NATIONAL ME/FM ACTION NETWORK
SINCE 1993

Quest Newsletter

www.mefmaction.com | Quest 146, Summer 2025 | mefminfo@mefmaction.com

CRPD Review Update

In Quest 144 (November 2024), we shared with you the submission that the National ME/FM Action Network made to the United Nations Committee reviewing Canada's implementation of the Convention on the Rights of Persons with Disabilities (CRPD). These reviews happen from time to time. Canada ratified the CRPD in 2010. The first review report was released in 2017. The second was released in March 2025. The next review cycle is expected to start around 2032.

The UN Committee notes on its website that the concept of disability in the CRPD is different from the concept of disability that was used prior to the CRPD. Generally speaking, the groups that were considered disabled before the CRPD were those with hearing, vision, mobility and intellectual difficulties. Disability programs were designed around them.

We noted in our submission that ME and FM were not traditionally considered to be disabling, that our people fit the CRPD concept of disability, and that it is extremely important for our people that the new concept be applied.

We identified five initiatives that we consider to be priorities. The first is familiarizing government officials with the new concept of disability. The next four focus on the need to ensure that the design of the health, statistics, income security and education systems consider ME and FM and not just traditional disabilities.

The UN Committee hearing took place in Geneva on the afternoon of March 10 and the morning of March 11, 2025, six hours in total. These hearings were webcast live. Recordings are available on the UN website. Some disability advocates went to Geneva to watch the formal

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hearings in person. These advocates were given several minutes each to raise issues with the committee in a private session on the morning of March 10. We were unable to go.

In the formal hearing, the chair of the UN committee sat at the head table and kept the meeting on schedule. The two chief delegates for Canada also sat at the head table. One was a high level public servant from Employment and Social Development Canada (ESDC). The other was from Global Affairs Canada, this being an international function. The Canadian delegation had twenty members in total from the federal public service and from the public services of Saskatchewan, Manitoba and Quebec. The federal government delegates came from ESDC and Global Affairs, plus the departments of Canadian Heritage; Indigenous Services; Statistics Canada; Justice; and Immigration, Refugees and Citizenship. There was no delegate representing Health. This was surprising, since health and disability are intertwined.

The meeting started with opening statements by the head of the Canadian delegation and the head of the Canadian Human Rights Commission. Then the meeting was turned over to several members of the UN Committee who had been given responsibility for leading detailed discussions around Canada's implementation of the specific articles of the CRPD. When the committee member asked a question, the ESDC delegate at the head table would answer it or redirect the question to another Canadian delegate. The delegates had prepared statements that were written to show government in the best light. The UN Committee members diplomatically expressed frustration several times that the delegates were not getting to the heart of issues. The other members of the UN Committee were called upon from time to time to raise questions or make observations. The meeting ended with closing statements by the head of the Canadian delegation and the head of the Canadian Human Rights Commission.

The report of the UN Committee was released on March 25, 2025.

What we wanted to see in the report is recognition that Canada is still using a pre-CRPD model of disability and needs to update its thinking. We also mention the need for different levels of government to work together.

Paragraph 7 of the report was one of the three topics given special notice. (The other two relate to medical assistance in dying and affordability). Paragraph 7 observed the following:

- *Significant disparities in the implementation of the Convention across jurisdictions and branches of government...resulting in the highly unequal enjoyment of the rights of persons with disabilities;*
- *The rudimentary incorporation of the Convention into domestic law, and its limited normative significance as a mere interpretative tool;*
- *The lack of close consultation and active involvement of persons with disabilities through their representative organizations...*

This paragraph can and should be interpreted to mean that Canada has not updated its social system to reflect the principles it committed to when ratifying the CRPD, that this lack of updating has a disproportionate impact on some groups, that governments in Canada are not working together, and that Canada is not paying attention to the whole disability community.

Disability is a complex concept. Quest 106 (2016) focused on disability. We repeat two pages from that newsletter on pages 8-9 of this newsletter. Those pages mention the CPP-Disability Guide and the Functional Capacity Scale. We would like to remind readers that the CPP-Disability Guide is available in English and French on our website. It is a valuable guide when completing CPP-D applications, but also when describing disability in general. The Functional Capacity Scale is included in that Guide. Simplistically, the scale runs from 0 to 10, with 0 describing someone completely bedbound and 10 describing someone healthy and very active.

Parliament Hill Events

Events have moved quickly on Parliament Hill since Justin Trudeau announced his resignation as Prime Minister in January 2025. The Liberal party chose Mark Carney to take his place. A general election was then called. The Liberal party won the most seats but were just short of a majority. With a majority, the next election is likely four years away. Without a majority, the next election could be much sooner.

Prime Minister Carney has appointed cabinet ministers who are responsible for various departments. He also appointed secretaries of state who are the focal points for various themes - seniors, nature, combatting crime, etc.

Canada has a new minister of health, Marjorie Michel. Her academic background is in social and organizational psychology. She has had various jobs on Parliament Hill and for the Liberal Party, so she is not a newcomer to politics. She just won the riding in Montreal that Justin Trudeau represented from 2008 to 2025.

Justin Trudeau wrote separate letters for each of his cabinet ministers outlining expectations for each of them. Mark Carney has written a single letter for the cabinet ministers outlining seven government priorities.

1. Establishing a new economic and security relationship with the United States and strengthening our collaboration with reliable trading partners and allies around the world.
2. Building one Canadian economy by removing barriers to interprovincial trade and identifying and expediting nation-building projects that will connect and transform our country.
3. Bringing down costs for Canadians and helping them to get ahead.
4. Making housing more affordable by unleashing the power of public-private cooperation, catalysing a modern housing industry, and creating new careers in the skilled trades.
5. Protecting Canadian sovereignty and keeping Canadians safe by strengthening the Canadian Armed Forces, securing our borders, and reinforcing law enforcement.
6. Attracting the best talent in the world to help build our economy, while returning our overall immigration rates to sustainable levels.
7. Spending less on government operations so that Canadians can invest more in the people and businesses that will build the strongest economy in the G7.

The mandate letter focuses more on economic and sovereignty issues than on health and social issues. There are, however, openings for social issues under priority 2 (nation building projects, which could include coordinating and strengthening the health and disability systems), priority 3 (helping Canadians get ahead) and priority 7 (investing more in people).

It should also be noted that the Prime Minister created a cabinet committee named "Quality of Life and Well-Being" which is to "consider ways to improve community safety and health, advance reconciliation with Indigenous Peoples, and augment the overall quality of life and well-being of Canadians". The members of this committee include, among others, the ministers of health, jobs and families, women, and justice.

The Prime Minister did not name a cabinet minister or a secretary of state with responsibility for disabilities. He did, however, appoint a cabinet minister for women and gender equality and secretaries of state for seniors and for children and youth. Why was disability left out?

Over the last decade, there have been several major disability initiatives, notably

- the Accessible Canada Act (which focuses on identifying, removing, and preventing barriers in various areas, including employment, the built environment, and information and communication technologies),
- the Disability Inclusion Action Plan (which focuses on financial security, employment, and accessible communities), and
- the Canada Disability Benefit (which will be payments to low-income working-aged Canadians who qualify for the Disability Tax Credit).

It is possible that the federal government considers its disability work to be done. If so, it should be pointed out that these three projects focus on the priorities of the traditional disability community. They assume that the non-traditional disability communities share those priorities and do not have other priorities. As was pointed out in our UN submission, the ME/FM community has issues with public service awareness and with the design of the health, statistics, income security and education systems. These concerns are not addressed in the three initiatives. Neither was the issue of inter-jurisdictional cooperation.

We would like to see the appointment of someone with responsibility for disabilities, but that person must have a strong and specific mandate to address the needs of non-traditional disabilities, not just those of traditional disabilities. Whether or not someone is appointed, we will continue to press for change.

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The Honourable Marjorie Michel, Minister of Health

Winnipeg Free Press writes about ME

On May 26, 2025, the Winnipeg Free press carried an article featuring three Manitobans dealing with ME. There was also an interview with a Manitoba physician and a history of the relationship between the medical system and ME. Congratulations to the Manitoba ME Support Group for getting this story into print, and thank you to AV Kitching who was the author of the article.

CareNow Ontario's Awareness Day Message

On May 12, International Awareness Day, we received this message from CareNow Ontario, formerly called The Myalgic Encephalomyelitis Association of Ontario. MEAO had been around since 1991. Working closely with the Environmental Health Clinic at Women's College Hospital in downtown Toronto, MEAO found itself involved in ME, FM and MCS issues and changed its name to reflect its broader scope. The name comes from the title of the 2018 Ontario Task Force Report on Environmental Health. The organization had a major role in having the task force established and in supporting the work of the task force. As you will see, they are continuing to work for better services for people with ME, FM and/or MCS in Ontario.

CareNow ONTARIO

CareNow Ontario is an organization representing and supporting the medical conditions of **Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)**, **Fibromyalgia (FM)** and **Environmental Sensitivities/Multiple Chemical Sensitivity (ES/MCS)**

Message from CareNow Ontario On International Awareness Day May 12th, 2025

Dear Members and Friends of CareNow Ontario:

Today, on International Awareness Day (May 12) for people living with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), Fibromyalgia (FM) and Environmental Sensitivities/Multiple Chemical Sensitivity (ES/MCS), we stand together to honour every person living with these disabling and life altering conditions.

This day is a reminder of the strength and resilience within the people living with these conditions, their families and supporters - and the urgent need for more diagnostic testing, effective treatment, research and policy change.

Too many have endured disbelief from health care providers, dismissal from society and years of isolation. These conditions are not rare, but they have been treated as invisible.

As you know CareNow Ontario works to create awareness and drive action for the development of a health and social services system that addresses the needs of those who have chronic and complex environmentally linked illnesses. Specifically, CareNow Ontario seeks to improve access to services for those who have ME/CFS, FM and ES/MCS.

In the absence of an established system of care, nearly one million people in Ontario live with these intrusive and often debilitating conditions knowing that their physicians lack the diagnostic tools they need to create and support effective treatment plans. CareNow Ontario advocates to make real and effective change happen at both the government and community level so that people have essential and affordable pathways to medical and social care.

Minister of Health Announces more funding for primary care providers

Minister of Health, Sylvia Jones and the Ontario Government continues to ignore these conditions and all requests for policy change and support. However, the Government of Ontario is making progress on making more family practitioners available and supported by interprofessional teams.

In February 2025, the Ontario Government announced that they would invest $1.8 billion to connect 2 million more people in Ontario to a family physician or nurse practitioner by 2029. May 2nd was the deadline to respond to the first round of proposals. The goal is to connect 300,000 by September 2025. Dr Jane Philpott's Primary Care Action Team is leading this work.

The goal is to support existing and new primary care providers with interprofessional team members so that a physician can refer you to the supports you need such as dietitian, social worker – thereby allowing the primary care provider to focus more closely on the medical challenges you face.

While we know many family physicians do not get trained or are knowledgeable about ME/CFS, FM or MCS/ES, the first step is that each of you have access to a primary care provider.

The need to educate primary care providers is one reason CareNow Ontario is adjusting its focus to include more education of primary care providers. See below some of our actions.

Education on ME/CFS, FM and POTS.

The Centre for Effective Practice (CEP) has released Clinical tools for family physicians and nurse practitioners for people living with ME/CFS, FM and POTS. However, the CEP did not support the wide distribution of these clinical tools so unless someone directs their physician to these guideless it is unlikely that they are aware of them.

CareNow Ontario is working with Dr Farah Tabassum, physician with the Environmental Health Clinic and Kathleen Dennis, a well informed person living with ME to do education with family practices throughout Ontario.

As good news, Dr Tabassum and Dr Kathleen Walsh from the Environmental Health Clinic were accepted to present a workshop at the Family Medicine Forum in Winnipeg in November 2025. This conference sponsored by the College of Family Medicine of Canada, is considered the premier family medicine conference in Canada.

CareNow Otario provided a small sum of financial support for the development of the workshop that can be used at the conference and with other family practices. It is hoped that interest from this conference will spread and Dr Tabassum will do more workshops in Ontario.

Multiple Chemical Sensitivities and Environmental Sensitivity.

As you also know the CEP did not develop a clinical tool for people living with MCS/ES citing a lack of consistent available research. No more update is available at this time on whether the CEP plans to develop a tool for MCS.

The Environmental Health Association of Canada (EHAC/EHAQ) sponsored a two-day conference called "Resilience International Conference – on Multiple Chemical Sensitivity Building Accessibility Together". The two days were full of the latest research, studies and actions we can do together. CareNow Ontario was one of the sponsoring partners. EHAC/EHAQ will be releasing the various sessions in modules over the next period of time. Watch your inbox for more information on these modules and how CareNow Ontario will partner with the EHAC to advance solutions for MCS.

A resolution is also going forward to the Alliance for Healthier Communities at their Annual General Membership meeting in June 2025. This resolution is sponsored by South Riverdale CHC and LAMP CHC calling on all members centres including all Community Health Centres, Nurse Practitioner Led Clinics to be educated about MCS/ES so that they can identify and support MCS clients and support them in having safer care if they need to go to hospital or other health facilities. We are cautiously optimistic that this resolution will pass.

Once passed the two CHCs will sponsor webinars with clinicians and other interprofessional team members to begin the education process with the goal that CHCs will begin to take on more clients with MCS/ES and advocate for safer care. Varda Burstyn an expert in MCS with the support of CareNow Ontario will facilitate these workshops.

Closing

While this work seems like just small steps forward, we want you to know, we support you and we see you. CareNow Ontario will never stop fighting for a system of care and supports for all people living with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), Fibromyalgia (FM) and Environmental Sensitivities/Multiple Chemical Sensitivity (ES/MCS).

CareNow Ontario
Board of Directors

FM Study Update

In Quest 142 (Summer 2024), we told you that Armand Lupien planned to bicycle across Canada to raise awareness of FM and to raise funds for FM research. In Quest 143 (Fall 2024), we let you know that Armand had completed his trip and had raised $12,303 which was given to us. We also told you that we were passing the money to Dr Alain Moreau, a researcher at the University of Montreal and Sainte-Justine Hospital. He had outlined a pilot study. “Research had found that a protein called MFAP3 (Microfibrils-Associated Protein 3) may play a key role in controlling pain, and its levels are lower in people with FM. This pilot study will explore how MFAP3 is involved in pain, how its levels are regulated in patients with FM, and how it interacts with a serotonin receptor (HTR3a), with the goal of developing it as a diagnostic tool or treatment target.” That pilot study has now been completed. Here is a message from Dr Moreau and his team:

“Our research has uncovered a promising new lead in understanding and treating fibromyalgia (FM)-a condition that causes chronic pain, fatigue, and sleep problems for millions. By studying saliva DNA in a family affected by FM across three generations, we found a specific change in a gene called MFAP3 that appears to influence how the body manages pain and stress. We then identified three distinct patient groups based on how active this gene is, with one group showing more severe symptoms like poor stamina and severe insomnia. These patients also had unique brain responses to physical exertion, pointing to a deeper biological difference. Most excitingly, we discovered that the MFAP3 protein can block signals related to pain and inflammation by interacting with known pain-related receptors. This breakthrough not only gives us a new biological marker to better diagnose and classify FM but also opens the door to developing more targeted and effective treatments. With your support, we’re closer than ever to bringing real relief to people living with this debilitating condition.”

Analyzing Disability

Reprinted from Quest 106, 2016

The United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD) defines disability as follows: **"*Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.*"**

Impairments. Barriers. Participation. What do these words mean?

You have undoubtedly heard of the ICD, the World Health Organization's (WHO) International Classification of Diseases. The WHO has a companion document which has a much lower profile, the International Classification of Functioning, Disability and Health, referred to as the ICF. The ICF, approved by the WHO in 2001, is based on this diagram.

Functioning refers to all body functions, activities and participation.

Body functions and structures can have **impairments**.

Activities are tasks or actions executed by the individual. Examples are watching, listening, speaking, grasping, lifting, walking, driving, cooking, cleaning, and dressing. Activities can be **limited**.

Participation is involvement in a life situation such as going to school, working, being part of a family or being part of a social group. Participation can be **restricted**.

Disability is an umbrella term for body function impairments, activity limitations and participation restrictions.

Environmental factors and **personal factors** can be facilitators or barriers.

The ICF provides codes for various body structures, body functions, activities and participation and environmental factors. Health conditions are coded in the ICD. There is no coding structure for personal factors.

Here is a simple case study applying the model. A knee is a body structure which is used for mobility, a body function. Jody has a tear of her cartilage which causes a lack of stability in her knee (impairment of body function). This affects her ability to walk, kneel, climb and carry objects (activity limitations). This inability affects Jody's ability to play with grandchildren or do housework (participation restrictions). She has crutches, does physiotherapy and has access to pain medications (environmental facilitators) but she lives in a home with stairs, her medications have side effects, and the sidewalk outside is covered in ice (environmental barriers). She is conscientious about doing her physiotherapy exercises (personal facilitator).

When ME/CFS or FM starts, people will notice symptoms like pain, fatigue and brain fog (impairments of body functions). Occasional illness is normal and society accommodates it. When participation restrictions become excessive (e.g. not being able to keep up with work/school, family and social life), the situation moves to a different dimension.

For help in articulating ME/FM impairments, activity limitations and participation restrictions in a work context, see Chapter 4 and the worksheets in the CPP-D Applications and Appeals Guide. This document lists symptoms [impairments] of ME/CFS and FM, activities that are part of normal living, and requirements for participating in the workplace. You can identify where problems exist and then draw linkages between the impairments, the activities limitations and participation restrictions.

Environmental Factors:

- Products and technology (drugs, assistive devices, building design...)
- Natural environment and human-made changes to the environment (climate, air quality, light, sound...)
- Support and relationships (family, friends, acquaintances, professionals, pets...)
- Attitudes
  - family,
  - friends,
  - care providers,
  - health professionals,
  - societal attitudes,
  - social norms, practices and ideologies
- Services, systems and policies

There are three problems with the ICF model as far as ME/CFS and FM are concerned.

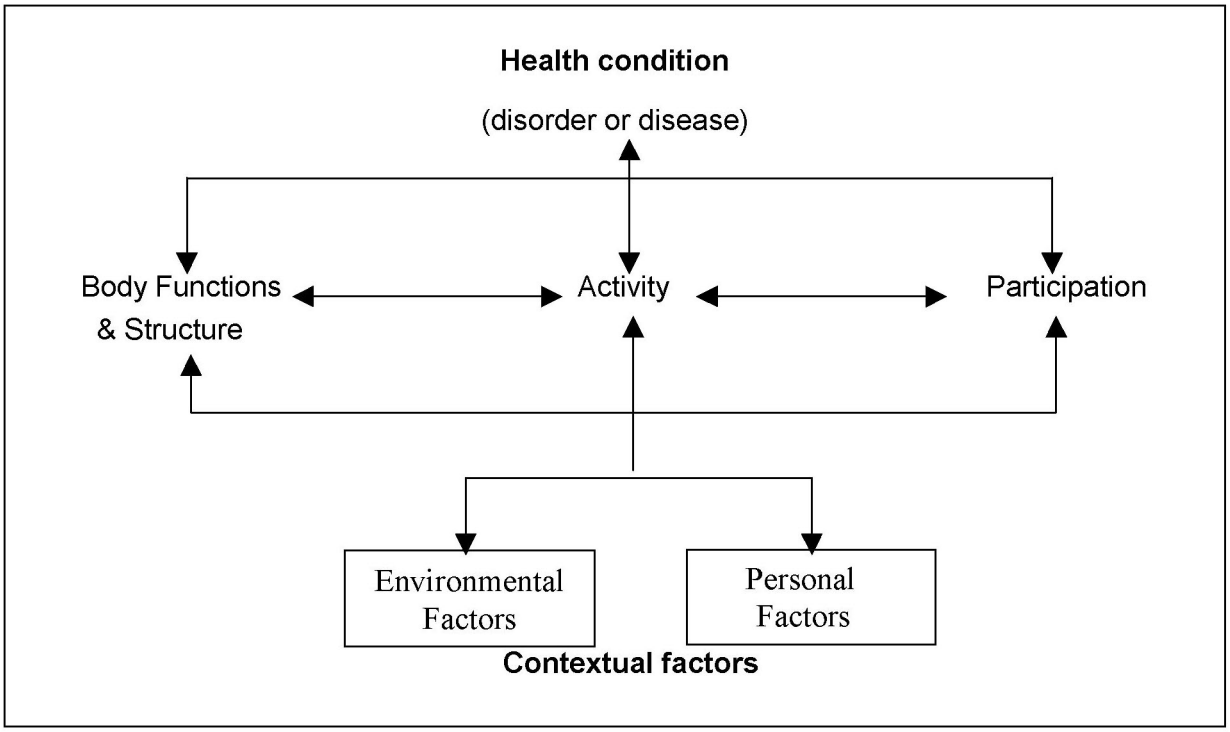
* The activity limitations that come with ME/CFS and FM are widespread. It isn't any one particular activity that is the problem, it is the across-the-board reduction in activities. Thus, looking at each individual activity in the ICF may fail to convey the big picture. In contrast to the ICF, the Functional Capacity Scale looks at the cumulative effects of ME/CFS and FM. The ICF would do well to build the Functional Capacity Scale into its model.

* The mechanisms through which ME/CFS and FM cause activity limitations and participation restrictions have not been explained though it is known that a number of body systems are involved. How do disability programs react to this uncertainty? There are several approaches:

- by treating the uncertainty of causation as irrelevant and focusing on the impact. Elections Saskatchewan simply says that if a person can't get to the voting place, the voting place will come to the person. The reason the person cannot get out to vote does not matter.
- by pretending that ME/CFS and FM don't exist. We see this with the Royal College of Physicians and Surgeons of Canada which does not have a specialty for ME/FM, with the Canadian Institutes of Health Research which funds almost no ME/FM research, and with the Ontario special education system which provides services for recognized conditions but ignores the needs of ME/FM students.
- by treating ME/FM applicants with suspicion. This was brought to light in the UK survey on home care where a third of respondents felt that ME/CFS was not being accepted as genuine. We noted it in the instructions to adjudicators in the CPP-Disability program.

In tying disability so closely to body structure, the ICF is leaving unexplained illnesses very vulnerable to being ignored or being disbelieved.

* The ICF model shows personal factors as having an impact on body functions, activities and participation. However, the ICF provides little guidance on the relationship. This leaves people very vulnerable to being blamed for their situation especially in the case of unexplained illnesses.



What I Wish I'd Known the Day Dream and Disability Collided

By Katie D

from: *https://themighty.com/topic/disability/tips-for-coping-after-a-life-changing-disability/?event*

February 6, 2015 was the day my dream career and lifelong, but recently diagnosed disability collided. Extremely long and incredibly painful story short, in the months that followed, my life collapsed. Combine that with existing anxiety and depression, and I fell apart. Here's what I wish someone had told me that day.

1. You are not alone. Everyone tells you to "find your passion and follow your dreams." No one tells you what to do when they get ripped away from you due to a disability. If you believe commonly quoted phrases like "nothing's impossible," this isn't even supposed to happen. But it does, and no one talks about it. You aren't the only one to have this happen; it only feels that way.

2. It's not your fault. I was convinced that I had done something wrong and this was my punishment. No matter how many times I was told it wasn't, I couldn't believe that. Your disability is not your fault; the loss of the life you imagined isn't, either.

3. Prepare for an emotional roller coaster. You are about to experience every intensity level of every emotion imaginable. This is where I realized that society's philosophy of "choosing happiness" didn't work for me. I eventually came to the conclusion that peace is a process. Your choice isn't whether or what you feel, but whether or not you work through it.

4. You may question everything, from your worth and abilities, to what you believe and how the world works, the list of questions bombarding your mind is probably endless. Unfortunately, you may never get answers. Even if you did, they probably wouldn't satisfy you.

5. Health and coping are key. You may be tempted to drown your sorrows and quiet your constantly spiraling thoughts in substances, junk food, endless hours of mindless TV, or 24/7 use of the internet. Try to maintain as normal and healthy a life and routine as possible. It's perfectly OK to indulge and find comfort, but letting healthy habits slip too much will make it harder to recover. Find a healthy coping mechanism early, and rely on it often.

6. Appropriate support is essential. When friends and loved ones rally around you, lean on them, but maintain appropriate expectations. There's no shame in seeking professional help. As much as others can offer support, your well-being is ultimately your responsibility. Also, remember to appreciate and treat your support system with respect. You're going through hell, but that doesn't give you the right to mistreat those who choose to go through it with you.

7. There is no timeline. Most people mean well, but they can be less than helpful at times. Whether it's expectations to get a job immediately, advice to "just get over it," pressure to hang out all the time to distract you, clichés meant to help you "look on the bright side," or well-intentioned reminders of how hard what you lost was, their pressure on top of everything else you're dealing with can be overwhelming. This is your journey, no one else's. As long as you're moving forward, you're doing just fine.

8. Avoid major decisions. When you feel like your life is falling apart, it's easy to frantically think through every available option for putting it back together. The problem is that desperate decisions often lead to regrets. If a decision or action is unavoidable, consult with those who have your best interests at heart. Otherwise, let the dust settle before taking any major steps.

9. Approach social media with caution. Posting to social media when you're upset can be a bad idea. You may also find your pages filled with reminders of life before your condition, so it suddenly feel like a constant slap in the face. There might also be questions or criticism from those who don't know the whole story. Remember, you always have the option to take a break, and you don't owe anyone an explanation.

10. Don't burn bridges. If I've learned anything from this, it's that life can be completely unpredictable. Don't ruin your own, or someone else's reputation on impulse. Your worst enemy today may be the best person to help you in 10 years. Maintain appropriate contact with your professional and/or academic connections. You never know what's coming in the future.

11. You will move forward. I know you may not believe me and this feels like the end of the world, but I promise it's not. You may be a different person after this, and your life won't look like what you expected, but you will find a way forward.

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