



**ME|FM Society of BC**  
Myalgic Encephalomyelitis & Fibromyalgia

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# PHONE LINES MANUAL

**ME | FM SOCIETY OF BC**

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## About the Support Line

The ME|FM Society of BC Support Line service is free and confidential. We are funded by membership fees and donations.

We are not an emergency service.

## The Type of Support We Offer

The ME|FM Society of BC will operate a confidential telephone support service for people with ME or FM, family members and professionals by providing information, listening and emotional support.

The Support Line does not provide formal counselling.

The Support Line is not an emergency or crisis line.

The ME|FM Support Line can:

- provide information about services and supports for ME or FM patients in their community
- listen, offer support and provide strategies to help patients or friends/families of patients manage their illness
- provide basic education about the illnesses and resources where callers can learn more

We can provide current information for callers about:

- Services
- Support Groups
- Medical Practitioners and Specialists
- Helpful Resources

**We do not diagnose people or provide medical advice.** While you can discuss treatment options with callers, make it clear that:

- we are not qualified to provide medical advice;
- that some treatments that work for one person often won't work for another;
- callers need to use their judgement regarding treatment options; and
- they also need to consult qualified health practitioners regarding treatment programs.

**We do inform people of the nature of ME and FM illnesses** such as common symptoms and various treatment options.

**We do not subscribe to/or promote any theory regarding the cause(s) or cures for these illnesses.** Our lines should not be used to promote any particular theory regarding the cause or



origin of these diseases. There are many theories about this subject and some interesting research but we do not, at this point, endorse any particular theory regarding the cause/origin/cure for these illnesses.

**Volunteers may not use the phone lines to promote/sell any products/services.**

**We do not provide professional legal or advocacy advice** although we can offer suggestions from others and refer to our own experiences. We can provide information on advocacy resources that are available in the community and provide contact with an advocate if requested.

### **SUPPORT LINE OVERALL WORKFLOW**

If a Support Line Volunteer has questions or concerns at any time during their shift, they should EMAIL the Volunteer Coordinator at [info@mefm.bc.ca](mailto:info@mefm.bc.ca) and we will get back to them as soon as possible.

If there is an emergency, the volunteer should call 911 and refer the caller to them, then send an email about the situation to the Volunteer Coordinator at [info@mefm.bc.ca](mailto:info@mefm.bc.ca).

### **Volunteer Objectives:**

Key Objectives to reach for each call:

- Provide a kind and compassionate ear and build trust and a sense of alliance with the caller.
- Resolve or refer the caller's issue.
- Provide the caller with additional resources that may be appropriate for their situation.
- Gather information about the caller (particularly name and email address) so we can continue to communicate with them as needed, or to follow up.
- Offer membership as well as subscription to our e-mail lists that will allow them to remain connected to the ME|FM community in BC.

Volunteers are to return calls and emails within 48h, including follow-up calls.

Volunteers are to be polite, courteous, and represent the ME|FM Society of BC to their best ability.

Volunteers are to be available as much as possible to answer calls within their shift time. When a volunteer is not available, they must ensure they are set up to receive voice messages.

### **Support Line Policies**

To protect our volunteers and our Society, we have basic policies for the phone lines.

These policies apply to all Support Line Volunteers taking calls. All Volunteers must therefore ensure



the service they provide are in accordance with these policies and the accompanying procedures.

The Volunteer Coordinator is responsible for monitoring implementation and reviewing the effectiveness of these policies and the related procedures.

### Providing Emotional Support:

All volunteers are expected to listen, provide support, offer strategies, and give callers information about ME and FM and wellness related services in their community.

**We do have the responsibility to be sympathetic listeners without judging.** We need to be respectful of everyone and their approaches to their illnesses. All volunteers are expected read, understand, and follow the emotional support guidelines provided in this manual. In any uncertain circumstances, volunteers should refer the call to an appropriate support resource, or contact the team lead or Volunteer Coordinator for help.

**We do have the responsibility to refer callers in serious emotional difficulties to a crisis line and not handle it ourselves.** See the inside front flap of White Pages (OR Google) for local crisis line numbers.

### Distress Services:

Greater Vancouver	604-872-3311
Toll Free – Howe Sound and Sunshine Coast	1-866-661-3311
TTY	1-866-872-0113
BC-wide	1-800-SUICIDE (784-2433)
Online Service for Youth	<a href="http://www.YouthInBC.com">www.YouthInBC.com</a>
Online Service for Adults	<a href="http://www.CrisisCentreChat.ca">www.CrisisCentreChat.ca</a>
Seniors' Distress Line	604-872-1234
Mental Health Support (BC-wide)	310-6789

Crisis Centre BC Website: <https://crisiscentre.bc.ca/distress-phone-services/>



## Privacy Policies

The philosophy of confidentiality of the ME|FM Society of BC Support Line is paramount. Each volunteer is responsible for ensuring the confidentiality of callers, Board members, and other volunteers and members of the Society.

Note: Anything discussed on the Support Line will be confidential between the caller and the ME|FM Society organization, not between caller and support worker.

### **The ME|FM Society of BC collects and uses personal information about:**

Employees for the following purposes:

- For the administration and management of matters relating to paid employees and the administration of the collective agreement
- For the administration of payroll and benefits
- To meet statutory Provincial and Federal requirements

Volunteers for the following purpose:

- For the administration and management of matters relating to volunteers

Callers for the following purposes:

- For providing information and referrals that are appropriate to a caller's unique situation (age range, gender, community)
- For providing follow-up assistance to callers who could possibly benefit from a return phone call.

**The ME|FM Society of BC will ensure appropriate security undertakings**, such as confidentiality clauses in contractual agreements, are employed with its staff and volunteers, to protect the transfer and use of personal information.

## **Caller Privacy**

**ME|FM Society of BC does not subscribe to call display** on any of its phone lines. Any individual's information collected by volunteers or staff is never shared with or sold to any third party.

**Personal information of callers will only be used or disclosed for the purposes for which it is collected.** We do not use personal information for additional purposes, except for Society communications, without securing consent to do so from the person(s) to whom the information pertains, or as required by law.

The ME|FM Society, its staff and volunteers, will make reasonable efforts to ensure that personal



information is accurate, complete, and current.

## Volunteer/Staff Privacy

**Our Society will also make reasonable efforts to ensure that staff and volunteer information is not divulged to any third party** without the consent of the individual named. The ME|FM Society of BC may disclose personal information in exceptional circumstances, e.g., when personal information is required for an emergency that may threaten someone's life, health, or personal security.

**We recommend that our volunteers consider use the \*67 service prior to using their home phones as a way to protect their privacy.** By pressing \*67 before phoning callers back, the person you are calling will not have access to your phone number using a call display device. This allows you to remain in control of when you respond to ME and FM related calls, and avoids people calling you at home when you are not "on shift."

Many volunteers feel comfortable leaving a message with their home number, which is fine. This can save the effort of calling people back. **However, you are not required to give out your home number, and if you do so please only do this at your own discretion.** If you feel any discomfort at this, please use the \*67 option to avoid giving people your number.

## Boundaries

**With callers:** In terms of emotional/listening support, people often need to tell their stories, which is important. However, to avoid getting burned out and not too overwhelmed, you need to be able set boundaries as to the length of call you are comfortable with.

Some Tips: After listening for a while, you sometimes may need to focus a caller on the present and what their most pressing concern is at the moment and what information or resources we can provide to help them out. This will help the caller and you feel less overwhelmed.

For example:

*"It sounds like there have been lots of challenges around this illness for you. I'm wondering what I can help you with today. What is your biggest concern at this time that we could discuss ideas/resources around?"*

*"I'm really glad you called the line and we had a chance to chat. It certainly sounds like there's a lot going on for you right now. I hope some of the ideas and resources we've talked about are useful. I'm going to let you go now, but I want to encourage you to call the lines again if we can help in any way, or to give us feedback about the resources, etc. Okay, take care, keep in touch."*



## Overall Procedures

### Becoming a Phone Line Volunteer

#### Forms and Information

When you sign up to become a phone line volunteer, you need to complete and review the following documents, and return them to us at [admin@mefm.bc.ca](mailto:admin@mefm.bc.ca) where necessary:

- **[Confidentiality Agreement](#) - Please sign and date, then email or print and mail to us before your first shift. Digital signatures are fine to use.**
- **[Membership Form](#)** - Please ensure you have become a member of our Society by joining online [here](#) or submitting [this form](#) and membership fee via email.
  - Please also review [this form](#) so you can share this info with callers who would like to become a member.
    - <https://drive.google.com/file/d/1jOPcVXPGbnUUBMUjpKkR4ZbWgm5YAlI7/view?usp=sharing>
  - You can also forward this document by copying the URL in the browser to any prospective members. (Anyone with the link should be able to view and download/print it.)
  - See the procedures for instructions on how they can become members.
  - Our preference is always for people to fill out the online membership form, but they can use this form if they do not have access to a computer or internet.
  - <https://www.mefm.bc.ca/get-involved>
- **[Donation Form](#)** - please review so you can share this info with callers who would like to make a donation. You can also forward this document to any prospective donors.
  - <https://drive.google.com/drive/u/0/folders/0B3ny6a7vZ3SNSFlN3pSMHBkSmM>
- **[Information Package](#)** - can be found at <https://www.mefm.bc.ca/get-involved>
  - please download and review so you can share this info with callers who would like to more information about the society and/or the illnesses. You can also forward this document to any callers wanting this info.
  - <https://www.mefm.bc.ca/get-involved>
- Join the team Facebook Group here:  
<https://www.facebook.com/groups/mefmphonelinesteam/>

#### What to do

1. Ensure you have completed and reviewed all the above forms, and particularly that you have submitted your Confidentiality Agreement form.
2. Review this manual entirely.
  - Ensure you know how to access the voicemail and know the overall steps and procedures for calls before your first shift. The rest you can read as you're able.
3. Ensure you know when your upcoming shifts are.





- Volunteers are generally on call (shift) for 1 week at a time beginning and ending on Mondays. You should receive calendar event invites for each shift that you can add to your phone or online calendars.
  - If you cannot receive these event invites, please contact us at [admin@mefm.bc.ca](mailto:admin@mefm.bc.ca) to ask when your shifts are.
4. Ensure you have had a look at our website at [mefm.bc.ca](http://mefm.bc.ca) and know where to direct people for certain requests.
    - Particularly ensure you know where the resource and support pages are, where to become a member, or receive more info, and how to join our Support Form.
    - If you have questions about any of this, just ask us at [admin@mefm.bc.ca](mailto:admin@mefm.bc.ca)
  5. At the beginning of each shift, check the voicemail to catch up on any messages left there.
  6. During your shift, ensure you check the voicemail AT LEAST every 24-48h and return any calls within that time.
  7. At the end of each shift, pass on the line by calling the next person scheduled to communicate any outstanding calls or information that they should know. If you're not sure who is next, send this info to [admin@mefm.bc.ca](mailto:admin@mefm.bc.ca) and we can pass it on.

### **Questions or Concerns**

If you have any questions at any time, regarding serving as a Phone Line Volunteer, contact us at [admin@mefm.bc.ca](mailto:admin@mefm.bc.ca) to request a phone call or ask your questions via email.

### **Accessing the VoiceMail**

1. Dial the MEFM Society of BC's phone number: 604-878-7707
2. When you hear the voice message press "\*"
3. When it prompts you for your password press: "2004"

### **Listening to Messages**

To listen to the messages, press "1"

To skip a message (without deleting it), press "#"

### **Erasing, Saving, and Forwarding Messages**

Once you have finished listening to a message you have a few options:

To Save, Press "9"

To Erase, Press "7"

To Send a Copy of the message to another voice mailbox (Telus and others), press "6" and follow the prompts. Use this function to send a copy of a message to another team member when it is addressed to them, or as appropriate.

### **Changing the Phone Message**

This is to be done by the Phone Line or Volunteer Coordinator only:

Access the voice mailbox, as above.



Press "4" to change greeting or recorded name  
Press "3" to change greeting  
Press "4" to create an extended absence greeting  
Follow remaining prompts  
Press "\*" to exit.

### Long Distance Call Procedures

If you are comfortable giving out your home or cell number, leave a message and let that person call you directly so they pay the long-distance charges.

#### OR

If you are not comfortable giving your home or cell number, you can use the "\*67" feature to block your phone number and then either:

- Purchase a long-distance phone card to be used only for your ME|FM long distance calls and expense the cost of the phone card on your expense claim form.
- Submit your phone bill with an expense claim form with the line items for ME|FM calls highlighted. Follow the expense claim instructions listed in this document.

### Returning a Call (within BC only)

All calls are to be returned within 48h.

Voicemail are to be checked once per day.

When leaving a voicemail, include the following information:

- Your Name and that you are from the ME|FM Society of BC
- Our phone numbers for them to call back.
  - (604) 878-7707 or BC toll-free: 1-888-353-6322
- You can also offer for them to email us at [info@mefm.bc.ca](mailto:info@mefm.bc.ca) for support if their request is not urgent.

### Starting a Call

Follow these steps when you first get a caller on the line:

- Introduce yourself and let them know you are a support volunteer with the ME|FM Society of BC.
- Ask how you might be able to help them today.
- Follow the "Request Procedures" below depending on what service the caller is seeking.



## How and When to End a Call

At the end of a call, the Volunteer should:

- Ensure they have the caller's correct name, email, and phone number (and mailing address if the caller would like an information package sent to them via post.)
- Thank the caller for contacting the ME|FM Society of BC.

If a caller presents a problem or turns inappropriate or abusive, the volunteer should politely end the call by:

- Letting the caller know that they are a volunteer and not able to handle this call any longer.
- Referring the caller to e-mail the Volunteer Coordinator at [admin@mefm.bc.ca](mailto:admin@mefm.bc.ca) if the caller still has concerns.

## Request Procedures

### Support Group Contacts

Here is the most recent list of Support Groups in BC. [Support Group Contacts](#) If there is no support group or contact person listed for a caller's area that you know of, make the following suggestions:

- Give them the closest local support group/contact person. That person may know of local resources we aren't aware of.
- Direct them to our website to the Support page: [mefm.bc.ca/support](http://mefm.bc.ca/support) and to the [online Support Forum](#) where they can find support from forum members or request info about other support groups or resources.
- Direct those who are on [Facebook to ME & CFS Canada \(myalgic encephalomyelitis & chronic fatigue syndrome\)](#)
- Suggest they try other online support groups, such as PhoenixRising.me. They can find other online groups on our website in the ME or FM sections of the Resources page: [mefm.bc.ca/generalresources](http://mefm.bc.ca/generalresources)
- Emphasize that there may be a support group in their community we aren't aware of, so they need to keep looking. If they find one, to please let us know so we can add it to our referral list.
- Suggest trying their local hospital, health clinic, local church, community or mental health centre. Sometimes these institutions run groups for people with chronic illnesses or specific conditions.
- If there is a local branch of the Arthritis Society, suggest they contact them as the Arthritis Society runs FM support groups in many areas.
- Ask them if they are willing to be a contact person for their area, and if we could give out their name and phone number and email to future callers from their area. This will enable us to connect people with their illness in their community.



- If they agree, take down their full name, telephone number, address, email address, whether they are willing to be a contact person for ME or FM or both, and pass it on to the volunteer coordinator via email at [admin@mefm.bc.ca](mailto:admin@mefm.bc.ca) .

### Requesting an information package

Inform the caller of these three purposes when you are sending an information package to them.

- To provide information about ME and FM
- To provide information about our society
- To invite new membership

Collect the names, phone numbers and email addresses of people wanting information packages sent to them and ask whether they are seeking FM or ME information (or both).

**Membership information can be found on our website here:** [mefm.bc.ca/get-involved](http://mefm.bc.ca/get-involved)

**Online Information packages can be found and downloaded from here as well:**

[mefm.bc.ca/get-involved](http://mefm.bc.ca/get-involved)

Be sure to offer every caller an information, package particularly if the caller is newly diagnosed and/or not a current member of our society.

**Do not offer to mail a package unless specifically requested by the member. If they do not have an email address, take their mailing address.**

Please let them know that we prefer to email information where possible since it saves us time and money and is more environmentally friendly.

### Wanting to find a Supportive Specialist

Here are some ways that people can try to find a specialist:

- Recommend our new website: [HealthFinder4ME.org](http://HealthFinder4ME.org)
- Recommend the Complex Chronic Diseases Program. New patients will require a referral from their GP, so they may wish to start there. Let callers know there is a 28 month wait and the program is only 18 months.
- Check with anyone they know with ME or FM to see if they have a supportive specialist.
- Check with their local support groups and our online Forum categories regarding general support or "Recommend a Practitioner"
- 
- Online Support Groups and other sites may provide info. Direct them to our Resources pages on our website: [mefm.bc.ca/generalresources](http://mefm.bc.ca/generalresources)



Specialists' reports become a permanent part of a patient's medical file and can have legal implications in relation to any disability claims they make. A negative report from a specialist can be hugely damaging and cause years of problems (although it is not insurmountable).

## **Making Referrals**

Callers should first be referred to our website and to the resources listed there or indicated in other sections of these procedures. Callers should be made aware that we can only provide referrals and recommendations, not medical or legal advice or endorsements.

## **Reporting and Resolving Problems or Concerns**

When encountering any problems, volunteers are to alert the Volunteer Coordinator by sending an email to [admin@mefm.bc.ca](mailto:admin@mefm.bc.ca) or by phone if the problem requires immediate action.

If there is an emergency, the volunteer should call 911 and then alert the Volunteer Coordinator as to what happened via e-mail at [admin@mefm.bc.ca](mailto:admin@mefm.bc.ca) as soon as possible.

## **Reporting Procedures**

### **After Each Completed Call**

After each call, fill out this [ONLINE CALL LOG](https://goo.gl/forms/kllMX7TVWPxqlpbD3) form:  
<https://goo.gl/forms/kllMX7TVWPxqlpbD3>

### **IF YOU DO NOT HAVE A COMPUTER:**

Record the following information in a log book or sheet to be submitted at the end of your shift by mail to

Please note that for each call (even those you forward) you must complete an online form or provide the call log info below via mail.

---

## **ME|FM Society of BC - SUPPORT PHONE LINE CALL LOG FORM**

Volunteer Name:



Date of Call:

Caller's Info

- Caller's Name:
- Caller's Phone Number
- Caller's Email:

Is the caller a member?

- If not, did you give them information about becoming a member?
- If not, would they like us to send them info about becoming a member?

Did the caller request an info package or brochures about ME and/or FM?

- If so, did you send them the info?
- If not, would they like us to send them an info package? What documents are they specifically looking for?

*If they requested an information package, please also send a specific request for one to be mailed to them with their name, mailing address, and email address, and phone number for us to communicate with them directly to [admin@mefm.bc.ca](mailto:admin@mefm.bc.ca)*

Caller's Concern/Inquiry:

Callback info:

- Date of Callback
- Did you leave a message?
- Is the call now completed?
- Did you forward the call on to someone else?

Comments/Follow Up:

---

## Ending Your Shift

Ensure all your call logs have been submitted.



At 6:00 pm on the day your shift ends, call the next phone worker on the schedule to ensure that they realize they are now on duty.

This information can also be found on our website

ME|FM Society of BC  
ME|FM Myalgic Encephalomyelitis and Fibromyalgia Society of BC  
Box 462 – 916 West Broadway  
Vancouver, BC V5Z 1K7  
Phone 604-878-7707  
BC toll free 1-888-353-6322  
Email [info@mefm.bc.ca](mailto:info@mefm.bc.ca)  
[www.mefm.bc.ca](http://www.mefm.bc.ca)

Annual membership: \$25.00

### **Canadian Organizations for ME and /or FM**

Millions Missing Canada  
Website: <https://www.millionsmissingcanada.ca/>  
Facebook (very active on FB): <https://www.facebook.com/MillionsMissingCanada/>

National ME/FM Action Network  
512 – 33 Banner Road  
Nepean, ON K2H 8V7  
Lydia Neilson  
Phone 613-829-6667  
Fax 613-829-8518  
Email [mefminfo@mefmaction.com](mailto:mefminfo@mefmaction.com)  
<http://www.mefmaction.com/>  
Annual membership of \$25.00 includes Quest quarterly newsletter

### **ME Victoria Association (MEVA)**

Website: <http://www.mevictoria.ca/>  
PO Box 50032, Victoria, BC V8S 5L8



**Organisations in other provinces can be found on our website**

## [Expense Claim Instructions](#)

When purchases are made, write ME/FM Society of BC on the receipt and indicate what the expense was for. Save your receipts!

Please fill out your expense form for each purchase electronically [here](#).

Email photos or PDFs of your receipts to [admin@mefm.bc.ca](mailto:admin@mefm.bc.ca) with the date and your name in the document title.

Be sure to keep a copy of the receipt for yourself in your own files and print a hard copy if you prefer.

### **IF YOU DON'T HAVE ACCESS TO A COMPUTER:**

- Photocopy your receipts to keep a copy for yourself.
- On the original receipt or an attached piece of paper, what each purchase was for and the date it was purchased, along with any other relevant info.
- Send the originals to the Society's mailing address (below). Be sure to include your name and address where you would like your reimbursement cheque mailed.

### **ME/FM SOCIETY OF BC**

Box 462, 916 West Broadway  
Vancouver, BC, V5Z 1K7

Tel: 604-878-7707

BC Toll-free: 1-888-353-6322

[info@mefm.bc.ca](mailto:info@mefm.bc.ca)

[www.mefm.bc.ca](http://www.mefm.bc.ca)





## Protecting your Privacy Procedures

We recommend that our phone line volunteers consider using the \*67 service prior to using their home phones as a way to protect their privacy. By pressing \*67 before phoning callers back, the person you are calling will not have access to your phone number using a call display device. This allows you to remain in control of when you respond to ME and FM related calls, and avoids people calling you at home when you are not “on shift.”

If no one answers when you call, you can leave a message saying you will call back (therefore not leaving your home phone number).

If you are unsuccessful at catching them at home after a few tries, leave a message recommending they call the phone line again and specify a good time for volunteers to reach them at home.

Many volunteers feel comfortable leaving a message with their home number, which is fine. This can save the effort of calling people back. However, you are not required to give out your home number, and if you do so please only do this at your own discretion. If you feel any discomfort at this, please use the previous procedures to avoid giving people your number.

## Pace yourself

We encourage you to take care of yourself by letting us know if the work becomes too much. Volunteers must let the phone line coordinator know if any of the following come up:

- Too many calls come in on your shift and you need help.
- You will be taking a vacation. Let the coordinator know in advance so that they can schedule a substitute
- You are finding your shift too long or too short and you want to decrease or increase your volunteer commitment.
- If you want to do a different kind of volunteer work for our society.
- Questions/suggestions around phone procedure/policies/etc.

## A Few Things to Remember to Support You in Supporting Others

**EMPOWERMENT: Our goal is to empower callers by giving them tools, ideas and resources to help themselves.** We don't have all the answers. We aren't in a position to rescue anyone. But we can give callers helpful suggestions on where to go for information, help with disability benefits, support groups, supportive doctors, treatment options, etc. Many of our callers are in difficult times and have a number of concerns that are not easily resolved.



**TEAMWORK: You are not alone. You are part of a team of phone workers and volunteers, all of whom have areas of particular interest and expertise.** We are here to support each other. None of us has to know it all. If you don't know the answer to a caller's question, there may be another member of the team who is knowledgeable about that caller's concern. The phone line coordinator will be happy to direct you to who that may be. If you have a special area of knowledge or expertise, let the phone line coordinator and the other members of the team know.

All publicity materials about the Support Line will include our local and Toll-Free telephone number. A call back service will be offered to callers from BC only.

All volunteers will be trained in offering support by the Volunteer Coordinator before working on the Support Line. Once on the line, they will continue to have ongoing training and support provided by the Volunteer Coordinator.

## **FAQ FOR CALLERS**

### **What happens when I call the ME|FM Support Line?**

A Support Line Volunteer will take your call or return your voice mail message as soon as possible.

If it is an emergency, please call 911. Our support line is not equipped to handle emergencies, but we will help you with non-emergency situations as much as possible.

The Volunteer is there for you to ask questions, find out about resources related to ME and FM and receive various forms of support. Volunteers also listen, provide support, and offer strategies to help you get started. We are here to help you with information, not to judge.

If the Volunteer does not have the answers to your question or the information you request, they will call you back with the correct information.

The Volunteer will take your name, email address, and other contact information so we can stay in touch. They will also ask you if you would like to subscribe to our regular email updates and if you would like to become a member of our Society.

### **Who can call?**

Anyone! You can call for yourself or for someone you care about.

### **Is your service free?**

Yes!



**I'm not ready to get help, can I still call you?**

We're happy to talk to you, even if you're just looking for general information. No question is too small. We're here to help.

**What does a Support Line Volunteer do?**

All calls are answered by volunteer members of our Society. Our Support Line Volunteers listen, provide support, offer strategies, and give you information about services in your community.



## **SUPPORT LINE CALL LOG FORM**

*To be filled out by the volunteer on call who is communicating with the specific caller*

Volunteer Name:

Date of Call:

Caller's Info

- Caller's Name:
- Caller's Phone Number
- Caller's Email:

Is the caller a member?

- If not, did you give them information about becoming a member?
- If not, would they like us to send them info about becoming a member?

Did the caller request an info package or brochures about ME and/or FM?

- If so, did you send them the info?
- If not, would they like us to send them an info package? What documents are they specifically looking for?

*If they requested an information package, please also send a specific request for one to be mailed to them with their name, mailing address, and email address, and phone number for us to communicate with them directly to [info@mefm.bc.ca](mailto:info@mefm.bc.ca)*

Caller's Concern/Inquiry:

Callback info:

- Date of Callback
- Did you leave a message?
- Is the call now completed?
- Did you forward the call on to someone else?

Comments/Follow Up:



**ME/FM Society of BC VOLUNTEER AGREEMENT**

The Myalgic Encephalomyelitis and Fibromyalgia Society of B.C. (ME|FM Society of BC) service to the community relies entirely on responsible and reliable volunteers. Please read carefully before signing.

- 1) In my capacity as a volunteer for the ME/FM Society of BC, I agree to comply with the rules and policies of ME/FM Society of BC. Any questions or issues relating to my work that arise outside existing rules and policies I will refer to the Volunteer Coordinator or Board of Directors.
- 2) As a volunteer, I agree that all information proved by clients with regards to their identity, donations or finances, and particular situation is to be kept confidential and is not to be discussed with anyone, including my spouse, close friends and/or relations.
- 3) I understand that any breach of the rules or policies of the society can, at the discretion of ME/FM Society of BC, result in my release as a volunteer.

I, \_\_\_\_\_, acknowledge that I have been provided with ME|FM Society of BC Confidential Information and agree to comply with complete confidentiality of all information shared with me by any member or employee of the ME|FM Society of BC. I will not, without proper authorization from ME|FM Society of BC, disclose or make known to the public or otherwise, any sensitive or personal information which comes to my knowledge by reason of my work and communication with ME|FM Society of BC.

This Agreement states the entire agreement between the parties concerning the disclosure of Confidential Information. Any addition or modification to this Agreement must be made in writing and signed by the parties.

**WHEREFORE**, the parties acknowledge that they have read and understand this Agreement and voluntarily accept the duties and obligations set forth herein.

Volunteer Name/Recipient of Information (Print or Type): \_\_\_\_\_

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

**Society Contact Sheet**

\*Private and Confidential\*



## Board of Directors

Co-Chair / Program Director  
Elizabeth Sanchez

Tel: 604-736-4272

Email: [elizabeth.sanchez@mefm.bc.ca](mailto:elizabeth.sanchez@mefm.bc.ca)

Treasurer  
Badrudin Moosa

Tel: 604-324-3709

Email: [moosa@telus.net](mailto:moosa@telus.net)

Program Administrator  
Jasical Grewal

Tel: 604-614-6174

Email: [admin@mefm.bc.ca](mailto:admin@mefm.bc.ca)

## Phone Line Volunteers

## Resources

ME|FM Society of BC Support Inform

Phone 250-384-4783

Email [me.victoria@shaw.ca](mailto:me.victoria@shaw.ca)

[www.me-cfsvictoria.org](http://www.me-cfsvictoria.org)

\$20.00 annual membership includes a newsletter 6 times per year.

[#MillionsMissing Canada](#) : The Facebook landing space for the Canadian campaign.

## **FM RESOURCES**

Victoria Fibromyalgia (Support) Networking Group

Fibromyalgia informational meetings are held the first Friday of each month from 2 – 4 pm (except for July and August) in the Woodward Room, Begbie Hall, Royal Jubilee Hospital, Victoria BC.

Contact Mary Brownscombe at 250-381-5202 or Carol Brown at 250-381-1182

[www.arthritis.ca/bc](http://www.arthritis.ca/bc)

Fibromyalgia

[http://www.niams.nih.gov/Health\\_Info/Fibromyalgia/default.asp](http://www.niams.nih.gov/Health_Info/Fibromyalgia/default.asp)

## **ME & FM CLINICS AND PROGRAMS**



### Complex Chronic Disease Program\*

Housed at the BC Women's Hospital & Health Centre, this program is for people who suffer from a group of complex chronic diseases that include, but are not limited to:

- Myalgic Encephalomyelitis/Chronic Fatigue Syndrome
- Fibromyalgia Syndrome
- Lyme Disease

The goal for the program is to provide patient and symptom-centered care with the support of the multidisciplinary team of healthcare providers. To visit the program, you must have a completed [referral form](#) from your primary health care professional (such as a family doctor, nurse practitioner, naturopathic doctor, or specialist) who will be supporting your daily chronic disease management and following your ongoing health.

### BC Women's Complex Chronic Diseases Program

BC Women's Hospital & Health Centre

Room B4 West, Shaughnessy Building

4500 Oak Street, Vancouver BC V6H 3N1

Phone 604-875-2061

Phone Toll Free in BC only 1-888-300-3088 local 2061

Fax 604-875-3738

Email [infoccdp@cw.bc.ca](mailto:infoccdp@cw.bc.ca)

[www.bcwomens.ca/Services/HealthServices/complex-chronic-disease-program/default.htm](http://www.bcwomens.ca/Services/HealthServices/complex-chronic-disease-program/default.htm)

### Dr. I A Hyams Fibromyalgia and Chronic Pain Clinic

A family physician with a special interest in fatigue and pain disorders.

1409 Bellevue Ave

West Vancouver, BC V7T 1C3

Phone 604-922-2426

Fax 604-947-9838

Email [info@drhyams.ca](mailto:info@drhyams.ca)

[www.drhyams.ca](http://www.drhyams.ca)

**Dr. Sean Gravelle - get info from HealthFinder4ME org (GET INFO FROM HEALTHFINDER)**

**add DR ANIZ KHALFAN**

**Also add HealthFinder4ME.org**

## LEGAL INFORMATION RESOURCES

For court decisions in BC

[www.courts.gov.bc.ca](http://www.courts.gov.bc.ca)

For court decisions across Canada



<http://library.ucalgary.ca/law>

Portal to all BC Legislation\*

[www.clicklaw.bc.ca](http://www.clicklaw.bc.ca)

Lawyer Referral Service\*

604-687-3221 or 1-800-663-1919

Access Pro Bono\*

Free Legal Advice for Low-income People

604-878-7400 or 1-877-762-6664

Dial-A-Law\*

(recorded legal information) 604-687-4680 or 1-800-565-5297

Tape 421 - Getting Your Medical Records

Tape 423 - Making a Complaint Against Your Doctor

[www.cbabc.org/For-the-Public/Dial-A-Law/Scripts](http://www.cbabc.org/For-the-Public/Dial-A-Law/Scripts) Select: Health

## **OTHER RESOURCES**

PainBC has a health coach program. Members would be assigned a trained volunteer who could help with a lot of common problems and serve as a point person.

[Pain Support Line](https://www.painbc.ca/about/programs/pain-support-line) - <https://www.painbc.ca/about/programs/pain-support-line>

Disability Alliance BC (formerly known as BC Coalition of People with Disabilities)

Helps people with disabilities access provincial income assistance benefits, Canada Pension Plan Disability and other disability-related programs and services. The website has an assortment of informational resources. Annual membership of \$15.00 includes a subscription to Transitions magazine.

204 - 456 West Broadway

Vancouver, BC V5Y 1R3

Advocacy Access 604-872-1278

BC Toll Free 1-800-663-1278

Fax 604-875-9227

<http://www.disabilityalliancebc.org/>

For website access to Help Sheets and informational resources go to:

<http://www.disabilityalliancebc.org/money.htm>

Home Adaptations for Independence\*

1-800-407-7757 (ext. 7055)

[www.bchousing.org/HAFI](http://www.bchousing.org/HAFI)

604-646-7055





#### Deferment of Property Taxes for the Disabled\*

<http://www2.gov.bc.ca/gov/content/taxes/property-taxes/annual-property-tax/pay/defer-taxes>

#### Newton Resource Centre

Disability Support Advocacy for provincial disability benefits.

A205 - 13588 88 Avenue, Surrey, BC V3W 3K8

Phone 604-596-2311

Fax 604-596-2319

<http://www.sourcesbc.ca>

#### SPARC BC - Disabled Parking Permit Application

SPARC BC advocates for the right of people with mobility issues and provides parking permits for people with disabilities. For more information on parking permit applications contact:

4445 Norfolk Street

Burnaby, BC V5G 0A7

Phone 604-718-7744

Toll free 1-888-718-7794

Fax 604-736-8697

Email [permits@sparc.bc.ca](mailto:permits@sparc.bc.ca)

[www.sparc.bc.ca](http://www.sparc.bc.ca)

#### Invisible Disabilities Association of Canada

For people with CFS, FM, environmental sensitivities and other disabilities.

[www.nsnet.org/idacan](http://www.nsnet.org/idacan)

#### Environmental Health Association of BC

Provides information and resources for those with food and chemical sensitivities.

Box 30033, RPO Reynolds, Victoria, BC V8X 5E1

Phone 250-658-2027

Email [info@ehabc.org](mailto:info@ehabc.org)

[www.ehabc.org](http://www.ehabc.org)

\$25 annual membership includes a newsletter

#### PeerNetBC

Provides training, information and resources aimed at strengthening peer support groups and peer-led initiatives throughout BC.

408 - 602 West Hastings

Vancouver, BC V6B 1P2

Phone 604-733-6186

Fax 604-730-1015



Email [info@peernetbc.com](mailto:info@peernetbc.com)  
[www.peernetbc.com](http://www.peernetbc.com)

Vancouver Women's Health Collective  
VWHC advocates for appropriate, quality healthcare for women, provides help and support to women facing health crises, operates a Health Practitioner and Therapist Directory to help women find a healthcare provider specific to their needs. It also offers a non-lending resource library and comprehensive collection of health files on a wide range of health and women's issues. Services are offered in 9 different languages.

29 West Hastings Street  
Vancouver, BC V6B 1G4  
Resource Centre 604-736-5262  
Email [whc.centre@gmail.com](mailto:whc.centre@gmail.com)  
[www.womenshealthcollective.ca](http://www.womenshealthcollective.ca)

St. Paul's Anglican Church  
Assists with Canada Pension Plan and other Disability-related claims.  
1130 Jarvis Street, Vancouver, BC  
Phone 604-685-6832  
Fax 604-683-3109  
Advocacy Office 604-683-4287  
[stpaulsanglican.bc.ca](http://stpaulsanglican.bc.ca)

St. Mark's Anglican Church  
Assists with BC disability benefits claims.  
1805 Larch Street  
Vancouver, BC  
Phone 604-736-2838  
[www.stmarks.ca](http://www.stmarks.ca)

## VIDEOS

### **update from website and add unrest**

#### Forgotten Plague

Feature documentary by Ryan Prior and Nicole Castillo

"Forgotten Plague" is a journey into the hidden world of myalgic encephalomyelitis (chronic fatigue syndrome). It is a chilling tale of our medical system's failures in addressing many chronic, complex diseases. Yet it is also a riveting story of science's remarkable ability to transform medicine and improve human life itself.



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

#### Voices From the Shadows

"Voices from the Shadows" shows the brave and sometimes heartrending stories of five ME patients and their carers, along with input from Dr Nigel Speight, Prof Leonard Jason and Prof Malcolm Hooper. It was filmed and edited between 2009 and 2011 by the brother and mother of an ME patient in the UK. The film shows the devastating consequences that occur when patients are disbelieved and the illness is misunderstood.

[voicesfromtheshadowsfilm](http://voicesfromtheshadowsfilm)

#### Invisible

A film by Rik Carlson & Michael Thurston

"Because CFIDS is dismissed, relegated to hysterical women, passed off as depression, and not taught in medical schools, in most, if not all cases, patients worsen dramatically.

This film is for parents, spouses, brothers, sisters, friends, neighbors, employers, and physicians. While this disease alone is immensely debilitating, the disregard and misdiagnoses by people of authority causes even more catastrophic results. When the true disease is denied, families are destroyed. When it's accepted, recovery programs can be developed and healing can begin.

[Invisible - the movie](#)

I Remember Me Video

Kim Snyder. The first nationally released film on ME.

You can purchase this film from:

Zeitgeist Films (in the US)

Phone 1-800-509-0448

[www.zeitgeistfilms.com](http://www.zeitgeistfilms.com) or [www.amazon.ca](http://www.amazon.ca)

## **Non-Profit Programs**

Government and Non-Profit Societies

### [Arthritis Society](#)

Website: [http://arthritis.ca/understand-arthritis/types-of-arthritis/fibromyalgia - ProgramsandResources](http://arthritis.ca/understand-arthritis/types-of-arthritis/fibromyalgia-ProgramsandResources)

### [Chronic Disease Self-Management Program \(CDSMP\)](#)

Free, province-wide patient education program offered in all five BC Health Authority regions

Suitable for people who are experiencing any type of chronic health condition and their partners

Province wide registration number: 1-866-902-3767

Website: <http://www.selfmanagementbc.ca/>



Vancouver Coastal Health Authority: [Living a Healthy Life with Chronic Conditions](#)

Address

5913 West Boulevard

Vancouver, B.C. V6M 3X1

Phone: 604.267.4430

E-mail: [feedback@vch.ca](mailto:feedback@vch.ca)

### **Private (for profit) Programs**

Remind callers that our society does not endorse any private health practitioners treating FM or ME. This information is offered to callers so they can make their own judgment about the resources available.

Teresa Clarke's Fibromyalgia and CFS 12 week Path to Recovery Program

12 sessions. Cost of course varies and is typically between \$150 – 250 including manual. For content cost, please contact the instructor directly.

Various instructors in the lower mainland:

[LlseonLife](#) - Lise Wearing (nutritionist) in Kitsilano. Call: 604-222-2215, [liseonlife@shaw.ca](mailto:liseonlife@shaw.ca)

**Dr Hyams should be included here, as should Dr. Eric Chan ND**

### **Phone Workers' Information for Vancouver Self-Help and Advocacy Group**

The Vancouver Self-Help and Advocacy Group assists sufferers of FM and ME with their initial Canada Pension Plan and BC Disability Pension application and provides some help with appeals.

The MEFM Resources guide directs callers to the MEFM Society phone line and e-mail address.

The advocacy service is provided by Wendy Snelgrove. Please pass on the assistance request to her by phone at 604-732-8764. Do not give Wendy's number out to people requesting assistance – her number is for phone workers only.

Suggested Specialists for ME / FM

Dr. Ian Hyams, General Practice, FM/ME Clinic

Suite 106, 22838 Lougheed Hwy

Maple Ridge, BC

604-467-0029



Dr. Cecil Hershler, Physical and rehabilitative medicine specialist  
104-2786 W. 16th Ave.,  
Vancouver, BC  
604-732-7060

Dr. James V. Dunne, Internal medicine & Rheumatology  
2184 West Broadway  
Vancouver, BC  
604-732-4993

add DR SEAN GRAVELLE

DR ANIZ KHALFAN

**Additional information (updated Feb 1 2019)**

211 is a free service with a wide range of resources. They might be able to help.

Virtual clinic covered by MSP

[EQ Virtual - Innovative Virtual Clinic in British Columbia](#)



## **The Doctor Dilemma**

### **Getting Your GP to Support You - REVIEW WEBPAGE 'WHAT TO TAKE TO YOUR DOCTOR'**

Switching GPs is a serious decision, particularly if you are in the midst of trying to secure disability benefits (long term disability, Canada Pension Plan or BC Benefits).

Here are some things (in no particular order) that people can try in order to improve their working relationship with their existing GP so that they may not need to switch:

- Look into articles about how to get the most out of their appointments, and how to create a working partnership with their health practitioners. Refer to our newsletter articles, Vancouver Coastal Health Authority “Chronic Illness Management” groups, local support groups, other articles, and books.
- See a supportive specialist. Often a strong supportive report from another doctor goes a long way to strengthen the GP’s support and understanding of the ME/FM diagnosis and its implications.
- Pass information to their GPs about their condition, particularly if it is written for doctors. ME patients, for example, should take the new Canadian ME Diagnostic/Treatment Protocol to their doctors, or have them order it. Patients should also take any other current information that has been recommended to them.
- With regard to disability forms, patients should explain clearly to their doctor what they need and its importance. Often a GP knows only the diagnosis but not the level of disability. Patients can often save themselves and their doctors a lot of headaches and revisions by offering to help their doctors with the disability forms by providing a rough draft of a form or letter as a guide. Patients can also attach yellow “Post-it” notes with relevant information onto the forms. Patients can also ask their doctor if they can book a longer appointment so that they can go through the form together. In any case, patients should make suggestions as a way to work together; this benefits the GP by assisting with the copious paperwork, and benefits the patient by getting the most accurate report possible. Patients should be honest and up front about the implications of incorrect wording on their disability claim and financial situation.
- Talk to their doctor directly and in a non-accusatory way about their working relationship. Patients should explain what is helpful and what feels difficult and try to understand their doctor’s perspective. Discuss how both they and their doctor can work together more effectively.
- Visit local support groups and get the feedback of others with respect to their GP experiences. This may confirm whether or not they need to switch to a different doctor.



## **Finding a New GP**

### **ADD HEALTFINDER4ME.ORG AND USE BLOG POST**

While some people will be able to improve their relationship with their GP, others will need to switch. Here are some ways that people can try to find a new doctor:

- Phone the College of Physicians and Surgeons of BC to inquire after the names of GPs accepting patients in their area. The list of GPs accepting patients is also published on the college's website:

College of Physicians and Surgeons of BC:

604-733-7758 or 1-800-461-3008

1807 W 10<sup>th</sup>

Vancouver, BC V6J 2A9

[www.cpsbc.bc.ca](http://www.cpsbc.bc.ca)

- Check with family and friends (especially anyone they know with ME/FM) to see if anyone is familiar with any of the available doctors and has any specific feedback. If a family member or a friend has a doctor who they hear is good but isn't accepting patients, the family member or friend may be able to put in a good word for them and ask the doctor if he would consider taking them on as a patient. Regardless, prospective patients always need to assess the doctor during an interview and check references with a local support group if possible
- Visit their local support group for feedback on their potential GPs. If there is no local support group (for example outside the GVRD), they can check in with anyone else they know with ME or FM, or other sources of information such as advocacy groups, other health-related support groups, the Arthritis Society, local hospital groups, etc.)
- Book appointments and interview each GP on their list. Patients should compile a list of qualities most important in a doctor. Prospective doctors should recognise ME and FM as real physical illnesses and be willing to work with the patient as a partner. Unfortunately, many doctors are not extremely knowledgeable about FM or ME, but some are willing to read articles and other material, and are willing to try different approaches to the illnesses. Patients should also try to find a doctor who is willing to work with them on the disability forms.
- Keep copies of their test results, specialist reports, etc. Patients need to have access to their own medical records and the best way they can to do this is by compiling their own file. If patients have to change GPs, they can show their records to prospective GPs without having to wait for the transfer of their official records. This will enable new GPs to understand the diagnosis and



disability quickly and eliminate the need to reconstruct the history of the illness and treatment.





## **Finding a Supportive Specialist**

Specialists' reports become a permanent part of a patient's medical file and can have legal implications in relation to any disability claims they make. A negative report from a specialist can be hugely damaging and cause years of problems (although it is not insurmountable).

Here are some ways that people can try to find a specialist:

- Check with anyone they know with ME or FM to see if they have a supportive specialist.
  - Check with their local support groups.
  - Contact specialists as suggested by the MEFM Society of BC on the specialist list.
- New patients will require a referral from their GP.