

Experiences of social isolation and loneliness in older people living with dementia and memory problems and their carers.

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UK Research
and Innovation

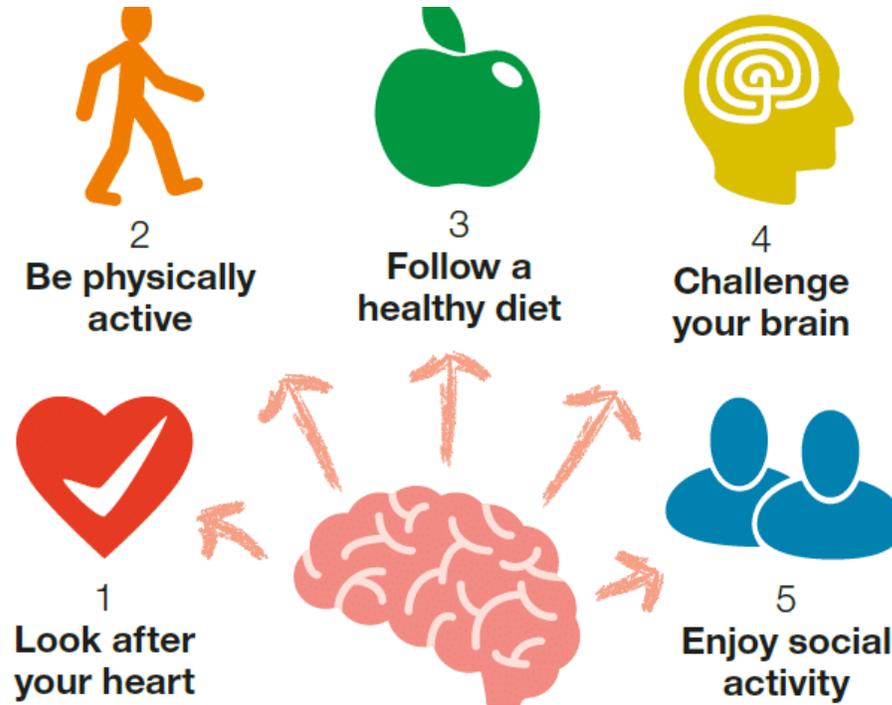
Background

- 70-80% of people with dementia are cared for at home by a relative or friend.
- 40% of family carers of people with dementia have depression or anxiety.
- Psychological symptoms in family carers predicts breakdown of care, transitions to care homes and abuse.
- Carers, report network sizes similar to the general population, but much higher levels of loneliness.



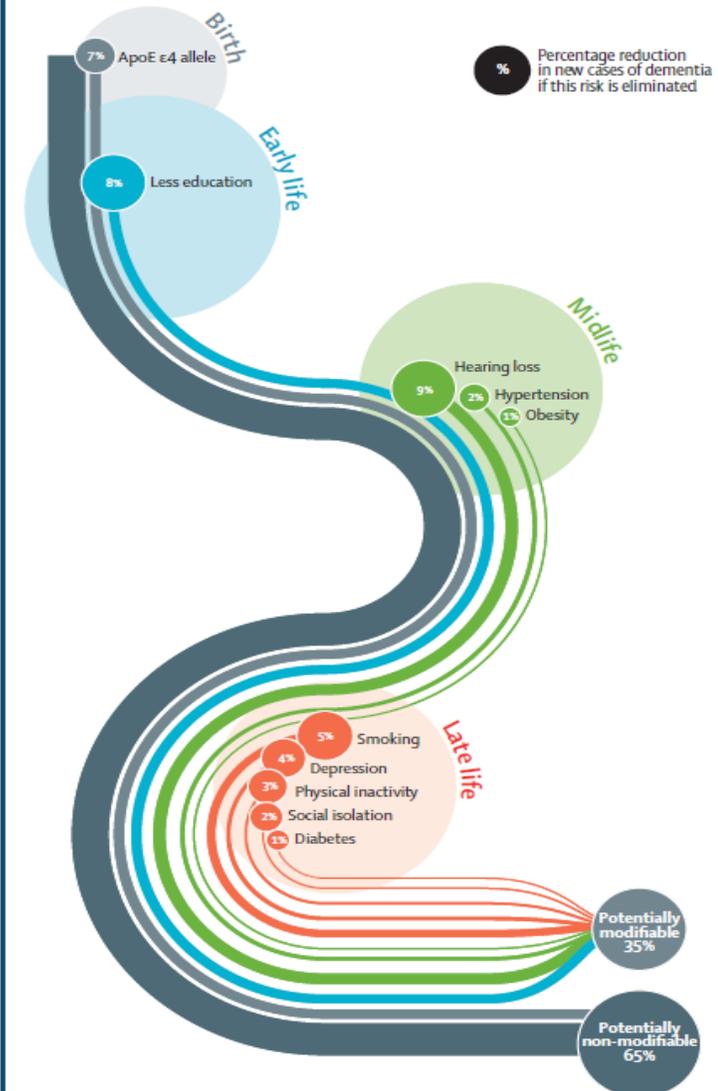
Background

Around 35% of dementia is attributable to nine risk factors, these include depression and social isolation in later life.



Risk factors for dementia

The Lancet Commission presents a new life-course model showing potentially modifiable, and non-modifiable, risk factors for dementia.



However



or



49% of people over 65 in the UK say that television or pets are their main form of company

- Nearly half (49%) of all people aged 75 and over live alone and spend less time with friends and family
- 9% of older people feel trapped in their own home 6% of older people (nearly 600,000) leave their house once a week or less
- 30% say they would like to go out more often

What can we do about this?

APPLE-Tree (Active Prevention in People at risk of dementia: Lifestyle, bEhaviour change and Technology to REducE cognitive and functional decline)



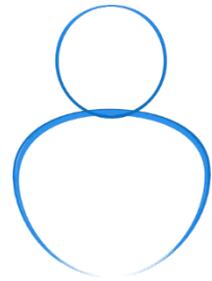
New Interventions for Independence in Dementia



Using qualitative work to inform understandings of social isolation in our target populations

Aim: To explore experiences of social isolation and loneliness and the impact of these experiences

Methods: Deductive secondary analysis of qualitative interviews with family carers, people living with dementia and memory problems



11 people
with
dementia

18 people
with memory
problems



28 family
carers

Primary NIDUS analysis: Rapaport, P., Burton, A., Leverton, M. et al. "I just keep thinking that I don't want to rely on people." a qualitative study of how people living with dementia achieve and maintain independence at home: stakeholder perspectives. *BMC Geriatr* 20, 5 (2020) doi:10.1186/s12877-019-1406-6

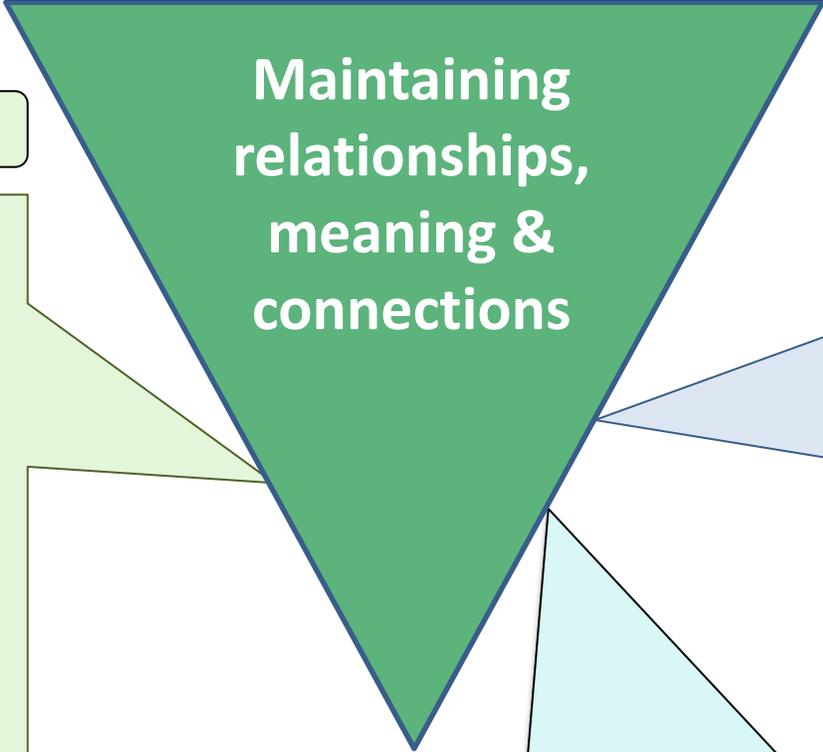
Primary APPLETREE analysis: Manuscript in submission

Findings

**Maintaining relationships &
meaning and connections**

**Changing roles and
relationships – together but
alone**

**Social disengagement as a
cause and effect**



Don't mention dementia

*"And they're always friendly, ask me if I'm alright and everything, and they always insist I get on the bus first to make sure I get on the bus. And they always ring the bell for me coming home to make sure I'm getting off, but none of them will mention the word dementia. They won't, because it's that fear again, even though they see me and I have dementia; they won't say the words." **Person living with dementia***

*"He had a phone call last night from his ex-neighbour. Before I gave him the phone I had to, and I did tell the neighbour, I've done it before, I said, I'll just tell him. I had to explain who this was, where he was, and then you could see the, oh okay. It's like a deck of cards falling into place. And then you pass the phone. Hello Bob, how's it going? So, I'm filling in the gaps in that sense." **Family carer***

Filling in the gaps

*"There are days when I will come home, I will find him sat in the living room, looking at a blank screen, just looking at a blank screen, which is the TV, but it's not on. He is consumed within himself. When he sees my face, it lights up like a child who is, I can't explain. That's what brings me back here every day." **Family carer***

Consumed within himself

Changing roles and relationships – Together but alone

*“If we tell her anything, she doesn't want show to us, her children, that she is weak. She goes, oh, I'm still the mother. You know, she doesn't want to come to us crying saying that. She'll get angry at us, saying, oh, this and that, but she doesn't want to show you that she's weak.” **Family carer***

Loss of role

Competing demands

*“Yes, but from my point of view I do have a problem with balance and my life, you know, of having the voluntary work and having the care and responsibilities. And what suffers in my life is the social side, I don't do much socially. Its work or it's my uncle.” **Family carer***

*“So going into a restaurant, he got it all down him, on the table, on the floor, people were looking at him. They don't understand. But it's embarrassing. And it's awful to say I felt embarrassed because I'm picking up things and I thought, I can't do this again. So everything stops in your life, everything.” **Family carer***

Shifting dynamics

*“Yes, as I said to you before, she's getting worse, she's getting like there's no communication like there was before, it's like we don't exist, you know? And I'm just a home help.” **Family carer***

*“I think, she sees me as like a jailer really. Which I'm not, I'm only trying to prevent her falling or helping her and this, that and the other.” **Family carer***

Gradually reducing social engagement

Fear of standing out

“They’re frightened of new things. They don’t really want to be shown up, so they won’t take the risk of being shown up, and therefore they don’t do it. So, I think it’s trying to get over that, really.”
Person with diagnostic label of MCI



Social
disengagement
– cause and
effect

“I suppose, it’s to a degree once you’ve retired and you’ve been working and you’ve been busy, yes, your social life is full because a lot of it was entertaining customers anyway. So if you stop that immediately, you’d have nothing.”
Person with diagnostic label of MCI

Ageism, sexism and stigma

“Well, I was going to look for an aerobics class. And then I thought to myself, well, if I do aerobics and I’m not very good and everybody else is good, and I’m... I’d look stupid. So, I didn’t bother.”
Person with memory problems

What are we doing? How are we learning from this?

Co-producing interventions to reflect the challenges that get in the way of maintaining independence at home, caring for a relative and taking steps to reduce dementia risk.

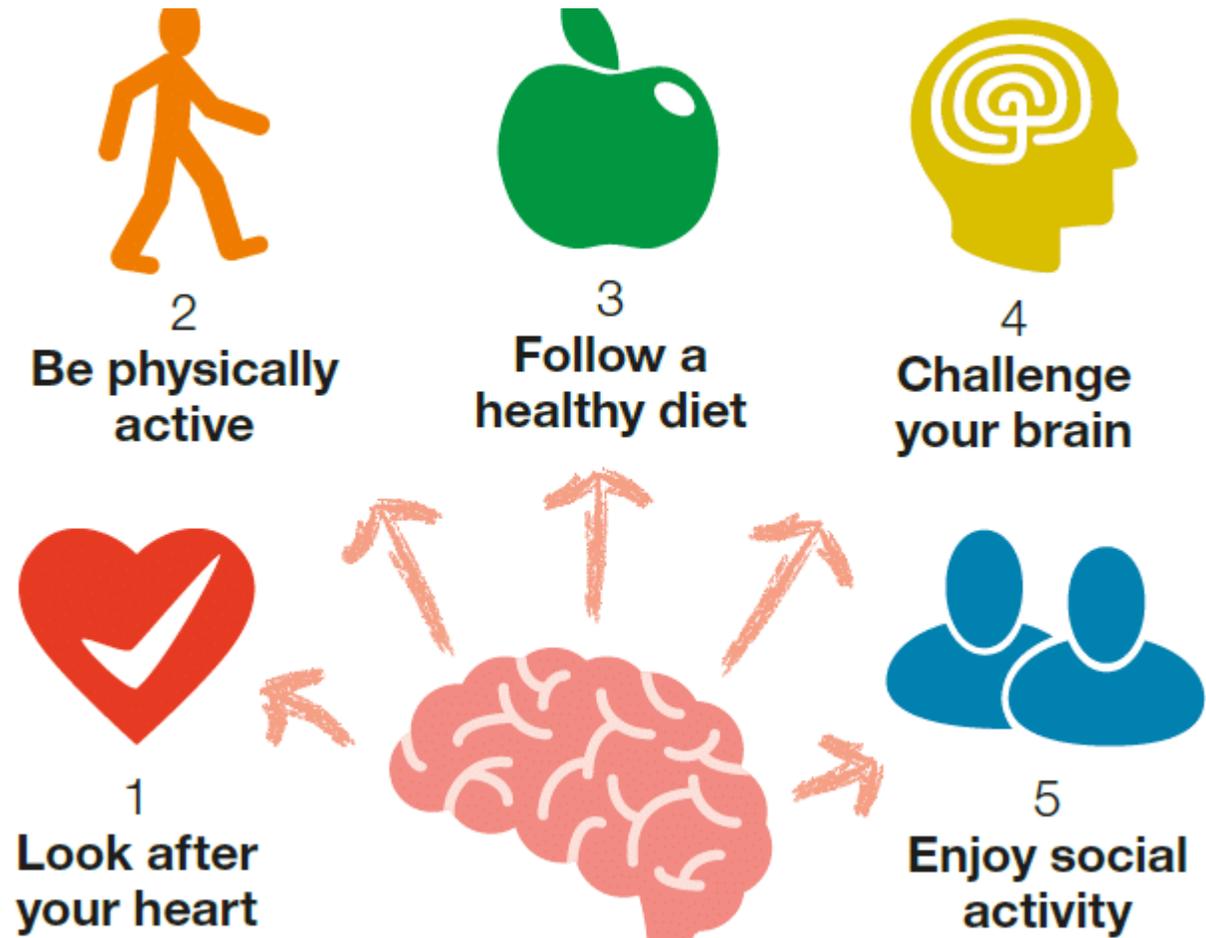
Supporting carers to find ways to reduce their own isolation

Promoting social interaction throughout the interventions both in content and form.



Engaging people in dementia prevention

1. Risk is individual
2. It can be increased or decreased
3. Motivation, opportunities and capabilities for change are individual
4. Goals for change are personal
5. Not everyone wants to change
6. If we make change easier, relevant (and fun), more people will do it



Thank you for listening



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