

The Morris Markowe Public Engagement Prize 2019: Winner Dr Joanne Younge for her article 'The Last Taboo- Let's Talk About Sex and Dementia.'



The Last Taboo- Let's Talk About Sex and Dementia

Nobody wants to think about their parents, never mind their grandparents, 'doing it'. As a group of health professionals at a recent research focus group about male carers of dementia sufferers, I was reminded that we don't like to think about our patients having sex either. When the question was asked about whether we enquire regarding sexual matters, there was much

foot shuffling, averted gazes and mumbling about not wanting to embarrass patients or carers, and not knowing what to do with the information. The anxiety of opening that hornet's nest was palpable and we became a gaggle of awkward, giggly teenagers.

The only time sex gets mentioned is when it becomes a problem- a referral for 'sexually inappropriate behaviour' in a care home, which needs suppressed e.g. unwanted touching of residents or staff, stripping or masturbation in public areas or, worse still, being in flagrante delicto!

But is it always 'sexually inappropriate behaviour', or is it society and professionals wanting older, particularly sick, people to conform to stereotypes? Society views older people as less attractive and sexual- older female actors find it more difficult to gain employment and 'When I'm 64' by the Beatles tells of the limited life expected for older people. Despite this, older people do have sex, as demonstrated by the increasing rates of sexually transmitted diseases in older adults, including new diagnoses of HIV in one European study covering 31 countries. One large Swedish study of 70 year olds, which excluded people with dementia, found that both the quantity and quality of sex improved over a 30 year period and that participants considered it a natural part of later life, so the study recommended that sexual health for older people should form part of medical care and education.

Netflix hit 'Grace and Frankie' starring 81y Jane Fonda and 79y Lily Tomlin has been trying to smash ageist stereotypes, dealing with issues of sexuality including same sex relationships and use of vibrators by older adults. It is no surprise that the series was devised by Baby Boomer Marta Kauffman of 'Friends' fame. The Baby Boomers have been turning 65y since 2011 and they have been known for both causing and being effected by social change, including having more liberal views regarding sexuality, alcohol or drugs and living through the advent of TV, civil rights movements, Beatlemania and rock and roll. These are the new cohort of people at risk of either developing dementia or becoming the carer of a partner with dementia and represent a demographic tsunami, both in terms of numbers and the likely different expectations, including regarding sexuality, than the previous so-called Silent Generation.

As doctors, we focus mainly on the concerns raised by others regarding the small number of patients with dementia for whom sexual behaviour has become a problem. Often a person with dementia is expressing normal sexual urges, but the context is wrong e.g. if they misidentify someone else as their partner or if they think they are in the privacy of their own home rather than the care home, where masturbating may well be frowned upon. Children become embarrassed and partners can be left devastated that they have been 'cheated' or that their loved one has been 'taken advantage of' by another resident. Issues of capacity to be able to consent are difficult and vulnerable adult policies are there to help protect people with dementia from exploitation, sexual or otherwise, but it should not be assumed that people with dementia lack capacity to maintain or form new sexual relationships. In some cases, care homes can be risk averse with incident forms being completed for a simple hug or hand-holding, which caused no distress to either party. At other times, behaviour is misinterpreted by others as being sexual e.g. stripping off when too warm or touching genitals due to painful infection.

Dementia changes the fabric of a relationship as it progresses- a lover becomes an exhausted carer, but both parties still have the need for comfort, closeness, affection and intimacy. If we overlook asking about sex, there may be missed opportunities to help resolve early problems and misinterpretations about whether sex can continue after diagnosis (and there is no reason why not, especially in the early stages, when it may actually be a source of normality in the relationship) and also to educate regarding STD prevention. In the later stages, discussion can help a partner to understand that 'conjugal rights' no longer apply.

One of the worst difficulties I have encountered is when a person with dementia no longer recognises their partner and spurns their affection, sometimes aggressively. The rejection felt by that partner is often palpable. They are left to mourn the loss of their sexual relationship, whilst trying to provide care to the best of their ability and having their own sexual needs unmet, or dealing with the guilt of meeting them elsewhere. Another difficult issue for partners is when dementia impacts the frontal area of the brain responsible for impulse control, which can result in hypersexual behaviour and increased demands and stress on the partner. Often this is not mentioned until it becomes unbearable for the partner, so asking about sexual changes early may prevent a crisis developing.

Patient organisations such as the Alzheimer's Society offer very helpful guidance on dealing with sexual and intimacy issues, including ways to adapt to the changing relationship. Even if a person with dementia is no longer able to consent to sex, they still have needs for closeness and this can be achieved by hugs, massage and holding hands, as appropriate. Dementia care planning should include sexual needs and it is good that Trusts are starting to develop relevant policies to allow people with dementia privacy for intimacy, either alone or with a partner, in care facilities; however, it may take a while for society's

attitudes to catch up. In the meantime, to be able to determine what adaptations need to be made to facilitate this important part of life for people with dementia and their partners, health professionals need to start asking the right questions, rather than saving themselves from embarrassment. If we don't start the conversation now, then what can we hope for when it becomes our time? To paraphrase Salt n Pepa:

'Let's talk about sex...

All the good things and the bad things that may be

Let's talk about sex.'

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