Sexuality and Intimacy

Behaviour vs Need
OR
Need vs Behaviour

It can be very difficult for care givers, families, or spouses of loved ones living with dementia to meet the ever demanding care needs throughout the progression of the disease. However, it can be even more difficult when a decision is reached that a move into a LTC home has been deemed necessary for their loved one. It is appreciated that this decision never comes lightly and for most caregivers it breeds feelings of helplessness, guilt, sadness, loneliness and fear. Throughout my years of experience within the nursing field, I have supported many families of loved ones who were faced with this very challenging transition. There is a strong sense of “fear of the unknown” and uncertainty as to what to expect from their loved one throughout the transition into LTC and beyond. There is almost an immediate sense of mistrust towards the staff working in the LTC home that they will be unable to provide the “right” care, or even enough care that a loved one deserves. From the perspective of the staff, there are significant challenges on their end also. They are doing their best to welcome a new person into the home with in most cases, limited information and restrictive time constraints as a result of gaps within the care system. As a result, the move into a LTC home can be both difficult and challenging for everyone involved, especially for the loved one themselves. As a Registered Nurse with over 23 years’ experience in the nursing field, I consider myself fortunate to have gained knowledge, skill and appreciation for a variety of different areas including: Adult Mental Health, Geriatric Psychiatry, Leadership, Community and LTC. It is through these experiences, that I have been alerted to significant challenges around the support of an individual’s sexual and intimate needs: i.e. determining the ability of a resident, living with dementia, to consent.

I encountered the following types of situations:

- Two LTC residents, whose spouses live outside of the home, begin to sit together, holding hands, hugging and occasionally kissing. **Is this wrong?**
- A male resident, seated beside a female resident, believes her to be his girlfriend and places his hand on her inner thigh. She gasps!
  Is this considered abuse?
- An ambulatory male resident moves behind a wheel-chair dependent male resident and begins massaging his back, shoulders and neck. **Is this inappropriate?**

In each case, resident actions were deemed inappropriate and documented as such. I began to question how we arrived here. Existing policies are vague and needs around sexuality/ intimacy are addressed as inappropriate behaviours in the care plan. The default becomes individual morals and beliefs around sexuality and intimacy.

Ministry of Long- Term Care (MOLTC) policies on abuse, including the algorithm for sexual abuse, were the default source. Current assessments used to establish a baseline for consent and capacity i.e. Montreal Cognitive Assessment (MoCa), Mini Mental Status Exam (MMSE) and computer coding mechanisms (RAI-MDS CPS scores) had nothing to do with sexuality and intimacy i.e. spell “WORLD” backwards. Acknowledging what we now know about dementia and its progression, these assessments focus on what a person has lost, as opposed to what they have left.

My review of existing policies, assessments and language, revealed that sexuality and intimacy was not being viewed as a need, but rather a behaviour.

If we consider the stages of human development with respect to intimacy and sexuality: we see from birth to age two that skin to skin contact is encouraged to breed safety, security and familiarity, develop trust and express our emotions. In early childhood; we depend upon the sense of touch, it helps us feel loved, explore our surroundings and build long lasting bonds. As we grow older; we become curious about our bodies, questions arise such as “where do I come from”? We are aware of gender and we begin to express our affections openly. Between the ages of nine to fourteen: we gain a strong sense of empathy, we flirt with others and begin to explore our bodies intimately (masturbation). Between the ages of fifteen to eighteen years: there is a strong emphasis on us and we seek intimate relationships that in turn become an important part of our identity. By the time we surpass the age of eighteen and older we enter sexual and emotional relationships. We are aware of our own sexual orientation, although we may still experiment. Emphasis is shifted from ourselves to others. We experience an increased intensity towards sexuality and understand it to be connected to commitment and planning for the future. From twenty- five years to forty five- years of age strong relationships are developed. Cohabitation is established. Futures are planned and families started. This is significant because intimacy and sexuality is a life long journey: an innate human need and an essential part of overall health, well-being and quality of life. Aging does not negate its’ necessity but rather solidifies it. This does not change in the presence of a dementia. In fact, according to Abraham Maslow’s hierarchy of needs (1943), Intimacy and Sexuality is the only need that appears twice, signifying its importance above shelter and food.

Through evidenced- based research, it is understood that dementia is a progressive disease with gradual changes over time. The person living with dementia will revert back to younger life experiences, events and capabilities. Let us gain further perspective of this statement and think back (hard as it maybe) to our very first day of school…. What is the first thing all of us wanted to do the minute we stepped out onto the playground, in an unfamiliar environment, with unfamiliar faces…? Make a friend! We naturally and instinctively yearned for comfort by seeking out someone who would help instill a sense of safety, security and familiarity. My question then becomes, why would this be any different for the person living with dementia? Could a LTC home represent the experience similar to that of the first day of school? Should it be considered normal and natural for people living with dementia to seek comfort in one another?

With the philosophy of sexuality and intimacy as a need versus behaviour, could there be three specific ways to convey this philosophy.

Language: Is there an opportunity to create a domain specific to love and belonging on the first page of the care plan, concurrent with other activities of daily living?
Conversations: Upon a person entering the home with their families for the first time, could there be more conversations occurring around inclusivity, that would better instill a sense of love and belonging within the home?
Assessments: Adopting questions specific to Intimacy and Sexuality and including the right questions in the right moment, recognizing people living with dementia live very much in the moment. For example, depending upon where they are in the progression of the disease, it may not make sense to them that they are married. How do we know that a particular encounter is uncomfortable for them? Is the baseline still relevant? How do we know whether a particular encounter presents with risk, if we are not aware of the true nature of the intention? Is attempting to kiss someone, hold a hand or give someone a hug ill willed or simply a display of affection? With so much uncertainty, it becomes essential to further distinguish sexuality and intimacy as a need first and foremost, which will aid in the distinction of risk, if any at all.

The Reality-
What I need in LTC is…….

"Personal space." "I don't like people too close to me." "I like my own space and that you please knock before entering my room". (***Anonymous)***
"My freedom respected." "I want to know that I can walk hand in hand with someone, visit with them, without feeling as though I am doing something wrong"! (***Anonymous)***
"Privacy". "The ability to display and receive affection in public, or behind closed doors without being labelled".
(Anonymous)
"The ability to explore with my hands". "I like how things feel and how they make me feel when I touch them." "But don't hug me; I don't like that kind of touch!"
(Anonymous)
"Patience". "I may forget if I have a spouse, or who they are". "I may need daily reassurance that changes from day to day".
(Anonymous)
"I deserve to live in an environment where a person's personal biases do not affect the way I am treated or cared for."
(Anonymous)
"Male intimacy with non-judgmental care. I need male skin to skin contact without the judgment of others". ***(Anonymous)***

How do we incorporate needs around sexuality and intimacy in the plan of care for those under our care? **THINK ABOUT IT!**

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