

Dementia Dialogue; Season 3, Episode 24

Happily Ever Older

Transcript of interview with Moira Welch

Moira - There's a real acceptance for change right now. I think now is the time. And I don't know that the time will last for years. I think we have to act now.

David - You are listening to Moira Welsh, our guest in this episode of Dementia Dialogue. Moira is the author of the recently published book Happily Ever Older: Revolutionary Approaches to Long-Term Care. Moira is also an award winning reporter for the Toronto Star, and her investigative writing about long term care has spanned an almost 20 year period.

Thank you very much for agreeing to do this. It's an honor on my part to be able to talk with you. But when I first read your article in The Star about the Butterfly Effect and the work going on in the Peel Region, my eyes lit up and I said, what a great idea to go from a what I would think would be kind of a discouraging narrative to constantly exposing the shortcomings of the long term care sector, to one of celebrating a solution, a positive idea.

And you attribute it in your book that transition to Dr. Bill Thomas. But I also think it was something that you were looking for within yourself to try and change that narrative a little bit from constant identification of shortcomings to one of the celebration of solutions.

I'm wondering if you might just talk a little bit about that process of change within yourself as a writer and investigator.

Moira - You're right. It is an interesting transition. And my first article on long term care, my first investigation began probably in 2002 and was published at the end of 2003. And it was very much focused on abuse and neglect in homes and that seemed like it might lead to some change. I was actually fairly hopeful at the time.

But as time progresses, I realized that this revolution that was promised by the then incoming health minister, George Smitherman, in 2003, it didn't come to pass. And so I continued to do stories that were focused on the problems in homes. And there was a little bit of traction here and there, reports were written and so on. But nothing really, truly changed.

And I remember this and I wrote about this in my book that after the nurse was arrested for the murder of eight people in southern Ontario nursing homes, several months after that, my editor, Kevin Donovan wanted me to write a story and look at inspection reports again. And I had at that point, I had come to the realization that I have written stories based on inspection reports many, many times, and nothing ever changes. And so I expressed that frustration to him and he sort of looked at me and said, "Well, then find something good to write about". Which was mildly shocking coming from Kevin because he is such a hard core investigative reporter himself. But I thought, Okay.

Fortunately, Peel Region was willing to let The Star's negative nursing home reporter follow them.

David - Yes. Yes, that was brave.

Moira - Yeah, it was brave. No stipulations on what I could or could not report. And that story was so inspiring to readers and their reaction was so profound. And that's what inspired me to do a book on better ways to look at long term.

David - In your book, you were talking about different models of care, and often we kind of characterize those models as a medical model versus a social care model. One that the medical model emphasizing disease processes, the avoidance of risk, the maintenance of kind of minimal standards of health, while the social model focuses more on growth, risk taking and in fact, risk taking for people to be able to maintain or develop new friendships, to grow as a person, to develop some purpose in their new way of being in the world.

I'm wondering if you could describe what the necessary ingredients are to move from one model of care to the social model of care? What are the key elements that you think we need to focus on?

Moira - I think one interesting element, and I've seen this repeatedly now, is the fact that we as a society need to accept that our views of older people are in many ways just plain wrong. And right now, we treat people who are frankly fortunate enough to have lived for a long time, as if they are others. And it's as if we think people lose their humanity with age. And by that I mean the natural desire for friendship, purpose, freedom and some fun.

So how do we enable the most vulnerable among us to access the care they need without living in an institution? And the programs and philosophies that I write about in Happily Ever Older all transform care from that old traditional dominant medical model, as you say, to models based on individualized care.

And first of all, I think it's really important that the homes need buy in from the administrators and the operators all the way to the front line staff. And that includes housekeepers, for example. And this would require training in new philosophies and ways to connect with people who including those who have dementia, and to understand that in the later stages they rely on feelings and emotions, often from the past.

I think it's also important that we start asking governments to look at long term care differently and to require outcomes that focus on individual well-being. And I talk about researchers in my book and I discussed the need for new ways to measure happiness or contentment. And we currently measure outcomes that look at depression or use of antipsychotic drugs or the activities of daily living. But we could go much, much further by requiring that homes enable people to engage in activities that offer them individually purpose or simply meet their interests.

And an example of purpose could be caring for pets or plants which are basics in the Eden Alternative Philosophy, or enabling people to step outdoors for fresh air and feel the natural rhythm of the day and sort of get into the flow of the timing of the day. You can see when a school bus goes by so you know that it's the morning or the afternoon.

But I think the goal is to really, really push for change and find ways to get the government and industry onside so people can move forward.

David – One of the words that you mentioned in the book was a simple concept of kindness that you observed permeated these homes where you saw positive interaction

not only with staff and residents, but with residents themselves. And I think of the example of the woman, I think she lives in Carol Woods, was the woman who is fully cognitively intact but has opted to live in a dementia unit because of her relationship with people.

I thought that simple idea of kindness is a very powerful word, because it's a word that's easily understood by all of us. I think it's not a clinical, technical word. It's a very human word.

You're right, and I think after the pandemic, people understand that word and think about it a little bit more than we did leading up to it, because we've all been living in some kind of isolation and feeling quite emotional in different ways.

And so I think people are talking even on Twitter, which is has its own set of issues. But people are talking about kindness as well on social media. And so that needs to continue, I hope, especially with long term care. There are people and the woman you're referring to, her name is Alice Carol. She actually lived in the Sherbrooke Community Center in Saskatoon and what a lovely woman she was. And she recently passed away. Actually, I had just heard. But she really enjoyed just being around people and wanted to interact with everyone. And what I saw there was this concept of purpose. So her kindness and connection also gave her purpose. She helped people, but in return they helped her as well. They had really interesting conversations and they might have helped her. She had a very bad leg so they could have helped her with her walking. So there was a mutual relationship based on kindness, essentially.

David - I wanted to just go to another reflection that I had as I read your book. When you look at the work, the Butterfly Project in Peel or in other situations, the Eden Alternative, the Greenhouse, Sherbrooke, most of the discussion or examples seem to take place in institutional settings. That is large congregate settings. And I'm wondering whether you might share a little bit about some of the observations or learnings that you observed in terms of smaller scale settings or efforts where people were trying to break down their borders between their setting and the neighborhood in which the residents were living? I'm wondering if you might comment on the question of size and also what your thoughts are around the current government talks around building long term care facilities.

Moira - From what I saw, small is better and the reality is, when did we ever live in households of thirty-two people? We didn't ever in our lives, it's not a natural way for us to exist. And so I think that by the time that most people arrive in long term care, they're very vulnerable. Many have some type of cognitive decline and are quite fragile. So all that noise, the bright lights, too many people in one place, can be extremely intimidating at best and for many terrifying at worst.

So the design of homes actually impacts the happiness of people living and working there. And from what I saw, the small households offer a much more natural way of living. We could, for example in the Green House Project homes, you can have roughly 10 people living in a household and still have connections, deeper, much deeper connections with workers. Greenhouse is usually in a residential neighborhood. In, for example De Hogeweyk, which is the village style in the Netherlands, there were quite a few people living there, but they lived in households, tiny households of about seven people maximum.

And so all of these small homes share similar design concepts. They have a kitchen, they have a living room. People can sit and chat, have a glass of wine before dinner at De Hogeweyk because it is an enclosed village concept. People could step outside and go for a walk in the sunshine and sit outdoors with a table and chairs like cafes, so to speak, and spend time even walking through gardens or working in gardens if they wish.

David - I'm wondering what your thoughts are around how we influence the physical design of long term care or the physical options even, that's to start there in Ontario, or in Canada, how we might be able to influence that design away from a return to large institutions, something that we know even at the worst of times we had given up and now they're being embraced again. So do you have any thoughts about how we might be able to intervene in that discussion?

Moira - Smaller households are really interesting. And this is picking up in Ontario. For example, I know of leaders of long term care homes, small, the small chain of long term care homes who are now designing, have received the licenses to build campus of care, so to speak, in different communities. And they are including condos, a retirement home and a nursing home. They'll have daycares in there. But because of the way they're designing this, they're able to use some of the funding from the government and some of the money from the privately paid retirement home to actually design small households for people with cognitive decline.

And so these new builds that they have will have eight people living in one household, they'll have a number of small households of eight people with access to outdoors and even the households for people who have lesser levels of cognitive decline or none will have sixteen people.

So that's much, much smaller than the thirty-two bed unit. And I think one of the ways to get more operators onside is to discuss the ways that these are very successful. So you have dedicated workers to a household. They have greater connections to the residents inside. So there's a real small community feeling to it. People get to know each other. Workers have in many of these homes (an example, again, Butterfly is used in these homes that I'm referring to that are being built in some of these new styles in Ontario, the Butterfly Program) but that gives workers a sense of autonomy and a belief that they have a say in the emotional care of the residents. I'm not talking about the medical care, the wellbeing of the residents.

So another plus then to these models of care, the smaller design, is the ability to attract staff to work there and to retain those workers as well.

David - I want to talk again for a moment about the question of leadership. When I, in my previous career, worked at the Ministry of Health and Long Term Care for twenty-eight years in southwestern Ontario or twenty-five years in southwestern Ontario and saw a real conversion there from residential care, the care of very fairly healthy people in many instances through to the care of people that are very medically compromised when they enter into long term care. However, I would visit twenty-eight or thirty or forty facilities and you go in and that's the budgets of these facilities were more or less the same. The per diem paid for was the same. The staffing complement, while they were different individuals, the profile of the staff were more or less the same in terms of their training, their attitude, the unions that were common among most of those facilities. The facilities

were often very much the same. They may vary in age, but the design components were more or less the same.

Yet there were very unique attributes in some instances. So my question was to myself, what makes the difference between Facility A and Facility B? At the end of the day, I reflected and thought it was really one of leadership. That's a conclusion that you reached and some of the people that you've talked with have reached the same conclusion. I'm thinking of David Shearer, for example. I'm wondering if you might comment on the concept of leadership, what are the qualities that you see are needed and how do we nurture that kind of set of qualities?

Moira - That's an excellent question. The qualities that I saw consistently and the people that I met who are running these programs or change agents in their own unique ways, I would say, first of all, they are bold. They do not sit back and say, what if the government or the compliance officer says no. They find a way to move forward. And I think that's a real key point.

There's also this very strong commitment to making life better, a commitment to social justice for people who are so vulnerable and for the most part in the later years of their lives. And the desire to create a better world for them. Even though they're living in a home, it's not their home. It's not the way that anybody wants to end up. Nobody wants to go to long term care. But many people are so vulnerable, they need it. And so these are people who have a very sort of global perspective of aging and see that we have value in our lives at all stages in our lives and are really pushing forward with new ideas.

So I think it's just someone who's always looking for a better idea that works and seeks out information from others. There's a lot of information sharing in this industry among those leaders and a willingness to work together to create change.

David - I want to make a comment about your book and see how you react. And it's not meant to undermine any of it. But I felt in a way that community care was overlooked in your analysis of options available to people as they age and become more disabled.

As you just mentioned, none of us want to, aspire to live in long term care. And certainly most older people want to continue to live in the community, if not in their own homes, than at least and in a more hospitable setting. I'm wondering if you might comment on what you see as the role of community care in the overall framework of the care of the elderly?

Moira - Well, I think it's really important that we have a strong continuum of care, and so with my book, I generally focused on long term care because that was my goal. After twenty years of writing about nursing homes with only incremental change and no real improvement, when I did finally decide to do a book, I decided, if I'm going to do this, I want to put my effort into really, really talking about long term care as a social justice issue, because it is the home, so to speak, for some of our most vulnerable people.

Same time I wrote about community care in Chapter Four when I talked about the need for enriched day programs such as those offered by the Glenner Family Town Square. And Glenner's is really interesting. They speak about Alzheimer's and dementia as if it's a family disease. It's not just an individual experience. And they believe that offering people good respite care during the day can actually help delay the entry in to long term care because families are better able to manage. People can work or depending on the age of

the caregiver, they have some quiet time in their life and some relaxation. So that's really, really important for people.

And I talk about the need for more programs like that. And in Chapter Nine, I look at ways that are devoted to people who are living differently. I interviewed a gentleman. He was recommended to me from the Alzheimer Society of Toronto. His name is Paul Lee and he talks about his life and his daily walks. He walks sometimes an hour every day. He has different hacks that he uses on maps, on his phone to familiarize himself with new areas if he's going to somewhere he hasn't been before. So that's his way of managing life in the community.

And then there are also, I noted, programs, movements I should say, like Momentia in Seattle or groups like the Alzheimer Society in Toronto that are all working to help people with dementia remain at home with supports and community events that keep people connected to each other.

In Toronto, the Alzheimer Society, as its societies in different cities, would train people who work in museums or, for example, the TTC in Toronto to recognize the subtle changes of people with cognitive decline and show how to sort of meet their needs.

And then I look at co-ownership like the Golden Girls house, NORCs (naturally occurring retirement communities) and so on. But I do believe and I spoke about home care through my parents experience because, while they didn't need a nursing home, they ultimately found a retirement home that helped them. They could have stayed in their home longer if they had supports like they do in countries like Denmark, where they come in and they say, "How can we help you live independently for a longer period of time?" And that could be helping maintain the home. It could be taking people to go grocery shopping, which in my parent's town, those options were not necessarily available. And people get worn out even if they don't need that extra care, they get worn out without the additional supports.

David - I really liked the way you told the story of your parents and as it was unfolding while you were writing the book. And as I would leave one vignette of their experience and go on to the next. And when it reappeared at a later stage, I was really a part of that story. I like the way that you built that unfolding into your book. I was very sad to hear about, to read about your mom's death. And it seemed to be sort of sudden, in a sense. Unexpected. And so I'm left with the question of how is your dad managing at this stage?

Moira - Oh, thank you so much for asking and noting. My dad lived for another five months without my mother. And I'm pretty sure my mother kept my father alive, to be honest with you. And that goes back to the need for home care and extra supports. But without her, he fell and broke his hip in his room at the retirement home and then was discharged from the hospital, not so long later and fell again and broke the same hip again and then ultimately declined. So very sad to see him go. He was super keen. And I really wanted him to come to Toronto and go to the day program that the University of Health Network puts on. I think the program may have closed through Covid, but at the time I thought that would be exceptional for him. So, again, that's where I speak about these day programs and the value of them to families and to individuals. Thank you for asking.

David - I wonder whether you might be able to provide some advice to our listeners as to what are some of the critical things that they might do as individuals to help advance the yardstick on the care of people with dementia in the community?

Moira - That's a great question, and to be honest with you, I wrote my book as a call to action to inspire families or to give them legitimate, tangible examples of good things that are happening out there to show that this is not magical thinking. It is being done and it can be done.

And so what I've been saying to people is that we need to raise our voices now to ensure that governments and long term care operators understand that there is a strong demand for change.

This week, I spoke with Frank Graves. He's the president of EKOS Research. And he told me that his polling through the pandemic has consistently found that long term care is a matter of huge public interest and that is not changing he said. And so a great many people were appalled by what they saw through the pandemic. I'm sure if his polling is showing that, then the governments, federally and provincially, their internal polling will be showing the same sentiment.

So there is a demand for change. I think people should focus on speaking to their federal MPs because there are strong calls for federal intervention in the provincial approach to long term care with national standards that we could use tied to funding, actually. And those standards could include language that would look at personhood and individual rights to ensure that these programs are in homes. So I would say meet or write with your federal MP or provincial MPP, join family councils like Family Councils Ontario, or advocacy groups like CARP or CanAge that have powerful voices and go to speak to the operator in your home. Tell them about these other examples that exist out there, because a lot of times the operators have said, "Well, we can't do that". And in fact, you can do that. It's happening in Ontario. You can work through the compliance system in Ontario and that is being done. So make them aware of that and don't accept anything less, because the homes, especially the homes that the government is building and funding right now, will be the homes that we all live in for the next thirty years. So all of the boomers, if they have to be in long term care and the Gen-Xers will end up in these homes.

So let's create a community that works for all of us.

David - Thanks very much, Moira. Again, I want to thank you for your investigative reporting, but even more so, I think the powerful contribution you've made by assembling these stories into a book and giving people some foundation for the kind of change that they want to see take place. So thank you.

Moira issues a strong call to action, and I know many of our listeners are or will be doing their part to make change happen. We are offering a copy of Moira's book to a lucky winner who writes to us at dementia.dialogue@lakeheadu.ca
Please put "Happily" in the subject line.

Our next episode will begin a four part series on spirituality and dementia.

Thank you to the Center for Education and Research on Aging and Health at Lakehead University, our institutional partner and to the Public Health Agency of Canada for its financial support.

My name is David Harvey.

