

# Advocating for the Self

The happy medium in being professional, productive, neurodiverse, and living with disabilities

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## Welcome

My name is [Amanda Rose Horsman](#). I am 35 years old, with a five-year-old, two cats, a dog, a busy life, and I am neurodiverse and I was born with disabilities. Over time they have accumulated to:

- [Blind in right eye \(prosthetic\)](#)
- [Deaf in left ear \(hearing aid to help with sound not language\)](#)
- [Fibromyalgia](#)
- [Endometriosis](#)
- [Autism](#)

I was an Anglophone “smart kid” that went through French Immersion, living in rural New Brunswick going on to university in bigger Canadian cities. I am a Master of Library and Information Studies and working on my doctorate. I grew up in an entrepreneurial family involved in land, sand and soil, and sewing. I now live by the quiet seaside near my hometown while I build my business as [The unLibrarian](#).

## Human Curiosity

I would get asked all the time, “[Do you mind me asking.. But why are your eyes two different colours?](#)” I would reply, “[Not at all! Questions are a sign of intelligence](#)”.

People will always be curious to know how or why. Some would call it morbid curiosity and others are genuine, then there are others who feel that is what they are expected to do.

I simply assume: They truly want to know and learn but not necessarily the whole life story. There is happy medium.

I also see it as an opportunity to inform them of tricks that I use to adapt or that they can do if they encounter another person like me – either way it is a teacher/learner experience.

## Self-Advocacy

Self-advocacy is necessary when living with disabilities if you wish to be accepted as a functional member of society.

People are not mind readers and most people do not think of accommodations until necessary.

[Would you know about the accommodations you need if it was not for your disability?](#)

It is better to create an open dialogue than assume accommodations are impossible to attain. You may be surprised.

## Awkward or Assertive

There is a fine line between coming off as awkward or assertive when it comes to disclosing personal information. For some reasons, disabilities are considered to be in the personal information domain rather than public disclosure. It does make sense, especially with fear of stigma and the “suck it up” culture. However, it is a personal choice of each person to make in disclosing information. **I believe there is always a safe way to disclose information. If it is not safe enough, that is a whole other discussion.** If you choose to disclose, it helps to practice/script it in your head, so you appear assertive. How you present your oddities directly influences the attitude your audience takes on in regard to your disability: they look for cues from you.

## Shunned

If you start feeling shunned at work, first check in with yourself to make sure you are not feeling your own shame or imposter syndrome. Shame comes from feeling inadequate or feeling that something important is in jeopardy. Imposter syndrome comes along when the natural instinct to compare to other people and one another hits full force. **Stay grounded with patience and kindness with yourself and others.** Each person has their path. Remember, your attitude regarding your own disabilities guides others in how to treat you and disabilities too. After that check in, if you are truly being shunned, that is a human rights violation. Find an ombudsman, a disability expert in HR, talk with your union, call the legal line for your EAP or call your jurisdictional human rights commission.

## Protecting Yourself as Vulnerable Population

Socioeconomically, a person with disabilities is a member of vulnerable population with low income/employment, low health indexes, and many barriers. Thankfully, our natural senses just know whether it is safe to disclose personal information. **Listen to your senses and reflect on why it might not be safe.** Could be conversations that you have heard in the workplace playing in your mind. Experiences you have heard rumoured other people having in disclosing disability information. Could also be fear from a past experience of your own.

If you are ever asked to participate in a study, read all the documents in detail. If you have any questions, always ask as it is their ethical responsibility to ensure that you understand to what you are consenting participation.

It is up to you who you disclose your disability, but you must be clear about who is allowed to know and in what capacity. I dream of a world where disability is simply seen as another natural human adaptation to be a functional member of society. Until then, it is a good idea to consider how you wish to self-advocate and for what you are advocating.

## Presenting yourself

I recommend that you look up on your employer's intranet for information on who is the proper person to speak with to ensure proper handling of the information, especially for accommodations. It's advisable to draft an accommodations plan on your own to present to your employer.

Often times, once faced with a person in who discloses disability information, employers are at a loss of what to do with the information.

As an advocate, it is your role to actively guide your audience along as well. They will be grateful and willing to work with you, as long as your requests are reasonable.

Look up your local community and government agencies as they are available to employers to assist those with disabilities.

## Choosing to wait

I will admit that I have waited to disclose my disabilities and simply made my own little adjustments that I am able to do without anyone really noticing for a long time until it would eventually come up in conversation. *Often times I am met with, "wow, really!"*. Being able to be participating member of functional society despite challenges is recognized as being an incredible thing by most people. It's humbling.

I do not want someone to pity me or view me any differently. That said, *the words of encouragement and little gestures of support go a long way to feeling accepted in your environment*, like talking to me on my right because I am deaf in my left. The good certainly outweighs the bad in disclosing, in the majority of circumstances.

## Living Well with Disabilities

Disability can happen at anytime from birth through to death in a person's lifespan. I was born into this world. So trust me when I say that, *I truly believe it is possible to live well and simply with simple changes and active communication strategies*. Therefore, if you choose to disclose, here is a little exercise to develop your own 30s Advocacy Speech.

## 30s Advocacy Speech

You often have 30 seconds to make your impression, the length of an elevator ride they say. Keep in mind who you are talking to and how your disabilities could impact them on the job. Say what you need to succinctly and directly  
Write out your 30 second advocacy speech

### 30s Advocacy Speech Elements

- Your name
- The most general way to describe your disabilities (I am deafblind, autistic, and have fibromyalgia, chronic pain).
- 1-3 specifics that the other person must know to ensure proper communication (ie. I may need to look at your face to hear your words)

### Describing Your Disabilities

The most general way to describe your disabilities (I am deafblind, autistic, and have fibromyalgia, chronic pain).

If mental health issues, you may or may not feel safe enough disclosing in fear of too many questions or assumptions. Talk with someone you trust to help you find the right words.

Disclose one at a time or in a logical grouping. Otherwise, it is possible for a person to lose track and forget.

If you have multiple disabilities, disclose in small chunks in applicable situations. Anytime safety is at play, it is best to disclose beforehand.

Disclosure can happen as a little reminder in daily tasks too.

### Your Audience

Keep in mind who you are talking to and how your disabilities could impact them on the job.

Who you are telling about your disabilities may change what you present and how you go about it. Who determines what kind of information you are presenting and why.

If you are requiring an accommodation from human resources, that would be differently delivered than to those with whom you work closely in day-to-day business.

The mindset you present sets the tone. Unless prejudices or processes already exist in their mind, then your audience will simply take your cue.

### 30S Advocacy Speech Coworker Example

In order to simplify for any setting, I came up with an advocacy speech for co-workers when I entered the workforce when I was fifteen in the fast food industry:

“Hey, just so you know: if I do not hear you or see you, it is not because I am ignoring you. If you are on my right side, it is because I am blind in that eye. If you are on my left side, it is because I cannot hear you.”

This speech worked well in retail and other close quarter jobs, where we are often handing things to one another and working on close quarters. Also helped if I did not notice a customer because of a lot of noise or it was really busy, my colleagues were able to help me out naturally.

*Caveat: not everyone remembers and that is okay. People have a lot on their minds often times and never get mad or resentful that someone does not remember; it takes time to establish new patterns. Gentle situational reminders can be a remedy.*

### 30S Advocacy Speech Human Resources Example

When I started working in office and government buildings, I would have to request to have lighting removed as I am sensitive to fluorescent lighting: they trigger nasty migraines.

First order was finding out who had to trigger the accommodation request.

Second was scheduling a meeting with the person.

Third, making the simple request: “Could you please remove the fluorescent lighting from directly above my desk? The rest does not bother me.” I did not want the lesser lighting to impact my colleagues and so was very specific as to which lights.

Finally, follow up with the person you met within 24 hours after meeting them to thank them for their time and to specify in writing what actions were determined in the meeting by both parties.

If an assessment is offered, always accept. *However, still request that the accommodation happen while waiting for the assessment.*

### Timing and Consistency

It is important for you to take responsibility for keeping track of the meetings and requests. Do your due diligence without being overwhelming. It often takes weeks between emails.

Consistency comes with having scripts. For example, whenever I am working in a team of people, I always use my 30s Advocacy Speech, with a laugh and a smile. In a team, it is important they know my disabilities for safety reasons.

Really, the sooner these conversations happen, the better. As a student, first of term conversation with the Professor goes a long way as they will be aware of your needs. It saves you from a lot of complaining and negative experiences over time.

## Contextualizing Accommodations

Say what you need to succinctly and directly with an idea of a plan.

For example, I knew a long time ago that working in most office buildings would not be possible due to migraines. Once I figured out that I could request them to remove lighting, I found more job opportunities.

I also have a history of panic attacks in hot, stuffy buildings, so I cannot work in buildings like that regularly. So I go for walks outdoors regularly so being inside such buildings does not become overwhelming.

There are always work arounds. Often, it is simple things. It requires open communication with your supervisor and some ingenuity. You can talk with others with disabilities by looking up various disability associations.

Accommodations such as time and space are trickier ones given the traditional contexts of work that are billed by the hour, in predetermined spaces. However, the world is changing.

## Examples of Accommodations

Ailment	Accommodations
Migraines	Lighting adjustments Fresh Air
Chronic Pain	Regular walking, stretching and breaks Fresh Air Awareness of regular doctor appointments Ergonomic Assessment
Hard of Hearing	Ask to see people's faces clearly Alert them you may not hear them
Visual Impairments	Verbal explanations of tasks Alert them as to what you may not see
Autism	Flexible Schedule Quiet Spaces Lighting adjustments Fresh Air
Endometriosis	Adjusted schedule or workload Work from home to manage symptoms
Mobility Issues	Ergonomic Assessment

## Final Words

Humans are naturally curious beings. Most people are learning to navigate the world, much like yourself. You just have added challenges that can be overcome with resourcefulness. Be assertive about your disabilities and clear on your accommodations.

If you do not know what kind of accommodations are available, then start your conversation right there with, “Hello, I have disabilities and wondering if you could help me find ways to improve my productivity through helpful accommodations.”

A nice side effect of self-advocacy is that it helps you build your community and generates a better understanding by your coworkers, friends, families, and sometimes even strangers.

Thank you for joining me today! I truly hope this helps you to live well with your disabilities.

From Amanda, The unLibrarian