

Towards a more balanced narrative of living with dementia

Preliminary findings from NIHR funded Clinical Research Masters

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ELIZABETH CASSON TRUST



Session aims

To increase awareness of the diverse and rich experiences of people living with dementia.

To highlight the opportunities for Occupational Therapists to support a positive start and a stronger foundation for living and coping with dementia.

Focusing on early stage dementia

So what messages are people with a new diagnosis getting and what impact might this be having on wellbeing?

Portrayal of dementia



Dominant social discourse remains one of hopelessness, loss with a focus on deficit (Wong et al 2015; Gerritsen et al 2016)

A body to manage as the mind diminishes (Lazar et al 2017)

Language of warfare, viewing people with dementia as “victims”, “non-persons” “shells” (George 2010)

SHARE



4 SHARES



COMMENT

"I love her and I can't believe she has this ghastly thing affecting her."

Sue, 69, shared the same agent as 81-year-old EastEnders star Babs and recalls her being "sharp as a razor" at remembering scripts.



Still in 2019?



THE
SPECTATOR



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For the adult children of dementia sufferers, too, the condition offers lots of perks. For one, you don't have to feel guilty if you don't go and see the aged parents all the time. Far from drumming their fingers, waiting for the family to phone or visit, the demented seem perfectly happy sitting in a chair. Resentment and anxiety appear to be things of the past. Having the retentive capacity of a goldfish means they lose all track of time: a micro visit is just as good as an hour or two. When I went to visit an elderly friend who'd lost her marbles, her face lit up at the sight of me. I was so pleased. But pretty soon she stood up and said 'Well, that was nice', signalling that our interview was over. I'd been with her for less than three minutes.

Impact

Internalising negative assumptions
leading to:

Anxiety and low mood (Ashworth
2017)

Diagnosis avoidance (Bunn 2012)

Social isolation (Keady 1995)

Giving up activities pre-emptively
(Low et al 2018)



But....

Involvement in everyday activities:
sense of belonging, retention of
identity and autonomy (Phinney
2007)

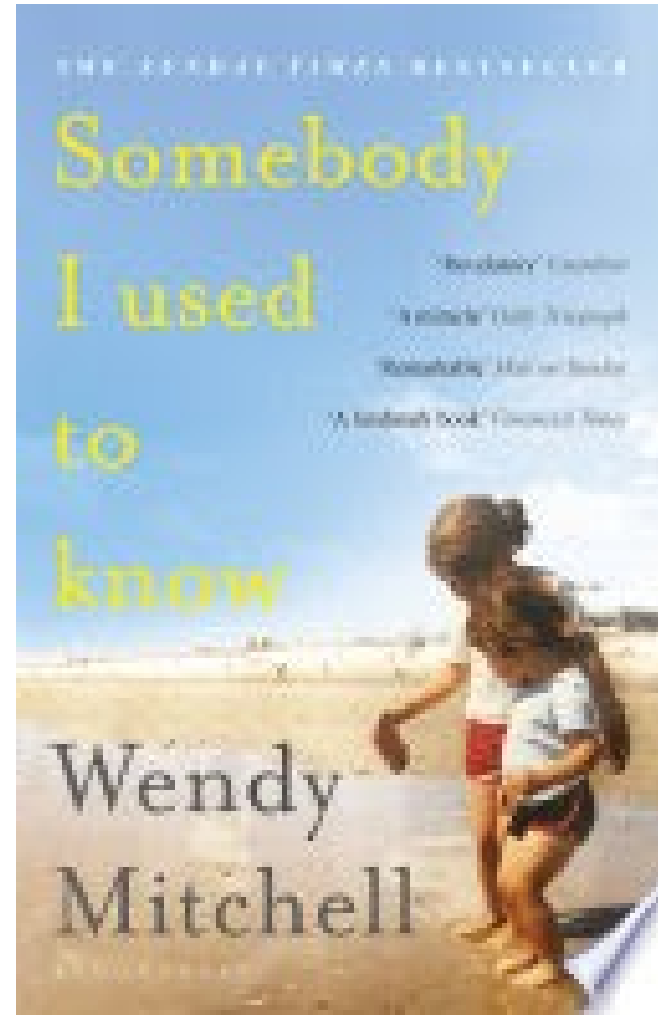
Thriving when focusing on abilities
and coping strategies (Cotter 2009)

Hope: central to the adjustment
process in early stage dementia
(Wolverson et al 2016)



Wendy Mitchell bestselling author of Somebody I used to know

*“When people think of dementia,
they think of the late stages. They
forget that there is a beginning
and a middle”*



Epistemic and Testimonial Injustice

Epistemic injustice results from partial or full exclusion of selected persons from the construction of knowledge (Fricker 2007)

Testimonial injustice occurs when the hearer undervalues the speaker's credibility due to their own prejudice (Young et al 2019)



The credibility and importance of the voices of people living with dementia becomes apparent when we listen and include them.

Therefore the aim of my study is to share the stories told by people living with dementia and highlight their relevance and importance within the narrative of dementia.

And then I found the dementia diaries.....

THEMES



Diagnosis and dementia



Loss



Having a voice



Memories



Health and Social Care



Public Perceptions

Dementia Diaries

is a UK-wide project that brings together people's diverse experiences of living with dementia as a series of audio diaries.

It serves as a public record and a personal archive that documents the views, reflections and day-to-day lives of people living with dementia, with the aim of prompting dialogue and changing attitudes.

“Words are very powerful – they can build you up or put you down. When you are speaking about dementia, remember this.” –[Agnes Houston](#)

Methods

11 Dementia Diarists opted in to the research

Each diary entry is between 2 and 6 minutes

I analysed 3.5 hours of diary entries from August to October 2017

This period precedes my involvement with transcribing for the project, thus removing any influence or coercion around the content of the diaries.

Thematic Analysis of the narratives within the Dementia Diaries

Theme one - Community



Theme one – Community

- Sense of community apparent throughout
- Talking collectively: we and our is more common than me and my
- Clear thread from early pioneers, through the current diarists onto encouraging the next generation
- As we have such a collective feel and theme one is looking at community the remaining 3 themes are in terms of our – our experiences, our strategies, our expectations

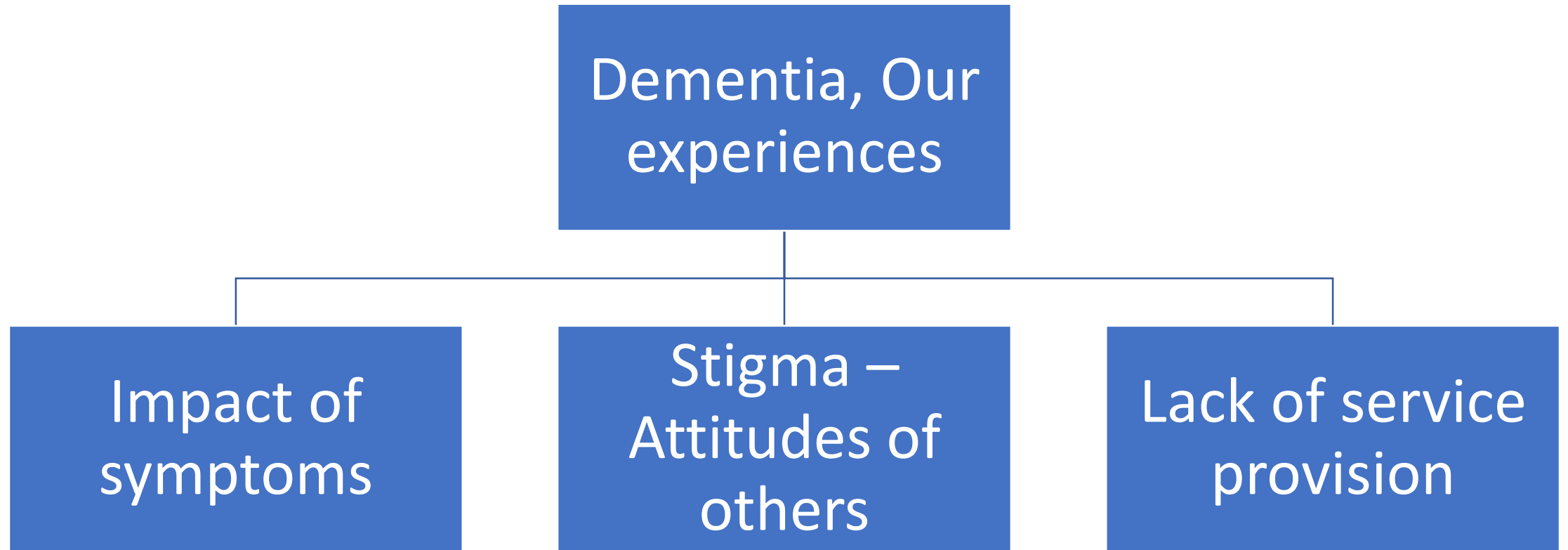
Peer Support

“Dementia is a lonely existence but hearing others, in the same boat, talk about their challenges and successes makes you feel part of one large extended family”



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Theme two – Dementia, Our experiences



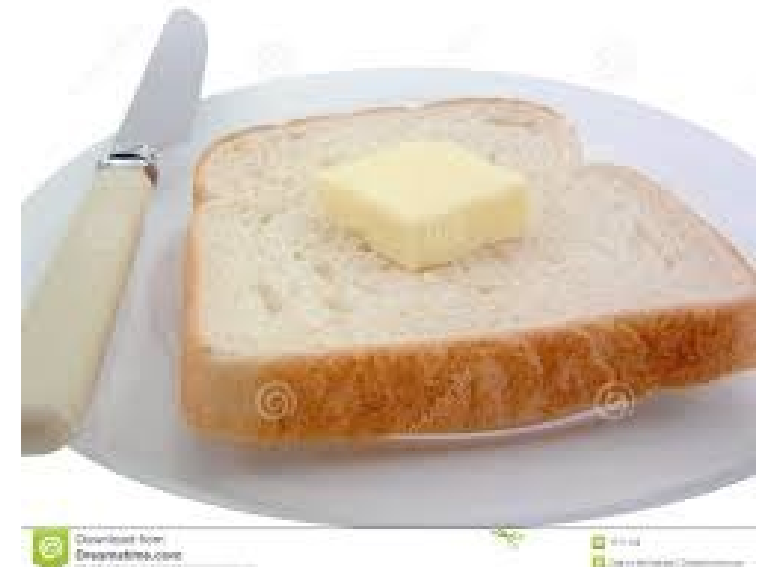
Presenting too well



“When I was out having a coffee, and I was speaking to this woman and she said she was a nurse. And I happened to say to her that I had dementia. And then she proceeded to tell me that I couldn’t possibly have dementia and I said “why do you say that?”. And I think it was because I appeared to be having a reasonable conversation or making sense to her”.

Underestimating our abilities

“One carer thought when I had dementia she proceeded to show me how to spread butter. So I told her “I am quite capable thank you of spreading some butter on the bread””



Prescribed Disengagement™



“I continually get told that maybe it’s time to slow down and stop and even those they’ll say it’s not good for you.”

Prescribed Disengagement™

“There are some people who seem to think because we have dementia that we shouldn’t, with help and support, have success, we shouldn’t be able to have amazing opportunities and experiences.”

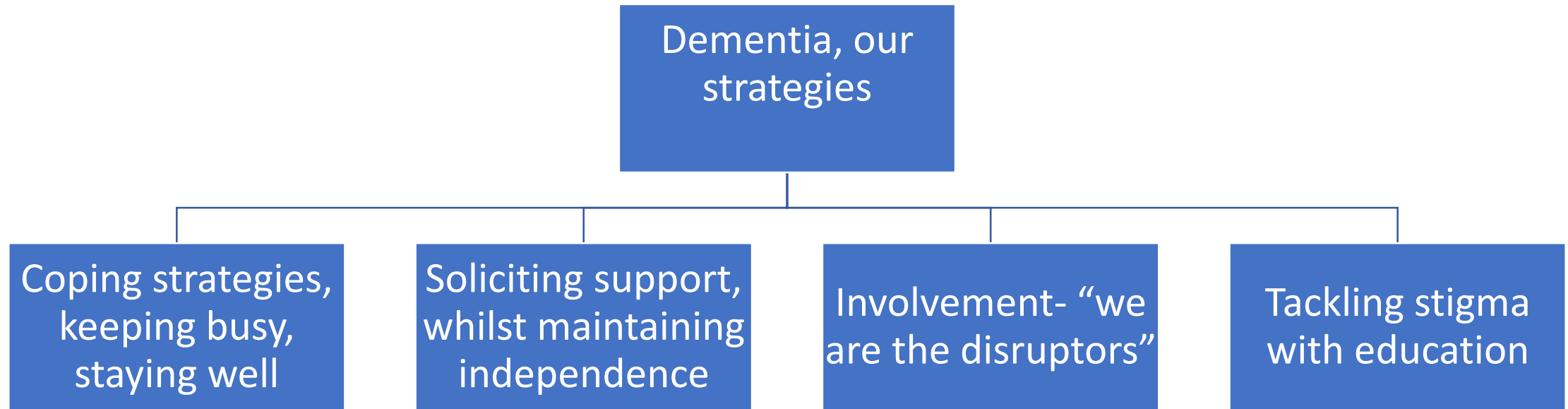


Prescribed Disengagement®

The description of the post-diagnostic advice given to people after a diagnosis of dementia, which suggests that the person should be slowing down or pulling back from activities. This results in isolation, loss of hope, self-esteem and self-identity, and threatens social health. (Kate Swaffer 2015).

And who amongst us would want to be told, go and sit down, get your affairs in order?

Theme three – Dementia, our strategies



Keeping busy, staying well



“Each person’s different, and for me it’s doing projects which are stimulating, interesting, challenging, but where I am also very well supported.

For me being busy is important to living well, I hate inertia and apathy. I think they’re the best allies for dementia.”

Soliciting support, whilst maintaining independence



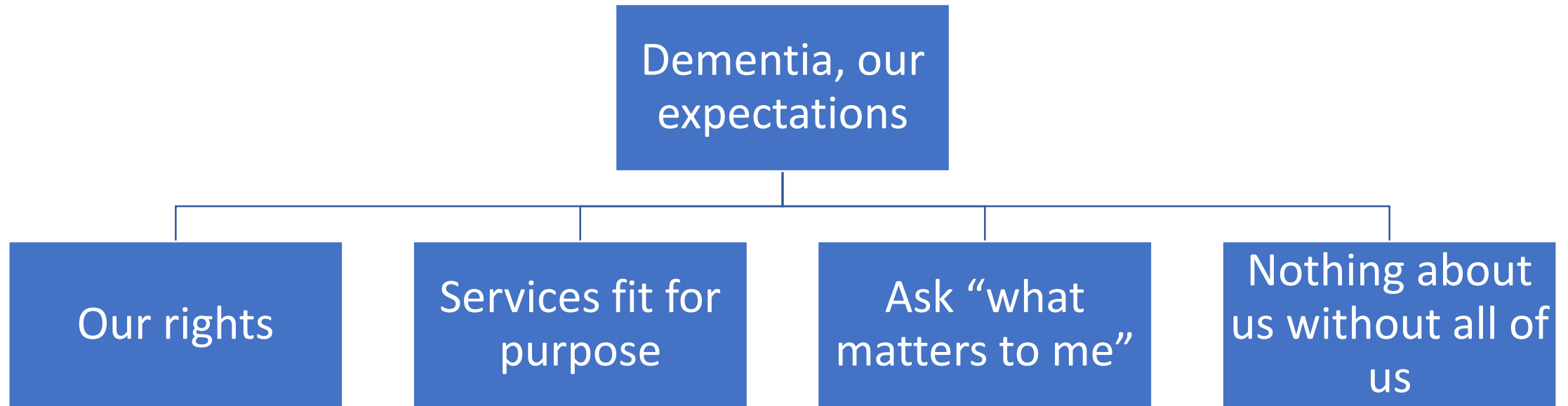
“Being able to continue to get out and about enables you to remain connected with others and reduces isolation. If I didn’t have coping strategies to remain independent and mobile, I’d be very lonely and soon sink into depression. The main barriers are often other people, other people thinking you can’t, instead of helping you to find other ways to remain independent.”

Involvement- we are the disruptors

“I’m beginning to realise now that actually, I and a lot of other people who live with dementia that really we are going to influence change by disrupting. And it’s a good thing, because the providers of services whoever they are, need to start by asking us, what matters to us and then endeavour to provide that.”



Theme four – Dementia, our expectations



Nothing about us without all of us

“There is a huge amount of stigma out there which needs to be changed. People like myself, who are living with Dementia are life experts as we experience the effects of Dementia each and every day. We are the people who can change this stigma.... People with dementia can and do live well”.



Sense of urgency



“I realise change takes time, but time is one thing not on our side. All the positive acknowledgements, positive comments will only make a difference if this is turned into a change of actions, a change of practice and a change of attitude”.

Are this group of amazing people unique?

Or is the act of finding your voice
part of the adjustment process to
living hopefully with dementia?

And can these voices support other
people to find theirs?

There isn't finite room, only an ever-
expanding space for the voices of
people living with dementia.

Hope

Receiving a diagnosis in an environment of hope will support a more positive start, giving a stronger foundation for living and coping with dementia.



How can OTs help

Enabling and empowering people to be "competent and confident in their daily lives" is at the heart of Occupational Therapy practice (Duncan 2011, p. 6).

Occupational Therapists are ideally placed to support and empower people living with dementia to regain hope and confidence, helping people to live not exist.



Our recommendations

<https://dementiadiaries.org>

<https://www.dementiavoices.org.uk/>

Share! Share! Share!

With people living with dementia

With colleagues

With students





A A A

[Home](#) / [DEEP Guides](#)

People with dementia have helped to write these DEEP guides. Some are aimed at groups. Others are aimed at organisations. The aim of the DEEP guides is to share good practice about the best ways of involving people with dementia. We welcome your ideas for new DEEP guides. We also welcome groups writing their own DEEP guides. Please **contact DEEP** for more information.

DEEP Resources

Final word from Teresa....

<https://dementiadiaries.org/entry/9458/the-importance-of-working-together-and-supporting-each-other-in-partnership-dory-quotes-andrew-from-me-myself-i-by-myself-i-am-a-twigs-and-together-we-are-a-branch>

We are all unique and beautiful
but together we are a masterpiece



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