



End of life care for people with Down's syndrome and dementia.

The appropriateness of different accommodation settings

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Centre for Research on Families and Relationships

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Agenda



- Why Down's syndrome and dementia?
- End of life research with professionals and siblings
- PhD research
- Personal stories

Keep Talking
ABOUT DEMENTIA



Information for Siblings and Professionals
about Down's Syndrome and dementia

Down's Syndrome
SCOTLAND

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Key issues from end of life research 2005 - 2007



- Nutritional needs
- Lack of awareness of dementia in learning disability settings
- Training
- Lack of awareness of learning disability in dementia settings
- Advance preparation
- Informed choice

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Let's talk about **DEATH**



A booklet about death and funerals
for adults who have a learning disability

Down's Syndrome
SCOTLAND • helping people • make their potential

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How do YOU feel?

It is important to talk about when you want to.

Talking about helps you remember them and the time you spent with them.

You may feel sad and shocked.

You may feel like crying. This is OK.

It may take a while to remember that is not coming back.



What will HAPPEN?

You may behave differently.

You might not sleep as well at night.

You might feel angry with the doctors and nurses for letting it happen.

You might feel angry with for leaving you.



It is normal to feel all of these things.

Try and talk about how you feel.

It is not anybody's fault that has died.

You will not always feel this sad.

A time will come when you think of and remember the good times that you had with them.

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"We knew he was deteriorating but no one openly talked to him about dying"

Manager

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*"I don't know if he, or even his family,
knew he was dying"*

Support Worker

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3 Research Participants



- Male - own accommodation with daily support
- Female - nursing home
- Female - learning disability group home

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Summary



- Difference in appropriateness of end of life care in different accommodation settings
- Scope within any of the settings to get to know the individual using appropriate communication methods, even at the end of life

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- Watchman, K. (2008) Changes in accommodation experienced by people with Down syndrome and dementia in the first five years after diagnosis, *Journal of Policy and Practice in Intellectual Disabilities*, 5(1) 65-68

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