

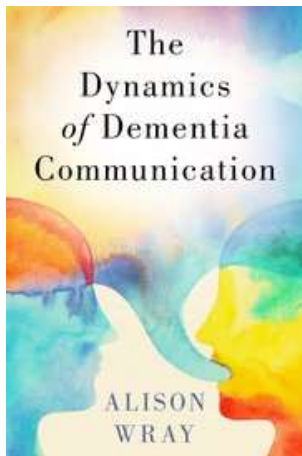
What if I get dementia?

Alison Wray

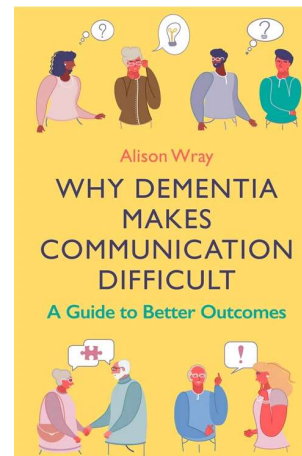
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Wray, Alison. (2020). *The Dynamics of Dementia Communication*. New York: Oxford University Press



Wray, Alison. (2021). *Why Dementia Makes Communication Difficult: A Guide to Better Outcomes*. London: Jessica Kingsley

Outline

- Dementia – a general introduction
- Does not having children increase your risk of dementia?
- Where does communication fit in?
- Communication with your nearest and dearest
- Advantages of not having family support
- The importance of future-proofing
- Discussion

Dementia – a general introduction

- Dementia **is common** – a significant risk in ageing
- Dementia **is a symptom** of brain diseases, e.g. Alzheimer's, vascular disease, Lewy Body disease, Parkinson's, alcohol poisoning
- Dementia **varies** with type of disease, e.g. memory impairment (recent or long-ago); hallucinations; disorientation; reduced processing speed; language difficulties
- Treatment:
 - No cure
 - Drugs to block enzymes damaging neural connections: Donepezil/Aricept, Rivastigmine/Exelon, Galantamine/Reminyl, Memantine/Namenda
 - Medication for symptoms, e.g. depression
 - Medication for conditions exacerbating or raising risk of dementia, e.g. heart disease, diabetes, kidney disease

Dementia – a general introduction

Why are some people more vulnerable than others?

- Genes (many)
- Environment/culture
- Infection?
- Injuries
- Inherent or developed brain connections (neural reserve)
- Regular use of complex brain connections (cognitive reserve)
- Capacity to manage early symptoms due to supportive context (social reserve)
- Personality – capacity to adapt, stay positive (emotional reserve)

Does not having children increase your risk of dementia?

Does not having children increase your risk of dementia?

What do we mean by 'not having children'?

- Not having children per se?
- Not having *available or involved* children?
- Not having anyone to take the 'child' role (partner, other relations, friends)?

Does not having children make *having* dementia harder?

- Research suggests dementia is more prevalent in those without children
- Possible reasons for higher incidence:
 - Giving birth or child-rearing affects susceptibility to disease?
 - Lifestyle differences? General health? Fitness?
 - Childless people live longer?
 - Families enhance social reserve?
 - *Outward*, e.g. Role as a provider and supporter. Worry! Joy! Time with grandkids.
 - *Inward*, e.g. Regular support with practical problems. The 'right' to socially connect
 - Symptoms are managed away, or covered up → later diagnosis

Does not having children make *having* dementia harder?

What might children (or other supporters) do that's important?

- Notice symptoms & encourage investigation
- Accompany to medical appointments, take notes, ask questions
- Check on general wellbeing, bring shopping, solve problems, step in
- Take on Power of Attorney
- Anticipate needs
- Convey interests and needs to others
- Know who their friends are, and facilitate connection
- Harness and sustain support: hiring professional carers, finding experts (advice on IT, home repairs, finance, etc)
- Bridge the financial gap (giving free care, paying the shortfall)

Where does
communication fit in?

Why is *communication* a particular issue in dementia?

- Dementia directly affects communication

Word finding issues, not recognising words, not recalling meanings

Repeating what's been said already

What effect do these problems have?

Not following conversations

Not recalling who people are & how to address them

Not recalling & tracking information

Why is *communication* a particular issue in dementia?

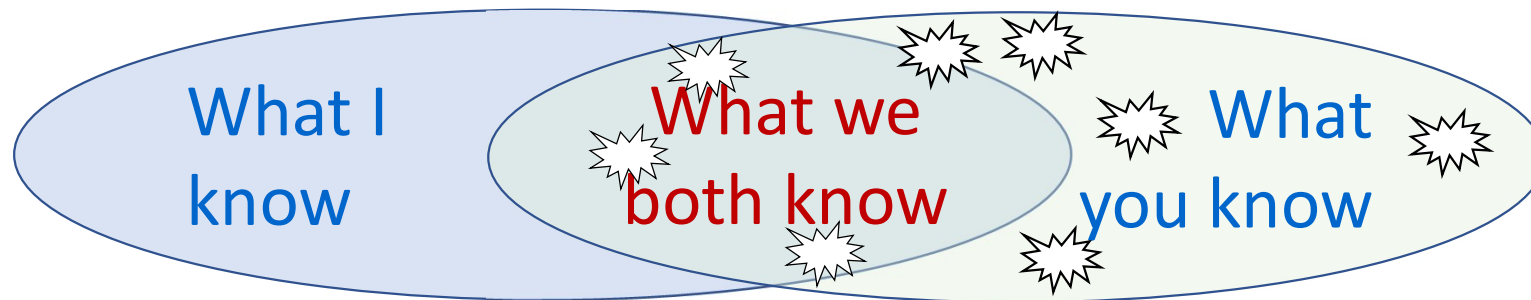
*Problems with language, memory
and general processing*



*Hard to keep track of
the context*

Effective communication relies on gauging shared knowledge

- We say the bit that the other person doesn't already know



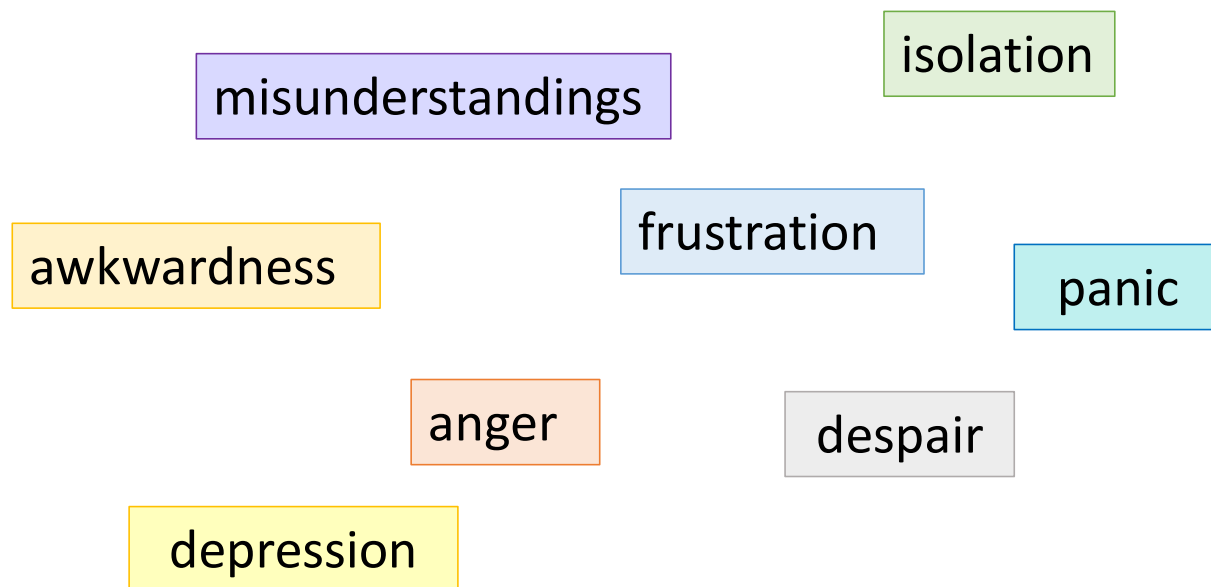
Neither party is sure...

- What the other person does and doesn't know
- What knowledge does vs doesn't need to be stated



Why is *communication* a particular issue in dementia?

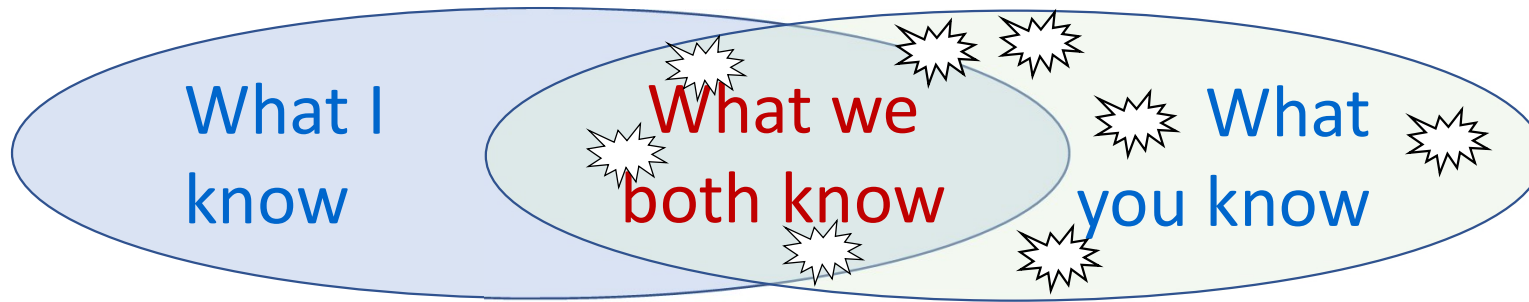
- Dementia undermines updating of contextual information → mismatches in expectations
- Risk of...



Does having kids
alleviate all this?

Probably not!
Here's why

Communication with your nearest and dearest



So, there are advantages to not relying on others?

The better you know someone (child, partner, friend):

- The more you (think you) can guess the shared context...
- ...so the more you can help fill gaps, but...
- ...the more it bothers you when it doesn't work
- The more likely you are to 'know better'
- The more you care about being right

Strangers:

- Share less context ...
- ...so can't helpfully second guess, but also...
- ... are less likely to contradict, causing friction
- Are less emotionally invested, so less easily frustrated
- Can more easily give up and walk away if it's not working

Advantages of living without family support

- Self-determination & independence
 - no one contradicting your view about what's best for you
- Impetus to keep going & take responsibility for own life
 - no one telling you to sit back while they sort it out
- No guilt about burdening others

BUT:

- Dementia is debilitating
- It affects your judgement
- It co-occurs with other challenges, e.g. illnesses, bereavements
- SO:

It is very difficult to manage, longer term, without help

The importance of future proofing

If not you, then who?

- Facing up to ageing: when is the right time to accept future risks and plan?
- Identifying an advocate – Friend? Relative? Solicitor?
- Being alert to cognitive changes and having a plan for managing them
- Know where to find support
- Joining with others in a similar situation (e.g. AWoC!)
 - Collaborate in planning?
 - Share information?
 - Share resources – jointly employ a carer?
 - Communal living?
 - Engage the local community in offering practical intervention?

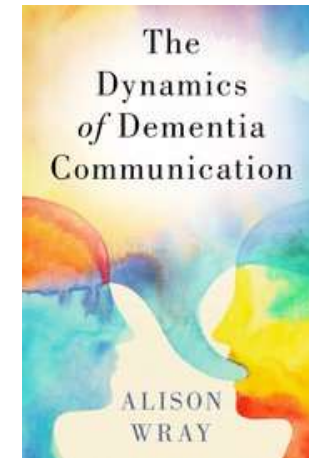
Over to you

Discussion

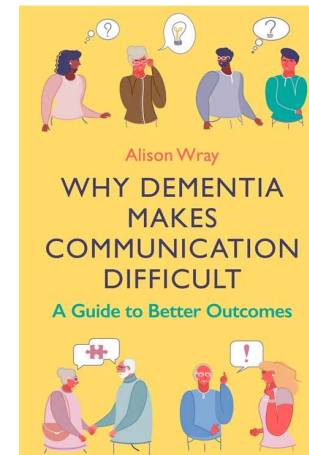
- To what extent do these issues cause you concern?
- How does one get beyond the anxiety, to practical action? What steps have you already taken?
- What role do groups like AWoC have?

For more information see my animated films, with voiceover by Tony Robinson

<https://www.youtube.com/@professoralisonwray881>



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