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Listening to the lived experience of people who have dementia

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Dementia Tas

Dementia is not a specific disease; rather, it is a group of conditions characterised by the gradual impairment of brain function. It commonly affects people's ability to think, remember and reason, as well as affecting their personality and impairing other core brain functions such as language and movement. The condition is degenerative and irreversible (Australian Institute of Health & Welfare <https://www.aihw.gov.au/reports-statistics/health-conditions-disability-deaths/dementia/overview>)

The most prolific type of dementia is Alzheimer's Dementia, with 50-70% of people being diagnosed with this condition. The other more common types are Vascular Dementia which affects around 20-30% of people, Lewy Body Dementia affecting 16-20%, Frontal Lobe Dementia, alcohol related dementia as well as many other types of dementia. In fact, there are more than one hundred different conditions that may be diagnosed as dementia.

Dementia affects everyone in a different way. It can depend on what type of dementia is present, as well as life experiences of the person, personality and other health conditions. The amount of brain reserve a person has can also determine how the dementia progresses. All dementia is progressive and it has recently been acknowledged as a cause of death. It is the second leading cause of death for all Australians, and the leading cause of death for females. <http://abs.gov.au/ausstats/>

Dementia can change many things in a person's life, however it does not always take away their capacity to make decisions, especially in the earlier stages of the condition. By supporting people with dementia to live a life that makes sense to them we can reduce negative responses and actions and assist them with their decision making.

It is vital to engage with the person as early as possible in the dementia journey to ensure that their wants, needs and wishes are understood and recorded for future access. The more we understand who the person is and acknowledging how they want to live their life are the first steps in becoming a good "voice" of someone with dementia. It is not what we think they need in their life – it is what they want! Recognition, inclusion and empowerment for people with dementia will ensure that their remaining life is lived with purpose, dignity and respect.

Person-centred care, based on the philosophy of Tom Kitwood, focuses on enhancing wellbeing for each person. It also looks at the person's perspective, taking into account their personality, life experiences and past history. The way people have coped or managed their life in the past can give

us a very good insight into how they might want to live their life into the future and can also assist us to help them to make decisions. Key words are knowing the person's history in order to assist them to make the decisions rather than making decisions for them based on how we feel or think.

(Kitwood, Thomas Marris, and T. M. Kitwood. *Dementia reconsidered: The person comes first*. Vol. 20. Buckingham: Open university press, 1997)

These personal enhancers are what we need to be focussing on when we are supporting a person who has dementia. By understanding and adopting this philosophy we can show genuine care and concern for the person while providing them with a safe, secure and comfortable environment. It is vital for people with dementia to feel they are in a relaxed atmosphere without needing to make too many decisions about day to day life, but still being engaged and treated as a valued member of society. If we are being truly supportive for the person with dementia we need to have an attitude of acceptance and hold the person in a positive regard while recognising and celebrating the skills and achievements of the person. Accepting each person with dementia as a unique individual and empowering them to live life with quality is all about putting our own needs and wants to the side and concentrating totally on the person we are supporting. Understanding body language is a really good way of determining the mood state of a person with dementia.

Personal detractors should be totally avoided when giving support to a person with dementia. These interactions are rarely created with malicious intent but can sometimes become part of the culture of support. The impact of personal detractors for the person with dementia can only be damaging both to the person's quality of life and wellbeing. The overuse of patronising phrases and words can rob a person of their identity and make them feel they are being treated like a child. It is very important not to focus on the negative, or what the person cannot do, but instead focus on the positive and what the person can do and celebrate that. When we are being supportive of a person with dementia we should always include them in the conversation and decision making, and not talk over them or about them as if they were not there. Even those of us who do not live with dementia dislike being spoken about as if we do not exist – it is infuriating for us and causes feelings of intense frustration – and it is exactly the same for people who have dementia.

Listening to understand is a great skill that supportive people should be aware of and work to develop. Often we just listen to hear what is being said, but when you are listening to a person with dementia what we hear can have several different meanings. A person not wanting to do something might mean that they don't remember how to go about it anymore, or just that they don't want to do it! Someone saying they are not hungry might mean that they cannot manage to eat independently, or that their mouth is sore, or they might even feel unwell. How we interpret what we hear can make a big difference in how we support a person with dementia. Understanding the person and knowing their past history can be very helpful in making sense of what they are saying. And coupling our listening skills with the understanding of body language will assist even more with "getting it right". Of course we must also understand that we cannot get it right all of the time. It is important to know when to go away and come back later if the interaction is not going well. There is wisdom in knowing when to stop and come back at a later time or maybe try a different approach. We need to listen to understand – especially in these instances.

It is not about us or what we think, or want the person to do. It is all about the person we are supporting. Who are they? Where have they come from? How have they lived their life until this time? People who have been brought up in the country are very different to people who have lived in the city all their lives. They will have different ethics, values and traditions that they have relied on for all their life. All this past history will make a big difference to the decisions the person might

make, and should become the basis of how we provide support to the person. It is all about recognition, inclusion and empowerment. “Make decisions with me, not about me”...

So take time to know the person with dementia. It will be time well spent. Ask the right questions and encourage reminiscing and storytelling.

To form an understanding of what the person with dementia wants, or what they are trying to do or say is pivotal in delivering positive support. Always keep in mind to “work with” rather than “do to”! What is it that they might need? Could they be hungry or thirsty? Might they be looking for something or someone familiar? What is meaningful and important to them right now? We must always remember to be in the present when we are supporting someone with dementia – it is about what is going on right now! How can we provide them with something positive and engaging? Again we need to have in mind what we know about the person, their past history, habits and routines.

A supportive person should always respond in a positive way by never arguing or contradicting the person with dementia. The interaction should not become a battle of wills. There should be no desire to win from the person providing support. Listen to understand, use validation strategies to explore what it is that the person with dementia needs. Ask questions that begin with who, what, when and how – never use why. Always allow the person to feel in control, avoid being bossy or domineering – this always results in a negative response. Always engage and interact with the person's pride firmly at the forefront of your mind when offering support. Pride is a strong feeling – make sure theirs remains intact!

If you are travelling with someone who has dementia or taking them out of their familiar environment, then these strategies are worth keeping in mind to ensure a pleasant experience for everyone. Busy airports, shopping centres and other places where there is elevated noise levels and crowds of people can be very confusing for people who have dementia. Often they cannot filter out different noises like we are able to, and they get everything at once and can easily be overwhelmed. This extra stimulation can elevate mood state and confusion for the person and requires extreme patience and understanding from the supporter. It is also a good idea to provide the person with an ID card that contains their name and photo and your name and phone number. It is not necessary to advertise the fact that the person has dementia with a name tag on their clothing – unless everyone else around them also has name tags! It is also important to carry some photos of the person with dementia, so if they do go missing you have a photo that you can give to security staff or others who might be helping you locate the person. You also need to remember what they are wearing on the day so you can add that to your description.

When travelling over long distances in a car ensure that the door lock is activated so the person cannot open the door themselves, and factor in frequent stops into your travel time. Always remind the person where you are going throughout the trip using friendly conversational strategies. Never ask them if they remember where they are going – we should never try and test a person's memory, but instead give them plenty of clues in the conversation so they can know.

Always be aware that a person with dementia will experience short term memory loss, and our questions re their memory capacity can be demeaning and upsetting for them.

These supportive and positive strategies are used by staff at Glenview Community Services within Merton House which is a safe unit housing people who are living with dementia. The strategies will also be adopted by workers who will be employed to work within Korongee Village, due to be opened in early 2020. This village will consist of twelve houses accommodating eight people who

have dementia in each of the houses. The village will also have a supermarket, café, and health centre all utilised to enhance the life of the person with dementia. We hope that this positive type of care delivery will lead the way in empowering people with dementia to continue to lead productive lives contributing to society and those around them and will eventually remove the stigma of dementia.

Korongee is an innovative creation being delivered by Glenview Community Services with the assistance of support from HESTA Super fund and Social Ventures Australia. Korongee will be a fully functioning village built in Glenorchy for people with dementia to live safely while they access services enclosed within the village environment. There will be a café, health clinic, supermarket as well as open community space and barbeque area. There will be twelve houses built in a cul-de-sac design, each housing eight people who have dementia. People will share a unit with like-minded people who have similar interests and lifestyles, where they can participate in everyday life decisions which are presently not always available to those in traditional residential based dementia care. Families would also be very welcome to make use of the facilities and would certainly be encouraged to share in the day-to-day activities of each house or the village.

Korongee Village is expected to be completed by early 2020 and enquiries can be made through Glenview Community Services.

Something to remember when you are supporting a person with dementia...

Make decisions with me, not about me.

Presenter

Ros Calvert works at Dementia Tasmania. For the last thirty years Ros has worked closely with people who have dementia, as well as their friends, family and carers. Through training and consultation Ros has provided practical and supportive strategies to enable people with dementia to live a life of quality and for their voice to be heard.