

## Stand by Me

### Literature review about the experiences of people with a learning disability and dementia: Easy-read summary



#### What is a literature review?

A literature review is looking for all the research papers and books that have been written about a topic.

#### Why did we do it?

We wanted to learn more about the experiences of people with a learning disability and dementia.

We wanted to hear these from their points of view.

We wanted to know how people's lives change when they have dementia.



#### What did we do?

We looked for research where the people who took part had a learning disability and dementia.

This could mean speaking to people with a learning disability and dementia, spending time with them or asking others about their experience of dementia.

We looked at over 6000 research articles.





## What did we find?

We only found 8 studies that included people with a learning disability and dementia as participants:

- 2 from Australia
- 3 from the UK
- 1 from Canada
- 2 from the USA



Most participants lived in shared group homes or residential settings.



Researchers found that using objects or photographs helped them talk to people who have a learning disability and dementia.



Some people with a learning disability and dementia found it difficult to speak about their experiences.

Instead, researchers spent time with the person, and others around the person, to learn about their life.

Spending time with people over longer periods of time helped researchers get to know them.



Some researchers also talked to family members and staff.

### **What we learned from the review**

Many people had not been told of their dementia diagnosis or had little knowledge of dementia.

People were aware that their lives and abilities were changing but they did not know why.

Not knowing why this was happening worried people.



Consistent relationships were important to help people be involved in everyday life.

Family members and staff who knew people well helped them to do activities they liked.

Family members and staff were able to tell social workers and managers what people needed.





Sometimes signs of distress were called 'challenging' behaviour.

Staff did not always understand that people's abilities and needs changed because of dementia.

Staff did not always understand that a person may be scared because they do not understand what it means to have dementia.



People with a learning disability and dementia were not always involved in decisions taken about their lives.

This included stopping activities or moving to a different home or care home without being asked.

We did the literature review as part of our Stand by Me study.

The study is funded by the Dunhill Medical Trust.

The review was published by the Journal of Applied Research in Intellectual Disabilities. You can read it by clicking on this link:

<https://doi.org/10.1111/jar.13063>

Jacobs, P., Watchman, K., Wilkinson, H., Hoyle, L., & McGenily, L. (2022). Experiences of people with intellectual disability and dementia: A systematic review. *Journal of Applied Research in Intellectual Disabilities*, 1– 18.

