



Alzheimer's
Australia
Living with dementia



Quality
Dementia
Care :

Understanding Dementia Care and Sexuality in Residential Facilities

Purpose of this Booklet

The Alzheimer's Australia Quality Dementia Care Series provides complex information in an accessible form for use by people living with dementia, families, carers and health professionals.

Dementia and Sexuality

This publication asks the questions that all those caring for with people with dementia need to reflect on in developing strategies that result in individualised responses to the different needs of individuals. The booklet discusses what sexuality is, the behaviours that may be present that can be perceived as sexual in nature, the human rights and responsibilities of people with dementia, duty of care issues, understanding family relationships, approaches to risk management and developing policies on sexual behaviour. Each section has issues for consideration and there are some case studies which draw out particular issues.

For the purposes of this paper carers refers to family carers; employed carers are those who work for organisations involved in aged care or disability services.

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Quality Dementia Care Series: Understanding Dementia Care and Sexuality in Residential Facilities

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Foreword

It is a great pleasure to be asked by Alzheimer's Australia to write this publication. For many years, in various professional capacities, both as a practicing nurse and as an academic, I have seen dementia and sexuality cause embarrassment and upset to people with dementia, their family carers and staff of community and residential care facilities.

The reality is that issues relating to sexuality are confronting and it is probably true to say that even in everyday life, they are not handled very well. For family carers, community care providers, residential care environments and for people living with dementia, the subject of sexuality can be a difficult one when obtaining guidance to ensure rights, self-esteem and duty of care are not compromised.

Readers should not look for easy solutions in this Quality Dementia Care publication. There is no one size fits all. There are perhaps two essential points to remember. First, no matter what our age or disability we have a need for sexual expression in some form. Second, that the art of good care is to enable sexual expression for individuals in a meaningful way without discrimination and/or loss of dignity or self esteem. That can only be achieved if issues are addressed in a non judgmental and sensitive way.

The challenge in handling complex issues is to be able to balance human rights and issues of duty of care. This paper contains some case studies, not with a view to saying how they should be handled, but to illustrate some of the issues that need to be addressed.

I hope that those who provide care for people living with dementia find this publication helpful. As I said at the outset, the issue of dementia and sexuality is something that I believe we need to discuss more openly, and in doing so, find the understanding necessary to develop strategies that can be tailored to individual needs.

I should like to thank the many people both in Alzheimer's Australia and outside who commented on the draft of this publication. My special thanks to Anne Kelly, Alzheimer's Australia, Tasmania, for her support and comments. The interest and volume of comments in itself says a lot I think, about the need for this publication.



Adjunct Associate Professor Sally Garratt

Introduction

Open discussion about sexual issues and older people is still difficult in our society. There seems to be a belief that older people do not enjoy sexual activity, are beyond any sexual expression and do not have the ability to be a sexual being (Alzheimer's Australia, 2006). This belief ignores the fact that all human beings have the capacity to express their need for sexual expression no matter what their age or disability. Sexual expression is more than physical sex acts; it is the very essence of what makes us male and female. This paper explores the ways in which those who provide care for people living with dementia can enable sexual expression for that person in meaningful ways without discrimination and loss of dignity or self esteem. The matter of human rights is discussed and the complex issues of duty of care. Each section has issues for consideration and discussion. This paper does not provide answers for all the issues surrounding sexuality and people living with dementia but rather gives some prompts for discussion and assistance in developing strategies for staff in residential care facilities and for family members who may be concerned.

The suggested strategies are not final answers in themselves, as every case is unique and will require individualised responses. Outcomes may not always be what the people involved want, or all problems neatly solved, but at the least attempts must be made to address the issues raised.

1. What is sexuality?

Sexuality can be defined as the expression of male and female sexual desires, instincts and activities (Mosby's Dictionary of Medicine, Nursing and Health Professions, 2006). All human beings have the need to be able to express their feelings for sexual recognition and desires. The act of copulation is a part of human activity that not only determines the continuation of the species but allows for human needs of belonging and relationships to develop that nurture the human spirit and wellbeing. As we age the actual practice of sexual intercourse may change but the need for sexual expression remains as a part of our being human, and is as unique to each person as is our ability to do any other human activity.

Nay (2004) defines sexuality as “referring to 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, fulfilments 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.”

As in all human expression of need, sexuality is a complex phenomenon, but one that we can all relate to and have an understanding of if we are honest with ourselves.

2. Providing care

How we provide care that encompasses the need for sexual expression without putting our own values, feelings and constraints on the person who is experiencing dementia is a concern for all those who propose person centered care. Carers are often in a position whereby they have to judge what is acceptable behaviour or what is not, without imposing their moral values on the person living with dementia. Frequently they are not able to make these decisions without causing distress to either the person with dementia or their families. Care staff who work in residential and community situations have additional ethical obligations to residents, their families, other health professionals and their employer. Conflict is generated between moral principle and professional duty and the need to give time to all people when there is never enough time to deliver the care they would wish (Tabak & Shemesh-Kigli, 2005). Opening dialogue with the person living with dementia if possible, their significant others and care staff is perhaps the best way to begin.

Key Questions

- Has a discussion been undertaken about a definition of sexuality with the family and employed carers to explore a consensus?
- How do you judge what is acceptable or not in your care environment? What is the basis of the judgment?
- Has any carer or employed carer been distressed over a perceived sexual incident?
- If so, what was done about it and how was the outcome evaluated?
- Who is the person who is most likely to open discussion with close family members about this perceived expression of need?
- Should all staff have education regarding sexuality issues in residential care?

3. What behaviours may be present that can be perceived as sexual in nature?

We have labelled behaviours that are considered disruptive or unsocial as 'challenging, difficult or behaviours of concern'. It may be more appropriate to say some behaviours are an expression of need.

The manifestations of a need for sexual expression may present as –

- Flirting with others by use of suggestive language and body movement
- Touching self or others in personal places while in public
- Masturbation in public spaces
- Removing clothing in public spaces
- Open request for sexual acts
- Depression, withdrawal and mood changes
- Forming a relationship with another that involves sexual expression

Other behaviours can be perceived as sexual but in fact may be expressions of other human needs to be cuddled or touched in a way that gives comfort. We can misinterpret these behaviours as being sexual when they are not. They can be a source of humour for some people and the person is regarded as a 'dirty old man or woman' etc. Family members can be distressed if they observe such behaviour and make comments such as 'my mother would never do this normally'. Other people may protest that they do not want to be near the person exhibiting 'abnormal' behaviour. Often the behaviour is normal but we have not provided a private place in which it may take place.

Key Questions

- Who decides what is and what is not acceptable behaviour in care situations?
- When overtly sexual behaviour is reported to others providing care how is it dealt with?
- How is this behaviour communicated to other care providers and, if appropriate, family members?
- Is poor attitude to sexual behaviour tolerated in your workplace?
- Can employed care staff give cuddles and expressions of comfort without feeling guilty or fear of misinterpretation?
- How do employed care staff react when observing perceived sexual behaviour?

4. What are human rights and responsibilities?

People with cognitive disability seem to have less freedom of choice and are often more supervised and controlled than those who have no cognitive disability. Employed carers become caught in the legalities of duty of care and adopt the 'prevention is best' attitude to risk taking. This can become so pervasive that the normal lifestyle of the person with dementia is devoid of decision making altogether. Whilst the need for reduced environmental stimuli is often necessary to prevent anxiety it must not be taken to the extreme of not having any choice or stimulus at all in life.

Duty of care means to 'do no harm' and to respect the rights of all people to self expression and self determination. Health care professionals are obliged under their registration Acts to follow codes of ethics and conduct and are subject to peer review and/or legal sanctions (ANCI 2003). Other employed care workers are obligated to work under policies and procedures of the organisation that employs them. All employed workers are required to follow the standards and values established by the Aged Care Act (1997) and the organisation's own values that are usually included in their philosophy of care, mission statements and position statements. Duty of care therefore, should be discussed when the person is employed so that they understand and accept that the rights of people receiving care are paramount. However, if the conduct of the person receiving the care impacts negatively on another, protection from harm to another will come before personal wishes. For example, if one person wishes to engage in behaviour that another person has not given consent to, the rights of the non-consenting person come first.

Person centered care means recognition of the person as a unique human being. Carers and employed carers seek to understand this uniqueness. As dementia progresses the ability to make considered decisions deteriorates and stress levels can increase. Social inhibition may be altered and behaviour that would once have been controlled becomes cause for instant gratification with no consideration of the consequences.

Employed carers are bound by their duty of care to do no harm and to manage the risk that may befall either the person displaying the behaviour, or the recipients of such behaviour. It therefore calls upon the judgment of the carer who witnessed the behaviour, and if appropriate management, to determine what is harmful and to whom.

Judgment of human behaviour is influenced by our own value system, the society in which we live, our attitude toward sexuality and the policies and controls of the workplace. If the residential facility has no policy or procedure in dealing with sexual matters, or it is against the principles of the management to discuss such matters, the employed carer is put into a dissonant situation.

4.1 Consent

Leadership from management sets the policy and procedural tone of the facility.

One of the principles of a liberal society is the freedom of individual choice (Rawls, 1999 cited in Graydon et al. 2008). When that freedom is curtailed the rights of the individual are legally compromised.

However, the law protects those who do not have the capacity for informed consent or who may be exploited. Each State has legislation to protect vulnerable people against exploitation (Graydon et al, 2008) but there is no clear statutory definition of exploitation, or judicial guidance as to its meaning. Assessment is made on a case-by-case basis and previous discussion seems largely related to those persons who have had an intellectual disability from an early age.

People who have dementia have had years of life experience and usually do not experience intellectual disability through cognitive losses until later years. This means they probably have some recognition of their previous lifestyle and past memory that may flash back at times to past experience. They are vulnerable from a physical and mental perspective because of frailty but may be able to make their feelings known through behaviour or verbal communication.

Informed consent implies that the person is capable of making decisions based on knowledge of the consequences of that decision. Making decisions about financial matters or other issues is not the same as seeking human contact through the usual feelings and means, as they used to do in the past. Consent in this case would be based on mutual agreement that would not be considered exploitative.

4.2 Privacy

In 1997 the Commonwealth Government incorporated into law an amended Charter of Resident's Right and Responsibilities, the User Rights Principles, under the Aged Care Act. The intent of this was to establish there is no diminution of rights merely by reason of admission to a nursing home

"People lose many things as they grow older. They lose their youthfulness. They often lose their agility. They may lose their vision. They lose some of their friends. They may lose the ability to live independently. They do not lose their legal rights"
(p75, Field & Garratt, 2004).

A key right enshrined in this Charter is one for privacy. What a person does in the confines of the person's own space is deemed to be the person's own business. The proviso being as long as it does not compromise others or inflict damage to property.

In communal living the notion of privacy is one that constantly requires attention. It is easy to forget the need for personal space and the need to have a sense of ownership and control over it. Another is the right to select and maintain social and personal relationships with any other person without fear, criticism or restriction.

Key Questions

- Does your workplace have the Charter of Resident's Rights and Responsibilities in a public space for all to see?
- Have you read the Charter and know what it means?
- Do employed carers have education on the need for privacy for all residents?
- Is there a concerted effort to knock on all doors and seek permission for entry?
- If two people form a consenting relationship are they able to have privacy?
- If two people enter a bedroom and close the door do employed carers leave them alone?
- If one person is cognitively impaired but implies consent to forming a relationship with another resident do the employed carers tactfully discuss this and come to a considered decision that is still mindful of their duty of care?

5. Understanding family relationships

Family dynamics are difficult to understand and for outsiders to appreciate such relationships they must have the trust of the family member and a professional approach that does not make or convey assumptions or make particular judgments. The heterosexual relationship between husband and wife, or male and female partners, is generally accepted as the norm and not questioned. How the couple relates to one another is partly ascertained by observation and open dialogue with both of them. Sometimes the feelings for the partner change over time, or perhaps they were not close for years. Others maintain the same loving and romantic feelings toward each other no matter how much one of them has altered cognition and changed. The same changes occur in same sex relationships but they are not generally understood or accepted so readily by outsiders.

Children may also have mixed feelings about their parents and relationships. They may not understand the need for sexual contact because they think old people, or people with younger onset dementia, do not have sex! Their parents did not do such things for years; they would/should not have such ideas now they are even older.

Often families are split because of poor relationships that develop for various reasons and reconciliation in later years may not be possible. A family member that has experienced abuse, aggression, criminal activity or neglect from a spouse, parent or other relative may well carry negative feelings that don't change because of ageing or loss of cognition.

Same sex relationships may challenge values and attitudes of some employed carers, relatives and other residents. The family of a gay or lesbian person with dementia may never have accepted their relationships and may deny they ever happened. It is well to remember that these relationships were usually hidden by the current older population. Disclosure now that one partner is receiving care may be very threatening and painful, especially if those in perceived authority positions are insensitive (Birch, 2008).

Employed carers may not be able to solve personal relationship problems but rather they need to have the tools and support to understand the impact these may have on their resident's life and perhaps the life of significant others. The employed carer may feel there is a need for counselling or other intervention but this must be discussed with senior staff and the medical practitioner involved in care.

Key Questions

- How comprehensive is the social and family history documented in your workplace?
- Are observations made on resident/family interaction and recorded/discussed?
- Do staff make assumptions and gossip about relationships amongst residents and their family members or other close visitors?
- Are there religious or community beliefs in the philosophy of care where you work that impact on whether relationships are accepted or not?
- What is the essential social and lifestyle history information that is needed to ascertain sexual needs?
- How much information is enough before such questioning becomes invasive?
- Do people living with dementia have the right to maintain close relationships with whomever they please where you work?
- Have employed carers received training on how to deal with difficult family relationships, same sex relationships and how these might impact differently on the person living with dementia?

6. Risk management

In the residential or community context risk management involves the implementation of strategies that will reduce the incidence of harm to residents, staff, volunteers and visitors and improve quality of care. In this sense risk management is a system related to quality assurance and is essential in the management of human issues where there is a balance between safety, freedom and rights. Residents have the right to live their life in an unrestricted environment where freedom prevails and personal lifestyle choices can be fulfilled. Management, however, also has to consider the safety aspects of care and the obligations of a practical work environment for staff.

‘Risk management is the logical and systematic method of establishing the context, identifying, analysing, evaluating, treating, monitoring and communicating risks associated with any activity, function or process in a way which will enable organisations to minimise losses and maximise opportunities’. (AS/NZS 4360 Risk Management Standard) There is no reason that this cannot be extended to dementia care in the home.

The Definition of Risk

- is generally accepted to be the chance of exposure to the adverse consequences of future events
- is a common occurrence in life, for every action contains some element of risk
- is an emotive word, one that often brings with it a sense of fear
- changes with perspective and context, (Sally & Donaldson 1998).

Traditionally risk management was instituted in health care to reduce the costs of litigation from adverse treatment or accident. It has now become an integral part of improving quality to prevent adverse events and reduce the cost of these events on the people involved, not just on potential litigation for management.

A Risk Management Program aims to –

- a) prevent or minimise the damage caused by early identification of adverse events, using either staff reports or a systematic screening of records;
- b) reduce the frequency of preventable adverse events;
- c) reduce the chance of a claim being made after an adverse event;
- d) control the costs of claims being made.

Reports of incidents are made before claims are initiated, and while memories are still fresh. The reports are used to create a database to identify common patterns and prevent future incidents. Residents and their families are also informed about adverse events and action is taken to minimise both physical and psychological trauma.

The question of what risks are involved in sexual activity between residents, or residents and their significant others, should take account of previous lifestyle when assessing health patterns, cognitive ability and relationships. Risk of sexually transmitted disease is usually low, risk of trauma or physical damage should be predictable, risk of emotional upsets is probably high. Where there is a risk of sexual behaviour impinging on the rights of others, boundaries need to be established and controls put in place.

What must be clearly established is whether or not the risk outweighs the benefits of such a relationship and exactly what harm is likely to occur and to whom. Each situation needs to be assessed on its own merits. There is no blanket solution to human need or feelings and if person centred care is practiced this should help guide the outcomes.

In some instances the person living with dementia may express a need for sexual relief through the use of a paid partner, sex worker or sexual aids. This is a matter for the person living with dementia, possibly family caregiver and the manager to work through. The risks involved in the provision of such services relate to the manner in which the service is provided.

Privacy must be ensured and the person living with dementia or their family pays at the time of the service.

Exploitation of an older person is possible but can be monitored through careful questioning by the manager as to costs, threats, abuse, criminal activity or other issues. Family involvement depends on the cognitive status of the resident and their past lifestyle.

Key Questions

- What do the employed carers understand about risk management?
- How is the need for sexual expression related to the risk management process?
- How are the risks involved explained to families or others involved?
- Do you think risk management could be used to easily solve complex decisions about sexual matters?
- How does person centered care assist in decision making?
- How do employed carers recognise that a person living with dementia has a need for sexual relief? To whom do they report this?
- How do you ensure that dignity and privacy is respected for both the person with dementia and their family?

7. Developing policy on sexual matters

Policy is generated to guide the management of the organisation and assist staff to work within acceptable standards and boundaries. Procedures are derived from policy to give further guidance. Staff who work outside these policies and procedures are putting themselves and their organisation at risk as well as being open to causing harm to the person living with dementia. Policy on sexual matters is not easy to develop but that should not deter a facility or community service provider from attempting to give the guidance that staff require.

Appendix A gives an example of how one organisation has decided to put words into action.

Key Questions

- Has your workplace developed a policy on sexuality, relationships and rights which includes consideration of people living with dementia?
- If not, how would you begin to influence development of such a policy?
- How would this policy relate to freedom of choice and privacy rights?
- How would you accommodate the personal beliefs and attitudes of staff that are uncomfortable talking about sexual issues, particularly for the cognitively impaired?

8. Anecdotes from real life

Scenario 1

Mr. B. is a tall well built man aged 80 who has severe dementia and has been admitted to your facility because he has shown aggression toward his wife who feels she can no longer provide care at home. He seems happy through the day but becomes restless after tea and wanders looking for his wife. When his wife appears in the evening he grabs her hand and pulls her toward his room quite roughly. They go into his room and she closes the door. After ten minutes she opens the door appearing quite upset. Employed carers noted this behaviour on many occasions and eventually prevail upon the supervisor to speak to Mrs. B. The situation was very distressing to Mrs. B. who eventually explained that the only way to control Mr. B's behaviour was to give in to his demands for sex by manual means. The only problem was he now insisted on this action every time he saw her.

Key Questions

- How would you help Mrs. B. to understand her husband's behaviour?
- What strategies could you try to make her visits less stressful for her?
- In using this method of control Mrs. B. has established a new pattern of behaviour that is now detrimental to their relationship. How would you explain to her that she also has rights as well as her need to please her husband?

Possible strategies

- The manager needs to try to establish how this pattern of behaviour started and whether it was a part of the usual sexual relationship before Mr.B. became cognitively impaired.
- Does Mrs. B. want to continue this or not? If yes then privacy and understanding is offered. If no then discussion should centre on the need to manage the behaviour.
- Perhaps Mrs.B. should not enter the bedroom with her husband but engage staff to help her to stay in a more public space. His reactions would have to be monitored in case of aggressive behaviour.
- She may consider bringing someone else with her when she visits as a distraction.
- She may consider coming at meal times and sharing a meal with him instead of other times.
- A firm no! and walking away from his advances may also help.
- Management may suggest other forms of sexual relief for Mr. B. e.g. videos, paid sex worker, if the need is causing further behavioural issues.
- It is important to make Mrs. B. feel she has support in her decision and that the staff will not interfere unless she requests their assistance.

Scenario 2

Mrs. J. has had a loving relationship with her husband for over 60 years. They were very close and when she developed dementia Mr. J. thought his world had come to an end. She was admitted into a residential care facility, and he visited every day, tried to help the staff to care for her and brought treats for her and other residents. Mrs. J. did not seem to recognise her husband and was trying to form an attachment to one of the other male residents who was also living with dementia. One day Mr. J. found his wife and the other resident on the bed in her room obviously engaged in sexual foreplay. He was distraught and blamed the staff for not protecting his wife from this other "predator". He demanded they be kept apart and threatened to bring the police in to charge the male with abuse. The staff was aware of the attachment that had begun but had not realised the extent of the behaviour of the two residents with dementia.

Key Questions

- What should employed carers do when they observe attachments occurring between residents?
- How would you assist Mr. J. to understand the behaviour he saw?
- How could you meet Mrs. J.'s need for sexual contact?
- What would you do to prevent Mr.J. taking further action and diffuse his anger?

Possible strategies

- Mr. J. must be given the opportunity to vent his anger and probably grief.
- He may feel a failure, he may be angry towards his wife, there may be past behaviour he does not wish to revisit.
- The manager needs to have a discussion with Mr.J. to establish their past sexual expression as a couple. If they have been sexually active until Mrs.J's admission they both may have needs. This will take time and understanding. Mr. J needs time to

realise the behaviour he witnessed does not mean his wife does not love him but rather that the dementia causes such disinhibition.

- Mrs. J. obviously has feelings and a need for comfort that is not being met. Does Mr. J. feel he could still meet these needs?
- If this possibility is not acceptable to him there may be some avenue for him to give his wife more attention, even cuddles, kisses, and massage etc.
- A plan to observe Mrs. J. and distract her from developing a serious relationship with the other resident could be agreed upon, but Mr. J. must recognise his wife may try other forms of behaviour to meet her needs.
- The other male resident also needs further observation and assessment to determine how to meet his needs.

Scenario 3

Jason and Grant had shared a life together for 40 years. Jason had provided care for Grant for five years after he survived a severe stroke. Grant had to be admitted because he needed two people to lift him and provide care and had developed vascular dementia. The couple were embarrassed to discuss their relationship and felt the staff were inquisitive and did not understand their lifestyle. Jason had retired and was able to visit every day to feed Grant and help wherever he could. One day he heard a staff member talking about him and saying "I suppose the old queen will come in today and interfere as usual. No wonder the other residents don't like them". He was upset and did not know how to handle the issue. Fortunately another staff member also heard the remark and reported the incident to the supervisor.

Key Questions

- As the supervisor what would you do about this?
- How would you deal with the carer who made the remark?
- How would you deal with the remark about other residents not liking them?

Possible strategies

- The supervisor needs to have a full discussion with Jason and let him know that the facility does not condone such behaviour from staff and that knowledge of the same sex relationship will not alter his partner's care in any way.
- Provide Jason with reassurance that he will be supported by the facility to continue to visit whenever he wishes and to participate in care.
- The issue of not being liked by other residents needs further clarification and evidence and will be addressed; he will be kept informed as to how this will occur. The supervisor should suggest regular meetings between them and allow him to discuss how he is coping.
- The employed carer who made the remarks should be required to apologise and will require counselling if they are to continue to work in the facility.
- The Supervisor needs to have a staff meeting and address the incident.
- Education about sexuality and the policy of the facility should be made mandatory for all employed carers.

9. Conclusion

Understanding that sexuality is central to who we are as humans and that sexual behaviour is an expression of perfectly normal needs may require tolerance and flexibility, and also alters the way in which we 'see' and respond to behaviours. Finding answers to human needs for sexual behaviour when there is cognitive disability is not easy. The best way to start is to open dialogue with all people concerned with the provision of care and the people living with dementia themselves, if possible. By being open and honest the way forward will be easier than ignoring the problem or trying to control the lives of others.

Developing a policy that respects carers' moral values, but does not impose them on the person living with dementia, and allows them to have control over their own decision making as far as they are able, will reduce uncertainty and, like all policies, provide a framework for practice.

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Appendix A

Sexual rights and responsibilities policy.

This policy has been copied from the chapter on Sexuality and Older People in the book Nay, R. and Garratt, S. (2004) (2nd Ed.). Nursing Older People: Issues and Innovations.

It is included as a guide as to how such a policy may be developed in residential care settings.

The North West Hospital Policy on rights and responsibilities related to clients affirms the following principles, notwithstanding that if there is any conflict with relevant legislation the law will always override these principles.

- Clients can expect their maleness, femaleness, sexual orientation and preference to be respected by and supported by management and staff.
- Where a staff member feels their own morals are compromised in relation to a client's sexual behaviour the staff member has a responsibility to refer the matter to their Supervisor and the right to be exempted from care that is felt to be morally compromising.
- Wherever possible, clients will be provided opportunities to enable their choice of sexual expression provided such expression does not impinge upon the rights of others.
- Where sexual behaviour is seen to impinge upon the rights of others or threaten professional practice, staff and/or clients will be expected to refer the situation to the relevant Department Head and appropriate boundaries will be negotiated and discussed with all parties concerned- if a resolution is not reached, the Department Head will seek advice from their line manager.
- In situations related to sexuality where a client is cognitively impaired and/or they request family/guardian involvement, the family/guardian will be consulted. However if the family's wishes

appear to conflict with the interests of the client, appropriate (e.g. depending on the circumstance this may be a religious minister, counsellor, legal advisor, etc.) mediation will be sought.

- Clients can expect staff to treat their sexuality confidentially – discussion with other health professionals should only occur with the permission of the client or if behaviour impinges on the rights of others and requires intervention.
 - Clients are entitled to be provided with maximum privacy, recognising structural constraints, to enable sexual expression.
 - Clients are entitled to the same assistance with hygiene surrounding sexual activity as is given to other activities of daily living – e.g. ensuring cleanliness before and/or after sexual activity should be treated no differently than occurs in regard to meals, toileting, incontinence and so on.
 - Staff should not assist clients directly with intimate sexual activity as this may compromise the staff member and constitute abuse of the client.
 - Staff should respect a client's rights to access sex support services and senior staff may assist access by, for example, providing a telephone or making a call for the client if they feel comfortable doing so.
 - Management will promote and staff will maintain sensitive, positive language and behaviour toward the sexual expression of clients.
 - Staff and Management will provide information for clients to assist with informed choice relating to consent, fertility and disease.
 - Chemical and physical restraint will not be used to control sexual expression except in crisis situations and/or when every possible supportive intervention has been tried, failed and the client remains a threat to others.
- Staff, relatives and clients are entitled to education and support to assist in the implementation of this policy.*

Alzheimer's Australia Publications

Quality Dementia Care Series

1. Practice in Residential Aged Care Facilities, for all Staff
2. Practice for Managers in Residential Aged Care Facilities
3. Nurturing the Heart: creativity, art therapy and dementia
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5. Younger Onset Dementia, a practical guide

Papers

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2. Quality Dementia Care, February 2003
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6. Dementia: Can It Be Prevented? August 2005 (superceded by paper 13)
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13. Dementia Risk Reduction: The Evidence. September 2007
14. Dementia Risk Reduction: What do Australians know? September 2008
15. Dementia, Lesbians and Gay Men November 2009
16. Australian Dementia Research: current status, future directions? June 2008
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18. Dementia: Facing the Epidemic. Presentation by Professor Constantine Lyketsos. September 2009
19. Dementia: Evolution or Revolution? Presentation by Glenn Rees. June 2010
20. Ethical Issues and Decision-Making in Dementia Care. Presentation by Dr Julian Hughes. June 2010
21. Towards a National Dementia Preventative Health Strategy. August 2010

Reports commissioned from Access Economics

The Dementia Epidemic: Economic Impact and Positive Solutions for Australia, March 2003
Delaying the Onset of Alzheimer's Disease: Projections and Issues, August 2004
Dementia Estimates and Projections: Australian States and Territories, February 2005
Dementia in the Asia Pacific Region: The Epidemic is Here, September 2006
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Making choices: Future dementia care: projections, problems and preferences, April 2009
Keeping dementia front of mind: incidence and prevalence 2009-2050, August 2009
Caring places: planning for aged care and dementia 2010-2050. July 2010

Other Papers

Dementia Research: A Vision for Australia September 2004
National Consumer Summit on Dementia Communiqué, October 2005
Mind Your Mind: A Users Guide to Dementia Risk Reduction 2006
Beginning the Conversation: Addressing Dementia in Aboriginal and Torres Strait Islander Communities, Nov 2006
National Dementia Manifesto 2007-2010
Dementia: A Major Health Problem for Indigenous People August 2007
In Our Own Words, Younger Onset Dementia, February 2009
National Consumer Summit Younger Onset Dementia Communiqué, February 2009
Dementia: Facing the Epidemic. A vision for a world class dementia care system. September 2009

These documents and others available on www.alzheimers.org.au



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