



# Stand by Me Research Report

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Experiences of couples with a learning disability  
when one partner has dementia



## Acknowledgements

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## Research team

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For information about the Stand by Me project please visit:

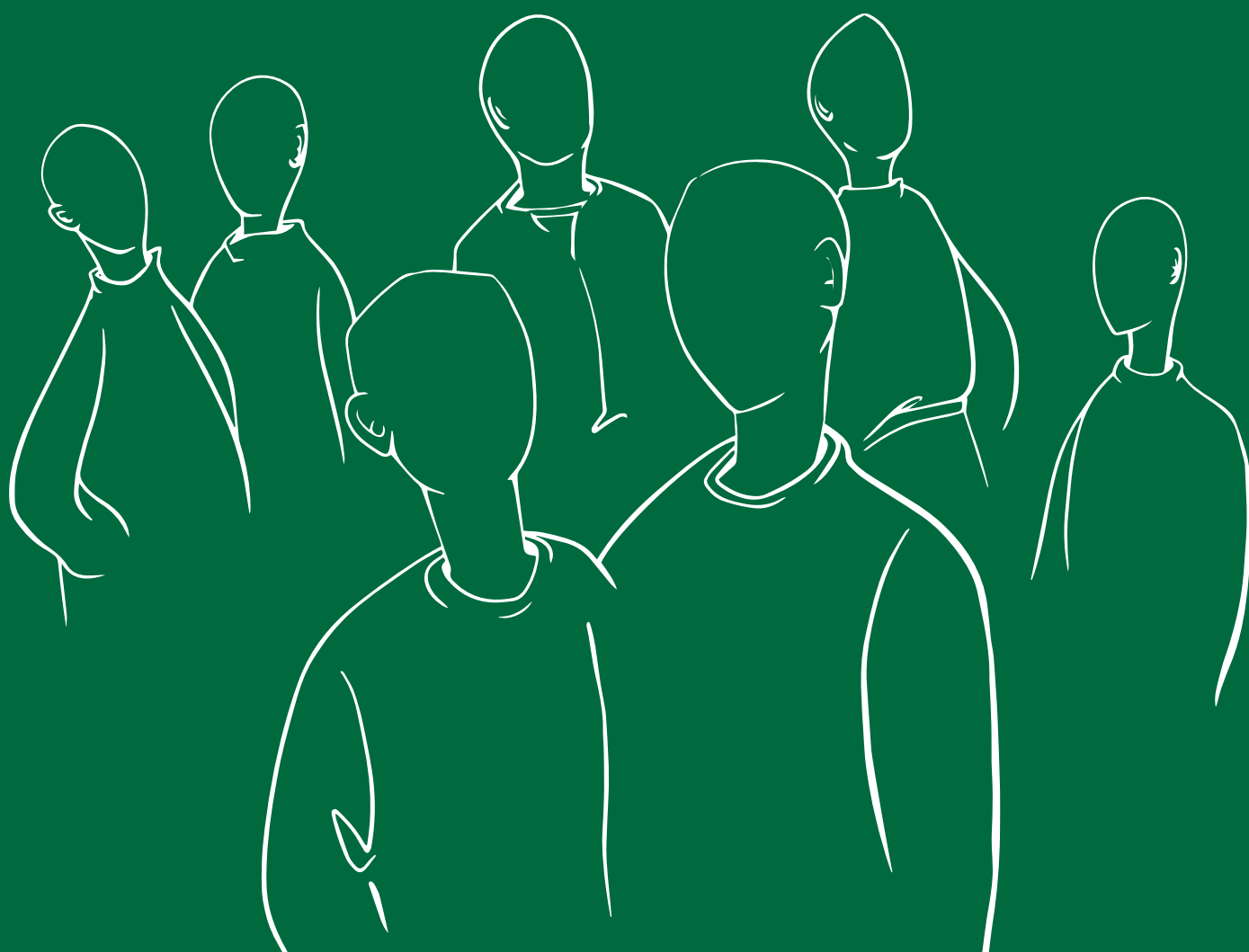
[sclد.org.uk/stand-by-me/](https://sclد.org.uk/stand-by-me/)

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# Introduction

People with a learning (intellectual) disability are now living for longer and it should be celebrated that individuals are enjoying relationships and marrying. Such relationships can provide a sense of belonging, security, acceptance, and enhance quality of life. Yet, many people with a learning disability continue to face barriers to intimate relationships, marriage or co-habiting with a partner.

The risk of dementia at an earlier age among people with a learning disability, especially people with Down's syndrome, is known. Experiences of carer dyads in dementia care is typically limited to couples who do not have a learning disability, with no previous evidence base informing how each partner with a learning disability may best be supported and how relationships may be sustained. Prior to our research, it was not known what coping mechanisms were developed or how couples wished to be supported. Evidence to inform practice is needed to support not just couples with a learning disability, but also staff and family members who find themselves at the intersection between learning disability and dementia.

This research provides the first known evidence of the experiences of couples with a learning disability when one partner has a diagnosis of dementia. The idea for the research came from a married man with a learning disability, Andrew, who had a diagnosis of dementia in 2019. His fears were about what it meant to have dementia, what changes he may experience and how quickly, and how his relationship with his wife might be affected. This led to further discussion about the need for new evidence. Consequently, this research focus is on a new group of older people; couples with a learning disability when one partner has a dementia diagnosis.

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“What if my behaviour to my wife changes, how will we cope?”

**Andrew**

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“This research provides the first known evidence to understand the experiences of couples with a learning disability when one partner has a diagnosis of dementia”

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We sought to understand the evidence from multiple perspectives: partners with a learning disability, in some cases with dementia, plus some of their social care support staff and family members. Initially, two literature reviews were conducted and published as part of our efforts to identify if similar studies had been conducted elsewhere.

## Scoping review

The first review sought to understand if there was any existing evidence on this topic. After identifying that there was not, we conducted two further literature searches as part of a scoping review, firstly to find evidence on couples without a learning disability where one partner has dementia. This highlighted the need for emotional support for both partners, emphasising interdependence over independence, and recognised that partners with dementia continued to show love and affection as the relationship became more unequal in other areas. The second review looked for evidence about older couples with a learning disability where neither partner had dementia. Studies that were included emphasised that the starting point for most couples with a learning disability is different to that of couples in the population generally. While formal support is likely to be in place, it can act as a facilitator as well as barrier to relationships.

The full scoping review is available at <https://bit.ly/3HTKNN7>

## Systematic literature review

We conducted a review of qualitative literature to systematically search for research that had involved people with a learning disability and dementia as research participants. Whilst acknowledging the complexities of speaking about dementia, findings challenge the view that people with a learning disability and dementia cannot be involved in research.

The full systematic review is available at <https://bit.ly/3WCZzfD>

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*“Findings challenge the view that people with a learning disability and dementia cannot be involved in research.”*

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# Study design

## Aims

The Stand by Me research sought to explore day to day experiences of couples with a learning disability and to identify factors that supported sustainability in relationships when one partner has a dementia diagnosis.

## Research advisory group

Advisory group membership consisted of three adults with a learning disability, one of whom had dementia and two who were married to each other, plus professionals from Alzheimer Scotland and Key and Community Lifestyles. The purpose of the group was to advise the research team, to support development of accessible information including consent and easy read material, to discuss and contribute to the analysis process and to take part in project dissemination. To identify if planned actions or goals were on target or achieved, we used a traffic light system, red (activity not yet started), amber (activity in development) and green (activity completed).

At intervals during the research, the team welcomed two research students who were on a short placement as part of the MSc Health Research at the University of Stirling. Each made contributions appropriate to the stage of the study, for example one student wrote a blog, developed skills in writing in an accessible and easy manner to support the advisory group. The second assisted with analysis and critical appraisal as part of the systematic literature review and was subsequently included as co-author. Towards the end of the study, two research interns from the University of Edinburgh PhD internship programme were employed to work for one day a week. Both provided consistency of support for advisory group members at, and between, meetings.

## Ethical issues

Ethical approval was given by University of Stirling NHS, Invasive or Clinical Research Committee (NICR 20/21 105) and NHS Health Research Authority Social Care Research Ethics Committee (20/IEC08/0042).

The inclusion criteria stipulated that both partners in the relationship were required to be aware of the diagnosis of dementia or have had an equivalent explanation of cognitive changes, recognising that 'dementia diagnosis' can be a difficult concept to understand.

## Sample

Purposive sampling was initially used to recruit participants in Scotland and England via two learning disability social care providers who work with people in supported living services or in their own home; and two third sector learning disability organisations providing support and information to families and practitioners in England and Scotland. Subsequently, snowball sampling was used to identify further participants with, for example, recruitment information shared on Twitter and LinkedIn and by families of people with a learning disability on closed social media groups.



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Research Study  
**Stand by Me**

Stand by Me

Research participants wanted!

Can you help us to better understand how to support couples with a learning disability where one partner has dementia?

Please get in touch: [paula.jacobs@stir.ac.uk](mailto:paula.jacobs@stir.ac.uk)



Image reproduced with permission from Jenny's Diary (Alzheimer's Society Dissemination Grant 225)

[www.learningdisabilityanddementia.org/relationships-study](http://www.learningdisabilityanddementia.org/relationships-study)

*Stand by Me flyer*



## Inclusion criteria

### People with a learning disability

- Required capacity to consent to take part.
- In a relationship lasting six months or more (or had been in a previous relationship) with a person who has a diagnosis of dementia. If the partner had died, then the death must have been more than twelve months before the participant was approached to take part in the study. This was to reduce potential distress during conversations about a sensitive topic.

**or**

- Had dementia themselves and was/had previously been in a relationship with a partner who has/had a learning disability.
- In either situation above, both partners had to be aware of the diagnosis of dementia and the relationship should be ongoing (or have previously been) for a minimum of six months.
- Received support from a social care organisation and/or a family member.

### Family members

- Has/had a family member in a relationship where one partner has dementia (the relationship should have been for a minimum of six months).

### Social care practitioners

- Has supported or currently supports a service user/client in a relationship where one partner has dementia (the relationship should have been for a minimum of six months).



## Methods of data collection and analysis

### Data collection

We collected data on eight couples from different perspectives.

- Life story interviews with five people with a learning disability, one of whom had dementia, to create a narrative of their relationship over time.
- Semi-structured interviews with four family members: two relatives of the partner with a learning disability and dementia; two relatives of the partner who did not have dementia.
- Semi-structured interviews with nine social care practitioners who provide or have provided, support for one or both partners in the relationships.

### Life story interviews

A life story interview, in research terms, means placing an individual and their experiences at the centre. Personal narrative is understood using a variety of methods, often creative or visual. Each story was unique to the couple, and it was important to respect different experiences. To facilitate conversation, we created a roadmap using signposts to the past, present and future.

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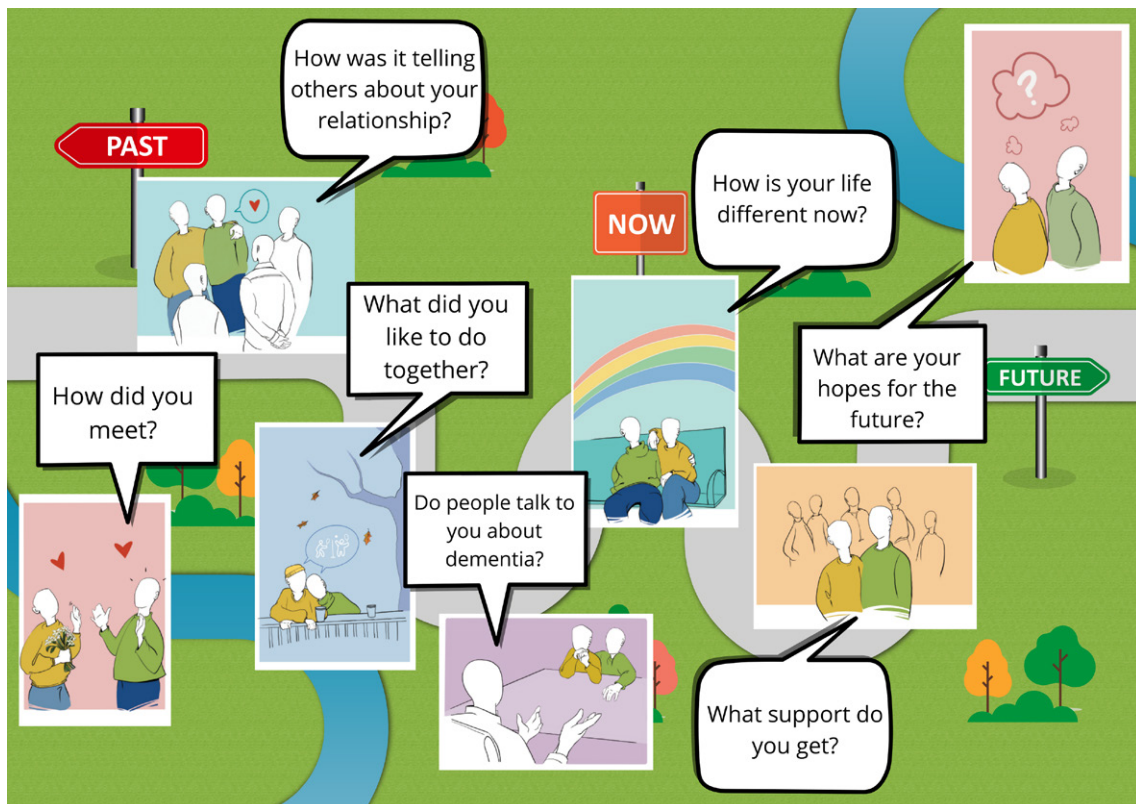
*“Each story was unique to the couple, and it was important to respect different experiences.”*

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Template of the roadmap developed as an option for data collection with participants with a learning disability



Example of how the roadmap supported life story conversations if this was desired by participants



*Using the roadmap in practice (This image was recreated and does not show actual data collection)*

The advisory group worked with an artist to create bespoke images that may represent different stages of the relationships of each couple. It was important not to make any assumptions about the ethnicity, age or gender of the couples in the images, or even which partner had dementia. The images created were tools to allow each story to be told in an individual way. However, it was important that they were used to guide, not lead or assume what was a positive or negative time in the relationship.

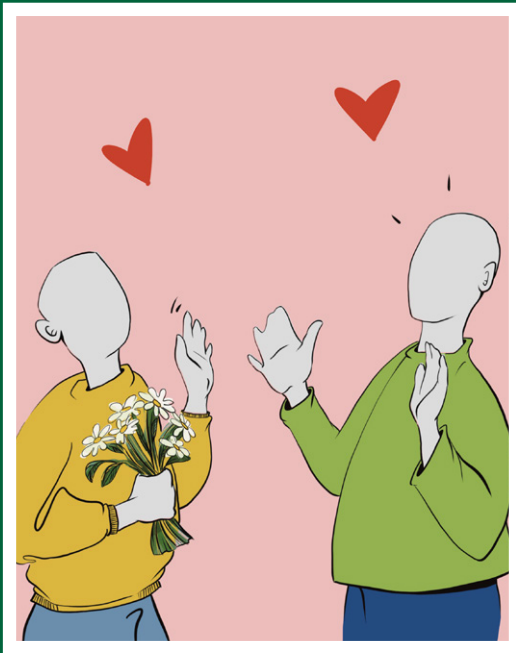
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*“It was important not to make any assumptions about the ethnicity, age or gender of the couples in the images, or even which partner had dementia.”*

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Two of the life story interviews were in-person (one with a couple). However due to COVID-19 considerations and at the request of participants, one was online and one was conducted by telephone. During the two in-person interviews, images were used to support conversations. For the online and telephone interview, images were posted to the two participants beforehand and referred to as part of talking about the past, present and future stages of their relationship during the interview.

# Images used in life story interviews



*When the couple first met*



*Past lives together*

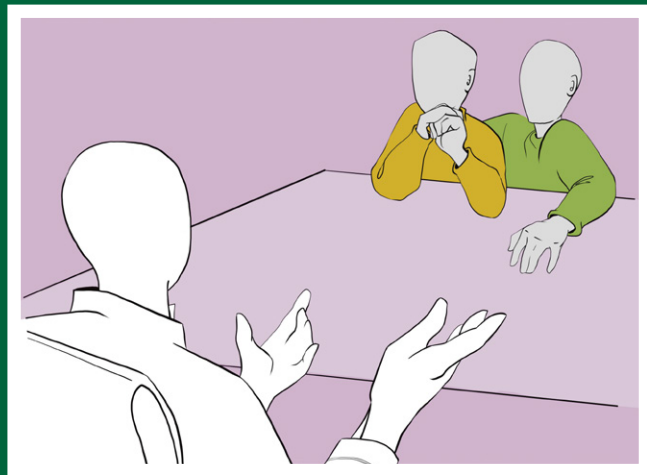


*Telling others about their relationship*

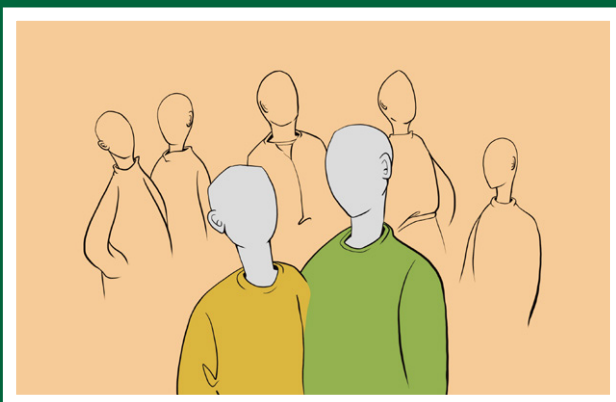
# Images used in life story interviews



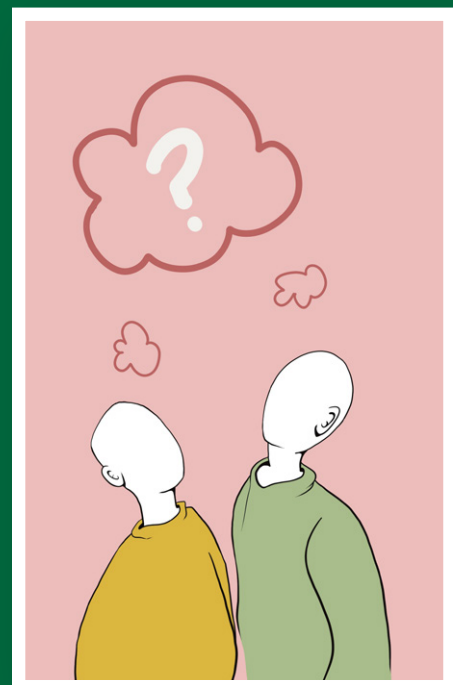
*Current life of the couple  
(where appropriate)*



*Receiving the dementia diagnosis*



*Social networks of the couple or partners*



*Thinking about the future*

## Semi-structured interviews

Social care support staff and family members (parents and siblings of participants with a learning disability) took part in semi-structured interviews. Due to COVID-19 considerations all except one were conducted online. Participants were asked about their role in the couple's life, how couples met, responses to, and support for, the relationship, the couple's life together before the dementia diagnosis and what changed afterwards.

## Analysis

Stories were developed about the eight couples, sharing how they met and how their lives had changed after the dementia diagnosis. As a form of respondent validation, each story was shared back with participants after first draft. This was to ensure accuracy and give the opportunity to review their contribution in case they felt anything had either been missed or, on reflection, they would rather not include. The stories were anonymised and shared with the advisory group, both in easy read format and read aloud.

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*“Stories were developed about the eight couples sharing how they met and how their lives had changed after the dementia diagnosis.”*

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Additionally, NVivo (research management software) was used to store, organise and categorise the data which was thematically analysed. Separate interpretation by two members of the research team completed the process of identifying patterns within and across the data sets. The advisory group took part in analysis through discussion of the life stories of each couple plus a focused workshop to share and discuss the preliminary findings and developing themes.

# Findings

Collectively, the eight couples had enjoyed over 170 years of relationships with most being together for 20 years or more. Four couples were married, three lived together and were not married, whilst one couple had never lived together. In four of the couples, the partner with dementia had died. Three of the eight relationships were between couples with Down's syndrome, one relationship was between one person with Down's syndrome and their partner with a different type of learning disability.

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*“Collectively, the eight couples had enjoyed over 170 years of relationships with most being together for 20 years or more.”*

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In all cases where the partner with Down's syndrome had dementia, progression had been more rapid from diagnosis to death at two, three and six years. This included a decline in living skills and reduced verbal interaction with associated need for increased support. Summary findings are shown below:

## **Partners with a learning disability spoke about:**

- The emotional impact of dementia.
- Trying to make sense of the diagnosis.
- Special occasions and positive memories in their relationships.
- Fear of changes without knowing how quickly this would happen; some assumed it would be immediately post-diagnosis.
- Fear of the terminal nature of dementia.
- Fear of being separated from their partner.
- Past experiences of communal living and institutional care which, at times, influenced perceptions of a care home.

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*“In two cases it was the partner without dementia who alerted others to the changes that they observed.”*

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### Family members spoke of:

- Early family memories and experiences of stigma and marginalisation.
- The historical context and perceptions at the time, with no expectation in the early years that their relative would wish to be part of a couple or married.
- Partners of their family member with a learning disability becoming part of their extended family, with relationships continuing even if their own relative had died.
- The importance of helping the couple to support positive interactions, whether this was holidays, day trips, or reminiscing about their relationship.

### Staff had known the couples for between six and twenty years. Staff talked about:

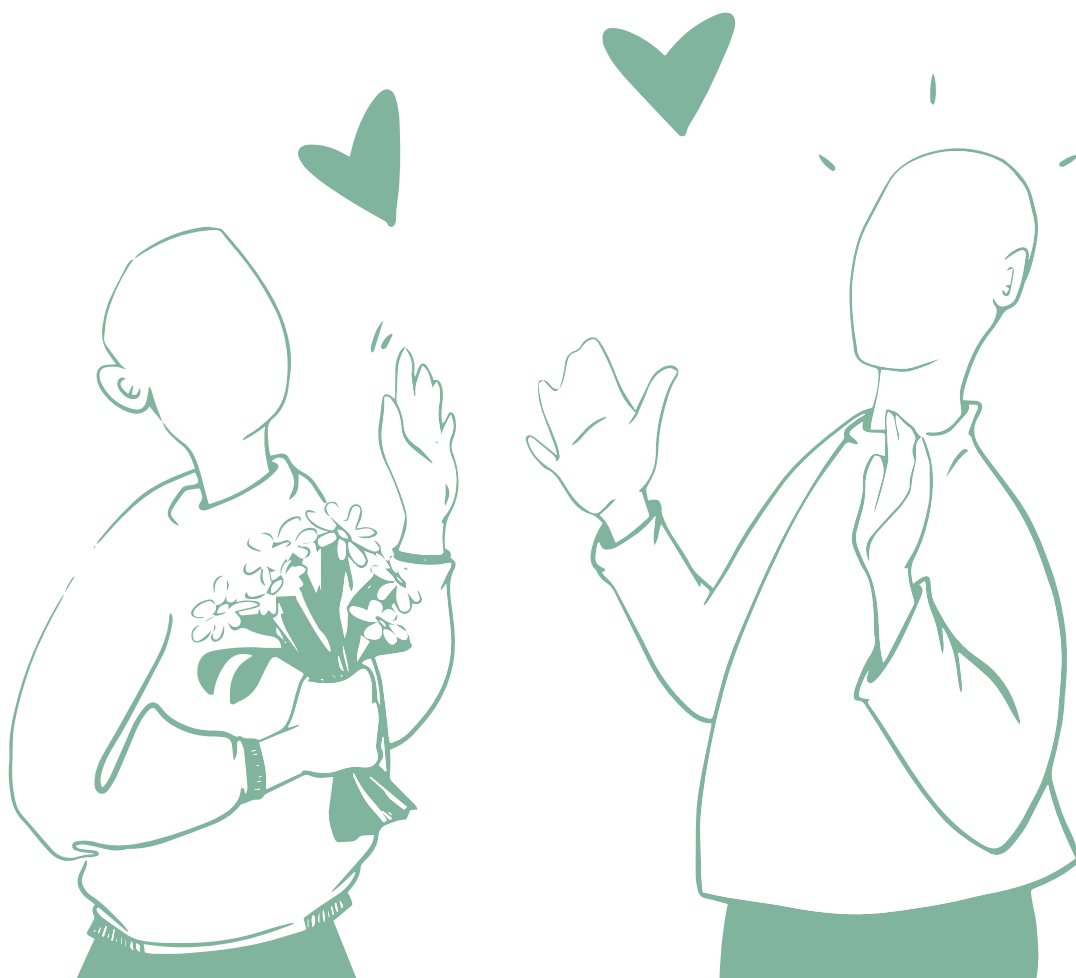
- How the couples met, and the process of moving in together or marrying.
- How, and when, the couple received the dementia diagnosis. The term 'dementia' was not used in the early stages with two of the couples, instead the focus was on explaining changes that were happening.
- The importance of explaining what dementia was and was not, including information about specific symptoms, and offering frequent reassurance.
- Their realisation that not talking about dementia increased worries and anxiety among people with a learning disability.
- How couples benefited from emotional support and a validation of their emotions such as anxiety, sadness, frustration and anger.
- Distress they observed in couples caused by negative representation of dementia in the media especially on television.
- Positive experiences of counselling among people with a learning disability.
- How two couples spoke to a lawyer as part of future planning and one couple were supported to write down their end of life and funeral wishes.
- Death becoming easier to accept by some people with a learning disability when dementia was advanced in their partner. Visible decline led to the acceptance that their partner was not going to get better.



- The importance of supporting and talking about the future with both partners together but also separately, recognising that wishes and preferences may not be the same.

**Four of eight couples experienced accommodation changes for one or both partners:**

- One couple moved together to a learning disability group home in order to receive 24-hour support.
- The partner with dementia in another couple moved to specialist provision for older people where she was supported by the same learning disability service provider whilst her partner visited daily.
- In another couple, the partner with dementia moved back to her family home and later to a care home as her health deteriorated.
- For a fourth couple, the partner without dementia was the person who moved, this was to a care home after a fall.



## Summary

People with a learning disability and dementia are often overlooked as research participants. This research identified an added complexity when couples with a learning disability affected by dementia were in long term relationships or married. Drawing on a narrative life story approach, we developed stories of the relationships of eight couples with a learning disability where one partner had a diagnosis of dementia. In doing so, we learnt of struggles for some to have their relationship accepted and past experiences of group living or institutional care which, in some cases, influenced perceptions of longer-term support.

Experiences of the couples naturally varied depending on the stage of dementia, and in some cases the partner had died. Conversations between people with learning disability and the research team highlighted the importance of their relationship showing love, commitment, and care between partners. People with a learning disability spoke about the emotional impact of a dementia diagnosis and about difficulties in trying to make sense of dementia. Assumptions and stereotypes were challenged throughout the research. Family members described how the relationship had caused them to rethink their own views. Individuals and couples with a learning disability demonstrated how dementia may have changed the direction of their relationship, but not the importance.



**Factors that supported sustainability in relationships included:**

- Access to consistent support networks, whether family, learning disability services or peers, especially if the couple were physically separated in the later stages of dementia.
- Support to understand the diagnosis and what it meant, and crucially did not mean, to have dementia.
- Adapting communication as dementia progressed.
- Challenging negative stereotypes, including those seen in the media.
- Acknowledging progression of dementia and preparing for end of life, for some this was easier to understand when it was a more visibly advanced stage.
- Recognition of identities, firstly as a wife, husband or partner, later a shift to carer.
- Involvement of the couple in future planning.
- The couple seeking legal advice as part of advanced care planning.
- Counselling for people with a learning disability.

Most importantly, the research has celebrated relationships between couples with a learning disability. We have been able to produce information based on hearing positive examples of living well with dementia so that, in the future, couples with a learning disability can be better supported when one partner receives a diagnosis of dementia.

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*“Most importantly, the research has celebrated relationships between couples with a learning disability.”*

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