# Podcast 7: The Impact of Sight Loss in People with Dementia

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

Marion: Hi there, I’m Marion MacMillan from RNIB. I’m here in the Connect Radio studios with June Neill, Training and Development Manager from the Older People and Complex Needs team at RNIB, and Dr Barbara Sharp, Policy and Practice Consultant with Alzheimer’s Scotland. June and Barbara will be talking about partnership working and the impact of sight loss on someone with dementia. Barbara, could you perhaps start things off by talking a bit about your partnership working?

Barbara: Yes, certainly. Well, Alzheimer’s Scotland and RNIB have been working together in a collaborative partnership for a long number of years and it makes perfect sense because we have our own specific skills and it’s to the benefit really of people with sight loss and people with dementia and people who are experiencing both that we bring those skills together. June, I think we’ve worked on a number of different projects over the years, haven’t we? And put local teams together from both organisations as well – up and down the country.

June: Absolutely, Barbara, I think we’ve worked together for a long time and one of the benefits of working together is that we’re able to reach out to a wider audience and we’re also able to bring together different parts of our organisation that are able to produce really good resources that provide that type of information.

Barbara: That’s right and it’s incredibly important because people with dementia experience sight loss very frequently and it’s not at all uncommon and in fact research would suggest that at the moment we’ve got about 750,000 people in the UK with dementia. And as many as 250,000 of them will be experiencing some degree of sight loss so it’s a really common issue.

June: And as we know, Barbara, the sight loss could be stemming from an eye condition, it could be from a health condition or it could be from the dementia itself. This might be a really good opportunity for you to talk about the impact of a person living with dementia.

Barbara: Dementia I suppose is something that’s best understood as a syndrome because it’s not one thing. It’s a collection of different features that actually arise from a whole range of different brain diseases. And there’s probably at least a hundred different types so you can understand from that that it’s important not to make assumptions because everybody’s experience is different but what makes a condition a type of dementia is that it’ll have some of the features that are in common for example that brain cells die at an abnormally fast rate and that there’s disruption and damage to the connections between the brain cells. That’s the kind of common thread in them all but beyond that in the different types, the pathology, the changes within the brain will be different in different ones. Some of the most common ones that people experience are things like Alzheimer’s disease, vascular dementia, Lewy Body dementia, fronto-temporal dementia, but there’s many, many others. So it’s important that we understand the type of dementia that the person is experiencing and the impact on them as an individual because clearly, while there’s those biological changes that take place in dementia and they take place over time, so there’s continuous changes to think about, it’s happening to an individual who’s already got an established life and life pattern and coping mechanisms and relationships and everything else so their reaction to experiencing the changes that dementia brings is going to be highly individual.

June: And I think, Barbara, there’s lots of similarities between the impact of living with dementia that’s progressive to what it can be like living with sight loss that equally can be progressive – the impact is not just on the individual but it can be on the family and as the sight loss progresses, the person has to adjust to living with the sight loss and again go through the grieving process and everybody has their own unique experience and their own unique journey. So there’s lots of common threads between the impact of living and progression of sight loss as what there can be with the progression of dementia from that point of view. So, Barbara, you talked a wee bit about the impact of living with dementia. Could you tell us a wee bit about from the sensory point of view of living with sight loss and dementia?

Barbara: The majority of people that have dementia, June are older. It’s important to appreciate that not everyone develops dementia in their older years, there’s an important minority that are younger. But the vast majority are older people. And that means that folks are already experiencing changes in their senses just because of the ageing process. So obviously the ageing eye has difficulty with things like visual acuity, common eye conditions like cataracts or macular degeneration, diabetic retinopathy, perhaps people have had a stroke and experienced some visual loss from that so these might be pre-existing conditions and then the dementia itself affects people’s vision very commonly and the sort of experiences people will have will be in relation to contrast sensitivity which gets more difficult, struggling with light levels, depth perception, you know, being able to judge, for example, the speed of oncoming traffic, or the depth as you step off a kerb or where the table is when you’re working to prepare your meal or whatever. And people will also experience a reduced visual field so that, you know, a range of conditions, can make it extremely difficult. And one of the major problems that we experience is that because somebody has a diagnosis like dementia and it’s so complex in itself, it’s got such a wide range of symptoms, it’s very easy for everything to be put down to that and so, you know, a really important aspect is that often, sight loss is missed when someone has a diagnosis of dementia because changes in behaviour, for example, might be put down to the fact that the person has dementia and a real issue with their sight that could receive treatment is overlooked.

June: I think, Barbara, a lot of our resource development has been in addressing that issue, trying to promote access to eye health care, trying to raise awareness that sight loss can often be masked or misdiagnosed and, as you’ve said, can often all be put down to the person having dementia. So it is really important to have access to eye health care early, so that we can have prevention or treatment and just how you were talking earlier Barbara, about how the risk of dementia does increase with age – it’s similar to sight loss – so we’re back to quoting the same old stats: “1 in 5 people over the age of 75 are going to be living with sight loss.”

Barbara: And these are useful comparisons to mention and the other thing I should mention is that, while these general changes in vision that are comment when people have dementia, there are also some specific types of dementia that have, in turn, various very specific vision-related issues and sometimes they’re actually the presenting symptom rather than, you know, what people think most commonly like memory loss etc. but there’s one condition called posterior cortical atrophy – it’s the posterior, the rear part of the brain where the vision centre is located and therefore, people present with issues with their sight, not what with people would commonly think of as symptoms of dementia.

June: And I think, as you’ve said, posterior cortical atrophy tends to affect people who are younger, so it might not necessarily be considered for a dementia diagnosis so again its really, really important that when people are accessing eye health care, that they talk about the difficulties and that they do go back to ensure that they get a correct diagnosis because it’s quite a rare condition, so not every optometrist is going to necessarily automatically think about posterior cortical atrophy when the person presents with these types of problems.

Barbara: That’s right and it’s common for people to tell us, as you say, that getting in diagnosis has in fact been very difficult. Because they’ll go and present with their difficulties with their sight and just consistently be told that their vision is OK –

June: Yup.

Barbara: - but their vision is affected by these visual processing difficulties and they’re distressed so it’s important that that distress is heeded.

June: Definitely.

Marion: Thank you both for all the valuable information that you’ve shared. I’m sure it will 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.

Voiceover: If you found this information useful, you can listen to our other podcasts. We also have further information and support online from our Sight Loss Advice Service at rnib.org.uk/advice. 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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