



**DEMENTIA
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Sexualities & Dementia

Education Resource for Health Professionals



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Sexualities & Dementia

Education Resource for Health Professionals

Prepared by:

Dr. Cindy Jones
Research Fellow. Griffith Health Institute
Centre for Health Practice Innovation

Reviewed by:

Expert Advisory Group

This education resource has been reviewed and approved for publication by the Expert Advisory Group on 4th September 2012. Members of the Expert Advisory Group are as follow:

- Prof Wendy Moyle (Chair)
Director (*Griffith Health Institute – Research Centre for Clinical and Community Practice Innovation*)
- Dr. Cindy Jones
Research Fellow (*Griffith Health Institute – Research Centre for Clinical and Community Practice Innovation*)
- Dr. Michael Bauer
Senior Research Fellow (*Latrobe University – Australian Centre for Evidence Based Aged Care / Australian Institute for Primary Care and Ageing*)
- Mr. Norman Radican
LGBTI Liaison Officer (*Alzheimer's Australia – South Australia*)
- Mr. Rajiv Chand
Team Leader (*Dementia Behaviour Management Advisory Service – South Australia*)
- Ms. Kerri Robinson
Nurse Manager for the Aged Care Early Intervention Management Program (*Queensland Health*)
- Ms. Marie Alford
Director (*South Australia & Northern Territory Dementia Training Study Centre*)
General Manager (*Alzheimer's Australia – South Australia*)
- Ms. Meredith Gresham
Senior Dementia Consultant – Research & Design (*HammondCare, New South Wales*)

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Introduction

“My sexuality has never been a problem to me but I think it has been for other people.”

Dusty Springfield

Sexuality (1) is:

The socially constructed roles, behaviours, identities and processes – prescribed and prohibited, enacted and avoided, admitted and denied, valued and devalued, relational and non-relational – associated with female and male eroticism, reproduction, sex acts, thoughts, feelings, beliefs and attitudes. It refers specifically to those aspects of sensual, psychosocial and physical stimuli and responses associated with the pleasure and pains, fulfillments and humiliations of the person in the name of sex. It is broader than, but includes, the acts of sex and being female and male. (pg. 199)

The expression of sexuality has several positive health benefits. It contributes to the overall physical, psychological, intellectual and social well-being in individuals (2, 3). Sexuality remains a sensitive topic due to its private nature. This is particularly so for older people where it is often disregarded or treated as a societal taboo, especially among younger people due to prevailing systemic ageism. The erroneous common postulation is that the geriatric population has minimal or non-existent sexual desires and needs. It should be noted that although the actual practice of sexual intercourse may change with ageing, the fundamental need for expression of sexuality remains and people may choose to redefine the meaning as well as reprioritise the role of sexuality in later years of life (4, 5).

Another layer of complexity is added when the individuals in question have a diagnosed dementia. Caring for people with dementia (PWD) who express their sexuality continues to be a major challenge for health professionals. People with dementia continue to possess the capacity and need for expression of sexuality. For example, they sometimes engage in sexual relationships with others who may, like themselves, live in residential care facilities. In most cases, many health professionals find this to be disruptive and problematic and regard it as an activity that should be controlled or curtailed (6). Not only are consultations with PWD regarding their sexual needs,

desires and concerns minimal, if they happen at all, the sexual rights of PWD are not often supported (7). Concerns regarding PWD's capacity to consent to involvement in a sexual or intimate relationship can at times result in their needs and wishes becoming secondary to those of family carers and health professionals. Compounding this is the lack of attention given to the concerns of non-heterosexual PWD. Therefore, the term “*Sexualities*” will be used in various context throughout the education resource in recognition of the different types of sexuality, including heterosexuality in all its forms, as well as lesbian, gay, bisexual, trans and intersex (LGBTI) expressions of gender and sexuality.

Aims

The aims of this education resource are to:

- Increase understanding of the concepts of intimacy, sexuality, sexual behaviours and expression of various types of sexuality (including the benefits of and barriers to expression of sexuality)
- Identify dementia-related sexual expression
- Discuss the roles of health professionals and approaches to the expression of sexuality by PWD
- Consider the cognitive capacity of PWD to have intimate and sexual relationships
- Provide a framework for developing policies / guidelines on *sexualities* for PWD
- Identify strategies to transfer knowledge of *sexualities* and dementia into care practices



Outcomes

By the end of this education resource, participants will have an awareness and understanding of the following:

- The intimate and sexual needs of PWD
- The importance of expression of sexuality for PWD
- The role of health care professionals in responding to the expression of sexuality by PWD
- A model to assess cognitive competency of PWD to have intimate and sexual relationships
- A framework to better support the expression of sexuality by PWD
- Knowledge translation of *sexualities* and dementia into care practices

These materials are written for students in undergraduate health professional programs and health professionals. These materials may also be of use for care workers and families of people with dementia.

How to Complete this Education Resource

To complete this education resource, work through the content associated with the four modules and complete the learning activities associated with each module. Each module will take approximately 1 – 1.5 hours to complete. To help your learning and time management, each of the four learning modules is also broken up into several learning units to allow you to complete each unit within a short time period. It also allows you the opportunity to put the materials down at any point and to pick up at a later time.

Several case studies and resources have also been provided to facilitate and consolidate your learning about the various content focus areas in the four modules.

References have been provided. However, journal publications were unable to be attached due to copyright conditions. Wherever possible, direct access to internet resources has been provided.

Learning Modules

This education resource is built around four learning modules:

- A. Intimacy, sexuality and sexual behaviour
- B. Dementia and the expression of sexuality
- C. Ethical considerations: policy guidelines development for *sexualities* and dementia in care settings
- D. Developing *sexualities* and dementia policy guidelines for care practice

Resources & References

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Module A: Intimacy, Sexuality and Sexual Behaviour

Unit I: Defining Intimacy, Sexuality and their Significance to Well-being

Aim

The aim of Unit I is to explore the meaning of intimacy and sexuality and to understand the types of sexuality as well as the significance of expression of sexuality to well-being. This unit will also provide an overview of some of the facts and common myths that exist in regard to *sexualities* and ageing. Such information will assist you in care provision for older people and in particular in understanding the needs of this population.

Outcome

By the end of Unit 1, you will have an awareness and understanding of the following:

- The meaning of intimacy and sexuality
- The various types of sexuality
- The myths and facts that surround sexuality and ageing
- The intrinsic value of expression of sexuality to being human

Meaning of Intimacy and Sexuality

Intimacy and sexuality exist in all relationships; our relationships with ourselves and with others, yet intimacy and sexuality are terms that are not easily defined and rarely understood distinctly. Central to who we are and how we present and engage with the world, whether we realise it or not, the drive for intimacy and sexuality is with us from the moment we are born to the day that we die (8).

The World Health Organisation (9) defines sexuality as *“a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction”* (pg. 5).

Sexuality can be thought of as a multi-layered construct that includes many interconnected concepts that have different meanings and expressions depending on the individual (10,11). It is not limited to the physical ‘sexual’ acts, such as intercourse, but has psychological and social components. Indeed, our sexuality is integral to our identity, it reflects our very personhood, and it is foundational to all individuals of all ages (6).

As noted, one of the key features of sexuality is the need for intimacy. Intimacy refers to the experience of connecting with another based on feelings of care and affection. Like sexuality, it is a loaded term with many meanings depending on the individual. There are many different levels of intimacy (12):

Mutual	A process of exchange
Physical	Sharing space with another to sharing body contact and/or sexual activities
Cognitive	Sharing ideas, information, values and goals
Committed	An ongoing process of connecting, being close and sharing personal truths
Emotional	Showing a deep positive regard for the other, care and compassion

Trust, choice, security, and reciprocity are other terms used to conceptually frame intimacy (13). Whatever shape intimacy takes, at its core is a desire to have companionship, ‘a shoulder to lean on,’ and thus be free from loneliness (11,13).

Module A
Unit I

Module A
Unit II

Module A
Unit III

Module B
Unit I

Module B
Unit II

Module C

Module D

What is the difference between intimacy and sexuality?

To be intimate requires a companion, whereas sexuality is more concerned with an individual's identity and its multiple ways of being expressed. While an individual can be sexually intimate with another as an expression of sexuality, that is neither the defining feature of an individual's sexuality nor is it the only way that an individual is able to engage in intimate relationships (10,14).

Sexuality reflects how individuals present themselves to the world and the roles that are taken on, whereas intimacy reflects how relationships with others are formed and maintained. There are many different expressions of intimacy and sexuality depending on the type of sexuality that an individual identifies with, as well as the needs of the individual at the time (10). Unit II will look at the differences between expressions of intimacy and sexuality in more detail.

Types of Sexuality

There are many types or forms of sexuality and gender included in gender identity, sexual identity and sexual orientation. According to the **Yogyakarta Principles** (15), sexual orientation is understood to:

Refer to each person's capacity for profound emotional, affectional and sexual attraction to, and intimate and sexual relations with, individuals of a different gender or the same gender or more than one gender. (pg. 6)

Heterosexuality

Heterosexuality refers to sexual, emotional, and/or romantic attraction to a person of a sex other than your own. Commonly considered 'attraction to the opposite sex', but such understanding precludes other sexual orientation and sex and/or gender identity, making the definition incomplete (16). While heterosexuality may have once been



considered the norm, since the sexual revolution of the 1960's, there has been an increasing awareness and acceptance of diverse sexual orientation and sex and/or gender identity, which may include any of the following: heterosexual, lesbian, gay, bisexual, trans and intersex.

Homosexuality

Homosexuality refers to sexual, emotional and/or romantic attraction to a person of the same sex. Within this category lies the lesbian, gay and bisexual orientation (**LGB**). Lesbian refers to women who are attracted to women; gay refers to lesbians and men who are attracted to men; and bisexual refers to individuals who are attracted to both sexes/genders, but not necessarily simultaneously or equally (16).

The Australian Bureau of Statistics does not collect information on sexual orientation, or acknowledge diverse sex and/or gender identity, which makes it very difficult to estimate the actual numbers of Australians that fall into diverse categories of sexuality (17). However, it is estimated between 2 – 15% of people have same sex experiences and it is generally accepted that about 8% of the population identifies as gay or lesbian (18).

Pansexual

Pansexual, also known as omnisexuality, refers to a fluid sexual, emotional and/or romantic attraction towards people of all biological sexes and gender identities (16).

Sex and/or Gender Identity

Sex and/or gender are both used to loosely refer to a person's sex (i.e. male or female) or gender (i.e. masculine or feminine) and are incorrectly used to label sexual orientation. However, it is gradually being recognised that the narrow or binary view of sex in terms of male and female alone is insufficient. Some individuals may not have or choose not to have a sex and/or gender identity that is exclusively male or female, as in the case of queer, transgender and trans and intersex individuals (16).

Trans

The term 'Trans' (T) may include but is not limited to transgender, transsexuals, transvestites, genderqueer, cross-dressers, and other gender-variant people. Trans is not a sexual orientation or preference, but rather an umbrella term (19) for individuals whose:

Psychological self (gender identity) differs from the social expectations for the physical sex they were born with. For example, a female with a masculine gender identity or who identifies as a man. (pg. 7)

Transgender people may or may not choose to alter their bodies hormonally and/or surgically. Furthermore, a 'Trans' person may be heterosexual, homosexual (i.e. lesbian, gay and bisexual), pansexual or asexual.

Intersex

Intersex (I) (19) refers to a naturally occurring variance of sex characteristics where individuals who possess:

A set of medical conditions that feature congenital anomaly of the reproductive and sexual system. That is, intersex people are born with sex chromosomes, external genitalia, or internal reproductive systems that are not considered 'standard' for either male or female. (pg. 7)

Health professionals should respect the sexual and gender diversity as well as privacy of older people. It is important to note that not all older people are comfortable with disclosing or discussing their sexual preferences to other people.

Although there is an increasing recognition of diverse genders, *sexualities* and same-sex couples including social, legal, medical and economic rights, the Australian Human Rights Commission and National LGBTI Health Alliance continue to work in addressing some of the issues of discrimination that are continually faced by Lesbian, Gay, Bisexual, Trans and Intersex (LGBTI) individuals in areas as far reaching as employment, workers' compensation, tax, social security, veterans' entitlements, health care, family law, superannuation, aged care and migration. It is widely acknowledged by human rights observers that Australia still has a long way to go before LGBTI individuals have the same legal rights and protections as heterosexuals (20). Given the level of discrimination still faced by LGBTI, it is not difficult to imagine the levels of discrimination faced by people with diverse sex and/or gender identity, especially when there is still a lack of formal consensus over the exact definition of sex and/or gender identity (20,21).

A note on terms: While it is recognised that matters regarding sexual orientation are quite different to matters concerning sex and/or gender identity, the acronym 'LGBTI,' which stands for Lesbian, Gay, Bisexual, Trans and Intersex will be used throughout the education resource, being mindful that some trans and intersex people feel strongly about the benefits of affiliation with the lesbian, gay and bisexual community (20).

Despite the diversity of sexual orientation and sex and/or gender identity, there remains a serious scarcity of directed educational information addressing non-heterosexual *sexualities* and diverse sex and/or gender identities and perhaps consequently, the subject is rarely discussed by aged care staff (10,13). Research increasingly shows that sensitive accounts of the full diversity of sexual orientation, sex and/or gender identity is a pressing requirement, especially by health care professionals, and is needed to ensure the health needs of the population are being adequately addressed (8,10,18).



ONLINE RESOURCES

Movie: GEN SILENT

Sponsored by the Brookline Council on Aging, Goddard House and the LGBT Aging Project, this is an award-winning documentary by filmmaker, Stu Maddux, that follows six Boston-area LGBT older adults over the course of a year as they deal with the challenges of aging and being gay, lesbian, bisexual or transgender.

http://stumaddux.com/GEN_SILENT.html



REFLECTIVE QUESTION

How would you feel about an older lesbian or gay couple coming to talk to you about their sexual relationship or sexual concerns?



ONLINE RESOURCES

Please click on the website link or copy and paste into your browser to view the materials.

Gay & Lesbian Elderly

Photography by Richard Renaldi

There are limited photographs of older gay or lesbian couples available. The Gay & Lesbian Elderly Collection, by Richard Renaldi, features a series of black and white photographs of older gay and lesbian people in their homes.

<http://www.renaldi.com/archive/#id=album-20&num=content-658>

Myths and Facts of Sexuality and Ageing

Although the nature of sexual expression tends to change as people age, the Viagra revolution has assisted in increasing societal awareness through highlighting that older people are concerned about *sexualities* and many still engage in sexual acts, thoughts or fantasies (22). A US study examining the prevalence of sexual activity, behaviors and problems in a national sample of 3005 adults (1550 women & 1455 men) aged 57 to 85 found that although sexual activity does decline with increasing age, 73% of those between 57 to 64; 53% of those between 65 to 74; and 26% of those between 75 to 85 are still sexually active (23). Similar findings were found in an Australian study of 2783 men between the age of 75 to 95 where 48.8% considered sex to be at least somewhat important and 30.8% had at least one sexual encounter in the past 12 months (24).

Even so, cultural bias remains with sexuality and sexual behaviour being seen as the preserve of youth, alongside persistent myths circulating that older people are asexual, no longer interested, or no longer capable (11). Specifically, two myths

that exist in regard to older people and sexuality are (25):

- Older people are physically unattractive and therefore undesirable
- The idea of older people attempting sexual activities is perverse and disgraceful



REFLECTIVE QUESTION

What are your personal attitudes, values and beliefs on sexuality and ageing? Where do you think your beliefs come from?



ONLINE RESOURCES

Please click on the website link or copy and paste into your browser to view the materials.

Backseat Bingo

An animated documentary that effectively dispels the societal preconceptions about romance and older adults is available at the website. It is a powerful reminder that love and desire remain an integral part of healthy ageing and personal well-being.

<http://vimeo.com/7584260>



Cultural myths have resulted in marginalising the sexuality of older people, with widespread health and well-being impacts for older people (8-11,18). Older people raised in the era of conservative

Judeo-Christian values grew up when knowledge of sex and *sexualities* was not freely available and considered to be a private matter (13,18). Many older people have internalised these cultural myths, which have been found to result in the disappearance of sexual enjoyment and arousal, affecting their ability to continue to lead fulfilling lives (18,26). Most alarmingly, research shows that the myths of the 'asexual older person' and the influence of Judeo-Christianity on many older people has made it very difficult for them to discuss intimacy and sexuality or communicate sexual health concerns, which in turn can have wide reaching negative impacts, including frustration and diminished self-worth (13,18). Many older gay men and lesbians in particular have faced a lifetime of stigma and discrimination, forcing them to live their lives 'in the closet' and they may find it particularly difficult to discuss sexual concerns; homosexuality was considered unacceptable for most of their lives and secrecy and invisibility were the key factors of their way of life (10,18).

While not all older people will want to be sexually active or vividly express their sexuality or even search for intimacy, international research confirms that older people are in fact still concerned about issues related to *sexualities* and many see it as a significant aspect of their life that they would like more discussion around (10,22,26,27). As *sexualities* incorporate intimacy, romance and sensuality, it is difficult to imagine any individual of any age not engaging, or at least entertaining a desire for some aspect of sexual activity (10,18).

Consequently, social researchers are insisting on a broadened definition of sexuality to ensure older people and diverse sex and/or gender identities are not overlooked; there is a growing effort to obliterate these myths of the asexual older person (10,18). As we face a growing ageing population, it is increasingly important that society addresses

the myths of the asexual older person and continually redefines the traditional boundaries of *sexualities* to ensure that all older people can live happy, healthy and fulfilling lives with the freedom to choose how, and when, they will engage in the many varied expressions of their genders and sexuality. The following quotation (8) sums up these views:

Time to come out and face it: sexy oldie or celibate oldie, we are all sexual and have a right to choose when and how we express this integral aspect of our identity. (pg. 80)



REFLECTIVE QUESTION

How do you feel about older people (e.g. your parents or grandparents) maintaining an active sexual life?



ONLINE RESOURCES

Please click on the website link or copy and paste into your browser to view the materials.

Timeless Love – Photography by Marie Bot

An exhibition of pictures taken by Marie Bot, author of Timeless Love, a photography book of older people making love has gained much attention, but the reactions of many people to viewing these photographs illustrate the taboo of sexuality in older people.

“Since the 1970s, we have become accustomed to seeing pictures of nudes in every conceivable context. Even soft porn tableaux in fashion magazines and erotic films on TV no longer have the power to shock – provided that the models are young and good-looking. But we are evidently still uncomfortable with the idea that elderly people can have active love lives and enjoy

sex. We would rather not be confronted by such images.” (Online Anonymous Review)

****Please note the following site has explicit photographs of nude older people. Do not open if viewing will cause discomfort.***

<http://issuu.com/bintphotobooks/docs/timelesslovebymarriebot>

Significance of Expression of Sexuality to Well-Being

The ability to express their needs for intimacy and sexuality is a key attribute to quality of life and well-being in older people (8,14,28). It is also imperative to their maintenance of healthy interpersonal relationships, positive self-concept and a sense of integrity (29). There can be detrimental consequences on social relationships, self-image and mental well-being of older people when they are denied the opportunity to sexually express themselves (6).

Since the expression of sexuality is of critical importance to an individual's health and well-being, health professionals are well placed to confront societal discomforts and misconceptions regarding *sexualities* and ageing to enrich the lives and improve the health and well-being of older people. Unit II will look more closely at the various ways of expressing sexuality and how this differs from behaviours of intimacy.



REFLECTIVE QUESTION

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?



Activities: Intimacy, Sexuality and their Significance to Well-being

Please complete the following short-answer questions as an indication of your understanding of Unit 1.

Short-Answer Questions:

Question 1. Outline the differences between intimacy and sexuality.

Answer:

Intimacy reflects how relationships with others are formed and maintained. Sexuality reflects an individual's identity and how individuals present themselves to the world and the roles that are taken on. There are multiple ways of expressing sexuality. While an individual can be sexually intimate with another as an expression of sexuality, that is neither the defining feature of an individual's sexuality nor is it the only way that an individual is able to engage in intimate relationships.

Question 2. What are the different types of sexualities?

Answer:

Heterosexual, homosexual (i.e. lesbian, gay and bisexual) and pansexual.

Question 3. If someone identifies himself or herself as a Trans, what does it mean?

Answer:

Psychological self (gender identity) differs from the social expectations for the physical sex they were born with. For example, a female with a masculine gender identity or who identifies as a man.

Question 4. Identify three (3) myths regarding sexuality and ageing.

Answer:

There are many myths regarding sexuality and ageing. For example:

- Older people are asexual and no longer interested or capable of expressing their sexuality.
- Older people are physically unattractive and therefore undesirable.
- The idea of older people attempting sexual activities is perverse and disgraceful.

Question 5. How and why is the expression of sexuality important to the well-being of older people?

Answer:

The expression of sexuality is a key attribute to quality of life and well-being in older people. Furthermore, it is imperative to the maintenance of healthy interpersonal relationships, positive self-concept and a sense of integrity in older people.

Unit II: Expressions of Intimacy and Sexuality

Aim

The aim of this content focus area is to understand the difference between intimate and sexual behaviours as well as the expressions of intimacy and sexuality from a psychological needs-based approach.

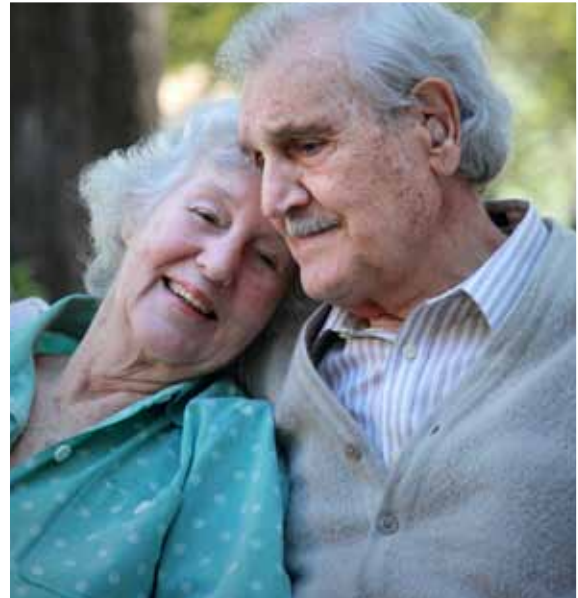
Outcome:

By the end of this Unit, you will have an awareness and understanding of the following:

- The concepts of intimate and sexual behaviours
- The various types of intimate behaviours
- The various types of sexual behaviours
- A psychological needs-based approach to the expressions of intimacy and sexuality

Concepts of Intimate and Sexual Behaviours

Healthy intimate and sexual behaviours reveal the human need for loving relationships with oneself and others as well as the need for giving and receiving attention and affection (30). Individuals sometimes confuse the behavioural indicators of the need for intimacy with sexual longing or desire and vice versa (4,30). There are countless examples 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 (13). As people age, intimacy often takes precedence to satisfying sexual desire (13,26). As Bauer et al. (10) note: *“when intercourse is no longer desirable or possible, intimacy becomes central to emotional connectedness and well-being”* (pg. 65). The drives for intimacy and sexuality are different though, as are the varying expressions of intimacy and sexuality.



Intimate Behaviours vs. Sexual behaviours

Behaviours of intimacy usually involve two or more people sharing a caring touch, empathic understanding, reassurance and/or comfort (26,30). Intimacy is often associated with friendship and can be either sexual or non-sexual depending on the nature of the relationship and the desires of the parties involved (31). A feeling of safety in the relationship is paramount to any definition of intimacy. Forms of intimacy can include (10,13,26,31):





Physical	touching, holding, kissing on the cheek
Emotional	offering a shoulder for someone to cry on
Intellectual	sharing ideas, humour or jokes
Social	being in the company of friends
Sexual	sensuous activities

Sexual behaviours, on the other hand, can be expressed with oneself or with another person(s), and are directly linked to attempting to satisfy sexual desire. Often more overt and pleasure based than intimacy, examples of sexual behaviour are more intimate touching, cuddling/ hugging, kissing, flirting, romantic gestures, oral sex, various forms of penetration and sexual intercourse; or on one's own through actions related to increasing one's body sensation and stimulation such as dressing up, reading sexually explicit books and magazines, watching pornography as well as through acts of self-gratification such as masturbation (10).

Psychological Needs-Based Approach to the Expressions of Intimacy & Sexuality

The need to express intimacy and sexuality is very important and regarded as natural components of

life that build self-confidence and communication with others (4,13,30). Expressions of intimacy and sexuality go beyond physical pleasure. In fact, they can form *“part of a complex relationship involving physical, psychological, spiritual and emotional aspirations and responses”* (pg. 77) (8). Clearly, expressions of intimacy and sexuality can manifest in different ways for different reasons depending on the individuals' needs. For instance, some people may wish to express their sexuality in the form of cuddling or kissing, or some or all of the activities involved to a highly intimate and sexual relationship. Others may simply wish to express their sexuality through their exterior appearance (i.e. dressing, hair and makeup) or via self-stimulated sexual acts (4,18).

Since the sexual revolution of the 1960's, there has been a rise in both the acceptance and practice of sex outside of marriage; multiple partners; co-habitation; and same-sex couples (10). Clearly, over time what has been conceptualised as 'appropriate' expressions of sexuality has been redefined and there is an increased recognition of the many possibilities for the expression of sexuality beyond sexual intercourse, as well as many possibilities for the expression of intimacy that does not imply sexual desire (18). It is anticipated that as the 'Baby Boomers' generation rapidly ages, the expressions of intimacy and sexuality in a care context will become more complex and challenging but nevertheless, important to understand, acknowledge and accommodate (32). Ultimately, the freedom to choose when and how to express intimacy and sexuality is important and as long as there is no harm to others, an individual's expressions of intimacy and sexuality should be considered a fundamental human right.



Activities: Expressions of Intimacy and Sexuality

Please answer the following true or false and multiple choice questions as an indication of your understanding of Unit 2.

True or False Questions

1	Intimacy is always sexual in nature	True / False
2	Sexual behaviour always leads to intercourse	True / False
3	Intimacy reflects a desire for sex	True / False
4	Sharing a joke with someone can be a form of intimacy	True / False
5	Sharing a cuddle with someone is a form of physical intimacy and can also be a form of sexual behaviour	True / False
6	Reading sexually explicit materials in private is regarded as a form of sexual expression	True / False

Answers: 1. False / 2. False / 3. False / 4. True / 5. True / 6. True



Activities: Expressions of Intimacy and Sexuality

Please complete the following multiple choice questions as an indication of your understanding of Unit 2.

Multiple Choice Questions:

Questions 1. Which of the following is a form of intimacy?

- A. Being in the company of friends
- B. Sharing ideas
- C. Offering a shoulder for someone to cry on
- D. All of the above

Answer: D

Questions 2. Which of the following statements are correct?

- A. Intimate behaviours, rather than sexual behaviours, reveal the human need for loving relationships with one and others.
- B. As people age, intimacy often takes precedence to satisfying sexual desire.
- C. People are rarely confused between behavioral indicators of the need for intimacy and cues for sexual longing or desire.
- D. Staff working in aged care settings are always able to distinguish between sexual behaviours displayed by other people and their exhibited signs of a need for intimacy.

Answer: B**Questions 3. What is one of the reasons for the expressions of intimacy and sexuality in a care context becoming more complex and challenging?**

- A. Improving ageist views
- B. Sexual revolution of the 1960's
- C. The rapid ageing of the 'Baby Boomers' generation
- D. Disapproval of the practice of sex outside of marriage; multiple partners; co-habitation; and same-sex couples.

Answer: C

Unit III: Barriers to the Expression of Sexuality in Care Settings

Aim

The aim of this content focus area is to identify and understand the barriers to the expressions of intimacy and sexuality in care environments.

Outcome

By the end of this Unit, you will have an awareness and understanding of the following:

- The various types of barriers that impede on older people's ability to express their sexuality in care environments

Story of Jeffrey

Jeffrey is a 67-year-old man living in a residential care facility. Care staff assume that he is heterosexual, and that he is no longer sexually interested or sexually capable. The truth is that Mr. McNamara is a bisexual man who continues to be sexually interested and wishes to be sexually active, which is the exact opposite to staff assumptions. When he informed care staff of this, they were speechless.

Barriers to the Expression of Sexuality in Care Settings

Across cultures, health care professionals often feel uncomfortable discussing the topic of sexuality with older people (8,14). Less surprisingly, few older people feel comfortable discussing sexual concerns with their medical practitioners. Such fears regarding sexual communication are detrimental to health care provisions and lead to a cycle of awkward attitudes and behaviours shrouded in uncertainty



John & Fred, 1999 by Richard Renaldi

(10). Indeed, such discomfort is a risk to physical health and emotional well-being and results in the expression of sexuality by older people being directly or indirectly discouraged (13). Barriers to the expression of sexuality in care settings include:

Issues relating to privacy



REFLECTIVE QUESTION

If you work or have worked in a care setting, reflect on the type of physical environment that was created for older people. Do you think such a physical environment is or was conducive to the expression of sexuality? Why or why not?

The lack of privacy in care settings is a major barrier to the expression of sexuality. Studies

show that residents of care facilities are less likely to engage in sexual behaviours than those living in the community due to concerns that such activities may become public knowledge, be judged by staff and other residents as well as compromising their dignity (6,26,33). The design of many care facilities is a cause of some privacy concerns. Following traditional medical architectural models, most care facilities have an open space and long halls with rooms along, which do not provide much space for privacy. Built with the intention of providing easy access to rooms for staff as well as creating the opportunity for 24-hour surveillance, the buildings typically only have a few private rooms. Some residents may share a room with separation by a curtain. Compounding the design features is that staff may neither knock nor wait for an answer before entering a room. It is therefore, not surprising those residents in care facilities feel less inclined to partake in behaviours that express their individual sexuality (6,13,26).

Able partner

The availability of a willing and able partner can be a crucial issue. For example, approximately 30% of men and 40% of women cite the lack of an able partner as one of the key reasons for sexual inactivity in care facilities. This issue may be more palpable for women as they may be less inclined than men to want to engage in extramarital relations and are more likely to live longer than their spouse as well as forming the larger gender proportion in care facilities (6). It is important to also consider the situation where one partner lives in the community while the other is in a care facility. The couple may wish to continue their relationship but find they are inhibited by a lack of private space.

Physical health

Poor health, physical difficulties in performing sexual acts and age-related decreases in libido

and increases in fragility can all hinder the expression of sexuality. Performance-related anxiety in men is one resulting effect from physical health decline that may become a barrier to sexual intercourse (6,13,26). Moreover, one third of women over the age of 65 reported dyspareunia (painful intercourse), which would no doubt discourage sexual intercourse (6). However, these issues should not need to impede on the many other forms of sexual expression but require adaption on the part of the older person concerned. For example, the use of lubricant and a slower sexual pace can alleviate pain, while other forms of expression, including intimacy and romance, can take centre stage (14,33).

Ageism

On another level, studies into feelings of attractiveness have indicated that poor self-image is another barrier. One survey of 63 residents living in care settings showed that 58% of men and 78% of women said they felt sexually undesirable (6). Social structures and cultural myths and bias regarding old age, such as those discussed in Unit 1, can bring about negative and adverse attitudes towards older peoples' *sexualities*, which have been shown to rub off on many older people in their feelings of abnormality, guilt, and decreased desire, limiting their ability to enjoy their sexuality (18). In recent times, there are encouraging signs from the social media in reflecting the emergence of older people's *sexualities* in the public arena and indicates that older people not only have sexual needs but are also sexually active (34,35).

Medications

Medications can have an impact on expressions of sexuality and affect sexual function, responsiveness, sensitivity, reaction and ultimately diminish sexual desire. Some medications can even interfere with the older person's ability

to fantasise and have sexual thoughts, which can also become a barrier to the expression of sexuality (14). There are ways to accommodate these changes. Medications can be altered and the way older people express themselves sexually can be changed to accommodate both their abilities and physical limitations.

Organisational culture and values



REFLECTIVE QUESTION

How would you and your family feel about an older relative of yours being threatened by care staff for trying to flirt and intimately touch another consenting resident?

Negative or poorly informed attitudes of health professionals often reduces the frequency of expression of sexuality by older people in care settings, especially in organisations where expression of sexuality is seen as a behavioural issue to be controlled, rather than a need to be facilitated and respected (13,14,33). Organisational culture and values can range from being responsive, aware and supportive of the sexual needs of residents to being unsupportive, restrictive and controlling to the point of not allowing any form of sexual expression (6,8,10,13,14,18,26,33).

Specifically, a study in 2004 (7) found that a restrictive care facility will neither facilitate social environments for residents nor private spaces and will seek to guard and manage against expression of sexuality by residents. Such facilities may erect physical barriers and use fear tactics to eradicate any such behaviour; such as threats and punishment, for example, 'If you continue with that sort of behaviour, we'll have to call your family and most people don't like that'. Another identified example of organisational culture and

values being a barrier to older people's expression of sexuality is when couples who have lived intimately together are separated on entering a care facility. Such practices show that some organisations are uncomfortable with or avoid altogether the issue of residents' *sexualities*. This may be the result of moral or religious values, or it may be because staff are ill equipped and unsure of how to respond (6,7,13,18,26,33). A lack of education in relation to *sexualities* is highlighted as being the number one cause of restrictive organisational culture (6,7,13,18,26,33). It has been suggested that restrictive facilities reflected the personal levels of discomfort staff felt with the topic of *sexualities* (7). Diverse values and cultural backgrounds among staff may result in inconsistent responses to the expression of sexuality as well as mixed messages to older people, leaving them feeling unsure to insecure and lonely (13,33).

Cultural beliefs, values, attitudes, expectations and sensitivity



REFLECTIVE QUESTION

What are some of the ways that cultural bias may have influenced your values and beliefs about older people and sexuality?

Concerns about an older person's sexuality are the reflection of conservative cultural beliefs, values, attitudes and expectations. In a care setting, the values and expectations of care staff and family become the most influential on older people. Family generally agreed that residents have the right to sexual expression. However, only some types of sexual behaviours were supported. Family believed that not only should they be kept informed of their relative's sexual behaviours, they should also be involved in decision making process (36). A religious family may see an older

relative's sexuality or engagement in a new relationship outside of marriage as inappropriate and unacceptable. Families hold expectations that their older relatives will remain single, if they have been widowed, and heterosexual, if they have been their whole life. They often become surprised when informed of changes by their older relative after entering a care facility (13,18). On another level, older people's own values and expectations may also be a barrier. As previously mentioned, many older people have internalised the ageist and heterosexual values of society so may resultantly find it difficult to express or discuss their *sexualities* because of perceiving it to be inappropriate and unacceptable (13,18). In addition, sexual behaviours accepted by one culture can be rude or derogatory to others from a different culture. Being culturally sensitive, that is being aware of the differences between cultures, is therefore imperative to avoid sexual prejudices and preconceptions in aged care settings.

Cognitive impairment



REFLECTIVE QUESTION

If you discovered that two older people with cognitive impairment were sharing a sexually intimate relationship, how would you react?

Individuals living with cognitive impairment, such as dementia, in care settings tend to be highly supervised and their expression of sexuality is generally restrained and discouraged by staff due to fears regarding consent and the safety of the older person (6,7,13,18,26,33). Dementia is complex and raises many considerations for providers of care that are legally and ethically responsible for the well-being of the older person (18). Dementia can lead to a range of different sexual behaviours, including reduced

sex drive and sexual confusion, which can be a barrier for healthy expression of sexuality. Alternatively, dementia can create lowered levels of inhibition which can lead to what are perceived as challenging sexual behaviours, such as undressing and masturbating in public (33).

Some studies have suggested that lowered inhibition manifesting in challenging public displays of sexuality may be the result of barriers other than cognitive impairment alone, such as a lack of privacy (33). The losses that surround a dementia diagnosis will have significant impact on the person living with dementia and their family and require context-specific and person-centred assessment to ensure the quality of life of the person living with dementia and their family is optimised (18). Alzheimer's Australia points out that those living with dementia may not experience intellectual cognitive losses until years later and many can still make their feelings known through verbal and non-verbal cues or behaviour (4). Bauer et al. (18) suggest that in such cases *"it is possible to balance the autonomy of residents with levels of perceived risk, including decisions regarding an individual's capacity to consent to sexual relations"* (pg. 304).

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Module B: Dementia and the Expression of Sexuality

Unit I: Sexualities and Dementia in Care Setting



Aim

The aim of this Unit is to address the expression of sexuality by people with dementia.

Outcome

By the end of this Unit, you will be able to:

- Identify the effects dementia may have on expression of sexuality
- Recognise signs of well-being or ill-being
- Detect signs of sexual abuse
- Identify sexual risks to vulnerable people with dementia

The Effects of Dementia on Expression of Sexuality

As covered in Module A, sexual expression can be with another person or with oneself (e.g. self-gratification through masturbation). 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, which includes the expression of sexuality (1). People living with dementia can continue to maintain an interest in intimate and sexual relationships especially if they have experienced satisfying intimate and sexual relationships

at some point in their lives (1). However, 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 (2). Other examples of dementia-related sexual expression (1-5) that may be deemed to be different from the person's norms include:

- Removal of clothing in public
- Exposing and touching their genitals (including masturbating) in public
- Attempting to touch, kiss, hug or flirt with others without the other person's consent
- Making rude sexual comments that may include swearing
- Requesting sexual acts from residents, staff and/or visitors
- Unwarranted sexual advances towards others
- Unexpected change in sexual orientation or sexual preference

Unmet Sexual Needs

The above list of dementia-related sexual expressions is by no means exhaustive and are often negatively branded by health professionals as 'challenging', 'inappropriate' and 'improper' in care environments. These sexual expressions can, in some people with dementia, be traced to damage in the frontal lobe. The frontal lobe area is responsible for many high level functions including thinking, reasoning, behaving and inhibition. The failure of the frontal lobe to inhibit sexual behaviours can lead to distress for the caregivers and families of people with dementia who often consider such expression as uncharacteristic for the person performing them. Sexually disinhibited behaviours are quite common in both men and

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Unit I

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women with dementia with a prevalence of between 2 – 17% (6). However, the negative referral of these behaviours as ‘challenging’, ‘inappropriate’ and ‘improper’ and something to be managed are not always beneficial as our subjective views of appropriate sexual behaviours are based on our own attitudes, beliefs and values and can differ from others.

We need to acknowledge that dementia-related sexual expression may not always be what it appears to be. At times, it can simply reflect the person’s need for touch and/or comfort (3,7). Sexual expression by people with dementia can also be considered to be appropriate; it may simply be the context that is inappropriate. For example, a staff member undressing a person

in a bedroom (prior to showering) may be easily misinterpreted as a sexual overture. Furthermore, as people with dementia often get confused about places and people, they may confuse a carer, resident or family member for their spouse or partner (5) and as people with dementia lose language skills, they often express themselves with actions. For example, a person with dementia who unzips his pants in the corridor may need to use the toilet and another who disrobes in the common living area may be feeling hot or in pain rather than needing to express their sexuality. It becomes vitally important for the health care professional to first determine the underlying need being expressed by the person with dementia before assuming the behaviour is sexually challenging.



Activities: Sexuality and Dementia in Care Settings

Please complete the following short-answer questions as an indication of your understanding of Unit 1.

Short-Answer Questions:

Question: *Mark, a 70-year-old man with frontal lobe dementia, has been found on several occasions taking off his clothes and masturbating at a small entrance hall with stained glass windows and tiled flooring in an aged care facility. What do you think may be happening here?*

Answer:

Mark may have mistaken the small entrance hall with stained glass windows and tiled flooring as a bathroom. In such cases, the sexual expression (i.e. taking clothes off and masturbating) is appropriate, it is simply the context (i.e. the place) that is inappropriate. Care staff can explain to Mark where he is situated and re-direct him back to his room for him to continue his sexual activity.

Recognising Signs of Well-Being or Ill-being

Story of Elaine

Elaine is a 63-year-old widow living with Alzheimer's disease for the past year. She enjoys socially interacting with other residents in the aged care facility and has a close friendship with one particular resident, Paul. However, care staff recently noticed that Elaine seems to be withdrawn and appears rather anxious whenever Paul is around her. When approached by care staff, Elaine first denied anything was wrong but eventually said that Paul has been rubbing his genitals against her body and touching her breast whenever they were alone.



Although people with dementia may have a changed or changing awareness, they can still agree to participate in sexual activities. For them, the capacity to decide to be in a relationship is 'decision-specific' where they may be capable of periods of insight, thus allowing them to make valid decisions on intimacy, sex and relationships, despite having deferred care to another (1). Assent to participate in sexual activities by people with dementia can generally be reflected through overall signs of well-being or ill-being. For instance, a person's assent will be accompanied by high levels of well-being (8) where he/she:

- can be affectionate
- communicates wishes and needs successfully
- connects with the people, objects and events around them
- engages in creative activities such as painting, singing, dancing
- appears to enjoy life
- has a positive mood shown by smiling, laughing has humour and playfulness

- is cheerful
- is comfortable with physical closeness
- is confident
- is cooperative with requests
- is relaxed in the body (facial expression and body posture)
- is sensitive to the emotional needs of others
- willingly participates in their own care
- makes social contact and shows an awareness of the well-being of others by being helpful
- shows enjoyment in interactions and events
- shows self-respect in attention to dress and appearance
- places trust in others

On the other hand, a dissenting person will usually demonstrate signs of ill-being that include (8):

- being agitated and/or restless
- being angry and/or aggressive
- boredom
- grieving and being sad
- high levels of body tension
- is easily dominated by others
- lonely
- makes noise, calls out or vocalizes
- negative mood (display of distress in facial expression, posture and sounds)
- physical discomfort or pain
- physically threatens others
- rejected and/or ignored by others
- showing anxiety and/or fear

- signs of lethargy and/or apathy
- signs of withdrawal
- suspicious of others
- unable to enjoy things
- verbally refuses care
- repetitive movement patterns such as rubbing

Detecting Signs of Sexual Abuse



REFLECTIVE QUESTION

What do you think are the possible signs of sexual abuse?

Sexual abuse can come in many forms and a number of cases have been reported as occurring to people with dementia in care settings (1). People living with dementia are more vulnerable to abuse as they have greater difficulty in speaking out and may be unable to fully understand the intent of the perpetrator and what is being done. Their confusion about the motivations of a perpetrator can be further complicated by their reliance on others for personal care (1). Sexual abuse can be perpetrated by a stranger, carer, a family member, friend or a spouse. Sexual abuse occurs in many forms and does not have to include penetration or rape, but may come *“in the way an enema is given, intentionally stimulating erogenous zones (nipples, breasts, genitalia) whilst attending to personal hygiene, or when inserting a catheter or applying/changing a continence absorbent aid”* (pg. 81) (1).



Some revealing signs of abuse include the following (1,7,8):

Physical symptoms can include:

- Unexplained bruising or bleeding around the breast, buttocks, lower abdomen, thighs and/or genital areas
- Unexplained visual signs of a sexual health infection
- Walking difficulties, pain when sitting and/or obvious genital trauma

Behavioural symptoms can include:

- Sudden reluctance to be undressed, changed or bathed
- Sudden mention of sexual acts
- Sudden agitation when being changed or when continence pads are being fitted

As a health care professional with a duty of care to protect people with dementia who are under your care, you should trust your intuition even with the lack of overt signs of sexual abuse. Any suspicion or observed misconduct signalling sexual abuse should be immediately reported to your management team (1,7,8). While reporting suspicion of sexual abuse or being a witness to sexual abuse of people with dementia may be daunting, it will however ensure that the well-being and safety of the people with dementia under their care are being upheld and that care staff continue to fulfill their care role professionally and responsibly (1).

Identifying Sexual Risks to Vulnerable People with Dementia

To identify the sexual risk for vulnerable people who are living with dementia, with the intention of reducing the possible incidence of serious harm, we must have an understanding of risk. In a care context, sexual risk may be seen as the probability

of an undesirable consequence resulting in harm to the person in care, families and staff. It may not be possible, or desirable, to entirely eliminate sexual risk (4). As Alzheimer's Australia points out, risk management requires weighing up the safety, freedom and rights of people in care (3). The Australian/New Zealand Risk Management Standard (AS/NZS 4360:2004) defines risk management as "the logical and systematic method of establishing the context, identifying, analysing, evaluating, testing, monitoring and communicating risks associated with any activity..." (3). Some initial questions that can be asked are:

- Does the sexual risk outweigh the benefits of the sexual behaviour/relationship for the person with dementia?
- Does the sexual behaviour/relationship of the person with dementia infringe on the rights of others?

Adding a layer of complexity is the diminished mental capacity to consent for people with dementia engaging in sexual relations. With such concerns in mind, there is a set of questions that health care professionals can ask to determine the risk and cognitive capacity of an individual engaging in sexual behaviour (5,9,10):

Awareness of Relationships

- 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?

Ability to Avoid Exploitation

- 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 nonverbal communication?

Awareness of Potential Risks

- 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?

It is acknowledged that the capacity to consent to sexual activity or physically intimate relationships for people with dementia continues to be a challenging issue for health professionals. Current legislation does little to assist. It is suggested that while ensuring every effort is made to protect people with dementia from harm, health professionals must respect their rights to make decisions about their sexualities, intimacy and physical relationships (11). Importantly, Tarzia et al. (11) proposed the adoption of a sexual decision-making framework for people with dementia that uses the pursuit of happiness as its guiding principle. Instead of rushing to initiate mediation or capacity assessment when sexual behaviour is encountered, using a common sense approach and observing the interactions of people with dementia may be more appropriate and beneficial.

Sexual relationships should be assessed on an individual basis, with the overriding intention

Broader Ethical Considerations

1. Is the behaviour in keeping with the person with dementia's past values, beliefs and/or religious views? If not, but the person with dementia appears content and happy, to what extent should it matter? (14-16)
2. To what extent do care providers have the 'right' to intervene in the sexual lives of people with dementia? What rights of people with dementia are being denied when such interventions occur? (14-16)
3. To what extent should others be allowed to make decisions about the relationship of people with dementia? (14-16)
4. How do you balance the safety of people with dementia while also empowering them to live their lives?
5. Have family and spouse/partner been informed by staff and aware of the new relationship?
6. If there is a spouse/partner living outside of the care home, is he/she aware of the new relationship? How will he/she feel about the new relationship?
7. Does the family or spouse/partner feel comfortable in expressing their views about the new relationship?
8. To what extent should the views of family or spouse/partner be taken into consideration if they are unhappy with the relationship?

of improving quality of life and fulfilling the needs of people with dementia, while reducing preventable potential harm to all parties involved in the sexual relationship (1-5,8,12). A thorough examination of the health and cognitive ability, previous and existing relationships as well as the preceding lifestyle of people with dementia through communicating with their family is needed for early identification of potential sexual risk (1). For example, when a person with dementia is first processed for admission in any care environments, his/her sexual history should be included as a routine component of care assessment (1-5,7).

Furthermore, sexual advance care planning can help to ensure that an individual's choices relating

to future intimate and/or sexual relationships are respected; in case a time comes that they are unable to make or communicate decisions for themselves. This is a process that will enable people to discuss their sexual health and preference and any choices they have made for their future health care with their health care providers, family members and other important people in their lives.

Communication is vital to sexual risk identification and every incident with an adverse impact should be reported by staff to management while memories of such incidents are vivid to ensure a running account of common patterns (3). The types of sexual risk to vulnerable people can include: (a) sexually transmitted infection

(evidence of increase incidence among older people (13)); (b) trauma or physical damage; and (c) emotional upset (3). However, prohibiting sexual activities due to fear of sexual risk is also a peril to the well-being of people with dementia and an abuse of their rights. Thus, in any care environments, health professionals should, to the

best of their ability, identify potential sexual risks for people with dementia while keeping in mind that risk exists in all actions being performed with the possibility of harm, at varying degrees, to the people with dementia and/or others. The best prevention is to be well informed and prepared.



Activities: Sexuality and Dementia in Care Settings

Please complete the following short-answer questions as an indication of your understanding of Unit 1.

Short-Answer Questions:

Question. *What are some of the initial questions you should be asking when determining the sexual risk to vulnerable people with dementia?*

Answer:

- Does the sexual risk outweigh the benefits of the sexual behaviour/relationship for the person with dementia?
- Does the sexual behaviour/relationship of the person with dementia infringe on the rights of others?

Unit II: Caregivers' Role and Responsibilities in the Expression of Sexuality by People with Dementia

Aim

The aim of Unit 2 is to outline the role and responsibilities of caregivers and offer insight into approaches to the expression of sexuality by people with dementia.

Outcome

By the end of Unit 2 you will be able to:

- Understand the role and responsibilities of health care professionals towards the expression of sexuality by people with dementia
- Identify ways to respond to the expression of sexuality by people with dementia
- Identify ways to respond to sexual advances from people with dementia

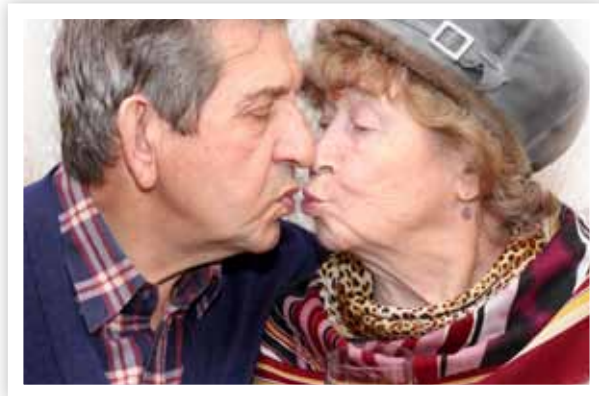
Role and Responsibilities towards the Expression of Sexuality



REFLECTIVE QUESTION

As a health care professional, how can you facilitate the expression of sexuality in aged care?

The expression of sexuality by people with dementia remains to be an important and challenging issue. For some, sexuality may be expressed through the uncomplicated longing to feel close to people such as wanting to share space, seeking a hug or a kiss from family or seeking affection and attention from staff. For others, expression may take the form of physical acts such as masturbation or undressing in public (1,5,7). At times, people with dementia may display their sexuality in unseemly



places or with people that may cause alarm to onlookers or the person being approached (1,5,7). Research suggests that while only very few people with dementia will express their sexuality 'inappropriately', the few that do may be aggressive or forceful in their approach and try to involve others against their wishes (1,5,7). If sexual expression is being directed 'inappropriately', there are strategies staff can employ to re-direct the expression into more appropriate channels and find ways to help a patient/resident meet their needs (explored later in this Unit). Ascertaining the 'appropriateness' of sexual expression may lead to questions of consent, which was previously discussed in Unit 1.

In the health care profession, duty of care is of utmost importance, requiring the identification and management of risks to those being cared for and determining what is harmful and to whom (3). The right to self-expression and self-determination needs to thus be weighed against a 'prevention of risks is best' approach to dementia-related sexual expression to ensure that people with dementia are not being harmed while supporting their freedom of choice and decision-making power as much as possible (3). The denial of the

right of people with dementia to express their sexuality is an infringement on human rights. Health care professionals have a responsibility to assist people with dementia to meet their need for expression of sexuality (1,3,5,7). Undertaking such a role in enabling expression of sexuality for people with dementia should be done sensitively, professionally and with respect to the dignity of the person, giving them the greatest assistance to make decisions about sexual expression for themselves (1).

Furthermore, pre-existing relationships should not end just because a person is now receiving care in a residential environment. While *“to the outside world it may seem uncomfortable or odd at first sight for a sexual or intimate relationship to continue when one partner has dementia... many couples do wish to maintain some level of intimacy and any problems can be handled and successfully navigated within the relationship”* (pg. 15) with the right approach (5). Similarly, it is the right of all people to form new relationships if they should please, which may occur between residents in the care facility (1). Therefore, health care professionals have a responsibility to monitor developments and assess risk, but to also uphold and support the decisions made by residents in care facilities.

Keeping in mind that the expression of sexuality in any given care context can raise tricky legal and ethical issues such as autonomy, privacy and cognitive capacity and consent, it is thus imperative to know what roles and responsibilities health care professionals have in relation to the expression of sexuality for people with dementia. Policy development, which guides care practices and the roles and responsibilities of health care professionals in approaching the expression of sexuality for people with dementia, will be an invaluable first step forward (1,3,5,7,17).

Responding to the Expression of Sexuality by People with Dementia

There are many productive ways to handle expression of sexuality by people with dementia. Remembering that it is perfectly normal and natural for people with dementia to have sexual needs, when genuine sexual needs are expressed, care staff need to respect the feelings and dignity of people with dementia and respond with sensitivity and empathy to their sexual behaviours. For example, if someone wishes to fulfill their own sexual needs by masturbating and/or reading/watching pornographic materials, it is very important to give them privacy (e.g. placing a *“do not disturb”* sign on the door of their room). In some cases, it may be appropriate to engage the services of an erotic body masseur and sex workers to meet the sexual needs of people with dementia.



Assessing Sexual Behaviours

Assessment of the sexual behaviour and whether it is a cause for concern is the first step. Legal and ethical dilemmas mainly arise when sexual behaviour, in care settings, involves new relationships where one, or both, of the parties involved have dementia. We should bear in mind that cognitive capacity to consent to a new relationship is not necessarily diminished by the illness itself and even if people with dementia cannot verbally communicate their wishes, consent can be implied through their actions like preferring to spend time with their new

partner, holding their hand or entering their room frequently (1). We need to ask ourselves whether those engaging in sexual behaviours have an insight, are able to make a judgement and retain some capacity to understand the consequences of their behaviour.

Rules of Thumb

- If people with dementia can make some, but not all behavioural decisions, they should still retain their rights to make as many decisions as possible without interference. If their consenting ability or the behaviour is questionable, or family members disagree, it may then be a cause for concern requiring assessment.
- If the behaviour is deemed 'inappropriate' because it poses serious risk to themselves or others, an immediate (i.e. on-the-spot) response may be necessary. When this occurs, staff need to remain non-judgemental, calm and objective. Strategies care staff can employ include (5):

- Try to remain calm, try not to feel embarrassed or show shock.
- Remember to be respectful to the person with dementia and try to preserve his or her dignity.
- Try to remember that the person with dementia may have no awareness that

his/her behaviour is inappropriate or shocking in any way.

- If others are present, and the behaviour is inappropriate, try to reassure the patients/residents or families present that the patient/resident with dementia means no harm.
- Depending on the situation, if the behaviour is taking place in a communal area, try to distract the patient/resident with dementia and lead them away.
- Appropriate jokes, witty replies and humour can sometimes be used to respond to some forms of sexual behaviour. It needs to be done tactfully and with respect to the patient/resident, staff and visitors.

However, when the expression of sexuality is deemed 'inappropriate' because of risk and is increasing in frequency, an intervention may then be necessary. Before introducing any intervention, we need to conduct a methodical assessment to identify underlying causes of the sexual behaviour by looking at the sexual and medical history. This will provide us with a contextual understanding of the nature of sexual needs and what the sexual behaviour may represent to the person with dementia (1,3,5,7). The following questions, which are linked to four key areas, can be used to guide the assessment process (5,6):

1. What form does the behaviour take?

- In what context? Potential environmental triggers?
- How frequently does it take place?
- Review the behavioural history and current routine of the person with dementia.
- If staff have not already done so, they need to speak to the family, friends or spouse/partner of the person with dementia to gain a greater understanding of his or her social and sexual history.

2. What factors may contribute to the behaviour? Could there be a social, environmental, medical or psychological cause?

- Has there been a change to the routine or environment of the person with dementia? For example, sometimes a lack of privacy can force patients/residents to express sexual behaviour in an overt fashion.
- Is it possible that the person with dementia is misinterpreting the actions of, for example, the care worker or believes them to be someone else he/she knows well or intimately?
- Have you checked that the person with dementia has no underlying medical condition, which may be contributing to this behaviour? Or that his/her medication has not been changed? For example, urinary or vulva/vaginal problems may lead to increased touching.
- Have you assessed the mental well-being of the person with dementia? Could he/she be depressed, experiencing delirium, be manic, or simply feeling lonely and looking for reassurance, comfort, or touch?
- If the person with dementia is trying to take his/her clothes off, is it because he/she is wearing an item of clothing that is irritating them or simply too hot?

3. Reflect on how you define and classify inappropriate behaviour

- Consider how you have formed this judgement and try to work out if the behaviour offends your attitudes, cultural or religious beliefs or values. Or do you find the behaviour inappropriate because you feel it would be judged so by other staff members, patients/residents or maybe the patients'/residents' family?

4. Consider what risks are involved

- Does the person with dementia pose a risk to others? A risk to themselves? Or to the wider residential community?
- Try to assess the awareness and understanding the person with dementia has of his/her behaviour.
- Make sure you report and record any behaviour that may be inappropriate.

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P-LI-SS-IT Model of Care

Involving the family during sexual history assessment of the person with dementia not only provides health professionals with a wealth of background knowledge and in-depth contextual understanding of the sexual behaviour but also proactively offers the family an opportunity

to discuss their concerns. This will assist the family to better understand what they may have considered to be different or distressing sexual behaviour displayed by their loved one. White (1) suggests using the P-LI-SS-IT model of care to guide sexual discussion with primary carers of people with dementia.

P-LI-SS-IT Model of Care

P	ermission	Gain permission first from family to discuss sexual behaviour of their loved one
L I	imited nformation	Give family some information showing how the process of dementia may impact on a person's sexuality, explaining that sexual desire does continue throughout a person's lifespan and it can be beneficial to well-being to maintain intimate contact with loved ones or form new relationships.
S S	pecific uggestions	Offer suggestions of how one may be able to approach caring for the sexual needs of the person living with dementia. Suggestions can include; sensory therapies (remedial massage, aromatherapy, music); inviting spouse or partner to stay overnight or to take the person living with dementia home for occasional overnight stays (if they are in residential care); and asking family to assemble an autobiographical account of the person's life with photos and reminders of good times to be used in later reminiscence-distraction programmes.
I T	ntensive Herapy	Advise family on the availability of counsellors, community support groups, sex therapists, psychologists, social workers or clinical nurse consultants that may be able to help family work through their own feelings and obtain support.

An example of the P-LI-SS-IT model being used in the case of Paul and Margaret Holmes:



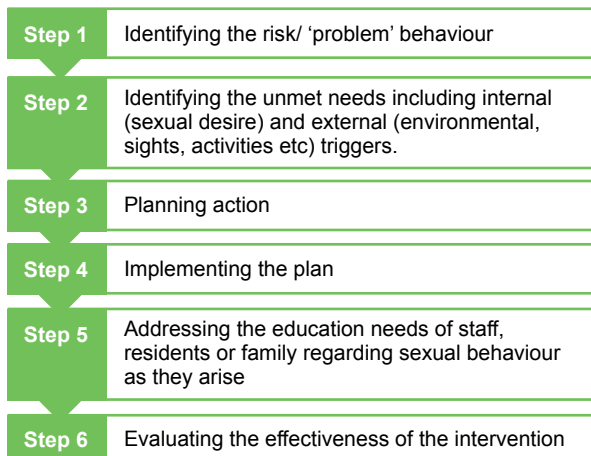
71-year-old Paul was diagnosed with Alzheimer's disease. He had been living in a dementia specific unit for approximately the last two years. His wife, Margaret (63-year-old), visits him on a daily basis. She was upset by his constant desire to engage in sexual intercourse. Noticing Margaret's discomfort, care staff sought her permission to discuss the situation. While Margaret was initially reluctant to discuss the situation, she eventually confided in the care staff. When questioned about their sexual history, Margaret indicated that she and Paul had an active sexual life right up till his admission

to residential care. She was concerned that Paul, given his Alzheimer's disease, may not be fully aware of his own actions (i.e. taking off his clothes, pulling her into the bed with him and touching her intimately). She was also particularly worried about the attitudes of other people and that if she agreed to his sexual advances, they would know what she and Paul were doing behind closed doors. Margaret felt embarrassed about the possibility of others laughing at them having sex at their age. Given her concerns, suggestions were made for Margaret to meet with a clinical nurse consultant in regular formal sessions to discuss her feelings. During these 'intensive therapy' sessions, it was noted to Margaret that the behaviours exhibited by Paul were not unusual from those prior to his admission to the care facility. Margaret was reassured that, in light of their active sexual life, it was quite normal for Paul to continue having and displaying sexual needs and desire. The clinical nurse consultant suggested that Margaret should consider taking Paul home for a night stay-over to once again share feelings of intimacy and have sex in the privacy of their own bedroom. This suggestion was proven to be a success for Paul and Margaret and a home overnight stay was organised on a regular basis.

Importantly, building rapport and discussing with the family the sexual behaviour of people with dementia will help prepare for any ethical dilemmas that may arise as well as allow for better planning in the event of a need for intervention (1). Intervention should be appropriate, justifiable, effective and not generative of other harm or greater harm than it seeks to prevent (18). Some possible interventions (1,5-7,17,18), beside those previously suggested, can also include selecting clothing that is soft to wear and does not irritate the person, as well as clothing that opens at the back if they are prone to undressing or masturbating publically; and substituting staff members to provide care to the person.

Needs-Based Approach

In residential care facilities, reviewing and learning from past displays of sexual behaviour of people with dementia can help health professionals identify triggers as well as adopt care practices to meet their sexual needs (7). Both McCarthy and White call for a needs-based approach incorporating the following steps (1,8):



Encouraging family members to provide hugs and kisses to their loved one, providing stuffed toys and time to interact with animals, as well as opportunities to exercise, may be enough to re-direct inappropriate and/or unsolicited sexual behaviour by satisfying the person's needs for touch, comfort and interaction. Promoting activities, like social outings, beauty services and romantic evenings can all enhance a resident's sense of self and beauty, which also re-channels sexualities into more context-appropriate behaviour (19). Remember, there are many ways to respond to sexual behaviour; the key is to focus

on the person and not the behaviour. Moreover, if a person is engaging in sexual behaviour by themselves or with their partner in the privacy of their own room, simply leave them alone. If you accidentally interrupt them, retreat quietly and respect their privacy (1,8).

Responding to Sexual Advances from People with Dementia

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. As a health care professional, when you feel uncomfortable by the touch of a person with dementia whom you are providing care for, you should clearly identify the behaviour and indicate that the behaviour is unacceptable and you feel uncomfortable while

reminding the person with dementia who you are (5). There are however suggestions that in cases of acute dementia (i.e. delirium), words will be generally ineffective as words will have no meaning to those who do not comprehend their behaviour in the first place (1). If you cannot distract the person and re-direct his/her behaviour to another activity and/or move the resident to another location and his/her behaviour is placing you at risk, then you must remove yourself from the situation and seek help. Health care professionals should report the behaviour and conduct a thorough assessment (see above) to determine the triggers of the behaviour and identify possible ways to avoid or limit future sexual advances. Following an incidence of uninvited sexual advance, you may feel upset, angry and/or emotional. Seek support and reassurance from your colleagues and make sure you report and record the incidence (5).



Activities: Caregivers' Role and Responsibilities in the Expression of Sexuality by People with Dementia

Please answer the following true or false and multiple choice questions as an indication of your understanding of Unit 2.

True or False Questions

1	Duty of care requires the identification and management of risks to those being cared for and determining what is harmful and to whom.	True / False
2	The expression of sexuality in an aged care context does not raise legal and ethical issues such as autonomy, privacy and cognitive capacity and consent.	True / False
3	Health professionals should remain non-judgemental, calm and objective when responding to sexual behaviours of people with dementia	True / False
4	Verbal responses are considered to be effective when countering the sexual advances of people with acute dementia (delirium).	True / False

Answers: 1. True / 2. False / 3. True / 4. False



Activities: Caregivers' Role and Responsibilities in the Expression of Sexuality by People with Dementia

Please complete the following short-answer questions as an indication of your understanding of Unit 2.

Multiple Choice Questions:

Questions 1. What does P-LI-SS-IT stand for?

- A. Permission, Limited Information, Specific Suggestions and Intensive Therapy
- B. Permission, Limited Information, Specific Sources and Intermittent Therapy
- C. Permission, Limited Information, Specific Suggestions and Intermittent Therapy
- D. Permission, Limited Information, Specific Sources and Intensive Therapy

Answer: A

Question 2. The right to self-expression and self-determination needs to be weighed against a '_____ ' approach to dementia-related sexual expression.

- A. Person-centred care
- B. Relationship-centred care
- C. Prevention of risks is best
- D. Maximum benefits

Answer: C

Question 3. Which of the following is not one of the four key areas you would consider when identifying the underlying causes of sexual behaviour for people with dementia?

- A. The nature and form of sexual behaviour
- B. Social, environmental, medical and psychological factors contributing to the sexual behaviour
- C. Definition and classification of inappropriate sexual behaviour
- D. Possible benefits for the person with dementia

Answer: D



Activities: Caregivers' Role and Responsibilities in the Expression of Sexuality by People with Dementia

Please complete the following short-answer questions as an indication of your understanding of Unit 2.

Short-Answer Question:

Outline the needs-based approach to sexual behaviour of people with dementia.

1. Identifying the risk/ 'problem' behaviour
2. Identify the unmet needs
3. Plan action
4. Implement the plan
5. Addressing the education needs of staff, residents or family regarding sexual behaviour as they arise
6. Evaluate the effectiveness of the intervention

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Module C: Ethical Considerations: Policy/Guidelines Development for Sexualities and Dementia in Care Settings



Aim

The aim of this content focus area is to discuss the legal and ethical issues that are to be considered in the development of policy and guidelines for sexualities and dementia in care settings.

The Case of Valarie and Linda

Valarie is a 69-year old widow with mid-stage Alzheimer's disease. She has been residing in a long-term care facility for the past two years, after the death of her husband of 48 years. Valarie often does not recognise her 2 adult children who visit her regularly. Linda is a 73-year-old single female with early stage Alzheimer's and a history of same-sex relationships prior to her admission into the long-term care facility a year ago. Her younger brother visits her regularly. Despite displaying some signs of memory loss and associated distress, she is very sociable and loves interacting with other residents. Six months ago, Valarie and Linda started spending time together. They ate their meals and attended activities together. Three weeks ago, they were found sitting together in Linda's bed, kissing and fondling each other by an attending nurse who entered their room without knocking. **(Case study adapted from Sokolowski, M. (2010 & 2011) *Sexuality and dementia in long-term care: Ethical issues.*)**



Outcome

Using a case example, by the end of this Module, you will have 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' vs 'Then')

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REFLECTIVE QUESTION

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.

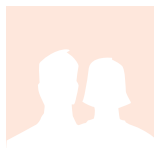
Content below adapted from Sokolowski, M. (2012) Sex, dementia and the nursing home: Ethical issues for reflection.

Staff's Reaction



Although the nurse quietly retreated from Linda's room, she felt uncomfortable with the relationship. She is also concerned about the possible relational exploitation by Linda given Valarie's cognitive state of capacity. The nurse reported the incident to her supervisor, who then discussed the matter with the facility manager. It was decided that both families should be informed of the relationship.

Valarie's Family (Children) Reactions



Valarie's daughter was aghast by the relationship and felt that her mother was being taken advantage of. She indicated that Valarie is a heterosexual, who had a loving and happy marital relationship with her father, and that she would be "dismayed" if she could really appreciate her behaviour. Valarie's daughter insisted on separating her mother from Linda. On the other hand, Valarie's son, while surprised, noted that his mother seemed much happier than before she had dementia and wondered if perhaps she is now enjoying living a somewhat different life with different values.

Linda's Family (Brother) Reactions



Linda's brother was happy that his sister has developed a new relationship. He felt that she knew what she was doing and it was nobody's business but hers.

As raised in Module B, duty of care (i.e. to do no harm) is of upmost importance for health professionals when caring for the person with dementia. Not only are they obligated under their professional registration act to abide by the codes of ethics and conducts, they are also governed by the established standards and values in the 1997 Aged Care Act (4) as well as their organisation's own values reflected in the philosophy of care, mission statements and position statements. As a result of the legalities of duty of care, health care professionals often take on an approach emphasising risk prevention (5).

It is challenging to define and measure risk as well as understanding the different experiences of it for all the stakeholders involved. It is also difficult to ascertain when the risks may override the benefits (and according to whom). Health care professionals need to make a judgement when responding and managing the risk that may befall either the person displaying the sexual behaviours, or the recipients of such behaviours. These judgements are influenced by their own value system, the society in which they live, their attitude toward *sexualities* and workplace policy or guidelines (3,5).

Case Study: Points of Discussion

Impact on Family

- What impact does this relationship have on both Valarie and Linda's families?
- Valarie's daughter is negatively affected by this relationship as her reactions include concerns about her mother's safety and values. While Valarie's needs ought to be privileged, is there also a need to mitigate and significantly reduce her daughter's concerns?

Impact on Others

- Is the privacy of other residents being invaded? Are other residents being negatively affected in other ways?
- What impact does this have on staff? Are they equipped to deal with this? Do they require additional support to deal with their own competing values?

Impact to Organisations

- Is there the possibility of a lawsuit from Valarie's family?
- Could such a relationship tarnish the organisation's reputation?
- Does the disclosure of the relationship impose a breach of trust of residents, staff, family and community?

*** The above impacts on family and others as well as to organisations could ensue even if there was no perceived harm incurred by either Valarie or Linda.**

(Above content adapted from Sokolowski, 2010 & 2011)

The lack of policy or guidelines to deal with sexual matters arising in care environments can lead to an experience of dissonance for health care professionals. People with cognitive disability seem to have reduced freedom of choice and increased supervision and control in comparison to those without cognitive disability. Time and again, this can become so pervasive that people with dementia are deprived of their basic human rights to decision-making when it comes to the expression of sexuality (5). Furthermore, many aged care facilities in Australia are operated by religious affiliated organisations whose values may negatively influence any support for expression of sexuality including same-sex relationships such as the relationship between Valarie and Linda. Hence, not only is the

development of policy or guidelines imperative, considerations must be given to dementia-related legal and ethical issues including privacy rights; cognitive capacity and consent; autonomy and solidarity; as well as personhood.

Privacy Rights

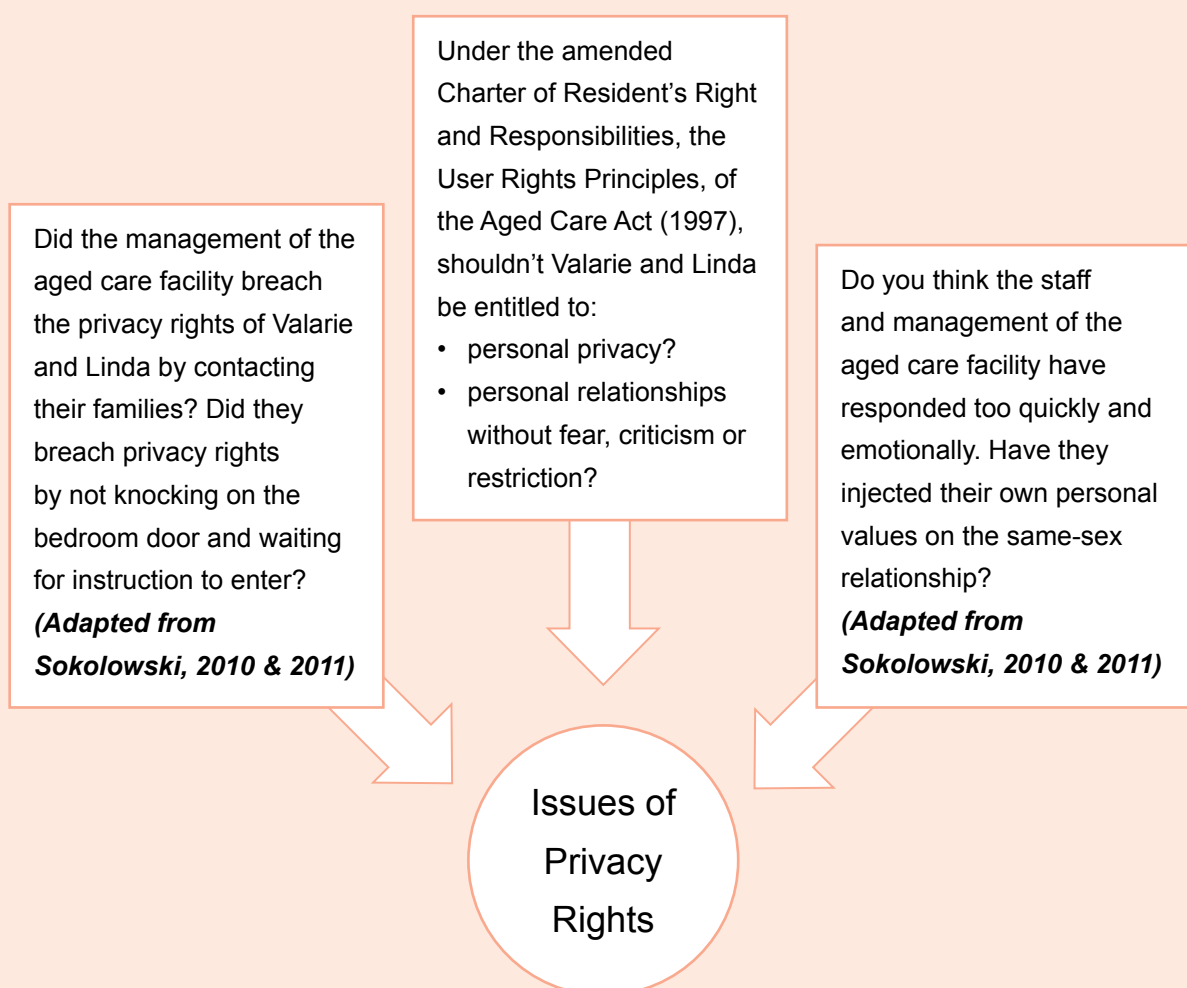
"They may lose the ability to live independently. They do not lose their rights"
(Field & Garratt, 2004, pg.75)

To ensure no attenuation of rights by the simple reason of admission to a residential aged care facility, in 1997, the Australian Commonwealth Government included into law an amended Charter of Resident's Right and Responsibilities,

the User Rights Principles, under the Aged Care Act (7). The fundamental component of this Charter is the right to personal privacy, meaning that what occurs in the confines of the person's own space is regarded to be the person's own business. Another is the right to select and maintain social and personal relationships with any other person without fear, criticism or

restriction. The stipulation being as long as it does not inflict damage to property or impinge on the rights of others or negatively affect the well-being of others. Regrettably, a person with dementia's need for personal space as well as the ability to maintain a sense of ownership and control over that space can be and is often easily overlooked in communal living settings (5).

Case Study: Points of Discussion



Cognitive Capacity and Consent

(Content from Sokolowski, 2010 & 2011)

The issue of cognitive capacity was discussed in Module B. As health care professionals, we need to ask ourselves whether consent to be involved in a sexual relationship is somewhat the same as consent to a medical treatment? In most democratic western countries, cognitive capacity (i.e. ability to perform a task or make a decision) is understood to be similar or even interchangeable with autonomy (i.e. privileges of self-determination/self-rule). When cognitive capacity is diminished, there is a tendency to pay less attention to the wishes of the person. This is not only morally incorrect but also encroaches on the autonomy and dignity of the person with

dementia (8,9). While dementia interferes with recall of past events, people with dementia often are still capable of experiencing meaningful relationships. It is possible that they are able to understand in a general way what it means to engage in a sexual relationship or activity. Importantly, we need to avoid subjecting people with dementia to rigorous assessments and imposing unrealistic expectations relating to their understanding or appreciation of what it means to be engaging in a sexual relationship or activity (i.e. at a higher threshold than what we would expect people without dementia to be able to do!). In fact, people often enter into sexual relationships without much rational thought at all. So why do we expect something different of those with dementia? (1,2,10)

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Case Study: Points of Discussion

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?

(Adapted from Sokolowski, 2010 & 2011)

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Autonomy and Solidarity

(Content from Sokolowski, 2010 & 2011)

Autonomy represents the ‘right to self-determination’ and ‘making our own choices’ (11) in accordance to one’s own beliefs and values. The conventional view of autonomy has a heavy reliance on one having a requisite intellectual level to be considered to have autonomy (12). This can lead to the notion that autonomy is only connected to what one wants or prefers prior to dementia and is no longer pertinent in the context of dementia (13). Consequently, in the event of expression of sexuality, limited consideration is given to the older person’s existing sexual desires and wishes, which can, in fact, also be a true reflection of his or her autonomy.

Assuming someone with dementia can no longer be autonomous is erroneous (1,2,14). From a medical perspective, we often regard autonomy to be dichotomous (i.e. able or unable to be autonomous). This dichotomy is impractical and does not reflect the reality of people with dementia possessing fluctuating abilities to govern themselves in different contexts and act according to the values and beliefs that are important to them. Indeed, autonomy for people with dementia is not static but dynamic and flexible. By and large, one becomes less autonomous overall as the dementia progresses. Nevertheless, even in later stages, vestiges of lifetime values and beliefs may continue to be maintained. It is wrong to assume that because someone has dementia, he/

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she can no longer be autonomous (1,2). Instead, it would be more beneficial and pragmatic to consider autonomy as existing on a continuum (i.e. more or less autonomous) for people with dementia where it is closely associated with their values and beliefs as well as being linked to the social, emotional, religious and spiritual realms of identity. Not only can older people with dementia still retain an interest in certain values and beliefs that shape how they wish to live their lives, but more importantly, ***new and different values can still conceivably be created (14,15).***

Even if incapable of expressing autonomous desires, people with dementia clearly have an

interest in being helped to maximise their well-being, an important aspect of which can be related to the satisfaction of their sexual desires and preferences (13). Moreover, when considering solidarity (i.e. the duty to support each other especially those unable to support themselves), older people with cognitive disability also need to be empowered and given a voice. Promoting and sustaining social justice, which is at the root of our notion of solidarity, must be realised as a willingness to support older people with dementia in their expression of sexuality throughout the course of their dementia and to help them in maintaining their autonomy as much as possible (13).

Case Study: Points of Discussion



Inspite 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?

(Above content adapted from Sokolowski, 2010 & 2011)

Personhood ('Now' vs. 'Then')

(Content from Sokolowski, 2010 & 2011)

Instead of focusing on cognitive ability as the sole determinant for any intervention, it may be more sensible to look beyond the reasoning abilities of the older person and to focus on 'personhood', such as what are the older person's current sexual desires, values, beliefs and relationships with others? (12) There is an enduring debate

about whether we ought to privilege the values, beliefs and wishes of the person before dementia (i.e. "then" person) or after dementia (i.e. "now" person) in sexually related matters (16,17). Generally, as seen in the above case example, there is a propensity to devalue the current sexual needs and behaviours (i.e. "now" person) and consider the previous behaviours displayed by the person prior to their dementia (i.e. "then" person)

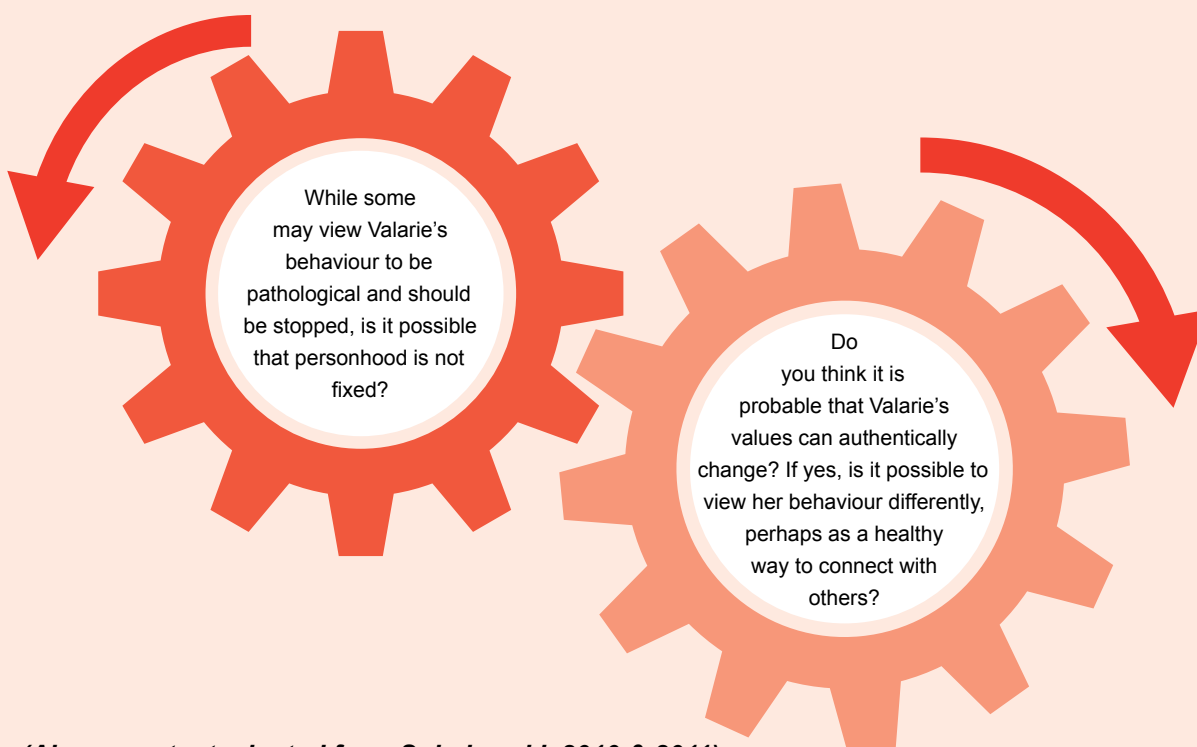
as 'authentic' especially in situations where the sexual needs and behaviours of the person following dementia contradict with those of former behaviours - "She is acting out of character." *"She would be so ashamed if she knew what she was doing now!"* (1,2,10)

Favouring the "then" person has to do with the common creed that a person has a relatively unified life with fixed and stable values and behaviours that are a reflection of the "authentic" self. With this in mind, deviations from usual or "normal" behaviour are seen as pathological (18). However, if 'personhood' can authentically change, then perhaps, the expression of sexuality can be understood differently and viewed as a healthy way to connect with others (10,19,20).

Changes in personality (i.e. character, behavioural, temperamental, emotional, and mental traits) in people with dementia are fairly

prominent when brain damage is primarily located in the frontal lobe (21,22). The deliberation lies in whether the new personality should be regarded less favourably simply because the older person displays different traits to their past life. Kitwood (23) argued that people with dementia can maintain their 'personhood' through relationships with other people. Within the context of person-centred care, the personal and social identity of a person with dementia arises out of what is said and done with them and there is an ethical obligation to treat people with dementia with respect (23). Hence, it would seem logical to neither dwell on the process leading to the change of personality in older people nor refute the genuinity of the new personality and the associated expression of sexuality. Instead, this should be acknowledged and respected.

Case Study: Points of Discussion



(Above content adapted from Sokolowski, 2010 & 2011)



Activities: Ethical Considerations: Policy/Guidelines Development for Sexualities and Dementia in Care Settings

The Case of John & Mary

John is an 83-year-old widower, with early stage Alzheimer's disease, who has been living in a residential aged care facility for the past three years, shortly after the death of his wife. His 3 adult children visit him on a regular basis. He has a history of chronic depression and displays some signs of memory loss with associated distress. Mary is a 79-year-old, with mid-stage Alzheimer's disease, who has been residing in the same long-term care facility for the past year. She has been married for 55 years to her husband who visits regularly and lives independently in their matrimonial home. Their 2 adult daughters also visit her every week. Mary is happy but quite forgetful and often does not recognise her family members, including her husband. Six months ago, John and Mary started spending time together and Mary is usually the initiator in seeking John out. Two weeks ago, they were found by the attending nurse in Mary's bed, lying naked together and caressing each other. The nurse was horrified and insisted that John return to "his room" and that they no longer "have sex again!"



(Case study from Sokolowski, 2010 & 2011)



REFLECTIVE QUESTION

- What are your beliefs, values, moral codes and cultural attitudes regarding the relationship between John and Mary? 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 John and Mary.
- Do you require additional support to deal with your own competing values?



Content below from Sokolowski (2010 & 2011)

Staff's Reaction



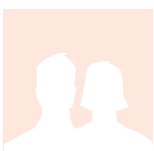
The nurse called for a staff team meeting with the following concerns identified by many of the team:

- Given Mary's state of cognitive capacity, *"there is no way she could have consented to have sex with John"*. There is a duty to protect her from possible exploitation by John.
- John is taking advantage of Mary who is likely to be seen as unfaithful by her family.
- Both families should be contacted as soon as possible to communicate what had happened.

- Steps ought to be taken to separate them to avoid any future re-occurrences.

However, the psychologist raised her concerns that the team was responding too quickly and emotionally and were likely to be projecting their own personal values. She felt that the residents' autonomy (i.e. their right to self-govern and make their own choices) was being violated. She was also worried that it would be a breach of privacy to contact the families. Nevertheless, the team decided to inform the respective families.

John's Family Reactions



All three adult children felt that in essence it was positive that he was forming a new attachment. He had been very lonely after the death of his wife and that it was his business how he conducted his personal life. They felt that he knew *"what he was doing"* but at the same time recognised that they might feel differently if he were to become more cognitively impaired.

Mary's Family Reactions



Mary's husband was shocked and felt deeply betrayed. He blamed the staff for not keeping a closer *"watch over her"*. He insisted that she probably mistook John for himself and that she was always a devoted and loving wife who is now clearly acting *"out of character"*. Two of the 3 adult children agreed with their father, and were worried that John was probably taking advantage of their mother. They felt that their mother would be *"appalled"* if she could really appreciate her behaviour and the two should be separated immediately. The third adult child, while concerned, noted that their mother appeared to be unharmed and much happier than before she had dementia. He wondered why the others kept referring back to the "old Mary" as if the "new Mary" needed some sort of protection or shouldn't get to "count" as much as the "old Mary" did.



Activities: Ethical Considerations: Policy/Guidelines Development for Sexualities and Dementia in Care Settings

As an indication of your understanding of Module C, please consider the ethical implications for the above case example:

Short-Answer Questions:

(Content for Questions 1 to 8 from Sokolowski, 2010 & 2011)

Question 1. What impact does John and Mary's relationship have on their family?

Answer:

Mary's family is more negatively affected by this relationship as their reactions include betrayal as well as concerns about her safety and values. While Mary's needs ought to be privileged, there is also a need to address the feelings of betrayal as well as mitigate and significantly reduce the concerns of her family. Consider using the P-LI-SS-IT model of care (*refer to Module B, Unit II*).

Question 2. Are other residents being negatively affected by the relationship between John and Mary?

Answer:

No other residents appear to be negatively affected by the relationship between John & Mary.

Question 3. What are the possible impacts of John and Mary's relationship for the organisation?

Answer:

Possibility of a lawsuit from Mary's family due to a breach in duty of care (i.e. if John was culpable of sexually exploiting Mary) and tarnishing the organisation's reputation.

Question 4. Do you think the staff and management of the aged care facility have responded too quickly and emotionally and have injected their own personal values on the relationship of John and Mary?

Answer:

It appears that staff and management of the aged care facility may have responded too quickly and emotionally and injected their own personal values on the relationship of John and Mary without considering their rights to privacy and autonomy.

Question 5. Did the management of the aged care facility breach the privacy rights of John and Mary by contacting their families? Under which circumstances, if any, should family members be informed?

Answer:

Yes. Beside their rights to self-govern and make their own choices (i.e. autonomy), according to the Charter of Resident's Right and Responsibilities, the User Rights Principles, under the Aged Care Act (4), John and Mary have the right to personal privacy, meaning that what occurs in the confines of their own space is regarded to be their own business. They also have the right to select and maintain social and personal relationships with any other person without fear, criticism or restriction. These issues were not thoroughly taken into account before the decision to contact their families was made.

Family members should only be informed when evidence of sexual exploitation surfaced and/or when signs of ill-being are detected (*refer to Module B, Unit I*).

Question 6. Should cognitive capacity be the sole or main determinant of whether or not John and Mary's sexual relationship should be interfered with or allowed?

Answer:

No. Cognitive capacity should not be the sole or main determinant in deciding if John and Mary's sexual relationship should be interfered with or allowed. Other issues of concerns such as privacy rights, autonomy, solidarity and personhood should also be taken into account (8,9). As indicated in *Module B, Unit I*, perhaps a sexual decision-making framework for people with dementia that uses the pursuit of happiness as its guiding principle should be considered. Instead of rushing to initiate mediation or capacity assessment when sexual behaviour is encountered, using a common sense approach and observing the interactions of people with dementia may be more appropriate and beneficial.

Question 7. Even if John and Mary could not "pass the competency to consent" test, they could probably assent to participate in their relationship (agree without full understanding). Wouldn't that be enough?

Answer:

People with dementia are often still capable of experiencing meaningful relationships despite their inability to recall past events. It is likely that they are able to understand in a general way what it means to engage in a sexual relationship or activity and could probably assent to participate in a relationship (agree without full understanding). Therefore, if John and Mary are able to assent to participate in their relationship, we need to avoid subjecting them to rigorous assessments and imposing any unrealistic expectations relating to their understanding or appreciation of what it means to be engaging in a sexual relationship or activity (i.e. at a higher threshold than what we would expect people without dementia to be able to do!).

Question 8. In the absence of their usual decision-making cognitive skills, do you think Mary and John demonstrate, through their ongoing relationship and desire to seek out each other's company, that they value friendship and physical intimacy?

Answer:

Yes. We should acknowledge and support John and Mary's desires for friendship, physical intimacy and advocate their rights to privacy, autonomy and solidarity.

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Module D

Module D: Developing Sexualities and Dementia Policy Guidelines for Care Practice

Aim

The aim of this Module is to discuss ways to enhance care practices in relation to *sexualities* for people with dementia through the development and implementation of policy guidelines as well as the use of a sexuality assessment tool in a long term care environment.

Outcome

By the end of this content focus area, you will be able to:

- Outline the steps needed to develop policy guidelines for *sexualities* and dementia
- Identify the strategies used to implement sexualities and dementia policy guidelines

Policy Guidelines Development for Sexualities and Dementia

Health care professionals' interpretation of intimacy, *sexualities* and sexual behaviours will vary greatly between individuals. Professional beliefs may be contradicted by their personal beliefs, values, moral codes and cultural attitudes about *sexualities*. Without a guiding policy, in situations where conflict exists among the values of people with dementia, their family and care staff, staff and family may decide on a response that disregards the preferences of the person with dementia. The development of policy guidelines on *sexualities* and dementia is therefore imperative to ensure consistency and congruency in response strategies. Furthermore, it will also make certain that people with dementia who are unable to object will be protected from unwanted sexual advances. Schindel-Martin (1) outlines the following 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

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Step 1 – Forming a working group

Identify the key stakeholders to be involved in developing the policy guidelines. Direct care staff must be involved in the process. Those who are not directly involved should be kept informed of the process and given an opportunity to provide their input. Key stakeholders can include (*this is by no means an exhaustive list*): Registered Nurse; Personal Support Worker; Health Care Aide; Social Worker; Diversional Therapist; Physician; Ethicist; Family; Management; Board Representative; and Pastoral/Spiritual Care/Chaplain Services. Where necessary and appropriate, external expertise can be brought into the working group.

Step 2 – Learning about the issues

To challenge pre-existing beliefs and biases about *sexualities* and dementia as well as educate and inform on issues relating to duty of care, privacy rights and ethical considerations, all working group members should read the resources and

articles listed in this education resource. With the assistance of an experienced facilitator, pertinent issues that arise from the readings should be discussed and worked through by the working group.

Step 3 – Conducting focus groups

Acting as facilitators, the working group members should consider conducting focus groups of individual staff members (as many as possible) to discuss:

- values, beliefs, attitudes and personal moral codes and how these may conflict with their stated professional position; and
- issues such as capacity, consent and risk assessment to assist in the identification of organizational comfort zones and a barometer through which normal behaviour, acceptable behaviour and risk behaviours can be viewed.

Step 4 – Review sample policies from other organisations

Contact other similar organisations or institutions to review their policies in relation to the expression of sexuality. Identify features from each policy to build practice guidelines that will best complement your own organization's philosophy and mission statement.

Step 5 – Create working definitions of key concepts in the policy guidelines

In addition to a clear definition of the terms '*consent*' and '*risk*', it is necessary to construct clear working definitions of the following concepts for inclusion in the policy guidelines (2):

- intimacy, *sexualities* and sexual behaviours
- conventional and atypical sexual behaviours
- sexual behaviours of concern or risky sexual behaviours
- sexual behaviours requiring assessment

For organisations with specific cultural or religious affiliations, values and position on the different types of sexuality need to be clearly stated and inherently reflected in the policy guidelines.

Furthermore, the working group needs to establish what constitutes consent for engagement in sexual behaviour and relationships. To determine under what conditions and circumstances a relationship between people with/(out) dementia should be supported to continue in care settings, the following questions (3,4), previously outlined in Module B – Unit 1, should be examined:

Awareness of Relationships

- 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?

Ability to Avoid Exploitation

- 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 nonverbal communication?

Awareness of Potential Risks

- 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?

It should be cautioned that the cut-off of the standardised Mini-Mental State Examination (SMMSE) (5) score can possibly be restrictive when considering the cognitive competency of people with dementia. As discussed in Module C, in addition to the issues of autonomy and solidarity, we need to refrain from arduous assessment of people with dementia and imposing unrealistic expectations related to their understanding or appreciation of what it means to be engaging in an intimate and/or sexual relationship. It is important to remember that those with a low SMMSE score can maintain awareness of the relationship, eschew exploitation and describe the potential risks of the relationship. Therefore, it may be unreasonable to prohibit the continuance of the relationship simply based on a SMMSE score alone.

Step 6 – Identifying interventions

Besides outlining expectations of how staff should respect the privacy rights and respond to intimate and sexual behaviours of people with dementia, the policy guidelines should also include a list of possible interventions for adoption by care staff. Depending on the risk level of the sexual behaviours, various sensory therapies or environmental and behavioural interventions can be introduced as a first-line response for low-risk behaviours. Pharmacotherapy should be avoided as a general practice unless there are clinical indicators to suggest high-risk persistent hyper-sexual behaviours.

Step 7 – Draft a working policy guidelines document

Expectations and issues concerning professional staff practice should be taken into account when developing the policy guidelines. These include:

- An evaluation procedure for assessing the level of risk associated with intimate and sexual behaviours (*refer to Appendix A*) including an

audit of sexual history upon admission and the implementation of assessment tools.

- A reporting procedure for observed intimate and sexual behaviours (*determine under what circumstances/conditions should sexual behaviours be reported*).
- A documentation procedure that includes the appropriate terminology (not personal values statements) to be used in recording objective observations of intimate and sexual behaviours. Notations that elucidate the frequency, intensity, duration and level of risk associated with observed intimate and sexual behaviours should be built into the documentation system.
- Develop a rationale and procedure that outline why, when and how families should be informed. Determine who should be the appropriate family member to be contacted.
- A team discussion/meeting review process incorporating the expected parameters of intimate and sexual behaviours in each case, and a strategy to identify, implement and evaluate interventions. Family, locum decision-makers and/or power of attorney should be involved in the team discussion/meetings and decision-making processes.
- Reference to the Department of Health and Ageing's Compulsory Reporting Guidelines for Approved Providers of Residential Aged Care (6) for reporting requirements (e.g. to the Police and Department of Health and Ageing) in relation to incidents involving alleged or suspected sexual assaults / unlawful sexual contact. Such reports must be made within 24 hours of the allegation, or when the approved provider starts to suspect a reportable assault. The legislation allows limited circumstances where there is a discretion not to report. These relate to alleged assaults that are perpetrated by residents with an assessed cognitive or mental impairment; and subsequent reports of the same or similar incident.

- The use of a decision-tree that assists staff to identify management responses to intimate and sexual behaviours.
- Provision of ongoing education and training for both staff and families of residents. Expected attendance and the organisation's intent and commitment for continuing staff training and induction as well as the orientation of new families to the policy guidelines should be clearly outlined.
- The inclusion of case studies as an appendix to the policy guidelines for new staff induction.

Step 8 – Implementing the policy guidelines

Circulate the policy as a draft to all stakeholders (e.g. staff and families) to gather feedback. Staff meetings should be held to introduce and distribute the final version of the policy guidelines and its implications for their practice. Other strategies to implement the policy guidelines can include:

- *Sexualities* and dementia awareness day/week for annual policy review.
- Holding guest seminars and workshops as part of an educational initiative for both staff and families either during the awareness day/week or on a regular basis.
- Holding discussion forums for both staff and families. Possible use of role-play and video clips to promote discussion about intimate and sexual behaviours in care environments and how the policy will determine the appropriate management response.

Step 9 – Evaluating the policy

Establishing an ongoing feedback mechanism will be important for the revision of the policy guidelines. The policy guidelines can also be adjusted as deemed appropriate by the working group, for example when intimate and sexual behaviours are observed and reported, so that it evolves into a working document that



is both practical and useful. Furthermore, the periodic review of *sexualities* and dementia related literature would assist in policy revision to ensure that it continues to reflect the current understanding of intimate and sexual behaviours for people with dementia.

If your organisation needs assistance with policy development, the following guide may also be of help:

<http://www.akeresourcecentre.org/files/Sexuality/Intimacy.%20Sexuality%20and%20Sexual%20Behaviour%20in%20Dementia.pdf>

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Appendix A: Response to the Classifications of Sexual Behaviour (7)

Level of Sexual Behaviour	Description of Sexual Behaviour	Response
Level 1	<p>Intimacy/ Courtship</p> <ul style="list-style-type: none"> • kissing, hugging, handholding, fondling, cuddling (not inclusive) • consensual (implies awareness of actions) 	<p>No risk associated with this behaviour, if both persons consenting:</p> <p>Overall goal of staff response is to provide socially appropriate context for relationship that offers comfort and reassurance.</p> <ul style="list-style-type: none"> • This behaviour is viewed primarily as an intimacy relationship between two adults that are mutually consenting, implied by behaviour toward each other. • Source of urgency associated with this behaviour is usually staff and/or family discomfort. Staff may wish to protect family. • The couple may need to have intimacy needs recognized and privacy respected (8).
Level 2	<p>Verbal Sexual Talk</p> <ul style="list-style-type: none"> • flirting, suggestive language, sexually laden language • not aggressive 	<p>Low level of risk associated with this behaviour:</p> <p>This behaviour may cause discomfort and reaction when directed toward staff; often occurring during personal care.</p> <ul style="list-style-type: none"> • Staff response is to recognize their feelings of unease if contrary to personal values and beliefs. Staff to respond respectfully. • If suggestive language directed at co-resident, visitor or staff, the behaviour should be redirected into a more socially appropriate context. • Punitive language will not be tolerated, for example, “I thought you were married, and nice, married men don’t say those kinds of things to ladies!” This is a negative value judgment that the resident will interpret as punitive. An example of an appropriate response: “John, it sounds like you would like to have a conversation with me, so let’s talk. Why don’t you tell me about...”

Level of Sexual Behaviour	Description of Sexual Behaviour	Response
Level 3	Self-Directed Sexual Behaviours <ul style="list-style-type: none"> • masturbating • exposing oneself 	<p>Low level of risk:</p> <p>For self-stimulating behaviours staff need to observe and answer the following questions:</p> <ul style="list-style-type: none"> • For male: is there evidence of erection? Ejaculation? Skin irritation? • For female: is there evidence of injury as a result of masturbation? Is resident using a foreign object for stimulation? • Does the resident engage in this behaviour in the presence of others? How does this affect others? <p>Focus on creative solutions and the provision of pleasurable and socially accepted sensory experiences for the resident (this may include erotic body message, sexually-explicit materials &/ or vibrators), while maintaining privacy, dignity, safety and least restriction (9).</p>
Level 4	Physical Sexual Behaviours <ul style="list-style-type: none"> • Directed towards co-residents with agreement 	<p>Moderate level of risk associated with this behaviour:</p> <ul style="list-style-type: none"> • In early dementia the capacity to make decisions regarding basic needs and immediate gratification such as sexual activity is retained (10). • The staff must be vigilant about observing the resident for any signs of sexual overtures that are unwelcome. Are staff members aware of the extent of sexual behaviours: one-on-one contact with the intent to kiss and caress, disrobing, oral sex or attempt to engage in penetrative intercourse? • Does one partner in the pairing look distressed, upset, worried? • Can the residents give an account of behaviours they would find acceptable/unacceptable? • Do they have the ability to say “no” or indicate refusal and/or acceptance? • Do they have the ability to avoid exploitation? • Does their life story indicate passivity in relationships?

Level of Sexual Behaviour	Description of Sexual Behaviour	Response
Level 4	<p>Physical Sexual Behaviours</p> <ul style="list-style-type: none"> Directed towards co-residents with agreement 	<p>If the resident is distressed or non-consenting move to Level 5.</p> <ul style="list-style-type: none"> If resident(s) are incapable of making decisions regarding their sexual expression it is critical to have management and family's involvement (i.e. previously determined person responsible) to establish resident values, beliefs and level of comfort, and ultimately make decisions that act in the best interest of the resident. Staff to provide support and education. The focus of interventions should be on creative solutions that allow the consenting couple privacy and dignity, plus opportunities to engage in social activities with others in a socially appropriate context.
Level 5	<p>Non-consensual, overt physical sexual behaviours directed towards others that are a source of distress.</p> <ul style="list-style-type: none"> Aggressive or repeated sexual overtures that are unwanted and rejected by others in the environment 	<p>A <u>HIGH</u> risk is associated with this series of behaviours:</p> <ul style="list-style-type: none"> A resident may enter another's personal space and clearly touch them in a way that is unwelcome and upsetting for the person (<i>this could range from sexual touching to penetrative sexual intercourse</i>). The incidence of sexual inappropriate behaviours in persons with dementia is very low ranging from 2.6%-8% (11). The response indicates the person is objecting and the staff views it as an unwanted invasion of personal space. The appropriate staff response is to protect the resident/ others from unwelcome sexual behaviour. The resident that is expressing overt sexual behaviour should be treated with respect and dignity. Are staff members aware of the extent of sexual behaviours: one-on-one contact with the intent to kiss and caress, disrobing, oral sex or an attempt to engage in penetrative intercourse?

Level of Sexual Behaviour	Description of Sexual Behaviour	Response
Level 5	<p>Non-consensual, overt physical sexual behaviours directed towards others that are a source of distress.</p> <ul style="list-style-type: none"> Aggressive or repeated sexual overtures that are unwanted and rejected by others in the environment 	<p>For this type of sexual behaviour there <u>MUST</u> be:</p> <ol style="list-style-type: none"> 1. A sexual behaviour assessment that includes a holistic assessment of possible causes/triggers to behaviour and any evidence of injury (<i>refer to Appendix B & C</i>). An assessment of resident(s)' awareness of actions is also required (<i>refer to Appendix D</i>). 2. Discussion with the resident and/or the spouse/partner to determine values, beliefs, life story and level of comfort in order to identify the need for support and education. Additional interventions will be identified through open dialogue. 3. Documentation to include the sexual behaviour assessment. All staff to be aware of interventions for sexual behaviour for each resident involved, with inclusion in care plan. 4. All infection control precautions to be followed as per care policy. 5. Reports are usually to be made to the Police and Department of Health and Ageing within 24 hours of alleged or suspected sexual assaults / unlawful sexual contact by the resident or intervening staff. However, the legislation permits discretion not to report under limited circumstances where it relates to alleged assaults that are perpetrated by residents with an assessed cognitive or mental impairment; and subsequent reports of the same or similar incident.

Appendix B: Sexual Behaviour Assessment: Part One

1. Provide a description of the sexual behaviour observed. This should be obtained, confirmed and validated with:

- a) persons involved such as resident(s) and/or spouse/partner if possible; and
- b) with cognizant witnesses such as Power of Attorney for Personal Care (POAPC), family, visitors &/or staff witnessing the event.

Objective documentation to include:

- a) verbal and physical actions of resident(s); and
- b) consequences including evidence of injury and interventions by staff

2. Is this a change in behaviour?

3. What is the degree of risk? See Appendix A Classifications of Sexual Behaviour

- ☐ No anticipated risk ☐ Low ☐ Moderate ☐ High

4. What are the antecedents (possible causes and triggers) and evidence of injury of sexual behaviour?

Physical: Disease, drugs, discomfort, delirium, disability and consider sensory loss, sleep disturbance, elimination etc., in addition to evidence of injury. Bruising may not be evident for 4-24 hrs after incident.

NOTE: In a critical incident where an aggravated sexual assault is suspected staff are not to wash person involved or change clothing. Wounds can be tended to, and resident kept warm and comforted with blankets etc. Call your local hospital to check Domestic Violence/Sexual Assault Protocols and request a sexual assault nurse be notified of incoming assault victim to ED. Victim or POAPC needs to give consent before a forensics evidence kit can be collected. Staff should escort resident to hospital.

Intellectual: Cognitive impairment, dementia, impaired judgment, disorientation, aphasia, altered perceptions, misinterpretation, impulsivity etc. Emotional: Fear, adjustment, anxiety, depression, bereavement, recent losses, delusions etc.

Capabilities: ADLs: continent/incontinent, self-care, ambulatory, assistive devices etc.

Environment:

Social/Cultural/Spiritual: See Life Story

Name (or initials) of other resident or person involved:

Staff witnessing the event, or first staff responding:

Other witnesses: _____

Nurse In Charge: _____ Date: _____

Adapted from:

Steele D. (2007). A best practice approach to intimacy and sexuality: A guide to practice and resource tools for assessment and documentation. PRC: Lanark, Leeds & Grenville Long-Term Care Working Group.

Sexual Behaviour Assessment: Part Two

1. Has an **Admission Sexual History** (refer to Appendix C) been previously completed?

☐ Yes ☐ No

If an **Admission Sexual History** has not been previously completed:

- Is there information the resident, spouse/partner, POAPC or family member(s) could share about the resident's life story that may help staff understand certain behaviours? Siblings can possibly be a better resource than children for past traumas of sexual nature and/or passivity.

2. What is the awareness of the resident involved? (complete Appendix D before proceeding)

If the resident is mentally capable, the POAPC and family are not to be involved unless at the request or consent of the resident.

3. Is there a POAPC or family member who should be consulted/contacted about the behaviour/ incident?

Person contacted: _____ Date/Time: _____

Response:

4. Do Police Services need to be contacted?

☐ Yes ☐ No

Police Contacted on (Date/Time): _____

By: _____

What was the outcome of this contact:

Date/Time of investigating officer's visit to facility: _____

What was the outcome of this visit:

5. A care conference involving all parties is valuable in developing an appropriate care plan & next steps: interventions, investigations, interaction and information, that will be shared & communicated. If the resident is not mentally capable to make decisions, it is the POAPC who interprets the last capable wishes of the resident. If wishes unknown, then the POAPC should act in the resident's best interests.

Date/Time of scheduled care conference: _____

What was the outcome of this care conference:

Completed by: _____ Date: _____

Adapted from:

Steele D. (2007). A best practice approach to intimacy and sexuality: A guide to practice and resource tools for assessment and documentation. PRC: Lanark, Leeds & Grenville Long-Term Care Working Group.

Appendix C: Admission Sexual History

Current Marital Status		
Number of marriages or serious relationships:		
Is there current involvement in a relationship?	Yes	No
Do you anticipate your spouse/partner will feel comfortable visiting/spending time with you in this place of residence? If not, how could we improve on this?	Yes	No
How do you, the resident, identify your gender identity: <input type="checkbox"/> Male <input type="checkbox"/> Female <input type="checkbox"/> X (indeterminate or unspecified)		
How do you, the resident, identify your sexual orientation: <input type="checkbox"/> Heterosexual <input type="checkbox"/> Homosexual <input type="checkbox"/> Lesbian <input type="checkbox"/> Gay <input type="checkbox"/> Bisexual <input type="checkbox"/> No comment		
Do you, the resident, enjoy giving/receiving hugs and/or showing affection?	Yes	No
Are you, the resident, accustomed to sleeping alone in bed?	Yes	No
Have you noted any changes in behaviour in the area of sexual expression over the past few months of which you feel our staff should be aware? Explain.	Yes	No
Are current behaviours consistent with formerly held beliefs and values? Explain.	Yes	No
Would you be comfortable providing a narrative of, your life story, to help us know you, the resident better?	Yes	No
Any known history of abuse (mistreatment) or trauma: sexual, physical, emotional or verbal?	Yes	No
Any known history of sexually transmitted infection?	Yes	No

Information received from: _____ Date: _____

Completed by: _____

Adapted from:

Steele D. (2007). A best practice approach to intimacy and sexuality: A guide to practice and resource tools for assessment and documentation. PRC: Lanark, Leeds & Grenville Long-Term Care Working Group.

Appendix D: Assessment of Awareness of Actions (Understanding & Appreciation)

Assessment of the sexual behaviour and identification of the terms under which the relationship between the two individuals/residents will be supported should also include a determination of the resident(s) awareness of actions: the ability to understand and appreciate, to participate in a relationship. Lichtenburg (1997) and Lichtenburg and Strzepak (1990) suggest that the following questions be asked to identify the conditions and circumstances if a relationship is supported to continue.

1. Resident's Awareness of the Relationship:

- a) Is the resident aware of who is initiating the sexual contact?
☐ Yes ☐ No ☐ Comments: _____
- b) Does the resident believe that the other person is a spouse or partner?
☐ Yes ☐ No ☐ Comments: _____
- c) Are they aware of the other's identity and intent?
☐ Yes ☐ No ☐ Comments: _____
- d) Can the resident state what level of intimacy they would be comfortable with?
☐ Yes ☐ No ☐ Comments: _____

2. Resident's Ability to Avoid Exploitation:

- a) Is the behaviour consistent with formerly held beliefs/ values?
☐ Yes ☐ No ☐ Comments: _____
- b) Does the resident have the capacity to say no (verbally or non-verbally) to any uninvited sexual contact?
☐ Yes ☐ No ☐ Comments: _____

3. Resident's Awareness of Potential Risks:

- a) Does the resident realize that this relationship may be time limited?
☐ Yes ☐ No ☐ Comments: _____
- b) Can the resident describe how they will react when the relationship ends?
☐ Yes ☐ No ☐ Comments: _____

Is the resident able to respond to questions adequately (verbally or non-verbally)?

Completed by: _____ Date: _____ Time: _____

Developed by:

Steele D. (2007). A best practice approach to intimacy and sexuality: A guide to practice and resource tools for assessment and documentation. PRC: Lanark, Leeds & Grenville Long-Term Care Working Group.

Adapted from:

- Lichtenburg, P.A. (1997). Clinical perspectives on sexual issues in nursing homes. *Top Geriatric Rehabilitation*, 12, 1-10.
- Lichtenburg, P., Strzepak, D. (1990). Assessments of institutionalized dementia patient's competencies to participate in intimate relationships. *Gerontologist*, 30(1), 117-120.

Conclusion

Sexuality is central to human existence and its expression will remain a normal perpetual need in our lives including those living with dementia. Supporting the expression of sexuality in people with dementia necessitates an open mind, tolerance, flexibility as well as modifying the manner in which we perceive and react to intimate and sexual behaviours. Neither disregarding the sexual concerns nor attempting to limit or control sexual expressions is the answer to human needs for sexual behaviour, particularly for those with a cognitive disability. There is no singular orthodox approach in responding to sexual behaviours of people with dementia. Instead, begin with an open and candid dialogue with the person with dementia, including those involved in their care provision. To reduce ambiguity and provide a framework for



practice, policy development needs to acknowledge health care professionals' moral values without imposing them on people with dementia; and most importantly, empower people with dementia in their own decision making process as much as they are able to. In conclusion, the following are 10 key points regarding sexualities and dementia covered in this education resource:



Confront your own values, attitudes and behaviours towards sexuality and older people.



People continue to be sexual beings with the capacity and need to express their sexualities regardless of age and cognitive disability.



Expressions of intimacy and sexualities have positive physical, psychological, intellectual and social benefits for individuals including people living with dementia.



Not all people with dementia are heterosexual.



Dementia-related sexual behaviours can, at times, simply reflect the person's need for touch and/or comfort. Adopt a psychological needs based approach when addressing the expressions of intimacy and sexualities for people with dementia.



No standard response to sexual behaviours of people with dementia. Assess each case on an individual basis.



People with dementia can continue to have the capacity to make decisions about their sexual needs and behaviours.



Besides the cognitive capacity for consent, consideration should also be given to the issues of privacy, autonomy, solidarity and personhood.



Familiarise yourself with your organisation's policy on dementia and sexualities (if there is one).



Communicate - Have an early open dialogue with your residents, family carers, colleagues and management on this subject.



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