CHALLENGES OF LIVING WITH FIBROMYALGIA©
in
BRITISH COLUMBIA

Prepared by

CHERY YOUNG
EXECUTIVE DIRECTOR
FIBROMYALGIA WELL SPRING FOUNDATION
PO Box 1600, Aldergrove, BC., V4W 2V1

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http://www.fibromyalgiawellspringfoundation.org/ 604-530-4173
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Executive Summary

Fibromyalgia is a condition that causes chronic muscle and soft tissue pain and tenderness on both sides of the body, above and below the waist. Fibromyalgia does not damage the body, destroy the joints, or cause any internal organ problems, but the pain may be severe enough to interfere with work and other activities...People often have trouble sleeping because of the pain. There may also be stiffness, weakness, and fatigue.1

In May 2007 the Foundation hosted the first meeting of its Fibromyalgia Support Group. Support Group meetings are chaired by the Foundation’s Executive Director who is herself a sufferer of Fibromyalgia. Findings from that meeting have become the basis for this submission.

Sufferers of Fibromyalgia;

i. require better diagnosis and monitoring from medical professionals.

ii. need access to affordable housing with supportive care.

iii. that are able to live at home need help with housekeeping and meal preparation.

iv. have psychological problems such as low self esteem and self worth as a result of the debilitating condition.

v. suffer from ‘Fibro-Fog’ which results in a lack of understanding and an inability to complete simple forms.

vi. suffer from the stress created by an inability to pay bill on time.

vii. are unable to perform simple acts such as the completion of Forms due to an inability to understand the contents of the form caused by the chronic condition.

Funding for Charitable Organizations and Support Groups that deliver services to sufferers of Fibromyalgia should be increased.

Funding programs to cover the expenses of volunteers working with charitable organization and support groups should be developed. These programs can be based on in-kind contribution of volunteer time to government funding.

Pro-active health care keeps sufferers of chronic conditions out of the already over burdened medical health system.

Charitable organizations and support groups can be more efficient than government bureaucracies in delivering pro-active health care services.
Purpose of this document

This document will describe the:

1. Condition known as Fibromyalgia,
2. Fibromyalgia Well Spring Foundation,
3. Fibromyalgia Well Spring Foundation Support Group,
4. Findings of the Support Group,
5. Solutions

1. What is Fibromyalgia?

1.1. Fibromyalgia

Fibromyalgia is a condition that causes chronic muscle and soft tissue pain and tenderness on both sides of the body, above and below the waist. Fibromyalgia does not damage the body, destroy the joints, or cause any internal organ problems, but the pain may be severe enough to interfere with work and other activities...People often have trouble sleeping because of the pain. There may also be stiffness, weakness, and fatigue. 

In 1987 the American Medical Association recognized Fibromyalgia as a ‘true’ illness. In that same year an article by a physician named Goldberg appeared in the Journal of the American Medical Association in which he named the disease Fibromyalgia.

Even though Dr. Goldberg’s article appeared in one of the most prestigious medical journals in the world, doctors still were slow to accept Fibromyalgia as a real disease because of a lack of “clinical” evidence.

1.2. Fibromyalgia 1990

In 1990 the American College of Rheumatology published the Criteria for the Classification of Fibromyalgia: Report of the Multicenter Criteria Committee which became the definitive criteria for the diagnoses of Fibromyalgia. The diagnoses required that the patient’s pain meet two requirements.

In the first part the patient had to show a history of widespread pain. The pain had to be in both the right and the left side of the body. Pain also had to be found above the waist and below the waist. This pain had to be present over a period of 3 months.
In the second part of the diagnosis the patient was tested at 18 Tender Points on the body. The physician performing the test was required to provide digital palpitation of 4 kg. force on each of the Tender Points. The patient had to state that the palpitation was painful at 11 of the 18 Tender Points.

While this protocol has become the definitive tests for Fibromyalgia there are other learned persons who have questioned the use of Tender Points rather than a more generalized approach.4

This document which included the work of the American College of Rheumatology went further and gave medical practitioners and others what would help them the most.

1.3. Fibromyalgia 2003


The National ME/FM Action Network [Canada] spear headed the drive for the development of an expert consensus document, which would include a clinical definition, diagnostic and treatment protocols, and a discussion of pertinent research for the Fibromyalgia Syndrome [FMS]. As increasing numbers of FMS patients asked about knowledgeable doctors, it quickly became clear that there was a need for more education about FMS among primary care practitioners. The Network sent out a questionnaire to doctors across Canada asking what items would be most helpful in assisting them with their FMS patients. The physicians concurred that a clinical definition, as well as diagnostic and treatment protocols, were of prime importance.6

The editor of the journal stated:
This undertaking can be viewed as the next step in a long-term plan. Since the development of the American College of Rheumatology [ACR] 1990 Classification Criteria for the Fibromyalgia Syndrome (3), it has been clear that eventually it would be necessary to determine what to include in a clinical case definition for use in community medicine.

Recently the co-authors have produced an overview of the original document to allow physicians and other practitioners an easier reference document.7

1.4. Taxonomy of Fibromyalgia8

<table>
<thead>
<tr>
<th>Localized</th>
<th>Regionalized</th>
<th>Generalized</th>
</tr>
</thead>
<tbody>
<tr>
<td>Entrapment Syndrome (e. g. Carpel Tunnel Syndrome)</td>
<td>Myofascial pain syndrome (MPS)</td>
<td>Fibromyalgia Syndrome (FMS)</td>
</tr>
<tr>
<td>Tenosynovitis (e. g. biceps tendonitis)</td>
<td>Masticatory Myofascial pain syndrome (TMD)</td>
<td>Chronic Fatigue Syndrome (CFS)</td>
</tr>
<tr>
<td>Bursitis (e. g. trochanteric bursitis)</td>
<td>Chronic Regional Pain Syndrome (CFPS, RSD)</td>
<td>Polymyalgia rheumatica (PMR)</td>
</tr>
<tr>
<td>Enthesopathies (e. g. tennis elbow)</td>
<td>Referred visceral pain (e. g. left shoulder pain due to angina)</td>
<td>Hypermobility syndrome (HMS)</td>
</tr>
</tbody>
</table>

2. What is the Fibromyalgia Well Spring Foundation?

2.1. The Start of the Foundation

In April 2006 the Founder Cheryl Young, herself a sufferer of Fibromyalgia spoke with a few friends and expressed her concerns with the lack of health care for other sufferers of Fibromyalgia. She wanted to do something but was unsure on how to proceed. After discussion it was thought that the best way to help other sufferers was to form a charitable organization, raise funds and use those funds to build and operate a home for sufferers of Fibromyalgia. After additional discussion with others over several weeks, it was thought that rather than a single home we should build a wellness center in a village setting where sufferers could live and receive treatments.

In June 2006 the Foundation applied for incorporation under the Society Act of the Province of British Columbia which was granted 26 July 2006.
At the same time application was made to the Canada Revenue Agency for registration as a charitable organization under the Income Tax Act of Canada. This was granted effective 1 January 2007.

2.2. Vision of the Foundation

We will work to reduce the physical suffering and mental anguish of those people who suffer from Fibromyalgia while increasing through education, the understanding and knowledge of those who do not have this disease.

2.3. Mission of the Foundation

We will operate a village for residents and a Wellness Centre for both residents and outpatients suffering from Fibromyalgia, to help alleviate the physical pain and mental anguish caused by their inability to function successfully in the present world.

2.4. Goal of the Foundation

Fibromyalgia Well Spring Foundation will operate a supportive housing village which will include health, education, food and recreational facilities in support of Fibromyalgia suffers.

2.5. Principals of the Foundation

Service: We will serve others and this is the force behind all our actions.

Respect: We will treat others with dignity and kindness. We will honour others for who they are, what they have accomplished and who they can become.

Integrity: We will say what we are going to do and then we will do what we have said.

Trust: We will create openness by having faith, confidence and belief in others.

Authenticity: We will be natural and genuine and not appear to be what we are not.

2.6. Purposes of the Foundation

The purposes of the Foundation shall be to:

(a) provide care for functionally independent persons suffering from fibromyalgia and other related illness and conditions,

(b) provide therapy and pain management to persons coping with fibromyalgia and other related illness and conditions,
(c) provide counselling services for persons suffering from fibromyalgia and other related illness and conditions,

(d) make the public aware of the suffering of persons with fibromyalgia and other related illness and conditions,

(e) fund research into the alleviation of fibromyalgia and other related illness and conditions,

(f) educate medical professionals and academia in complementary or alternative treatments of fibromyalgia and other related illness and conditions.

2.7. Supportive Living

The Province of British Columbia describes supportive living.

Supportive housing operators do not need to register their residences. Supportive housing refers to situations where an operator offers only two components: housing and hospitality services.

Some supportive housing operators may also offer personal assistance but only at a support level, not at a prescribed services level. This situation does not meet the definition of assisted living residence. To learn more about the difference between the support and prescribed services levels of personal assistance, see the section “What are prescribed services?” on page 4 of this guide.11

As well as providing affordable housing for sufferers, it is the intention of the Foundation to develop a Wellness Center staffed by the appropriate professionals at the village for both residents and out-of-village clients.

3. The Fibromyalgia Well Spring Foundation Supportive Group

3.1. Operation

In May 2007 the Foundation hosted the first meeting of its Fibromyalgia Support Group. Support Group meetings are chaired by the Foundation’s Executive Director who is herself a sufferer of Fibromyalgia. The support group meets as often as practical, approximately every month.

3.2. Purpose

The purpose of these meetings is to:

- share the day to day challenges of sufferers with others in the group,
- provide counselling on how health and circumstances can be improved,
- suggest ways that the challenges identified may be overcome,
- provide positive support, turn negatives into positives,
- identify the types of support each member requires,
3.3. Information Gathering

The Executive Director ensures to:

- gather information to make medical practitioners and governments aware of these problems and,
- suggest methods to mitigate the problems of sufferers.
- lobby on behalf of the Foundation, its members and the support group.

At the latest meeting the attendees were asked to identify their greatest challenges living with Fibromyalgia.

4. Findings of the Support Group

4.1. Medical Professionals

.1 Physicians

While it was recognized that physicians have a place in the treatment of sufferers of Fibromyalgia the support group members all described the inability of physicians to speedily diagnose the condition.

What could not be determined by the sufferers was the reasons behind this situation. The sufferers are not in a position to determine whether this situation;

i. was a lack of knowledge about the condition by the physicians or,

ii. was it a lack of practical skill in applying the physical tests as described in the American College of Rheumatology Criteria.\(^{12}\)

.2 Prescribed Medicine

The support group feels that physicians are unsure of the proper treatment protocol for this condition.

As a result physicians have prescribed drugs for pain and depression, which other general practitioners with more specific knowledge and experience of Fibromyalgia then determined were in fact contra-indicated for the condition.
.3 Follow Up

Sufferers are concerned about the inadequate follow by physicians after prescriptions have been made.

They also feel that ongoing monitoring and supervision is inadequate and does not take in to account the affect of the medication on their lifestyle.

.4 Dentists

The support group members were unanimous in their identification of the challenges associated with a lack of knowledgeable dentists.

One member of the support group related how 3 visits of 20 min. each were required for a simple cleaning. The level of pain after 20 minutes of cleaning became unbearable and the procedure had to be stopped. It was continued several days later after the pain had subsided to a level that could be withstood by the sufferer.

Needless to say this was very costly to the sufferer and time consuming for the dentist and dental hygienist.

4.2. Housing

.1 Making the Mortgage

Fibromyalgia is a debilitating condition which does not permit its sufferers to hold gainful employment. This inability to obtain and keep employment results in the:

i. primary wage earners being unable to obtain and keep a job,

ii. families losing their homes when the wage earner is unable to pay the mortgage,

iii. families being evicted and becoming a charge on the tax payer,

iv. families breaking apart because of the lack of a stable home environment.

v. harassment by creditors due to an inability to regularly pay bills on time or not being able to pay them at all.

.2 Maintaining a Healthy Home

Fibromyalgia is a debilitating condition which does not permit its sufferers to do simple household functions. This inability to perform simple tasks around the house results in sufferers;

i. being unable to perform cleaning tasks,
Challenges of Living with Fibromyalgia in British Columbia

ii. being unable to keep their homes clean,

iii. being unable to prepare meals for themselves,

iv. becoming alienated from friends, spouses and relatives.

.3 Homelessness

Fibromyalgia is a debilitating condition which forces the sufferer to constantly move in the search for affordable, suitable housing with appropriate support.

The Fibromyalgia sufferer becomes homeless not because of alcohol or drug related challenges, but because of an inability to find affordable, suitable housing with appropriate support.

4.3. Psychological Impact

Fibromyalgia is a debilitating condition which causes the sufferer to live in constant pain. This constant pain affects the sufferers because:

i. psychologically they are ashamed of their physical shortcomings,

ii. psychologically they have a low level of self-esteem, and self-worth – suicidal,

iii. psychologically they are not physically able to socialize with their friends,

iv. physically they do not live in a clean environment,

v. physically they are unable to keep and enjoy their home gardens.

vi. of the need for emotional and mental counseling.

4.4. Form Completion

.1 Fibro - Fog

A person suffering from Fibromyalgia lives in constant pain. To obtain assistance from the various levels of government the sufferer must make application and complete numerous forms.

“Fibro – Fog” does not allow sufferers to clearly read, understand and complete forms.

What is Fibro Fog?
When fibromyalgia sufferers, forget what they are doing, saying or where they are going we refer to the temporary memory loss as 'Fibro Fog'! It's not really funny when you have FF!!
.3 Painful Duplication of Effort

Some of the organizations that require sufferers to complete forms are: Insurance Companies, Employment Insurance, Work Safe BC, Canada Pension Plan.

Unfortunately these organizations require the same information but each on their own form.

This means the sufferer describes the same condition, on several different forms.

While this is onerous to people without the condition it is a monumental challenge for Fibromyalgia sufferers.

5. Solutions

The following suggestions are submitted as possible solutions to some of the many Challenges of Living with Fibromyalgia in British Columbia.

5.1. Health Professionals

i. Educate the medical profession on how to correctly and quickly diagnose this disorder. It takes some time to diagnose the condition. Using the 1990 Criteria for the Classification of Fibromyalgia it takes 18 months of observation and testing.

ii. In British Columbia a panel of doctors, practitioners and Fibromyalgia Sufferers should form a committee to review the 1990 Criteria as other, more recent information is now available and produce a definitive protocol for BC.

iii Funding should be allocated to the promotion of more awareness of Fibromyalgia and other related illness, e.g. Myofascial Pain Syndrome, to the general public.

iv. Dentists must be made more aware of the condition and the correct protocols during treatment of patients with Fibromyalgia.

5.2. BC Medical Services Plan

i. The Medical Services Plan should cover the full cost of dentistry for sufferers of Fibromyalgia.

ii. Sufferers need better access as part of the B.C. Medical Services Plan to paramedical professionals, i.e. physiotherapist, chiropractors, naturopathic, etc. The number of visits per year needs to be increased for Fibromyalgia sufferers.

iii. Fibromyalgia sufferers should be able to charge the use of Natural Supplements to the BC Medical Services Plan. Any personal savings a Sufferer may have now is used to provide Natural Supplements and paramedical services, leaving little money for their housing and nutritional needs. This leaves nothing for their retirement so they have to depend on government pensions.
and subsidies to live. As government subsidies are inadequate the overall health of the Sufferer deteriorates. This forces the Sufferer in to the hospital system which is already over crowded and so health care costs are driven even higher.

5.3. Funding for Charitable Organizations and Support Groups

i. Individuals working within charitable organizations and support groups to assist Fibromyalgia sufferers, to complete government, insurance and other forms and documents, need financial support. A program should be developed to fund expenses of volunteers. The funding should equal the in-kind contribution of time provided by the volunteers in the program. This program then becomes a partnership between the charitable organization or support groups and the Health Ministry.

ii. Programs are needed to allow charitable organizations to provide affordable supportive housing with basic needs i.e. adequate nutritional food, to sufferers of Fibromyalgia. These funding programs could be in the form of grants or low interest loans. Some government funding programs already exist but the amount of funds for capital expenses is very limited.

iii. Funding programs are needed for charitable organization to act as Resource Centers for the publication and distribution of information to help sufferers is needed.

iv. Charitable organization and support groups that take on the task of educating sufferers of Fibromyalgia need funding support to deliver their program. Topics such as: relaxation techniques, goal setting and mental relaxation are but a few subjects which have shown to increase the quality of life for the sufferers. Funding is needed to cover space rental, printing and distribution. Funding is also needed to cover the transportation of Fibromyalgia sufferers enabling them to attend the meetings as many sufferers are unable to drive themselves and public transportation can either not be available or be painful for the sufferer.

6. Conclusion

The medical health system was never designed to provide pro-active health care.

Pro-active health care keeps sufferers of chronic conditions out of the already over burdened medical health system.

Charitable organizations and support groups can be more efficient than government bureaucracies in delivering pro-active health care services.
Challenges of Living with Fibromyalgia in British Columbia

1. B.C. Health Guide
2. B.C. Health Guide
6. *Ibid* pg. 1