Transcript of Interview with Guy Chadsey

David - Welcome to our Dementia Dialogue podcast where we are discussing changing and adapting when dementia enters a person's life. This is one of four themes we're exploring in our series Living the Dementia Journey. Our goal in sharing personal stories, is to help us better understand what it means to encounter dementia and to gain some insight into how we can live more fully in the face of such a challenge. Dementia Dialogue thanks our sponsor the Centre for Education and Research on Aging & Health at Lakehead University, Thunder Bay Ontario.

Our guest today is Guy Chadsey, whose wife Allison is living with dementia. Their story as related by Guy, illustrates a struggle many people have in recognizing and acknowledging dementia in the early stages. I was also struck by Guy's articulate description of how he is adjusting to a new normal in his life and how he is reconstructing his future for himself while honouring his commitment as a husband and care partner of Alison.

I was wondering if we might start by you just describing a little bit of the story and how you entered into the dementia journey. Your wife, I understand, has frontal temporal dementia and if might just talk a little bit about that.

Guy - In fact my wife has early onset frontal temporal dementia and very briefly, she began to demonstrate those symptoms at the age of 59 although she was not officially diagnosed until October of 2012. The doctor said that he could have diagnosed her a year earlier had she been willing to go to see the doctor. Her progression was speedy by comparison to many which I gather is not untypical of the people who are earlier in age in the late 50s early 60s. So between October 2012 and March of 2013, Alison progressed extremely quickly to the point where I was unable to care for her. She had a urinary tract infection in late February where she didn't recognize me and obviously I had to leave the house. The police very kindly and efficiently got her to the hospital where she went into the mental health unit. They cleared up the infection but at that point the dementia was clearly visible so they kept her in the mental health unit. After three weeks, she moved directly to a nursing home, to a secure unit because she would have wandered within the nursing home. She has lived there for just short of five years now and has continued to deteriorate but certainly at a slower pace

David - I want to go to the incident where you had mentioned that your wife had developed a UTI and didn’t recognize you and I suppose became very afraid. You had to leave the house and called the police. That must have been pretty tricky situation.

Guy - You never, I don't think you can ever prepare yourself for those situations. So it is traumatic when you feel that shortness of breath and there is that sense of helplessness and panic. So my first inclination was to leave the house because clearly she saw me as a threat and I left the house. Fortunately there was a neighbour who knew something about some incidents that had occurred and who came out with me and I phoned the police. Why does this always happen on the coldest night of the year? I took the car with me because my great fear was that she would try get in the car and drive. I waited for the police to come. They came and of course they treat everything as a domestic abuse situation.

So he went in and talked to her. It was clear to him that she had some mental health issues at the very least, and he very gently and kindly persuaded her to accompany him to the hospital where she could have someone look at her and make sure she was okay. Would it be okay if I followed in my car? So we did. And sure enough when she got here and they diagnosed the urinary tract infection. They then phoned the GP and he confirmed that she had dementia and should be held in the mental health unit.

I think at that point that sense of helplessness, that sense of panic - where do I turn? What do I do? What are the decisions that I am expected to make? And suddenly there is this sense that now I really am responsible for her as well. I am making decisions on her behalf because there is some doubt as to her capacity and competency to make decisions. So there's that's somewhat overwhelming and of course there are no, you know you can’t take out a guidebook and say ‘Oh well I am on step two so I need to go to Step Three”. So there is a good deal of thrashing around at this point. Needless to say all of those professionals - police doctors nurses were all extremely helpful calm and particularly patient. Being patient with somebody with dementia. Being patient with a caregiver who suddenly [is] confronted with “now it's hit. Now we're not just dealing with symptoms, we're dealing with the actual moment”. Patience is a virtue there that can never be overrated.

David - You mention that you and probably Alison had sensed that things were changing in that her capacity was diminishing but she was resistant to going forward to talk to a physician to look at her diagnosis. Can you talk a little bit more about how that resistance manifest itself?

Guy - I now realize that resistance is more common than I thought. I just put it down to stubbornness on her part, a sense that she wasn't quite right but didn't want to admit that. She had always been very much a person in control of her own life. The word dementia was never used between us in a conversation. I attribute that to the situation with her mother, her parents and their grandparents that she saw dementia as a death sentence. So we never talked about dementia.

We talked about memory loss and the way in which I introduced that, was to talk about something that was common to ageing and that I had as well. And that was the only way in which I was able to get through to a memory clinic, was to say you know I think we've reached a point where we really should just have it tested. And I'll go for the test as well. I was observing symptoms and the symptoms that were most noticeable were confusion about day, the day of the week, confusion about time, forgetting appointments, confusing appointments so she would show up at the hairdresser at 9 o'clock for a 10 o'clock appointment. The hairdresser was not open, so she'd just assume the hairdresser business had closed and gone away. Now where was she going to get her hair done? And social withdrawal. We didn't want to have people in the house and if we were to go out, within half an hour or 45 minutes she would want to leave which is a real problem when you're invited for dinner and it's the first course that's only just been eaten. And clearly other people weren't talking to me. They weren't telling me what they were observing because sure enough when she went into the mental health unit everybody came forward-"Oh yes we noticed this and we noticed that. We noticed this".

I think the first moment of decision came when in the fall of 2009 she was teaching, commuting to Burlington from Stratford. It is no small distance every day and part of it on the 401 which is stressful. The school was commenting that she was setting an exam and not administering it, failing to turn up to cover recess, marking only half the papers and not the other half, forgetting to distribute things. So I had a conversation with the principal of the school who said that they were concerned and at that point I made the decision that she should retire to all intents and purposes. And so we pulled her out of her job and it was over the intervening two years that I really noticed this the increasing number of symptoms and their occurrence, their almost daily occurrence.

David - So Alison was working at the time that these symptoms began to emerge and then the symptoms and her behaviour were impeding her capacity to do the job. That must have been challenging situation for her and her employer.

Guy - It must have been and I think it's somewhat odd that neither of them mentioned it to me. I thought that this perhaps was just related to stress and was confined to when she was at home and essentially let our guard down a bit and relaxed but at school she remained focused and very professional. It wasn't till we had reached this turning point in essentially Christmas of 2009 that it came home to me that the school had been observing these for the past six months.

David - I wonder if you might talk about that sort of experience that you would have had as Alison, as her capacity became more diminished and then you began to consider placement in a long term care. Where did you go for support in that kind of decision?

Guy - I had been encouraged fairly early on by friends to go to the Alzheimer's Society and I think it's typical of many people to delay going, to put it off because it's almost a public admission that there is a problem. And I put it off and put it off. And finally I sidled in late one afternoon trying to be as anonymous as possible and got a few pamphlets and so forth and read them. As I read them I realized that my fears were for real.

When the situation got more dire, I went back to the Alzheimer's Society and this time I met with the First Link the support worker and they very gently guided me through what steps might be, what I needed to think about and that they were there to support me and perhaps most importantly, guided me through that labyrinth that is CCAC or was the CCAC. I will say right up front that my experience with CCAC, Community Care Access., I think the worker, the officer who was assigned to my case was fantastic and that the process was extremely good so I [have] nothing but good things to say about CCAC and my experience with them. But for a novice or somebody like myself, it was daunting and if it had not been for the Alzheimer's Society being there at my side as aide, as someone who could reframe my questions so that they were more accurate or more pointed, who could raise things gently with me that I could then ask [or] that I wouldn’t have thought, was of tremendous help.

David - That last comment Guy reminds me of a comment that I read in your notes that you'd sent along in preparation for the interview. I thought it was an interesting dichotomy that you described there. You described Alison as a victim of dementia yet you went along in the same sentence to describe your struggle and seeming achievement, perception of living positively, even though dimension's entered your life. I wonder if you might talk about that conflict that must exist between those ideas of victimhood and living positively.

Guy - And I think we see, we talk about the victims of an illness whether that's cancer, whether that's a heart attack, whether that's dementia, mental health or any disease. And we think solely in terms of the person who has been diagnosed, who is living with that but it also affects those who care for that person. The person, the people closest to them, whether that's a mother or father or sister or brother or a husband or children. That that kind of intimacy. And I think that we somehow tend to forget them. Alison was diagnosed and in a sense things started to fall into place in terms of her care and it made me realise that I too, could become a victim. With the greatest of respect, my sister-in- law, when my in-laws, my mother-in-law became ill, sacrificed her life to become the caregiver for her mother. [She] gave up almost everything in her life for almost 24 hour care for her mother for close to 10 years and then moved on caring for her father. Now that both are gone, you know, who is she in a way?

I have said very early on I refuse to be conquered by dementia. I refuse to be taken as a victim by dementia, so I have to find a purpose. I have to find the resilience. I have to find a way forward and I have to do it myself [and] I think that refusal to be defeated by dementia, gives me a strength which then makes me more positive in terms of moving forward. I don't want to live in a gloomy house where I am bemoaning my own loneliness and my own unhappiness. I don't want to become angry and say, "Well what about my retirement? What about our retirement plans? How am I going to support this financially? You know what am I going to do? Can I ever go out again? How will people perceive me?" I can't live like that and no one should have to live like that.

David - In many ways, I have observed that it brings out the best in people in some ways. If they respond to the situation in a positive way it really engenders a - 'here is a set of strengths that they may not knew they had- a way of communicating in a more profound way than one might in just the normal discourse of life. Is that part of your response to this situation?

Guy - I believe strongly that I am a better person because of Alison’s dementia. I think I know myself better. I think I have discovered in myself a-depth that I never knew I had of patience, of understanding, of tolerance that manifest themselves in other ways in my life now. That somehow I have come through this I am changed forever but I am a better person. I have a better view of life as a whole. I have a more understanding and sympathetic view of other people's sufferings and indeed of other people’s failings and flaws. And so I am eternally grateful to Alison for giving me that's a lasting legacy that she still gives me. And I talk about Alison in the present tense because she's still very much part of my life. I am still very much involved in her life. We still have a marriage.

David - Interesting. How do you go through the process of redefining relationships? A marriage is thought to be a marriage of equals where people both contribute. As one person's ability to contribute, it diminishes.

Guy - Well you know, that's a really interesting question and it's one that I have been wrestling with for the last six months. It has been five years now since Alison and I have ceased to live together, almost five years. So obviously the marriage has been redefined. We have one party who is not present in the marriage, both physically and mentally in the marriage and one party who is still involved. You think of a marriage as common activities, common goals, common experiences. Well clearly, that doesn't exist anymore. So what is a marriage in this state? You know they talk about dementia as the long goodbye. But a marriage in dementia is in a limbo. So how [does] someone in their 60s or 50s move on with their life and re-establish a normal relationship with somebody when they're still when they're living in a limbo. I am not being very articulate about this because I am still wrestling with this idea. So I don’t know what to do. I mean I am 67. I do not want to spend the rest of my life alone. I find winter nights very difficult because of the darkness and the loneliness and that sense of closing in. I suffer from more from panic attacks in the winter than I do in the summer time. I would like to have a partner in my life with whom I experience things but I don’t ever want to lose that moral or legal responsibility for Alison’s care. I promised her that I would never abandon her I would never leave her alone but I [don’t] want to be left alone and I don’t know what the answer is. I wrestle with that constantly.

David - One of the other comments you made in your note was the use of the term empathy, that one of the qualities that you've found within yourself for a strength you observe in yourself is empathy. I wonder if you might just explore that all that or more.

Guy - I think the opposite of empathy is arrogance and I look back on my life and I realise how arrogant I've often been, particularly in my quick responses to situations. My not listening, my quick condemnation, my turning away and I think that what Alison has taught me is that I need to listen. I need to be more patient. I need to be more understanding. I need to accept that other people are different and think differently and do things differently and that doesn't make them bad people it doesn't even make them wrong, it just means they different. And so I think empathy often becomes humility which is the other thing that I've really discovered and humility has great value. Humility and also acceptance and that has helped me to accept my own situation and my ongoing situation, my ongoing responsibilities but has also given me strength. Empathy has given me a strength as well.

David - And acceptance of what is inevitable in some ways. Things that you cannot influence but I sense at the same time that you don't want to accept things that are amenable to change.

Guy - Yeah I think one of the personal examples is that I am trying to downsize. Now downsizing is an interesting exercise because you do it because you want to move into a smaller place, you think I don’t need all this stuff. I am downsizing Alison's clothes because she's lost a lot of weight so she's never going to wear these clothes again but I can bring myself to throw out certain things because they’re a jacket or a skirt or an outfit or accessory with which I associate her and some event and I think I can’t throw that out because it has it has a nostalgic meaning for me but also what I think is more interesting is the fact that there exists some little part of me that thinks maybe she'll come home. I know there's no cure. I know that even if there was a cure, it's far too late for her. But some part of me will never let go of the possibility that she will one day come home and be whole.

David - One of the phenomenon that we've noticed in the research around this question of changing identity adjusting to a new normal, if you will. It sounds like you're struggling with that in some ways. In your own personal life, you've been able to establish a new identity but in some places you're a little slow or reluctant to do that because.

Guy - And I'm grateful for those. I’m grateful for those because I think and I've had this conversation with a couple of people and it's an issue which has only just raised its head. I'm grateful for those –the retarding effect of those moments or those experiences because I worry that I will move on to the point where I forget, where it will be easy for me to say’ oh I just didn't get to see Alison this week. It doesn't matter because she doesn't know me anyways’ That I will start to forget and that would be tragic and it would be it would be a betrayal. I never want to forget. I never want to be glib in any way. I don't want to accept her dementia to the point where I can just shrug my shoulders. And I fear that that happens. I have actually seen it with one or two people that I have met through the Alzheimer's Society. It would be different when Alison dies because then that is the goodbye. But I don't want to end up in a situation where I've taken down all the pictures of Alison because they're no longer relevant. That would be tragic.

David - [We are] Nearing the end here. I wonder if you have any particular thoughts parts you wanted to leave with our listeners.

Guy - Just a quick story. When Alison was diagnosed by our doctor, who in their diagnosis conversation with her never mentioned the word dementia but she seemed to accept his diagnosis because I don't think she really understood it. But I did. He immediately turned to me and said, “Well we know Alison's path now, how are you doing?” And it was the first time they walked to the role of being a caregiver. If I have a purpose at the moment it's to advocate for the role of the caregiver, for the care of the caregiver and the big part of that is getting rid of the stigma.

David - Thanks Guy.

For information about our series and the research underlying it, please go to our website Dementiadialogue.ca. There you will also find useful resources to help you learn more about living the dementia journey. You were also invited to join us on Facebook at Dementia Dialogue. Feel free to make a comment or perhaps to share a bit of your experience with dementia. Thanks again to our sponsor for today's episode, the Centre for Education and Research on Aging & Health at Lakehead University Thunder Bay Ontario. Please join us next week on Dementia Dialogue as we continue our conversation on changing adapting as part of the dementia journey. My name is David Harvey.

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