8

Personalising Care with Older People Who Have Cognitive Changes or Dementia

Kirsten James and Trisha Dunning

> *I am daily learning to be the reluctant guardian of your memories. There was light in those eyes; I miss that.*
>
> *(Ratliff R)*

Key Points

- Impaired cognition is complex; it can be temporary, degenerative and static and/or fluctuate. Considered, collateral, individualised assessments, accurate diagnosis and regular reviews in consultation with the person and their carers are vital to help to determine appropriate personalised management and care.
- An older person's life story, including past social and medical history are as important as their current circumstances. They provide context for their plan of care and personalised treatment. Capturing this information can help carers to focus on the person's strengths and support their wishes.
- Impaired cognition does not replace an individual's right to self-determination or prevent them from expressing their preferences and participating in care decisions. Situations can be fraught as cognition declines or is acutely compromised. Importantly, the contribution carers make and the significant care work professional and family carers undertake should never be taken for granted.
- Proactive engagement with older people and their carers in the early stages of cognitive decline as well as during 'windows of clarity and lucidity' are the 'right times' to plan, document and share information. The principles of dignity

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and respect can be used to guide and support older people, their carers and health professionals to make choices, promote independence and minimise risk.
- Care needs to be goal-directed, holistic, personalised, realistic, and adaptable to accommodate changing circumstances. Sometimes carers have to change their expectations. Lateral thinking and creative, practical strategies can help address problems and decide effective outcomes.

8.1 Introduction

Dementia is a global challenge associated with longevity and affects 47 million people globally, most are age 65 and older (Lancet Commission 2017). Risk factors for dementia include the following risk factors, some of which could be reduced by a healthy lifestyle and social connections:

- Genetic predisposition
- Social isolation
- Hearing loss
- Inadequate exercise
- Inappropriate diet
- Smoking
- Depression and other mental health disorders
- Diabetes, which is associated with all types of dementia including vascular, Alzheimer's and Lewy bodies.
- Hypertension
- Mild cognitive impairment (Lancet Commission 2017).

All major mental health disorders are associated with effects on cognitive performance (Geerlings et al. 2000; Rock et al. 2013) and people presenting to a memory or dementia clinic have a 40–50% chance of developing a mental health condition (Fisher 2017). Mental health disorders and dementia affect executive functions including memory, processing speed, language and alertness. Therefore, screening for mental health conditions and asking about drug and alcohol use is important. Cognitive enrichment programmes that support positive attitudes and social engagement influence health behaviours (Hertzog et al. 2009) and may be important risk minimise strategies.

Age is the greatest risk factor for cognitive impairment, and as the Baby Boomer population, those born between post World War 2 and 1964, reach age 65, the number of people living with dementia is expected to jump dramatically (Alzheimer's Disease International 2013). The United Nations (UN) (2015) indicated the number of older people tripled in the last 50 years and will triple again over the next 50 years. Although developed regions have relatively high proportions of older people, there is a faster growth rate of older people in less developed regions (UN 2015; World Health Organisation (WHO 2015).

This situation will create overwhelming demands on global communities and health systems. An estimated >20% of the global population will be older than 65 by 2050 and there will be fewer people to take care of them (Gill 2015, UN 2015). In addition, there is a corresponding decline in the number of specialists training in geriatric medicine, which will create other care challenges for health professionals (HP), service providers and society (Girdwain 2011; RACP and ANZSGM 2012; Hafner 2016) and may affect safety and the quality of care.

Cognitive changes can occur during hypoglycaemia and hyperglycaemia or be a long-term complication of diabetes and other factors. Many health professionals, family carers and people with diabetes incorrectly believe people cannot be engaged in care decisions if they are cognitively impaired. This chapter will encompass “the right time and right way” to discuss care with older people and cognitive impairment. The role of lateral problem-solving and other creative ways to care will be considered.

8.2 Overview of Changes in the Brain as People Get Older

Changes that occur in the brain are part of general ‘slowing down’. Fear of dementia is a major concern for most older people and their families. Biologically, brain ageing begins early, even from the twenties. There is a small but continuous loss of white matter, which means the number of myelinated axons that carry fast information around the brain are decreasing. The brain is adept at compensating for changes and build new connections.

Cellular research shows brain plasticity continues in the eighties and older people generally become more knowledgeable and practiced at doing things; their vocabulary increases and they can generally problem-solve except under time pressure.

- Some parts of the brain are particularly vulnerable to the effects of ageing, e.g. the limbic system and the prefrontal cortex.
- Older people may become a little less inhibited and take less time to think before making decisions. Encouraging them to reflect on important issues might avoid inappropriate decisions.
- Some older people become ‘set in their ways’.
- Memory lapses increase in frequency with older age. However, some mental abilities improve with age. Some people are resilient to the effects of age. They often find it difficult to remember things that have no specific relevance to them. Cues to memory, giving people more time to think and do things, and avoiding distractions help.
- A healthy diet, regular exercise, adequate sleep and continuing to use the brain are important protective activities. They are also key diabetes management strategies and help maintain cardiovascular health.
- Cardiovascular health is essential to carry oxygen and nutrient to the brain and remove waste products and toxins.
- Cognitive functions most commonly affected by age are:
  - thinking speed—ability to make quick decisions, process directions, mental arithmetic

- executive functions such as planning ahead, using complex strategies and being flexible such as change of plans
- memory, especially recalling people's names and word finding. (The Curious Minds Series, The Twilight Years in *How it Works: Book of the Brain* future publishing 116–125).

8.3 Diabetes and Dementia

The global prevalence of diabetes is also increasing. Diabetes affects cognition in a number of ways (see Chap. 1). More than 46.8 million people are living with dementia in 2017 and the number is estimated to reach 131.5 million by 2050 (Alzheimer's Disease International (ADI) 2015). Pre-diabetes and diabetes are associated with cognitive impairment, accelerated cognitive decline and contribute to dementia in older adults (Velayudhan et al. 2009, McCrimmon et al. 2012, Biessels et al. 2014; Marseglia et al. 2016). People with diabetes have greater decline in cognitive function and are 1.4-2 times more likely to develop dementia than people without diabetes (Puttanna et al. 2017).

Glycaemic control is associated with declining cognitive function (DCCT/EDIC 2014). The Accord-Mind trial showed that there is a 0.14 drop in the MMSE score for every 1% rise in HbA1c. Glucose variability might also play a role (Chap. 1). Hypoglycaemia also increases the risk of short- and long-term cognitive impairment and can occur at any HbA1c level (Lipska et al. 2013). The symptoms of hypoglycaemia change with duration of diabetes and hypoglycaemia might not be recognised or treated. In the short term important cognitive functions such as problem-solving and decision-making are compromised.

Diabetes and dementia share common lifestyle risk factors. Both are associated with disabling complications, which present considerable management challenges for the person with dementia and diabetes and for their carers and HPs. These challenges include difficulty recognising symptoms of undiagnosed diabetes, hyper- and hypoglycaemia and complications, problem-solving and being able to follow and/or remember lifestyle and medical advice. These factors place the person with diabetes and cognitive impairment at higher risk of under- or overtreatment, adverse events, hospital admission and mortality (McCrimmon et al. 2012; Dunning et al. 2014; Hill 2015).

A number of metabolic, vascular, endocrine and central nervous system factors contribute to the development of cognitive dysfunction in diabetes. For example, chronic or acute hyper- or hypoglycaemia, micro- and macrovascular disease, and depression (McCrimmon et al. 2012). Evidence shows hypertension, obesity and diabetes all impair cognition (The Lancet Commission on Dementia Prevention, Intervention, and Care 2017). However, sensory changes such as sight and hearing can also contribute to disorientation and confusion. It is important that these sensory changes are considered and managed and the person has their glasses and hearing aids checked and maintained, and especially used during care encounters.

Therefore it is important to encourage early diagnosis of both conditions by considering the possibility at every consultation and undertaking targeted screening when indicated. Early diagnosis of both diseases enable baseline and parameters to be collected to guide treatment plans, timely access to support services, manage complications to reduce the associated risk and as a basis for ongoing monitoring (TREND 2013).

Retinal sensitivity is related to cognitive status and the MRI, and 18 FDG-PET parameters related to brain neurodegeneration (Ciudin et al. 2017). Thus, retinal microperimetry may be a new non-invasive way to identify people with diabetes at risk of dementia (Ciudin et al. 2017).

Cognitive impairment can occur in people with T1DM and T2DM and affect motor and mental processing speed, executive functioning and attention. A primary distinguishing feature between T1DM and T2DM is that people with T2DM often demonstrate learning and memory deficits, but these deficits are seen rarely in T1DM. As indicated, diabetes-related effects on cognition can be transient or permanent. Transient changes can be due to high or low blood glucose (McCrimmon et al. 2012).

With more people living longer there will be larger numbers of people experiencing declines in physical and mental capacity who may need care for day-to-day activities…there is a pressing need to develop comprehensive community-based approaches to prevent declines in capacity and to provide support for family caregivers (WHO, ICOP Guidelines 2016).

8.4 Considerations When Deciding Diabetes Management for a Person with Dementia

It is essential to develop practical, flexible care and education plans that individuals and their carers can adapt to suit their changing needs. Planning includes discussing and documenting Advanced Care Directives when the person has capacity to understand the implications of their decisions and make informed decisions. The person's blood glucose at the time, environment in which such discussions occur, the way the information is presented and the time allowed affect the individual's ability to participate in decision-making. It is important not to create cognitive overload.

Key management interventions include:

- Managing metabolic risks: hypertension and hyperglycaemia.
- Providing a rich environment that includes sensory and cognitive stimulation as well as social connections.
- Healthy diet, activity and sleep.
- Using technology to make early diagnosis and keep the individual safe, e.g. wearable sensors, assistive technology and safety devices (see Chap. 9).
- Using reminiscence-based communication, which encompasses:
  - introducing themselves
  - explaining what is happening

- doing one thing at a time and using a step-by-step approach
- avoiding negative language and verbal communication
- allowing the person time to respond
- help them find words

8.5 Impaired Cognition: A Complex Phenomenon

Cognition refers to the mental process involved in knowing, learning and understanding things (Collins 2011). Processes such as thinking, remembering, judging and problem-solving involve high level brain functioning such as imagination, perception, planning and problem-solving. If one or more of these processes are affected cognition can be impaired, depending on the underlying cause. Cognitive impairment can also manifest as acute and temporary, chronic and degenerative, fluctuating and unpredictable. It does not necessarily present as a linear, predictable occurrence but can sometimes seem random and unexpected. In some instances, bystanders may not understand that a person's behaviour change could be due to their medical condition. Consequently appropriate treatment may be delayed or not provided, making the situation worse.

The son had arranged for his older mother to be admitted to an aged care home because she had 'cognitive impairment.'

Aunty Joan, Doc Martin's aunt and the lady's long-time friend visited her every morning to make her a cup of tea. She has cellulitis of one leg, which affected her mobility.

Doc Martin assessed the lady's cognition for orientation to time and place at Aunty Joan's request because the lady did not want to go, and, in Aunty Joan's opinion she was 'not demented.'

She stayed at home. During a subsequent visit, later in the day, the lady was disoriented and refusing to drink because she did not want to be incontinent. She had been limiting her fluid to her morning cup of tea because she could not get to the toilet and was very concerned about 'wetting herself.'

Dehydration was the underlying cause of her confusion/cognitive changes. This anecdote shows there can be physiological causes of or contributors to impaired cognition. These include:

- Delirium, which can be caused by acute infection, severe pain, hyper- and hypoglycaemia, gastrointestinal disturbances, liver failure and medication side effects.
- Intellectual disability, mental health issues including depression or psychosis, dementia, acquired brain injury (stroke, head injury), alcohol and drug abuse.

Multi-disciplinary teams working together to support the individual and communicate through the primary care provider, often a GP, and supported by a designated personal carer, can make a big difference for the individual with diabetes and cognitive impairment. The author's personal experience suggests some allied health staff are disinclined to report changes in a person's behaviour, yet, with the person or their legal representative's permission, sharing their concerns can be very helpful to alert the GP and to trigger further assessments and earlier access to treatments.

There is some debate about the best screening tools to use to assess cognitive impairment and dementia. In UK, the Mini Cog is used because it is a simple, quick test with 83% accuracy that can indicate whether a person has normal or abnormal cognition (Sinclair et al. 2013). Folstein's Mini-Mental State Examination (MMSE) is widely used to screen for dementia screening. However, it has limitations for people from culturally and linguistically diverse backgrounds and does not assess frontal lobe function, which is involved with executive functions such as problem-solving, impulse control, understanding consequences and socially appropriate behaviour.

The Rowland Universal Dementia Assessment Scale (RUDAS) is increasingly used as an alternative to the MMSE because it effectively discerns deficits and is not affected by culture, language or gender. RUDAS also has high predictive accuracy in a broad population sample for a range of cognitive functions.

The Montreal Cognitive Assessment (MoCA) is also a rapid screening instrument and is useful to detect mild cognitive dysfunction. It assesses multiple cognitive domains and takes approximately 10 min. Regardless of what cognitive screening tool is used it is important that a specialist undertakes a formal comprehensive assessment, for example, in a specialist memory service. The assessment should include a full dementia screen including thyroid function test, serum vitamin B12 and brain scan and electroencephalogram (NICE 2010; TREND UK 2013). Repeated, periodical screening is useful to monitor improvement/decline and to ensure the care plan continues to suit the individual's needs, preferences and goals and consider family carers needs and health.

8.6 Understanding the Impact of Dementia

Diagnosing dementia is a start, but HPs, the individual and family all need to understand the differing impact on all concerned. Ideally, a specialist such as a Neuropsychologist, Geriatrician or Old Age Psychiatrist is consulted to refine the diagnosis, analyse the results of tests and investigations and discuss how to identify and use the individual's strengths to conserve cognitive function, mental and physical health and involve them where possible. For example, a person's memory is not always affected. When memory is, it can be affected in different ways depending on the part/s of the brain involved, the underlying cause of the cognitive impairment, and whether the dementia is in an early or advanced stage.

Understanding the impact of dementia on the person's cognition can help them, their families, friends and other carers find ways to accommodate the changes and select appropriate memory aids and cues to reduce stress demands on all involved.

With appropriate and personalised modifications and visual supports, people with dementia can participate in lifelong interests and hobbies, maintain personal identities and roles in the community, and maintain a quality of life that is noticed and valued by others (Bourgeois et al. 2005).

Examples include:

- Engaging in meaningful, pleasurable and personalised activity programmes that may reconnect the person to skills and experiences from their past work or home life, hobbies and interests.
- Modifying the environment, including the reduction of clutter and ambient noise, ensuring adequate lighting, home-like/familiar furniture and rooms and providing simple, legible instructions as way-finding and instructional cues (The Lancet Commission 2017).
- 'Taking it slow'

This is MY Story: Please do not define me by my illness!

> *Everybody has a story. When we don't take the time to know someone's story or worse, create our own version of it, we lose the chance to understand what they need which is the first step to empathy.* (Acuff 2017)

The traditional medical model of health assessment emphasises the medical history and pays less consideration to the importance of the person's life story. The importance of people's stories, how to elicit them, understand them and use them to plan care with the individual and their families is discussed in Chap. 3. Stories could have another significant role for people with dementia by helping emphasise the individual's personhood and conserve their dignity. They also help HPs have a conversation with an individual and conserve their life history for their families.

Older people are often judged on the basis of their physical appearance. For example, others might consider a thin older person as fragile and vulnerable and miss the frailty in an overweight person. Such judgements arise from ignorance and are perpetuated through stereotypical and ageist attitudes.

Interactions are challenging when the individual has sensory deficits such as hearing or vision impairment. Mobility compromises self-care. Cognitive overload can occur in the 'busy-ness' of hospital, Emergency Department, GP practice and community health clinics and make it difficult for HPs to assess cognitive function. Often they label the person confused and do not try strategies such as speaking clearly, more slowly, using simple sentence structure and avoiding jargon, or using visual prompts to communicate with them. Sometimes family members are consulted for information rather than the person themselves, to save time.

To ignore the person's prior knowledge, life experience, belief systems and preferred ways of learning, as well as their goals and preferences makes it difficult for HPs to truly develop personalised care plans and conserve the individual's dignity, see Chap. 3.

We are teachers and students to each other (Jampolsky 2000)

The individual's living arrangements and circumstances are important aspects of their story and provide context for personalising their treatment and care. An older person with cognitive impairment and diabetes can be compromised by difficult environmental conditions including unstable housing or homelessness, limited income, and either no carer or an inappropriate carer who may subject them to some form of elder abuse including physical and financial abuse. Inadequate health literacy, language difficulties and access to transport can further complicate an individual's access to appropriate, timely care and support. These situations impact food and fluid intake, quality of sleep, access to monitoring equipment and medications, medical and care support and engender significant stress that further compounds the individual's ability to cope and may result in mental health issues including anxiety, depression and suicidal thoughts. Families and HPs should take an older person talking about 'wanting to die' seriously. It is a warning sign that the issue needs to be discussed sensitively and the person referred for treatment and advice (Ganzine in Rapport 2017).

Capturing both the life story and medical history in a practical format to share with relevant service and care providers can be challenging due to issues such as access, privacy and the need to accommodate frequent changes. Life story 'passports' that the cognitively compromised person and/or their carer can take with them to new medical appointments, allied health and respite care providers can be helpful. The other advantage of utilising such records is the individual does not have to rely on memory in stressful new situations and avoids the need to repeat themselves.

'Passports' are also helpful for new residents of nursing homes to share with the staff and help staff 'see the individual as a whole human being'. Many dementia care and support organisations promote the use of story templates that record cultural background, life history, personality, spirituality, values and beliefs, social connections and support networks, sexuality, interests and hobbies, significant life events as well as habits and routines. These can be adapted into different formats, including "Life Story Boxes" and wall displays in the person's bedroom, Life Story DVDs, and Memory wallets and Memory Boards that the person can carry with them (Bourgeois et al. 2005; Alzheimer's Australia Tasmania 2017; Alzheimer's Australia, 2017a, b).

8.7 When the Going Gets Tough…

Most diabetes and cognitive impairment management guidelines do not address some of the most concerning and distressing behaviours that can occur with acute delirium and advanced dementia. Personal and professional carers are often inadequately skilled and trained to respond appropriately in hospital, community and residential care settings (Burns et al. 2012; Sinclair et al. 2014). Unfortunately, the complexity of both conditions in addition to other co-existing comorbidities makes care challenging. Medical training as well as public education and information about both subjects has raised awareness about appropriate assessment and care in recent years, in keeping with the World Health Organization ICOP Guidelines (2016), but there appears to be a lot more work to do.

For example, over 90% of people with dementia will develop Behavioural & Psychological Symptoms of Dementia (BPSDs) at some time during the course of their illness (International Psychogeriatric Association 1996). BPSDs are the non-cognitive symptoms of dementia such as disturbed perception, thought, content, mood and behaviour. Examples include physical and verbal aggression, pacing, restlessness and wandering, sleep disturbance, apathy, anxiety, hallucinations, delusions, misidentifications and sexualised behaviours (International Psychogeriatric Association 2002).

According to Sinclair et al. (2015) 'Major aims of diabetes care include maintenance of independence, functional status, and quality of life by reduction of symptom and medicine burden, and active identification of risks'. However, the added diagnosis of dementia can make management challenging for everybody involved in care. For example, the individual can misinterpret blood glucose checks, glucose lowering medicines and giving insulin injections as invasive and threatening. They may react violently (physically and/or verbally) because they do not understand or remember why they are important.

Comprehensive, person-centred assessment is important to:

Prevent. Know the person well—encourage carers to maintain physical and emotional equilibrium through a person-centred approach to engagement/occupation in daily activities; avoid triggers such as boredom, changes in environment and medication. Also, have routine checks with flexible blood glucose level limits to accommodate changes in behaviour.

Minimise. As soon as behaviour change is noticed, prompt assessment to exclude organic causes should be undertaken. If the person is agitated, try again later. Avoid making the situation worse. Address unmet needs before trying other methods such as distraction. Physical exercise and mental stimulation activities can be helpful to induce natural tiredness.

Manage. Prompt critical analysis of pain, behaviour, delirium screening; ask—what is the problem and who is it a problem for? Refer to care plan and ensure that GP has included flexible reportable levels and management strategies. If blood tests are to be required, make it 'count', e.g. undertake multiple pathology tests at the same time. Having blood taken is often distressing for the cognitively impaired person who is not only unlikely to accept, but will probably not understand or remember a rational explanation for taking the blood. Food and fluid charting may be advised during a period of ill-health to ensure adequate intake and to avoid hypo- or hyperglycaemia.

8.7.1 What's Going on with the Carer?

Another consideration is the role and health and well-being of the carer/s: personal and professional. It is important not to presume that:

- The person is cooperative, has a stable carer or number of carers who all get along well with the person and each other.
- That the carer has the person's best interests in mind.
- That the carer understands what is required to care for the person, is coping and is able and willing to seek help if required.

- That the primary care provider can and does review the person on a regular basis and makes appropriate treatment adjustments that are being followed.
- Provides appropriate general health checks and vaccinations when required.
- That all members of the health and care team are qualified and skilled sufficiently to minimise/manage the person's condition, and on the 'same page' and
- Are able and willing to follow a goal-directed care plan that is in line with the person's aims, wishes and is tailored to suit their individual circumstances.

Caring for older people, especially when they have multiple comorbidities like cognitive impairment and diabetes, can be particularly burdensome and stressful. Family and friends can experience higher levels of depression than non-carers, social isolation, disruption to sleep leading to exhaustion, deterioration in physical health, need time off from paid work which can impact on finances, and have feelings of sadness, grief, guilt and persistent worry (Adelman et al. 2014; Alzheimer's Australia 2017a, b).

Lack of control and frustration can sometimes develop into anger and the carer may act out towards the person they are caring for. Others involved may need to monitor for signs of depression, elder abuse, and respond to protect the vulnerable person as well as encourage the carer to obtain support. General carer issues are discussed in Chap. 1.

Photo courtesy "Love, Loss, and Laughter: Seeing Alzheimer's differently" (Greenblatt 2012)

8.7.2 My Rights: At the Right Time, and in the Right Way

The current philosophical frameworks of many countries in the OECD guiding the care of older people with chronic conditions such as diabetes and dementia are underpinned by core principles that promote the individual's independence, choice where and when possible, minimise risk and focus on quality of life (Dunning et al. 2014; United Nations 2015; WHO 2016).

The National Health and Medical research (NHMRC) Partnership Centre for Dealing with Cognitive and Related Functional Decline in Older People in Australia developed Clinical Practice Guidelines and Principles of Care for People with Dementia (2016). These guidelines are underpinned by the 10 Principles of Dignity in Care, developed by the UK's Social Care Institute for Excellence. These documents complement the communication principles espoused by Alzheimer's Australia (known as Dementia Australia since October 2017) that were co-designed in consultation with people with dementia and invite people to *Talk to Me… speak clearly…avoid jargon…keep questions simple and don't question my diagnosis (as) symptoms are not always obviou*s (Alzheimer's Australia 2017a, b).

The documents emphasise the importance of respect, engaging directly with the consumer, and treating each person as an individual. The philosophy is consistent with the current trend for consumer-lead health care, greater consultation with consumers and carers, including their involvement as co-designers of organisational policy frameworks and roles such as peer-support workers, interview panels and as committee members. They are also consistent with the intent of this book.

Measuring the quality of care is important and may be more important than strictly adhering to clinical practice guidelines. Boyd et al. (2005) suggested HPs try to balance the following guidelines and adjust recommendations to suit individual's needs. The WHO Integrated Care for Older People (ICOPE) Guidelines were released in 2016 and emphasise the need…*to ensure an integrated approach focussing on 'problems' that matter most for older people, rather than specific conditions*.

The National Commission on Safety and Quality in Healthcare (2008) developed The Australian Charter of Healthcare Rights, which include the right to:

- Access (I have a right to health care)
- Safety (I have a right to safe and high quality care)
- Respect (I have a right to respect, dignity and consideration)
- Communication (I have a right to be informed about services, treatment, options and costs in a clear and open way)
- Participation (I have a right to be involved in decisions and choices about my care)
- Privacy (I have a right to privacy and confidentiality of my personal information)
- Comment (I have a right to comment on my care and to have my concerns addressed)

The charter applies to all health settings in Australia and is equally relevant globally. It enables consumers, families, carers and service providers to have a common understanding of the rights of people receiving health care. In some countries there are also legal entities such as Office of the Public Advocate in Victoria (Australia) that promote and safeguard the rights and interests of people with a disability, including investigating complaints or allegations of abuse or exploitation, providing advocacy and acting as legal guardian or appointing financial administrators to act in the vulnerable person's best interests (OPA 2017).

The Older People's Advocacy Alliance (OPAAL) UK is an organisation that promotes advocacy for older people. They offer a range of resources relevant to anyone involved in helping vulnerable adults to take decisions, make choices, manage risks and support independence. Their Support Decision tool can be used to promote choice while managing risk proportionately and realistically (2007).

These frameworks imply that people are entitled to receive information tailored to their needs and their level of understanding and that they are encouraged to participate in their care (see Chap. 2 for information about shared decision-making and older people). Therefore, it makes sense to encourage early diagnosis and develop practical and flexible treatment and care plans that individuals and their carers/representatives can adapt to suit their changing needs over the course of their illness.

For example, substitute decision-making arrangements such as Enduring Powers of Attorney for financial, legal and medical matters and Advanced Care Directives should be documented when the person has capacity to do so. Capacity assessment needs to be determined by appropriately qualified professionals, and in accordance with the legal and ethical guidelines of the country and culture the person belongs to. In the UK, a framework to decide whether someone has capacity to make specific decisions, and if not, who the designated alternative decision maker is, has been included under the Mental Health Act (The Lancet Commissions 2017).

Play to my strengths; support me; don't be afraid to be creative, and keep it real!

8.8 Real Life

It is important to note that just because a person makes a decision that could be considered 'unwise' or is contrary to a health professional's advice, does not mean that they necessarily lack capacity to give informed consent. That is, a person has a right to make bad decisions. The following vignettes describe two aged care home residents with moderate vascular dementia and diabetes whose wishes were challenged:

Val's granddaughter took her to a Dermatologist to have her dermatitis reviewed. The Dermatologist recommended a course of oral and topical steroids. The granddaughter stated that Val had always preferred naturopathic remedies and would not want to follow the specialist's recommendations. Val's GP verified the granddaughter's view because he had known Val for many years.

Some of the nursing home staff were unhappy about the suggestion to use naturopathic remedies because they believed the more orthodox medical treatment the Dermatologist recommended should be followed. A local qualified Naturopath/Aromatherapist who was also a Nurse was approached. Non-steroidal creams using essential oils were prescribed and administered after the GP clearly documented that he believed this would have been in keeping with Val's wishes in her records.

The creams took a little longer to work, the outcome was successful. The care home manager appeased the staff who objected, by providing education from the Nurse/Naturopath about the creams, and pointing out that due ethical considerations had been taken in choosing this course of action.

Both stories demonstrate a person-centred approach that considered the individual's Life Story, pre-morbid personality and weighing-up of the risks and benefits of each situation. The individual's wishes were respected, and carers as well as primary care providers consulted.

Dan had travelled around the roads of New Zealand for many years before vascular dementia and diet controlled type 2 diabetes made it too unsafe for him to continue to do so. He came to live closer to his eldest daughter who lived in a small country town in Australia, where he moved to the local nursing home. His hypertension grew worse, and he was advised to take anti-hypertensives to minimise stroke. He declined, as he had never liked taking medications. The GP explained to both Dan and his daughter (who had medical Enduring Power of Attorney) the risks of not taking the medication, and the nursing home manager discussed how a stroke might affect him. Dan and his daughter decided to take the risk, and he lead a comfortable life until 6 months later, a major stroke left him with a dense hemiplegia, speech and swallowing difficulties and he died 2 months later.

Evidence supports the use of psychosocial and non-pharmacological interventions and a person-centred approach when faced with behavioural and psychological symptoms of dementia (BPSD). It is also considered best practice to try these techniques first. Psychotropic medications are indicated as a last resort, and at low doses for short periods of time to avoid side effects that include increased risk of falls and mortality (WHO 2012; Burns et al. 2012). Creative approaches including the role of pet and music therapy, sensory treatments such as massage, aromatherapy and learning what makes the older person happy and content is more likely to maintain equilibrium and improve their quality of life.

> *Connection is the energy that exists between people when they feel seen, heard and valued; when they can give and receive without judgement; and when they derive sustenance and strength from the relationship*. (Brene Brown, The Gift of Imperfection 2010.)

The following are two stories that further illustrate the philosophies of a person-centred, ethically sound, realistic approach to care of the older people with diabetes and cognitive impairment.

8.9 Story 1: Wayne

8.9.1 Background

Wayne was a 65-year-old gentleman with an intellectual disability and significant hearing impairment, who had left school at age 13 and had worked for the Post Office until he was 24. He was living with his 93-year-old mother and 61-year-old brother in their own home. All three family members had been diagnosed with type 2 diabetes, Wayne most recently. His brother, John had noticed that Wayne had bilateral swollen feet, weeping leg ulcers, and was going to the toilet frequently. John encouraged Wayne to be reviewed by his GP (Wayne hadn't seen a doctor for 40 years!).

Once examined, the GP arranged for Wayne to be admitted to hospital. He was formally diagnosed with type 2 non-insulin dependent diabetes, hypertension, and he was put on a waitlist to have a large inguinal and scrotal hernia repaired. His cognition was assessed using a Mini-Mental State Examination (MMSE) with a score of 24/30, and he could read and comprehend simple instructions. In hospital, his diabetes was stabilised, treatment of his tinea and leg ulcers was commenced. He was discharged home with referrals in place for community nursing for second daily wound dressings and medication supervision, and follow-up with a GP.

8.9.2 Care Interventions

The community nurses reported that the family were living in crowded, cluttered and unhygienic conditions, and were all sleeping in lounge chairs (unable to access their bedrooms due to their apparent hoarding). They referred Wayne to a government funded community-based service where short-term case management is provided to work with the client and carers to develop a person-centred *Goal Directed Care Plan* that included a list of service contacts for Wayne, his GP and a longer-term case manager to access and share. Wayne's goals were to stay living at home, have his ulcers heal and avoid readmission to hospital. The clinicians and professional carers involved had several other concerns, but soon realised that their expectations would have to be curtailed, in keeping with Wayne's reality, circumstances and rights.

The case manager, in getting to know Wayne, identified that he was the family's food shopper and cook, and drove them all to appointments. Referrals were made for Wayne to engage with a Diabetes Nurse Educator, Dietician, Podiatrist, Audiologist, Hoarding/declutter Consultant and Pharmacist. With Wayne's agreement, and his mother's encouragement, this multi-disciplinary team provided education and support using a range of health literacy documents that were pitched at Wayne's level of understanding (Diabetes Australia Victoria 2014), calendar as an appointment diary. Capacity building and sustainability were key to promoting Wayne's self-management for the longer term.

After a few trials and errors, and a lot of practice and encouragement, Wayne mastered his blood glucometer and medication administration. The most success was had with his use of a pictorial "Healthy Eating Guide" (Novartis 2015) that used green colours and ticks indicating the best foods for his diabetes, and red colours and crosses for the foods to be discouraged. As the family shopper and cook, the changes in the family diet meant that they all benefited with more stable blood glucose levels. He successfully had his hernias repaired, enabling him to mobilise more freely, experience less discomfort and avoid complications (had he not had the operation).

Little headway was made with decluttering and cleaning but to *reduce risk*, the case manager (with the family's permission) had new smoke detectors fitted, and reported the home address to the fire brigade so that two fire units would automatically be sent to the home in the event of a fire. The beds were still unable to be accessed, so recliner chairs were purchased so the brothers could lay flatter at night, and reduce pressure load. The case manager and visiting nurses found evidence to suggest that Wayne's brother was taking financial advantage of Wayne, so steps were taken to have a Financial Administrator appointed.

Independence was encouraged, yet risks were minimised, with the philosophical guidelines of "path of least restriction" being followed (Office of the Public Advocate, Victoria).

8.10 Story 2: Elvira

8.10.1 Background

Elvira was an 86-year-old widowed lady, who had been a shopkeeper in a small country town for over 30 years until her husband died. Her family all lived in other states, so she rarely saw them and would speak with her eldest son by telephone, a few times per year. She had no active friends visiting her at the time of her transfer from a low-care hostel to a high-care dementia-specific nursing home in a bigger country town.

Elvira had been living at the hostel for 2 years because she had worsening dementia and diabetes. The staff from the hostel had limited training in dementia care, and had described Elvira as moody; she would apparently become aggressive whenever staff tried to "make her do anything she didn't want to do".

This included the staff trying to test her blood glucose levels up to four times per day. They were concerned that her moody behaviour was impacting on her blood glucose levels, and her GP had recently commenced her on insulin. Elvira was not keen on the blood glucose tests nor injections, and hostel staff had been restraining her (against the hostel's policy) to give her these. They were keen to discharge her due to her increasing verbal and physical aggression (possibly triggered by the restraint).

8.10.2 Care Interventions

The qualified and more experienced staff of the dementia-specific nursing home ascertained that Elvira had moderate dementia, with a MMSE score of 19/30 on admission. They used a *Concept Map* that documented her *abilities and needs* around Communication, Activities, Physical health, Personal Story and Personality, Environment and how her Dementia impacted on her. This was a strengths-based model, used as a foundation for her *Goal Directed Care Plan*. For example, her language skills were reasonably intact, she was prone to confabulation, had no problem-solving abilities and no short-term memory, but was easily distracted and engaged in activities she enjoyed.

The team determined that it was important for her to be allowed to settle in, and were wary of attending to too much blood glucose testing. The GP supported the team's plan to avoid stress-inducing situations, and agreed that frequent blood testing was not necessary. They would let her settle in by building trust and rapport, and learn about the things that put her in the best possible mood. There were three things that always impacted Elvira's mood positively—spending time with the dementia unit's resident cat, a rousing rendition of "Pack up Your Troubles in Your Old Kit Bag" and vanilla custard.

The staff soon learned to employ at least one of these before attempting any testing, and this usually worked. If not, they would leave her alone, but would be watching for any symptoms of hypo- or hyperglycaemia. Rather than subject Elvira to frequent blood glucose tests, the GP was comfortable with her having 3 monthly HbA1c tests (always attend to, once her good mood was established and she was likely to cooperate). He was happy for her to have a higher target for her blood glucose to avoid hypoglycaemia.

Staff soon learned that she loved to be contrary, which proved quite handy. They would say to her "I bet you can't take this tablet", or "I bet you won't let me take this little blood test"; to which she'd forcefully reply "I bet I can!". She would then (usually) either take the medication, or let the staff take the blood test.

One morning, a staff member reported to the Unit Manager that "Elvie won't put any clothes on, and is refusing to shower". The manager confirmed with the staff member that Elvira was in her own warm room, and although naked, it was deemed best to just leave her alone for the next 10 min. The staff member was advised to re-enter the room singing Elvira's favourite song, and pretending that it was the first time she'd seen her that morning.

The staff member followed this plan, and Elvira cooperated without any incident, on this second attempt. This happened on several occasions, with the same outcome. The staff concluded that she had most likely slept in the nude at home, and staff seemed more accepting of this behaviour when they considered it part of Elvira's story, and who she had always been.

About 6 months after moving to the dementia-specific home, Elvira's appetite declined and she started to lose weight, with no obvious underlying organic cause being identified. Staff had to adjust her insulin dosage accordingly, and she started to experience fluctuations in her blood glucose levels. With the advice of a Dietician and Diabetes Nurse educator, the staff provided Elvira with a mixture of food supplements, plus treats like ice-cream, cake and her favourite custard—sometimes for breakfast.

This degree of creativity and flexibility kept Elvira's mood stable, her blood glucose levels were managed, and aggressive interactions avoided. Her GP was happy because Elvira was happy, had a good quality of life, and lived happily at the home for another 6 years, passing away peacefully at the age of 96 with the resident cat snuggled next to her in bed.

8.11 Reflection Points

- Reflect on people with dementia's stories shared in the chapter. Do they reflect the key management strategies described in the introduction?
- Think about the following quote:
- *There were thousands of secrets hidden in her purse, secrets and memories that took her elsewhere. She held onto them tightly and kept them to herself. Even God did not know of them. (Suzka Collins 2016)*
- What do you think it means?
- How could you use the 'secrets hidden in her purse' to engage with the lady?
- What memories would you hide in your purse?

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