

Advancing practice in the care of people with dementia

3rd edition

Module 5:

Social and lifestyle considerations



**Dementia
Training
Australia**

Contents

Module 5: Social and lifestyle considerations	3
Legal considerations	4
Driving	12
Safety and risk.....	14
Restraint.....	14
Sexuality.....	18
Spirituality.....	24
Grief and loss	25
Early life trauma	26
Transition to community services.....	27
Transition to residential care	29
Summary.....	31
References.....	32

Module 5: Social and lifestyle considerations

Introduction	This session explores the social needs of the person with dementia and how the health professional can support dignity and freedom of expression for the individual. The session presents information regarding legal considerations such as decision-making and capacity, driving, and advance care planning. The session 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	<p>On completion of this session you will be able to:</p> <ul style="list-style-type: none"> ■ 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 <p>Demonstrate an understanding of the issues surrounding sexual expression in older people with dementia.</p>
Module topics	Legal considerations Driving Safety and risk Restraint Sexuality Spirituality Grief and Loss Early life trauma Transition to community services Transition to residential care Current issues and controversies References
Suggested readings for this session	<p>Ames, D., Burns, A., & O'Brien, J. (2010). (Eds.), <i>Dementia</i>. (4th Ed) London: Hodder Arnold Publishers Ltd.</p> <p>Darzens, P., Molloy, D. W., & Strang, D. (2000). <i>Who Can Decide? The six step capacity assessment process</i>. Glenside; SA: Memory Australia Press.</p> <p>Nay, R., & Garratt, S., & Fetherstonhaugh, D. (2013). <i>Nursing Older People: Issues and Innovations in Care</i> (4th ed.) Sydney: Elsevier Churchill Livingstone.</p>

Legal considerations

Many legal issues pertain to the care of people with dementia, the main 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 are able to 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 particular 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.

Capacity must be determined by neuropsychological assessment. Capacity cannot be determined by common screening or assessment tools such as the Mini-mental state exam (MMSE). A guardian may need to be appointed once capacity is lost.

Why is this important?

Legal implications – reduced capacity has implications for testamentary capacity, such as wills and other legal documents

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 conducting day-to-day activities such as financial management

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 are discussed below and include:

- Common types of decisions that present to a clinician
- Forward planning proactive approach to changes in capacity – anticipating issues
- Types of dementia and their relevance to capacity
- Determining capacity
- Disease progression and effect on capacity and earlier decisions
- Legal and regulatory authorities relevant to capacity
- Common specific situations explained in detail
- Power of Attorney
- Guardianship and Administration

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?
- Does the person have the ability to appoint an Enduring Power of Attorney (EPOA)?
- Is the person safe to drive?
- Does the person have the ability to consent to things such as sex, 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.

Determining capacity

Forward planning proactive approach to changes in capacity – anticipating issues

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.

Defining capacity and competency

The words 'capacity' and 'competency' are often used synonymously but are, in fact, quite distinct. Competency is a legal construct and determined by a court.

The distinction is a clinical versus legal one. The words are used interchangeably to say a person's decision-making is impaired. The word 'capacity' reflects a medical assessment about whether a person has the capability (i.e., capacity) to understand and make decisions. The word 'competent' is a legal expression which means a person has been determined as competent to make the decision and their decision has legal standing. So it is possible for the clinician to argue a person has

impaired capacity because of early dementia and for a court to state the person is competent to make a decision.

Why is this important?

- Self-determination is an important human right
- Better able to match cognitive ability with decisions required
- Reduces risk of simplistic approach (e.g., relying on bedside cognitive testing)
- Enhances clinician-patient relationship
- In determining capacity the person must demonstrate that they:
 - Know and understand the problem
 - Know and understand the choices
 - Understand foreseeable consequences of the choices
 - Decisions are not made based on a delusion construct

(Darzins, Molloy, & Strang, 2000).

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 their first feature of dementia
- Executive function impairment (e.g., frontal lobe involvement) likely to require earlier forward planning
- Delusion constructs needs to be actively considered as rarely volunteered
- Use of cognitive enhancers may complicate decision-making process.

Why is this important?

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

Disease progression and effect on capacity and earlier decisions

Dementia is a progressive disease process and decision-making capacity will deteriorate over time. Whilst a decision today may not hold in the future, it may inform what a person wants once their condition has deteriorated.

Activity

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

One year ago a client with dementia agreed to residential care if functional capacity declined. Now he/she wishes to remain at home despite sustaining injuries from falls. He/she claims 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 decision made a year ago is still valid now?
- How would you determine internal consistency?
- 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 in the current situation?
- What resources might assist to inform your decisions?

Why is this important?

- The above is a common scenario as everyone changes their mind as circumstances alter
- Capacity determines whether a person is able to make a decision
- Assume patient has capacity unless proven otherwise
- Complex decisions are still possible for patients with impaired cognition (Feingold et al., 1990; Kitwood, 2001; Koch, 2002).

Legal and regulatory authorities relevant to capacity

Legal avenues available to assist with determining competence include:

State-appointed guardian and advisory services such as The Public Guardian in Tasmania and the Office of the Public Advocate (OPA) in most Australian states and territories.

The Victorian Civil and Administrative Tribunal and the Tasmanian Guardianship and Administration Board have legal authority to determine competence and appoint administrators and/or guardians and revoke Enduring Power of Attorney (EPOA).

Driving licence authorities can impose driving tests and restrict or revoke driving licences. See section in this session relating to driving for more information.

Why is this important?

- Adhere to and comply with law
- Decisions about competence are NOT a clinical responsibility
- Afford an opportunity for an objective and independent umpire to resolve an issue
- Affords impaired patients a level of protection

Medical treatment and consent

A person is often emotive in stressful situations; state laws provide very clear guidance for action in four major situations: emergent and life-threatening; elective; semi-urgent; and end-of-life. The following information assumes there is no existing Medical Enduring Power of Attorney or Guardian:

- Emergent and Life-threatening situations: As an example, in Tasmania the Directions For Medical Treatment Bill and in Victoria the Medical Treatment Act provide direction for clinicians facing consent and decision-making issues in a range of situations including emergency and life-threatening situations. Both pieces of legislation allow for treatment without consent where it is necessary to save life, prevent serious health implications, or to alleviate severe pain.
- Semi-urgent: Where treatment is considered semi-urgent, and the person is deemed to have no capacity to provide consent—request an immediate hearing at the state guardianship body. For example, in Victoria it is the Victorian Civil and Administrative Tribunal (VCAT) or Guardianship and Administration Board (GAB) in Tasmania.
- Elective treatment or procedures allow sufficient time to determine capacity and to identify “the person responsible” as defined in relevant legislation, or appoint a medical EPOA/guardian to make the decision.
- When ‘end-of-life’ decisions are required to be made the principles are the same, though often clinicians and families become overwhelmed with this matter because of the impending death.

Medical Power of Attorney is known under different names in different states: Enduring Power of Attorney (ACT); Enduring Power of Attorney (Medical Treatment) in Victoria; Medical Power of Attorney (SA); Enduring Guardianship (NSW and Tasmania); Guardianship Orders (WA); and Medical Enduring Power of Attorney in the Northern Territory.

Where a person with dementia does not have the capacity to give consent to medical or dental treatment the law in each state allows a person identified as ‘the person responsible’ to give consent. A hierarchy of those able to consent is provided within each state’s legislation.

The relevant agency in each state provides information; for example, in Tasmania the legislation can be found at:

http://www.guardianship.tas.gov.au/persons_responsible

There is also provision for treatment without consent in certain situations, including where treatment is necessary to save life or where there is no ‘person responsible’.

Why is this important?

- Significant life and lifestyle implications
- Emotionally charged
- Looking for guidance
- Highlights need for early planning and advanced care directive.

Consent to participate in medical research

The National Health and Medical Research Council (NHMRC, 2007, updated 2014) 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. The NHMRC indicates that consent must be gained from the person with dementia wherever possible. If the person is not able to do so “the person’s guardian, or any person or organisation authorised by law” (NHMRC, 2007, p. 59) may give consent. The NHMRC also recommends that if a person with dementia, though not able to consent, is reluctant to participate or refuses to participate, this should be respected (NHMRC, 2007, p. 59).

<https://www.nhmrc.gov.au/guidelines/publications/e72>

https://www.nhmrc.gov.au/files/nhmrc/publications/attachments/e72_national_statement_march_2014_140331.pdf Accessed online July 2014

Resources

Flow chart: Example approval process for medical research procedures to be performed on adults with a disability who lack capacity to consent. This example is Victoria-based but other states and territories may have similar tools:

Office of the Public Advocate Victoria

<http://www.publicadvocate.vic.gov.au/medical-consent/176/>

Medical Treatment Act (Victoria)

<http://www.health.vic.gov.au/mta/>

Victorian Civil and Administrative Tribunal

<http://www.vcat.vic.gov.au>

Government bodies concerned with justice, legal rights, guardianship, medical treatment include the Public Advocate, departments of justice and/or the Attorney-General’s departments in many states and territories.

Office of the Public Advocate (ACT)

<http://www.publicadvocate.act.gov.au>

Office of the Public Advocate (Queensland)

<http://www.publicadvocate.qld.gov.au>

Office of the Public Advocate (WA)

<http://www.publicadvocate.wa.gov.au>

Office of the Public Advocate (SA)

<http://www.ofa.sa.gov.au>

Department of Justice

www.justice.tas.gov.au

The Public Guardian (Tasmania)

<http://www.publicguardian.tas.gov.au/>

Forward Planning

Once a diagnosis of dementia has been made it is important that the person and the family/carer consider what arrangements need to be made for a time when they can no longer make decisions regarding legal and financial issues.

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 choices 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.

Should they become incapacitated, individuals in Victoria and Tasmania are able to nominate an Enduring Power of Attorney to deal with financial matters.

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

Here are the relevant government websites for each state. Just type 'power of attorney' into the search window of the web page.

New South Wales <http://www.tag.nsw.gov.au/>

Northern Territory [http://](http://www.nt.gov.au/justice/bdm/land_title_office/power.shtml)

www.nt.gov.au/justice/bdm/land_title_office/power.shtml

Queensland <http://www.justice.qld.gov.au/justice-services/guardianship>

South Australia <http://www.lsc.sa.gov.au>

Tasmania <http://www.publicguardian.tas.gov.au/>

Victoria <http://www.justice.vic.gov.au>

Western Australia <http://www.dotag.wa.gov.au/>

Advance care planning

Advance care planning is a process enabling a patient to express wishes about his or her future health care in consultation with their health care providers, family members and other important people in their lives. Based on the ethical principle of patient autonomy and the legal doctrine of patient consent, advance care planning helps to ensure that the concept of consent is respected if the patient becomes incapable of participating in treatment decisions. (Singer, Robertson & Roy, 1996, p. 1689)

Essentially, advanced care planning 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.

Advance care plans can take the form of:

- Advanced Directives – a document clearly stating the person's wishes
- Enduring Power of Attorney – the appointment of a proxy to make treatment related decisions. (AMA, 2006)

The Australian Medical Association (AMA) also states that less formal communication of wishes can also be seen as advance care plans. These include:

- A letter to a person who will be making the decisions
- Verbal instructions from an individual to another
- A written entry in a person's medical records.

Legislation surrounding Advance Care Planning varies from state to state. The Royal Australian College of General Practitioners (RACGP) believes that 'advance care planning should be incorporated into routine general practice'. The RACGP links to Australian states and territories concerning all aspect of advance care planning:

<http://www.racgp.org.au/your-practice/business/tools/support/acp/>

Respecting Patient Choices

A program entitled Respecting Patient Choices began in Victoria at the Austin Hospital in 2002 and has been implemented in hospitals and residential care settings in other states. The program promotes advance care planning and supports education and support for health professionals. An evaluation of the community implementation of the *Respecting Patient Choices* program can be found at:

[http://www.health.gov.au/internet/nhhrc/publishing.nsf/Content/018-wilsileta1/\\$FILE/018%20William%20Silvester%20et%20al%20Submission%20B.pdf](http://www.health.gov.au/internet/nhhrc/publishing.nsf/Content/018-wilsileta1/$FILE/018%20William%20Silvester%20et%20al%20Submission%20B.pdf)

Alzheimer's Australia Fact sheet: About early planning

<http://www.fightdementia.org.au/services/planning-early.aspx>

Royal College of General Practitioners

<http://www.racgp.org.au/your-practice/business/tools/support/acp/>

Despite improved legislative guidance much confusion and uncertainty remains about the validity of advance care plans. The literature shows that, where they exist, they are not always followed by treating clinicians. Read the article entitled *Determining the validity of advance directives* by Biegler, Stewart, Savulescu and Skene, which is available on-line at http://www.mja.com.au/public/issues/172_11_050600/biegler/biegler.html

Consider your own perspective on Advance Care Directives:

- Would you encourage a person with dementia to complete a directive?
- Would you honour an advance directive?
- Would you respect the wishes of a family member or carer if they were in conflict with an advance care plan?

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. The suggestion that an individual may be unsafe to drive often strains the relationship between doctor or health professional and the patient. However, older people and people with dementia do have a greater risk of motor vehicle collisions putting at risk not only themselves but passengers and other road users. It is imperative that the issue of driving competence, although sometimes considered too difficult, must be addressed (Zur, 2010). See Alzheimer's Australia Help Sheet 2.7 Driving at:

http://www.fightdementia.org.au/common/files/NAT/20130912_NAT_HS_CaringForSomeoneHelpSheet_7.pdf

Early negotiation with the client and carers can reduce subsequent conflict so that health professionals caring for people with dementia must ensure that every client with dementia has a documented management plan to minimise risk and ultimate transition from driving. Early referral to third parties such as Aged Care Assessment Team (ACAT) or the relevant road traffic authority is frequently necessary, particularly in relation to assessment of 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 have the ability to recommend restrictions be placed on an individual's driving licence rather than revocation of the licence. 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 licencing 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 licencing authority seeking an assessment. These assessments are compulsory and tend to result in passing or failing a driving test (Austroads, 2006).

Resources

Remember that revocation of a driving licence does not necessarily stop a person who lacks the understanding that they are a driving risk; it is therefore important to determine how to remove access to driving a motor vehicle. Developing and implementing strategies to prevent a person from driving must be done in consultation with family and carers. It may be necessary to remove motor vehicles from the home or to disable them. It is important, however, to ensure access to alternative transport.

Austroads and the relevant licencing authorities provide detailed information and advice for health professionals regarding driving regulations and guidelines for medical assessment of competency to drive

Austroads

PO Box K659

Haymarket NSW 2000

Australia

Tel: 02 9264 7088

Fax: 02 9264 1657

e-mail: austroads@austroads.com.au

Web: <http://www.austroads.com.au/drivers-vehicles/assessing-fitness-to-drive>

Changed conditions ahead: Dementia and driving guide for families and carers

Alzheimer's Australia Victoria and Royal Automobile Club Victoria (RACV)

http://www.fightdementia.org.au/common/files/VIC/Dementia_and_Driving_guide_for_family_carers.pdf

Dementia and driving in Victoria

Alzheimer's Australia victoria Discussion Paper

[http://www.fightdementia.org.au/common/files/VIC/Dementia\)and\)Driving_2013.pdf](http://www.fightdementia.org.au/common/files/VIC/Dementia)and)Driving_2013.pdf)

Australian Government Department of Social Services aged care portal

<http://www.myagedcare.gov.au/eligibility-and-assessment/acat-assessments>

Victoria Government. *Maintaining Mobility - The Transition from Driver to Non-Driver* provides information regarding practical support to older drivers as they stop driving

<http://www.transport.vic.gov.au/research/research-and-policy-development-publications/maintaining-mobility>

RACV Dementia, driving and mobility guide

<http://www.racv.com.au/wps/wcm/connect/racv/internet/primary/road+safety/older-drivers/dementia+and+driving/dementia,+driving+and+mobility>

Ibrahim, J. Driving with dementia animated video

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

Safety and risk

All health professionals are eager to ensure the safety of those in their care 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. The legal aspects of the health professional's obligation in relation to people with dementia and risk-taking behaviour are also presented.

Cheung and Yam (2005) identified that:

Over the past 20 years, there has been a shift in emphasis in health care from a strong paternalistic approach to a greater concern and respect for the personal autonomy of patients (Dodds, 1996). There is also an increasing demand for an individualised approach to care which is more supportive than controlling. The awareness of patients' rights and self-determination has filtered through all medical, nursing and allied health education programmes. (p. 38)

This shift of emphasis has meant that 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 and choice.

The responsibility of the health professional is to ensure that the person, if capable, and/or family and carers are informed of the risk, and that options are discussed (Waring, 2000).

Restraint

Physical restraint is often seen as an effective way to maintain the safety of a person with dementia exhibiting unmet needs behaviours or at an extreme risk of falling. Much has now been written about the dangers of physical restraint and there is a growing acceptance that it is not an appropriate intervention (De Bellis, Mosel, Curren et al., 2011; Wang & Moyle, 2005). This section presents a discussion as to the challenges faced by healthcare professionals as environments move away from restraint as a first-line intervention.

A couple of the key points in Alzheimer's Australia's (2014) report on *The use of restraints and psychotropic medications* was that it should only be used as a last resort; there are alternative measures to the use of restraints and strategies to be implemented in the prevention of abuse of older people with dementia.

Health practitioners have a responsibility to ensure individual rights are upheld and quality care is provided.

Anticipating
and managing
the challenge
to restrain

Definition of restraint

Evidence of why restraint is used revolves around the following:

- Fear of injury to the client/patient/resident
- Fear of injury to others: staff /other patients/visitors
- Consideration that the environment is in some way unsafe
- Insufficient staff to observe the person and therefore restraint is the only option available
- Fear of legal action if the person sustains an injury if not restrained, or harms others
- Family members place pressure on health practitioners to ensure the safety of the individual
- Models of care that are task-orientated rather than person-centred are more likely to use restraint
- Lack of understanding of risk management strategies.

Any physical, chemical or environmental intervention used specifically to restrict the freedom of movement—or behaviour perceived by others to be antisocial—of a resident designated as receiving high or low care in an aged care facility.

It does not refer to equipment requested by the individual for their safety, mobility or comfort. Neither does it refer to drugs used—with informed consent—to treat specific, appropriately diagnosed conditions where drug use is clinically indicated to be the most appropriate treatment.

When defining restraint the literature shows a trend away from using the methods or equipment contained in the definition. In more recent times the definitions have described the intent of the action. The above definition reflects this change.

Thus restraint by definition may be seen to be a human rights rather than a medical issue.

However, it is important to remember that:

- The only legal definition of restraint use is within the Mental Health Act
- There are no other legal definitions of restraint in Australia.

Evidence of efficacy of restraint

The initiative to reduce restraint use is not new. Dr Philippe Pinel is credited with being the pioneer for removing restraints in eighteenth-century France. His legacy was revived in the USA in the 1970s when more than half of the nearly 1.5 million Americans in nursing homes were restrained (Levine, 1996).

The use of restraints is an affront to human rights, dignity, autonomy and choice. Increased public awareness and the availability of alternatives to restraint use had led to significant policy review and revision, both locally and internationally (Mitchell, 1994). US federal regulations in response to the *Omnibus Budget Reconciliation Act 1987* maintained that nursing home residents had the right to be free from unnecessary physical and chemical restraint (Rader et al., 1992).

Issues related to avoiding restraint

Current research shows increased scrutiny in Australia and elsewhere regarding physical restraint for people with dementia reflected in publications both government and the non-for-profit sector (Qureshi, 2009; Department of Health & Ageing, 2012; Alzheimer's Australia, 2014)

- Legal ramifications of using restraints include:
- Consent
- Trespass to the person
- Assault and battery
- False imprisonment
- Negligence

Some side effects of restraint include:

- Diminished functional capacity
- Skin irritation and breakdown
- Incontinence
- Impaired circulation
- Nerve damage
- Constipation
- Pneumonia
- Agitation; humiliation
- More severe injury
- Death

It would appear that in creating an environment for change to take place, some strategies could be employed.

These include:

- Providing an environment which convinces others that change is necessary. If health practitioners do not see the need to change practice then they won't. You need to have or be the champion for the cause and bring others on-side.
- Providing role models that care can be provided, in most instances, without the need to restrain
- Providing health practitioners with the knowledge and understanding regarding restraint use/removal. This would include the need for alternative strategies and/or perhaps other resources
- Providing an environment that supports an advocacy on behalf of the resident when the intervention of restraint was perceived as not acceptable, or required.

Alternatives to restraint

Evans, D., Wood, J., & Lambert, L. (2002). Physical restraint – Part 2: Minimisation in acute and residential care facilities. in the *Joanna Briggs Best Practice Information Sheet* relating to restraint use at: <http://connect.jbiconnectplus.org/ViewSourceFile.aspx?0=4327>

Restraint-related resources

Hartford Institute for Geriatric Nursing, Consultgerirn.org - *Use of Physical Restraints with Elderly Patients* that can be found at:
http://consultgerirn.org/topics/physical_restraints/want_to_know_more

Alzheimer's Australia. (2014). The use of restraints and psychotropic medications in people with dementia. Accessed online July 2014 at:
http://www.fightdementia.org.au/common/files/NAT/20140321_Publication_38_A4_print%20version_Web.pdf

Burns, K., Jayasinha, R., Tsang, R., & Brodaty, H. (2012). Behaviour Management - A guide to good practice. Managing behavioural and psychological symptoms of Dementia (BPSD). NSW: Dementia Collaborative Research centre - Assessment and Better Care
http://www.dementiaresearch.org.au/images/dcrc/output-files/328-2012_dbmas_bpsd_guidelines_guide.pdf

Dementia Behaviour Management Advisory Service in each state and territory
<http://dbmas.org.au/>

Developed by the Commonwealth Department of Health and Ageing this decision-making tool aims to inform decisions regarding restraint use in response to BPSD:

Department of Health and Ageing. (2012). *Decision-making tool: responding to issues of restraint in aged care*. Commonwealth of Australia: Canberra.
Decision-making tool: responding to issues of restraint in aged care
<http://www.health.gov.au/internet/main/publishing.nsf/Content/publications-D>

Department of Health and Ageing (2012). *Decision Making Tool- Supporting a restraint-free Environment in Community Aged Care*. Commonwealth of Australia: Canberra.
<http://www.health.gov.au/internet/main/publishing.nsf/Content/ageing-decision-restraint-residential-handbook>

Hospital Bed Safety Workgroup. Guidance for the assessment and implementation of bed rails in hospitals, long-term care facilities and home care settings (2003)
https://www.ecri.org/Documents/Patient_Safety_Center/BedSafetyClinicalGuidance.pdf

Qureshi, H. (2009). Knowledge Review 24: Restraint in Care Homes for Older People. Social Care Institute for Excellence: London. Accessed online July 2014 at:
<http://lx.iriss.org.uk/sites/default/files/resources/kr24.pdf>

Sexuality and identity

Sexuality

The World Health Organization (WHO) defines 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, 2006a)

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. 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.

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

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

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 associates sexuality with 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

All older people are:

- Asexual
- Physically incapable of sex
- Uninterested in sex
- Unattractive
- Heterosexual
- Monogamous
- Do not want to discuss their sexual health
- Perverted if they think about sex

Facts

All older people may:

- think sex is important
- be sexually active

a recent study of sexual health in older adults reported that 53 per cent of people aged 65 to 74 years were sexually active (Stacy, Tessler, Lindau et al., 2007)

- 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.

Source: Department of Health. (2010). *Well for Life, Improving Emotional Wellbeing for older people in residential aged care*. Help sheet 42: Sexual Expression, p.55.

Health professionals often struggle with the notion of older people, and especially older people with dementia, having sex. This, combined with the scarcity of policies or guidelines to assist health professionals, has resulted in sexuality being sidelined or ignored.

The Department of Health's *Well for Life* resource that focusses on emotional wellbeing in residential aged care includes a chapter on sexual expression (Department of Health, 2010).

Some strategies to give staff permission to talk about sexual expression include the following:

Facilitate regular forums for staff to:

- discuss case studies or experiences in relation to sexual expression
- raise awareness of the needs of gay, lesbian and bisexual people and learn about their historical experiences of discrimination
- understand sexual expression as a person's right.

Talk about sexual expression at handover.

Invite staff to discuss what they think about sexual expression in order to:

- acknowledge values, beliefs and staff discomfort
- address myths
- understand the impact of discriminatory responses
- enable staff to differentiate between their needs and the resident's needs
- identify inappropriate sexual expression
- simplify discussion around consent, vulnerability and duty of care
- enable staff to feel supported.

Identify staff boundaries and clarify limits of professional responsibility.

Differentiate between inappropriate sexual expression and staff discomfort with sexual expression.

Ensure staff responses to sexual expression are consistent

- When sexual expression is not discussed staff responses can vary.
- Residents who have cognitive impairment may have difficulty understanding what is required of them if staff responses are inconsistent.
- Consistent responses from staff can send a clear message to residents about what is acceptable and what is not.
- Consistency can assist individual team members to feel supported.

Develop a written policy that supports the above and includes, but is not limited to:

- Identifying the responsibilities of staff in relation to homophobia and how to protect residents from this form of discrimination
- Strategies to support sexual expression and diverse sexual identity
- A description of appropriate and inappropriate sexual activities
- Consistent strategies to respond to inappropriate sexual expression
- Documentation that protects resident privacy and dignity
- The prescription of medications for inappropriate sexual expression only considered after all reasonable alternatives have been explored, and are not used for treating staff embarrassment or to compensate for a lack of resources.

Source: Department of Health. (2010). *Well for Life, Improving Emotional Wellbeing for older people in residential aged care*. Help sheet 42: Sexual Expression, p. 55–56.

A recent evidence-based Sexuality Assessment Tool (SexAT) has been developed to assist residential aged care facilities support the expression of sexuality of residents. The tool aims to make residential aged care facilities aware of the issues and to guide practice (Bauer et al., 2013). This tool when used as intended 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:

<http://www.agedcare.org.au/publications/agendas-docs-images/sexuality-assessment-tool-sexat-for-residential-aged-care-facilities>

There is little evidence as to the impact of dementia on sexual behaviour but it is known that dementia can affect the sex life of both the person with dementia and their partner (Warner, 2005). Warner states that in the majority of cases sexual activity decreases in Alzheimer's disease but suggests that an increase in activity may be more probable in other forms of dementia, particularly those involving the frontal lobe.

Possible causes of diminished sexual activity are cited as:

- The impact of the dementia (Alzheimer's Australia, 2010)
- Coping with the diagnosis (Warner, 2005)
- The transition from partner to caregiver (Warner, 2005).

The person with dementia may also not be able to express their sexuality in the same way as they did prior to having dementia and may exhibit a change in sexual behaviour (Alzheimer's Australia, 2010).

Clients may be reluctant to discuss issues relating to sexuality and sexual activity but health professionals must be aware that problems might present; professionals must be available to offer explanation and information as necessary.

See <http://www.fightdementia.org.au/services/intimacy-and-sexual-issues.aspx>

for information on intimacy and sexual issues for the person with dementia and their family/carer.

https://www.fightdementia.org.au/common/files/NAT/20101001_Nat_QDC_6DemSexuality.pdf

The issue of capacity to consent poses perhaps the largest dilemma in relation to people with dementia who express their sexuality. This can often lead to over-protection of the person with dementia or their wishes taking second place to those of family carers and health professionals (Jones, 2014).

As with all other decisions capacity to consent to sexual relationships should be assumed unless proven otherwise. Formal assessment may be required where doubt exists about the person's capacity. Health professionals should, however, be wary of subjecting a person with dementia to rigorous assessments and be mindful they may be expecting a higher level of understanding than they would from someone who does not have dementia (Jones, 2014).

The Queensland Dementia Training Study Centre's Sexualities and Dementia resource provides health professionals with some questions which can assist in determining the level of understanding the person with dementia has and the risks associated with a relationship. These questions focus on determining the person's awareness surrounding relationships, awareness of Potential Risks and their ability to avoid exploitation:

- To what extent is the person with dementia capable of making his/her own decisions?
- Does the person with dementia have the ability to recognise the person with whom he/ she is having the relationship? Could he/she have mistaken,
 - for example, said individual for his/her original spouse/partner?
- Can the person with dementia understand what it means to be physically intimate?
- What is the person's ability to avoid exploitation? Does he/she have the capacity to say 'no' to unwanted sexual contact?
- Is the person with dementia capable of expressing his/her views and wishes within the relationship through either verbal or non-verbal communication?
- How may the person react or be affected if he/she is ignored, rejected after intimacy or the relationship ends?
- What is the person's ability to understand future sexual risk?

More information and guidance about capacity and consent in relation to sexual relationships can be found in the Queensland Dementia Training Study Centre's Sexualities and Dementia resource available on the DTSC website (<http://www.dtsc.com.au/sexualities-and-dementia-an-education-resource-for-health-professionals>)

Sexually inappropriate behaviour

Sexually inappropriate behaviours are defined by Warner (2005) as:

- Sexually explicit remarks
- Exposing breasts or genital area in public
- Touching someone (except a partner) on the breasts or genitals.

Often, behaviours considered normal in private, such as masturbation, 'groping', nakedness, 'genital scratching' and intercourse are labeled sexually inappropriate when exhibited in public. Health professionals must examine whether the environment and a lack of privacy is the issue rather than the behaviour.

Consider:

- Is it sexual behaviour?
- Is it a sexual need or expressing another need (e.g., boredom, need for touch, control, self-esteem)?
- Is it 'our' moral problem?
- Is it a family problem?
- Are both people expressing 'yes' or 'no'?
- What past history?

Behaviours deemed sexually inappropriate, although uncommon, can cause concern and distress to health professionals caring for people with dementia. However, minimal research has been conducted into the effectiveness of strategies aimed at addressing sexually inappropriate behaviours.

Strategies that have been suggested include:

- Use of modified clothing to limit the ability to undress in public
- Reinforcement of desired behaviour
- Not reinforcing inappropriate behaviour
- Allowing masturbation in private.

Resources

Alzheimer's Australia. (2010). Quality Dementia Care Series 6. Understanding dementia care and sexuality in residential aged care facilities

https://www.fightdementia.org.au/common/files/NAT/20101001_Nat_QDC_6DemSexuality.pdf

Bauer, M., Fetherstonhaugh, D., Nay, R., Tarzia, L., & Beattie, E. (2013). *Sexuality Assessment Tool (SexAT) for residential aged care facilities*.

http://www.dementiaresearch.org.au/images/dcrc/output-files/678-dcrc_formatted_sexat_jan_10_2014.pdf

Department of Health. (2010). *Well for Life, Improving emotional wellbeing for older people - In residential aged care*. Published by Wellbeing, Integrated Care and Ageing Division, Victorian Government, Department of Health, Melbourne, Victoria.

http://www.health.vic.gov.au/agedcare/maintaining/wellforlife_pubs.htm

Sexualities and Dementia: Education Resource for Health Professionals
Dementia Training Study Centres
<http://www.dtsc.com.au/resources/>

Spirituality

Van Loon (2001) defined spirituality as “the inner essence which is the basis of an individual’s vital life principle” (p. 52). Health professionals seeking to take a holistic and person-centred approach to care acknowledge that the person with dementia has spiritual needs. Spirituality is inherently linked to a person’s value system and being aware of your own value system will greatly improve your ability to assess and meet the spiritual needs of clients (Van Loon, 2001). Module 6: *Philosophy of care* provides a detailed discussion relating to recognising the impact of health professionals’ personal values on the care they deliver. 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.

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?

Activity

Spirituality resources

Van Loon, A. (2001). Assessing Spiritual Needs. In S. Koch and S. Garratt (Eds.), *Assessing Older People: A Practical Guide for Health Professionals*, p. 51–73. Sydney: Elsevier.

Wallace D. (2003). Spiritual care and the person with dementia: the development of guidelines to support staff working with people with dementia. *Dementia*, 2(3), 422–6.

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, although this may be manifested in the later stages by changes in behaviour such as exhibiting restlessness or agitation (Doka, 2004). People with dementia and their carers encounter many losses and will therefore experience grief at many stages as the syndrome progresses. Loss of future plans, 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 Session 10: *Carer health*.

Little is written about how people with dementia cope with loss and this is an area in which more research could be conducted (Doka, 2004); however, 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 (Rando, 1993).

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 (Doka, 2004). Validation of their feelings is appropriate. An information sheet by Alzheimer's Scotland (2011) discusses how persons with dementia can be best helped through grief and loss:

http://www.alzscot.org/information_and_resources/information_sheet/1788_loss_and_bereavement_in_people_with_dementia
http://www.alzscot.org/assets/0000/0176/loss_bereavement.pdf

Early life trauma

Trauma experienced in earlier life often re-emerges in people with dementia and can cause great anxiety and distress.

Trauma can occur in many forms throughout the life span. Trauma may be caused by other people, inadvertent neglect or through circumstances beyond anyone's direct control (Miesen & Jones, in Hunt et al., 1997)

Trauma is generally seen as a condition where the individual has no power or support and therefore no protection. The feature common to all people experiencing trauma is isolation and alienation from others, and ultimately from themselves. Fear, apathy and aggression are commonly exhibited by people experiencing trauma.

Miesen and Jones (1997) suggest that people living with dementia continually experience loss as their disease progresses and that many secondary symptoms of dementia such as fear, restlessness, sadness, aggression and apathy can be explained as being reactions to loss (Miesen, 1993). "These behaviours are a response to the 'consequences' of the disease rather than being symptomatic of the disease itself" (Miesen & Jones, 1997, p. 149).

A review of the literature by Browne and Schlosberg (2006) indicated the frequency in occurrence of attachment behaviours and also a parent fixation of people with dementia living in residential aged care facilities. The authors further found that the pre-morbid attachment style of the person with dementia has been shown to interact with their emotional and behavioural display during the course of dementia.

However, for some people living with dementia, problems and losses from the past (old trauma) can also resurface, creating additional psychological or emotional difficulties or pathological grieving (Miesen &

Jones, 1997). This resurfacing of a traumatic experience can result in people reliving the experience through 'flashbacks'. Much of the writing regarding past trauma re-emerging in people with dementia has related to holocaust survivors and a description of the impact of past trauma on a holocaust survivor with Alzheimer's disease can be found at:

<http://articles.latimes.com/2007/aug/23/local/me-rachel23> Intervention measures to effectively manage patients with dementia in residential aged care settings who are suffering from psychological trauma have been discussed in a paper by Flannery (2002).

Interventions

Miesen and Jones (1997) detail a range of goals in planning interventions to help a person to work through the grieving process:

1. The achievement of insight into the past, to reach the stage of acceptance and possible forgiveness and to achieve resolution of one's life story.
2. The experience, as often as possible and either alone or in groups, of moments of overt happiness (indicated by smiling, laughing, singing or dancing).
3. The development of feelings of being more at peace with oneself, with others and with the environment, leading to contentment and to meaningful relationships (even if these are only momentary).
4. The maintenance of maximum orientation and alertness.
5. Participation in meaningful activity.

However, the ability of the person with dementia to participate in these strategies may be restricted depending on the level of cognitive impairment at the time. The first goal requires a capacity to learn and a willingness to engage in such psychological work. The other goals (two through to five) are chosen if the first goal is inappropriate or does not work, and are regarded by Miesen and Jones (1997) as palliative psychological treatment. The aim of palliative psychological treatment is to provide as much emotional comfort and support as possible.

Techniques such as reminiscence work, validation therapy, music therapy, art therapy and so on may all be appropriate, either singly or in varying combinations, for use in the person with dementia.

Interventions should focus on the core goal of realising the identity of the person, enabling him or her to trust others and to feel trusted and to facilitate psychological and emotional safety.

Transition to community services

As dementia progresses there becomes a need for carers to seek external assistance from community-based services (AIHW, 2012). There are now large numbers of services assisting people with dementia and their carers in the home. Funding of community services has become very complex as both federal and state governments are involved. This section provides a brief summary of available services.

Aged Care Assessment Teams are multidisciplinary groups offering advice on appropriate needs and services. ACATs will provide advice and referrals to a range of community services. ACATs are also responsible for assessment prior to admission to residential aged care. Information regarding your local ACAT can be found at www.myagedcare.gov.au The Australian Government introduced new Home Care Packages on August 1, 2013, as part of its *Living Longer Living Better* reform package. The new home care packages replaced the former home care packages. There are four levels of care:

Level 1 supports people with basis care needs

Level 2 supports people with low level care needs (formerly Community Aged Care Packages)

Level 3 supports people with intermediate care needs

Level 4 supports people with high level care needs (formerly Extended Aged Care at Home and Extended Aged Care at Home Dementia packages).

The packages support people to remain in their own home as long as possible and provide choice and flexibility in the way the care and support is provided. Eligibility is determined through an ACAT. A member of the team which may include a doctor, nurse, or allied health professional will assess care needs at home. Access to all care packages requires assessment and approval by an ACAT. For further information:

<http://www.agedcareguide.com.au/home-community-care-information.asp?i=128>

Home and community care (HACC) services: commonly provided by local councils, HACC services include such things as personal care, nursing care, allied health assistance, home help. There is normally a small fee connected to these services depending on the individual's situation.

http://www.health.vic.gov.au/hacc/hacc_victoria/funding.htm

National Respite for Carers Program (NRCP): funds respite services to support carers. The program incorporates the Commonwealth Carer Respite Centres, Commonwealth Carer Resource Centres and the National Counselling Program. ACAT assessment is not necessary for community-based respite but is required if respite is sought in an aged care facility. (AIHW, 2012)

<http://www.health.gov.au/internet/main/publishing.nsf/Content/ageing-carers-nrcp.htm>

Other services such as Helping Hand in South Australia offer services for people living in their own homes or residential care, respite care for carers, counselling, advice and therapy services and dementia, disability and mental health support. <http://www.helpinghand.org.au/>

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. The type of situations that health professionals may encounter are:

Activity

- 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'.

Despite the growth in numbers of care packages health professionals may still be faced with a delay in accessing a package (Robinson et al., 2008)

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 Department of Social Service's aged care portal: www.myagedcare.gov.au

Transition to residential care

As the care needs of the person with dementia increase and can no longer be met at home, family and carers may decide to seek residential care.

The move to residential care means change and transition and can be very difficult for all concerned. Issues that may arise include finding a suitable facility, the level of acceptance held by the person with dementia and the feelings of the family carers. Admission to residential care requires Aged Care Assessment Team referral and assessment. This assessment determines whether the client is in need of admission to a high or low level care facility. This assessment may also determine whether the client's needs would be best met in a dementia-specific facility.

Health professionals have a role at each stage of the transition process:

Decision-making – health professionals from all disciplines may be involved as families/carers work through the process of deciding on residential care. The disciplines involved will vary according to whether the client is in hospital or the community immediately prior to the

decision being made. The role of the health professional may include assessment of care needs, advising the family/carers of care needs, providing information about local residential facilities and explaining the procedures surrounding admission.

- Finding an appropriate facility – providing advice and guidance to families/carers as to care needs and what to look for in a facility.
- Preparing both the person with dementia and the family/carer for the move – providing information as to what to expect.
- Supporting the person with dementia and the family/carer after admission.

More information regarding supporting families and carers through the transition to residential care can be obtained from Alzheimer's Australia <http://www.fightdementia.org.au/understanding-dementia/section-4-residential-care-and-dementia.aspx>

Transfer trauma can be problematic in the transition to residential care and suggested interventions can be found at:

<http://www.crisisprevention.com/Resources/Article-Library/Dementia-Care-Specialists-Articles/Treatment/Transfer-Trauma-A-Real-Issue-for-Many-Individ>

Staff within residential care facilities have a large role to play in supporting both the person with dementia and the family/carer after admission. The transition can be eased by good communication between the facility, health professionals and the family/carers of the resident. Involvement of the family/carer in care decisions from the beginning promotes this relationship.

Facility staff must also recognise that the person with dementia may be extremely anxious, distressed and afraid and may appear more confused and cognitively impaired than at home. Ensuring that the person has special items from home may ease the transition.

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.

Resources

Aged Care Assessment Teams
<http://www.myagedcare.gov.au/>

References

Assessment

Feingold, E., & Werby, E. (1990): Supporting the Independence of Elderly Residents Through Control Over Their Environment, *Journal of Housing For the Elderly*, 6, 1-2, 25-32. Accessed July 2014 at http://dx.doi.org/10.1300/J081V06N01_02

Kitwood, T. (2001). *Making Choices*. Reith Lectures, ABC.

Koch, S. (2002). *The tension between human rights and protective custody*. PhD Thesis. La Trobe University.

Legal considerations

Darzens, P., Molloy, D. W., & Strang, D. (2000). *Who Can Decide? The six step capacity assessment process*. Glenside; SA: Memory Australia Press.

National Health and Medical Research Council. (2007, updated March 2014). *National Statement on Ethical Conduct in Human Research*. Canberra: Australian Government.

Advance care planning

Australian Medical Association. (2006). *The Role of the Medical Practitioner in Advance Care Planning*, accessed on 16/07/14 at <https://ama.com.au/position-statement/role-medical-practitioner-advance-care-planning-2006>

Biegler, P., Steward, C., Savulescu, J., & Skene, L. (2000) Determining the validity of advance care directives, *Medical Journal of Australia*, 172 (11) pp. 545-548. Accessed online July 2014
<https://www.mja.com.au/journal/2000/172/11/determining-validity-advance-directives>

Singer, P. A., Roberston, G., & Roy, D. J. (1996) Bioethics for clinicians: 6. Advance care planning. *Canadian Medical Association Journal*, 15(12), 1689-1692.

Risk management/restraint

Burns, K., Jayasinha, R., Tsang, R., & Brodaty, H. (2012). Behaviour management a guide to good practice: managing behavioural and psychological symptoms of dementia. DCRC and DBMAS Commonwealth, Canberra. Accessed online July 2014
http://dementiaresearch.com.au/images/dcrc/output-files/328-2012_dbmas_bpsd_guidelines_guide.pdf

Castle, N.G., Fogel, B., & Mor, V. (1997). Risk factors for physical restraint use in nursing homes: pre- and post-implementation of the Nursing Home Reform Act. *Gerontologist*, 37(6), 737-47.

Cheung, P. P. Y., & Yam, B. M.C. (2005). Patient autonomy in physical restraint. *Journal of Clinical Nursing*, 14(1s), 34-40.

- De Bellis, A., Mosel, K., Curren, D., Prendergast, J., Harrington, A., & Muir-Cochrane, E. (2011). Education on physical restraint reduction in dementia care – a review of the literature. *Dementia*, 12(1) 93–110. Accessed online July 2014 at: <http://dem.sagepub.com/content/12/1/93.full.pdf+html>
- Evans, D., Wood, J., & Lambert, L. (2002). Physical restraint – Part 2: Minimisation in acute and residential care facilities. *Best Practice – Evidence Based Practice Information Sheets for Health Professionals*, 6(4). ISSN 1329 – 1874, Joanna Briggs Institute,
- Frengley, J. D. (1996). The use of physical restraints and the absence of kindness. *Journal of the American Geriatrics Society*, 44(9), 1125–7.
- Levine, J. M. (1996). Historical notes on restraint reduction: The legacy of Dr Philippe Pinel. *Journal of the American Geriatric Society*, 44, 1130–1133.
- Mitchell, G. (1994). The dignity of risk and the right to failure: one profile of patient-focused care. *Illuminations*, 2(4), 10.
- Molassiotis, A. (1995). Use of physical restraints 1: consequences. *British Journal of Nursing*, 4(3), 155–7.
- Molassiotis, A., & Newell, R. (1996). Nurses' awareness of restraint use with elderly people in Greece and the UK: a cross-cultural pilot study. *International Journal of Nursing Studies*, 33(2), 201–211.
- Moody, H. (1998). The cost of autonomy, the price of paternalism. In R. Disch, R. Dobrof, & H. R., Moody (1998). *Dignity and Old Age*. New York: Haworth Press.
- Murray, J., & Cott, C. (1998). Nursing staff perceptions of the use and reduction in the use of physical restraints. *Perspectives*, 22(1), 2–10.
- Nay, R. (1993). Benevolent oppression: lived experiences of nursing home life. PhD Thesis. University of New South Wales.
- Neary, M. A., Kanski, G., Janelli, L., Scherer, Y., & North, N. (1991). Restraints as nurse's aides see them. *Geriatric Nursing: American Journal of Care for the Aging*, 12(4), 191–2.
- Rader, J., Semradek, J; McKenzie, D., & McMahon, M. (1992.) Restraint strategies: reducing restraints in Oregon's long-term care facilities. *Journal of Gerontological Nursing*, 18 (11), 49–56.
- Retsas, A.P., & Crabbe, H. (1997). Use of physical restraints in nursing homes in Queensland, Australia. *Collegian*, 4(4), 14–21.
- Wang, W. W., & Moyle, W. (2005). Physical restraint use on people with dementia: A review of the literature. *Australian Journal of Advanced Nursing*, 22(4), 46–52.
- Waring, A. (2000). Constructive risk in the care of the older adult: a concept analysis. *British Journal of Nursing*, 9(14), 916–924.
- Zur, B. (2010) Engaging community partners to address at risk drivers with dementia *Occupational Therapy Now* Volume 12.5 Accessed 16/07/14 at <http://www.cata.ca/otnow/Sept10/Engaging.pdf>

Sexuality

Alzheimer's Australia. (2005). Help Sheet: Intimacy and sexual issues. Retrieved July 2014 <http://www.fightdementia.org.au/services/intimacy-and-sexual-issues.aspx>

Alzheimer's Australia. (2010). Quality Dementia Care Series 6. Understanding dementia care and sexuality in residential aged care facilities. Retrieved July 2014

https://www.fightdementia.org.au/common/files/NAT/20101001_Nat_QDC_6DemSexuality.pdf

Department of Health. (2010). *Well for Life, Improving Emotional Wellbeing for older people in residential aged care*. Help sheet 42: Sexual Expression, p. 55–56

http://www.health.vic.gov.au/agedcare/downloads/wellforlife/ewb_res_i_complete.pdf

Alzheimer's Australia – Quality Care Dementia Series:

<http://www.fightdementia.org.au/research-publications/quality-dementia-care-papers.aspx>

Jones, C. (2014). Sexualities and Dementia, Education resource for Health Professionals. Dementia Training Study Centres www.dtsc.com.au

Litz, B. T., Zeiss, A. M., & Davies, H. D. (1990). Sexual concerns of male spouses of female Alzheimer's disease patients. *The Gerontologist*, 30, 113–116.

Nay, R., Barrett, C., Gorman, D. & Berryman, C. (1997). *Developing a sexual health policy for long-term facilities*. GNPU: Melbourne.

Warner J. P. (2005). Sexuality and dementia. In Burns, A., O'Brien, J., & Ames, D. (Eds.), *Dementia* (3rd ed., p. 208–214). London: Hodder Arnold.

Woods, N. (1984). *Human sexuality*. CV Mosby: St Louis.

Grief and Loss

Doka, K. J. (2004). Grief and dementia. In K. J. Doka (Ed.), *Living with Grief: Alzheimer's Disease* (pp. 1–14). Washington, DC: The Hospice Foundation of America.

Rando, T.A. (1993). *The treatment of complicated mourning*. Champaign, IL: Research Press.

Spirituality

Van Loon, A. (2001). Assessing Spiritual Needs. In S. Koch & S. Garratt (Eds.), *Assessing Older People: A Practical Guide for Health Professionals* (pp.51–73). Sydney: MacLennan + Petty

Early life trauma

Browne, C.J., & Shlosberg, E. (2006). Attachment theory, ageing and dementia: A review of the literature. *Aging & Mental Health*, 10(2), 134–142.

Flannery, R. B. (2002). Addressing psychological trauma in dementia sufferers. *American Journal of Alzheimer's Disease and Other Dementias*, 17(4), 281. Retrieved July 2014 from <http://aja.sagepub.com/content/17/5/281>

La Ganga, M. L. (2007). Fearing the Nazis again. Los Angeles Times August 23. Retrieved July 2014 from <http://www.latimes.com/la-me-rachel23aug23,0,718123.story?coll=la-home-center>

Miesen, B., & Jones, G. (1997). Psychic pain resurfacing in dementia. In L. Hunt, M. Marshall, & C. Rowlings (Eds.), *Past trauma in Late Life*. London: Jessica Kingsley Publishers Ltd.

Miesen, B. (1993). Alzheimer's disease, the phenomenon of parent fixation and Bowlby's attachment theory. *International Journal of Geriatric Psychiatry* 8, 147–153.

Transition to community services

Australian Institute of Health and Welfare. (2012). Dementia in Australia. Cat no AGE 70. Canberra: AIHW. Retrieved July 2014 from <http://www.aihw.gov.au/publication-detail/?id=10737422958>

Robinson, A. L., Hemmings, L., Lea, E. J., McCann, D. E., Nichols, H., Rumble, R. H., et al. (2008). Issues in the transition from home to respite day care. *Australasian Journal on Ageing*, 27(1), A29. ISSN 1440-6381.