hope that this resource will also help providers, Trusts and other organisations work with families both to provide answers and to make changes in practice to reduce the possibility of people dying in the future.

Dr Sara Ryan
Connor Sparrowhawk's
mum
Co-founder #JusticeforLB

Dimensions would like to thank Sara Ryan, Rosie Tozer and George Julian for their advice and support in producing this guide.
Lead author: Andie Gbedemah.

Contents

Foreword 2

What you should reasonably expect from organisations involved in your family member's care and support following their death 4

How organisations respond to a death of someone with a learning disability and how does it involve you 5

What questions do you want to ask about your family member's death? 8

Will there be an inquest following your loved one's death? 10

What will happen before, during and after an inquest? 12

Useful websites 14

What you should reasonably expect from organisations involved in your family member's care and support following their death

Family members sometimes report not knowing what sort of communication to expect from the organisation that cared for their loved one after that person's death.

Here are a few things you may reasonably expect:

- To be treated with sensitivity and honesty by the providers or NHS Trust involved in the care and support of your family member.
- To be told about their death promptly and openly.
- To receive a genuine apology about what has happened.
- To be able to ask questions about what happened and why.
- To be kept informed and updated about any investigation, review or action that follows.
- To be engaged in the investigation process; for example helping to set the terms of reference for any investigation.
- To receive copies of medical records, notes and paperwork promptly.
- To be offered bereavement support.

How organisations respond to a death of someone with a learning disability and how does it involve you

The processes outlined below normally follow a death **that has been recognised as unexpected.**

If your family member's death has **not** been recognised as unexpected and requiring further investigation, you may want to contact the organisations involved in their care and support.

In the first instance, your loved one's next of kin will be the main point of contact for an organisation. The Chief Executive of an organisation is the best person to write to if you are unsure of who to contact.

How should social care providers respond to an unexpected death of someone with a learning disability?

Social care providers have a legal duty of candour to let you know about incidents that happen when someone is in their care.

An unexpected death should be considered an incident by the social care provider.

Following an incident, the duty of candour means the provider must provide in writing:

- All of the facts about your loved one's death, to the best of their knowledge
- Details of what further enquiries they see as appropriate
- An apology – this means an expression of sorrow or regret

The provider must also try to notify you in person – by phone or face to face – to discuss the circumstances of your family member's death.

How will you be involved?

As a family you should be involved in the ongoing investigations, if you choose to be. You can write to the provider, or meet in person to explain what enquiries you think should be made into your loved one's death and raise any questions you have.

If you were expecting to hear from a care provider following a family member's death but do not do so, you can write to the Chief Executive.

If you are dissatisfied with the provider's plans for further enquiries you can make a complaint to the provider. They should have a complaints procedure that should involve you in their decision making on whether to investigate further.

It is helpful to keep a written record of the interaction you have with the care provider – for example, name, date and time of telephone conversation and brief note of the content.

How should NHS Trusts respond to an unexpected death of someone with a learning disability?

NHS service providers have a legal duty of candour to let you know about incidents that happen when someone is in their care.

An unexpected death should be considered an incident by the NHS Trust.
NHS Trusts have a process for investigating Serious Incidents Requiring Investigation (SIRI).

An unexpected death should be considered a Serious Incident Requiring Investigation.

Following an incident, the duty of candour means the NHS Trust must provide in writing:

- All of the facts about your loved one's death, to the best of their knowledge
- Details of what further enquiries they see as appropriate
- An apology – this means an expression of sorrow or regret

The NHS Trust must try to notify you in person about the circumstances surrounding your family member's death.

The NHS provider should carry out an investigation into the Serious Incident Requiring Investigation (SIRI).

The investigation should involve a Root Cause Analysis (RCA). A Root Cause Analysis is a way of understanding why a fault or problem has happened.

This Root Cause Analysis means the NHS Trust should consider the role its own systems and individuals played in your loved one's death.

How will you be involved?

As a family you should be involved in the ongoing investigations, should you choose to be. You can write to the NHS Trust, or meet in person to explain what enquiries you think should be made into your loved one's death and raise any questions you have.

If you were expecting to hear from the NHS Trust following a family member's death but do not do so, you can write to the Chief Executive.

If you are dissatisfied with the Trust's plans for further enquiries you can make a complaint. They should have a complaints procedure that should involve you in their decision making on whether to investigate further.

It is helpful to keep a written record of the interaction you have with the NHS Trust – for example, name, date and time of telephone conversation and brief note of the content.

How do local authorities respond to an unexpected death of someone with a learning disability?

If the local authority paid for your family member's social care then they have a responsibility for the quality of that care. You can raise concerns about a social care organisation through the local authority. You can do this by writing to the adult social care department.

The local authority has responsibility for safeguarding all adults that live in their area. If they have failed to safeguard someone from harm then the Safeguarding Adults Board (SAB) should carry out a Safeguarding Adults Review (SAR).

How will you be involved?

You might be asked as a family to contribute to a Safeguarding Adults Review. Families offer valuable insight into how someone was cared for and the role of different organisations and individuals in their life.

If you want to be involved in a Safeguarding Adults Review you can write to the local authority and let them know. You can write to the adult social care department.

The Learning Disability Mortality Review programme (LeDeR)

The LeDeR programme has been established to review all deaths of people with learning disabilities, including unexpected deaths. The programme aims to identify factors associated with learning disability deaths to help prevent future deaths.

Anyone can report a death to LeDeR using the programmes website: http://www.bristol.ac.uk/sps/leder/

What questions do you want to ask about your family member’s death?

Why do families ask questions?

Some families just want to understand exactly what happened when their loved one died. This is important for its own sake.

Some families who have concerns about how their family member died want to make sure that any lessons that can be learned are identified to prevent future similar deaths. Some families want accountability from the organisations involved. They want answers to questions to make sure people or organisations take responsibility for any part they have played in someone’s death. This can also help to prevent future deaths.

Whatever the motivation, families have the right to answers when a loved one dies.

Questions to help understand the circumstances of your loved one’s death

These questions can help you decide if you are confident that you understand the circumstances of your loved one’s death.

If you feel that you don’t have answers, or you are concerned by how your loved one died, then you might want to ask the organisations involved in your family member’s care and support for more information, or seek formal investigations.

Questions about the circumstances of death

- When did my loved one die?
- How did they die?
- Where did they die?
- Who was with them when they died/who found them?

Questions about care or support

- Did the people caring for or supporting my family member know them and understand their needs?
  - Did they treat them with dignity and respect?
  - Did they have a sense of their personality?
  - Were they able to communicate effectively?
  - Did they take steps to involve them in the care or support they were receiving?
- Were reasonable adjustments made for them?
- Would the same thing have happened to someone without a learning disability?

Questions about preventability

- Should my loved one have died when they did?
- Were there any actions anyone could have taken, or would have been expected to take, to prevent their death?
- Did they receive the health/care they should have?

Some providers or NHS Trusts might not provide this information whilst they are carrying out an investigation into your family member's unexpected death. If this is the case, it is still worth letting the organisation know your questions and any concerns so these can inform the review.

Organisations should benefit from working with families collaboratively after the unexpected death of someone with a learning disability. This helps families get the answers they are looking for and gives the organisation the opportunity to learn from their perspective.

> **“...families have the right to answers when a loved one dies.”**

Will there be an inquest following your loved one's death?

What is a coroner?

A coroner is responsible for concluding how someone died. Following an unexpected death the coroner will normally carry out a post-mortem to try and establish how someone died.

It is important that guidelines are followed during a post-mortem as they can be important evidence if an inquest is opened into your loved one's death.

A coroner must open an inquest into someone's death after a post mortem if they have not been able to establish a cause of death, or if it was violent or unnatural death.

What are inquests?

Inquests are a legal process to determine how someone died. Inquests are inquisitorial, this means they hear evidence to answer questions about how someone died.
The coroner has four questions to answer through an inquest:

1. Who died
2. Where they died
3. When they died
4. How they died

How do inquests change what happens after someone dies?

The cause of someone's death needs to be established in order to register their death and provide a death certificate.

If your family member's death is referred to the coroner then the coroner will be responsible for looking after their body until the post-mortem has been carried out.

If there is an inquest then the coroner will release your loved one's body with a temporary death certificate, this means you can make arrangements for their funeral.

A post-mortem might cause a delay for when you can make funeral arrangements. The coroner should try their best to accommodate any religious or cultural practices you would like to follow after your loved one has died. You can notify the coroner about these.

As findings from a post-mortem can be important evidence in an inquest, you may want to consider this before deciding to donate your loved one's organs, so the coroner can carry out a full examination. Of course, those precious organs may well help other people to live so this is an important decision.

Inquests and learning disability deaths

Most coroners will not have much knowledge or understanding of learning disability care. This can mean that unexpected deaths may not be recognised as such, or omissions or actions in someone's care aren't spotted as issues requiring further investigation.

In some cases, coroners still misattribute someone's death to simply having a learning disability.

There can also be a lack of scrutiny around unexpected deaths from complications that rarely occur with people who don't have learning disabilities, or deaths of people with learning disabilities who die much younger than would be expected for someone without a learning disability.

This can mean that inquests are not opened into unexpected learning disability deaths without contact with the coroner to explain why an inquest might be appropriate.

What should you do if you think there should be an inquest into your loved one's death?

If you think the coroner should hold an inquest into your family member's death then you can write to them.

If there is a post-mortem for your loved one then there will be a Coroner Liaison Officer assigned to your family. They will be able to assist you with contacting the coroner.

It is helpful to contact the coroner as early as possible after your loved one has died.

You should set out any concerns you have about the circumstances surrounding your loved one's death and give the coroner information about the care and support they received. This will help to inform the coroner and highlight where any omissions or actions might have played a role in your loved one's death.

What will happen before, during and after an inquest?

As a family member you will be involved in the inquest as an interested person. An interested person is entitled to see all the documents for the inquest and receive a copy of the coroner's final report if one is produced.

You can appoint legal representatives for the inquest. Only in certain circumstances will legal aid be available - meaning that families will need to fund any legal support or come to an arrangement with a law firm of their choice.

What happens before an inquest?

Pre Inquest Review Hearings

Pre Inquest Review Hearings (PIRH) are held before an inquest. The coroner will set out the scope of the inquest and agree dates for when the inquest will take place.

You and/or your legal representative will be able to attend the PIRH as an interested person.

The other interested persons will be able to attend the PIRH with their legal representation.

The coroner will consider what the nature and scope of the inquest should be.

The coroner will make a decision on whether to hold an Article 2 inquest and whether there will be a jury at the inquest.

The PIRH is an opportunity to explain what you think the scope of the inquest should be and tell the coroner about the care and support your loved one received. The coroner might not know much about learning disability care so the PIRH can help the coroner make informed decisions about the evidence they need to listen to.

Article 2 Inquests

Article 2 inquests allow the coroner to consider 'by what means and in what circumstances' someone came to their death. This is broader in scope than answering the 4 main questions.

Article 2 inquests can be opened when public servants may be implicated in the death. Health and social care organisations might be considered within this definition.

Inquests with a jury

The coroner will normally preside over an inquest alone, but can decide a jury is needed in certain circumstances. Juries are only called in a small number of inquests, but the coroner can make the decision to do so because it is in the public interest.

A jury will be called if your loved one died whilst detained under the Mental Health Act (1983) or if it's believed they died an unnatural death in custody.

What happens during an inquest?

Evidence

The coroner will hear evidence about your loved one's death. The coroner will ask questions and legal representatives for interested persons will also be able to ask questions of witnesses.

Some witnesses may give evidence via a statement. If you feel someone should give evidence in person then you should notify the coroner.

The length of time taken to hear evidence will vary and will have been agreed in the Pre Inquest Review Hearing.

Who will be there?

Inquests are public, which means anyone can attend them.

Your family will be able to attend. You are also permitted to leave the inquest at any point if you feel the need.

You can bring friends and supporters with you. If you have legal representation then they will attend the whole inquest.

If there is media interest in the inquest then there may be some journalists who attend.

Summing up and conclusion

At the end of the inquest the coroner will sum up the evidence that they have heard.

A Coroner will return a ‘conclusion’ answering the four questions about someone’s death, based on the evidence they have heard.

Conclusions can be short form, drawn from a list of prescribed conclusions, such as ‘natural causes’ or the coroner can give a short narrative explaining how someone came by their death.

The coroner cannot apportion blame or determine civil or criminal liability.

What happens after an inquest?

The coroner’s recommendations

The coroner must report on any concerns that comes out of the inquest that are relevant to the prevention of other deaths. This is the coroner’s legal duty to take ‘action to prevent other deaths’.

In their report, the coroner can make recommendations. Some coroners will allow lawyers to put forward suggestions for their recommendations.

The coroner must provide their report to all interested persons and can share it with organisations and individuals they feel will find it useful.

The recommendations cannot be enforced, but any organisation that receives a recommendation must respond within 56 days to explain if the action has been or will be taken or explain why no action will be taken.

Useful websites

More about bereavement support
https://www.cruse.org.uk/
https://www.nhs.uk/livewell/bereavement/Pages/bereavement.aspx

More about learning disability advocacy services
http://www.bild.org.uk/about-bild/advocacy/

More about coroners and inquests
https://www.inquest.org.uk/
https://www.judiciary.gov.uk/related-offices-and-bodies/office-chief-coroner/

There for you

Dimensions provides evidence-based, outcomes-focused support including sector leading positive behaviour support for people with learning disabilities, autism and complex needs. We help the people we support to be actively involved in their communities.

Contact us to find out more:

www.dimensions-uk.org
0300 303 9001
enquiries@dimensions-uk.org

Find us on social media **@DimensionsUK**

Dimensions
2nd Floor, Building 1430, Arlington Business Park, Theale, Reading, RG7 4SA

Dimensions (UK) is a charitable registered society number 31129R. Building 1430, Arlington Business Park, Theale, Reading RG7 4SA. May 2018