

Just like the rest of the population people with learning disabilities are living longer. Although this is of course very positive, it also means that there are new areas of concern.

Living longer means that people with learning disabilities are more likely to experience bereavements, become aware of their own mortality and have an increased risk of developing dementia (particularly people with Down's syndrome) and other terminal illnesses with a long dying phase.

These losses cause anxiety for everyone: for the older people themselves, for the direct care staff supporting them and also particularly for older families. At present there is very little support available, the Respond Elder's Project has been established to address these issues.

Getting Older

As people with learning disabilities grow older, they are more susceptible to a wide range of experiences which may affect the quality of their life. These include:

Loss and Bereavement

As people grow older they will experience the death of friends and family. Older people with learning disabilities who live with their family may also lose their home when a parent becomes frail or dies. Such instances of bereavement can become more complex when the losses are multiple.

People with learning disabilities have not always been given the opportunity to learn about the life cycle and have sometimes been prevented from taking part in rituals which help people grieve.

Terminal Illness

As people live longer they are more likely to die from an illness with a long dying phase (a terminal illness), for example cancer. Research shows that many people with learning disabilities are not accessing palliative care services during this final phase of their lives. This project will highlight the need for palliative care and help staff supporting people with learning disabilities to access and work with such services.

Dementia

Older people are at risk of developing dementia. For some people with learning disabilities this is a particular risk, for example people with Down's syndrome. Dementia is not always easy to diagnose in the early stages and can easily be mistaken for depression or challenging behaviour. People with learning disabilities may develop early onset dementia when they are still relatively young.

With early diagnosis and appropriate support, people can maintain a positive lifestyle and have their complex health care needs met. It is important for services to know how they can best support someone before a crisis situation arises.

How We are Able to Help

The project will offer a range of services to older people with learning disabilities, their families, paid carers and professionals.

Older People with Learning Disabilities

People are more likely to cope when someone close to them dies if they have some basic understanding of the life cycle and the concept of death. For most people, this knowledge is gained during childhood. For many reasons, people with learning disabilities can miss out on this learning. The Elder's Project intends to work with services to set up education groups to address this gap in knowledge.

We will offer psychotherapy which can help clients understand and manage difficult feelings that they may have in connection with growing older. These may include:

- Anger
- Depression
- Sadness
- Fear
- Guilt

Our therapeutic work has a psychodynamic orientation and respects the uniqueness of each person's experience and how they communicate and express themselves.

Families

Some parents or siblings may have looked after their relative for 50 or 60 years with little or no support. Family carers live with the constant worry about what will happen when they can no longer cope or if there is an emergency.

The project will support families by providing:

- Advice and Information
- Telephone support
- Counselling
- Advocacy

Professionals and Paid Carers

Up until recently, learning disability professionals have been focusing on empowering people with learning disabilities to live active and fulfilling lives.

However, as people become older, services are met with new challenges. Our project will work with agencies to create policies and provide models of good practice. It will do this through:

- Training
- Consultation
- Supervision
- Advice and Information

National Helpline

Our national helpline is available to older people with learning disabilities, families and professionals. For advice and information on any issues related to ageing and learning disability please call 0808 808 0700. It is open Monday to Friday, from 1:30pm to 5pm and all calls are free.

Accessing Services

For further advice on any information in this leaflet and on how to access any of these services please contact the Elder's Project Manager.

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RESPOND
from hurting to healing



Elder's Project

Providing support to older people with learning disabilities, their families, carers and professionals