The Last Taboo

Sexuality and Intimacy in Dementia

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Introduction

The sexuality of older adults is treated as a taboo, a subject that is very difficult to broach. We tend to assume that, as people age, the “correct” way to live is for sexuality to diminish or — better still — to disappear altogether.

Doctors routinely ask about sexual problems in the context of cardiovascular disease, diabetes, or depression — yet dementia is almost invariably left out of this assessment, remaining one of the most consistently avoided subjects in everyday medical practice.

This omission might seem neutral, but it reveals a toxic intersection between ageing, the stigma of dementia, and our cultural discomfort with the sexuality of older adults — a combination that ultimately leaves patients without support, their partners without guidance, and caregivers without any tools to intervene.

The spectrum of sexual expression in dementia

It is important to stress from the outset that, although dementia is itself a tragedy, its effects on sexuality need not always be negative. For many people in this situation, physical closeness remains a source of comfort and mutual support long after other channels of communication have narrowed.

Popular understanding links dementia with sexual disinhibition — inappropriate behaviour, unwanted advances, crude language. The reality is considerably more nuanced: studies show that the sexual changes seen in dementia span a wide spectrum, in which a decline in desire (hyposexuality) is the predominant picture.

Ahmed and colleagues (2018) showed that, regardless of the type of dementia, the most common manifestation is a blunting of desire, intimacy, and physical affection. Disinhibited sexual behaviours are present in a minority — estimated at up to 17% of patients — and depend on the type of dementia and the region of the brain affected.

From a medical standpoint, the most relevant distinction is between frontotemporal dementia and Alzheimer’s disease. In frontotemporal dementia, the frontal lobes of the brain are affected — the areas that govern social behaviour and impulse control; this is why contextually inappropriate behaviours may appear, such as gestures or remarks of a sexual nature. Mendez and Shapira (2013) reported such behaviours in 13% of patients with frontotemporal dementia, compared with none in the Alzheimer’s group. In Alzheimer’s disease, the picture is reversed: the gradual loss of memory and of partner recognition frequently leads to emotional withdrawal and disinterest, and sometimes to

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affection being directed toward people other than one's life partner — a painful situation for those closest to them.

This distinction is not merely theoretical: disinhibited behaviour in a person with frontotemporal dementia is not a choice but a symptom of the illness, one that calls for a different approach than the emotional withdrawal of a person living with Alzheimer's.

Most situations, however, do not arise in care homes or in new relationships, but within a couple of some standing. Studies consistently show that the majority of partners — around 80% — notice a change in their intimate life after the onset of the illness, as the person with dementia becomes indifferent to sexual life. One observational study (Wright, 1998) found that, five years after onset, only 27% of affected couples were still sexually active, compared with 82% of healthy couples of the same age.

Behind these percentages lies the partners' own ordeal: living alongside someone who, though physically present, gradually becomes another person, their personality slowly fading because of an illness that does not merely diminish desire but sometimes erases the very recognition of the other.

Added to this is a shift in role: from partner, husband, or wife, one gradually becomes a caregiver. And the caregiver's role, with its routine of hygiene, medication, and supervision, often erodes the romantic and erotic dimension of the relationship. One detail from a five-year study is worth noting: the healthy partner's affection declined steadily over the course of the illness — but recovered significantly once the person with dementia was admitted to a care facility.

This ordeal raises a problem few dare to name: guilt. Some partners gradually lose their attraction; others seek closeness elsewhere; many feel guilty simply for still wanting intimacy, as though desiring someone who is ill were a betrayal. None of these reactions is a moral failing. They are human responses to a difficult situation.

Consent — the ethical dilemma

The question is this: can a person with dementia give valid consent to an intimate relationship?

The simplistic answer — "they cannot" — is both incorrect and potentially harmful. The capacity to consent is not an all-or-nothing matter, and it is not lost uniformly upon diagnosis. It fluctuates, and it depends on the situation and the stage of the illness. Wilkins (2023) argues that many people with mild or moderate dementia are perfectly capable of consenting to an intimate relationship with a long-term partner, especially when the relationship predates the illness and the emotional bond is preserved. No diagnosis — not even dementia — automatically rules out a person's capacity to make decisions in a given area of their life.

Yet the legal framework in many countries does not reflect this nuance. Sorinmade, Ruck Keene, and Peisah (2024) show that the law in England and Wales, for example, requires

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consent to be expressed at the very moment of the act — which in practice excludes anyone with advanced dementia, regardless of the relationship's history.

The problem becomes truly difficult in new relationships, particularly in care homes, where a person with dementia may seek closeness with someone else. Here, the assessment of the capacity to consent should be individual and take several factors into account: whether the person understands the nature of the relationship, whether they can protect themselves from exploitation, whether they are aware of the risks, as well as their emotional state and any signs of pleasure or discomfort. Peisah and colleagues (2021) propose a graded model for assessing capacity, sensitive to the context of the relationship, as an alternative to the rigid "yes/no" approach.

Practical implications

We must understand that the person living alongside a partner with dementia carries a burden that society rarely sees. Any approach to this subject must begin by acknowledging that ordeal, not with a list of behaviours to be corrected.

The most valuable support such a partner can receive is often not medical but a matter of understanding. Having it explained why a loved one's behaviour has changed — that it is the illness, not a personal rejection — can bring a sense of relief. Equally important is to be told that the absence of a sexual life does not mean the end of intimacy: a hug, holding hands, physical closeness remain valuable forms of connection and do not lead to problematic behaviour. The partners of people with dementia have a right to their own emotional life, and their needs do not vanish because the other has fallen ill.

There is also an institutional dimension to the problem. Grigorovich and Kontos (2022) identify the main barriers in care homes: negative staff attitudes, the lack of clear policies on intimacy, and the absence of private spaces. Sexuality is not only the sexual act but a broad range of gestures — touch, tenderness, closeness — and many institutions, through restrictive rules, deny residents even these gentle forms of connection. Recognising the need for intimacy and creating decent conditions for it is also a matter of respect for the dignity of the person.

A few guiding principles can help families and caregivers:

Acknowledge; do not ignore. A person's emotional and intimate life should be part of the conversation about dementia, both at diagnosis and throughout the illness.

Behaviour is, most often, a symptom, not a choice. The changes — whether a decline in desire or disinhibition — are consequences of the illness, not moral failings. Understanding this reduces guilt and guides the family's response.

Distinguish illness from normality. A person with frontotemporal dementia who makes inappropriate advances is in a different situation from one with Alzheimer's who longs for closeness with a lifelong partner. The response should reflect that difference.

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Managing inappropriate sexual behaviour

When inappropriate sexual behaviours arise, there are two main avenues of approach: psychological and environmental interventions on the one hand, and medication on the other. The general rule is that medication should be considered only after the other measures have been tried without success. The choice depends on how urgent the situation is, on the type of behaviour, and on the person's other conditions.

The first line of intervention is therefore behavioural and environmental, with no side effects. A few strategies that have proven useful:

- **Do not unintentionally reinforce the behaviour.** Strong reactions — whether of irritation or of amusement — can paradoxically encourage it to recur. Instead, attention and approval can be directed toward appropriate behaviours.
- **Provide distraction.** For many people, a gentle redirection toward another activity is enough.
- **Reduce stimuli.** TV or radio programmes with heavy sexual content can trigger such behaviours; removing them helps.
- **Adapt clothing.** Where there is a tendency to undress or to masturbate in public, clothing that is harder to remove can reduce the behaviour.
- **Explain simply and repeatedly.** Sometimes a calm, repeated explanation of why a behaviour is inappropriate is helpful.
- **Offer privacy.** In institutions, access to a private room or visits home can reduce the frequency of inappropriate behaviours by meeting a natural need.

These interventions require time and patience, but they lack the sometimes serious side effects of medication. At present, there is no drug approved specifically for these behaviours, nor any official treatment guidelines. The available data, drawn from uncontrolled studies and case reports, suggest variable efficacy for some antidepressants, antipsychotics, and hormonal treatments — all used off-label, with caution and under medical supervision, given the heightened risk in older adults.

Conclusions

Sexuality does not disappear with a diagnosis of dementia. It is transformed, and it confronts partners, families, and clinicians with genuine dilemmas — ethical, legal, and relational. Ignoring this dimension protects no one; it leaves patients without dignity, partners without support, and caregivers without guidance.

A mature approach needs clear benchmarks for assessing consent, support for those who provide care, and legislation nuanced enough to tell protection apart from paternalism. Until then, the responsibility falls to each of us — and, above all, we must dare to ask the question: does sexual life truly come to an end with age?

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References

- Sorinmade O, Ruck Keene A, Peisah C. The Law, Dementia, and Sexuality. The Gerontologist. 2024;64(11).
- Peisah C, et al. Sexuality and the Human Rights of Persons With Dementia. Int Psychogeriatr. 2021.
- Mendez MF, Shapira JS. Hypersexual Behavior in Frontotemporal Dementia. Arch Sex Behav. 2013;42:501–509.
- Ahmed RM, et al. Neural Correlates of Changes in Sexual Function in Dementia. J Neurol. 2018;265:2562–2572.
- Wilkins JM. Dementia and Concurrent Consent to Sexual Relations. J Med Ethics. 2023.
- Grigorovich A, Kontos P, et al. Dementia and Sexuality in Long-Term Care. Dementia. 2022;21(4):1077–1097.
- Bouman WP. Sexuality in Later Life. In: Oxford Textbook of Old Age Psychiatry. Oxford University Press.
- Wright LK. Affection and Sexuality in the Presence of Alzheimer's Disease: A Longitudinal Study. Sexuality and Disability. 1998.
- NIA. Sexuality and Intimacy in Older Adults. National Institute on Aging. 2026.

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