Researchers develop a guide to dementia-friendly eyecare

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Being diagnosed with dementia can be devastating, but you can live well for many years with the condition. An important part of this is staying independent, living at home and continuing to do the things that you
enjoy.

Perhaps you might even like to try something new—there are many tailored well-being and activity programs designed for people living with dementia including dancing, art and exercise.

But how many of these activities rely on your eyesight to fully participate?

Good eyesight is actually really important to people with dementia. As part of our research, we interviewed 13 people with dementia and 15 caregivers and asked people with dementia what they enjoyed doing and the majority of these activities were visual: gardening, art classes, even picking up the ukelele or seeing the family.

Maybe that's not such a big deal and your favorite pastime is listening to music, but good eyesight is also important for spatial navigation too, and for other aspects of living with dementia, including visual memory aids like calendars and smartphone apps.

The 2022 World Alzheimer's Report now includes a dedicated chapter about why looking after your senses is so important.

The Report states that, "The long-term goal of addressing sensory health in dementia is to create environments and opportunities that enable people to be and do what they value throughout their lives."

Unfortunately, current research indicates that people living with dementia are more likely to experience preventable sight loss compared to people without dementia.

Major sight-threatening eye diseases, and even simply outdated spectacles, can be identified via a routine eye examination, something
every Australian over the age of 65 is entitled to under Medicare every year.

But having an eye test is more than just getting a new pair of specs: think of optometrists as like a GP just for your eyes—in Australia, they are extensively trained to evaluate your eye health as part of this examination.

This is especially important as we age because the likelihood of developing a sight-threatening eye condition rises exponentially after the age of 60.

Early detection of these problems allows prompt referral to specialist eye services for intervention and preservation of sight.

A U.K. research study of more than 700 people living with dementia in the community and in residential aged care, found that one in three people had some form of visual impairment. For nearly half of these people, a simple glasses update was all that was needed to restore sight.

One in four of those studied also had an untreated cataract and many were overdue for their eye test.

The bottom line is that people living with dementia can struggle with poor vision from a variety of causes, many of which are treatable, and they really benefit from being able to access routine eye care. But right now, they often aren't.

Sight loss makes living with dementia harder, so we want to do everything we can to prevent it. A big part of this is ensuring that everyone with dementia gets their eyes tested on a regular basis.

But what are the barriers to getting regular eye tests, and what can we do
to break these down?

When we asked people with dementia and caregivers about the eye test experience from their perspectives, they told us that they want to be seen by an optometrist who knows about dementia.

Our study showed that their experiences with the routine eye test were very mixed. Good experiences were associated with the caregiver being present in the consulting room to provide support, as well as clear, positive communication that included the person with dementia.

Lastly, appropriate adaptations of the eye test were important to accommodate different levels of cognitive impairment. The eye test can be very tiring when not adapted, as it includes many types of tests and subjective judgements to be made, for example, "Which is better, one, or two?"

Optometrists told us that they wanted to provide high-quality eyecare to people with dementia but felt they lacked specific training on adapting testing, often picking up techniques from colleagues or by trial and error.

Another thing that made it harder for optometrists was having to figure out the dementia diagnosis for themselves.

People with dementia and caregivers often did not feel it necessary to tell the optometrist about the dementia diagnosis, because they weren't sure how it would change anything about their eye test experience or were not aware of the connection between the eyes and the brain.

To break down barriers in accessing dementia-friendly eyecare, our research suggested that there were three things we needed to do:
1. Make it easier for people living with dementia and caregivers to find an optometrist who knows dementia.
2. Upskill the optometry workforce so they are ready to be part of routine post-diagnosis care for people with dementia.
3. Help people with dementia and caregivers understand why it is helpful to let the optometrist know about a dementia diagnosis in advance and make it easy for them to do this.

We have now developed a training course for optometrists to provide dementia-friendly eyecare and information booklets for people with dementia and their caregivers to understand more about eye tests and looking after the eyes at home.

The information booklet includes a pocket card to discreetly declare a dementia diagnosis to the optometrist and indicate key areas of difficulty such as communication or energy levels.

The booklet will be available from dementia and caregiver support organizations, community groups and Dementia Australia. A print-at-home version is also available online.

You can now also search for a dementia-friendly optometrist. As people complete our training course, there will be more optometrists in Australia who are confident about adapting their clinical practice to support people with dementia.

We hope these materials will help to break down barriers to accessing dementia-friendly eyecare and help people living with dementia to see as well as possible, for as long as possible.

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