# Podcast transcript: Enhancing communication in people with dementia and sight loss

Introduction: This podcast is brought to you by RNIB Older People and Complex Needs team. The information in this podcast will be useful for people who support people living with sight loss living with complex needs such as learning disabilities and dementia.

Marion: I’m Marion MacMillan at RNIB. Today’s podcast is the second in a two-part series on dementia and sight loss, with June Neil from RNIB and Dr Barbara Sharp from Alzheimer’s Scotland. In the first podcast, the impact of sight loss in people with dementia, June and Barbara discussed the similarities between some symptoms of dementia and sight loss and how some types of dementia can have sight related issues. Today, June and Barbara will be chatting about ways to enhance communication with a person who has dementia and sight loss. June and Barbara, I’m just going to hand over directly to you.

June: So, Barbara, one of the things that we’ve been working on is some of our communication tips and I think it would be really good for us just to have a wee chat or a wee think over how we can support people to enhance their communication when they are supporting someone who is living with sight loss and dementia.

Barbara: I think the starting point is always the person themselves, June. Know as much as you possibly can about that individual, because, as I said, the changes in the brain, that’s one thing, but the way that people react to that, the kind of difficulties that people are experiencing because of the impact of the changes in their dementia, that’s what’s really crucial, isn’t it, it’s understanding how that’s impacting in people’s day to day lives and how they feel about things, what’s important to them and how we best approach this to be as supportive as possible. The range of dementia types, as I say, is vast and that very individual reaction to things means that you have to think quite carefully about is this somebody who’s been diagnosed fairly recently and therefore is not experiencing really great changes, or, as you say, it’s progressive, so over time things are going to change quite dramatically and it might be somebody that you’re seeing that’s at a much later point in the illness and have very complex situations to deal with in terms of the symptoms they’re experiencing. So, understanding the person themselves and where they’re at in relation to their dementia and what kind of impact is it having on their day to day lives? There’s a useful document we use in Scotland called the "Getting to know me" document and we encourage families to complete that and encourage staff to look out for it, because it tells you about the really core important information about the individual and it will help your early communication with the person, because it’ll have details like the sort of things that might help someone feel calmer, as people with dementia often will feel more confused and really disorientated in a different environment from what is their usual, so, for example, visiting a clinic or whatever, it might be a very stressful experience, and so that information can be harnessed by the staff to build a relationship with the person more easily and learn how to best communicate and put the person at their ease.

June: And I think it’s important just to mention, in England and Wales, there is a document called "This Is Me", which is a similar structure and does contain that information, so a really good starting point to find out about the person. And I think, from a sight loss point of view, everything you’re saying regarding the dementia I would say think about the person’s eye condition, how it impacts in that individual, where’s the best place for you to position yourself so that you can make the most of that person’s vision, and if someone is living with dementia, maybe a wee bit of support around ensuring that they are wearing the correct glasses, that they are the current glasses, that the glasses are clean, and that the glasses are comfortable, because one of the ongoing issues that I’m often hearing when I’m delivering training and from carers is that, as the person with dementia progresses in their dementia journey, sometimes they need a bit more support to be wearing their glasses. So, we do need to make sure that these simple things are done, because, as we know, Barbara, sometimes it’s the simple changes that make the big difference. So, definitely thinking about all these aspects, knowing about the person’s dementia, and understanding how the person’s sight loss impacts on that person, so that we can begin to enhance our communication.

Barbara: I think these are really important points and they can get overlooked so easily, because you’re dealing with quite complex conditions, sometimes we seek complex solutions and approaches and actually it’s the simple things, as you say, that get overlooked and just making sure that the person has the right glasses and they’re in good condition can make such a difference, as can other simple things like good lighting.

June: Yeah, that was my next line, Barbara, good lighting. We always talk about good, even, consistent lighting, because you want for the person to be able to see you as much as possible when you’re speaking to them. We always think about reducing glare, reducing sunlight, so that that doesn’t affect the person, because sometimes it might affect the person but they can’t actually communicate how it’s affecting, so you, as a carer or a family member, need to be much more aware of the environment and how it will impact on the person.

Barbara: You do, and with the kind of visual changes that people with dementia experience, things even like the colour on the walls, the carpets, the flooring, if you have a lot of what we call visual clutter, maybe lots of different colours, crazy patterns, that can be really quite disturbing.

June: And I think even taking that further, Barbara, and thinking about what you’re actually wearing, because if you’re wearing something that has a lot of visual clutter, lots of patterns, rather than the person concentrating on your face, so they can see what you’re saying and hear what you’re saying and pick up the visual clues, because, again, if you’re smiling, the person knows that you’re happy and will want to engage with you, if there’s a lot of visual noise going on, or visual clutter, they’re going to be looking at that and trying to make sense of the pattern, rather than looking at you. So, I think, again, it’s just thinking not only about the wider environment but what you can do to enhance that too.

Barbara: That’s right, and our senses are all connected, aren’t they, so you’ve used the term visual noise, but actual noise too is something that’s really important to control.

June: And, again, it’s back to that whole co-morbidity thing, Barbara, if you’ve got people over the age of 75 living with three or four more long-term conditions, the chances are that they’re probably going to be living with some degree of hearing loss as well. So, we do have to think about the environment, reducing the noise in the environment, again, just to enhance that communication.

Barbara: So often, June, you and I have conversed with people with dementia and various sight difficulties over the years and people consistently come back to it was those simple things that helped, it was being able to have good light, see people, have an air of calmness about and people taking their time to just introduce themselves, what is happening, keeping the person informed.

June: Yeah, and these are basic things that anybody who’s supporting someone with sight loss would always think about is introducing yourself, telling people who’s in the room with them, telling people if you’re leaving the room, and verbalising your actions so that anything you’re doing, you’re giving a running commentary to the person, so they know what’s happening. I think the other thing that we’ve also included in one of our tip cards, Barbara, is the OWL principle, as we would call it, and that’s to Observe, so observe the person to see that they’ve understood anything that you’re trying to communicate, Wait to give them time to process that information, and then Listen to make sure that you’re understanding what they’re saying and that there’s good communication between the two of you. So, I think also adopting that OWL principle will certainly enhance communication.

Barbara: I think that is helpful and sometimes words are difficult to retrieve for people with dementia, just finding a different way of saying something, describing it in a different way, using the senses again to enhance someone’s understanding can be really helpful.

June: Yeah, and I think it’s also, if you’re thinking about activities with the person, it’s building in all the attributes, so thinking about sensory needs, so how do you create the perfect environment? Thinking about the activity, how can you pull on the sensory things there? Thinking about your communication, keep it short, keep it simple, uncomplicated language, and adopting the OWL principle, and always remembering to have an understanding of the person’s sight loss, making sure they’ve got their glasses on, and maybe using task lighting, their magnifiers, maybe audio description in things, just so that the person can get the most out of that activity.

Barbara: I think also remembering people’s routines that they’re familiar with, not changing too much.

June: Definitely.

Barbara: You sometimes think you’re helping by maybe changing something to a more modern piece of equipment or whatever, but if the person’s used to using a familiar thing, it can really undermine their confidence and their abilities. So, it’s being cautious about those things, but not ruling out, at the same time, the potential for new technology, particularly to be helpful, because that’s a growing area, isn’t it, June?

June: Definitely.

Barbara: Where support is possible for people.

June: And I think as well, Barbara, if maybe the person can’t use a bit of equipment or engage in an activity because they can’t maybe see the on/off buttons, it’s remembering there is things like bump ons that can make it easier to locate things. So, I would say to people, check out the RNIB website and there’s also the Dementia Circle as well, and they do some reviews of products that seem to be a wee bit more suitable for people living with dementia, and also it does seem to take in the person’s sight loss, because it’s making sure there is good colour contrast on things and the location and the way that you’re able to use or access that bit of equipment is quite simple as well.

Barbara: Absolutely, and in Alzheimer’s Scotland we have a digital team now, so it’s a small team but it’s a team of experts around the range of technology that might be able to support someone to be as independent as possible around their own home, or indeed they’re increasingly working with our teams in hospitals and other environments too, so they’re a really, really useful source. And you mentioned Dementia Circle and I think what’s key about that is it’s families that are affected by dementia that are testing things out and sharing their knowledge and their experience of using different bits of technology, sometimes very simple things, but sharing them with everyone else, and that’s all available online.

June: And just again, one of the things that we’ve been working on, with your colleagues from the digital team, is the IT Effective Practice Note, which is online, and, again, that gives some really helpful tips for carers and health and social care professionals when they’re beginning to think about technology and how it can enhance that person’s daily living. So, I think probably it might be quite useful, Barbara, if we just kind of summarise some of the things because when you and I get together we can certainly blether. So, really if we just have a wee think about what’s the most important thing if we’re enhancing communication?

Barbara: I would always come back to know the person as best as you can, find out from them and their family how you can best support them because their needs will be very individual. What will help will be unique to them, make every effort to find that out.

June: And, for me, it’s going back to the sight loss, so thinking about the eye condition, thinking about if they have an eye condition stemming from a health condition, thinking about how the dementia itself can affect visual processing, ensuring that the person does have the correct, current, clean and comfortable glasses on, so that they will be encouraged to wear them, and to think about the environment and reducing the impact. And, again, I think probably to highlight is check out "This Is Me", or "Getting to Know Me", where it will cover the sensory issues in there.

Barbara: And I think to always be considering sight loss when things are changing, because it is, as we said, vastly overlooked.

June: Yeah, so we would always advocate accessing eye healthcare, if you’re over 60 and living in Scotland, definitely an annual appointment, but be governed by your optometrist who might want you back earlier if there is an ongoing concern.

Barbara: Yeah, I think we can’t stress that highly enough, because the research suggests that not only is the incidence of sight loss really high in people with dementia, higher than the general population, often it’s simple solutions, again, like the right glasses, that would resolve things.

June: Makes a big difference. It’s the small changes, Barbara, that make the biggest impact.

Barbara: It is.

June: Thanks for your time.

Marion: Thank you both for all the valuable information that you’ve shared, I’m sure it’ll be very useful to people listening. Remember, there’s plenty of information and resources on the RNIB and Alzheimer’s Scotland websites too. RNIB also have an open badge on the Scottish Social Services Council website, which you can apply for if you’ve listened to one of our podcasts.

Closing: If you found this helpful, you can listen to our other podcasts. We also have further information and support online from our Sight Loss Advice service at [www.rnib.org.uk/advice](http://www.rnib.org.uk/advice). For more information about working with people with sight loss and complex needs, go onto the RNIB website at [www.rnib.org.uk](http://www.rnib.org.uk) and type in complex needs in the search box at the right hand side. You can also call the RNIB helpline on 0303 123 9999. We are the Older People and Complex Needs team at RNIB. For more information about what we do search for us on the RNIB website.

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