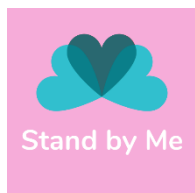


Response to the Consultation on the New Dementia Strategy

The new strategy was discussed at a meeting chaired by Professor Karen Watchman (University of Stirling) on the 6th of December. Aim of the meeting was to highlight the experiences of people with a learning disability affected by dementia (and those who support them).

Present was the advisory group to a current research project which explores the support needs of couples with a learning disability affected by dementia ([Stand by Me](#)) and staff from Key Scotland.

Contact email: Karen.Watchman@stir.ac.uk



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What did we do?

The Scottish Government is developing a new dementia strategy.

They are asking people to share their experiences of dementia.

We met in Glasgow to discuss how the new strategy can support people with a learning disability affected by dementia.



Who was there?

The Stand By Me advisory group.

Staff from Key who provide support to people with a learning disability.

A policy advisor from the Scottish Government.

On the next pages you will find a summary of what we talked about.



When we use the word 'staff' we mean social care support staff.

The feedback from people with a learning disability here reflects their experience of receiving social care provision, and of living with others who have a learning disability rather than with family.



Dementia experiences

Many adults with a learning disability know someone with dementia.

This can be friends or relatives such as parents or grandparents.

People with a learning disability sometimes care for a parent, partner or friend who has dementia.

Seeing people with dementia change or behave differently can be confusing and scary.

People worry how dementia will affect their friends, relatives, partners or themselves.

Dementia is different for each person. This makes it difficult to understand dementia and to know how it will affect people in the future.

Thinking about the future can be scary.

Living in the moment can help but small pieces of information are still needed on a day-by-day basis.



Diagnosis of dementia

Partners or friends might be the first ones to notice changes.

Staff and family don't always talk to people with a learning disability about dementia.

Sometimes this is ok as some people might prefer not to know.

Some people do want to know what is happening to them.

It is important to think about how to have conversations about dementia.

Too much information at the point of diagnosis can be overwhelming and scary.

Information about dementia should be broken down into small chunks using easy language

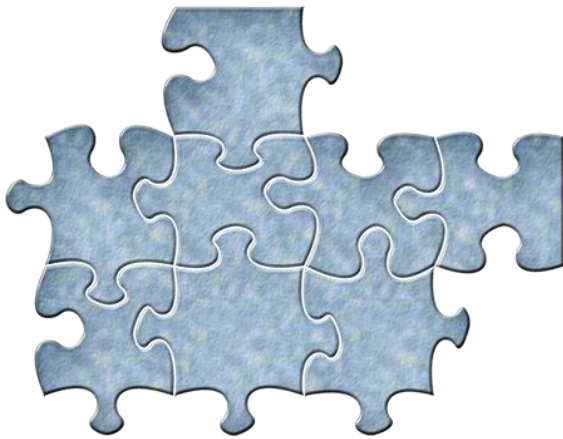
It is like a jigsaw where all the pieces of information come together to help people see the bigger picture.

But not all the pieces of jigsaw might be caused by dementia.

No information at all means people might think the worst or that they will change and get a lot worse immediately or overnight.

It can be difficult to understand different types of dementia.

Sometimes people say dementia and sometimes they use words like Alzheimer.





What can help people with a learning disability affected by dementia?

Staff play an important role because they can support people to speak to doctors and other professionals.

If the person with a learning disability feels able to talk about what they would like to happen in the future, this can help if decisions need to be made.

This might be about where to live for example.

If possible, people should be supported to stay in their homes.

Sometimes decisions are made too quickly about moving someone.

A move may never be needed. Sometimes these decisions are made before dementia is even confirmed. This is wrong unless the person wants to move.

Sometimes people with a learning disability and dementia move to a care home to get more support.

This can mean they lose contact to regular support workers, partners or friends.

These relationships are important to keep.





New staff do not know the person well.

Use of photographs, social stories or life story work are important to support people whether or not they change where they live.

What needs changed?

People with a learning disability might help their partner with dementia.

Both partners will need support, but different kinds of support and it might be from different people.

Sometimes people with a learning disability live at home and help their parents with dementia.

It should be recognised that people with a learning disability can be carers too and need support.

People with a learning disability are not always told about dementia.

This might be to protect people, but not knowing can be scarier.

It would be helpful to have more positive stories about dementia and information about how people with dementia can be supported to live active and happy lives.



Staff who support people with a learning disability should have training on dementia.

This helps them to spot early signs of dementia.

Staff will be able to better support people and this might enable people to stay in their home.



Mobile phones or other types of technology can help people to stay independent.

But some phones are hard to use or people do not remember to charge them.

It would be good to have phones, tablets and laptops or other types of technology that are easier to use for people with a learning disability.

Staying active and being involved in local communities helps people.

But people with a learning disability say that there are fewer activities for them especially after the pandemic.

Centres have not opened and some activities have not started again.

In some parts of Scotland there was only one activity anyway so now there is nothing.





People with a learning disability and dementia are not seen as part of the dementia community.

People say that they do not know what is available for people with dementia generally and if it would help them.

There are not many support groups for people with a learning disability and dementia or for their families.



The Scottish Government said that every person with dementia should get support for a year after their diagnosis.

This should be done by a post diagnostic link worker.

Having a link worker might make it easier to know what other supports could be available.

It should include developing a person-centred plan.

No one knew of someone with a learning disability and dementia who had a link worker.



Some people already had support, such as Community Learning Disability Nurse.

It is important to keep this and other support from a team in health and social care.



People with a learning disability have the right to make decisions about their lives.

This includes where they want to live, with whom to live, their finances or medical care.

Sometimes others such as family members or workers support people to make decisions.

But the person with a learning disability should always be involved in those decisions.

Under the Adults with Incapacity (Scotland) Act others might become legal guardians to make some decisions for the person.

Those decisions should be based on what the person would want.

This is why having early conversations can help later when dementia gets worse.

We think that too often others make decisions for people with a learning disability without trying to involve the person.

Not everyone always follows the guidelines of the Adults with Incapacity (Scotland) Act.





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Anything else you would like to tell us?

People with a learning disability should be involved in conversations about dementia.

People with a learning disability should be involved in research about dementia.

People with a learning disability are not the same as others in 'minority' or 'excluded' communities.

Each group has very different needs and experiences.

We want this to be reflected in the new strategy.

