



Support and Services to Mesothelioma Patients and Families

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mesothelioma



CMF: Building a nation-wide support network for patients and families



■ Key activities:

- Support groups for patients, caregivers and bereaved
- Online directory of support services specific to mesothelioma patients and their families/caregivers
- Dissemination of support materials and relevant information through the CMF website, social media and other means
- Educational workshops for patients and caregivers on topics of interest
- Peer support network



CMF support groups



- Launched private, invite-only online support groups for patients, caregivers and bereaved in April 2013
- Have about 20 members now from across Canada
- Support provided 24/7, participation at will
- A powerful initiative for combatting feelings of isolation, helplessness and loneliness through peer support
- Membership is extremely active and supportive of each other – many new friendships have been forged
- Exploring alternative support groups formats, including by teleconference, face-to-face meetings etc.
- Join by sending an email to info@cmfonline.org





Online directory of support services



- Canadian Mesothelioma Patient Support Network
 - Currently developing an online database of patient support services on the CMF website, nation-wide, specific to mesothelioma
 - Both free and pay services
 - Examples might include:
 - Mesothelioma medical centres and specialists, clinical trials
 - Patient and caregiver support groups
 - Legal resources
 - Financial aid etc.
- Intended to compliment the Cancer Society's Community Services Locator, not duplicate
- Currently recruiting service providers!





Information dissemination through online and print media



- Continued development of the CMF website with relevant information and resources including:
 - Basic clinical and scientific aspects of mesothelioma
 - Treatment options and resources
 - Compensation, insurance and other financial considerations
 - Personal stories, memorials
 - Event calendar, support group activities
 - Lifestyle: diet, travel, future planning etc.
- Continued outreach through social media (FB, Twitter)
- Development of a quarterly newsletter for patients and caregivers (medium term)





Information dissemination through educational workshops and events



- Face-to-face workshops and events with patients and caregivers
 - On topics of interest to patients and caregivers : compensation, financial aid, pain management, diet...
 - Partner with other organisations across Canada to offer workshops nation-wide
 - Target 1-2 more patient/caregiver workshops in Toronto in 2014
- Continued timely response to direct inquiries from patients and caregivers via email and phone



Peer Support Network



- Participating patients and family members are matched with a program volunteer for one-on-one peer support (long term)
- Program volunteers:
 - Patients themselves, or family members that have been affected by mesothelioma
 - Understand what participants are going through and want to help
- Similar to the Threads of Life Family Support Program which supports those that have lost loved ones in workplace tragedies



Questions/Suggestions?



- Afternoon strategy session will have a break out group on strengthening support and services for patients and families
- We look forward to hearing your ideas on how we can strengthen our patient support program!
- My contact information:
 - Alissa Boardley at info@cmfonline.org

