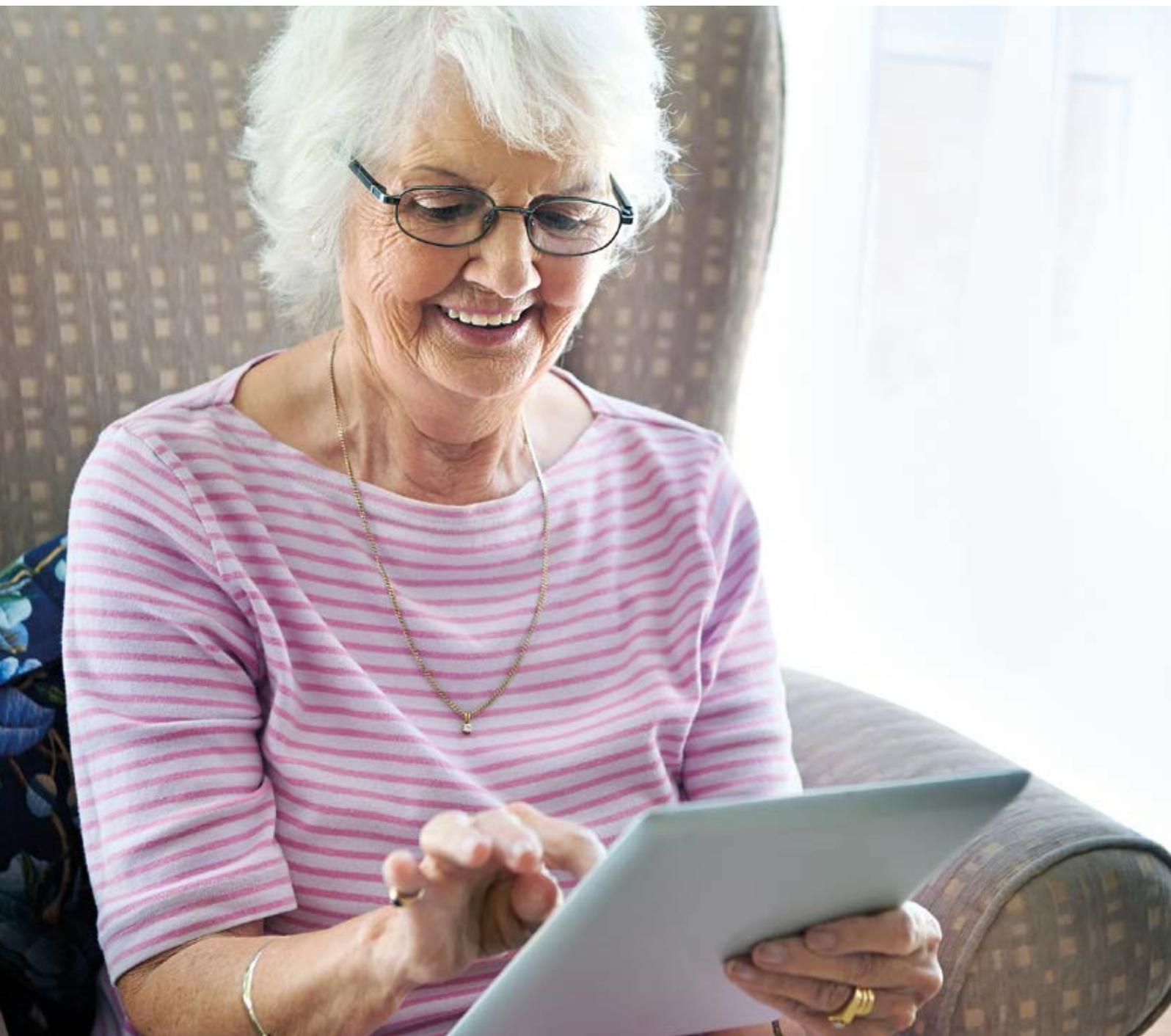


Good practice guidelines for using technology to support people with sight loss and dementia



R N I B

See differently

 **Alzheimer
Scotland**
Action on Dementia

This guide is part of a range of materials available to support people with sight loss and dementia.

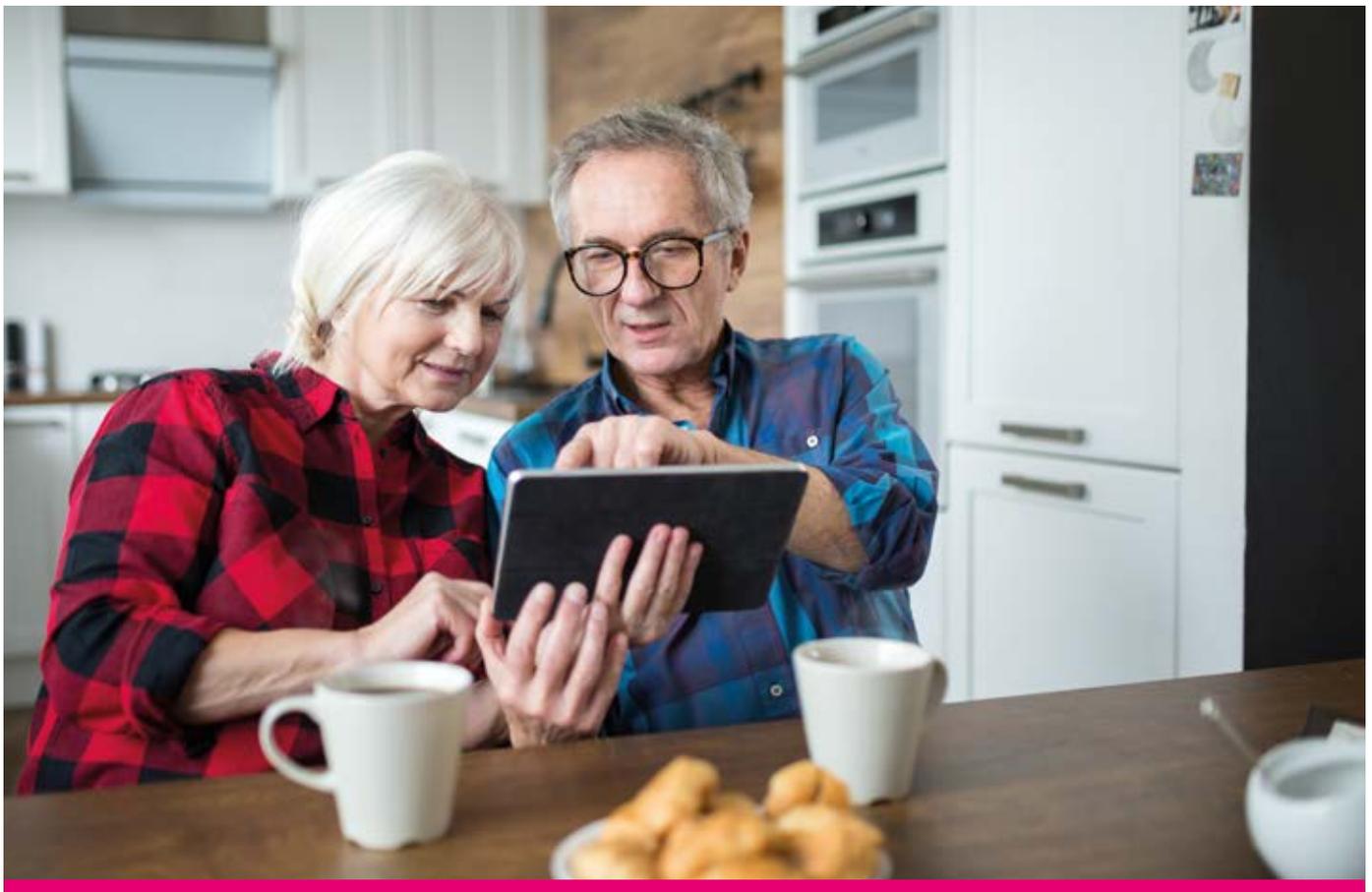
Please go to the RNIB website for further information:
<https://tinyurl.com/RNIBDementia>.

“When my Dad got short term memory loss, I thought there must be technology to help me solve this issue... (it is crucial to) look for the real problems and look for simple solutions”

Keith Spink, carer

Purpose

This good practice guideline has been created for health and social care professionals. It outlines the potential of everyday technologies and digital solutions to support those living with sight loss and dementia, and to support their carers.



What is dementia?

There are around 850,000 adults in the United Kingdom with dementia. By 2025 the number is expected to rise to over one million and by 2051 it is projected to exceed two million [1].

Dementia is a syndrome arising from different conditions which cause abnormal loss of brain cells and damage to their complex connections. Dementia is a life limiting condition which is usually progressive and associated with a wide range of risk factors, including ageing.

The conditions which give rise to dementia bring about a range of different changes in the brain and it is not uncommon for the brain to be affected by more than one of these conditions. Some of the most common causes of these changes are:

- Alzheimer's disease
- Vascular dementia
- Lewy Body dementia
- Frontotemporal dementia.

Symptoms in dementia relate not only to the changes in the brain but to individual responses to these symptoms and the impact of a person's social and physical environment.

As the majority of people with dementia are older, the experience of co-existing conditions is common. These co-existing conditions will frequently include eye conditions. The changes in the brain associated with dementia itself can impact on vision. These visual changes often go unrecognised, even by eye care professionals.

Living with dementia

It is important to be aware that dementia gives rise to a diverse and changing range of symptoms. These symptoms can be physical, behavioural, psychological and cognitive. Support in the following areas may be required:

- communication – expressing and understanding
- orientation – time, place, person
- memory – especially for recent events and information
- recognition of people and objects
- movement and co-ordination
- thinking and reasoning about facts and situations
- concentration
- visual processing (light, contrast, depth perception, complex visual scenes/patterns)
- susceptibility to stress – a busy environment, lots of people, excessive noise and visual distractions can be especially stressful.

Key facts

- The experience of dementia is unique to each individual.
- The social and physical environment can impact profoundly on that experience.
- People with dementia may have existing eye conditions or develop new eye conditions.
- The dementia itself can affect vision and visual perception.
- Professionals often miss visual difficulties when a person has dementia.

Key messages

- At least 250,000 people are living in the UK with sight loss and dementia [2].
- Eighty per cent of people living with sight loss are over 60 years old, which is further complicated by co-existing conditions such as dementia. The majority of people over 75 have three or more long term conditions [3].
- People with learning disabilities are 10 times more likely to have serious sight problems than other people and are at greater risk of developing dementia at a younger age, particularly people with Down's Syndrome [4] [5].
- People with dementia may not be able to tell you about all aspects of their sight loss or perceptual difficulties.

- Even if the person does not wear spectacles or have a known eye condition, they may still experience visual or perceptual difficulties.
- A recent study into the prevalence of dementia and sight loss found that nearly one third of people with dementia aged 60-89 years, also had significant sight loss. Almost half of the study participants could have their sight loss corrected by wearing up-to date spectacle prescriptions [6].

Sight loss and dementia

- People with dementia may have an eye condition and may also have difficulties with processing visual information.
- Posterior Cortical Atrophy (PCA) is a lesser known type of dementia which initially affects vision. The issue for those affected lies in the interpretation of visual information received by the brain. PCA predominantly presents in younger people (under the age of 65).
- In the early stages of PCA, most people do not have markedly reduced memory, but memory can be affected in later stages. It is not known whether PCA is a unique disease or a possible variant form of Alzheimer's disease. For more information on PCA please visit Alzheimer's Association at: <https://tinyurl.com/PosteriorCorticalAtrophy>.

What is meant by the term “technology” and digital”?

Here, the term “technology and digital solutions” refers to electronic devices being used for practical purposes. Technology can meet the various different requirements of people who need care and support, wherever they are living. Technology is changing fast, offering a greater range of options all the time. However, it is often simple changes to the style, design and functionality of the very familiar that supports independence, for example sensor lighting.

The term “technology” includes existing telecare solutions as well as everyday technologies such as smartphones, apps, tablets, social media, smart home devices, locator technologies, environmental controls, email, audio books, and so on.

Technology supports the delivery of integrated health and social care and can help manage risks, enhance lives, promote independent living and complement care and support. Technology has the potential to improve quality of life and support people to stay in their own home for as long as possible.

Demonstrating Technology

Here are some ideas to support people living with sight loss and dementia when discussing the use of technology, or when they are learning about or trying out technology solutions.

- As excessive noise can cause stress or distress, work within a quiet space and ensure minimal distraction and disruption.
- People with dementia can experience tiredness and fatigue and may take longer to plan and get ready. Ask if there is a ‘best time of day’ for the person and remember to build in comfort breaks within sessions.
- Relatives or friends should be welcome to attend and participate.
- If organising a workspace or venue, it should be clutter free and free from complex wall and floor patterns. The venue or workspace should be easy to access with suitable chairs and desks to accommodate those with mobility issues.
- The venue or workspace should have good lighting, with task lighting available.
- Also consider the acoustics of the space and ask if a hearing loop is required.
- Give practical demonstrations of any products or systems you might be discussing.
- Step-by-step pictorial or auditory guides for the use of products or systems can be useful.
- Use reminders when making appointments, for example: letter, phone call, email or text message.

- If sending letters, emails or other written correspondence, it is good practice to add a photo of yourself to aid recognition and provide context.
- Correspondence may also be more readily accessible if sent on a particular colour of paper and produced in a larger font size (this can vary for individuals, but yellow paper frequently works well).
- Other accessible formats e.g. braille, audio, or large print should also be offered. This should be discussed at the appointment and noted on the individual's file.
- It should be noted that it is a statutory requirement for public sector agencies to make 'reasonable adjustments' to their practice, to make them as accessible and effective as they would be for people without disabilities [7][8].



Enhancing communication

When supporting the person living with sight loss and dementia:

- Always introduce yourself fully with your name and the purpose of your role every time you meet with the person.
- Find out about the person's background, connections, routines, hobbies, interests and preferences, including what is likely to be helpful to them. If available refer to the documents Getting to Know Me [9] or This is Me [10]. The What Matters to You structured conversations may also be useful
- Provide a narrative to the person during the session explaining what you are doing and when you are going to do it.
- Use simple language and short sentences. Present one idea or question at a time.
- Always be clear, concise and calm, ensuring body language reflects active listening.
- Allow the individual time to understand and respond.
- It may be necessary to repeat information, or repeat it slightly differently, if the person is unsure.

Technology considerations and making recommendations

It is helpful to consider the following four areas when designing a personalised technological solution for an individual.

The person using the technology

It is important to have an understanding of the eye condition(s), the specific symptoms of dementia being experienced and any other health condition the person may have. It is important to understand the interplay of sight loss and dementia, and how these impact on the individual's overall functioning. Consider the following questions and statements:

- How are they going to use the technology?
- Why are they going to use the technology?
- What are the specific tasks that can be more easily achieved by using technology?
- Do they have past experience of technology, for example at work?
- What about their physical dexterity? Would typing or swiping work best?
- Do they require a screen magnifier or screen reader?
- Are they a braille reader? Think about a braille Notetaker.
- Would a voice activated package work best? Consider using Siri, for example.
- Why not include the person's preferences and requirements for technology in their Getting to Know Me [1] or This Is Me [4] document? This information could influence care plans and support the achievement of personal outcomes.
- Adults are considered to have capacity to consent, including those with dementia, unless legally determined otherwise.
- Abilities in dementia often fluctuate and are influenced by varied social, psychological and environmental factors.
- Consider manual dexterity problems and how it may affect the individual's ability to operate technology.
- Vision can be influenced by lighting levels, tiredness and medication.
- Failure to use equipment successfully can cause distress and anxiety and create a negative association with technology.
- Dementia has a wide spectrum of effects and people with dementia can often learn new skills and adapt to changing circumstances until the condition is very advanced.

The purpose of the technology

- Is the technology for communication, home environmental controls, entertainment and interest or to support the activities of daily life? Or a combination of these?
- Is the technology to be used at home only or is it to be mobile? Or both home and mobile?
- If only very basic functions are required, think about operating systems that offer the user a key options list such as, "Do you want to write an email?". However, the options offered by this sort of package can be limiting. One such option is GuideConnect [14] by Dolphin.
- Similar packages are also available for Android tablets and phones. They present the user with a simple, menu driven interface that can make the device easier to use. One such option is Synapptic [15].

The equipment

When thinking about the person and the purpose of the technology, consider the following:

- Is internet access needed?
- The physicality of the hardware and what would work best for the intended purpose? A personal computer (PC), laptop, tablet or Smartphone?
- If size of screen is not a consideration, all usual technology functions can be carried out by Smartphone. However, a tablet is a better choice if a larger screen is more suitable.

- Consider decluttering screen settings and utilising contrast features.
- Consider costs when looking at operating systems (Microsoft, Apple etc.), cloud-based storage and on-going potential costs of software updates to maintain accessibility of packages, such as Windows or security packages.
- If several functions are required (see The Purpose of the technology section above), it is important to factor in how well things will work together and how systems, apps and devices all connect. It is better to have as few devices as possible.
- Battery life should be thoroughly considered. Can someone ensure the battery is charged? There are apps that will monitor battery depletion and send alerts.
- Many mobile technologies can be linked to a Smart TV to improve visibility of the screen and this can reduce the need for a PC.
- Alerts or reminders to support daily living can be set up on a Smartphone, tablet or smart home device.
- Smartphones now have accessibility technology built in; this may diminish the need to buy additional technology.
- Mobile technologies are sometimes better as they can be carried by the user.
- Voice activated technology, such as Google or Amazon Echo, is also now readily available and can be used in the home.

The environment

- If a PC or laptop is required, consider the space needed to accommodate the hardware.
- Consider other environmental considerations, such as desk space, task lighting, work surface, need for tidiness of wiring, size of screen, etc.

Making recommendations

An individual with sight loss and dementia may present with complex requirements and needs. The following suggestions may assist when designing a personalised technological solution.

- Consider a virtual team approach by bringing together RNIB technical advice, dementia expertise and the individual's own preference and choices.
- Alzheimer Scotland offers tailored training around digital solutions for people living with dementia, their carers and professionals alike.
- Some local sight loss societies and dementia resource centres can offer the individual an opportunity to try out and test products to see what works for the person.
- RNIB and Alzheimer Scotland have information about a range of domestic solutions and everyday assistive technology. The RNIB Helpline can direct people with technology queries to the right place.
- RNIB Technology for Life volunteers can help set up equipment and offer support to the individual.

- RNIB offer grants of up to £500 for certain small items of technology to people who are registered as blind or partially sighted, on a means-tested benefit and who have been unable to get statutory funding. For more information about these grants, visit our website at: rnib.org.uk/grants

Practice principles

- If you have identified a technological solution to problems or difficulties, or a beneficial way of working with a person with sight loss and dementia, then this information should be shared with staff and appropriate others, and added to any care and support plans.
- Consideration should be given to the way information will be understood by the person with sight loss and dementia. This information may need to be in alternative formats to ensure the information is accessible.
- Ensure advice about potential technological solutions will help to maintain or enhance quality of life.
- Refer to the Alzheimer Society Dementia Friendly Technology Charter or Alzheimer Scotland's Technology Charter on the website: <https://tinyurl.com/y7jaheef>.

Signposting and useful resources

1. Alzheimer's Society

Provides information about dementia and dementia services in England, Wales and NI.

Website: www.Alzheimers.org.uk

Helpline: **0300 222 11 22**

Opening times:

9am – 8pm Monday to

Wednesday 9am – 5pm on

Thursday and Friday 10am – 4pm

on Saturday and Sunday

2. Alzheimer's Society

Dementia-Friendly Technology Resources <https://tinyurl.com/ydbyke5b>

3. Alzheimer's Scotland

Within Scotland provides information about dementia and dementia services and has a dedicated digital and technology team.

Website: www.alzscot.org

Helpline: 24 hours **0808 808 3000**

4. The Social Care Institute for Excellence (SCIE)

The Social Care Institute for Excellence (SCIE) improves the lives of people who use care services by sharing knowledge about what works. We are a leading improvement support agency and an independent charity working with adults', families' and children's care and support services across the UK. We also work closely with related services such as health care and housing.

Website: www.scie.org.uk

5. Dementia Managed Knowledge Network

The Dementia managed knowledge network offers up-to-date information, new resources and opportunities for discussion.

Website: <http://tinyurl.com/h3ypg85>

6. Technology Charter for People Living with Dementia in Scotland

This can be found at:

<http://tinyurl.com/hpbnc4p>

7. AT Dementia

Provides user-friendly information on assistive technology (AT) for people with dementia including what is available, how it can be obtained and used.

Website: www.atdementia.org.uk/

8. Thomas Pocklington Trust

Sight Loss and Dementia publications and design guides.

These can be found at:

Meaningful Activity: <http://tinyurl.com/jelndvz>

Assistive and Inclusive Home Technology: <http://tinyurl.com/z9lyjlz>.

9. The Dementia Centre

Website: www.dementia.stir.ac.uk/

10. ADAM

Information about products designed for and tested by people with dementia and their families.

Website: meetadam.co.uk

11. RNIB Training: Sight Loss and Dementia

Our award-winning training packages are aimed at professionals, parents, carers and individuals throughout the United Kingdom and will help you to understand the impact of sight loss on daily life. The training will provide you with the skills, knowledge and confidence to meet the needs of the person you are supporting. More information can be found at our website: <http://tinyurl.com/jj4c5sk>

Additionally, the website provides access to resources specifically to support people with dementia and sight loss. These include tip cards on:

- communication
- mobility
- environmental recommendations.

Further resources consist of:

- Dementia and Sight Loss leaflet
- Sight Loss and Dementia Falls Practice Guide
- Frequently asked questions
- Tips for promoting eye health for people with dementia
- Links to other Sight Loss and Dementia websites.

12. Disabled Living Foundation (DLF)

DLF helps the general public and healthcare professionals find out about daily living equipment and assistive technology.

Website: <http://tinyurl.com/ha5s7tb>

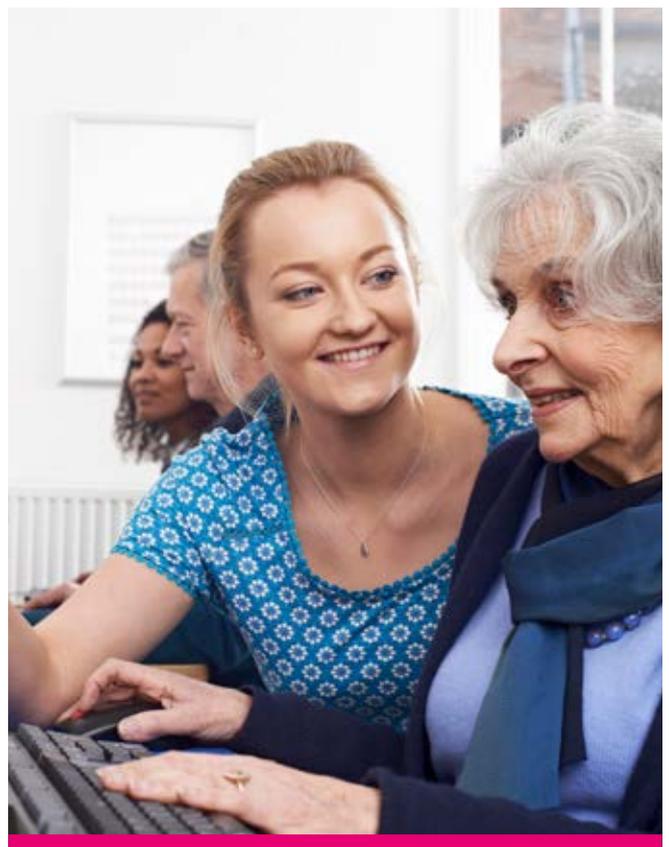
13. AskSARA

Your self-help guide to how technology can help you to live well with dementia.

Website: <http://tinyurl.com/h8l7qxs>

14. Echoes around the home

Presentation by Nick Firth, University College London, on whether the Amazon Echo be used in the home to help those living with dementia? Accessible from: <https://tinyurl.com/yd39e5pr>



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