<u>Challenges of Seeking Shelter for Disabled Persons</u>

By Rachel Culver

You have asked me to write about how I have personally been affected by a critical illness in my family and what resources may be required to provide more assistance during this time.

My family and I have been personally affected by Multiple Sclerosis (MS). It is an incurable disease of the central nervous system that can affect the brain, spinal cord and optic nerves. My nana was diagnosed with this debilitating disease about 30 years ago, and it has aggressively affected her mobility along with many other things. In addition to her diagnosis of MS, she also had to overcome the tragic loss of her husband. A drunk driver killed him on his way home from work, which left my nana as a single mom with three children to raise, ages 7, 5, and 2. My dad was seven years old when he lost his father. Dealing with the disease and the loss of her husband has impacted most of the decisions and changes in her life.

Consequentially, there were many, many hardships along the way for her. Especially, financial, emotional and physical, but I wanted to focus on how the community could help with some of the obstacles we encountered during the countless physical changes in her life.

Because of her disease, she was forced to move out of her home a lot sooner than she would have liked. This was an extremely stressful time, not only for her but for

my family too. The modifications to her home that were needed to aid the disease started off slowly with equipment such as a bath bar, bed poll, raised toilet seat, cane, walker then came an elevator, ramp and wheelchair. Eventually her disabilities outgrew her home and we faced one of the biggest challenges - trying to find appropriate housing for her in Oakville. Our focus was to keep her as independent as possible, for as long as possible.

The colossal dilemma we faced, once her disease progressed, was the lack of resources and available information about programs and trades and services within the Oakville community. My nana was extremely blessed with respect to my immediate family and our family support, but not everyone facing a disability or aging process has the same support network and piece of mind.

Our community needs to be more resourceful in this area. This is where, I believe, the Oakville Milton and District Real Estate Board could aid in such transitions to help lower the stress levels for families facing this situation or similar situations. If the Real Estate Board in Oakville could introduce a "trading services" program or "one stop shop" pamphlet and website it would certainly aid in keeping these people in our community, independent for a longer period of time and help in continuing to make them feel "normal" within the community. Therefore, this program would need to be designed to aid seniors, disabled home owners and parents of disabled children acquire mounds of available resources at their fingertips.

Not every disease or disability leaves you with the same struggles or issues and I can only speak on behalf of MS, as this is the disease that I am aware of personally. I believe most of the basic needs are the same though. The service the Real Estate Board could provide could be Internet based, but a large majority of seniors are not computer savvy and prefer something in paper form. I respect the "green community" as this is extremely important to my generation, and me, but I also respect the generation that my nana comes from and their need for written resources. None of my grandparents own a cell phone let alone a computer. If the Real Estate Board were to reach out to the community in a pamphlet form or even provide seminars and information sessions on where to go to get the help you need and the community services that are available. This would be a huge comfort to families. Having an abundance of information in one location, well-advertised and easy to find is a well over-due service. My nana would happily sit in a community room and listen to someone speak about all the extended services Oakville provides. I know there are services out there; we just can't find them all. When you are faced with a disability you just don't have the same energy to hunt for these services.

There are the obvious services that are needed (i.e. medical, handyman, contractors etc.) but what about the services that don't come to mind straight away - volunteers these services are essential to function as a disabled person. A volunteer database or section in a pamphlet is a service that is extremely important in the community. The assistance with day-to-day tasks as simple as grocery shopping, changing a light bulb or even going for a walk is an enormous relief especially when you know its

available to you.

The outside community is not fully functional for wheelchairs even though we'd like to think it is. Curb ramps providing access to streets and sidewalks are a basic town service. As the sidewalks are not expected to be perfect, some are rough, uneven and with dangerously sloping grounds, make it extremely dangerous and unsafe for people wheelchairs especially if they are venturing out alone. Due to needed repairs in the community, the sidewalks are sometimes blocked off. This can create havoc for a wheelchair, as wheelchairs are not a completely stable vehicle. Even though they are equipped with stability bars (tip bars), they can still tip. We have experienced this personally. On an uneven curb my nana's wheelchair fell over and even though she was belted in, it was a horrible trauma to witness. Imagine if she were alone when this happened. Having a volunteer beside you is a precious commodity for any disabled person, and being able to find this service is even more of a precious commodity. People can only take advantage of services that they are aware if available to them.

Another much needed service that goes over-looked, is hair cutting and pedicures. Finding professionals that will travel to your place of residence is difficult to find yet these services are a must. It is extremely difficult for some, and impossible for others to cut their own toenails. It might sound silly, but when you have MS you may not be able to reach your toes, so cutting your toenails doesn't get done unless

you have help. Just knowing that this service is available feels like Christmas. It's a simple service yet can make you fresh and clean.

In our experience in Oakville, we have never been able to find one place or even several places that you can go to that's full of resources and ideas for disable persons. It would be incredible for the public to have access to something like this.

There are all kinds of advertising for "first time home buyers" but what about "last time home buyers", or "independent living". This service needs to provide housing information for wheelchair accessible homes but I mean "real" wheelchair accessible homes. Sometimes it's easier to move than live through renovations. Information with respect to rental properties, senior residences, assisted living residences and long-term care residences would provide you with many options from one place. With lots of options, you don't feel like the door is closing so fast.

We need to get the information to the public that there are art classes, music lessons, reading groups, bus trips, etc. that are available for the disabled and seniors. This makes a great daytrip for them, but it also provides a much-needed break for a caregiver or spouse. You can't take advantage of the services if you are unaware of them.

A real estate agent is the first person you call when you decide to sell your home.

That's because of their knowledge, expertise and experience. Why not capture the

other side of the market for the physically challenged.

My nana has progressed through all of these different stages of independence and loss of independence and is now residing at Post Inn Village in Oakville. We are extremely grateful for her care and all the extra-curricular activities they provide. We just wish we could have known about all these services much earlier and therefore would have made her journey a little less stressful along the way.

Bibliography

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