



*“Innovative Approaches to
Supporting Workers with Chronic,
Episodic Conditions”*

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Four questions will be answered

- What does it mean to live with an episodic health condition?
- What solutions do people with a chronic disease use in order to facilitate and manage their participation in work?
- How do we improve conditions in the workplace?
- What support do people with chronic disease need in the workplace?

What are episodic health conditions

- Anxiety
- Depression
- Chronic pain
- Arthritis
- Migraines
- Crohn's disease and ulcerative colitis
- Multiple Sclerosis
- Asthma
- Post Traumatic Stress Disorder
- Diabetes
- Bi-Polar Disorder
- Epilepsy
- HIV/Aids
- Lupus
- Cancer
- COPD
- Parkinsons
- Menieres Disease
- CIDP
- Hepatitis C

What do all the episodic health conditions have in common?

- Unpredictability
- Uncertainty



“Never being able to relax and take care of myself because of work. I cannot afford to not work. So, I am in pain all of the time mentally and physically. It doesn't leave much for my family at the end of the day.” (Female, 25-34 years, anxiety, arthritis, bi-polar disorder, depression, epilepsy, PTSD)

Acceptance and coping

“But you need to focus on what you can do, rather than on what you can’t do. That is my motto in life.” [Participant 18]

- Individuals indicated that they needed help learning to accept the chronic condition.
- Health professionals could help by acknowledging the chronic condition.
- Important not to struggle with the chronic condition alone.

“Unpredictability of symptoms; feeling like I am letting my co-workers / students down because of fatigue; feeling frustrated because I want to do more with my job, and outside of work; disappointed because this is not the career direction I planned to stay in” (Female, 35-44 years, multiple sclerosis, fatigue)

Insight into abilities and limitations

- “It’s mainly about finding your own limits. The saying goes “once bitten, twice shy” – well ... I think I’ve been bitten at least ten times already ...” [Participant 11]
- The workplace can provide support in assisting the individual in identifying their abilities and limitations.
- Access to a modified job bank for episodic periods when the workers abilities fluctuate.
- Access to rehabilitation professionals who can evaluate the abilities and limitations of an individual. Quantify the workers’ maximum functional ability when experiencing a flare-up.

- “I never know when there will be a flare up. My job requires me to be available on a phone for 8 hours a day which doesn't always work for me since a flare up can keep me in the restroom for a long time & suddenly. Despite taking meds, seeing specialist and eating right I still have flare ups & it makes it hard to be social, work, eat out. I don't like to be caught in crowds. Worry about having access to a bathroom.” (Female, 35-44 years, Crohn's/colitis)

Setting boundaries

“Whenever I work too long, my supervisor says, ‘Time to go home!’. Then she simply says: ‘Since you’ve worked half an hour more today, tomorrow you can leave half an hour earlier.’ So now she’s really the one who sets my limits.” [Participant 10]

- Workplaces can offer a safe environment for workers to be able to voice their boundaries.
- Encourage workers to use tools such as alarms and other resources to respect their abilities and limitations.
- Train supervisors to understand and respect the working boundaries of the individual.

“My survey shows that my current work is very accommodating (which it is) which is why I can work there. However, it is not what I want to be doing and does not make use of my education and training. The last jobs that did make use of my education and training (university setting scientific research and university sessional instruction) were very unaccommodating.” (Female, 35-44 years, migraines, irritable bowel syndrome)

Disclosure

“So, being open allows you to let other people see what you can or can’t manage and what your needs are.” [Participant 1]

- Individuals have expressed the need for empathy, interest and understanding from their employer after they have disclosed their chronic illness.
- Without a workplace culture that supports individuals with episodic conditions it is unlikely that the individual will choose to disclose.
- Considering the implementation of a disclosure policy may go a long way to creating the element of trust needed to support the individual.

Disclosure

The fear

- Being fired
- Focus on disability not ability
- Losing health care benefits
- Opportunities for promotion limited
- Supervisor will not be supportive
- Treated differently, viewed differently

The solution

- Demonstrate willingness to create an inclusive workplace
- Observation of other employees being successful
- Disability included in diversity statement
- Inclusive recruiting and hiring
- Promotion materials that support

“I get extremely anxious when someone needs to confront me about any issues. I am taking mindfulness classes to deal with this. The pain I have often means I walk with a limp or am unable to do stairs or pick up my grandson while I care for him. I sometimes get bad enough that I am unable to dress myself (socks and bra the most difficult) open jars or even soda bottles. Some days I can't join recreational things I have always enjoyed such as dancing, rock climbing, or even taking a long walk etc.” (Female, 55-64 years, arthritis, chronic pain, lupus and PTSD)

Managing energy levels

“But your body automatically starts operating at half capacity. And as soon as you notice this, you have to accept that you are no longer capable of functioning at full capacity. Fortunately, in my line of work, this usually doesn’t mean getting less work done. It only means that people need to work more independently and show me the results. In this way, I can take a short nap and return after an hour to take a look at what they have done with the scenes.” [Participant 13]

- Individuals are seeking training in goal setting to support their energy levels.
- Workplaces that considered flexibility in the break schedule, task assignments
- Flexibility in the working hours
- Flexibility in the location of work

“The unpredictability of flare ups; dealing with triggers in the workplace (i.e. meetings with men alone behind closed doors).” (Female, 35-44 years, anxiety, chronic pain, depression, PTSD)

Asking for help

“Can you take care of the printing work for a bit, while I take over some of your tasks during that time?” Simply keep negotiating over the tasks to be done and, with a bit of help from your colleagues, you can manage.” [Participant 4]

- Individuals are seeking support with exploring solutions and addressing problems, with their input.
- Clear communication of what resources and assistance are available.
- Skills training on how to effectively ask for help.

“Not knowing when I'll have a flare up; occasional intense pain; restaurants; stores, etc. not allowing the use of their bathrooms. Finding a toilet!!”
(Female, 55-64 years, anxiety, and Crohn's/colitis)

Mutual agreements

“During my performance appraisal interview, I agreed with my supervisor to make Friday my regular day off and to work at home on Tuesdays. So now it’s down on paper and everyone knows about it.” [Participant 2]

- Assistance from health professionals to document the chronic illness so that the employer can understand in preparation for negotiating a work agreement.
- Documentation of process and communication when a flare-up occurs, understanding that advance notice is not likely to happen, and duration of the flare-up may not be known.

“My income meets my basic needs, but not the additional expenses caused by my disability. The extended health benefits I receive are appropriate for the average worker, but not someone with complex and ongoing health needs. Chronic pain and fatigue caused by my condition makes commuting a challenge, and means that I ought to work reduced hours. However, if I do that, I won't be able to afford rent.” (Female, 25-34 years, asthma, chronic pain, PTSD and neuromyelitis optica)

Autonomy of work

“If a deadline is set for Friday, for me it automatically shifts to the preceding Tuesday or Wednesday, so that if I have a bad day, I can still finish it on the Wednesday or Thursday.” [Participant 3]

- Autonomy to work from home
- Autonomy to select their tasks and plan around their limitations imposed by the chronic episode
- Autonomy to set their work hours

Adaptation to the work environment

“I notice that there are many targeted solutions available, such as a specific course or a particular possibility. Whereas it should be the other way around – they should listen to you and ask you what you need, what kind of help you require. Asking the question is part of the solution.” [Participant 11]

- Collaborating with health professionals to identify appropriate accommodations
- Offer financial support for assistive devices and workplace adaptations

<https://askjan.org/articles/9to5.cfm>

What does the Canadian landscape look like?

With respect to disclosure respondents who are in non-precarious jobs have the highest rate of disclosure of all their health conditions to their present/previous employer – 59%

Respondents were asked if their co-workers are/were aware of their episodic health condition(s). Among the 447 respondents who answered the question and who had a non-precarious job, only 7% reported that their co-workers are unaware of their health conditions.

Workplace scorecard

- Of the 447 respondents who are employed in non-precarious jobs and who answered the questions on workplace accommodation, 26% reported that they needed no job accommodation and 4% did not answer the question. Among the remaining 313 respondents,
 - 31% got everything that they asked for;
 - 33% got some of what they asked for;
 - 26% needed accommodation but did not ask their employer;
 - 10% asked but did not get the accommodation.

How do we
improve?

Increased awareness

Increased income support

Improved health coverage

Improved conditions in the labour market

Improved conditions in the workplace

Your workplace homework!

Increase awareness



Improve conditions in the
workplace

Increase awareness

Strive

Strive to be an employer of choice because you understand and support your employees.

Be

Be a workplace that offers resources and opportunities to fully understand what it is like to live with a chronic episodic illness.

Train

Train your supervisors and educate your employees on how to understand and respect individuals living with chronic episodic illness.

Improve

Improve leave policies to accommodate intermittent work capacity

https://askjan.org/toolkit/The-JAN-Workplace-Accommodation-Toolkit.cfm?csSearch=2457039_1

Increase

Increase awareness of the nature and extent of “soft” accommodations required to support persons with episodic health conditions

<https://askjan.org/publications/index.cfm>

Develop

Develop guidelines concerning disclosure

<https://link.springer.com/article/10.1007/s10672-013-9227-9>

Improve conditions in the workplace

References

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<https://askjan.org/publications/index.cfm>