Advancing practice in the care of people with dementia

4th Edition

Module 6:

Social and lifestyle considerations

Dementia
Training
Australia

Contents

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Introduction

This module explores the social needs of the person with dementia and how health professionals can support dignity and freedom of expression for the individual. The module presents information regarding legal considerations such as decision-making and capacity, driving, and advance care planning. The module also discusses legal considerations for health professionals in maintaining the personal safety of the person with dementia. There is a discussion aimed at provoking the health professional to consider their beliefs regarding sexuality and sexual expression in older people with dementia.

Objectives

On completion of this module you will be able to:

- Demonstrate an understanding of legal considerations involved in the care of people with dementia
- Discuss concepts of safety and risk
- Demonstrate an understanding of why physical restraint is to be avoided in the care of people with dementia
- Demonstrate an understanding of the issues surrounding sexual expression in older people with dementia.

Module topics

Legal considerations
Driving
Safety and risk
Employment
Restraint
Sexuality
Spirituality
Grief and Loss
Early life trauma
Transition to community and residential services

Suggested readings for this session

Ames, D., O'Brien, J. & Burns, A. (2017). *Dementia*. (5th ed.). London. CRC Press. Chs 27, 30, 31, 33.

NSW Government, Attorney General's Department. (2009). *Capacity Toolkit*. https://www.justice.nsw.gov.au/diversityservices/Documents/capacity_toolkit0609.pdf

Victorian Law Reform Commission. (2012). *Guardianship Final report. Ch 7: Capacity and incapacity*. https://www.lawreform.vic.gov.au/sites/default/files/Guardianship_FinalReport_Ch%207_Capacity%20and%20incapacity.pdf

Legal considerations

Many legal issues pertain to the care of people with dementia, the focus of which concerns the ability of the person to make informed decisions. Decision-making requires different levels of cognitive function; people with cognitive impairment can make some decisions. Medical practitioners therefore need to determine the nature of any decision facing the person and evaluate whether the person has the cognitive ability to make that decision. It is important to note that impaired cognition does not automatically equate with impaired capacity, although the ability to make informed decisions such as risk-taking, financial, lifestyle and consent to medical treatment is lost in advanced dementia. It is important to remember that legal capacity is assumed unless proven otherwise.

Terminology in this respect can be confusing. Globally, the terms capacity and competence are defined differently. Additionally, people often use these terms interchangeably. It is important to check you are using the term correctly depending on which jurisdiction the situation is occurring in (Series & Jacoby, 2017).

Determinations of capacity vary across Australia (Purser & Rosenfeld, 2014). You will need to make yourself familiar with the relevant guidelines and legislation in the jurisdiction you are practising in.

The challenge is that medical practitioners are not trained to assess legal capacity; while legal professionals are not trained to assess the impact of medical conditions, such as dementia, on a person's legal capacity. Clear communication is required if there is concern about a person's ability to make decisions. A legal professional may undertake legal activities with a person who has minimal evidence of diminished capacity. A medical opinion is likely to be required if there is evidence of mild impairment; more serious impairment will probably require a formal medical capacity assessment (Purser & Rosenfeld, 2014).

The NSW Government Capacity Toolkit (2009) refers to the following Capacity Assessment Principles:

- Always presume a person has capacity
- Capacity is decision specific
- Don't assume a person lacks capacity based on appearances
- Assess the person's decision-making ability – not the decision they make
- Respect a person's privacy
- Substitute decision-making is a last resort

Assessing capacity can be challenging. It has been described as 'the search for the holy grail' and as 'an artificial construct' (Victorian Law Reform Commission, 2012, p 101). The other complicating factor is that different standards of capacity apply depending on the nature of the decision. Thus, there may be different concerns depending on whether the person is seeking to:

- Enter into a contract
- Make a will

- Vote in an election
- Consent to sexual relations
- Get married, or:
- Be held responsible for criminal conduct

(Victorian Law Reform Commission, 2012)

It cannot be assumed people living with dementia have impaired capacity. Indeed, the person with dementia must be assumed to have capacity unless proven otherwise. When a person living with dementia is being assessed for capacity, the assessor needs to consider the person's level of understanding, their ability to communicate a choice, their appreciation of the matter, and their reasoning leading to the choice. The assessment of capacity needs to reflect the type of issue needing resolution (Hegde & Ellajosyula, 2016). These four elements are further explained by Karlawish (2020):

- Understanding – knowing the meaning of the information being presented
- Expressing a choice – clearly communicate a choice between multiple options. Frequent reversals of choice in the context of neurological or psychiatric diagnoses are suggestive of impaired capacity
- Appreciation – the person's ability to recognise how the current circumstances are relevant to themselves. A failure to acknowledge illness due to impaired insight or delusional beliefs is suggestive of impaired capacity
- Reasoning – the ability to compare options and recognise consequences of choices. This aspect of capacity is related to values and beliefs; e.g. refusing high-risk procedures in order to spend more time at home with family

(Karlawish, 2020).

Referrals for assessment of capacity are likely to be made to several types of health professionals recognised as being able to conduct capacity assessments:

- Geriatrician
- Psychiatrist
- Neuropsychologist
- Psychogeriatrician
- Neurologist
- Psychologist
- Aged care assessment team

(The Law Society of NSW, 2016; The Law Society of WA, 2016)

Capacity for a person living with dementia is ideally determined by neuropsychological assessment. Capacity cannot be determined by common screening or assessment tools such as the mini-mental state exam (MMSE) (Hegde & Ellajosyula, 2016). The lack of a 'gold standard' for capacity assessment is challenging (Mills, 2017). No current tool is suitable to use as a standalone. The assessor needs to consider broader individual and contextual factors in order to find a balance between the person's right to autonomy and the need for protection of a vulnerable adult (Pennington, Davey, Meulen, Coulthard & Kehoe, 2018). Validated instruments that may be useful in more complex and potentially litigious cases are the MacArthur Competency Assessment Tool for Treatment (MacCAT-T), the Assessment of

Capacity for Everyday Decisions (ACED), or the Capacity to Consent to Treatment Interview (CCTI). Findings from these tools must be integrated with other data about the person and the decision required in order to make a judgement of capacity (Karlawish, 2020). An assessment indicating diminished capacity may lead to activation of a Power of Attorney or the appointment of a guardian (NSW Government, 2009).

Why is this important?

Legal implications: reduced capacity has implications for testamentary capacity, such as wills and other legal documents or situations.

Work implications: may impact on ability to continue working safely particularly where the person has responsibility for others; for example, a bus driver.

Social consequences: social consequences of reduced capacity arise for issues such as ability to drive and con ducting day-to-day activities such as financial management or decisions about where to live.

Lifestyle consequences: reduced capacity can dramatically alter a person's lifestyle and cause isolation and depression.

Issues arising in relation to capacity

Issues arising in relation to capacity for a person living with dementia include:

- Types of decisions presented to clinicians
- Forward planning – being pro-active and anticipating issues
- Types of dementia and their relevance to capacity
- Progression of dementia and impact on capacity

Common types of decisions that present to a clinician

Common types of decisions that present to a clinician include:

- Is the person able to give informed consent to medical treatment?
- Is the person able to make lifestyle decisions, especially regarding living arrangements?
- Does the person have testamentary capacity; the ability to make a will or to sign other legal documents?
- Can the person appoint an Enduring Power of Attorney (EPOA)?
- Is the person safe to drive?
- Can the person consent to things such as sexual interactions, giving gifts, and disposal of property?

Why is this important?

The above issues are important to the health professional because they are common scenarios for people with dementia and a potential legal pitfall. They are not an 'all or none' phenomena and they have broad clinical applicability. Managing these situations requires specific knowledge and skills.

Forward planning

The need for key life decisions such as those discussed above can reasonably be predicted; forward planning with the person and/or their family is therefore possible.

It is important to identify the purpose of the decision rather than the process of making the decision (e.g., want to drive because need to shop; an alternative would be to organise home delivery).

Negotiated solutions are more likely and easier to achieve early and provide the opportunity to discuss prognosis and natural history of the condition.

Why is this important?

The person with dementia is better able to contribute to decisions, thus earlier decisions are more likely to reflect patient wishes. Making decisions early also removes anxiety and arguments in the future and saves time and resources for clients and families—ultimately reducing acute crises and the need for precipitous decisions to be made.

Types of dementia and their relevance to capacity

Not all types of dementia present the same issues in terms of capacity. For capacity and decision-making, it is important to elucidate the deficits in cerebral function rather than rely on the diagnostic sub-type of dementia. Some sub-types are rapidly progressive so forward planning is even more critical.

It is important to be aware that:

- Some people present with capacity issues as the first feature of dementia. Financial capacity may be an early feature for some people with frontotemporal dementia (Gill et al, 2019).
- Cognitive state may fluctuate. E.g. Lewy body disease or delirium (Pennington et al, 2018).
- Executive function impairment (e.g. frontal lobe involvement) is likely to require earlier forward planning.
- Constructs that are delusional need to be considered. They may not be volunteered.

Why is this important?

- Supports or stimulates a review of the diagnosis
- Focuses on functional ability rather than disease
- Helps de-stigmatise and promotes independence
- Preserves self-esteem for people.

Disease progression and impact on capacity

Dementia is a progressive disease process and decision-making capacity will deteriorate over time (Pennington et al, 2018). Disclosure of the dementia diagnosis to the person is important. Early diagnosis allows the person to consider future needs and put forward planning in place so that their wishes may be respected after they no longer have capacity (Hegde & Ellajosyula, 2016).

It is important to recognise that capacity is always specific to a situation. A person may have capacity to make one decision but not another; e.g. a person may have capacity to appoint a Power of Attorney but be deemed not to have capacity in managing a complex financial portfolio. Capacity is also time specific. The person may have had capacity at the time the decision was made, however, sometime later they may have deteriorated and no longer have capacity. Occasionally, loss of capacity may be reversible; e.g. medication complications or delirium from an infection. Treating the cause of the problem may allow the person to regain capacity (Series & Jacoby, 2017).

Another factor is that complex decision making involves multiple cognitive domains. More complex decisions require greater cognitive ability. Thus, a person with dementia may be able to decide about a simple medication change but be unable to fully appreciate the potential risks and/or benefits of a complex surgical procedure (Pennington et al, 2018).

The literature also notes a correlation between what is perceived to be a poor decision with lack of capacity (Pennington et al, 2018). There may be disagreement between the person living with dementia, their closest supporter(s), and health professionals. There can be tension for health professionals between their desire to support autonomy and to keep the person living with dementia safe (Mills, 2017).

Universal principles of health care include autonomy, beneficence, non-maleficence and justice. Health professionals involved in the care of people living with dementia may find it challenging to prioritise one principle over another when they appear to be contradictory (Hughes & Strech, 2017).

Health professionals may find it useful to refer to the National decision-making principles around supported decision-making (Sinclair, Field & Blake, 2018). Not all Australian legislation currently complies with these principles, however, they have been designed to be used as a framework for future reviews and policy development. Supported decision-making is defined as

> *"the process of enabling a person who requires decision-making support to make, and/or communicate, decisions about their own life. The decision-making is supported, but the decision is theirs" (Sinclair et al, p 7)*

The four principles are:

- All adults have an equal right to make decisions that affect their lives and to have those decisions respected
- Persons who require support in decision-making must be provided with access to the support necessary for them to make, communicate and participate in decisions that affect their lives
- The will, preferences and rights of persons who may require decision-making support must direct decisions that affect their lives
- Laws and legal frameworks must contain appropriate and effective safeguards in relation to interventions for persons who may require decision-making support, including to prevent abuse and undue influence

(Sinclair et al, 2018, p 5).

ACTIVITY

Consider how you would respond to the questions raised by the following typical scenario.

One year ago, a client living with dementia agreed to being admitted to residential care if functional capacity declined. Now he/she wishes to remain at home despite sustaining injuries from falls. He/she states that the earlier decision was made to appease family.

Questions

- ***Is a decision made in the past applicable now even though the patient refutes his/her earlier decision?***
- ***How would you ascertain whether a decision made a year ago is still valid now?***
- ***How would you examine a pattern of decisions with time?***
- ***What risks would you consider?***
- ***How would you determine what has changed?***
- ***How would you reassess capacity for decision making in the current situation?***
- ***What resources might assist to inform your decisions?***

Why is this important?

- The above is a common scenario as everyone may change their mind as circumstances alter.
- Capacity determines whether a person can decide.
- Assume the person living with dementia has capacity unless proven otherwise.
- Autonomy with decision making can still be possible for patients with impaired cognition.

Medical treatment and consent

The Medical Board of Australia defines informed consent as:

> *"a person's voluntary decision about medical care that is made with knowledge and understanding of the benefits and risks involved" (2014, p 9).*

Valid informed consent should always be sought from the person with dementia. If the person is deemed to lack capacity to make these decisions then a substitute decision maker must be determined, according to relevant state and territory laws (Guideline Adaptation Committee, 2016).

A valid consent must satisfy several conditions:

- The person must have capacity to give consent
- The person must understand what they are consenting to
- Consent is freely given, and
- The consent must cover the actions of the specific persons involved in the procedure (JBI, 2019b).
- The information given needs to include:
- The nature of the proposed treatment

- The effects of the proposed treatment
- Why the proposed treatment is being recommended?
- Alternative options to the proposed treatment, and
- The consequences of not agreeing to the treatment (JBI, 2019b).

But what happens in an emergency?

In the situation of a person requiring life sustaining medical treatment and it not possible to obtain consent from the person or their substitute decision maker, then emergency treatment may be given (ELDAC, 2018). In other circumstances consent needs to be obtained.

The person living with dementia may have reduced capacity to consent, especially as the dementia becomes more advanced. Assessment of capacity must be assessed on an individual basis, there is no gold standard about determining capacity to make treatment decisions (JBI, 2019a).

When it has been determined the person living with dementia is unable to give valid consent, clinicians must determine who the substitute decision maker is. All Australian states have legislation regarding legal guardianship. Every state has a different system and different rules. Please refer to your local jurisdiction (JBI, 2019a). Generally, the substitute decision maker is based on this type of hierarchy:

- An agent appointed by the individual under government legislation
- A person appointed by a Guardianship Tribunal
- A person appointed under a Guardianship Order
- A person appointed by the individual as an Enduring Guardian
- A person appointed by the individual informally in writing, or
- An individual’s spouse, primary carer, or relative (Slade, 2019).

Remember, this varies across jurisdictions in Australia. Clinicians need to be familiar with local legislation. The law requires that substitute decision makers consider either (or both) of these factors:

- Is this in the person’s best interests?
- Is this decision consistent with what the person would have decided if deemed competent? (ALRC, 2014).

Why is this important?

- Significant life and lifestyle implications
- These situations can be emotionally charged
- People are looking for guidance in what can be highly stressful situations
- Highlights need for early planning and advanced care directive.

Consent to participate in medical research

The National Health and Medical Research Council (NHMRC, 2018) states that gaining informed consent from participants is an ethical responsibility when conducting medical research. This raises complex issues when potential participants are cognitively impaired.

It is recognized that people with cognitive impairment are entitled to participate in research. However, care must be taken to ensure the person's unique vulnerabilities are considered. Consent needs to be obtained directly from the person living with dementia unless it has been determined they no longer have capacity to give a valid consent. In this case, consent needs to be obtained from the legally recognized substitute decision maker. The NHMRC also recognize that when a person with a cognitive impairment indicates refusal or reluctance to participate in research, this must be respected (NHMRC, 2018).

Forward Planning

Once a diagnosis of dementia has been made it is important that the person and their family/carer consider what arrangements need to be made for a time when they can no longer make decisions regarding legal and financial issues. The person living with dementia should consider their preferences in appointing an Enduring Power of Attorney or legal guardianship, and advance care planning, while they still have capacity (Guideline Adaptation Committee, 2016).

It is the role of health professionals to encourage the person with dementia to discuss the future with their family/carer and to put affairs such as finances and their will 'in order' whilst they still have the decision-making capacity to do so. They should also be advised to discuss future lifestyle decisions such as accommodation with their family/carer. Promoting these discussions can help ensure that the individual's affairs are managed according to their preferences once they are not able to make decisions.

More information can be found through the relevant state or territory agency.

Advance care planning

What is advance care planning (ACP)?

It's about conversations and planning for your future health and personal care so that you, your family, friends, carers and doctors know your values and preferences (Advance Care Planning Australia, 2020).

Essentially, ACP enables a person with dementia to express their wishes regarding medical treatment while still able to make informed decisions. Advance care plans can assist families/carers once the person with dementia is no longer able to make decisions. Health professionals should encourage people with dementia and their family/carer to make advance care plans.

The key issue is that the person making the advance care plan must have the capacity to understand the implications of doing so. See section above regarding determination of capacity for more information. Legislation surrounding ACP exists in all Australian states and territories. However, it varies from state to state (Fountain, Nolte, Wills, Kelly & Detering, 2018). See the Advance Care Planning Australia website for information regarding each specific jurisdiction: http://www.advancecareplanning.org.au/for-health-and-care-workers/legal-requirements#/

Advance care plans can take multiple forms depending on which jurisdiction of Australia applies to the person. State and territory terminology vary. It may be called a:

- Health direction (ACT)
- Advance personal plan (NT)
- Advance health directive (Qld, SA, Vic & WA)

NSW and Tasmania do not have a nominated document prescribed by legislation; common law applies.

Best practice for ACP includes:

- Preferences of the person and family are documented
- Healthcare professionals receive ongoing education regarding ACP discussions
- ACP decision aids are used as required
- ACP discussions are held regularly to allow people time to make informed decisions
- Online resources are utilized to store documents

(Marin, 2018).

Communication of the advance care plan is also required. Distribution of the plan is the person's responsibility. This needs to be encouraged by the health professional. Distribution will vary depending on the systems in place in each local health area. It can be challenging to ensure the information is available when required by all relevant parties (Therapeutic Guidelines, 2016).

ACTIVITY

Consider your own perspective on Advance Care Directives/Plans:

- ***Would you encourage a person with dementia to complete a plan or directive?***
- ***Would you honour an advance plan or directive?***
- ***Would you respect the wishes of a family member or carer if they conflicted with an advance care plan or directive?***
- ***Have you considered creating your own plan or directive? If not – why not?***

Driving

The issue of driving competence is a complex social, clinical and legal matter and requires a skilled and sensitive approach by the clinicians involved. Many people view driving as a right rather than a privilege, and as the last external sign of independence. Driving is also seen as essential to maintaining a person's social activities and lifestyle, particularly in rural and isolated settings.

As a generalisation, people should be allowed to drive if possible, without compromising the safety of others (Hughes & Strech, 2017).

Older drivers in general can compensate and adapt to changing circumstances and are in fact the safest demographic group when all factors are accounted for. Older drivers tend to avoid high risk situations and are less likely to drive under the influence of alcohol. However, accidents in the older age group are more likely to be fatal – this reflects increased frailty and reduced reserve in older people. Poor health is strongly associated with driving cessation. This generally relates to issues with vision, cognition, neurological disease, cardiovascular disease, and reduced functional status (Fallon & O'Neill, 2017).

There is no evidence that mild cognitive impairment increases the risk of driving. Drivers in the early stages of dementia are more likely to restrict their driving and avoid complex driving situations. An analysis of crash rates in people with dementia showed there was no difference in risk during the first two years of dementia compared to the general population. Dementia commonly co-exists with other co-morbidities; these other conditions may be more likely to cause driving impairments. Thus, a driving assessment needs to include all aspects of health and function. As with any chronic condition, a declaration of fitness to drive will need to be reviewed regularly (Fallon & O'Neill, 2017).

Dementia may affect driving ability in several ways including:

- errors with navigation, including forgetting routes and getting lost in familiar surroundings
- limited concentration or 'gaps' in attention, such as failing to see or respond to 'stop' signs
- errors in judgement, including misjudging the distance between cars and misjudging the speed of other cars
- confusion when making choices, for example, difficulty choosing between the accelerator or brake pedals in stressful situations
- poor decision making or problem solving, including failure to give way appropriately at intersections and inappropriate stopping in traffic
- poor insight and denial of deficits
- slowed reaction time, including failure to respond in a timely fashion to instructions from passengers
- poor hand–eye coordination

(Austroads, 2017).

The suggestion that it may not be safe for an individual often strains the relationship between them and the doctor or health professional . Health professionals need to consider the impact loss of mobility not being allowed to drive may cause. Health professionals may also encounter barriers such as a lack of resources or family/carer resistance. All parties will need to be familiar with local driving license authority requirements. Drivers will also need to consider their motor insurance policy requirements (Fallon & O'Neill, 2017).

Referral to a social worker can help the person and their family/carer identify alternative transport arrangements. If the person is reluctant to comply with ceasing driving then consideration needs to be made to remove or disable all accessible vehicles (Fallon & O'Neill, 2017).

Early negotiation with the client and family/carer can reduce subsequent conflict, so developing a documented management plan to minimise risk and ultimate transition from driving is essential. Early referral to third parties such as the Aged Care Assessment Team (ACAT) or the relevant road traffic authority is frequently necessary, particularly in relation to assessment of driving capability.

Options for assessment

1. Referral to a healthcare professional for assessment of driving skills. The major advantage of assessment conducted by an appropriately qualified health professional is that they can recommend restrictions be placed on an individual's driving license rather than revocation of the license. Examples of restrictions could be that the person only drives in daylight hours, or that driving is restricted to a given distance from the person's home.
2. Referral to relevant licensing authority for assessment. Where a health professional has concerns regarding the ability of a person to drive safely, where perhaps the person does not agree to referral to a health professional or where a person continues to drive against advice, they are able to notify the relevant licensing authority seeking an assessment. Once the referral is made these assessments are compulsory and tend to result in passing or failing and, if failed cancellation of license (Austroads, 2017).

Resources

Austroads

Assessing fitness to drive: https://austroads.com.au/drivers-and-vehicles/assessing-fitness-to-drive

Dementia Australia Help sheets

Driving: https://www.dementia.org.au/files/helpsheets/Helpsheet-CaringForSomeone07-Driving_english.pdf

Driving and dementia: https://www.dementia.org.au/files/helpsheets/Helpsheet-InformationForPeopleWithDementia04-DrivingAndDementia_english.pdf

Driving with dementia

Animated video presented by Professor J. Ibrahim.

http://www.youtube.com/watch?v=4F9z8mPhcTw

Royal Automobile Club Victoria

Is driving with dementia possible?

https://www.racv.com.au/on-the-road/driving-maintenance/road-safety/archive/is-driving-with-dementia-possible.html

VicRoads

Dementia and driving

https://www.vicroads.vic.gov.au/licences/health-and-driving/medical-conditions-and-driving/dementia

Safety and risk

All health professionals are eager to ensure the safety of clients and this becomes of greater concern in people with dementia. This section will explore the issue of physical safety in the context of a person's right to take risk.

Risk may be defined as:

> *"a chance or possibility of danger, loss, injury, or other adverse consequences" (Benbow & Kingston, 2017, p 92).*

People living with dementia can find their lives are impacted on by a pre-occupation with risk from family/carers. There may be a struggle to maintain autonomy whilst balancing risks. It is important to consider the person, meaning understanding the person and their individual preferences is essential to manage risk in a balanced way. Some risks may be identified as 'acceptable' in order to ensure quality of life for the person living with dementia. There is no single approach; all decisions need to be on an individual basis (Dickins, Goeman, O'Keefe, Iliffe & Pond, 2018).

Traditional risk management regarding people living with dementia has focused on preventing physical harm. Care needs to be taken to avoid overlooking social and psychological wellbeing when trying to prevent physical harm. In order to preserve these other aspects of a person's wellbeing there may need to be an acceptance of appropriate or 'acceptable' risk (Clarke & Mantle, 2016).

Health professionals are required to respect the rights and autonomy of the individual and this is no less so in people with dementia. The difficulty arises when the person with dementia is not able to make decisions regarding their own safety and it falls to others to protect them.

Health professionals need to identify and manage risk but take account of the whole person.

Health professionals may be required to take on different roles when considering risk for a person living with dementia:

- Hazard manager – identify hazards and either remove or minimise to avoid harm
- Risk facilitator – identify and support activities that improve the person's quality of life
- Dilemma negotiator – identify and reconcile differing opinions of the potential risk and support all parties to agree on a plan. This may include the person living with dementia, family members, and different members of the interdisciplinary team.

(Clarke & Mantle, 2016).

The responsibility of the health professional is to ensure that the person, if capable, and/or family/carers are informed of the risk, and that options are discussed (Clarke & Mantle, 2016).

Employment

Traditionally employment issues were only seen to be relevant to people with younger onset dementia. However, older people are now encouraged to remain in the workforce and delay retirement. Thus, it is now more likely that workplaces will need to consider the impact of developing cognitive impairment in larger numbers (Silvaggi et al, 2020). It is estimated that approximately 1:1400 people living with dementia in the UK are in the workforce (Robertson, Kirkpatrick & McCulloch, 2015).

Swaffer (2015) has coined the term 'prescribed disengagement' to describe her experience of receiving the diagnosis of dementia and giving up paid employment. Swaffer describes this as disempowering, devaluing, and demeaning in addition to problems of:

- Increased isolation
- Loss of identity
- Reduced income and
- Increased costs

Participation in the workforce is important for people on many levels. It defines identity, social roles and social status. People in the workforce with early symptoms of dementia typically experience the development of minor problems where their duties become more difficult and errors become more common; they may become slower and struggle with more complex tasks. Early changes can be subtle, e.g. forgetfulness and disorganization. This can lead to poor time management, missed appointments and meetings, forgetting names, loss of ability to use equipment, unfinished tasks, and loss of ability to cope with workplace changes. These changes may initially be dismissed or not noticed until the problems start to increase as the symptoms of dementia further develop. Work performance deteriorates and other people start to notice there is a problem. This can change work relationships and people with dementia may experience difficulties with supervisors, managers, or colleagues. The person living with dementia may also complain of increased fatigue related to work (Evans, 2019).

Early identification of the dementia diagnosis is important for both the person living with dementia and the employer to mitigate health and safety risks and to enable the person to remain at work for as long as possible as they prefer. This can be challenging as the person living with dementia may try to conceal symptoms to avoid stigma. The other problem is that confirmation of the diagnosis can be a difficult and lengthy process. Employers need to create an environment where dementia can be discussed and information about support is available (Thomson, Stanyon, Dening, Heron & Griffiths, 2019).

However, in most cases, people living with dementia leave the workforce following their diagnosis. Many workers report a lack of control over the decision to remain in the workforce. There are reports of people on sick leave being terminated without an opportunity to farewell their colleagues (Andrew, Phillipson & Sheridan, 2019). Loss of work has both social and financial consequences for the person (Chaplin & Davidson, 2016).

All Australian workers are protected against discrimination in the workplace and are entitled to seek ‘reasonable adjustment’ in the case of disability, this includes a diagnosis of dementia. ‘Reasonable adjustment’ may mean simplifying tasks, deployment to other duties, or modified hours. However, options may become limited if the symptoms of the person living with dementia impact on their ability to safely perform their duties (Andrew et al, 2019). The Australian Government (2018) recommends the following workplace supports and adjustments for people with cognitive impairments:

- fostering a friendly, open work environment, where verbal and written input from workers regarding operations, work processes and methods is valued and encouraged
- establishing a buddy program with a co-worker to provide mentoring, as well as providing extra support and encouragement to keep on task
- avoid or eliminate distractions and do not multitask as this will divide attention
- break down job tasks into small steps and use visual prompts for each step to assist with refocus and continuation with tasks
- use a pin-up board/white board to display task flow charts
- use ‘to do’ lists which can be ticked off as completed to help with tracking actions
- schedule regular breaks to accommodate a reduced attention span
- schedule the early part of the working day for ‘attention demanding’ tasks or activities, with less demanding tasks scheduled later in the day
- rotate between tasks to increase interest
- establish a set work routine to make it easier to remember and allow time to adjust if the routine alters
- minimise potential distractions to concentration, for example, partition off the workspace, have a workstation away from other colleagues and reduce noise or other distracting factors
- incorporate the use of acronyms and mnemonics which can be short poems or sayings used to remember information
- foster a healthy lifestyle for workers, for example, be conscious of stress levels in the workplace, encourage physical fitness and, if food or meals are provided, make healthy foods available
- There are also different aids and products that can help prompt memory:
    - calendars
    - clocks, watches and timers with built-in prompts
    - colour coding
    - electronic organisers

Australian Government. Job Access: https://www.jobaccess.gov.au/cognition1

In many cases people living with dementia can be supported to remain in the workplace. This enables the person to continue to contribute to society both socially and economically. There is no clear consensus on the actual supports required; this needs to be addressed on an individual basis. Several case studies demonstrate a person-centred proactive approach utilising existing disability management strategies are most successful. However, some occupations may not be able to accommodate the person living with dementia due to health and safety concerns e.g. truck driver, ICU nurse (Ritchie, Tolson & Danson, 2018).

Dementia Australia provide a help sheet for people living with dementia about making employment decisions: https://www.dementia.org.au/sites/default/files/helpsheets/Helpsheet-InformationForPeopleWithDementia10-MakingEmploymentDecisions_english.pdf

Restraint

Historically, physical restraint was often seen as an effective way to maintain the safety of a person with dementia when exhibiting responsive behaviours or assessed as being at risk of falling or wandering (Bellenger, Ibrahim, Bugeja & Kennedy, 2017).

Use of restraint in both acute and long-term care facilities is common, despite several negative consequences. These problems include:

- physical e.g. pressure injuries or incontinence
- psychological e.g. anger or depression
- social e.g. social isolation

Physical restraint can also cause problems for the family and close contacts such as anger or worry. Health professionals are likely to feel worries or experience feelings of guilt (Scheepmans, de Casterle, Paquay & Milison, 2018).

Chemical (or pharmacological) restraint is also commonly used. A study in the acute hospital setting found the main methods to manage responsive behaviours were antipsychotic medications and simple psychosocial interventions. About 20% of patients with dementia were found to have some form of restraint implemented. This study also found that patients prescribed antipsychotic medications were more likely to die (White et al, 2016).

Restraint is also known to occur in the community or home care setting. Sometimes the restraint is at the initiation of the family member or informal care giver, sometimes it is initiated in consultation with a home care nurse. GPs were usually only consulted if chemical restraint was being requested. The most common reason for implementing restraint was patient safety. Other reasons included as a response to behavioural symptoms, environmental safety, and lack of care givers. Respite for the informal care giver was also identified (Scheepmans et al, 2018).

Restraint has ethical, legal and clinical consequences. It violates a person's right to freedom and dignity. In addition to the potential problems identified above, restraint increases the risk of death (Department of Health and Human Services Victoria, 2018). This risk of death is confirmed by a study investigating deaths in nursing home residents due to physical restraint in Australia (Bellenger et al, 2017).

Legal definitions in Australia are available in the Quality of Care Principles 2014 (amended 2019). This document provides the following definitions:

Restraint is defined as:

> *any practice, device or action that interferes with a consumer's ability to make a decision or restricts a consumer's free movement.*

Physical restraint:

any restraint other than:

(a) *a chemical restraint; or*

(b) *the use of medication prescribed for the treatment of, or to enable treatment of, a diagnosed mental disorder, a physical illness or a physical condition.*

Chemical restraint:

a restraint that is, or that involves, the use of medication or a chemical substance for the purpose of influencing a person's behaviour, other than medication prescribed for the treatment of, or to enable treatment of, a diagnosed mental disorder, a physical illness or a physical condition

(Australian Government, 2019)

Legislation in Australia

The Quality of Care Amendment (Reviewing Restraints Principles) Principles 2019 (Australian Government Department of Health, 2020) came into effect on 29 November 2019. The legislation applies to Residential Aged Care providers and now:

- makes it clear restraint must always be used as a last resort
- refers to state and territory legislation for prescribers' responsibilities regarding informed consent

The amended Principles require services to exhaust all alternative strategies and ensure restraints are used only as a last resort and are regularly monitored and reviewed.

The regulatory changes require residential aged care providers to satisfy several conditions before restraint can be used, including assessment by an approved health practitioner (for physical restraint) and assessment by a medical practitioner or nurse practitioner who has prescribed the medication (for chemical restraint).

Strategies for alternatives to restraints

The Standardised Care Process document from the Department of Health and Human Services Victoria provides several strategies as alternatives to restraint. These include the physical environment and social and emotional environmental strategies. This document can be found at: https://www2.health.vic.gov.au/about/publications/Factsheets/standardised-care-processes-SCP-factsheets

A British study considered how to reduce the use of chemical restraint in the recovery room area for patients with dementia. This study found these strategies all contributed to less use of inappropriate sedation.

- music,
- distraction therapy,
- utilising the 'About Me' document that came with the patient, and
- improved staff training

(Edis, 2017).

Residential Aged Care providers can also request assistance with individual residents. The service is provided by Dementia Support Australia through the Dementia Behaviour Management Advisory Service (DBMAS). https://www.dementiacentre.com/programs/dementia-support-australia

Best practice recommendations

- Implement a restraint free nursing care environment
- Ensure management strategies respect the person's dignity and autonomy
- Establish mandatory and routine educational programs for staff regarding restraint avoidance and alternative strategies

(Marin, 2019).

Sexuality

Sexuality and identity

In 2006 the World Health Organization (WHO) defined sexuality as:

> *"...a central aspect of being human throughout life encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, legal, historical, religious and spiritual factors." (WHO, 2020)*

http://www.who.int/reproductivehealth/topics/sexual_health/sh_definitions/en/

Sexuality encompasses all aspects of a person's life and is often described in the literature one of the most natural and basic aspects of life that affects an individual's identity as a human being. Sexuality is therefore much more than sexual intercourse and genital contact. Determining the gender of a baby seems to be an important consideration of parents to be and others. We tend to relate to the child in ways we consider appropriate to that gender. Boys and girls are dressed differently; usually given different toys and career and leisure expectations may differ. In short, our sexuality is integral to our identity.

Our sexuality is one of our basic aspects of being human. It includes multiple dimensions such as gender identity, sexual orientation, intimacy, beliefs, behaviours and roles (Stratford, 2017).

The aim of this section is to raise awareness of the stigma associated with sexuality issues in people with dementia and the health professional's role in the management of sexuality in people with dementia.

Sexuality and age

ACTIVITY

Write down four things you think of in relation to the following topics:

- ***Sex***
- ***How the media portrays sex***
- ***What you need to feel sexual***
- ***When you conjure up a picture of a 'dirty old man'***
- ***When you conjure up a picture of a 'dirty old woman'***
- ***Things that are 'perfectly normal' activities in private BUT you would not expect to do /see them in public.***

(Activity reproduced with permission from the Australian Centre for Evidence Based Aged Care, La Trobe University, Melbourne)

1 ______________________________

2 ______________________________

3 ______________________________

4 ______________________________

Typical responses to this question are:

Own sexuality

- Romance
- Intimacy
- Love
- Hygiene
- Companionship
- Privacy

Media Sexuality

- Sex
- Sexy clothes on perfect models
- No wrinkles/ grey hair or cellulite
- Firm breasts
- Youthfulness
- Muscles
- Slim body

You will note that when we think about our own sexuality we are not bound by age-related issues. It is only when we look at media representations that age becomes a barrier. The media represents sexuality as beauty that in turn is defined as young. The reality is that older people are sexual beings and do engage in sexual activity. This media focus on youth and beauty perpetuates the myth that older people are asexual. The reality is that older people, including those with dementia, are sexual beings. Health professionals must recognise this and consider sexuality as they consider other needs such as nutrition, mobility and safety.

Myths and facts about sexual expression and older people

Myths

- Sex is for the young and attractive
- Older adults are unable to have sex because their bodies are too old or sick
- Residents of aged care facilities can't have sex
- Residents living with dementia shouldn't have sex

(State Long-Term Care Ombudsman, 2015)

Facts

All older people may:

- think sex is important
- be sexually active
- A Swedish study of sexual activity in older adults (aged over 70 years) reported that 66% of men and 34% of women were sexually active (Stratford, 2017)
- have more than one partner
- masturbate
- have same sex partners
- hide being gay, lesbian or bisexual for fear of discrimination and judgement
- require opportunities to express their sexuality in an appropriate way
- become depressed or lose their will to live if their sexual identity is suppressed.

Attitudes and ethics

Ageism and negative attitudes to older people is prevalent in Western societies. Ageism is also evident in the media where older people are often presented as sexless and undesirable. These same societal attitudes can also be held by health professionals. This means sexuality is not regarded as a priority in care planning, especially for people living with dementia. However, research indicates older people want their sexuality and sexual expression to be acknowledged and included in health care discussion with health professionals. (Bauer, Haesler, & Fetherstonhaugh, 2015).

The diagnosis of dementia can have a significant effect on the sex life of the person and their partner, although there is very little evidence to support any changes in sexual behaviour. The diagnosis does not mean the person's sex life has to cease. People living with dementia have the right to express their sexual feelings. Concerns arise over capacity and consent. This can be difficult (Stratford, 2017).

In an existing relationship it is argued there is a case for recognising prior consent when one partner develops dementia. This assumes that in a relationship that previously included consensual sexual activity, this activity is permissible if the partner with dementia can indicate assent (Director, 2019).

Frameworks about capacity and consent include consideration of being informed and understanding the potential benefits and negative consequences. This is useful in financial, legal or medical decision making. But is it the best framework for issues such as choosing to engage in sexual activity? It is argued that sexual relationships are not necessarily logical or carefully considered, passion and sentiment are more likely to feature (Tarzia, Fetherstonhaugh & Bauer, 2012).

There is an ethical duty to support the person living with dementia who wishes to express their sexuality within an aged care setting. Best practice recommendations include:

- Development of a policy addressing:
    - A supportive environment that improves overall quality of life, including sexuality.
    - Opportunities for privacy should be promoted and respected. Consider providing 'Do not disturb' signs
    - Support for the resident's autonomy
    - Risk management
    - Training and support regarding sexuality and diversity for staff
    - Guidelines for resolving dilemmas involving sexually intimate relationships between residents
    - Information provided to family/legal guardians regarding facility policy and guidelines on intimate relationships prior to admission
- Develop a humanised approach for managing inappropriate sexual behaviours
- Respect for the resident's freedom and right to enjoy sexual expression

(Pamaiahgari, 2018)

Inappropriate sexual behaviour

Sexual relationships in the context of dementia can cause ethical concerns, especially in aged care facilities. The resident with dementia may forget their previous relationship and form attachments with other residents. Another concern may be with sexual disinhibition (Hughes & Strech, 2017).

There is no clear definition of inappropriate sexual behaviour. The literature uses terms such as hypersexuality, sexual disinhibition and inappropriate. The context of these behaviours is critical. Sexual behaviour in a private space may be considered acceptable – the same behaviour in a public or communal space may cause distress. The following framework may assist with objective descriptions:

- Sexual talk
    - Inappropriate comments and propositions
- Sexual acts
    - Inappropriate touching of oneself or others
    - Exposure of genitals
    - Masturbation
    - Intercourse
- Implied sexual acts
    - Reading/watching pornographic material

(Stratford, 2017)

Strategies for managing inappropriate sexual behaviour need to commence with a comprehensive assessment. Include careful and sensitive exploration of the person's sexual history, behaviour and attitudes. The assessment also needs to consider if this is even a problem – who is affected and/or distressed?

Consider if there are other issues – is there a misinterpretation of cues? This may occur during personal care such as assisting with hygiene.

Recommended strategies for responding to inappropriate sexual behaviours include:

- Provision of adequate space for privacy
- Staff being sensitive to the residents needs for sexual expression
- Use of distraction techniques
- Consider allocating same-sex care givers if appropriate
- Utilise clothing designed to prevent inappropriate disrobing

(Stratford, 2017)

Supporting intimacy in aged care facilities

Strategies to support intimacy:

- Describe and document what someone is doing in objective terms. Ask 'Is this a problem and if so, for whom?'
- If it is a problem for the person with dementia, family member or facility, identify what triggers the actions.
- Develop and use a care plan and evaluate its use.
- Focus on people's needs.
- Educate and counsel staff and families, where appropriate, to help them understand older people's need to express intimacy and sexuality.
- Establish a process for discussion so staff can voice concerns about close relationships among those in their care.
- Provide opportunities for families concerned about individual intimacy and sexuality to discuss their feelings

Strategies for staff training and awareness:

- Run a staff workshop on sexuality.
- Include intimacy and sexuality as topics for staff orientation and continuing education programs.
- Develop procedures for difficult incidents involving sexual expression.
- Accept such incidents can be complex and may have no easy answers.
- Use a case example of a real sexual incident to help staff explore their feelings.
- Encourage staff to voice their anxieties and discuss ideas and attitudes to reduce stress and respond reflectively.
- Encourage supervisory relationships open to issues of older people's sexual needs

(Victoria State Government, 2020)

ACTIVITY

Consider the trajectory of Alzheimer's dementia and write a summary of what treatment and interventions you might choose for yourself if you were living with dementia.

Resources

The evidence-based Sexuality Assessment Tool (SexAT) assists residential aged care facilities to support the expression of sexuality of residents. The tool aims to make residential aged care facilities aware of the issues and to guide practice. This tool can help management develop educational programs for staff in order to support the sexuality needs and sexual expression of people with or without dementia in their care.

The tool can be downloaded from: https://www.latrobe.edu.au/__data/assets/pdf_file/0008/746711/DCRC-Sexuality-Assessment-Tool-SexAT.pdf

Help sheets from Dementia Australia:

Intimacy and sexual issues. https://www.dementia.org.au/files/helpsheets/Helpsheet-CaringForSomeone19-IntimacyAndSexualIssues_english.pdf

Disinhibited behaviours. https://www.dementia.org.au/files/helpsheets/Helpsheet-ChangedBehaviours10-DisinhibitedBehaviours_english.pdf

Spirituality

The term spirituality is Latin in origin and means ‘breath of life’. Recent literature presents a diverse range of definitions of spirituality and it is noted that for some people spirituality and religion are interchangeable (Daley, Fahey-McCarthy & Timmins, 2019). It is suggested that the function of spirituality is to bring peace and serenity when a person is faced with life’s difficulties (Agli, Bailly, Ferrand & Martinent, 2018).

One definition of spirituality is:

> *“a search for answers to existential questions about the meaning of life and the individual’s relationship with the scared or transcendent. This … may or may not involve affiliation with a specific religion” (Toivonen, Charalambous & Suhonen, 2018, p 880).*

Another description of spirituality states:

> *“spirituality is integral to, but not confined by, religion and faith. It is about what gives us purpose to our lives. It is about our sources of meaning and hope, which in turn is intimately related to our connectedness to ourselves, to others and to the world” (Meaningful Ageing Australia, 2016, p 14)*

Meaningful Ageing Australia (2016) has published a guideline on spirituality in aged care. The guideline can be accessed here: https://meaningfulageing.org.au/wp-content/uploads/2016/08/National-Guidelines-for-Spiritual-Care-in-Aged-Care-DIGITAL.pdf

This guideline is based on these core values:

- Respect and acceptance
- Compassion and empathy
- Inclusion and diversity
- Dignity

The guideline includes the following domains:

- Organisational leadership and alignment
- Relationships and connectedness
- Identifying and meeting spiritual needs
- Ethical context of spiritual care, and
- Enabling spiritual expression

(Meaningful Ageing Australia, 2016).

Health professionals seeking to take a holistic and person-centred approach to care acknowledge that the person with dementia has spiritual needs.

Spiritual care has value to people living with dementia and their significant others. It may enhance meaning and purpose in life, assist with maintaining relationships, provide comfort and hope, and add to the suite of coping strategies in place (Palmer, Smith, Paasche-Orlow & Fitchett, 2020).

Spirituality is expressed differently by everyone and may be achieved openly through religion or in less obvious ways. It is important that the spiritual needs of the person with dementia are considered and addressed wherever possible, as this can promote wellbeing, a sense of identity and self-esteem. Spirituality should form part of the assessment of the person with dementia and pre-morbid expressions of spirituality should continue to be observed.

Spiritual care is provided within the context of the relationship between the health professional and the client. It is therefore important that the appropriate spiritual practices are incorporated in an individual's care.

Examples of ways in which health professionals can enhance their understanding of the person's spiritual needs include:

- Attentive listening to the person's spiritual perspective
- Close observation and documentation of what provides spiritual inner peace and comfort to the person
- Provision of space, respect and enablement of spiritual practices for the person
- Utilise the person's life story
- Consider use of reminiscence and validation therapies to assist in discovering what is spiritually meaningful for the person

(Keenan & Kirwan, 2018).

ACTIVITY

Consider: How would you/do you ensure that you identify and meet the spiritual needs of the person with dementia?

What, if anything, limits your ability to meet the spiritual needs of the person with dementia?

Grief and loss

Much is written about the losses felt by carers of people with dementia, but it is important to note that grief and loss also affect the person with dementia. People with dementia and their carers encounter many losses and will therefore experience grief at various stages as the syndrome progresses. Loss of future, loss of independence and loss of the past as the memory deteriorates are a few examples. Major milestones such as moving to residential care are extreme causes of grief. Issues regarding grief and loss in carers are discussed in Module 9: Carer health.

It is well recognised that people with chronic health and neurodegenerative conditions experience loss and grief. For people with a diagnosis of mild cognitive impairment there may be an experience of grief and loss equivalent to chronic sorrow. Research identifies themes such as:

- Uncertainty and ambiguity
- Loss of self and roles
- Disenfranchisement and disconnection
- Emotional distress

(Ali & Smart, 2016).

Research suggests there may be some differences in the mourning processes of people living with dementia compared to the general population. The mourning process is likely to vary depending on the stage of dementia. There may be significant differences in the recognition and ability to recall the death of the partner. The person living with dementia may experience the pain of bereavement repeatedly. They may express puzzlement of the partner's absence. It may take a year or more for the person living with dementia to remember their partner has died. More time may be required to process grief, become accustomed to the partner's absence, and then find an enduring connection with the deceased within their ongoing life. Both health professionals and family caregivers are uncertain about how to support the person living with dementia through the experience of significant loss, such as the death of a partner (Watanabe & Suwa, 2017).

An earlier study found that people living with dementia who experience grief and loss may seem more irritable, lose their appetite, have increased bodily complaints, become less physically active and less interested in events. These non-verbal expressions may reflect an inability for the person with dementia to verbally express their grief. However, they enjoyed being visited and did not withdraw from social activities to the same degree as the general population. This difference was attributed to memory impairment (Johansson & Grimby, 2012)

It is important that health professionals acknowledge that people with dementia do experience loss and experience and exhibit grief, and that emotions are preserved well into the later stages of dementia.

Health professionals must also be sensitive to the common circumstance where a person with dementia asks repeatedly for a family member, usually a spouse, who has in fact died. Each time the person is told this they may experience grief, which can cause distress to those providing care. This needs to be recognised as a workload issue when health professionals and family caregivers need to repeatedly describe the death and cope with the bereavement each time (Johansson & Grimby. 2012).

Early life trauma

Early life trauma has already been identified as a potential risk factor for developing dementia. Research indicates that about 70% of people living with dementia have had at least one traumatic event earlier in their lives (Wang et al, 2016). Other research indicates that over half the general population have experienced at least one traumatic event in their lifetime (Ganzel, 2018). Trauma as a risk factor is particularly evident in the Australian Indigenous population and research into this area is continuing. Refer to Module One for further discussion.

Trauma is defined as "events that threaten death, serious injury, or sexual violence to self or other" (Ganzel, 2018, p 410). Traumatic events include extraordinary threatening and catastrophes that may be natural or man-made. These include natural disasters, serious accidents, and war (Wang et al, 2016).

Trauma reactivation may become more evident in older people and may present as a type of post-traumatic stress syndrome (PTSD). PTSD can manifest as difficulties with processing and regulating emotions, poor concentration, irritability, jumpiness, distrust, flashbacks, insomnia, nightmares, feelings of numbness, apathy, and/or a distorted sense of blame. Anxiety and depression often occur co-morbidly with PTSD (Ganzel 2016).

This can cause great anxiety and distress to both the person and the caregiver (Ganzel, 2018). People who have experienced trauma and then develop dementia may have difficulties integrating the past with their present challenges in life. This means their traumatic past and current functioning may become enmeshed (Craftman, Swall, Bakman, Grundberg & Hagelin, 2020).

Common triggers for trauma reactivation may include:

- Provision of personal hygiene. Being undressed and showered may trigger memories of assault or rape
- Serving meals. Access to food, especially bread is seen as very important. Some people may try to hide or hoard food and become distressed when meals are cleared away
- Clothing and physical appearance of caregivers. Uniforms may trigger memories of prisons or camps.
- Medical interventions. These may trigger memories of being subjected to military or prison camp experiments

(Craftman et al, 2020).

The importance of knowing the person is particularly evident in these cases. However, caregivers and family are not always aware of events in the person's background. Older people often do not discuss earlier traumatic events in their lives. There is a need for a validated trauma assessment tool (Ganzel, 2016).

Provision of care for people living with dementia and reactivated trauma requires skill and sensitivity. A strategy is to adapt and follow the person's expression of their situation. This means:

- Know the life story so that care can be adjusted. Appreciate the significance of person-centred care (See Module ??? #).
- Be flexible in managing emotional expressions. Recognise challenging situations. Avoid and adjust for potential triggers.

(Craftman et al, 2020).

Transition to community and residential services

As dementia progresses there becomes a need for external assistance from community-based services. This is a very difficult decision for people living with dementia and their family/caregivers.

There are large numbers of services assisting people with dementia and their carers in the home. This section provides a brief summary of available services.

There are two pathways depending on the age of the person requiring assistance.

People aged 65 years or older need to access services via 'My Aged Care'. Eligibility for services will be ascertained by the Aged Care Assessment Teams.

My Aged Care: https://www.myagedcare.gov.au/

Aged Care Assessment Teams: https://www.servicesaustralia.gov.au/organisations/health-professionals/services/assessment-aged-care

Aboriginal and Torres Strait Islander people may access 'My Aged Care' from the age of 50 years:

https://www.myagedcare.gov.au/support-aboriginal-and-torres-strait-islander-people

People aged less than 65 years need to access services via 'National Disability Insurance Scheme (NDIS)

NDIS: https://www.ndis.gov.au/understanding

Many issues can arise in the transition from independence to accepting external assistance from community services. The situation is often made more complex when the recipient of services has dementia. There may be resistance from the family carer and/or the person with dementia. The person with dementia may also insist that services are not needed and 'turn them away'.

The other issue is that demand for these services greatly exceeds the capacity of the system. People may find there are extended waiting periods before funded services commence. https://www.myagedcare.gov.au/assessment-decision-home-care-packages

ACTIVITY

Think about how you might respond in the following situation

Mr H has moderate dementia and lives at home with his wife. Mrs H has trouble showering her husband and is having difficulty cooking for herself and Mr H. Following referral from Mr H's local doctor, an ACAT worker visits to assess Mr and Mrs H's needs. The worker notes that Mrs H appears stressed and anxious. The worker suggests home delivered meals for them both and some personal care assistance for Mr H. Mrs H agrees to this and appears quite relieved that she is going to get some help. Mr H becomes angry, stating that he can look after himself and that he does not want any 'strangers' in the house. Mrs H becomes very distressed and says she doesn't need the services after all and that she can manage.

What would you do?

The level and accessibility of services may vary depending on the area. More detailed information regarding availability of services in your local area can be obtained through the Australian Government aged care portal: www.myagedcare.gov.au

As time goes by and the person living with dementia becomes more advanced in their disease trajectory, there may need to be a discussion about transferring to residential care services on a permanent basis.

Dementia Australia provides a help sheet regarding this decision: https://www.dementia.org.au/files/helpsheets/Helpsheet-ResidentialCare01-ResidentialAgedCare_english.pdf

Relocation into residential care can have a negative impact on the person living with dementia. Studies have found increased mortality, negative physical effects, negative psychological effects, and negative social effects (Ryman et al, 2018).

These negative effects have implications for practice. Older adults, family members, and staff in residential aged care facilities need to be aware of the risk of this phenomenon. Suggestions to manage relocation stress include:

- Monitor new residents and assess for symptoms of relocation stress in the first 12 months
- Adapt current relocation guidelines for cognitively intact adults to assist people living with dementia
- Use positive reframing of the move

(Costlow & Parmelee, 2019).

These additional help sheets from Dementia Australia have advice:

Choosing a residential aged care home: https://www.dementia.org.au/files/helpsheets/Helpsheet-ResidentialCare02-Choosing-Residential-Aged-Care-Home_english.pdf

Coping with placement: https://www.dementia.org.au/files/helpsheets/Helpsheet-ResidentialCare05-CopingWithPlacement_english.pdf

Summary

This session has highlighted the fact that dementia impacts on all aspects of life and that people with dementia undergo many life transitions as the condition progresses. The session has identified the important role of health professionals in addressing social and lifestyle factors when caring for a person with dementia. Health professionals are in the position of being able to promote optimum quality of life for the person with dementia and their carers.

References

Advanced Care Planning Australia. (2020). *What is advanced care planning?* http://www.advancecareplanning.org.au/individuals/what-is-advance-care-planning#/

Agli, O. Bailly, N. Ferrand, C. & Martinent, G. (2018). Spirituality, quality of life, and depression in older people with dementia. *Journal of Religion, Spirituality & Aging. Vol 30*(3) pp 268-278.

Ali, J. & Smart, C. (2016). *Mourning me: an interpretive description of grief and identity loss in older adults with mild cognitive impairment*. Conference Paper. Alzheimer's Association International Conference. Toronto, Canada.

Andrew, C. Phillipson, L. & Sheridan, L. (2019). What is the impact of dementia on occupational competence, occupational participation and occupational identity for people who experience onset of symptoms while in paid employment? A scoping review. *Australian Occupational Therapy Journal. Vol 66*. Pp 130-144.

Australian Government. (2018). *Cognition – Managing problem solving, thinking, attention and memory at work.* https://www.jobaccess.gov.au/cognition1

Australian Government. (2019). *Quality of Care Principles 2014* (amended 2019). https://www.legislation.gov.au/Details/F2020C00096

Australian Government Department of Health. (2020). *Minimising restraints in aged care.* https://www.health.gov.au/health-topics/aged-care/providing-aged-care-services/working-in-aged-care/minimising-restraints-in-aged-care

Australian Law Reform Commission. (2014). *Informed consent to medical treatment.* https://www.alrc.gov.au/publication/equality-capacity-and-disability-in-commonwealth-laws-dp-81/10-review-of-state-and-territory-legislation/informed-consent-to-medical-treatment/

Austroads. (2017). *Assessing fitness to drive.* https://austroads.com.au/drivers-and-vehicles/assessing-fitness-to-drive

Bauer, M. Haesler, E. & Fetherstonhaugh, D. (2015). Older people's sexuality in health care. *Health Expectations. Vol 19*. Pp 1237-1250.

Bellenger, E. Ibrahim, J. Bugeja, L. & Kennedy, B. (2017). Physical restraint deaths in a 13-year national cohort of nursing home residents. *Age and Ageing. Vol 46*. Pp 688-693.

Benbow, S. & Kingston, P. (2017). Spontaneous concerns about risk and abuse reported by people with dementia and their carers. *The Journal of Adult Protection. Vol 19* (2). Pp 92-99.

Clarke, C. & Mantle, R. (2016). Using risk management to promote person-centred dementia care. *Nursing Standard. Vol 30* (28). Pp 41-46.

Costlow, K. & Parmelee, P. (2019). *The impact of relocation stress on cognitively impaired and cognitively unimpaired long-term care residents*. Aging and Mental Health. DOI: 10.1080/13607863.2019.1660855

Craftman, A. Swall, A. Bakman, K. Grundberg, A. & Hagelin, C. (2020). Caring for older people with dementia reliving past trauma. *Nursing Ethics. Vol 27*(2). Pp 621-633.

Daly, L. Fahey-McCarthy, E. & Timmins, F. (2019). The experience of spirituality from the perspective of people living with dementia: a systematic review and meta-synthesis. *Dementia. Vol 18* (2). Pp 448-470.

Department of Health and Human Services Victoria. (2018). *Standardised Care Process: Physical restraint*. https://www2.health.vic.gov.au/about/publications/Factsheets/standardised-care-processes-SCP-factsheets

Dementia Australia. Helpsheets:

About you...making employment decisions. https://www.dementia.org.au/sites/default/files/helpsheets/Helpsheet-InformationForPeopleWithDementia10-MakingEmploymentDecisions_english.pdf

Choosing a residential aged care home. https://www.dementia.org.au/files/helpsheets/Helpsheet-ResidentialCare02-Choosing-Residential-Aged-Care-Home_english.pdf

Coping with placement. https://www.dementia.org.au/files/helpsheets/Helpsheet-ResidentialCare05-CopingWithPlacement_english.pdf

Disinhibited behaviours. https://www.dementia.org.au/files/helpsheets/Helpsheet-ChangedBehaviours10-DisinhibitedBehaviours_english.pdf

Driving. https://www.dementia.org.au/files/helpsheets/Helpsheet-CaringForSomeone07-Driving_english.pdf

Driving and dementia. https://www.dementia.org.au/files/helpsheets/Helpsheet-InformationForPeopleWithDementia04-DrivingAndDementia_english.pdf

Intimacy and sexual issues. https://www.dementia.org.au/files/helpsheets/Helpsheet-CaringForSomeone19-IntimacyAndSexualIssues_english.pdf

Residential aged care. https://www.dementia.org.au/files/helpsheets/Helpsheet-ResidentialCare01-ResidentialAgedCare_english.pdf

Dickins, M. Goeman, D. O'Keefe, F. Iliffe, S. & Pond, D. (2018). Understanding the conceptualisation of risk in the context of community dementia care. *Social Science & Medicine. Vol 208*. Pp 72-79.

Director, S. (2019). Consent's dominion: dementia and prior consent to sexual relations. *Bioethics. Vol 33*. Pp 1065-1071.

Edis, H. (2017). Improving care for patients with dementia in the recovery room. *British Journal of Nursing. Vol 26* (20). Pp 1102- 1108

ELDAC. (2018). *Emergency Medical Treatment*. https://www.eldac.com.au/tabid/5274/Default.aspx

Evans, D. (2019). An exploration of the impact of younger-onset dementia on employment. *Dementia. Vol 18*(1). Pp 262-281.

Fallon, A. & O'Neill, D. (2017). Ch 31: Driving and dementia. In Ames, D., O'Brien, J. & Burns, A. (2017). *Dementia*. (5thed.). London. CRC Press.

Ganzel, B. (2016). Trauma-informed hospice and palliative care. *The Gerontologist. Vol 58*(3). Pp 408-419.

Guideline Adaptation Committee. (2016). *Clinical practice guidelines and principles of care for people with dementia*. Sydney. Guideline Adaptation Committee.

Hegde, S. & Ellajosyula, R. (2016). Capacity issues and decision-making in dementia. *Annuls of Indian Academy of Neurology. Vol 19* (Supp 1). S34-S39.

Hughes, J. & Strech, D. (2017). Ch 33: Ethical issues. In Ames, D., O'Brien, J. & Burns, A. (2017). *Dementia*. (5thed.). London. CRC Press.

Ibrahim, J. (2013). *Driving with dementia*. Video resource. YouTube. https://www.youtube.com/watch?v=4F9z8mPhcTw

JBI. (2019a). Recommended Practice. *Dementia: Consent issues*. The Joanna Briggs Institute EBP Database. JBI@Ovid. JBI2419.

JBI. (2019b). Recommended Practice. *Informed consent (older people): residential aged care provision*. The Joanna Briggs Institute EBP Database. JBI@Ovid. JBI2136.

Johansson, A & Grimby, A. (2012). Grief among demented elderly individuals: a pilot study. *American Journal of Hospice & Palliative Medicine. Vol 30*(5). Pp 445-449.

Karlawish, J. (2020). *Assessment of decision-making capacity in adults*. UpToDate. Topic 98592. Version 7.0. https://www.uptodate.com/contents/assessment-of-decision-making-capacity-in-adults#H125608126

Keenan, P. & Kirwan, M. (2018). Nurses' understanding of spirituality and the spirituality of older people with dementia in the continuing care setting. *Religions. Vol 9*(50). Pp 1-10.

Marin, T. (2018). *Evidence Summary. Advance care planning/advance directive*. The Joanna Briggs Institute EBP Database. JBI@Ovid. JBI4969.

Marin, T. (2018). *Evidence Summary. Physical restraint residential aged care (effectiveness and use).* The Joanna Briggs Institute EBP Database. BI@Ovid. JBI1115.

Meaningful Ageing Australia. (2016). *National guidelines for spiritual care in aged care. Parkville, Meaningful Ageing Australia*. https://meaningfulageing.org.au/wp-content/uploads/2016/08/National-Guidelines-for-Spiritual-Care-in-Aged-Care-DIGITAL.pdf

Medical Board of Australia. (2014). *Good medical practice: a code of conduct for doctors in Australia*. https://www.medicalboard.gov.au/Codes-Guidelines-Policies/Code-of-conduct.aspx

Mills, M. (2017). *Dementia and guardianship: challenges in social work practice. Australian Social Work. Vol 70*(1). Pp 30-41.

NSW Government, Attorney General's Department. (2009). *Capacity Toolkit*. https://www.justice.nsw.gov.au/diversityservices/Documents/capacity_toolkit0609.pdf

Palmer, J. Smith, A. Paasche-Orlow, R. & Fitchett, G. (2020). Research literature on the intersection of dementia, spirituality, and palliative care: a scoping review. *Journal of Pain and Symptom Management*. Pp 1-19.

Pamaiahgari, P. (2018). *Evidence Summary. Sexuality and dementia*. The Joanna Briggs Institute EBP Database. JBI@Ovid. JBI3474.

Pennington, C. Davey, K. Meulen, R. Coulthard, E. & Kehoe, P. (2018) Tools for testing decision-making capacity in dementia. *Age and Ageing*. *Vol 47*. Pp 778-784.

Purser, K. & Rosenfeld, T. (2014). Evaluation of legal capacity by doctors and lawyers: the need for collaborative assessment. *Medical Journal of Australia*. *Vol 201*(8). Pp 483-485.

Ritchie, L. Tolson, D. & Danson, M. (2018). Dementia in the workplace case study research: understanding the experiences of individuals, colleagues and managers. *Ageing and Society*. *Vol 38*. Pp 2146-2175.

Ryman, F. Erisman, J. Darvey, L. Osborne, J. Swartsenburg, E. & Syurina, E. (2018). Health effects of the relocation of patients with dementia: a scoping review to inform medical and policy decision-making. *The Gerontologist*. *Vol 59*(6). Pp e674-e682.

Scheepmans, K. de Casterle, B. Paquay, L. & Milison, K. (2018). Restraint use in older adults in home care: a systematic review. *International Journal of Nursing Studies*. *Vol 79*. Pp 122-136.

Series, H. & Jacoby, R. (2017). Ch 30: Legal issues and dementia. In Ames, D., O'Brien, J. & Burns, A. (2017). *Dementia*. (5thed.). London. CRC Press.

Silvaggi, F. Leonardi, M. Tiraboschi, P. Muscio, C. Toppo, C. & Raggi, A. (2020). Keeping people with dementia or mild cognitive impairment in employment: a literature review on its determinants. *International Journal of Environmental Research and Public Health*. DOI.org/10.3390/ijerph17030842.

Sinclair, C. Field, S. & Blake, M. (2018). Supported decision-making in aged care: a policy development guideline for aged care providers in Australia. 2nd Ed. Sydney, Cognitive Decline Partnership Centre.

Slade, S. (2019). Evidence Summary: Dementia and informed consent. The Joanna Briggs Institute EBP Database. JBI@Ovid. JBI1502.

State Long-Term Care Ombudsman. (2015). *Sexuality and Aging: Debunking the myths*. Iowa Department of Aging.

Stratford, J. (2017). Ch 27: Sexuality and dementia. In Ames, D., O'Brien, J. & Burns, A. (2017). *Dementia*. (5thed.). London. CRC Press.

Swaffer, K. (2015). Dementia and prescribed disengagement. *Dementia*. *Vol 14*(1). Pp 3-6.

Tarzia, L. Fetherstonhaugh, D. Bauer, M. (2012). Dementia, sexuality and consent in residential aged care facilities. *Journal of Medical Ethics*. *Vol 38*. Pp 609-613.

The Law Society of New South Wales. (2016). *When a client's mental capacity is in doubt*. The Law Society of NSW. Pp 1-23.

The Law Society of Western Australia. (2016). *When a client's capacity is in doubt*. The Law Society of WA. Pp 1-22.

The National Health and Medical Research Council. The Australian Research Council. Universities Australia. (2018). National statement on ethical conduct in human research 2007 (Updated 2018). National Health and Medical Research Council.

Therapeutic Guidelines. (2016). *Advance care planning*. https://tgldcdp.tg.org.au/viewTopic?topicfile=advance-care-planning&guidelineName=Palliative%20Care#toc_d1e47

Thomson, L. Stanyon, M. Dening, T. Heron, R. & Griffiths, A. (2019). Managing employees with dementia: a systematic review. *Occupational Medicine*. *Vol 69*. Pp 89-98.

Toivonen, K. Charalambous, A. & Suhonen, R. (2018). Supporting spirituality in the care of older people living with dementia: a hermeneutic phenomenological inquiry into nurses' experiences. *Scandinavian Journal of Caring Sciences. Vol 32*. Pp 880-888.

Victorian Law Reform Commission. (2012). Guardianship Final report. Ch 7: *Capacity and incapacity*. https://www.lawreform.vic.gov.au/sites/default/files/Guardianship_FinalReport_Ch%207_Capacity%20and%20incapacity.pdf

VicRoads. (2018). *Dementia and driving*. https://www.vicroads.vic.gov.au/licences/health-and-driving/medical-conditions-and-driving/dementia

Victoria State Government. (2020). *Sexuality*. https://www2.health.vic.gov.au/ageing-and-aged-care/dementia-friendly-environments/strategies-checklists-tools/sexuality

Wang, L. Yang, L. Yu, L. Song, M. Zhao, X. Gao, Y. Han, K. An, C. Xu, S. & Wang, X. (2016). Childhood physical neglect promotes development of mild cognitive impairment in old-age – a case control study. *Psychiatry Research*. *Vol 242*. Pp 13-18.

Watanabe, A & Suwa, S. (2017). The mourning process of older people with dementia who lost their spouse. *Journal of Advanced Nursing*. *Vol 73*(9). Pp 2143-2155.

White, N. Leurent, B. Lord, K. Scott, S. Jones, L. & Sampson, E. (2016). The management of behavioural and psychological symptoms of dementia in the acute general medical hospital: a longitudinal cohort study. *International Journal of Geriatric Psychiatry. Vol 32*. Pp 297-305.

World Health Organisation. (2020). *Sexual and reproductive health*. https://www.who.int/reproductivehealth/topics/sexual_health/sh_definitions/en/