



Sexualities & Dementia

Education Resource for Health Professionals

Facilitator's Guide













Acknowledgements

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Sexualities and Dementia - Education Resource for Health Professionals. Facilitator's Guide

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Important note

This Facilitator's Guide is designed to be used in conjunction with *Sexualities & Dementia:* Education Resource for Health Professionals.

Sexualities & Dementia: Education Resource for Health Professionals

Workshop program - Day one

9:00 – 9:45 (45 mins)	Introduction Getting to know each other Workshop agenda and objectives Overview of sexuality, ageing and dementia
9:45 – 10:00	Morning Tea (15 mins)
10:00 – 12:00 (2 hrs)	 Module A - Intimacy, Sexuality and Sexual Behaviour Unit 1: Defining Intimacy, Sexuality and their Significance to Well-being Meaning of intimacy and sexuality Types of sexuality Myths and facts of sexuality and ageing Significance of expression of sexuality to well-being Unit 2: Expression of Intimacy Concepts of intimate and sexual behaviours Intimate behaviours versus sexual behaviours Psychological needs-based approach to the expressions of intimacy and sexuality
12:00 – 12:45	Lunch (45 mins)
12:45 – 2.00 (1 hr 15 mins)	 Module A - Intimacy, Sexuality and Sexual Behaviour Unit 3: Barriers to the Expression of Sexuality in Care Settings Types of barriers that impede on older people's ability to express their sexuality in care environments
2.15 – 4:00 (1 hr 45 mins)	 Module B - Dementia and the Expression of Sexuality Unit 1: Sexualities and Dementia in Care Settings Effects of dementia on expression of sexuality Recognising signs of well-being or ill-being Detecting signs of sexual abuse Identifying sexual risks to vulnerable people with dementia Questions & Answers
4.00	End of Day One Workshop

Workshop program - Day two

9:00 – 10:30 (1 hr 30 mins)	Module B - Dementia and the Expression of Sexuality Unit 2: Caregivers' Role and Responsibilities in the Expression of Sexuality by People with Dementia Roles and responsibilities towards the expression of sexuality Responding to the expression of sexuality by people with dementia Responding to sexual advances from people with dementia
10:30 – 10:45	Morning Tea (15 mins)
10:45 – 12:15 (1 hr 30 mins)	Module C - Ethical Considerations: Policy/Guidelines Development for Sexualities and Dementia in Care Setting • Privacy Rights • Cognitive Capacity for Consent • Autonomy and Solidarity
12:15 – 1:00	Lunch (45 mins)
1:00 – 2:30 (1 hr 30 mins)	Module C - Ethical Considerations: Policy/Guidelines Development for Sexualities and Dementia in Care Setting • Personhood ('Now' versus 'Then') • Case Study Discussion
2.30 – 2.45	Afternoon Tea (15 mins)
	 Module D - Developing Sexualities and Dementia Policy Guidelines for Care Practice Steps to the development of policy guidelines Sexuality Assessment Tools Questions & Answers
	Conclusion
	Evaluation
4.30	End of Workshop

Day One

Content	Notes
Introduction	■ 45 mins
 Getting to know each other Objectives: To help facilitator and participants to begin to know each other and become involved in the workshop. To reduce nervousness and encourage interaction. Facilitator is to provide a brief introduction about himself/herself. Participants are to take turns to introduce themselves (i.e. name, area of discipline and what they hope to achieve from the workshop). Ice-breaker activity: each participant is to come up with a word or a short 	■ 20 mins • PowerPoint slide 2
phrase to describe sexuality and ageing. Facilitator writes their responses on a whiteboard.	
 Workshop agenda and objectives Objectives: To remind participants why they are there and help ensure all necessary issues are addressed. To ensure that the workshop is relevant, time efficient and stays on track. Provide participants with information such as the location of restrooms, emergency exits, availability of beverages, timing of breaks and workshop 	■ 10 mins
 Discuss the objectives of the workshop and provide all participants with a copy of the (a) Sexualities and Dementia: Education Resource for Health Professionals; and (b) PowerPoint slides. 	▶ Refer resourcepg. 1 - 2◆ PowerPoint slide 3
Overview of sexuality, ageing and dementia	■ 15 mins
 Objectives: To provide definition of sexuality and understand the importance of sexuality to individuals. To raise awareness of the expression of sexuality by older people and people with 	► Refer resource pg. 1
 Referring back to the ice-breaker activity, ask participants for their definition of sexuality before presenting the definition of sexuality. Lead a discussion on how expression of sexuality can be atypical for older people and people with dementia. Inform participants that the term "Sexualities" will be used in various contexts throughout the education resource in recognition of the different types of sexuality. 	● PowerPoint slide 4 - 6
MODULE A - INTIMACY, SEXUALITY AND SEXUAL BEHAVIOUR Unit I: Defining Intimacy, Sexuality and their Significance to Well-being	■ 1 hr 15 mins
Objectives: In this unit, Facilitator is to assist participants' understanding of: The meaning of intimacy and sexuality; The various types of sexuality; The myths and facts that surround sexuality and ageing; and The intrinsic value of expression of sexuality to being human.	► Refer resource pg 5 - 11

Day One

PowerPoint slides 8 - 12 Meaning of Intimacy and Sexuality Split participants into groups of 4 – 5 to brainstorm the difference between intimacy and sexuality on butcher's paper. Follow-up with a presentation on the meaning and difference between intimacy and sexuality. Emphasise that the drive for intimacy and sexuality exists in all individuals but intimacy and sexuality are terms that are not easily defined as they have many meanings depending on the individual. Types of Sexuality PowerPoint slides Ask participants if they know what the acronym 'LGBTI' stands for. L = Lesbian; G = Gay; 13 - 16 B = Bisexual; T = Transgender; I = Intersex. Include an overview of the different types of Pose reflective question to participants: How would you feel about an older gay or lesbian couple coming to talk to you about their sexual relationship or sexual concerns? Display on-screen the "Gay & Lesbian Elderly Collection" by Richard Renaldi http://www. renaldi.com/archive/#id=album-20&num=content-658 Myths and Facts of Sexuality and Ageing PowerPoint slides Ask participants what they know about sexuality and ageing. Write responses on 17 - 23whiteboard and identify myths and facts from the responses. Pose reflective questions to participants: What are your personal attitudes, values and beliefs on sexuality and ageing? Where do you think your beliefs come from? Discuss. Follow-up with a presentation on the common myths and actual facts about sexuality and ageing. Show "Backseat Bingo" animated documentary on-screen http://vimeo.com/7584260 Pose reflective question to participants: How do you feel about older people (e.g. your parents or grandparents) maintaining an active sexual life? Discuss. Display on-screen the "Timeless Love" photographs by Marie Bot http://issuu.com/ bintphotobooks/docs/timelesslovebymarriebot Caution participants that explicit photographs of nude older people, which may cause some discomfort, will be displayed. Significance of Expression of Sexuality to Well-Being PowerPoint slides Explain the importance of expression of sexuality to the well-being of older people in 24 - 25 terms of quality of life, healthy interpersonal relationships, positive self-concept and sense of integrity. Pose reflective question to participants: Are you comfortable with discussing the topic of intimacies and sexuality with an older patient or an older person for whom you provide care. Why or why not? Discuss. **MODULE A - INTIMACY, SEXUALITY AND SEXUAL BEHAVIOUR** ■ 45 mins Unit II: Expression of Intimacy and Sexuality **Objectives:** In this unit, Facilitator is to assist participants' awareness and understanding of: ► Refer resource The concepts of intimate and sexual behaviours: pg. 12 - 15 The various types of intimate and sexual behaviours: and A psychological needs-based approach to the expressions of intimacy and sexuality.

Day One

 Concepts of Intimate and Sexual Behaviours Indicate that healthy intimate and sexual behaviours reflect the human need for loving relationships with oneself and others. However, the drives for intimacy and sexuality are different, as are the varying expressions of intimacy and sexuality. Behavioural indicators of the need for intimacy and sexual longing or desire can be confused. There are cases in care environments where staff have assumed that an older person is displaying sexual behaviours when instead they were exhibiting signs of a need for intimacy. 	PowerPoint slide 27
 Intimate Behaviours versus Sexual Behaviours Ask participants to give example of intimate and sexual behaviours. Write responses on whiteboard. Follow-up with a table presentation of both intimate and sexual behaviours. 	• PowerPoint slides 28 - 30
 Psychological Needs-Based Approach to the Expressions of Intimacy and Sexuality Highlight that expressions of intimacy and sexuality can form part of a complex relationship involving physical, psychological, spiritual and emotional aspirations and responses and can manifest in different ways for different reasons depending on the individuals' needs. Provide examples. 	PowerPoint slide 31▶ Resource pg. 13
MODULE A - INTIMACY, SEXUALITY AND SEXUAL BEHAVIOUR Unit III: Barriers to the Expression of Sexuality in Care Setting	■ 1 hr 15 mins
Objectives: In this unit, Facilitator is to assist participants in identifying the various types of barriers that impede on older people's ability to express their sexuality in care environments.	► Refer resource pg. 16 - 20
 Present the "Story of Jeffrey". Split participants into groups of 4 – 5 and ask them to identify what they think are the barriers to Jeffrey's expression of sexuality as well as other older people in care environments. Write responses on whiteboard. Follow-up with a presentation of the various types of barriers: privacy; able partner; physical health; ageism; medications; personal cultural beliefs, values, attitudes, expectations and sensitivity to organisational culture and values; as well as cognitive impairment. 	PowerPoint slides33 - 37▶ Resource pg. 16
MODULE B – DEMENTIA AND THE EXPRESSION OF SEXUALITY Unit I: Sexualities and Dementia in Care Settings	■ 1 hr 30 mins
Objectives: In this unit, Facilitator is to assist participants in: Identifying the effects dementia may have on expression of sexuality; Recognising signs of well-being or ill-being; Detecting signs of sexual abuse; and Identifying sexual risks to vulnerable people with dementia.	► Refer resource pg. 21 - 27

Day One

Effects of Dementia on Expression of Sexuality

- Bring to participants' attention that the onset of dementia gives rise to challenges in many areas of life and can have significant impact both for people with dementia and their partner or potential partner including the expression of sexuality. As a consequence of diagnosed dementia, some may also start to exhibit atypical or uninhibited sexual behaviours including diminished sexual interest, increased sexual demands and the loss of sexual reticence. Provide examples.
- State that sexually disinhibited behaviours are common in people with dementia.
 Acknowledge that dementia-related sexual expression can at times simply reflect the person's need for touch and/or comfort. Sexual expression by people with dementia can also be considered to be appropriate; it may simply be the context that is inappropriate. Activity "Mark".
- PowerPoint slides39 42
- ► Resource pg. 21 22

Recognising Signs of Well-Being or III-Being

- Present the "Story of Elaine".
 - Split participants into groups of 4 5 and ask them to identify what they think are signs of well-being or ill-being for Elaine. Write responses on whiteboard.
 - Remark that people with dementia can still agree to participate in sexual activities despite a changed or changing awareness. Their capacity to decide to be in a relationship can be 'decision-specific' where they may be capable of periods of insight, thus allowing them to make valid decisions on intimacy, sex and relationships. Assent to participate for them can generally be reflected through overall signs of well-being or ill-being. Provide examples of signs reflecting well-being or ill-being.
- PowerPoint slides43 47
- ▶ Resource pg. 23
- ► Resource pg. 23 24

Detecting Signs of Sexual Abuse

- Bring to participants' attention that people with dementia can experience sexual abuse perpetrated by a stranger, carer, a family member, friend or a spouse. It occurs in many forms and does not have to include penetration or rape, but can be an intentional stimulation of the erogenous zones (nipples, breasts, genitalia) whilst attending to personal hygiene, or when inserting a catheter or applying/changing a continence absorbent aid. People living with dementia can display revealing physical and behavioural signs of abuse. Provide examples.
- Remind participants that suspicion or observed misconduct signalling sexual abuse should be immediately reported to management.
- PowerPoint slides 48 50
- ► Resource pg. 24

Identifying Sexual Risks to Vulnerable People with Dementia

- Consider the issues of sexual risk and diminished mental capacity to consent for people with dementia engaging in sexual relations.
- Indicate that sexual risk to vulnerable people can include: (a) sexually transmitted disease (b) trauma or physical damage; and (c) emotional upset.
- Suggest that health care professionals can raise questions to determine people with dementia (a) awareness of relationships; (b) ability to avoid exploitation; and (c) awareness of potential risks. Provide specific questions for each of the three areas.
- · Have a discussion on the broader ethical considerations.
- Highlight that communication is vital to sexual risk identification. Health professionals should, to the best of their ability, identify potential sexual risks for people with dementia. However, prohibiting sexual activities due to fear of sexual risk is also a peril to the wellbeing of people with dementia and an abuse of their rights. The best prevention is to be well informed and prepared.
- PowerPoint slides51 55
- ► Resource pg. 24 25
- ► Resource pg. 26 27

QUESTIONS & ANSWERS

 This is an opportunity for participants to seek clarification or ask questions about the content covered in Day One Workshop. ■ 15 mins

Content	Notes
BRIEF RECAP OF DAY ONE WORKSHOP	■ 15 mins
Objectives: To recap the key content covered in Day One Workshop with participants. Recap the key content covered in Day One Workshop via the use of short-answer, multiple choice and true or false questions.	PowerPoint slides58 - 62
MODULE B – DEMENTIA AND THE EXPRESSION OF SEXUALITY Unit II: Caregivers' Role and Responsibilities in the Expression of Sexuality by People with Dementia	■ 1 hr 15 mins
 Objectives: In this unit, Facilitator is to assist participants in: Understanding the role and responsibilities of health care professionals towards the expression of sexuality by people with dementia; Identifying ways to respond to the expression of sexuality by people with dementia; and Identifying ways to respond to sexual advances from people with dementia. 	► Refer resource pg. 28 - 37
 Role and Responsibility Towards the Expression of Sexuality Pose reflective question to participants: As a health care professional, how can you facilitate the expression of sexuality in aged care? Discuss. Highlight to participants that: To ensure that people with dementia are not being harmed while supporting their freedom of choice and decision-making power as much as possible, the right to self-expression and self-determination needs should be balanced against a 'prevention of risks is best' approach to dementia-related sexual expression. Pre-existing and new developing relationships in care environments should be supported. For 'inappropriate' sexual expression, consider re-directing such expression into more appropriate channels and find ways to help a patient/resident meet their sexual needs. Provide examples. 	PowerPoint slides64 - 66
 Ascertaining the 'appropriateness' of sexual expression may lead to questions of consent (as discussed during Day One Workshop). Read and be aware of any relevant organizational policy and guidelines (if any). 	► Resource pg. 63
 Responding to the Expression of Sexuality by People with Dementia Remind participants that it is normal and natural for people with dementia to have sexual needs. When such needs are genuinely expressed, health professionals need to respect the feelings and dignity of people with dementia and respond with sensitivity and empathy to their sexual behaviours. Provide examples. Present the 'Rules of Thumb' for assessing sexual behaviour to determine whether there 	PowerPoint slides67 - 81
is a cause of concern.	► Resource pg. 30

 Indicate that even if the expression of sexuality is deemed 'inappropriate' because of risk and an increase in frequency, before introducing any intervention, a methodical assessment to identify underlying causes of sexual behavior should first be conducted. Questions in the following four areas should be considered: What form does the behaviour take? What factors may contribute to the behaviour? Could there be a social, environmental, medical or psychological cause? Reflect on how you define and classify inappropriate behaviour. Consider what risks are involved. Introduce the 'P-LI-SS-IT' model of care. It is a useful model to guide sexual discussion with primary carers of people with dementia to not only gain an understanding of the person with dementia's sexual history and behaviours but also proactively offers the family an opportunity to discuss their concerns. 	► Resource pg. 30 - 31 ► Resource pg. 32
 Present the "Story of Paul & Margaret Holmes". Split participants into groups of 4 – 5 and ask them to apply the 'P-LI-SS-IT' model of care in the case of Paul & Margaret Holmes. Introduce the six steps needs-based approach to help professionals identify triggers to sexual behaviour in people with dementia and adopt care practices to meet their sexual needs. 	▶ Resource pg. 32▶ Resource pg. 33
 Responding to Sexual Advances from People with Dementia Caution participants that people with dementia may confuse health care professionals for intimate spouse/partner or misinterpret the meaning of certain words or actions, especially during personal care activities like dressing or showering/bathing. Provide response strategies when such incidents happen. Reassure participants that following an incidence of uninvited sexual advance, it is normal to feel upset, angry and/or emotional. It is important to seek support and reassurance from your colleagues and make sure you report and record the incidence. This will allow a thorough assessment to determine the triggers of the behaviour and identify possible ways to avoid or limit future sexual advances. 	PowerPoint slides82 - 84▶ Resource pg. 34
MODULE C – ETHICAL CONSIDERATIONS: POLICY/GUIDELINES DEVELOPMENT FOR SEXUALITIES AND DEMENTIA IN CARE SETTING	■ 3 hrs
Objectives: In this unit, Facilitator is to help participants gain a better understanding of the following dementia-related legal and ethical issues for the expression of sexuality in care settings: Privacy rights; Cognitive capacity and consent Autonomy and solidarity Personhood ('Now' versus 'Then')	► Refer resource pg. 39 - 51

- Present the "Case of Valarie and Linda". Including the reactions of staff and both Valarie's and Linda's families.
 - Pose reflective question to participants: What are your beliefs, values, moral codes and cultural attitudes regarding the relationship as outlined between Valarie & Linda? Consider if such beliefs, values, moral codes and cultural attitudes may contradict your professional beliefs and influence your professional role and responsibilities when caring for Valarie and Linda. Discuss.
 - Discuss the possible impacts of the Valarie and Linda relationship on their family and others as well as to the organisation.
- Highlight that the development of policy or guidelines is imperative, discuss and consider the case of Valarie and Linda from the following key legal and ethical perspectives:
 - Privacy rights
 - Under the amended Australian Commonwealth Government Charter of Resident's Right and Responsibilities, the User Rights Principles, of the Aged Care Act (1997), shouldn't Valarie and Linda be entitled to personal privacy? personal relationships without fear, criticism or restriction?
 - Did the management of the aged care facility breach the privacy rights of Valarie and Linda by contacting their families? Did they breach privacy rights by not knocking on the bedroom door and waiting for instruction to enter?
 - Do you think the staff and management of the aged care facility have responded too quickly and have injected their own personal values on the same-sex relationship?
 - Cognitive capacity and consent
 - Even if we were to believe that Valarie and Linda could not "pass the competency to consent" test, they could probably assent to participate in their relationship (agree without full understanding). Is it appropriate to ask for more than this?

- PowerPoint slides 86 95
- ► Resource pg. 39 40

- PowerPoint slides97 98
- ► Resource pg. 41 42

- PowerPoint slides99 102
- ► Resource pg. 43

- Autonomy and solidarity
 - In spite of their cognitive impairment, do Valarie and Linda demonstrate, through their ongoing relationship and desires to seek out each other's company, that they value friendship and physical intimacy?
 - Should we acknowledge and support their desires for friendship and physical intimacy?
 - Is it conceivable that the same sex relationship, which Valarie is involved in, may either be a reflection of her new values or perhaps her past dormant values unknown to her family?
- Personhood ('Now' versus 'Then')
 - While some view Valarie's behaviour to be pathological and should be stopped, is it possible that personhood is fixed?
 - Do you think it is probable that Valarie's values can authentically change? If yes, it is possible to view her behaviour differently, perhaps as a healthy way to connect with others?
- · Present the "Case of John & Mary".
 - Split participants into 4 groups. Assign each group with a key legal and ethical issue (i.e. privacy rights; cognitive capacity and consent; autonomy and solidarity; or personhood) for consideration and discussion.

- PowerPoint slides103 108
- ► Resource pg. 43 44
- PowerPoint slides 109 114
- ► Resource pg. 44 45
- PowerPoint slides116 124
- ► Resource pg. 46 50

MODULE D – DEVELOPING SEXUALITIES AND DEMENTIA POLICY GUIDELINES FOR CARE PRACTICE	■ 1 hr 15 mins
Objectives: In this unit, Facilitator is to assist participants in: Outlining the steps needed to develop policy guidelines for sexualities and dementia; and Identifying the strategies used to implement sexualities and dementia policy guidelines.	► Refer resource pg. 53 - 67
 Policy Guidelines Development for Sexualities and Dementia Highlight the importance of policy guidelines on sexualities and dementia in aged care. Outline the following 9 steps for the development of policy guidelines on intimacy, sexualities and sexual behaviour: Forming a working group Learning about the issues Conducting focus groups Review sample policies from other organisations Create working definitions of key concepts in the policy guidelines Identifying interventions Draft a working policy guidelines document Implementing the policy guidelines Evaluating the policy guidelines Inform participants of the upcoming assessment tool to guide staff in providing a conducive care environment that supports opportunities for social interactions and expression of sexuality among residents which is funded by the Australian Dementia Collaborative Research Centre – Consumers and Carers. Draw attention to appendices: A: Response to the Classifications of Sexual Behaviour B: Sexual Behaviour Assessment C: Admission Sexual History D: Assessment of Awareness of Actions (Understanding & Appreciation) QUESTIONS & ANSWERS This is an opportunity for participants to seek clarification or ask questions about the content covered in Day Two Workshop. 	• PowerPoint slides 126 - 142

