COMMUNICATION CONNECTION # 3 December 2007



End-of-Life Care

Our third of three Spirituality and Dementia sessions began with a review highlighting some key learning from the previous two sessions. In Reviewing strategies and approaches that caregivers can use when offering care and assistance for persons with advancing dementia issues around managing and accommodating for changes in language, vocabulary, understanding and a persons ability to express their thoughts and ideas were touched on. For example, with language – often persons with Dementia will loose their second and third languages and revert back to their mother tongue/first language. They may understand other languages however only be able to respond in their own. As the dementia progresses, even their mother tongue will disappear.

Important highlights regarding the differences between meaningful engagement and keeping a person busy were made. All those caring for persons with dementia need to deepen their understanding of the person as an individual to address their body, mind, and spirit. Marrying communication techniques with meaningful engagement, we can practice more ordinary and wonderful moments together. Key to working with less communicative individuals is learning to be present and figuring out what is important to the individual from their past and what is now important to them at that moment in time. Relationship based care using Love as a key tool has been demonstrated to enhance verbal and non-verbal communication and provides a feeling of attachment and inclusion in the culture, not only in the environment but in the culture as in their ethnicity such as spirituality among cultures and within specific environments.

Other important approaches have included listening with all of our senses. Labeling persons with Dementia is a difficult and sometimes unfortunate thing to do in terms of making them seem to be "not normal" when in fact they are just having difficulty coping with the influences and advances of their acquired illness.

We have remembered that all persons are unique! Their basic core needs are different than your own as a caregiver.

PAIN

How do we help persons who cannot verbally express their pain? A unique example was given by Sharon Preston about and intellectually disabled client who was demonstrating behaviours that were a result of pain and not of an intellectual disability or dementia, however this person was unable to convey her pain so that it could be treated at the end of her life. When her care team rallied around her to discuss possible issues that could be causing distress the client was treated for pain with both medication and also a meaningful activity that she found comfort in. This activity was the gift of a simple piece of string that she found comfort in twirling and winding around her fingers. The string represented something she was familiar with and found pleasure in playing with

A second panelist, Jeyasingh David, shared with the participants how his organization, Providence Healthcare in Toronto, is addressing the care of specific cultures of persons at end-of-life with Tamil residents. These residents originally lived in the northeast of Sri Lanka and Jeyasingh shared some of the key cultural and faith based characteristics that Providence are addressing in their end-of-life care practices. For example, he cited that the Tamil population are historically quite traditional and this is a belief and filled with rituals, shrines and symbols that they worship in front of and that help them in their relationships with God. He also stated that Tamils believe in Karma whereby all actions have an equal and opposite reaction. Strong belief systems have supported many of these persons in knowing themselves and their needs. They are a "God-fearing" community and spiritual conversations "comes from the heart." In caring for Tamil persons with Dementia in LTC strategies included singing, sitting with them and providing them with the holy ashes, and providing shrines and other icons for time of prayer. Jeyasingh also mentioned that Tamil communities often stay very connected with the individuals in LTC who are at the end-of-life and in all stages of their life. Hinduism is the religion adopted by many in the Tamil population and is a strong presence in the lives of Tamil persons.

Our third panelist spoke about different services that are available on behalf of the Alzheimer's Society. Support and education is offered through support groups, literature/brochures for persons with dementia, family members and other partners in care. Counseling may be available from your local Alzheimer Society Chapter by phone or on outreach visits. These visits are anonymous at all times and kept in the strictest of confidence. Educational workshops are also available in many areas of the province through the Alzheimer's Society.

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