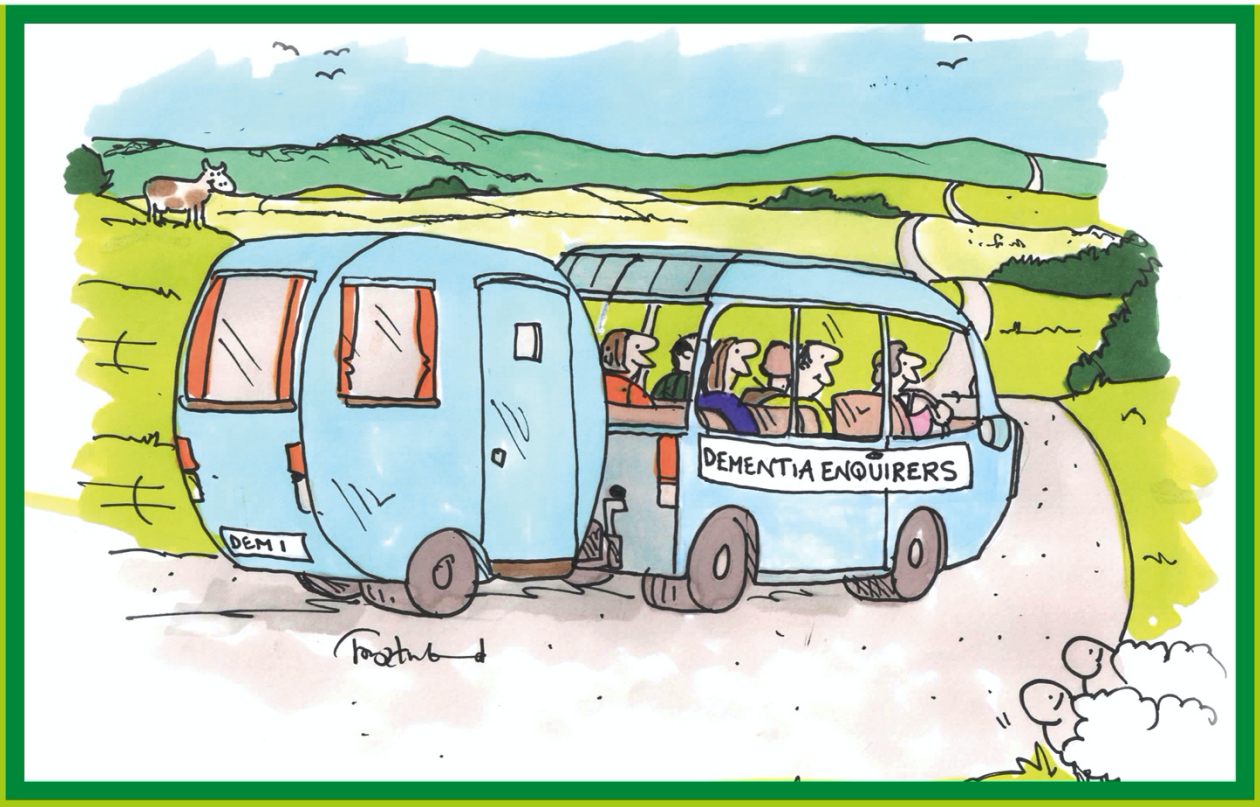
York Minds and Voices

Dementia Enquirers Report



The pros cons and particular needs of those living alone with dementia and those living with a care partner

Dementia Enquirers

COMMUNITY FUND

Innovations in Dementia

Key messages from Dementia Enquirers projects

1. People with dementia can lead their own research projects – both drawing on previous life skills and learning new ones to explore the questions that most interest them.

2. The research questions that people with dementia generate can be different from existing research questions. They are based on lived experience – on topics that will make a real difference in people's lives.

3. "Being in the driving seat of research" doesn't mean that you have to do everything yourself. Team work and support can really help. But controlling the research and leading the way gives people with dementia a huge boost in confidence.

4. Making the language and processes of research more accessible helps everyone!

5. Research *between* people with dementia makes communication and engagement more possible, because having something in common increases trust.

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You can download this report here:
https://dementiaenquirers.org.uk/individual-projects/minds-and-voices-in-york

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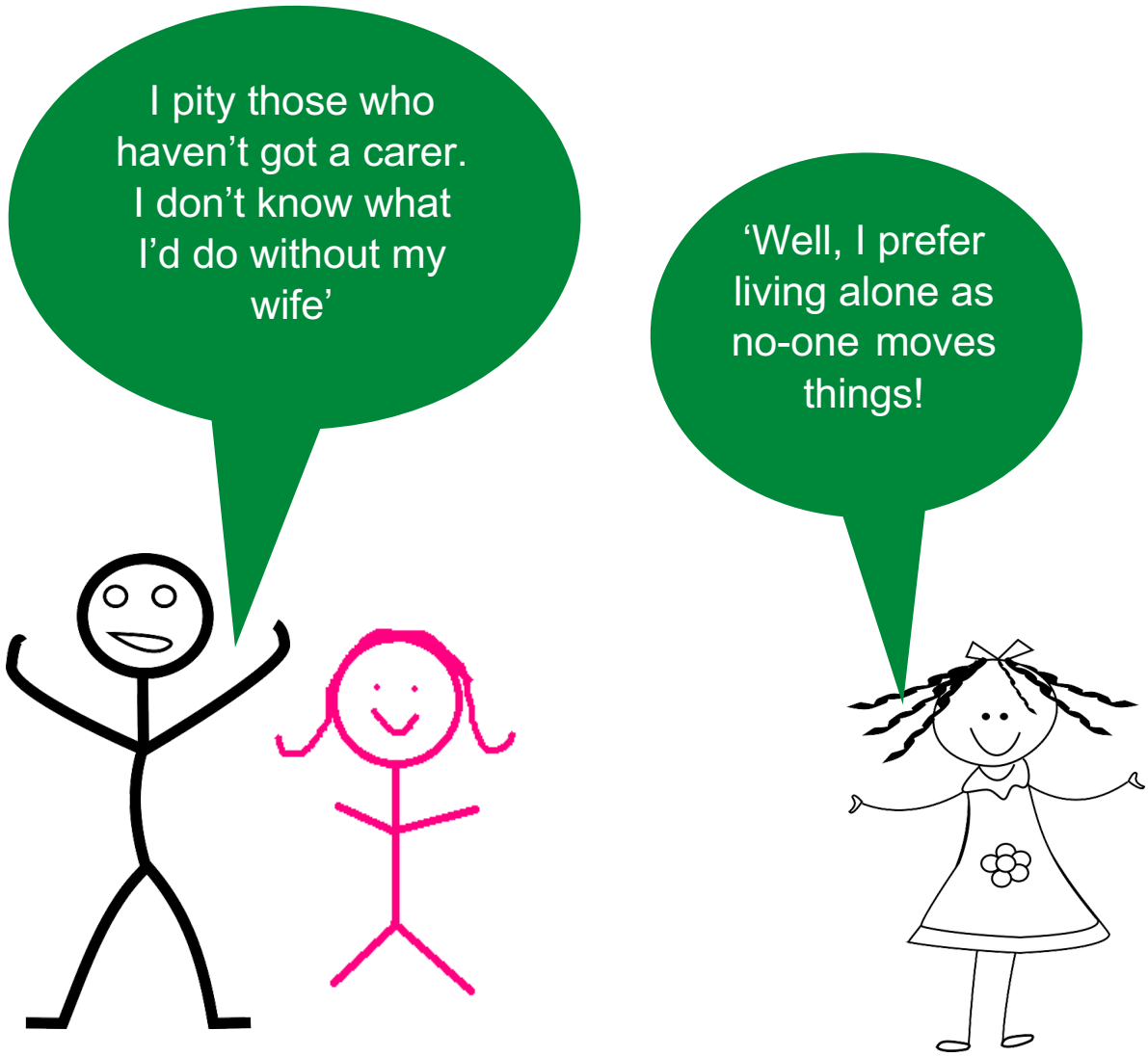


(a forum for people living with dementia in York)

Abstract

As members of Minds and Voices, a forum for people living with dementia in York, we devised and led our own research enquiry to find out about the benefits, challenges and differing needs of those people living alone with dementia and those with a care partner.

We carried out a series of individual interviews and a focus group involving 9 people living with dementia in total (4 living alone and 5 with care partners).

We analysed the interviews and have produced 11 recommendations for practice.

We also share elements of our experience in carrying out this research.

Who we are

- Minds and Voices is a forum for people living with dementia in York
- We still have a great deal to contribute and strongly believe that you CAN live as well as possible with dementia
- We are keen to change people's perceptions of people with dementia by our level of engagement, influence and activism
- We are one of many such groups nationwide forming part of DEEP - the UK network of Dementia Voices

The aims of our research

We want to find out about the benefits, challenges and differing needs of those living alone and those with a care partner.

What we did – our methods

Planning together

As a group we held several conversations in our monthly meetings about how we might go about doing our research.

We decided upon running focus groups and individual interviews and to design questions to put out to the DEEP network.

To find out what other work like this has been done (or not) the group wanted to look on academic sites to review the literature.

Brian

Well you might want to see what is out there on t'internet first

Paul:

Yes, we should speak with a group of people who live with carers and with a group of people who live on their own. We should do that separately

Stewart:

Of course we should interview people one-to-one too because in a big group some people might not get their say, or be too shy to speak up

Eddy:

Well we need to find people to interview, where will we find them?

Rita:

Well we could get together again with the other groups we know in Yorkshire

So, we decided upon interviews, questionnaires, focus groups and a literature review. Our discussion also focused on what we should ask, where we should go, and how different people would define caring.

Creating our information sheet and consent form

Damian and Stewart met together and followed the guidance in the Dementia Enquirers Handbook as to what should go in the information sheet and consent form for potential participants.

(See Appendices 1 and 2).

Our approach

Damian and Wendy met in her office (local pub!) to chat about establishing guidelines for good practice to help not only members of Minds and Voices but also those participants in the research. The guidelines we created are in Appendix 3.

In our original plan we aimed to obtain ethical approval for our research from the University of Hull. The approval process was too big and daunting for us given the time available. It really did not fit who we are and was geared up for people already working as researchers within the university.

We fed this back to the Dementia Enquirers Pioneers group and hope that it has contributed to the design of the new DEEP ethics Gold Standards for Dementia Research.

Looking at the literature

Brian

‘We could look what’s on t’internet

Below is a summary of each of the articles we looked at:

1. **Experiences of loss and relationship quality in couples**

On relationships between couples. The message – encouraging couples to do things together and to keep engaged. Leaflet produced – sent to us by the author.

2. **Living with a partner with dementia: a systematic review and thematic synthesis of spouses' lived experiences of changes in their everyday lives**

This was summed up by Brian as ‘one way traffic!’ An example of how most research has just looked at one side of the caregiving relationship.

3. **“We live as good a life as we can, in the situation we’re in” – the significance of the home as perceived by persons with dementia**

This study asks the question “is being at home, rather than who you are living with, the most important thing?” We’re just passing through! – Brian.

4. **It's our pleasure, we count cars here': exploring 'neighbourhood-based connections' for people living alone with dementia.**

People on their own in the community are more likely to make their own connections. Couples may be more inclined to stay in (or not go into the community) with each other.

5. **The value of "us"—expressions of togetherness in couples where one spouse has dementia**

Calls to 'focus on the positive things in life. Positive, but we feel it's a bit more complex than just saying remember the good times.

6. **Living alone with dementia: findings from the IDEAL cohort**

Little or no difference in quality of life or satisfaction between those alone and those in a partnership. But what about need? It's what you make of it - Brian!

7. **A qualitative study of the shared experience of humour between people living with dementia and their partners.**

Message: humour is a good buffer against stress.

8. **The precarity of older adults living alone with cognitive impairment**

There's a need to develop new programmes and interventions to provide reassurance around the many uncertainties presented by dementia.

Summary

Our literature review revealed there was still a gap in being able to more clearly identify the benefits, challenges and different needs of people living alone and people living with a partner.

Our questions decided as a group were:

- **What would you say are the advantages of your situation?**
- **What would you say are some of the challenges you face in your situation?**
- **What if things changed? (either someone now lived with you or you found yourself living alone) How would you feel about that?**
- **What would be the benefit of that?**
- **What would be difficult about that?**
- **What help might you need in that situation?**

Capturing the data

We interviewed 2 women living on their own and 3 people living with a spouse (2 men and 1 woman).

We ran one focus group involving members of another Yorkshire-based group in the DEEP network. There were 2 people living in couples (1 man and 1 woman) and 2 people who live alone with dementia (1 man and 1 woman).

In total 9 people with dementia were involved in the interview process.

Wendy transcribed every single interview and the focus group from the recordings made.

We also drew upon the shared experiences and comments of members of York Minds and Voices in our analysis.

Before the Covid lockdown we had intended to interview between 15-20 people through one-to-one interviews and 2 or 3 focus groups. As travel was no longer possible and we all had to re-group somewhat to get used to meeting online the whole process stalled for a while.

The interviews

All the interviews and focus groups were held via Zoom. Eddy and Wendy from Minds and Voices carried out all the one-to-one interviews between them, each asking the same set of questions.

At each interview the group facilitator was present as Zoom host and to introduce the project information and consent forms.

These forms, as well as a list of the questions we were to ask, had been sent out to all participants in advance. We re-visited them at the start of each interview.

All consent was gained verbally at the point of interview which was recorded.

The focus group

Questions about anonymity and the format of the session were exchanged between group facilitators in advance of the group.

That helped us create a clear format which we shared with all those taking part.

Participants were sent the format and questions in advance of the meeting so they could discuss as a group and individually prior to the Zoom.

The focus group was co-facilitated by Wendy (asking questions to those living alone) and Barbara (directing questions to those living with a spouse). Damian revisited and recorded consent from participants at the start.

The findings ‘alone’

People living alone

Individual circumstances

People live alone for a variety of reasons. All those we interviewed living alone were in the main happy with their choice and found it much better for them than living with others.

The advantages of living on your own

All participants said living alone meant they could easily avoid the following:

Arguments

Misplacing things moved by others

Bad relationships

Another person speaking for me

Any upset to my own routine

Anyone telling me off for mistakes

Being dependent on others. We have to find a way

Solutions and tips abound as to what works e.g.

- ‘Warden call’
- ‘Carelink’ pendants
- Alexa
- The television, especially in the evenings
- Social Zooms with friends

Being alone also helped individuals flourish. There was a strong message of loving one's own space, freedom, routine and social connections.

"**The only companion I have at home is dementia. I find I only have to cope with me outmanoeuvring dementia and not having to cope with someone else coming at it from another direction"**

"I've never been in need of constant company. I do constant crosswords as I can't remember the clues! I read, I play the piano, and I watch television. Don't let anyone tell me that I'm not happy. That just suits me fine"

"Freedom to keep in touch on my terms"

What are some of the difficulties of living alone?

Generally, those we spoke with were very happy in their living situation as we did not speak to people who had lost partners, for example. (Our conversations with couples revealed a lot more of the potential difficulties if their circumstances were to change).

Not many difficulties were identified, although loneliness and company, especially around the evenings, was very much a thing.

"Evenings can be very stressful at times"

"I think the worst time is when I have hallucinations at night. There's no one there, you know to comfort me or anything, that's the worst part"

What if things changed and you were to live with someone else?

This happened to one of our co-researchers during our investigations. He was living alone. Risk, as perceived by other people was a big challenge.

A recent 'rehab' stay made things worse as it fuelled a delirium. He was not used to seeing so many people moving around in his living space

The risk of staying with someone who disempowers you (however good their intentions) meant that 'moving in with his sister was detrimental'

Daughter: "Glad I didn't move in with you, I'd have taken over too much"

Anyone moving in would really need to know me. A spouse or a family member might not necessarily be the best fit

"I can take the risks, positive risks if I want to, without someone telling me I can't do that"

The findings ‘together’

People living with a care partner

Individual circumstances

What are the advantages of living with a partner?

Everyone loves the advantages of living with a partner – the help, the company, the fun, the reassurance.

What would you say are some of the challenges you face living with your care partner?

Commonly expressed issues by people in couples were frustration in both parties at individual shortcomings and loss of skills.

“2 people in the house, you know, you have to keep the cart on the wheel”

“Sometimes it’s reversed into a parent and child-relationship”

Believing “**but I’m a burden”** when my partner says **“NO you’re not!”**

“You don’t want to upset the other person so you have to bite your tongue”

“You’ve got to make it work and whereas before maybe one of you would get the huff and perhaps not speak, um, now you know you’ve got to get on”

What if things changed and you were living alone?

Traditionally this sort of question is just aimed at the care partner. It brought out ideas as to what might be needed if things changed, what could be a safety net now and even some hidden wishes!

I'd find it awful not having him/her there

"I'd struggle – he/she does everything"

If I was on my own I'd be stumped

I'd miss her but we've spoken about the future

"He does all the admin and security"

"Alone at night in a big house – very scary"

"Often I think it would eradicate my wife's burden…but I couldn't cope. I don't know what I'd do without her"

What might be the benefit of living alone?

I could have my china cups out on display – drives him crazy!

Sometimes peace and quiet is nice too

Our recommendations re: people living alone

For all service providers, support staff, GP and memory services we recommend that you:

1. **Establish why people are on their own. None of our 'singles' wanted to change their circumstances but our 'doubles' expressed a lot of fear and particular needs about the possibility of being alone**

2. Introduce positive risk taking into any assessment and include the individual in those discussions to ensure you are not just seeking to satisfy someone else's peace of mind

3. **Avoid 'telling' 'allowing' or 'permitting' people with dementia what they can and can't do**

4. Include evening time interaction. For example, services to arrange visits out of usual office hours, or arrange peer group support that meets in the evenings

5. **Support a conversation with and between friends and family – about whether people should move in with each other or not!**

6. Explore greater, more flexible, options for live-in care – e.g. Shared Lives (although: *'Well, people can come around – but they're certainly not to stay!*)

Our recommendations re: people living with a care partner

For all service providers, support staff, GP and memory services we recommend that you:

1. Ask about any benefits of living alone if things change – you might discover some little hidden wishes that could be sorted now

2. **Offer an opportunity for partners to talk together about future fears and concerns. It's important for all parties to get their house in order – talk about it or get help to talk about it**

3. Help couples still to enjoy the help, the company, the fun and the love within their relationships

4. **Challenge the idea often held by people with dementia themselves that they are a burden (it is not fair) and work on addressing exactly what is!**

5. Provide a couple's programme such as 'Getting Along' - offered to all couples/partnerships around the time of diagnosis and beyond

Some final thoughts from the group:

What message would you give to someone with dementia now living on their own?

- There are lots of us out there living alone, so don't feel it's only you. Adaption is key, while you're still able

- Look at the Tip-Share web site for strategies that may help https://dementiatip-share.org.uk

- Talk to your family about enabling you to continue to live on your own if that's what you wish

What message would you give to someone with dementia now living with a partner?

- Talking is a two-way conversation

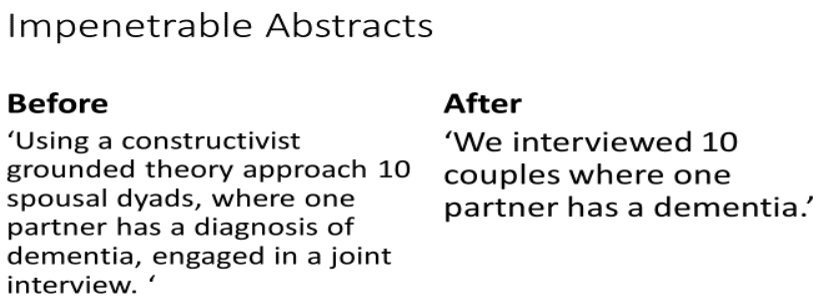
- Support is a two-way need

- Ask your partner what they're struggling with as well as telling them what you may be struggling with, otherwise how can you support each other? Consider the Getting Along course to understand the changing relationships that may occur

People with dementia in the driving seat - our experience of carrying out research

Literature review

Damian met with Brian and they looked over about 10 abstracts from Google Scholar. Even the short summaries (abstracts) were impenetrable. Here's just one before and after example



It was only after we simplified the abstracts that Brian could comment on them before giving his feedback.

- You've got to put something down that's easy to understand for everyone - basically that's it
- **It's just like starting school**
- You've got to start from nothing then work up slowly over time. If we can get it done it can put us well up in the ladder!
- **I'm not intelligent but I know what's what and what's not. All these names they've come up for things is a load of crap'**
- We'll end up being the best bloomin' network in the world. Cos we know what we're doing, there's lots of us
- **Just make sure that everything written down is clear enough for everyone to read. Take it steady and it'll all come together in the wash**

Ethical Approval

The documents that came through relating to gaining ethical approval for a piece of research were wholly inappropriate in terms of the detail requested.

It was set up to have a University academic with a University email as principal investigator which immediately takes away the ownership of the project away from members of Minds and Voices – defeating the object of people with dementia being in the driving seat.

Although the group relished a trip to the University or the opportunity to invite academics to York to grant approval, the time we had left ourselves for the study was limited and we needed to commence our interviews.

What next?

We did not interview anyone who was living alone through no choice of their own such as bereavement, for example. However, the interviews with our couples did reveal some of the fears of living alone and the needs they might then have. Perhaps this could be explored further.

We would like to see our recommendations disseminated, tried out and implemented as widely as possible.

We feel this can add to any local dementia strategy.

Appendix 1

Information Sheet

Dementia Enquirers' Research Project.

Living with dementia with and without a care partner.

Who we are:

- Minds and Voices is a forum for people living with dementia in York.
- We still have a great deal to contribute and strongly believe that you CAN live as well as possible with dementia.
- We are keen to change people's perceptions of people with dementia by our level of engagement, influence and activism
- We are one of over 100 such groups nationwide forming part of DEEP - the UK network of Dementia Voices

Background to this research project

'I pity those who haven't got a carer. I don't know what I'd do without my wife' (E)

'Well, I prefer living alone as no-one moves things!' (W).

Following this discussion, as several of us live alone in the group, we decided to investigate the pros and cons of living with dementia with and without a care partner.

Aims

We want to find out about the benefits, challenges and needs of those living alone and those with a care partner.

How will we do that?

We shall carry out a **review of literature.** The aim of this is to find out what work has been done or written about the needs of people on their own and those living with partners

We shall have a focus group made up of people living with dementia who live alone and those who live with a care partner.

We also hope to carry out individual interviews with people about their experiences of living alone or with partners.

Risks and benefits of taking part
If you are willing to take part, we will ensure we meet at a time and place of your convenience and will cover any expenses you incur.

We hope it will be an interesting discussion for everyone involved in a welcoming, non-judgemental environment.

If the interview covers any topics you are uncomfortable with, you can withdraw at any time.

If you participate, we will store your personal information securely and it will be used only for the purpose of keeping in touch with you. All names of participants in the final report will be changed to protect your identity.

We will ensure that this information sheet is presented to you and shared with you in person.

If you want further information about the project or have any questions during the project, please feel free to contact:

Damian Murphy
by phone on 07927 405 854
or by email on **Dementiafriendly@outlook.com**

Appendix 2

Consent Form

Dementia Enquirers' Research Project.
Living with dementia with and without a care partner.

I have been told the potential benefits and risks of joining in this study

(Tick if agree) ☐

I understand that I am able to leave this project at any time without giving a reason

(Tick if agree) ☐

I know my personal information will be anonymous and stored securely

(Tick if agree) ☐

I know who to ask for help if I have any questions

(Tick if agree) ☐

My name:……

My Signature…… Date……

Appendix 3

Our guidelines for good practice

Dementia Enquirers' Guidelines for the Minds and Voices research.
By Wendy with Damian

Once we identify a group we need to make sure we as a group of enquirers are ready and prepared. We came up with a bit of a checklist:

- Ensuring we can capture what's said through recording as well as scribing
- Ensure we are consistent with our questions and the way we ask them (eg not being leading)
- Ensure questioners have prompts
- Ensure as a group we practice the questions and process amongst ourselves
- Limit our focus groups and interviews to 3 or 4 questions.
- Ensure we send questions in advance to focus groups and interviewees in advance to help them prepare.
- Choose a team for the focus group and a team of interviewers

Appendix 4

References of reviewed articles

Anna Colquhoun, Jennifer Moses, Rosslyn Offord 2017 Experiences of loss and relationship quality in couples living with dementia. 'Dementia' Volume: 18 issue: 6, page(s): 2158-2172. Article first published online: November 30, 2017; Issue published: Aging & Mental Health Volume 23, 2019 - Issue 5

Barbara Egilstrod, Maiken Bay Ravn & Kirsten Schultz Petersen 2018 Living with a partner with dementia: a systematic review and thematic synthesis of spouses' lived experiences of changes in their everyday lives Pages 541-550 | Received 11 Aug 2017, Accepted 22 Jan 2018,

Fæø, S.E., Husebo, B.S., Bruvik, F.K. *et al (*2019) "We live as good a life as we can, in the situation we're in" – the significance of the home as perceived by persons with dementia *BMC Geriatrics* volume 19, Article number: 158

Odzakovic, E., Kullberg, A., Hellström et al (2019) It's our pleasure, we count cars here': an exploration of the 'neighbourhood-based connections' for people living alone with dementia.

Anna Swall PhD, RN Christine Williams RN, DNSc, PMHCNS-BC Lena Marmstål Hammar PhD, RN 2019 The value of "us"—Expressions of togetherness in couples where one spouse has dementia

Linda Clare,1 et al Living alone with dementia: Findings from the ideal cohort

Hickman, H., Clarke, C., & Wolverson, E. (2020). A qualitative study of the shared experience of humour between people living with dementia and their partners. Dementia,

Elena Portacolone, MPH, MBA, PhD, et al 24 January 2018 The Precarity of Older Adults Living Alone With Cognitive Impairment