

## Dementia Awareness Month Panel discussion – transcript

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**Cindy-Lee Goodwin**  
**Department of Human Services**

Hello I'm Cindy Lee Goodwin. Welcome to our Dementia Awareness Month Q&A. Joining us today are Dementia Australia executive director Dr. Kaele Stokes and Department of Human Services Financial Information Service Officer Justin Bott. Dr. Stokes has a wealth of experience in roles that have seen her advocate on key issues for people impacted by dementia and has been working for Dementia Australia for several years. Justin works with the department's financial information service. Every day Justin provides customers with information to help them make informed financial decisions including helping them navigate the services and support that our department provides and helping them prepare for retirement. Earlier this month we did a call out for questions on social media and today we'll be asking Kaele and Justin to answer those questions you've sent in. But before we get to questions, Kaele can I stop by asking you what is dementia and how does it impact us here in Australia?

**Dr Kaele Stokes**  
**Dementia Australia**

Thanks Cindy Lee. So dementia is actually an umbrella term that we use to describe a whole range of illnesses that causes progressive decline in a person's functioning and the way that that impacts a person can impact their memory which is the most commonly thought of symptoms of dementia, but it can also impact the way that they're able to interpret their surroundings. Their visuospatial skills their moods and behaviours and a whole range of other things. So it can have huge impacts on an individual and the people around them. We know that there's about 425, 000 people living with dementia in Australia at the present time. And what a lot of people don't know is that dementia is actually the second leading cause of death in Australia and it's the leading cause of death for women.

**Cindy-Lee Goodwin**  
**Department of Human Services**

I absolutely, didn't know that. That's amazing. We got a lot of questions in, so we'll kick off with those and Justin the first ones definitely for you. What happens to my dad's pension, if my mum goes into aged care?

**Justin Bott**  
**Department of Human Services**  
**Financial Information Service**

Okay, so the rate of a pension for a member of a couple there are two standards if you like are two levels. The first one is just a normal member of a couple which is everybody, but when a person goes into an aged care facility they move into what we call an illness separated rate of pension. The separated right of pension is actually increased to help cover those aged care costs. So just by one or both having to go into an aged care facility, even if in the same room bed beside each other they're still defined as an illness separated and the aged pension will go up as a consequence.

**Cindy-Lee Goodwin**  
**Department of Human Services**

And I guess it must get more complicated if one person's in aged care and perhaps the person still living in the family home decides to downsize to move closer. What happens in those circumstances?

**Justin Bott**  
**Department of Human Services**  
**Financial Information Service**

So that's the big thing about the pension rate. The big thing is what the finances are doing in the background. If I'm a member of a couple and I have enough assets then my partner who is going to care, will be required to pay a one off lump sum called a refundable accommodation deposit. Now they can pay that deposit as a one off or they can pay it as an interest rate, called a daily accommodation payment. But that lump sum is not an asset for Centrelink purposes. So if I have a large amount of assets and I might not have a pension eligibility. If my partner goes into care and I have to pay 300, 400, 500, 000 dollars for that to happen the consequence could also be that I've actually created an age pension eligibility when I didn't have one beforehand because the refundable accommodation deposit isn't assessable as it fits into it. Now the other also applies, if I don't have a lot of assets but then I do something like sell the family home to downsize and move somewhere else. What I've done is, I've released a new lot of assets or created money that wasn't there beforehand and that money will affect the right pension that I'm getting and will also potentially affect the aged care fees that I'm going to be going through with. So the basic message I'd be saying to anybody that's looking at selling and downsizing and moving to the nursing home is that it could have an unintended consequence of significantly reducing my pension and also increasing my aged care fees. All of those people should really make an appointment with the financial information service. The 13 23 00 number is a number that you need to call to do that. They can talk the implications through before they actually do the change, so they know what's exactly going to happen.

**Cindy-Lee Goodwin**  
**Department of Human Services**

It's obviously very complex but what I'm getting from you there is that if the money that's used from downsizing is, you know, refundable deposit it's not assessable but if it's sitting in the bank then it could really change a situation.

**Justin Bott**  
**Department of Human Services**  
**Financial Information Service**

That's right. If I didn't have to use that money to pay and it's now extra, I didn't have it before, I've got it now. Everything my whole financial circumstances are going to change and I need to take that into account and working out where we go from here.

**Cindy-Lee Goodwin**  
**Department of Human Services**

Kaele, is this something you see a lot of?

**Dr Kaele Stokes**  
**Dementia Australia**

We do, and the added, it's obviously a very complicated process to go through. And the added complication for people impacted by dementia is that they're normally going through quite personal traumatic experiences at the time and often the move into residential aged care is pre-empted by a health issue, or a sudden deterioration in the state of their cognitive function. And so, there's that additional stress of really having to come to terms with those changes and then look at the practical implications of what that means.

**Cindy-Lee Goodwin**  
**Department of Human Services**

Kaele, one for you, talking about this as a family can be tricky. What's the best way to discuss dementia and the changes they may see with kids?

**Dr Kaele Stokes**  
**Dementia Australia**

Look does not there's not one way. Obviously, it depends on the individuals involved in the type of family that you have. But one of the most important things really is to have the conversation. A lot of people particularly those affected by dementia and families and carers come back and tell us that that we're really fearful of having that conversation with their friends and families. But there was a sense of relief when they did and it really combated the kind of fear that people had in having that conversation where it is in relation to younger families the way they might be children or grandchildren. There's a whole range of different ways that you can bring the topic up so particularly for younger children talking to them by using a book as a prompt to have those discussions can be really effective. It's also for older children talking about the sorts of impacts that it's had on them. Their observations of the changes that may have occurred in the person diagnosed with dementia can be really useful just to start that conversation and unpack what dementia actually is and what it means as far as as far as having that particular disease. Most people with dementia say that they'd like to be front and centre of that conversation and talk about what it means for them as well. So you know being really honest and transparent around the impact that it does have on a family and having those conversations early is so important because it means that all aspects can be discussed all of the members of the family and friendship group including the person living with dementia themselves can be involved in that discussion.

**Cindy-Lee Goodwin**  
**Department of Human Services**

So what kind of supports available for all people living with dementia, their families and loved ones?

**Dr Kaele Stokes**  
**Dementia Australia**

Well as Justin said, one of the first ports of call is the My Aged Care website and there's also a range of other resources available to people living with dementia and their families and carers through, the integrated Carers Support Network and also through organizations like Dementia Australia that have a National Dementia Helpline, which is 1800 100 500 and we also have a range of resources and information available on our website at [www.dementia.org.au](http://www.dementia.org.au)

**Cindy-Lee Goodwin**  
**Department of Human Services**

Kaele the next question touches on the fact that dementia is often associated with older people. What age do people usually get diagnosed from?

**Dr Kaele Stokes**  
**Dementia Australia**

So diagnosis generally tends to happen in individuals probably in the late 60s to mid 70s as the majority of people receiving a diagnosis, but it can occur much earlier or much later. Typically we see that there are actually people with younger onset dementia, that is, dementia before the age of 65. And these individuals can develop dementia, or at least start to show symptoms of dementia in their 30s and 40s and 50s. So it can affect all age groups. It really is a very common misconception that dementia is a natural part of ageing and that it's an older person's disease.

**Cindy-Lee Goodwin**  
**Department of Human Services**

So what are some of the challenges and support available for younger people being diagnosed?

**Dr Kaele Stokes**  
**Dementia Australia**

For younger people, it's often got a range of specific challenges, if you think about you know, where you're at in your life as a mid 40s, or mid 50s person, it may be that you've still got a fulltime job, you may have young children, a mortgage. All those sorts of things. So a diagnosis of dementia at that stage, can raise particular challenges for that age group that perhaps aren't in place for people who are older. So there's a range of, increasing range, of services available for people with younger onset dementia, particularly in terms of age appropriate services and we also have Dementia Australia a younger onset dementia case worker program which is rolled out nationally across the country and provides that individualised support for people that are going through dementia at that age.

**Cindy-Lee Goodwin**  
**Department of Human Services**

My mother in law has been in Australia for 50 years. There's a family history of dementia and we're starting to notice little things. The main thing, is that she's been speaking less and less in English. Is this something that we see a lot of?

**Dr Kaele Stokes**  
**Dementia Australia**

Absolutely. It is a really common thing particularly for people who, English is the second language and as the dementia progresses, they resort return back to their native tongue. So we do say this a lot and it can be quite challenging for the person impacted by dementia and also for the people around them, to be able to communicate because we know that communication is so important, in being able to determine what people's wishes are their comfort levels. You know, whether they're happy in their surroundings, how they're going emotionally and psychologically, and in fact communication is more challenging because, you don't have common language to speak it in, it can be really it can be really complicated. So it obviously depends on the way that the dementia

progresses in a particular individual. So it may be that in the earliest stages, they can still comprehend English, but they'll answer in their native tongue. Later on it may be that they can only speak in their native tongue, and that can be quite complicated when, we have, instances where they may speak a specific dialect of language, rather than you know, the kind of more mainstream language. So there's a whole range of resources, and services available in that, so the Translating and Interpreting Service run through the Australian government is one point of call for getting support in those sorts of areas and also tapping into local community languages seeing whether there's, you know local speakers that can come and converse with the person, and there's a whole range of other prompts and resources around perhaps using, signage, or pictures to communicate particular needs that can also be explored. But yeah, it's certainly a big issue.

**Cindy-Lee Goodwin**  
**Department of Human Services**

Justin, what about from a Department of Human Services perspective, what extra support do we have that we can help people with?

**Justin Bott**  
**Department of Human Services**  
**Financial Information Service**

From the department we have access to sign telephone interpreter services or even people coming into your office to help interpret as well, so, that from that perspective it's not an issue. But often the person with dementia, will not be the person who's coming into the office. So from that perspective, what we need to make sure is that their representative is actually authorised to deal with, Centrelink, and with the department and that's through the nominee arrangements that we have in place. So from that, that's generally how we would deal with it. Just two of the points on that. Sometimes you're lucky, certainly from an aged care perspective sometimes you're lucky that you actually go to a facility that is culturally based and you'll be able to find, that there are people that will be able to speak your language in an aged care facility, but that's more often a luxury, than a standard. The other side to remember is that there is a lot of resources that the federal government has put in to allow people, to still stay at their home and have a lot of care provided in their home called, home based care. So, it might well be that, certainly the earliest stages as this is coming through all the services that then they can be provided in their home. The access to that again, is the aged care website is supposed to go to find out about those sorts of things too.

**Cindy-Lee Goodwin**  
**Department of Human Services**

Great, thank you Justin. We've had two questions come in that relate to power of attorney arrangements, Kaele I think the first one sits with you. At what point should families look at power of attorney arrangements for someone living with dementia?

**Dr Kaele Stokes**  
**Dementia Australia**

As early as possible, would be our answer. So, particularly for people with a new diagnosis. It's obviously quite confronting to work your way through what the implications are for a diagnosis of dementia. But having conversations around powers of attorney and advance care planning and those sorts of things are really, really important. Particularly at that early stage when the person with dementia is able to participate in the conversation as well, and express their wishes, and needs

in terms of power of attorney arrangements, advance care planning. You know, it's really important for that to happen earlier rather than later.

**Cindy-Lee Goodwin**  
**Department of Human Services**

Justin, one for you. Do you have to set up a nominee arrangement if you already have a power of attorney in place?

**Justin Bott**  
**Department of Human Services**  
**Financial Information Service**

I just want to add something on the power of attorney, this is not a dementia specific need. Everybody should have a power of attorney. It's a document that you create when you don't need it, for a time that you do. And the thing about a power of attorney, is if the person that wants to give it, is not seen as being capable of understanding what they're doing, then the power of attorney can't be given. And that makes it much more complicated. So this is certainly something that people want to be doing before, there's even any question, at what point with dementia? I should have before dementia, I should have before there's even a question of dementia. People who have mortgages should have power of attorney as well as the other two. So it's part of a three. It's the power of attorney. There's also the enduring guardian and then there's even care directives. The enduring guardian gives a person the right to make more social decisions for a person, with the power of attorney is only focused on the finances. So it's not enough to just have power of attorney you need to have all three if you want to properly care for somebody else. Now from a Sunni perspective we will recognize power of attorney but the system is designed to work around what we call the nominee arrangement and a nominee arrangement is through a similar form not requiring any power of attorney or a Department of Human Services Forum. You authorise a third party and declared to be one person to act as if they were you. And they are able to call the department to do up changes on your record. But more importantly nowadays a nominee form also gives that person the ability to use myGov and do it online. So the nominee actually allows the person who's been given that authority to go to their myGov account and do updates on your record through their myGov account.

We can't do that with power of attorney. So you're getting that nominee arrangement implies we'll just absolutely make your dealings. Your ability to make updates with since they're much better off.

**Cindy-Lee Goodwin**  
**Department of Human Services**

The next one's for you. Um. For people living with dementia their family and loved ones. The thought of what the future holds must cause, a lot of concern and the next question is exactly that. If someone has dementia, and its effect if, someone has seen dementia if their mom or dad, does this mean that they'll probably end up the same way?

**Dr Kaele Stokes**  
**Dementia Australia**

The short answer is No. Because dementia is very common even if you have one or more family members diagnosed with dementia it does not mean that you will be diagnosed yourself. I think if we, if we, think about dementia we have a range of modifiable and non-modifiable risk factors. Non modifiable risk factors are things like your age. So you are, so your risk for developing dementia

increases as you age, particularly after the age of 65. But it doesn't guarantee that you'll receive a diagnosis of dementia. If you have dementia in your family or you have a particular genetic link, then it may increase your risk of developing dementia, but it does not guarantee it. In fact, familial dementia which, familial Alzheimer's Disease specifically really only accounts for 1 to 2 percent of all cases of Alzheimer's disease. So it's a very small proportion that have that very strong genetic link to receiving a diagnosis. And, and, often in those particular instances diagnoses are received much earlier so that you know, they tend to develop symptoms in their 30s and 40s. But it's a very small proportion, so it is not a guarantee that because you have dementia in your family that you, that you, will have dementia yourself.

**Cindy-Lee Goodwin**  
**Department of Human Services**

You touched on modifiable risk factors. What are they and what can we do?

**Dr Kaele Stokes**  
**Dementia Australia**

So it tends to be what's good for your heart is also good for your brain. So, we tend to think about modifiable risk factors as things that we can do to positively impact our lives and that can be something as simple as having, a healthy diet. Modifying our alcohol intake, having plenty of exercise, remaining socially engaged, that's a really important one that can have significant impacts on people's wellbeing regardless of whether they have dementia or not. Keeping your brain active and learning new things, can really help. So, and being very mindful of decreasing your risk of developing heart disease, diabetes, a lot of the risk factors for those sorts of diseases are the same as they are for dementia. So paying attention to those sorts of things can actually make a positive difference and reduce our modifiable risk factors.

**Cindy-Lee Goodwin**  
**Department of Human Services**

Now before we wrap up, one final question for both of you. What advice would you give to people living with dementia, their friends' family and carers when it comes to getting set out for the future?

**Justin Bott**  
**Department of Human Services**  
**Financial Information Service**

I was, oh you first. (Laughing)

**Dr Kaele Stokes**  
**Dementia Australia**

Look I think the first thing is to not be frightened of seeking a diagnosis if you have concerns about your cognitive function. A lot of people living with dementia in their families talk about the relief that they feel when they finally do get a diagnosis and know what they're dealing with. So being able to actually practically unpack what a diagnosis of dementia means and the sorts of steps that a person can take, the sorts of services that they can access. You know having those having the ability to go through that process is actually really important. So I think that would be one of the first things and then look seeking advice and support where it's available, going to the My Aged Care website, going to the National Dementia Helpline and calling on 1800 100 500, is, really important it can be

just as simple as receiving some information on, you know, what services are out there, or it can be tapping into a more intense counselling and support services. You know, you know, there are options certainly.

**Justin Bott**  
**Department of Human Services**  
**Financial Information Service**

From the financial information service perspective, are great for, planning for retirement, planning for the funding, coming and making an appointment with the financial information service officer is going to be a great way to help you, to give you some understanding of what's coming up. But the biggest concern that I have often in these circumstances is not actually the person with dementia but the carer, of the person with dementia. They're the ones that seem to be missing out on the services and support they could, because they don't have the time, or they think somehow that it's, they're not worthy because they're looking after this person, is their whole purpose. So there are a range of payments for carers that are out there but also a range of support services as well. So we will often see the person with dementia cared for, or the person in the nursing home cared for but the partner using all of their money to fund their husband or wife in the nursing home and living off baked beans and water, because they've got no money to look after themselves. Our purpose is to try make sure everybody's taken care of that, if I look after myself, I've therefore got the power to then look after another person. So it's the carer that we want to make sure is reached as well and that level of information that they need too.

**Dr Kaele Stokes**  
**Dementia Australia**

That is really important, I mean, we know that more than 70 per cent of people with a diagnosis of dementia live in the community with informal care. So, so, those sorts of care supports are really important.

**Cindy-Lee Goodwin**  
**Department of Human Services**

That's an excellent point to finish on. Justin, Kaele, thank you for your time. That's all from us today. I hope you've enjoyed our Q&A event for Dementia Awareness Month. Thanks to everyone who sent in questions and thanks again to our panel. Thanks for watching. Bye for now.

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