"You Should Not Need to Go to a Table in the Corner": Experiencing Transitions with Jim Mann, Dementia Educator and Advocate

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COLLECTION: AGEING THROUGH A TRANSITIONS LENS

MULTI-MEDIA ARTICLE

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ABSTRACT

On April 5th, 2022, the author, Dr. Josephine McMurray, sat down with Jim Mann, former Director of Government Affairs at Air Canada, who in 2007 at the age of 58, was diagnosed with Alzheimer's Disease. Since then, Jim's transition from retiree to "person living with dementia" was swiftly replaced with "advocate and educator" after observing and experiencing the sharp stings of stigma and stereotyping that can accompany a dementia diagnosis. Since then, Jim has dedicated his life to living positively with his diagnosis. He has appeared before federal and provincial Parliamentary committees, been interviewed for radio, television, and podcasts, and spoken throughout Canada to large and small groups as a keynote speaker or discussant at conferences, meetings, and in classrooms. He also collaborates with researchers across Canada on grant applications and academic publications. Above all, Jim's message about dementia-awareness is one of education and hope. In 2020, he was awarded an honorary Doctor of Laws degree from the University of British Columbia (UBC) for his advocacy on behalf of the rights of people with dementia. The University noted, "he has been acknowledged as the single-most influential person in Canada for countering negative stereotypes and promoting an inclusive society in which persons with dementia can make an active and meaningful contribution." Jim Mann is a Canadian national treasure, and after reading our conversation with him (presented verbatim but divided into sections for clarity to highlight key aspects of transition), we are confident you'll agree that his personal transition to dementia advocate and educator has been our gain. At the conclusion of the interview, the author provides a reflection on the interview and its possible interpretation situated in the context of contemporary transitions theory.

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BEING DEMENTIA AWARE

Author: Perhaps you could start by telling us something about yourself, your previous work, your current work, your family, and your health.

Jim: Sure. Right now, I have Alzheimer's and I was diagnosed in 2007 when I was 58. I was doing some consulting work at that point because I had retired after 25 years with the airline. The last eight years with them, I was the director of government affairs, so I did the lobbying for the company. Those eight years I was in Ottawa, and while there, my father had a massive stroke. For a number of years, my mother was alone in her condominium [in Vancouver], and we were helping her cope with being alone and adapting to having her husband in long-term care.

Then we moved back [to Vancouver] in 1994, something like that. Then gradually understood that she was maybe having more issues than just what we had thought about and there were memory issues. She told us about a friend of hers going into independent living. I basically said, "Get your hat and coat, we'll take you to a place." We took her to a brand new, independent living apartment situation. She fell in love with it right there and then. As we were leaving, we were standing in front of this big fireplace that was at the entrance and it said, "Welcome home," and as we're leaving, the manager came and put his arm around her, reassuring her and everything. It was just, "What about your place?" "Oh, Jim will look after that." I thought, "Well, thank you. I'm glad we had this chat." [laughter]. She basically moved in two weeks after that and that's where she stayed for almost four years, I guess. During that time, I had created a Word document called "momisms" because I didn't know what else to call them. Rereading them, which I have done recently, I see so much of what I'm doing or have experienced. It's fascinating. It really is fascinating.

Author: How does that make you feel as far as her legacy through you or what you're experiencing through her?

Jim: Basically, what I've said in many presentations is, because I was diagnosed almost a year before she passed away, I had a preview if you will, and so where so many people talk about getting a diagnosis, and it feels like a punch in the gut, and they go home, and they Google and so on. When I was diagnosed, I didn't have to do that and so it wasn't a punch in the gut for me. Which I think allowed me to, if you will, hit the ground running as far as advocacy is concerned.

BECOMING A DEMENTIA ADVOCATE: REFLECTION, STIGMA, AND STEREOTYPING

Author: I wonder if you could reflect on other transitions that have got you to this advocacy point.

Jim: I've always volunteered since high school. For me, it's my business background in marketing and communication and advocacy and seeing the transitions of my mother doing the journey of condo living, and then independent living, and then long-term care, and then my own diagnosis. To me, all of that joined together. When I was diagnosed then, it was a matter of, "Okay, what now," because I saw that I could not carry-on doing consulting work. Because I did have a couple of contracts that I reflected on after and realised that I did not do them well because I was forgetting some of the details. Beyond the fact that I felt really badly, really badly about that. I thought, "Well, what am I going to do?" I had no idea. I guess I'll volunteer. At one time when we were following my mother, we did go to the Alzheimer's Society and get a few brochures. I knew about them [the Alzheimer's Society], and I knew what they were doing and so on. You deal with what you know and so I went to them and said, "Here I am." In the fall of 2007, there was a public policy forum that the Alzheimer's Society had convened. I invited myself to it and as I am sort of want to do.

I think I was the only person in the room that had Alzheimer's. There weren't very many people, but I think they were all caregivers plus some Society people and a professor from UBC. I spoke up and talked and so on and the rest is history as far as what I've done. Part of that is being open about having Alzheimer's and that's been so very important to me.

Author: Can you explain why that is important for you?

Jim: I think for me, there were probably more, but the one example that really stands out for me to this day is seeing the stigmatisation of dementia when my mother was in independent living. I was sitting with her in the lounge waiting to go in, we were going to have lunch together. I saw

these two older ladies sitting or standing a ways away. They were looking at us and I thought, "You know what? You're not looking at me. You're talking about us." And it became almost like that schoolyard bullying thing. They were talking amongst themselves, they'd talk, couldn't hear anything, but they would talk and then they'd look up, and then they'd talk some more.

I thought, "Wow, here you are, you're amongst people who are at that point." Well, still, I mean, a number of years older than I am, but closer to my mother's age. I'm sure they were probably a bit older than her but here they were and talking like that (about her). Then the other example that has spurred me on is still to do with the stigma of dementia. They would sit at the same table all the time, every resident. I went one day on my way home from downtown [Vancouver]. I thought I'd drop in and see her. I went up to the table and there were four people at the table and my mother was not one of them. Immediately, I'm thinking, "What the hell has happened to my mother?" I said, "Where's Margaret?" They pointed over to a table in the corner and said, "Oh, she's moved over there." The other people at the table finally lost patience with her, I'm guessing. They booted her out. Stuck her in the corner.

MAKING A DIFFERENCE: CHANGING LIVES THROUGH AWARENESS AND EDUCATION

Author: These two incidents made you determined to address this kind of behavior that isolates people with Alzheimer's?

Jim: Yes. That's why I say I advocate to educate. I mean, the thing is that if you don't talk about it nothing's going to change. I thought I'll be damned if I'm going to at least not have some sort of impact on one person, the whole bunch of people or whatever, because dementia is with us. If the elderly, because it is primarily the elderly, so if the elderly cannot themselves have patience with each other in a situation like independent living, then who will? Who is ever going to have patience with a person with dementia? I don't know.

Consequently, again, as I said, with my background in marketing and advocacy, I thought I know how to market it, if you will, and to lobby and to make my point, and so on. That's what I did. I became more aware of words because I have to admit, there was some debate in the Senate. Was it 2008? Maybe. I remember the senator saying something about mental... It was either mental illness or mental health. I don't remember, but I wrote her a letter about it saying, "I'm sorry, but I'm not mental so don't say those two words in the same sentence as Alzheimer's".

I guess she talked to the CEO of the Alzheimer's Society of Canada. When there was a meeting in Vancouver, he and I had lunch, and less than a year later, I was on their board. I do remember before that, I was invited by the Alzheimer's Society of Canada, by the staff actually, to go and make a presentation to the board about lobbying about government relations, about the need for advocacy work on the political side and departmental side, I mean government per se, not being political. I went down and gave my presentation, promoted the idea, told them why, and so on. Then, as I say, however many months later, I was invited onto their board, and so I served a six-year term.

'VISIBILISING' DEMENTIA: LANYARDS AND UNDERSTANDING

At some point, I don't remember what year it might have been, but this is 2022, and it's been many years, maybe 2013, something like that, that I've actually worn a lanyard and have a name badge at the bottom. I have a few things in that, but the most visible is the little Alzheimer's Society, little card that I got laminated that says, "Please be patient. I have Alzheimer's disease." Anytime I leave the house, I put that on because to me, I either by virtue of walking or talking will educate people who don't think you can [do things].

I hope that people will see this and think, "Maybe I can talk to you about it," and for all those years, they've never done that. I also wear it or started wearing it because when I was on the board of the Alzheimer Society of B.C., one of the board members was a lawyer, and we had meetings at their law office which was in a business tower downtown. I would go in early and just relax over a cup of coffee and I would stand at the counter. There was music in the background and there was chit-chat, writing everywhere, and so on, so I'd end up standing there and going, "I have no idea what I'm doing. I don't know why I'm here." I'd just look around.

The clerk never said anything to me, but you could tell [by her] body language. Nobody was behind me, but you could tell she was like, "When are we going to talk?" I guess after the second time I had done that, I talked to Alice, my wife, and she said, "Well you have that "Please be patient" in your wallet. Just take it out and show them." Well, first of all, when you're in that disorientation, you're not going to think, "Well, I'm going to get my wallet and show it to you."

Also, for me, that is a reactive behavior, and doing that would put the other person on the defensive, I guess, is how I would phrase it because they're going to think, "Oh, what have I done to make you do this?" I don't like to do that especially when I'm trying to help people understand around dementia. I thought, "Well, here's what I can do. I'll wear the lanyard," because you know that when people have something around their neck and something at the bottom, you know they look at it. I thought, "There's my communication piece." This gets me out of a problem because then they get, "Oh, okay, now I understand."

For the third time when I was once again disoriented, I reflected on how her body language changed. There was more what I took to be patience shone, it wasn't, "When are we going to get this party started?" It was, "Okay. I'll give you a moment," and so that's why I do it.

STEPPING UP, PARTICIPATING, AND ADAPTING

Author: You went through a transition from patient to advocate because of this desire to attack this stigma and to help others to understand the disease better. What else is driving your need to remain involved? Is control what drives you, or what are some of the things that you think drive your ability to manage these transitions so well?

Jim: The need is there, or what I perceive to be a need is there. I take part. I participate in addressing it. I realise that I'm going to say a lot of people with dementia will pull back, will certainly not put a lanyard on. I've heard people say, "Well, I feel so vulnerable." I don't know. They just are not comfortable being that forward about it. I appreciate that. I guess I'm more comfortable because of my background because that's what I'm comfortable doing, comfortable meeting people, and comfortable adapting. The airline industry has always required adapting.

I went through many years that it would be almost annually, there'd be a reorganisation and I'd be in another position, and so on. You just go with the flow, you adapt, but at the same time, I guess I've also identified the stigma and the discrimination in so many other ways beyond the independent living and your peers not having any patience, and so on. Even with like the patient-oriented research from CIHR [the Canadian Institute for Health Research, a national research institute funded by the Canadian federal government], it's one thing to have CIHR say, thou shall do, and whatever. It's another thing to put that in place in research.

FINDING PURPOSE THROUGH RESEARCH

Jim: There were teething problems, I would call them. It became I think a challenge for long time researchers to figure out how to do it, how to involve people with dementia in research, beyond being, what do they call, 'the subject', as compared to the participant? I had read about or heard about some of the challenges, and it became more of a tick a box. Sure, they're here [people living with dementia]. It's fair to say, I didn't quite grasp the whole meaning of that until I was in a situation where I was a tick in the box, and I swore I'd never be a tick in the box after that.

For me, it went beyond the direct stigma, the direct discrimination to some of those offshoots, so that it's not stigma per se, but you are still stigmatised because you have dementia. What can you contribute? CIHR says, "You have to be here. Here you are. Thanks very much." I thought, I will do what I can to help researchers understand [what] I called unconscious bias.

I remember I was invited by the W. Maurice Young Centre for Applied Ethics at UBC to be their invited community scholar or whatever. I spent a week there, and I remember the first interview of the first day I had with a professor. We were talking and I brought up unconscious bias. She said that she had really not heard that much about it. I remember saying that I really have only heard it in relation to human resources, getting all these CVs and you start deciding on the basis of a name or something. That discussion then got me thinking more and more about it. I remember talking to a long-time researcher at a reception. I said, "In so many

people's minds, you go from diagnosis immediately to long-term care. There is no journey in between. That's where you go." After talking a little bit about it, she looked at me and she says, "That's in my mind." That's another role I've of played along the way.

TRANSITION AS AN INNER REORIENTATION: LOSS, SUPPORT, AND A NEW NORMAL

Author: Jim, you talked about your background contributing to what I think we could probably characterise as resilience. What do you think has allowed you to move through these transitions as seamlessly as you have?

Jim: That's a tough one. I don't know. In some ways, I guess I have done some things differently along the way. I don't know. This is an odd example, but driving is the biggest, biggest bugbear, especially for men, is losing their license after being diagnosed with dementia. I remember in the earlier support group I attended; this man arrived a bit late. It was his first time. Well, he hijacked the meeting, basically, it became him. Because I think that day probably earlier, he had lost his license. Wow. The world had come to an end.

Do you know, I don't know, five years later, whatever, if I wasn't at some other Alzheimer's Society thing in that same area of the city, if he wasn't there. I couldn't pick him out of a crowd, but as soon as I saw him in that setting, if you will, I thought, "Oh my, you're that man," and do you know what his first thing was? It was "I lost my license", and he went on about it again.

Author: Five years later.

Jim: Yes, and so it is raw for some people anyway. I have been going for a number of years to a support group that is different. We have breakfast. It normalises things, people go to a restaurant, people eat, it's public, and so on. One day these two men who were along the same lines of their journey, different lives and everything else, but anyway, they were there, and they were both down in the mouth over not driving. I said, "Well, you can take a bus." "Oh, don't take a bus," this one man said, "Well, I went out and stood at a bus stop and the bus never came so I went home." Well, I've taken a bus since my first job, and I know sometimes you can stand out there and the minute feels like 60. Anyway, I said, "Oh, well, that's easily fixed because you can go on the computer on the bus site and figure out the times of the bus." Oh, they both said, "We don't use the computer."

Okay, so now you don't drive, you don't take the bus, you-- Oh crap. There are three things, so what do you do?

CURIOSITY, GIVING, AND ROLE MODELLING SELF-REDEFINITION

Author: Yes, that's really interesting. Were you computer literate early? Do you think that that makes a difference if somebody is not digitally literate, and what impact do you think that had for people in this present day as they try and move through these changes in their lives?

Jim: Well, I think a lot of it is curiosity but certainly when I was living in Ottawa and doing the advocacy work, I had to keep up on the news. I had to always be aware of issues. I had a TV in my office and would watch *Question Period* every day and see what was being said and so there is that desire to keep up to date on news. I get the Globe and Mail [a national Canadian daily newspaper], not every day, I can't afford that, but on Fridays and Saturdays and I have access to it online, which I don't particularly like, and I get the Vancouver Sun [a Vancouver based daily newspaper]. There is that, but there's also that need to fill a void. There is that I can't sit around and not do anything so what am I going to do, I'm going to do what I know.

I'm not sure I should say this, but I go to the support group, not necessarily to get the support, but to give the support because so many people, as I said at the beginning, it's that punch in the gut, and they need that reassurance. They need that idea that you can use the bus, they need the idea that you-- it's a journey so you have to get used to it because it's going to be with you, but don't count yourself out.

I do think that a lot of the people in-- well, the breakfast group have really, I don't know how to say it, like appreciated seeing what I do, because before the pandemic I would do a lot of travel. When I was on the board of the Alzheimer's Society of Canada. I would fly back east and everything and I would come back and they'd always [say], "Oh, what's happening in research or where did you

go? What did you do," and I think it encouraged them. There was that sense that if he can do it so can I because I've used in presentations a lot about how early on there was a woman who was told by her doctor that she had Alzheimer's and she went home and shut the door.

A VALUED SELF-IDENTIFY: OWNING DEMENTIA AND TALKING ABOUT IT

Jim: She did not tell her daughter that she had been diagnosed with Alzheimer's. She only went out when she really [needed to], she didn't tell a soul. There was a newsletter that the Alzheimer's Society would send to donors, and I guess she was a donor, so she got a newsletter that had a little item across the bottom that had my picture and talked about something I had done. She looked at that and said, "If he can do it, so can I." That got her to tell her daughter that she was diagnosed.

She then did go out and attend our support group and it's that little bit of reassurance but it's also in many presentations like the keynote speech I gave to the AGE-WELL Conference in 2015, where you're saying, "I have Alzheimer's," and "you guys [in that case it was a lot of younger people] need to include the people that you are doing some of the preparation for, looking at computers [sic] solutions or different solutions. If you don't do it [include people with dementia in research] how will you know it [new technology] will even be applicable?" It's all part of that. Still, it has that basis in stigma. It has that basis in discrimination because those have so many offshoots. Because it has so many offshoots, I end up getting involved in so many different things because there's, I don't know, I guess, in my own, I guess, arrogant way I feel somebody needs to hear and so I'm willing to say it.

There is, I don't want to say such a need, but there is that normalisation about having to mention that is just so necessary. To this day I thank the city of Vancouver for producing the trainer video that was really meant for their staff to normalise having dementia in the community. Because I have heard from [dementia advocates] that [when] they got the diagnosis, they Googled and saw not very nice stories and got the stories that reinforce that you go from diagnosis to long-term care with no in-between.

Then they stumbled on *Jim's Story* from the city of Vancouver. There I am having ice cream in the market, there I am on the bus, and all of a sudden, they realise, that, "Oh, wow. Maybe there is a journey involved and maybe I can be a part of that journey." I never really understood the power of that video. I was at a conference in Vancouver, and I think there were some people there from a Scandinavian country. We talked and I said something about *Jim's Story*, and they ended up asking the city if they could get it translated into that language.

I've had a few other requests that I've sent on to the [Alzheimer's] Society. One from Spain or Portugal for the same thing. It's that need to normalise having dementia. As much as it is not normal, we need to normalise it. For me, I experienced it with my mother in independent living. It illustrated so, so much the need to normalise it. You should not need to go to a table in the corner.

THE AUTHORS' REFLECTIONS

Bridges has described how 'every transition begins with an ending' (2004, p. 11). The 'ending' for people diagnosed with dementia is rarely an abrupt event. Many experience months or years of frustrating changes in the way they recall details, their ability to make decisions, and manage relationships with others, before a clinician recognizes, tests, and confirms their diagnosis. Despite the wait, many will describe hearing their dementia diagnosis as a "beginning" – the start of a process of understanding their symptoms in the context of an uncertain future, and reflecting on and reconstructing their lives with less autonomy (Vernooij-Dassen et al., 2006). Jim's sensitisation to the disease through his mother's diagnosis and both their lived experiences of events afterwards, wasn't "a punch in the gut" as Jim describes others' experience of the diagnosis, or "shock, fear and sorrow" as described by others (Robinson et al., 2011, p.1036). He was able to "hit the ground running" reimagining his life – in Jim's case this meant stopping paid work and eventually committing to dementia research and advocacy.

In his seminal work on rites of passage, van Gennep (2013) identified life as a series of transitions that follow a three-stage format: the first stage is a transition that involves separation from a current

familiar role, the second is a marginal or liminal state of transition that is aptly described by Turner (1964) as "betwixt and between", and the third is an aggregation stage where understanding is incorporated into a new way of knowing. Perhaps Jim's immersion in his mother's transition from non-disabled to disabled, from being socially active to enforced isolation, allowed Jim to observe and reflect in the preliminal period before his diagnosis, on the types of personal, relational and situational adaptation that people living with dementia (PLWD) must continually make as this progressive disease affects one's cognitive and physical abilities, and emotional experiences. In effect, transitioning from one's everyday 'normal' into a new phase of life.

As a funded researcher with AGE-WELL, a Canadian national research network focused on building technologies to support older adults to age independently in a place of their choosing, I understand that many PLWD do not experience the type of transition that Jim describes. As a generally healthy, educated, well-resourced, white man, Jim's understanding of the disease, his expectations of outcomes, and access to new knowledge and resources, privileges his ability to plan and to manage periods of uncertainty, all factors that influence a "smooth transition" (Schumacher & Meleis, 1994, p121). In this way, Jim's social and human capital may have tempered the disrupting potential of his transition experiences.

Nevertheless, Meleis' Theory of Transitions (Meleis et al., 2000) suggests that as Jim adjusted to the role of being a PLWD, he entered a period of self-identity reconstruction; a process brought on by the need to adapt to and normalize changes and disruptions as a result of his Alzheimer's that appeared permanent (Kralik, Visentin, and van Loon, 2006; Ruthven, 2022). Driving Jim's transition from identifying primarily as a person with a chronic and progressive disease, to an educator and advocate, was a burning desire to address the pervasive stigma associated with dementia. "I thought I'll be damned if I'm going to at least not have some sort of impact on one person". The level of stigma Jim describes coheres with the 2019 World Alzheimer Report on attitudes towards dementia that found that 40% of the general public think that medical personnel ignore PLWD, and 42% of PLWD reported being avoided or shunned (Alzheimer's Disease International, 2019). Jim's desire to talk about his condition, to raise awareness and develop understandings of PLWD as a way to build awareness, is not only consistent with our understanding of education as a tool to lessen dementia stigma (i.e. Kim et al. 2019), but also allowed him to normalise his own dementia. Going one step further, he 'visibilises' his acceptance, using a lanyard that not only contextualises behaviour that might be stigmatising such as appearing confused, lost, and fearful, by loudly declaring his dementia, and requests beneficence from the reader. "Please be patient", spells out the responsive actions most useful to PLWD - patience over intolerance, care over indifference, and interaction over isolation. Jim explains that his lanyard draws people's attention, and visibly changes his social interactions.

For many people diagnosed with dementia, self-stigma or the process of internalising negative societal conceptions of cognitive decline, can lead to isolation and withdrawal (Milne & Peet, 2008). Jim relates how his advocacy role not only pushed him to seek opportunities to publicly own his condition, but also pulled him deeper into social groups of researchers and professionals who had similarly chosen to align themselves as advocates or champions for societal change in attitudes towards PLWD. For Jim, the liminal period of transition is self-described as brief, and one where he was able to identify those attributes that he would retain from his previous identity that could be incorporated into the new one (sociability), those that he would discard (independence), and those that he needed to develop (the ability to accept help).

Transitions have several characteristic properties that help us understand and define them, as well as to better understand how to help those who are experiencing change over time. We understand that transitions often bring periods of disconnectedness and disruption, involve a loss of familiarity and existing networks, and makes us question the skills and capabilities that we use to define success (Meleis, 2015). Our aging bodies, changing roles in family, work, and society over time, mean we must adapt and change throughout our life journey. As such, transition is our normal state of being. Some critical milestones such as a dementia diagnosis may signal beginnings or ends that immediately challenge our self-identity, as Jim describes. But transitions may also be more gradual, where the lines between *'then and now'* occur more organically allowing almost imperceptible adaptation, such as Jim's transition from a symbolic representative, the "face of dementia", to a more integrated and embedded role as an active collaborator in research and as co-author of peer-reviewed publications.

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Transitions DOI: 10.5334/ijelt.48 Transitions theory has been applied in a number of disciplines such as anthropology and education studies, and across the life course to examine events such as motherhood, retirement, or illness (Kralik et al., 2006). In this deconstruction of a conversation about the experience of a person diagnosed and living with dementia, the many parallel and sequential transitions such as son to caregiver, worker to retired person, healthy person to one living with a chronic disease, are revealed. Future research might explore what interventions during the liminal period might help people diagnosed with dementia to adapt to their new life circumstances, and to the extent possible, reconstruct their sense of self.

We might be forgiven for characterising Jim's transition from a non-disabled retiree to advocate and researcher following his diagnosis of dementia, as the essence of a successful transition. He has been recognised with a Queen Elizabeth II Diamond Jubilee Medal for volunteer service to the community, he received the Governor General's Caring Canadian award, and was hailed as the "most influential person in Canada" in countering stereotypes and building an inclusive society by the University of British Columbia in awarding him an honorary Doctor of Laws degree (Alzheimer Society of British Columbia, 2020). Jim's journey has not been easy, and he has experienced personal and social loss in transitioning to his new normal. Yet his self-described *'curiosity'* and willingness to re-define himself, sees him actively seeking new opportunities to contribute which will continue to demand adaptation, and present more endings and beginnings. One thing is for sure though – if he has anything to do with it, he will never settle for being relegated to a "table in the corner".

ETHICS AND CONSENT

This study was reviewed by the Wilfrid Laurier University Research Ethics Board (REB#8474). Mr. Mann provided consent to the sharing and publication of his interview data with edits for length and clarity.

You can contact Jim Mann by emailing cbsl@telus.net. Jim's Story, produced by the City of Vancouver is available at https://www.youtube.com/watch?v=Lzd2aYpuKdk.

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Josephine McMurray is a member of the *Ageing Through a Transitions Lens* special issue editorial team. She was removed from any decision making related to the abstract submission and acceptance as well as the review process to ensure independent review and editing.

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