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Reflections on advocating for age-appropriate care in B.C.: an intricate dance of crip time and governmental processes

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Abstract

What happens when you're chronically ill and your community supports can no longer care for you at home? In B.C., you go into a long-term care facility, if there are beds available, where the average age of clients is 85. Multiple sclerosis (MS) affects four times more women than men, and many women face these decisions in their thirties and forties. Those who enter long-term care facilities often never leave, and are forced to live in a medicalized environment designed for people twice their age. Advocating for change as a disabled activist requires an intricate dance, weaving in the strands of crip time and the political calendar to achieve change for those who are forced to live in a time that is out of step with their needs and desires.

Keywords: Care, age-appropriate care, advocacy, chronic illness, crip time

Reflections on advocating for age-appropriate care in B.C.: an intricate dance of crip time and governmental processes

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Advocating for change, no matter the issue, requires that the advocate navigate the expectations and the time constraints of those they advocate for and those they advocate to. For me, a disabled activist advocating¹ for disabled people, this advocacy becomes an intricate dance of many strands, weaving the separate timelines of all the dancers, with the complexities of crip time² and my own disability competing for time alongside the overriding schedule of those with the power to make changes happen. The separate timelines of all of the dances create what I term “temporal dislocations,” where the time of one dancer is out of step with that which is considered the norm. For one dancer time has stood still for them alone, whereas for others, they are not in control of a pace which is at odds with their needs. At times, it feels like there are two different dances being performed at the same time, at different tempos, and with no synchronicity between them. This personal reflection of my advocacy begins with the subjectivity of those with the lived experience of care and moves on to blend this with the objectivity of the political process in the attempt to advocate for lasting systemic change.

Advocating for age-appropriate care has been a priority of the MS Society of Canada since at least 2006. In reports such as *Finding my place* (2006) and *Continuum of care* (2008), the MS Society of Canada makes the case that home care options are often inadequate for those with advanced multiple sclerosis (MS), and that those in need of more advanced care often found no other option than to move into long-term care (LTC) facilities ill-suited for young disabled people. The reports focus on the stories of people with MS, people in their twenties and thirties in LTC facilities with roommates far older than them; procedures that do not allow them to continue to

access the outside world; and limitations to autonomy that work against their physical needs, requiring them to stay in bed far longer than they needed to manage their MS symptoms. I joined the Government Relations Committee of the B.C. and Yukon division of the MS Society in 2015, and of the four priorities³ that were being advocated for at that time, it was the issue of care, and the related injustices, that drew my attention. The MS Society advocated for age-appropriate care for young people with MS younger than the age of 65 who were living in LTC facilities where the average age was 85 (Office of the Senior's Advocate British Columbia, 2018). I felt the personal connection as a disabled woman with a form of MS that was also advancing quickly, knowing that my own situation could become equally tenuous. I felt that I needed to talk to someone with MS who lived in a LTC facility to really understand what life was like as a young person living in such a way. As I was chair of the local MS Society chapter, I reached out to staff and asked if there was someone in my community who would be willing to talk to me. Mary⁴ offered to meet with me. When I first met her, she was 42 and had had MS for 10 years. She had been living in a LTC facility for roughly five years at that point. Before MS, just 10 years prior, she had been a barrel rider in the rodeo.

During my first visit to Mary, I remember thinking how pleasant the facility was. There were murals based on the local history, posters advertising music events set in time gone by, and outside every room there was a small display case with artefacts from the life of the person living in it. Photos, ornaments, trophies, all mementos of a long life, of time spent in the community. However, Mary didn't fit this timeframe. For Mary, her display was based in the present, revealing a life 'cut short'—photos of her teenage son, medals and trophies from her career in the rodeo, photos of her riding her horse, looking the same as she looked now—except that she was riding a power wheelchair instead. It created a temporal shift, a dislocation in time. Her display was from

the present, not from the past. For myself as a disabled woman, this kind of shift had happened before, when the only appropriate fitness programs available to me were for seniors, but nothing was as stark as Mary's situation. Alison Kafer's *Feminist, queer, crip* (2013) gives a thought-provoking discussion of crip time, and the many ways in which time, and the normate expectations of time, impact the lives of disabled people. Kafer talks of shifts in timing and pacing which "lead to departures from 'straight' time, where straight time means a firm delineation between past/present/future" (p. 34). Through this lens, Mary's cabinet represents a present that has now been labelled as past, and her future is beyond anything that could have been expected in 'straight' time.

During my first meeting with her, Mary described her life. Twenty-three hours a day she is alone in her room, except for the people who feed her, wash her, and dress her. A radio station of her choosing plays all day, but with no way for her to switch it off, change channels, or alter the volume, unless someone else does it for her. There is no way for her to do anything independently. The bland food, with no options, is made with seniors in mind. She has a bath once a week—Thursday is her day—and some physiotherapy on Tuesday. Neither of these appointments are by her choice; they are set by an institutional schedule over which she has no control. Other than that, every day is the same, seven days a week. A recent survey by the B.C. Senior's Advocate (Office of the Senior's Advocate, 2017) targeted over 22,000 seniors in LTC facilities in B.C. While participants responded positively about the quality of their facilities, many of the responses that related to their ability to live independent, quality lives gave a more negative view, particularly for bathing, mealtimes, and personal interactions (p. 5). While Mary's experience is the same, the effect on her is exacerbated by her younger age, in comparison to the seniors, and the lack of interactions and activities that are appropriate for someone of her age. Crip time, Kafer (2013)

says, “is an awareness that disabled people might need more time to accomplish something” (p. 26), meaning that “rather than bend disabled bodies and minds to meet the clock, *crip time* bends the clock to meet disabled bodies and minds” (p. 27). However, Mary’s experience, backed by the responses to the Senior’s Advocate survey, is that *crip time* is absent from LTC facilities, and that disabled bodies continue to be bent to meet a schedule that serves no purpose other than the ‘efficiency’ of the facility. Mary is expected to rest, eat, and bathe on a schedule imposed by the facility, rather than one of her own choosing, and this schedule means that her life is devoid of spontaneity.

Those of us with chronic illnesses are often out of step with conventional life. As Wendell (2013) puts it, “We are considered too young to be ill for the rest of our lives, yet we are not expecting cure or recovery” (p. 164), meaning that people like Mary often have no option than to move into a LTC facility that was not designed with their needs in mind. Mary feels that she has no freedom. She can’t leave, because the care attendants aren’t allowed to take her past the front door, and she can’t go out independently, because of her disabilities. She is unable to pay for supports to increase her opportunities to access the world beyond the facility, because her only income is the B.C. disability allowance, of which the facility is required to take 80% to pay for her lodging. If she wants anything other than the institutional shampoo, for example, she has to buy her own, which also means she has to find someone to buy it for her, because the purchase of personal products is not a service offered by the facility. Drugs, vitamins, mobility aids, telephones, food to supplement the bland institutional offerings, clothes—they all have to come out of the roughly \$200⁵ a month she has left of her disability allowance.

When I was first diagnosed with MS, I felt that my life was like the opening credits of the television show “Without a Trace.”⁶ Each week, the team investigated a person who had gone

missing. The show begins with the last place the person was seen, and they fade from the scene as they ‘go missing.’ I have faded out of my career, my social life, and a variety of activities I can no longer do, as I have become too impaired to continue them. As time has passed, I have realized that I have faded into a different life, different activities that are just as fulfilling—perhaps even more so. For Mary, however, while she has faded out of her previous life as a rodeo rider, she has not faded into an equivalent or better experience like I have been able to do. Instead, she describes herself as being left behind, as if life has moved on without her. Kafer (2013) comments that “the present takes on more urgency when the future shrinks” (p. 37), but for Mary, the present is underwhelming and not urgent, and with the combination of the progression of her disease and her immense dissatisfaction with her living conditions, she says she feels she is merely marking time until she dies. Equally, Kafer’s discussion on the “fetishization of longevity” (p. 40) is set against “a culture that continually supports cutting services to disabled poor people and that continues to warehouse disabled people in institutions and nursing homes, two practices that very well may ensure those disabled people do not live long lives” (p. 41). Hence, for people like Mary with progressive illnesses, the quality of life in LTC facilities directly impacts their lifespan. So is that a blessing? These are complex thoughts, all intertwined on a personal level with my own progressing, advanced MS, my current care needs, and planning for my care in the future.

To put Mary’s life into context, it is far from unique. Data I obtained through a Freedom of Information⁷ request from the B.C. Ministry of Health (2017) shows that of the 35,000 residents of LTC facilities, only 1865 are between the ages of 19 and 65, a pattern that Gibson et al. (2012) say is common across Canada. Not only are younger residents isolated by their age, but their physical and emotional characteristics differ significantly from the older residents who make up the vast majority of LTC facility residents. Riazi, Bradshaw, and Playford (2012) and Newland,

Wilke-Tevis, Williams, Rantz, and Petroski (2005) highlight that MS residents are usually at least 20 years younger, more physically disabled, more cognitively able, and with different symptom profiles than the seniors they live with, of which as many as 90% are cognitively impaired and 65% have dementia. Gibson et al. (2012) and Newland et al. (2005) further comment on the lack of research into young disabled people living in LTC facilities, particularly those with MS. People with MS at these advanced stages of the disease that require complex care have specific needs relating to pain, fatigue, and depression. Newland et al. (2005) present an extensive discussion on the “Impact of Pain on Outcomes in Long-Term Care Residents with and without Multiple Sclerosis.” They highlight that these “young, cognitively intact, well-educated” residents with MS were “more physically disabled and had a higher prevalence of pain, pressure ulcers and depression” (p. 1494) on admission than other residents presenting with pain. Complicating this, up to 90% of people with MS present with fatigue as one of their most disabling symptoms (Janardhan & Bakshi, 2002, p. 51). Residents regularly report that they are not able to lie down and get up at times of their choosing. For example, in *Finding my place*, John says that he has fatigue at midday, and wished to go to bed, but he was told by staff that he would have to stay there for the rest of the day (p. 4), an issue he has in common with Mary. Spending time in bed, unable to move, directly contributes to the development of pressure ulcers, so it is no surprise that Newland et al. (2005) say that “residents with MS present a significant challenge to LTC staff” (p. 1496), and that there is a need to educate staff as to the needs of people with MS. The role of depression in residents with MS also needs further examination. A recent report in *The Star* highlighting the rates of depression in LTC residents says that the average rate of depression in LTC facilities in Canada is 23.8% (Boyle, 2015). However, in all people with MS, not just those in LTC facilities, rates are far higher, with Janardhan and Bakshi (2002) reporting that up to 60%

of people with MS have depression. It can be presumed that this rate is even higher in those with MS living in LTC facilities. Newland et al. (2005) report that this depression has multiple origins, from living with a chronic disease, to medication side effects, to brain atrophy from MS itself. Janardhan and Bakshi (2002) go on to say that “[a]ffective disorders, including depression ... may contribute to morbidity” (p. 56), while multiple commentators (Fruehwald et al., 2001, Newland et al., 2005, Riazi et al., 2012, MS Society of Canada) say that depression has a significant impact on the quality of life of people with MS, in a group that already has significantly less quality of life than the general population (Janardhan & Bakshi, 2002, p. 51). Deborah Cross (Goffin, 2017) describes the many activities she tries in order to improve the emotional part of her quality of life, given that the activities planned in the LTC facility are less stimulating than she needs. Like Mary, she says that she tries to make friends with staff who are closer to her age, which is difficult, given that it was reported in B.C. that 49% of all residents say that they “only sometimes, rarely or never have the same care aide on most weekdays,” and that less than half of the staff they see make time for “friendly conversations” (Office of the Senior’s Advocate, 2017, p. 5).

However, Cross also reports that while she tries to make friends with the other residents who are much older than her, she sees them pass away again and again. Given the 15 years she has already been resident in the LTC facility, with the potential for at least 15 more years, this is particularly traumatic. Hence, placing young people with MS in LTC facilities contributes to advancing their physical decline by forcing them to adhere to structures and schedules that are directly opposed to the needs of their MS symptoms, and contributes to their mental and emotional decline by creating conditions that fail to adequately stimulate them mentally or provide age-appropriate social interactions, while also failing to address the high rate of depression in people with MS.

I left our first visit furious. This was no way for someone to live. Mary's life did indeed reflect Kafer's assertion of warehoused people, trapped by a lack of services to poor disabled people. Prince (2009) contends that disabled people are converted into citizens with "spoiled identities" because of the pressure of a neoliberal society that values individualism and marginalizes disabled people by underfunding the services they rely on. For Mary, the absence goes a step further. With no ways to interact with life beyond the walls of the facility, Mary is invisible, and I felt the need to advocate for her, and people like her. Talking to Mary had made the MS Society's priority real to me.

However, advocating means more than understanding the issue. It means getting to those that can make change happen, and demonstrating that your issue demands their attention above the myriad of issues they have in front of them. My local MLAs (Members of the Legislative Assembly in B.C.) were all members of the governing party at this point, and as such they controlled the finances and the policies that could make substantive change in the lives of people like Mary. I asked them to visit Mary with me, with the hope of making the issue real to them too, and they agreed. During the visit, Mary and I spoke passionately about Mary's life in the facility. Her final words to the MLAs, when asked if there was anything she wanted to tell them about her life in the facility, were simply "it sucks!" I've returned to those words many times in our subsequent conversations as a way to bring us back to the reality of her life and those in similar circumstances, a life far away from budgets and government priorities.

There's another temporal dislocation at play here. There are gaps between the reality of Mary's daily life and the extent to which those in power are prepared to make change. Compromise is certainly not the right term, because there are no more "compromises" that those receiving age-inappropriate care can give. The reality is that they continue to live in substandard conditions, with

the hope that changes will be implemented that make life creep slowly towards being acceptable. These changes might not even happen within their lifetime, given the precarious nature of the health of people living in LTC facilities, and the slow changes that have to be negotiated, added to provincial policy, budgeted, and finally staffed and implemented. With the local MLAs, I talked about local solutions, about creating a wing within a LTC facility that was for people of a similar age, and the challenges that that might bring, or creating smaller group home environments designed for a younger population. Any talk of the effects of institutionalization will have to come later.

And we also talked about the facts. At least five percent of LTC facilities do not meet the B.C. government's mandated target of 3.36 hours per day of care for each resident (Office of the Seniors Advocate of BC, 2018)—and 3.36 hours represents the average care per day, not the care hours each resident can expect to receive. In a LTC facility with residents with high needs, many residents can receive much less care than this in a day. There are struggles to retain staff, leading to less than optimal care; high turnover means that new staff are always learning about their clients and their needs. These areas were highlighted in *An action plan to strengthen home and community care for seniors* (British Columbia Ministry of Health, 2017) , and while it has ambitious plans to improve all sectors of care for seniors, the care of disabled people in general, and particularly young disabled people, is missing. In the case of Mary's LTC facility for over 100 people, one person was 55 years old, and the rest were 65 and older. Other than with the care assistants, who changed frequently and were there to work, not to socialize, Mary has no interactions with anyone close to her own age. As the Senior Advocate's report reminds us, the staffing of care assistants is inconsistent, making it difficult to even continue a conversation from one day to the next with the only people she sees who are close to her age.

With the issue firmly planted in my mind, and conversations started with local MLAs, I had to make some tough decisions about my personal role in this advocacy. My own struggle with crimp time and severe fatigue from my MS keep me in bed for around 16 hours a day, with all afternoon in bed every day. A trip to visit Mary required me to be physically capable of the trip, and took at least three hours, with two hours of travel time and a one-hour visit, which required me to find a driver as well as to use some of my valuable care assistant hours, and often left me so exhausted that more hours in bed were needed to recover; as Kafer says, “the present moment must be measured against the moment to come” (p. 39). My personal life began to weave another strand. As much as I wanted to visit Mary, to hopefully give her strength through sisterhood, the reality of my husband’s cancer diagnosis, and his receiving chemotherapy every two weeks, gained precedence. LTC facilities are large-scale Petri dishes of germs and viruses, and I simply couldn’t risk him getting ill from something ‘extra’ I brought home from a visit. I chose to withdraw from face-to-face visits with Mary and concentrate on areas where my advocacy could be more effective and conducted from my bedside iPad. To maintain contact with Mary, I send emails to be read to her, a bizarre type of one-way communication where I write through a staff member at the LTC facility but never hear how the emails are received by Mary. Coincidentally, I am also writing to the mother of a former student, Khalida, a Palestinian parliamentarian who has been imprisoned for a year by the Israeli military on “administrative detention,” an imprisonment without charges and without end.⁸ Equally, there is no mechanism for me to hear if these letters are received or for her to reply. Each letter to Khalida and each email to Mary reminds me of the carceral qualities of institutional life with an advanced chronic disease, a life separate from an outside world that moves on without you.

Creating change as an advocate requires me to be present in ways that are difficult within the bounds of *crip time*—to attend meetings in the afternoon when my severe fatigue means I am in bed, for example, and to react spontaneously to issues and opportunities as they arise, which is rarely in step with the fluctuations of my life on *crip time*. Wendell (2013) talks of those of us with chronic disease as being “unhealthy disabled,” where our ability to participate fluctuates along with our illness, as opposed to “healthy disabled,” referring to those disabled people whose disability is mostly stable. In the context of activism, Wendell says that “[f]luctuating abilities and limitations can make people with chronic illnesses seem like unreliable activists, given the ways that political activity in both disability and feminist movements are structured. On a bad day of physical or mental illness, we may be unable to attend a meeting or workshop, to write a letter, to answer the phone, or to respond to e-mail” (p. 167). I make no apologies for this appearance of unreliability, as it would be disingenuous to advocate for change for people with MS without demonstrating my own embodied limitations. However, instead I recognize that *crip time* is in control, that this is a teachable moment for those I advocate to, and that “*crip time* is flex time not just expanded but exploded” (Kafer, 2013, p. 27).

My attention turned to advocacy at a provincial level upon returning to my MLAs with a sharpened focus on my advocacy. Each time I have met with politicians, they have asked: “What is it going to cost?” Chappell, Dlott, Hollander, Miller and McWilliam (2004) reported on Health Canada research into the cost of care, focusing on care costs in Victoria and Winnipeg. They found that, no matter the complexity of the care, long-term residential care costs more than home care—and in some cases, considerably more. On top of that, B.C. offers a type of independent care called Choices in Supports for Independent Living (CSIL) (British Columbia Ministry of Health, 2017). Recently, the B.C. Care Providers Association (2017) reported that home support (where a rotating

cast of carers comes to one's home just to perform the functions of care) costs \$44 an hour, whereas CSIL costs \$31. Caring for people in their own homes and putting them in control of that care not only has the potential for better quality of life, it's cheaper.

One of the biggest challenges in fighting for systemic change within the political system is that the change takes much longer to implement than the cycle of each parliament. It takes a long time to get attention directed to a specific issue by politicians, to agree on actions in what are often bi-partisan committees, to get those actions added to budgets, and to have governmental staff assigned. In a four-year provincial parliamentary cycle, the first year is spent getting priorities in place, and the last year is spent preparing for the election, and in the months nearing the election, work becomes embargoed to prevent influencing it. The two cycles—the slow pace of the systemic change cycle and the regular, almost metronomic pace of the parliamentary cycle—do not work together. This is another temporal dislocation, but one entirely within the political arena.

However, recently, some synchronicity happened. On May 7, 2018, I went to the B.C. legislature as part of the MS Society Government Relations team, lobbying for four priorities, including age-appropriate care. One of the meetings I was asked to attend, at a time I was physically able to go, was with the Opposition Health Critic. The first piece of synchronicity was the timing. Often, a meeting with the opposition is not particularly useful, but this week was different as the Estimates Committee meetings were taking place. The second piece of synchronicity was that six weeks earlier, my MLA, Norm Letnick, was appointed as Opposition Health Critic and my previous meetings with him, and our visit to Mary, meant that we had already built a rapport, despite very different political beliefs. As a result, our meeting was more than an introduction to the issue, and we were able to have a more substantive discussion on the changes we would like to take place. MLA Letnick offered the opportunity for me to write the preamble to

a question on one of our concerns that he would present to the Health Minister in the Estimates Committee. Hansard shows (Legislative Assembly of British Columbia, 2018) that he presented the issue and the research by Chappell et al. (2005) to the minister, and that a thorough discussion took place between the two of them, allowing both sides to get their opinions on the record. Broadly speaking, they agree with our concerns and even with some of the solutions. Words are cheap, and actions cost money, but these words are now on the record. Given that the balance of power in B.C. is precarious right now, with one by-election enough to overturn the government, as an advocate, the power of the words being on the record is that either party can be held to account to act on the promises of their words—and I will remind them of their words as priorities and people change within the political landscape.

This dance is not over. Its intricacy continues, as time continues to be stretched, paused, and re-examined. Parliament is now in summer recess, so my attention turns to local approaches and changes that can be made within existing structures. For me, the personal toll of this work has caught up, and crimp time is definitely in control. Time passes slowly, and items stay on my to-do list for longer than I would wish. The more I look at the dance, the more strands are apparent. There is the complexity of the LTC facility as an institution, with staffing, budgets and policy constraints that distill into a level of care that is simply inappropriate for the young people with MS that live in LTC facilities. Then there is the political machine, with its inner workings that set and implement policy, overseen by the apparatus of Parliament and its own cycle, which appear to be at odds with each other. Most importantly, however, is the effect that these separate dances have on real people like Mary, dancing solo to a beat that they do not control. As for me, the advocate, I weave in-between these separate dances as best I can, looking for similar steps, looking to link dance partners wherever I can. It seems to me a new dance is needed, a dance that is centred on

the needs of people like Mary, where all of the dancers come together, unified, to act in the best interests of these young people with MS. For me there are many new dances that need to be written with all of these partners—politicians, governmental staff, LTC facility staff, medical personnel—all led by the young people with MS for whom the change is most relevant. What might the first dance be? Perhaps a chronic disease protocol in LTC facilities, where young people with MS receive care that is driven by their needs, and not the institution. Perhaps a protocol that allows care based on the needs of their symptoms, not institutional practices that suit most people but not them—a protocol that reacts to their social and emotional needs, rather than expecting them to be content to fit into the life of an 85-year-old, a protocol for them, led by them, that allows them to live with the dignity we all deserve.

Notes

- 1 I see myself as an activist and an advocate simultaneously, and I echo the thoughts of Eva Lewis, a teen activist and advocate, in my use of the terms. See <https://theblog.adobe.com/whats-difference-advocate-activist-mislabeling/>
- 2 For me, ‘crip time’ represents all the occasions that disabled bodies take an alternative schedule from that of the ‘norm,’ whether through taking extra time to complete tasks, or as bodies that sometimes require time to stretch and at other times to stand still, or as lives lived ‘out of step’ with the normate expectation of the passage of a lifetime, etc. Time is a fluid concept, and no more so than for disabled people.
- 3 The other three priorities were income, timely access to drugs, and disability legislation, both in B.C. and nationally.
- 4 A pseudonym, to protect privacy.
- 5 When I initially met with Mary, the disability allowance was \$983 a month, leaving Mary with \$196 for herself each month.
- 6 This episode of “Without a Trace” was chosen at random from YouTube. After the first minute, the young male leaves the kitchen, turns a corner, and fades away, as this is the last time his family sees him. See <https://youtu.be/PTTu5MOVdCs>
- 7 The Freedom of Information request has the identifier HTH-2018-81161, from the Government of B.C.
- 8 Links to Khalida Jarrar’s situation from both a Palestinian and an Israeli perspective: <http://samidoun.net/2018/06/reports-khalida-jarrars-administrative-detention-extended-keep-up-the-campaign-for-freedom/> (Palestinian) <https://www.timesofisrael.com/israel-extends-administrative-detention-of-palestinian-lawmaker/> (Israeli)

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