

Stand by Me - Ageing and Society

Scoping review about couples with a learning disability and couples with dementia - Easy-read summary

With thanks to Andrew Doyle, Louise Boustead, Jan Murdoch, Gillian Fitzsimmons and Sumeiyah Koya.



What is a scoping review?

A scoping review looks for all the research articles and books that have been written about a topic.



What did we do?

We looked at over 3000 research articles.

Why did we do it?

We wanted to see if there had been any research about couples with a learning disability where one partner had dementia.



What did we find?

We did not find any research about couples with a learning disability where one partner had dementia.

Our study will be the first.



What we did next

We did two literature searches on different topics related to this.



Search 1 – Couples with dementia who did not have a learning disability

First, we searched for research about couples where one partner had dementia and neither had a learning disability.



We looked more closely at 8 reviews that summarised 73 studies.

Most studies were conducted in North America and in Europe.



What we learned

The research reviews showed us how couples experienced and responded to change in their relationship.

One partner often started to help the partner with dementia more.



This can include taking over household tasks, as well as helping their partner get dressed.

There was very little mention of couples getting regular support from professionals or services.



Many researchers only spoke to the partner who did not have dementia.

These studies talked more about stress

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When researchers spoke to both partners, they found more positive experiences of relationships.

The couples spoke about their love for each other and how they helped each other.



Search 2 – Couples with a learning disability who did not have dementia

In the second search we looked for research about older couples with a learning disability where neither partner had dementia.



We found 10 research studies.

- 5 from the UK.
- 3 from Israel.
- 1 from Ireland.
- 1 from Spain.

Researchers spoke to people with a learning disability, professionals and parents.



In three studies people with a learning disability were coresearchers.

Most studies focused on what helped people with a learning disability to start or end a relationship.

There were not many studies about what helped people to be in a relationship for many years.



What we learned

Workers and family members are often very involved in the lives of couples with a learning disability.

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Workers and family members sometimes support couples.

They can also stand in the way of some relationships.



For example, some couples with a learning disability were not allowed to share a bedroom or move in together.

Most partners already had support before a change in their health, such as a dementia diagnosis.

We did this scoping review as part of our Stand by Me study. The pictures are by Photosymbols.

The study is funded by the Dunhill Medical Trust.

The full review was published by the journal Ageing & Society. You can read it by clicking on this link: <u>Link to journal article</u>

Jacobs, P., Watchman, K., Wilkinson, H., & Hoyle, L. (2023). Couples with intellectual disability where one partner has dementia – a scoping review exploring relationships in the context of dementia and intellectual disability. *Ageing & Society*, 1-40. doi:10.1017/S0144686X22001416







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