

Intimacy and Sexuality

BACKGROUND

Everyone has a need for companionship and physical intimacy. People with Alzheimer's or a related disease are no different. They may fill this need through marriage, partnership or friendship. Whatever the relationship, it will be affected by the changes brought on by the disease, including changes in the need for companionship and physical intimacy.

Expressions of physical intimacy between two people can range from a handshake and pat on the back between two colleagues, to hugs and strokes between friends, to sexual relations between lovers. The closer one moves towards the more intimate forms of expression, the greater the need for privacy.

Relationships with partners are unique. Each person has chosen the other for different reasons. Relationships can be straightforward or become more complex with the passage of time and life experiences. Regardless of the type of relationship, it is important that it is satisfying for both people.

Note: For ease of reading, the term "partner" is used throughout this document to describe the person with whom the person with Alzheimer's disease has chosen to meet the needs for companionship and physical intimacy, whether it is a spouse, partner, lover or friend.



THE ISSUES

For people with Alzheimer's disease:

Meeting needs for physical intimacy: The changes in the brain caused by Alzheimer's disease increase some people's need for sexual relations, which may create conflict in their relationship with their partner. For some people, this increased need for sex is constant. If this sexual energy is expressed in inappropriate places or directed towards non-consenting people, medication may be required to lessen its intensity.

Others with the disease may find that their sexual energy and interest are reduced due to depression. With treatment of depression, sexual interest often returns.

The changes in relationships and in needs of both the people with the disease and their partners can be frustrating. A lack of understanding and insight into the issues may cause people to find ways to meet their needs that may not be considered acceptable or appropriate.

Seeking companionship with a new partner:

As the disease progresses, people may no longer recognize or remember their partners, and may seek companionship and physical intimacy with a new partner in a long-term care facility. Due to the sensitivity of this issue, family members and staff may try to prevent people from fulfilling their needs outside of previously existing relationships.

Disinhibition: The disease process may cause some people to lose their inhibitions and act and behave in ways that they did not before, or in ways that others might consider inappropriate. This is because the usual mechanism to keep activities in check may no longer be working. For example, a woman may become flirtatious towards men other than her partner.

Misinterpretation of behaviour as sexual: Some people with the disease will react to situations in ways that are interpreted as inappropriate sexual behaviour when the person may actually be trying to communicate a need or convey a response. For example, a man may remove his pants in public to indicate that he has to go to the bathroom, but someone may view his action as a sexual expression.

For partners of existing relationships:

Meeting needs for physical intimacy: The changes Alzheimer's disease causes in a person's interest in sex may conflict with the partner's needs. Partners may feel guilty or not know how to respond. Also, as partners take on more of a caregiving role, the idea of physical intimacy may become less appealing.

Seeking companionship with someone new: Partners may have needs for companionship and physical intimacy that are not being met by the person with Alzheimer's disease, and may seek to meet their needs outside the relationship. This can create dilemmas and concern.

For health-care professionals:

Balancing needs: Those who provide care in long-term care facilities may be aware of situations where a person with Alzheimer's disease has sought companionship and intimacy with a new partner. Health-care professionals face challenges in determining if both parties are willing participants and have given consent to the new relationship, and in assisting families with adjusting to the change.

RECOMMENDATIONS

It is recommended that the needs for companionship and physical intimacy of people with Alzheimer's disease and their partners be met, wherever possible, and treated with respect and dignity.

When the physical intimacy needs of the two people in the relationship differ, it may take open and honest discussion and creative thinking to find ways to meet each person's needs.

As the disease progresses, people with Alzheimer's disease may no longer be able to recognize their partners. The partners will need a lot of support and understanding. If the person with Alzheimer's disease chooses a new partner, it is important to ensure that those involved agree to the relationship, whatever form it takes.

For family members and staff of long-term care facilities, an awareness of their own feelings and attitudes toward sexuality, sexual expression and later-life relationships may help them to support others. Also, learning about a person's patterns of sexual expression and intimacy over a lifetime may give insight into current behaviour. As well, it would be helpful for family members and staff to look at the needs of the person with the disease and the needs of the partner as priorities.

Staff in long-term care facilities may also need to find ways to provide privacy or to help partners deal with changes in their relationships. This can include:

- finding enjoyable activities a partner can share with the person during visits;
- drawing attention away from a new relationship that might upset a partner;
- providing overnight private accommodation for couples wishing to be alone.

Some partners of people with Alzheimer's disease may want to meet their companionship and physical intimacy needs with someone else, especially if the partner is no longer recognized. If so, they will need support and understanding to work through their feelings and to find ways of meeting their needs that make them comfortable.



IN CLOSING...

Relationships are complex at the best of times. Add to this the changes brought on by Alzheimer's disease and you get the kinds of dilemmas that partners and families face. Talking about intimacy and sexuality is not always easy but it is a good starting point for resolving issues relating to companionship, intimacy and sexuality in Alzheimer's disease.

RESOURCES:

Intimacy, Sexuality and Sexual Behaviour in Dementia (How to Develop Practice Guidelines and Policy for Long Term Care Facilities). McMaster University, Hamilton, Ontario.

Also available at: www.fhs.mcmaster.ca/mcah/cgec/toolkit.pdf

Sexuality and the Alzheimer's Patient. E. Ballard and C. Poer, Duke University Press, 1993.

A Thousand Tomorrows: Intimacy, Sexuality and Alzheimer's Disease (videotape). Terra Nova Films, 1995.

Website:

Disability Online. Victoria, Australia.

www.disability.vic.gov.au/dsonline/dsarticles.nsf/pages/Dementia_sexuality_and_intimacy?OpenDocument

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