

## Written evidence submitted by Professor Claudia Cooper (PHS0020)

### Introduction

I lead the Centre for Psychiatry and Mental Health. I am a consultant old age psychiatrist in East London NHS Foundation Trust memory services.

I currently lead the Alzheimer's Society Centre of Excellence for Independence at home, in which we are developing interventions to support people living with dementia at home; and the NIHR/ESRC APPLE-Tree programme (Active Prevention in People at risk of dementia:Lifestyle,bEhaviour change/Technology to REducE cognitive decline). The National Institute for Health Research and the Economic and Social Research Council funded the APPLE-Tree study. This six-year study (2018-24) explores how to support people with memory concerns to make changes that reduce their chances of getting dementia.

- **Why the Health and Social Care Committee should consider this issue as part of its Prevention inquiry**

About half of people aged over 65 experience memory problems, and one fifth have symptoms of 'mild cognitive impairment,' which means their thinking, memory and decision-making skills are impaired. These people are at increased risk of developing dementia, although most will not.

Many live with this awareness of an increased risk of dementia, without knowing what they can do about it. There are currently no guidelines for how health and social care services support people with memory problems that are not dementia, and yet these symptoms have a profound impact on lives.

- **Why the Committee should look at it now: in particular, whether there is an opportunity for it to add value to existing research and evidence**

There has been a shift towards earlier diagnosis of dementia, which means more people are coming forward with memory problems. However, if told they have mild cognitive impairment, there are few NHS services to support them in the lifestyle changes that might lower their chances of developing dementia.

Age-specific dementia incidence rates have declined 13% globally in the last ten years, raising hopes that lifestyle and preventative health care measures can offset the expected increase in dementia cases from global gains in life expectancy.

While the possibilities heralded by the new drug Lecanemab, to slow the progression of Alzheimer's, which NICE is currently reviewing are exciting, it won't be suitable for many people living with dementia. Lifestyle and preventable health changes can make a difference now to the number of people diagnosed with dementia.

- **Why this area would benefit from scrutiny**

In the APPLE-Tree qualitative study, researchers interviewed people with memory problems, family members, healthcare professionals and voluntary sector workers. They told us that:

- people with memory problems and their families were left in limbo between the normal retirement and holiday plans of healthy ageing, and the doubts and fears of dementia. They were uncertain and worried about how to plan for the future. There were few services

available and they and their families felt alone with healthcare professionals not seeing their situation as a problem.

- people needed help to make the changes that might reduce their risk of dementia. Challenges included physical frailty, low self-confidence and social isolation.
- successful services would build on people's preferences and backgrounds. This might mean tailoring suggested activities to something people had enjoyed in the past, or thinking about diet change within the type of food people already eat and prefer.

We used these findings to design a new dementia prevention intervention held on video-call is a potentially cost-effective way of delivering the support people need to make lifestyle changes associated with reduced their risk

- **Why the Government needs to take action in this area.**

Simple life-style and behaviour interventions may be able to delay or even prevent the on-set of dementia, prolonging independent living, and increasing quality of life. These include:

- Being more socially and mentally active
- Eating more healthily
- Being more physically active
- Looking after their mental and physical health
- Stopping smoking
- Reducing alcohol

APPLE-Tree is the first trial of a dementia prevention intervention delivered by non-clinically trained staff, so if it works, it will be potentially accessible to many people who are at increased risk of dementia. Most participants taking part have not used video-calling before. The sessions are facilitated by graduate mental health workers, with a facilitator from a third sector charity. Facilitators are not from clinical backgrounds and received a short training course and regular supervision from a clinical psychologist.

Our programme has learnt from large trials globally, including the FINGER trial in Finland, which showed that lifestyle interventions can delay dementia.

Currently most people with memory concerns that are not dementia only get a leaflet, or brief conversation from memory services, to tell them what they could do to reduce their dementia risk – eat more healthily, move more. Our research show that people want more help than this, support to make these changes.

12/17 participants approached took part in the pilot study. Participants were invited to 10 group zoom calls, between July and September 2020, to plan changes they could make to their lifestyle to reduce dementia risk. They attended over 80% of sessions, and met 4/5 of the goals they set themselves, according to the findings published in *Dementia*. With most sessions now delivered, intervention adherence rates in our main trial have been at least as high.

Facilitators helped participants set up zoom, and organised food deliveries so groups could try out new recipes and share healthy foods, over zoom.

Participants reported valuing the groups as a source of social support. As one participant commented:

*“because we have learned all these things through discussions and connecting to each other, I think we will not forget it.”*

We coproduced the APPLE-Tree intervention with broad coalition of people with lived experience of memory concerns, from third sector, NHS and academic organisations.

We used results from this pilot study to plan our randomised controlled trial for which we have just completed recruitment of 748 participants, to test whether the APPLE-Tree intervention reduces their risk of dementia over 2 years.

To raise awareness of the needs of people with memory concerns that do not have dementia, we worked with 19 trial intervention participants to co-design a photography exhibition. This new and poignant photography exhibition highlights the experiences of people living with memory problems during and beyond the pandemic. It was displayed for one week in the House of Commons in January 2023, to highlight the needs of this group to policymakers.

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