Breaking down the taboo of sexuality in residential aged care: Resources to assist aged care facility staff and family carers
Representations of sexuality
The reality

- Sexual activity declines with age, but interest, desire and capacity remain...even into the nineties!

- People living with dementia still have a need to express their sexuality and are capable of forming meaningful relationships
  - integral part of being human
  - linked to quality of life, sense of well-being
  - component of personhood

- Sexual rights embrace human rights... (WHO 2006)
Sexuality and residential aged care

- remains a major challenge
  - for people living there to express their sexuality
  - for staff to accept
- inadequate education/training & understanding of dementia
- negative and judgemental staff attitudes
- sexuality easily dismissed and labelled ‘inappropriate’ behaviour
- a ‘vulnerable population’- fears about consent, duty of care, risk taking
- paternalistic and family centred responses
- no assessment of residents’ needs, no discussion
- no privacy
- few resources/policies to guide practice
### Australian residential aged care facilities in 2011 (response rate 39.7%)

<table>
<thead>
<tr>
<th>Activity</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>Facility gathers information about residents' sexual needs</td>
<td>20.2%</td>
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<tr>
<td>Facility gathers information about residents' intimacy needs</td>
<td>31.7%</td>
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<tr>
<td>Facility gathers information about residents' sexual history (before they entered care)</td>
<td>13.4%</td>
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<tr>
<td>Facility gathers information about residents' disruptive sexual behaviour</td>
<td>66.1%</td>
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<tr>
<td>Assessment occurs when disruptive behaviour occurs</td>
<td>96.9%</td>
</tr>
<tr>
<td>Facility has a written policy that covers sexuality</td>
<td>22.7%</td>
</tr>
<tr>
<td>Never had education and training about sexuality and older people</td>
<td>40.7%</td>
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Less than 3% of facilities in Victoria had addressed the topic of sexuality, love, intimacy, relationships in promotional information for residents and families.

What people living in aged care and family say

- Expression of sexuality & intimacy remain important
- Importance and how one expresses it, is very individual
- Limited privacy
- Limited opportunities to form new relationships...or maintain old ones
- No-one to talk to about it
- Staff are uncomfortable and hold negative attitudes
- Not a matter for the family

- Appearances are important
- What ever makes them happy...
- Accepting only up to a point
- We need to know what’s going on
- It needs to me mediated by staff
Supporting aged care facilities to address sexuality as a legitimate component of care

- to identify how well the environment and practices recognise and support the rights of people to express their sexuality, including for people living with dementia

- to identify areas in which aged care organisations need to improve and develop and implement strategies

http://www.dementiaresearch.org.au
Using the sexuality assessment tool

- Completed by facility manager or similar
- Each item scored and points for sections added

<table>
<thead>
<tr>
<th>Needs improvement</th>
<th>0-20</th>
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<tbody>
<tr>
<td>Good</td>
<td>21-40</td>
</tr>
<tr>
<td>Very good</td>
<td>41-59</td>
</tr>
<tr>
<td>Excellent</td>
<td>60-69</td>
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### TRANSLATING DEMENTIA RESEARCH INTO PRACTICE

#### SCORING and HELPFUL RESOURCES

**0-20: NEEDS IMPROVEMENT**

Your facility may need to rethink its policies and procedures in order to become more supportive of older people’s needs with regard to expression of sexuality. Greater emphasis needs to be placed on balancing residents' rights with duty of care, staff, residents, and family members are likely to need more education, information and/or support. You may need to consider ways of educating the staff about the importance of changing the environment, developing an education program for staff and or preparing other resources which may improve knowledge and attitudes towards the sexual expression of older people. A list of helpful resources you can use to improve your facility’s performance has been provided – do not be discouraged!

24-40: GOOD

You are on the right track, but some work still needs to be done for the facility to successfully support older people’s sexual expression. Policies and procedures and the physical environment need to take residents’ needs and rights to express their sexuality into account to a greater extent. Your facility needs to consider the impact of sexuality on the quality of life of older people and their families needs to either. Staff are likely to need more appropriate on topics related to sexuality and sexual health. The list of resources may be helpful!

41-59: VERY GOOD

Your facility is supportive of residents’ expressions of sexuality; however, there is still some room for improvement. You may need to increase the amount of support for education, or the amount of information about sexuality and the adultress. You could use our other tool on this section.

60-69: EXCELLENT

Your facility is supportive of residents’ expressions of sexuality. The facility is a good role model for residents to learn how to express their sexuality in a respectful and safe manner. The list of resources may be helpful on this section.

**Helpful Resources**

- **Dementia Training Studies Centre (2011). Sexuality and Dementia Education Resource.** Downloaded from [http://dtscentre.co.uk/sexuality-resource](http://dtscentre.co.uk/sexuality-resource)
- **Alzheimer’s Scotland (2011). Information sheet: Sexuality and Dementia.** Downloaded from [http://www.alzheimers-scotland.org.uk/sexuality.htm](http://www.alzheimers-scotland.org.uk/sexuality.htm)
- **Royal College of Nursing, UK (2011). (Older people in care settings: Sex, sexuality and intimate relationships (Jan OTs) discussion and guidance document for the nursing workforce).** Downloaded from [http://www.rcn.org.uk/-/attachment/065e4c75-2b54-4376-88e8-f9d8e6f26d14](http://www.rcn.org.uk/-/attachment/065e4c75-2b54-4376-88e8-f9d8e6f26d14)
- **Continuing Gerontological Education Cooperative, Canada (2002). Best practices in sexuality and sexual behavior in dementia: How to develop practice guidelines and policy for long term care facilities.** Downloaded from [http://www.reporter.com/105/care/longi](http://www.reporter.com/105/care/longi)
Translating dementia research into practice

- Review of literature, resources, workshop feedback
- Focus groups and interviews
  - six facilities Victoria and Queensland (public, private, NFP)
  - staff (care, allied, lifestyle, managers), residents (living with and without dementia), family members
- Item development
- Review and comment by two facilities
- Delphi surveys with experts & refinement:

<table>
<thead>
<tr>
<th>Law</th>
<th>Ethics</th>
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<tbody>
<tr>
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<td>Medicine</td>
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<tr>
<td>Dementia care</td>
<td>Nursing</td>
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<tr>
<td>Facility management</td>
<td>Aged care governance</td>
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<tr>
<td>Consumers</td>
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Sex-AT sections

1. Facility policies
2. Determining the needs of the person
3. Staff education and training
4. Information and support for the person living in the facility
5. Information and support for families
6. The physical environment
7. Safety and risk management
The development of the information resource to support families

- Search of the academic and grey literature
- Search of resources on the web
- Drafting and multiple iterations
- Review and comment by family/carers and people living with dementia via webinar, teleconference and email (Alzheimer’s Australia Consumer Dementia Research Network / National Consumers Advisory Committee)
- Review and comment by Dementia Collaborative Research Centre (DCRC) members
Sexuality and people in residential aged care facilities:

A guide for partners and families

Aim: to provide education and support for residents’ partners and families
Sexuality and dementia

- The need for companionship, relationships, intimacy and human touch does not change because someone has dementia. People living with dementia have lived with their sexuality for much longer than they have lived with dementia.
- Sometimes it can be difficult to understand and accept that a person living with dementia may still have sexual needs, especially if they are unable to verbally express these needs.

Relationships
- A person with dementia may forget about the relationship they had before and not know they have a partner and they may look for a new partner. It can be very difficult for a partner or a family member to know that a loved one wants to spend time with someone else living in the facility.
- People with dementia living in an aged care facility who do not have a partner may want to form a relationship with another person living in the facility. They may also have sexual needs and may become frustrated when these are not met.

Interpreting behaviour
- Sometimes how a person is behaving can be interpreted as sexual when it is not. A person may undress in public or touch themselves for example, but this may be because they:
  - Are uncomfortable because their clothing is too tight, or they feel itchy or hot
  - Want to use the toilet
  - Are bored or agitated
  - Want to be cuddled or comforted.

Making decisions
- There is much debate about whether or not a person with dementia can make decisions. Different decisions require different levels of mental ability. A person with dementia may not be able to make

Sexuality and living in an aged care facility

- When a person moves into an aged care facility, the need to express sexuality and experience intimacy with another person can remain important and can offer comfort and pleasure.
- Looking and feeling attractive, by paying attention to personal grooming and the choice of clothing worn each day, can be important for self-esteem and self-worth.
How might changes in your loved one affect you?

- As a partner it can be hurtful if the person you feel close to no longer remembers your name, does not recognise you as their partner and develops an interest in someone else. It may be especially upsetting if, when you are visiting, you see them sitting or holding hands with someone else. It is normal to feel sadness, loss, upset, anger, embarrassment, anxiety or frustration if this happens. It may take a long time to accept these changes and come to terms with this.
- You may not want to visit the facility because you are upset, or embarrassed by your loved one’s behaviour, or because someone else thinks their

Meeting the needs of the person living in aged care

- Personal appearance, dress, style and grooming can be very important to how a person feels about themselves. Aged care staff can assist by helping the person to dress in their preferred clothes and attend to their personal grooming and care. You may be asked questions about your loved one’s personal presentation, grooming, and

How can the residential aged care facility be supportive?

One of the roles of a residential aged care facility is to promote an optimal quality of life for the people who live there. Staff working in residential care facilities often come from a variety of cultural, religious and ethnic backgrounds where sexuality may be viewed quite differently. It is important that the values and beliefs of

Questions to ask may include:

1. Does the facility have a policy about sexuality and sexual health and has this been communicated to staff?
2. What are the responsibilities of staff and those of the organisation with respect to supporting the sexual expression

Translating dementia research into practice
Where do you get the resources?

SexAT:
• http://www.dementiaresearch.org.au/

Consumer resource:

OR
Thank you