Older People, Relationships and Intimacy

November 2012

Twitter - @ILCUK

About the ILC-UK

- The International Longevity Centre-UK is a think tank on longevity and demographic change. It is an independent, non-partisan think-tank dedicated to addressing issues of longevity, ageing and population change. We develop ideas, undertake research and create a forum for debate.

- Our policy and practice recommendations are based on qualitative and quantitative research and analysis of trends and forecasts which provide new and innovative solutions to lead and influence national and international policy.

Overarching aim of the presentation

1) Explore why relationships and intimacy are important for older people.
2) Consider why relationships and intimacy can be equally as important for people with dementia, but perhaps harder for us all to navigate.
3) Look at some of the associated challenges, issues and opportunities with regard to relationships and intimacy for people with dementia in care homes.
4) Discuss what is meant by and how we should respond to ‘inappropriate’ or ‘challenging’ behaviour in a care home or a health care environment and the development of good practice and policy on this topic.

Background to presentation

- Commissioned by the Department of Health in 2011 to write a good practice guide.
- Why? Anecdotal evidence significant issue in care homes.
- Neglected area of policy, practice and research.
- Overarching aim to raise awareness for families, carers and care workforce and improve quality of life for people with dementia.

Overarching aim of The Last Taboo – Myth Busting

- Older people do not have or enjoy sexual relations/ relationships
- Double jeopardy - our construction of dementia does not include intimacy, sexual behaviour and relationships
- Older people with dementia need protecting*
- Older people with dementia are prone to ‘challenging sexual behaviour’

Our approach

- Evidence review from academic, policy and practice related literature
- Interviews with care home workers and managers
- Sourced real life case studies from care homes
- Result? A guide for care home managers, care home workers and the wider care community

Definitions

- Intimacy *"A close familiar and usually affectionate or loving personal relationship with another person or group."*
- Sexuality *"Pertaining to copulation, having sex or involving sex, implying or symbolizing erotic desires, capable of sexual feelings."*

Source: World English Dictionary

Basic Human Need

Sexuality and intimacy are fundamental to an individual and intrinsic to a person's self and well being.

At any age we require

- Companionship
- Intimacy
- Love

What do people really think of older people having relationships and sex?

- “Old people are sexless”
- “I think it is gross if they kiss”
- “Sex is for younger people”
- “How do I know this is what they want?”
- “What will people think if we let them have an intimate relationship”?

/

And what about for people with dementia?

- Care plans often do not address sexual needs of individual clients. (Wallace 2003)
- Need for human intimacy for most people, lasts until end of life. (Kuhn 2002)
- Dementia does not diminish need for human affection, warmth and intimacy.

Fact

“Benefits of sexual expression and intimacy for older adults with dementia are often overlooked but the evidence suggests that they enhance general health and well being.”

(Kuhn 2002)

And yet most people…

"Are not even willing to consider or contemplate that people with dementia may have intimate or sexual needs."

This is due to our own misconceptions, preconceptions and prejudice.

Range of patient issues to consider

- Autonomy
- Dignity
- Mental Capacity
- Safe Guarding
- Perceived Need to Protect

What does research say about dementia and sexual behaviour and expression?

- It is not particularly common. (Higgins 2004)

- More likely to occur in severe stages of dementia. though sometimes evident in persons with mild cognitive impairment.

  (Alagiakrishnan 2004)

Individual sexual behaviour and expression

Reasons for sexual disinhibition or inappropriate behaviour *may* be linked to;

- Disease related factors
- Social factors
- Psychological factors
- Certain medications, illicit drugs and or alcohol
- Currently, the reasons are unclear and more research is needed.

Subjectivity and reporting

- Staff, resident and family disagree on what is meant by appropriate or inappropriate behaviour. (Gibson 1999)
- Some studies state that it is of equal frequency of inappropriate behaviour in men 8% and women 7 %. Other studies report higher rates for men.
- Men's behaviour may be over reported vs. women's behaviour.

How do we categorize sexual behaviour?

There are no hard and fast rules when it comes to assessing sexual behaviour and responses and there is no particular definition as when the behaviour becomes abnormal. (Manchip and Menon 2007)

- “One older gentleman with dementia often started masturbating in the lounge, admittedly shocking some of the other residents and staff. The thing is, you could not really call his behaviour inappropriate as he was doing what felt nice to him. The problem was the location was completely inappropriate.”

Verbal behaviour

- Sexualized comments to staff and others.
- May include swearing

Physical behaviour

- Masturbating in private
- Masturbating in communal areas
- Touching in private
- Touching in communal areas
- Undressing or disrobing / exposing genital areas
- Defecation or urination

Physical actions linked to others

- Prolonged kissing & hugging that exceeds normal affection.
- Touching or grabbing personal parts of a member of staff or another resident's body.
- Attempting intercourse or oral sex with staff or resident.
- Attempting sexual acts with objects. Not to be confused with sex toys.

Relationships in Care Homes

- How can care homes can facilitate existing or possibly new relationships in care homes for people with dementia?
- While the onset of dementia may change the expression, form and nature of a sexual relationship, we should not assume older people with dementia no longer have any desires of a sexual or intimate.
- Each situation and individual is unique, so we know there is no set response.

Pre-existing Relationships

- Some couples may wish to maintain a sexual relationship, experiencing sexual intimacy a source of comfort, reassurance and mutual support (Bouman, 2007).
- Perhaps most common scenario will be one partner with dementia in the care home and the partner without dementia remaining in their own home.
- ***'There are few reports of behaviours being characterised as bizarre or inappropriate expressed outside the marital relationship.'*** (Bouman, 2007)

Possible changes to a relationship

- Awkward sequencing of sexual activity
- Requests for activities not normally performed
- Lack of regard or consideration for the sexual satisfaction or feelings of the healthy partner.
- Increased sexual demands.
- Loss of sexual interest/ inadequate sexual advance by the individual with dementia.
- Concerns over mental capacity.
  - E.g. The dementia patient no longer recognises their partner.

How can you support a pre-existing relationship?

- Acceptance / acknowledgement that older people with dementia have a need for intimacy and sexual expression.
- Promote a culture of acceptance, dignity and privacy. E.g. privacy for couples to be together, perhaps a designated room / private room with “Do Not Disturb.”
- Provide education and awareness to workers / family / partner / resident on sexual and intimate needs.
- Continue to monitor and assess in terms of resident with dementia and mental capacity.

Forming New Relationships

- What do you do when a resident with dementia with a partner wants to form a new relationship with someone else in the home?
- Staff and family responses will be determined by the nature of the relationship.
- Cuddling or hand holding does not generally provoke a response by family or staff.

But what happens when it's more than hand holding?

When relationship appears more sexual in nature, several issues may / or will need to be addressed.

But at same time keep in mind;

- Autonomy
- Preservation of dignity
- Competence related to informed consent
- Privacy
- Protection from harm

Remember

- People with dementia can make new relationships and intimate relationships.
- If a person with dementia can make decisions about their life than this should be respected.
- If, the resident is not physically or mentally vulnerable as a result of relationship, than consider ways to facilitate and support the relationship.

- It may be difficult to assess to the extent a resident has full mental capacity, partial capacity or limited capacity and so the team may have difficulty reaching a consensus or appropriate response.
- A resident may perform poorly on mental status test but his /her preference for the special friend is evident.

How to determine the capacity and risk to the individual

- To what extent are the residents involved capable of making their own decisions?
- Does the resident with dementia have the ability to recognise the person with whom they are having the relationship? Are they mistaking the person for their original partner?
- Is the resident with dementia capable of expressing their views and wishes within the relationship through either verbal or non verbal communication?

- Can the residents involved understand what it means to be physically intimate?
- What is the resident's ability to avoid exploitation?
- What is the resident's ability to understand future risks?
- How may the resident be affected if they are ignored, rejected after intimacy or the relationship ends?

There are no hard and fast rules to respond to a specific situation.

- A person centered care approach is recommended. Each situation and *each resident* is unique so your approach and assessment / evaluation of behaviour, function, cognition will be individualised for each person.
- Involve the team, family, partner.
- Development of company policies, assessment tools and evaluation protocol will help you as a team develop person centered care plans.

Wider considerations and ethics

- Is the behaviour in keeping with their past values, beliefs and or religious views?
- If the behaviour is not in keeping, but the resident appears content and happy, to what extent should this matter?
- To what extent do care providers have the “right” to intervene in the sexual lives of people with dementia and what rights are denied when such interventions occur?

How should you respond to inappropriate behaviour?

- Check your own response – is it driven by your own beliefs or ideas?
- Currently there are no medications specifically for sexual inappropriate behaviour- some non-pharmacological approaches have been found to helpful.
- Alternative reasons for apparently sexual behaviour
  - Behaviour log
- Be aware that not everyone is heterosexual. Educate and be sensitive to LBGT: Lesbian, Gay, Bisexual, Transgender, and different forms of sexual identity.

Abuse

- Observe for forced signs of intimacy such as bite marks, blood or tears or bruises in genital areas.
- If you suspect any form of sexual abuse take action immediately!
- Remove resident from risk.
- Protect and support the resident.
- Inform your supervisor immediately and follow facility protocol for suspected abuse.

Regardless of the legal standard, an even greater challenge is the lack of a clear standard for the assessment process, i.e., the evaluative criteria and tools to be used in the assessment of capacity to consent to sexual relations.

Source: Assessment of Older Adults With Diminished Capacity

Developing good policy and practice

- Legal framework
- Support and training for the care workforce
  - Awareness and care
- The care home environment; allowing for privacy and security
- Other policies within the care home – dignity?
- Policies and practices created with staff

Was anyone actually interested and did we make a difference?

- Foreword by National Clinical Director of Dementia, Alistair Burns
- Rolled-out to many major care homes as a good practice guide
- Endorsed by the National Council of Dementia Practitioners in USA as best practice
- Requests from New Zealand, Australia and Singapore
- Front page coverage throughout care and nursing press
- One of the most downloaded publications from our website.
- Lessons? Those on the frontline can be best placed to identify research gaps/opportunities.

Many thanks

Jessica Watson

Research Officer

International Longevity Centre - UK

sallymariebamford@ilcuk.org.uk

www.ilcuk.org.uk

+44 20 7340 0440