

## Introducing this blogpost

As a young adult, it can be difficult to acknowledge your need for 24/7 care and assistance. I use the term “24/7” loosely here – I, the author of this post, as a 26 years-old woman with Spinal Muscular Atrophy Type II, only need care and assistance at certain points during the day and night, such as morning and night routines, cooking, showering, etc. While these needs can differ drastically for other individuals with similar neuromuscular conditions, depending on a myriad of factors such as diagnostic severity, age, comorbidities, environment, etc., most of us *will* need to be supported by a caregiver or a team of caregivers for the entirety of our lives.

In this blog post, I aim to merely describe the role of caregivers in my life and go on to recognise a scary but indubitable reality – that I cannot exist and/or function properly without my caregiver’s support. However, I do not seek to find solutions, nor do I propose any systemic change in my immediate or societal surroundings, but I aim to put context to an area we are identifying as a priority for research based on our ongoing scoping activity. This is a no-nonsense post for those interested in improving, disrupting and reshaping the current social care structures for those with neuromuscular conditions. More specifically, I ask myself and you, the reader: what societal structures and systems do we need to develop and build so that young adults with neuromuscular conditions have consistent care, well-paid caregivers, and safe ones as well? In other words, how do we ensure caregiving security for those whose lives literally depend on it?

## Independence

With the almost constant need for care, physical independence is out of the picture. My muscles have been progressively decaying since minute one, and I have never consciously experienced the ability to stand or walk. I have my manual wheelchair (electric ones cost an arm and leg) to give me a sense of mobility and independence, and I have my caregivers, friends or solicited (sometimes even unsolicited) strangers to push me around to further enhance the said sense of independence. Thus, I can only function “normally” in my wheelchair, yet I cannot push it by myself, the muscle decay has done its job well in my hands as well as my legs. The decay effects apply to most areas of my life, and I need help with the following: transferring myself from the bed to my wheelchair, or from my wheelchair to the toilet chair, cooking (unless the kitchen is fully accessible), cleaning my house very well or in entirety (unless the house is fully accessible), showering, wiping, brushing or doing my hair very well, cutting my toenails, waxing, you get it. And there you have it – if my environment isn’t fully accessible (it never is) and my carers aren’t *around and able*, I am unable to function. In fact, I am only as physically independent as my carers enable me to be.

## Good caregivers, great caregivers

A good caregiver will enable me to be physically independent, but a great caregiver will do wonders for my mental health. In the best case scenarios, my caregivers are not only my enablers – most of them are also my friends, confidantes, and supporters, and my caregiving is a team effort. Sometimes though, I wish I didn’t rely so heavily on others’ support, and I feel like I am “too much”, or that my needs could inconvenience my caregiver. This is unfortunately a common experience among individuals with similar care needs, and one that I have been determined to explore and change for the past years (shoutout to my therapist <3). Sure, I don’t always feel like this, and it mostly depends on the relationship I have with my caregiver. For example, I once had a caregiver who would help me dress and cook for me, but they wouldn’t necessarily be empathetic or attuned

to my needs. In these cases, I remind myself that my needs are real and valid and that I need to own them, even if I feel like a burden. A great caregiver, however, will likely never make me feel like I am too much - in fact, they celebrate the little “annoyances” of my disease. They support me physically and emotionally and advocate on my behalf. Great caregivers are also my friends (as with my friends who are sometimes acting as my caregivers), and in the best of cases, our relationships are less transactional and more of a friend-helps-friend dynamic.

## **My condition isn't disabling, but the lack of proper care is**

As a researcher with lived experience of disability, I recently learned: it's the things that are not easy to talk about, that is of utmost importance to be transparent about. Things like being unable to exist and/or function without external support – that's the sort of realisation that never really sinks in, for me at least. I never really fully acknowledge it, only for something to make my carer unavailable for bits or longer periods and to make me realise, I've never fully integrated one simple thing: if my carer can't help me go wee, I won't be able to go wee. In time, I have developed the ability to plan and organise with almost military-grade precision to ensure a smooth caregiving process and day-by-day activities. But some things are out of my control: if my carer gets sick, and I don't have a second carer to replace them for a while, it can go hours, if not days of not eating (properly or at all), going to the toilet, or getting in and out of bed. Indeed, it is one of the most humbling experiences when I only have one caregiver, and they can't show up, or when they fall sick and are unable to care for me anymore. Depending and fully relying on someone else's support is a scary thing, and it often feels more paralysing than my condition itself.

The certainty is, my caregiver and I share a sacred bond, and there is an ecosystem that we both exist in, and although we support each other, I cannot exist and/or function without their support. And although I have learned to sit with the discomfort of not having total or much control over most aspects of my life, there is one (thing?) that terrifies me to the core and puts me on the verge of panic attacks: what do I do if my caregiver is unavailable or unable to care for me?

## **Last, but not least**

In this blog post, I have sought to give context and meaning to an area we, a group of 6 working collectively to scope social care research priorities for young adults with neuromuscular conditions have identified as such. How can we ensure that those living with neuromuscular conditions never get left without the lifeline that are their caregivers? Surely, we need to think thoroughly about caregiving security, i.e., the development and re-development of the societal structures and systems needed to ensure consistent care, well-paid caregivers and safe ones for young adults living with neuromuscular conditions. Providing answers to these questions through research is truly (!) paramount.