“When you can no longer rely on facts, logic, reason, or memory, it is your feelings and emotional truth that you trust.” – Dr. David Sheard.

In July 2015, Dr. David Sheard’s Butterfly Home® Pilot Project was launched as the first of its kind in Canada. Lifestyle Options Whitemud in Edmonton was chosen as the first of three sites in Alberta (that include Covenant House, Red Deer and Copper Sky Lodge, Spruce Grove).

This project stems from Dementia Care Matters, founded in 1995 by Dr. Sheard, and based on the principle that dementia care is about emotional care. From this, Dr. Sheard developed a philosophy that “Feelings matter most” and a core belief that individuals with dementia are more feeling beings than thinking beings. Through his Dementia Care Matters, he developed an approach using the butterfly as a metaphor of transformation: “Being natural in dementia care involves flitting between people, being still, connecting, creating colour, and changing moments.”

April 2016 marks the eighth month of the pilot. Renate Sainsbury, General Manager, Lifestyle Options Retirement Communities was instrumental in the project’s introduction to Alberta. After seeing the European model first-hand, she became more aware of how far Canada lags behind in our approach to caring for persons with dementia.

“Here in Canada, we really medical- ize everything,” she says. “We use a lot of anti-psychotics. Mealtime is not the greatest. It’s not a household model; it’s a very institutional model. The Butterfly Household Project is and, quoting Dr. Sheard’s words, it’s about the “lived experience”, bringing out the best in people. Dementia care should focus on what they “can do” instead of what they cannot do. For example, staff members are sitting down and eating with the clients and getting to know who they are. The staff now is encouraging the residents who can help themselves do so. They do not wear uniforms, just like our home; we do not have people standing while we are eating, wearing uniforms.

“I’m a recreational therapist by profession,” she says. “So I’m all about meaning and quality of life. When I first went to work in a hospital, I saw people who weren’t dressed for two years.” At that time, Sainsbury had the great fortune of working with top geriatricians, and with time, she focused on the patients’ abilities and strengths. From this approach, she was able to get them dressed, and a lot of them were able to return to their homes in a short span of time. By doing so, it has decreased the length of stay in the hospital.

“I’m a capabilities person. Just because an individual has a diagnosis of dementia doesn’t mean their purpose in life has ended. I think our clinical model really has to change to more of a wellness, model about people’s capabilities, and focusing on quality and meaning in life model.

“When I went to Europe and came back, I said, ‘What have we done to people.’ Then I met Dr. Sheard of Dementia Care matters and I knew we had to change the culture of care with people living with a dementia - and I said, ‘If you ever pilot
Sainsbury and her staff are excited to have junior high school students involved in this pilot project as they’ve made it a priority to change the culture of care in dementia. They have partnered with St. Theresa’s School. “We’re incorporating kids because I think we need to educate the children not to be afraid. Just because you have a label or diagnosis doesn’t mean you’re not a human being. At St. Theresa’s School, they do community work. Grade seven students go down to the Bissell Centre, and now they’re coming here.”

On the first visit, the students went to Lifestyle Options to meet the residents in their households. The second visit, students and the residents baked together. “Now on their third visit, they’re coming and doing things. I think if we break down barriers at a school level, and they see these are human beings, the kids become excited and they want to come back.

They want to be a part of this.”

In Europe, they have high school classes in seniors’ facilities. “That’s how you create communities of compassion and care!” Sainsbury exclaims. “Why can’t we do that? We need to be more progressive.”

Sainsbury looks forward to the future with this approach. “If you look at the latest neuro-science,” she explains, “Brain cells regenerate from emotional self-awareness; and it’s based on feelings, emotions, needs and wants and Dr. Sheard’s model is all about that. Our residents’ strengths are maximized, doing more within their household they are feeling happier, they feel at home. Dr. Sheard will be coming back again on April 21. It’s quite amazing how far we’ve come. It makes my heart giddy, and the families are happy; this is what they want for their mom and dad or for themselves.

Sainsbury added, “This project is where it is right now because the rest of my team at Lifestyle Options Whitemud was 100% supportive of this decision to pilot this project. There was fear of the unknown, but like me, they believe that it is the right thing to do. This is what I want when I grow older. So my challenge to all of you is to ask yourselves, what do you want when you grow older and are living with dementia?”

For more information about the Butterfly Home Project®, refer to the dementia care matters website: www.dementiacarematters.com