



## ONLINE CHRONIC ILLNESS COMMUNITIES & RESOURCES

### Disclaimer

The external resources are provided for informational purposes only and does not reflect an endorsement of specific practitioners whether or not they are affiliated to the Complex Chronic Disease Program (CCDP). The CCDP does not stand to benefit from community resources or external referrals, and choosing or refraining from access to any services outside of the CCDP, will not affect your care and treatment within the program.

### ME & FM Society of BC

<https://www.mefm.bc.ca/>

The Society works to educate, raise awareness, advocate for and provide support to the ME and FM community in BC. They have twice a month peer-led social support groups for people living with ME & FM, as well as a monthly group for Allies and Loved Ones. The Society also has a phone support line, online forum, and as well as information and videos.

### CFIDS Self-Help

<https://www.cfselfhelp.org/>

In addition to being an excellent, evidence-based self-help resource, this website features stories from people who have ME/CFS or FM. They have a large online library of resources and offer free and low cost courses for friends/family members and those living with ME/CFS.

### #ME Action

<https://www.meaction.net>

This is a grassroots international organization with different chapters around the world. They provide advocacy, resources, support and information to people living with ME, caregivers, healthcare providers, allies and the public. They have a comprehensive website with numerous resources, and organize advocacy and political awareness campaigns and activities (many through social media). The site has also recently launched a podcast: <https://www.meaction.net/chronically-complex-meaction-podcast/>

### Phoenix Rising: ME/CFS Community Forum

<https://forums.phoenixrising.me>

Phoenix Rising is one of the largest online discussion forums on the web for people with ME/CFS. There are many different forum topics, ranging from Living with ME/CFS to Symptoms and Advocacy and many other threads.

### Facebook:

<http://www.facebook.com>

Search for chronic pain/FM/CFS support groups. Please note that “CCDP Facebook Groups” have no affiliation with the CCDP or PHSA. There are many peer support facebook groups.

### The Mighty

[themighty.com](http://themighty.com)

The Mighty is a digital health community created to empower and connect people facing health challenges and disabilities. You can read stories from others, contribute your story, as well as connect with others on their digital platform.

### Instagram

There is a thriving chronic illness community on Instagram. If you decide to post about your experiences, use hashtags so that others can find and comment on your posts. The sky is the limit with hashtags – some examples to start with are #chronicfatigue, #myalgicencephalomyelitis, #Fibromyalgia, #chronicpain, #chronicillness, #spoons.

Chronic Illness ‘Grams:

[Kaia | she/her \(@thewillowswork\) • Instagram photos and videos](#)

[Chronic Love Club \(@chronicloveclub\) • Instagram photos and videos](#)

[Bev - Healthcare, Chronic Illness & Disability \(@unwellunlimitedly\) • Instagram photos and videos](#)

### Cheryl Crow

<https://www.youtube.com/channel/UCDEZnSHMkC5FJ6enOwHsRKg>

[https://www.instagram.com/arthritis\\_life\\_cheryl/](https://www.instagram.com/arthritis_life_cheryl/)

<https://twitter.com/realcc>

[https://www.facebook.com/ArthritisLifeCheryl?modal=admin\\_todo\\_tour](https://www.facebook.com/ArthritisLifeCheryl?modal=admin_todo_tour)

Cheryl is an (OT) occupational therapist who lives with rheumatoid arthritis and other complex chronic conditions. She is very active on social media and shares her personal and professional stories as an OT, a mother, and person living with chronic, invisible illnesses. Cheryl shares her “life hacks” and general education in a fun, easy to understand and often humorous ways.

### **Reddit**

Reddit is composed of “subreddits” – smaller communities that are public. While these run the gamut from toxic to supportive, small to enormous, there are some very support subreddits that may be helpful. Things to remember – for most subreddits, what you post is publicly accessible, you can withhold identifying information from you account when you sign up, it is a good idea to read the guidelines for a subreddit before posting – they are different from subreddit to subreddit, it is also a good idea to scan recent posts and comments to get a sense of the community – how supportive it is, etc.

Reddit.com/r/cfs

Reddit.com/r/Fibromyalgia

Reddit.com/r/Chronicpain

Reddit.com/r/Chronicillness

Reddit.com/r/Spoonie

### **Dr Ric Arseneau**

<https://drricarseneau.ca/>

Physician who offers MSP covered groups on living with ME or FM, Long Covid, shame & trauma, and hosts webinars and lectures on topics related to complex chronic illness. Also facilitates private pay groups on neuroplasticity.

### **Dr. Eleanor Stein**

<https://www.eleanorsteinmd.ca/>

Psychiatrist specializing in ME, FM, Long Covid and Environmental Sensitivities. Has a free science and news blog, some videos, as well as private pay online courses and webinars.

### **My Cuppa Jo: Blog/Website**

<https://mycuppajo.substack.com/>

Joletta Bolten is a person living with chronic pain and health conditions. She is also an advocate, speaker and author. Her blog talks about her personal experiences and making sense of pain through a blend of stories and pain science. She aims to bridge the gap between patients and health professionals.

### **Dr Andrea Furlan YouTube Channel**

<https://www.youtube.com/c/DrAndreaFurlan/videos>

Dr Andrea is a pain specialist in Toronto, Canada. Her YouTube channel has short videos and posts about chronic pain conditions, treatments and prevention. Content is varied and includes information about specific health conditions, movement/stretching, tips for communicating with physicians, dietary support etc.