



Northern Health
and Social Care Trust

When Someone Dies

Supporting people with learning disabilities through bereavement

PEN Awards Finals | Excellence in Personalised Care | 1 October 2026

Northern Health and Social Care Trust



BEREAVEMENT SUPPORT SHOULD INCLUDE EVERYONE

The inequality we needed to address

People with learning disabilities can experience an additional layer of exclusion at the very time they most need understanding and support.

- Information about death and grief may use language that is difficult to understand
- People may be left out of conversations because others want to protect them
- Families, carers and staff may want to help but feel unsure about what to say



ONE RESOURCE FOR THE PERSON AND ONE FOR THOSE SUPPORTING THEM

Our response

ACCESSIBLE BOOKLET

‘When Someone Dies’ explains death, grief and what may happen next using clear language and accessible design.

PRACTICAL GUIDANCE

The accompanying guidance helps families, carers and professionals introduce the booklet and support compassionate conversations.

The two resources work together: accessible information for the person, supported by confidence and consistency around them.



LIVED EXPERIENCE WAS PART OF THE DEVELOPMENT PROCESS

Co-production shaped every page

- 1 People with learning disabilities** Reviewed the language, images and meaning
- 2 Families and carers** Brought experience of supporting grief in daily life
- 3 Clinical and professional partners** Added expertise in communication, palliative care and bereavement

The resource reflects the needs and preferences of the people it was created to support.



LAUNCH, EDUCATION AND EVERYDAY USE

A resource that changes practice

The booklet became the starting point for a wider change in how services approach bereavement.

- A Trust-wide launch brought health, social care and partner organisations together
- Education sessions help staff and care providers use the booklet with confidence
- The resource now supports real conversations with people experiencing grief and loss



EARLY EVIDENCE WHILE FORMAL EVALUATION CONTINUES

What we are seeing

FOR PEOPLE

Clearer explanations and greater participation in conversations about bereavement

FOR SUPPORTERS

Practical help for families, carers and staff when words can feel difficult

FOR SERVICES

A more consistent and compassionate approach across health and social care

Feedback has been consistently positive. Formal quantitative evaluation is ongoing, so we are careful not to claim more than the evidence currently shows.



GOVERNANCE, EVALUATION AND WIDER RELEVANCE

Built to last and ready to share

- The Adult Learning Disability Service owns ongoing governance, review and development
- Education keeps the resource visible and supports consistent use across settings
- Feedback and formal evaluation will guide future revisions and publication
- The model can transfer to hospitals, community care, hospices, supported living and education



PERSONALISED CARE AT A MOMENT OF PROFOUND VULNERABILITY

Why this work matters

‘When Someone Dies’ makes inclusion practical.

It gives the person accessible information and a place in the conversation.

It helps those around them respond with confidence and compassion.

It turns a simple resource into a sustainable change in practice.

People with learning disabilities deserve the same honesty, dignity and support in grief as anyone else.



PRESENTATION EVIDENCE

Sources and acknowledgements

PRIMARY SOURCE

Northern Health and Social Care Trust
PEN Awards Submission Form
'When Someone Dies'
2026

PROJECT RESOURCES

'When Someone Dies' accessible booklet
Guidance for families, carers and professionals
Adult Learning Disability Service education
programme

With thanks to people with learning disabilities, the Adult Learning Disability Service User Forum, families, carers and all multidisciplinary partners.