Twenty years ago in the U.K., Dr. David Sheard began quietly piloting a radical model of care for people with dementia that he hoped would make a difference in one or two care homes. Today, he is the CEO and founder of Dementia Care Matters and his Butterfly Care prototype has become a global dementia model. This past July, the first of several Canadian pilot projects launched here in Alberta.

In 1995, the belief was that dementia led to behaviours like pacing and picking, and the behaviours led to the need for a safe environment and the use of antipsychotics to calm people down. Sheard believed the complete opposite — that the behaviours of people with dementia were being caused by the culture of care around them and not by the disease.

Sheard believes licensed practical nurses (LPNs) have a crucial role to play in Butterfly Homes. He sees LPNs as being the glue between different staff teams, the person who orchestrates the various players to engage with residents and create well-being.

“I think LPN have seen themselves as singular professionals. I would describe them as not realizing they’re the conductor of an orchestra. What I’m wanting them to do is create a connected team where the core role of the LPN is the lived experience of people,” said Sheard.

The foundation of the Butterfly Care model is that there is a language of dementia. This language is about feelings, not facts. If you learn this language and join a person with dementia in their reality, accepting the things they say as making complete sense, then the behaviours associated with dementia diminish and eventually disappear.

Sheard began his career as a social worker and spent a total of 14 years moving up the administrative chain in the U.K., eventually overseeing dementia care services for the National Health Service. His despair at how dementia care was handled made it “humanly intolerable” for him to remain in that culture.

“Feelings matter most to every one of us each day. That was missing in dementia care. It was so medicalized. So institutionalized. So about them and us,” he said.
A Butterfly Care Home is set up like a household. There are no uniforms. The environment is not clinical or sterile. There’s no watching people eat. Nursing staff and residents all assist with the functioning of the household.

LPNs, in particular, are released from task-based care to a model of care that’s all about connecting to people by creating a meaningful environment, through purposeful occupation and through shared mealtime experience. Staff do not push facts or logic but instead live in the moment, the resident’s moment, connecting with their present, not their past. Transforming the environment into a place of acceptance is where people with dementia come alive, according to Sheard.

“People with dementia are searching inside for a role again, to feel they matter, to feel love. Without those feelings of meaning, it turns into behaviours,” said Sheard. For some people with dementia, finding their role may mean taking care of a doll that they view as their baby. In one memorable case in the U.K., staff hid hard-boiled eggs in the yard for one retired farmer with dementia to collect each day before he had his tea. This formerly aggressive resident spent the next 2.5 years of what would be the rest of his life, happily carrying out his farming ‘chore.’

Sheard admits the model divides people and recognizes that some find it a lot to take in. In his experience, they usually come around to understanding that it’s just common sense, that this is the sort of care that all of us would want, whether we have dementia or not.

Recruiting nursing staff for Butterfly Model Homes is also a little different than your average interview. Some questions may be: Do you wear your heart on your sleeve? Would you share your life history with a stranger? Would you be able to walk into a room and change the moment?

Sheard says the people who answer in the affirmative are people who are instinctual about life. “They know what matters most. They are in touch with their own emotional life journey. They’ve thought about moments in their life where they didn’t have comfort, they didn’t have a sense of belonging, they felt lonely, they weren’t secure,” said Sheard. “Those are the nurses who flourish in this model, who are naturals. They feel like they have permission to be the kind of nurse they always wanted to be.”

In October 2014, Dr. Sheard presented the outline of his model and general elements of culture change at CLPNA’s Think Tank. He will be presenting again at the CLPNA conference in April 2016 where he says he will be drawing from eight months of learning from the inaugural Canadian Butterfly Home pilot projects. These first three projects are underway at Copper Sky Lodge in Spruce Grove, Whitemud Lifestyle Options Retirement Community in Edmonton and Villa Marie in Red Deer. Sheard will be sharing learnings from these homes and speaking about how LPNs can take centre stage in this culture change model.

“Leadership is key to this. Real leadership is freedom to think outside the box. It’s about trust, openness, empowering and enabling staff to find the answers. This isn’t rocket science,” said Sheard. “This is giving permission to the staff to be human and to find the humanness in each other.”

Dr. Sheard believes you can change a person with dementia’s life in thirty seconds, even working outside of a Butterfly Home model. He uses the example of someone with dementia asking for a slice of toast: “Do you give them the piece of toast silently? Do you give them the toast, with some choice and say you hope they enjoy it? Or when asked for a slice of toast, do you rub your stomach and say you’re hungry too, that you’d like to share toast with them, offer them white or brown bread, show them real choice — offer them jam or marmalade, smell the marmalade and talk to them about oranges? It takes 30 seconds to transform a task. Any LPN in any care setting can decide to change that moment.”