



Dying to Matter:

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

This leaflet is designed to support families following the death of someone with a learning disability. It forms part of a guide that can help families to understand the circumstances of their loved one's death.

When someone with a learning disability dies in a care setting, be it independent supported living, residential care, hospital, an assessment and treatment unit or in day services, family members might be left with questions about the support they received.

Unexpected and preventable deaths of people with learning disabilities and autism

You might already have questions about your loved one's death if their death was unexpected. An unexpected death is one that was not anticipated as a significant possibility 24 hours before the person died.

Sometimes unexpected deaths happen because good and effective care has not been provided. In these cases, a death might have been preventable. Not all unexpected deaths are preventable, but as a family member you have the right to ask questions and get answers about the circumstances surrounding your loved one's death. You are under no obligation to ask questions, but you have the right to answers about what happened.

Attitudes to learning disability deaths

A recent study found that 43 % of learning disability deaths were unexpected and 42 % were premature – this means that, without a specific event that led to the death, the person was likely to have lived for a year or longer¹.

There can be a lack of scrutiny around unexpected deaths of people with learning disabilities – such as the deaths of young people with learning disabilities or deaths from complications that would not normally be experienced by people without learning disabilities. This can mean unexpected, preventable deaths go un-investigated.

“...as a family member you have the right to ask questions and get answers about the circumstances surrounding your loved one's death.”

¹ Confidential Inquiry into Premature Deaths of People with Learning Disabilities, University of Bristol, 2013

Although these facts are known, organisations involved in your loved one's care might not initially recognise their death as requiring further investigation, even when it was unexpected or preventable.

Getting answers

If your loved one's death is not recognised as unexpected by relevant organisations, you may have to play an active role in asking for proper investigation into their death.

This guide explains the different processes that can happen after someone with a learning disability dies. It provides information and practical advice on being involved in these processes as a family.

Your rights

Social care and health care providers have legal duty of candour. This means that after an unexpected death they 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

You should expect answers to your questions from the organisations involved in your family member's care and support.

You should expect to be kept updated about ongoing investigations.

You should expect that organisations providing care and support will follow their stated policies on involving and working with families.

You have the right to contact the coroner if you think there should be an inquest into your family member's death.

You have the right to attend an inquest into your loved one's death as an interested person.

Things to consider after a family member with a learning disability dies

- Was your loved one's death unexpected?
- Are you confident you know what happened when they died?
- Do you feel they were given the right level of care and support?
- Do you think their learning disability played a part in their death?
- Do you feel they were treated with dignity and respect?

For more information, please visit www.dimensions-uk.org and search for 'unexpected deaths'.

You can get further help on these topics and more through the full Dying to Matter guide. This is available at www.dimensions-uk.org/dyingtomatter.

There for you

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