NATIONAL ME/FM ACTION NETWORK

Quest Newsletter

www.mefmaction.com Quest 121, Winter 2019 mefminfo@mefmaction.com

In This Issue

Does FM affect your sex life? Indeed it does. But the news is not all bad. Having a positive sex life does not depend on how much sex you have. The key is that your sexual behaviour has to align with your sexual values and those of your partner.

We would like to thank the University of New Brunswick for sharing with us a poster describing a study they undertook. We would also like to thank Liana Brittain who provides insights into issues around sex, intimacy and FM.

Thank you also to Dolores Griffin (PEI) for her insights into applying for Long Term Disability coverage.

Canada's new Minister of Health

from Wikipedia

Patricia A. Hajdu PC MP (/ˈheɪdjuː/; born November 3, 1966) is a Canadian Liberal politician, who was elected to represent the riding of Thunder Bay—Superior North in the House of Commons of Canada in the 2015 federal election. Since November 2019, she has been the Minister of Health in the federal Cabinet. Previous to this, she was the Minister of Status of Women and Minister of Employment, Workforce Development and Labour.

Early life and education

Born in Montreal, she spent her early years in Chisholm, Minnesota, raised by her aunt and uncle. Her last name comes from her stepfather.

At 12 years old, Hajdu moved to Thunder Bay to live with her mother. Due to a tumultuous relationship, she ended up living on her own at age 16, attempting to finish high school. After graduating high school, she got a job in Thunder Bay through an employment-insurance initiative, at a non-profit adult-literacy group, where she trained in graphic design.

Hajdu then attended Lakehead University, graduating with a Bachelor of Arts degree with Honours in anthropology. She later earned a Masters of Public Administration from the University of Victoria.

Career

Hajdu worked mainly in the field of harm prevention, homelessness, and substance misuse prevention, including nine years as the head of the drug awareness committee of the Thunder Bay District Health Unit. She also worked as a creative director and graphic designer in marketing. Prior to her election in 2015 she was the executive director at Shelter House, the city's largest homeless shelter.

On November 4, 2015, she was appointed the Minister of Status of Women in the federal Cabinet, headed by Prime Minister Justin Trudeau. In this capacity, she convened in July 2016 an advisory council to help develop of Canada's strategy against gender-based violence. She was sworn in as Minister of Employment, Workforce Development and Labour on January 10, 2017.

On October 29, 2018, Minister Hajdu, alongside Status of Women Minister Maryam Monsef and President of the Treasury Board and Minister for Digital Government Scott Brison introduced proactive pay equity legislation for federally regulated workplaces, which ensures that women are fairly compensated for the work that they do. This legislation will ensure that all federally regulated employers examine their compensation practices to reflect equal pay for work of equal value for both men and women.

Contents

Priorities of the new Minister of Health include:

- tweaking Canada's assisted-dying law,
- dealing with the country's long-standing opioid crisis,
- delivering equitable health-care to Indigenous communities, and
- developing a national pharmacare plan.

November 27. 2019

The Honourable Patty Hajdu
Minister of Health
House of Commons
Ottawa, Ontario
Canada
K1A 0A6

Dear Minister Hajdu,

The National ME/FM Action Network would like to welcome you to your new position as Minister of Health.

We are a registered charity that has been working on behalf of Canadians with Myalgic Encephalomyelitis (ME), Fibromyalgia (FM), or both for over 25 years. (ME used to be referred to as Chronic Fatigue Syndrome).

The 2016 Canadian Community Health Survey, conducted by Statistics Canada, found that there are almost one million Canadians with a diagnosis of ME, FM or both. These Canadians consistently show high rates of unmet health care needs, disability, poverty, social isolation and food insecurity. Our 2014 report provides a good introduction to the issues: https://www.mefmaction.com/docs/CCHS_Stats_2014.pdf

ME and FM have been badly neglected by the health research and health care systems. Thanks to concerted efforts of the international ME/FM community, we are seeing growing recognition that ME and FM need attention. In a media conference held by your predecessor in August of this year, Minister Petitpas Taylor announced funding of a ME research network. In her statement, she recognized the need for equitable research funding, public awareness, training of health professionals and improvements to government programs and policies.

We want to emphasize how important it is to follow up on the issues that Minister Petitpas Taylor has identified. We look forward to working with you to build on these priorities.

Yours truly

Margaret Parlor

President, National ME/FM Action Network

Fibromyalgia and the Gut Microbiome

Scientist used to think that our DNA largely determined our health and development. Then they came to realize that we all co-exist with microorganisms such as the bacteria in our gut or on our skin. The types and quantities of various bacteria could be a factor in health and development.

A recent study out of McGill University showed that people with FM had different proportions of various bacteria in their stool samples (more eloquently referred to as gut microbiota) compared to healthy controls. In fact, the researchers were able to diagnose FM correctly 88% of the time based solely on stool samples. See *Altered microbiome composition in individuals with fibromyalgia* by Minerbi et al in the journal PAIN.

Scientists at the University of Alberta (Edmonton) would like to replicate this study to see if they arrive at the same results. They would also like to take the study a step further – seeing if the difference in the microbiota could be causing symptoms. What they would do is to take stool samples from people with FM and from health controls and inject them in mice. If the FM mice start showing certain behaviours like pain sensitivity or inflammation, this would suggest that the mix of bacteria could be responsible for FM symptoms. That in turn would suggest that rebalancing the gut bacteria could be a technique to treat FM. The scientists are looking for $50k in funding for a feasibility study.

Edmonton resident Ivan Tolentino is interested in fund-raising for this research study and has started an organization called The Fibromyalgia Research Project (FMRP) for this purpose. Along with his partner, Briony, they want to create greater awareness and better understanding about FM. The National ME/FM Action Network has agreed that this research study is worth pursuing and will issue charitable tax receipts for donations to this research study.

October 2019 - Publicity for New ME Research Network

The new ICanCME research network received some media coverage when it was officially announced on August 22, but it received another round of coverage in October.

Dr Alain Moreau in a CBC Interview

It was featured on CBC's national news on October 22. Special guests were Dr Alain Moreau and Marie-Josée Ménard. To view the recording, go here. *https://www.cbc.ca/news/health/chronic-fatigue-recognition-research-1.5330712*

There was also an interview with Dr Moreau on the CBC Toronto morning show the next day.

The new Research Network was also featured on Edmonton's Global channel on October 28. The segment was rebroadcast by Global National news in November. Special guests were Dr Amir Landi and Judy-Anne Wilson. To view the recording, go here:

https://globalnews.ca/video/6095250/new-research-network-may-provide-more-answers-for-people-with-chronic-fatigue

It is wonderful to get the publicity.

13th International IACFS/ME Research and Clinical Conference: Advancing Science and Clinical Care

CALL FOR ABSTRACTS AND WORKSHOP PROPOSALS

June 10-13, 2020

Stony Brook University, Stony Brook, New York, USA

Abstracts accepted from Wednesday, November 20. 2019 to Wednesday, February 5, 2020, at 11:59 pm Eastern Standard Time.

Contact us if you need futher information.

Chronic Pain

We featured the first report of the federally-appointed Chronic Pain Task Force in our last newsletter. The Task Force is about to start cross-country consultations, but we don't have details yet. We will keep you posted.

The following statistics come from a survey conducted by the Chronic Pain Association of Canada. The survey targeted Canadians who said that they took or should have taken opioids in the last two years. CPAC argues very strongly that recent actions taken to deal with the "opioid crisis" are having a very negative effect on people with chronic pain.

Canadian Pain Patient Survey: Responses (1)

Qualifiers: All respondents were asked to choose their province or territory of residence, non-Canadians were asked to exit the survey. Respondents were asked if, in the past two years, they took/should be taking opiate medicine. 'No' and 'no answer', were excluded. Partially completed surveys were excluded.

In the past two years, have changes to your pain care been

Harmful	204	27.6%	combined 48%
Very harmful	151	20.4%	
No change	222	30%	
Helpful	112	15.1%	
Very helpful	23	3.1%	
No Answer	28	3.8%	
Total	740		

Use of Opioids in the past two years (n=807)

No, or No Answer	67
Yes	740

Relationship with doctor in the past 2 years (n=740)

deteriorated	220	29.7%	combined 44.6%
no longer have the MD	103	13.9%	
improved	67		
no change	318		
N/A	32		
Total	**740**		

In the past 2 years have you been dropped by your doctor or had your doctor refuse to prescribe

Yes	248	33.5%
No	471	
No Answer	21	

Forced to reduce against will

Yes	354	47.8%
No	359	
NA	27	

Do OTC or other non-opioids help your pain?

Yes	105	
No	615	83.1%
NA	20	

If yes, what helps

Numerous answers including wine and beer but some form of marijuana alone or in combo 47 out of 105 or 49.6% with varying reports of efficacy

More pain in past 2 years

No	207	
Yes	533	72.0%

More disability and can do less

No	218	
Yes	523	70.6%

Quality of Life Declined

No	228	
Yes	512	69.2%

Found more effective treatment than opioids

No	700	94.6%
Yes	40	

Don't really needs opioids

I need them	724	97.8%
I don't need them	16	

Canadian Pain Patient Survey: Responses (2)

Doctor who prescribed has stopped practicing

No	644	
Yes	96	13.0%

Forced to provide urine samples against will

No	582	
Yes	158	21.4%

Forced against my will to sign that I have taken opiates

No	635	
Yes	105	14.2%

Dropped by doctor for failing a drug test

No	733	
Yes	7	0.9%

Pharmacist refused to fill opioid prescriptions

No	687	
Yes	53	7.2%

Have considered suicide

No	452	
Yes	288	38.9%

Attempted Suicide because of pain

No	700	
Yes	40	5.4%

Know someone who committed suicide because of uncontrolled pain

No	492	
Yes	248	33.5%

Not adequately treated in ER for pain

No	445	
Yes	295	39.9%

Referred for addiction treatment

No	691	
Yes	49	6.6%

Prescriptions now for shorter periods of time

No	466	
Yes	274	37.0%

Insurance refused to pay for pain treatment

No	613	
Yes	127	17.1%

Pharmacist refused to fill prescription until the day due or later

No	476	
Yes	264	35.7%

Obtained opiates illegally for pain control

No	667	
Yes	73	9.9%

Know people who have obtained opioids illegally for pain control

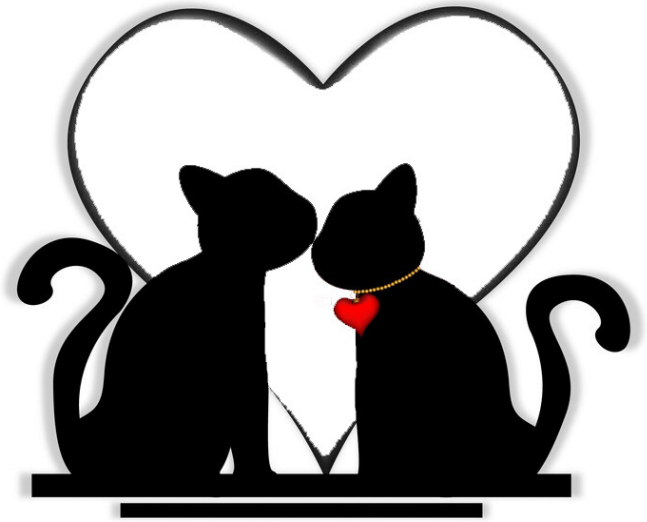
No	512	
Yes	228	30.8%

Feel discriminated, degraded, etc because you use opioids

No	250	
Yes	490	66.2%

In the past 2 years, have you received adequate pain care

No	474	64.0%
Yes	226	
NA	40	



Sex, Intimacy and Fibromyalgia

by Liana Brittain

"Is Sex Worth the Pain?" is the title of a poster published by the Department of Psychology, University of New Brunswick. This study is a focused look at the correlation between sexual intercourse, relationship satisfaction and chronic pain in women who were diagnosed with Fibromyalgia. The women who participated in this research ranged in age from twenty-eight to sixty-seven and were in committed relationships.

As a woman who was in a committed relationship when I was diagnosed with Fibromyalgia in my late forties, I have lived this and am prepared to comment on this topic based on my personal experiences and on conversations I have had with others.

One of my first questions when looking at this report was why men were not included. It may be a matter of numbers – more women than men are diagnosed with FM. But let's not forget the experiences of men with FM as we move forward.

In order for a committed, intimate relationship with a partner to work, it must involve more than just sexual intercourse. It requires alternatives to "success in the sack", if I may be permitted to use the vernacular. A contented, happy relationship includes so much more than the physical act of arousal, penetration and ejaculation. It requires a partner who is also interested in having sex with a person who lives with chronic pain and all the other symptoms of Fibromyalgia. I've heard several women in my situation complain that their partner no longer found them sexy when they knew she lived with unremitting pain. It made them nervous, anxious, fearful of hurting their lover. Some also said their partner wanted it "right then and there" and wasn't interested in planning, preparing or creating opportunities. That was "just way too much effort". In other words, the attitude of the partner in the relationship plays a very significant role.

There are other important factors as well. "Flaring" is unpredictable. If your Fibromyalgia symptoms are heightened due to an increased intensity in the symptoms (known as "flaring" or having a "flare up") having sex can get complicated. If you don't know from one hour to the next how you're going to be feeling, it's difficult to plan a romantic, intimate encounter. Kiss spontaneity goodbye! (Yes, pun intended) Under these circumstance, being "in the mood' can become a challenge and sex risks be relegated to the category of just another chore. Sometimes, both partners in a relationship are interested and willing, but one is not physically capable of participating for a variety of different reasons. That creates an entirely different set of challenges.

Beyond Intercourse

Regarding the importance of intimacy, in "Psychology Today", Stephen Stosny PhD says the following - "We come into the world with a drive for intimate contact that develops and articulates itself in various complex ways throughout life. When the most important attachment relationships provide more reward than punishment, the likelihood of health and happiness increases. With little intimate contact, lives are often emotionally impoverished. With no intimacy, depression or instability is likely to loom."

The question then becomes, if we need intimacy to achieve a good quality of life, how do we acquire it in the presence of an obstacle such as the symptoms of Fibromyalgia, the physical inability of one of the partners to participate or perhaps the absence of an interested, willing partner? It also becomes necessary to ask if intercourse in the only way to achieve intimacy and enhance both our senses of well being and our quality of life. By exploring alternatives, perhaps we can find more options to help resolve the very complex issues of sex and intimacy in and outside a relationship. Let's be

continued on page 8

Is Sex Worth The Pain? Willingness To Engage In Sexual

Kirsten M. Gullickson[1], Lyndsay Crump[1], Diane L. LaC

[1]Department of Psychology, University of New Brunswic

INTRODUCTION

BACKGROUND

- Up to 97% of patients with fibromyalgia (FM) report it adversely affects their sexual lives[1].
- Commonly reported impacts of FM on sexual well-being include decreased sexual frequency, lower sexual desire, difficulty with arousal and orgasm, and reduced sexual satisfaction[2-3].
- However, previous research has not assessed:
  - Women's willingness to engage in sexual activity despite FM
  - The extent to which women with FM view the changes to their sexual lives as distressing to themselves or their partners
- Improving our understanding of the impact of FM on women's sexual lives is essential because sexual well-being is an important contributor to relationship satisfaction and stability, psychological health, and quality of life[4].

PURPOSE

- This project was part of a larger study exploring women's lived experiences of the impact of FM on their sexual well-being
- Our aim was to understand women's:
  - Feelings about FM-related changes to their sexual lives
  - Perceptions of how these changes affect their relationship
  - Willingness to adjust their sexual scripts to accommodate FM

METHOD

PARTICIPANTS

- 16 women with FM who were in a committed romantic relationship
  - *Age (years): M* = 45.19; *SD* = 12.03; Range = 28-67
  - *Relationship length (years): M* = 14.4; *SD* = 12.31; Range = 1-43
  - *Time since diagnosis (years): M = 10.08; SD = 6.56,* Range = 3-22

PROCEDURE

- Audio-recorded semi-structured interviews in person or via telephone lasting approximately 60 to 90 minutes

ANALYSES

- Semantic and latent content was coded based on the principles of Thematic Analysis[5]

REFERENCES

1. Fitzcharles, M. A., et al. (2013). 2012 Canadian guidelines for the diagnosis and management of fibromyalgia syndrome: executive summary. *Pain Research and Management, 18*(3), 119-126.
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ACKNOWLEDGEMENTS

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- *Resource support:* UNB Psychological Wellness Centre

***For a copy of this poster please visit http://www.rehabilitationpsychologyresearchlab.com**

- Consistent with existing literature, the vast majority of women reporte
- Latent content underlying participants' narratives suggested **sex was a**
- Related to this, some women expressed **willingness to engage in sex d**
  - Willing individuals described attempts to adjust their sexual scrip
- Participants reported varying levels of **personal distress and relationsh**
  - For women whose sexual behaviour was consistent with their sex
    - **Group 1:** valued sex and were willing to engage in sex despi
    - **Group 3:** did not engage in sex because it was not a strongly
  - For women whose sexual behaviour was not consistent with their
    - **Group 2:** valued sex, but were unwilling to engage in sexual
    - **Group 4:** engaged in sex despite not valuing sex as a means

"Sometimes if I'm having a really bad day I might just have to t knee hurts, we're not gonna have sex in that position, let's do i really a non-issue… there's never any conflict about it." – Partic

"Right now I'm not concerned [about our sex life]… we're in a g smooth sailing." – Participant 8

"The pain doesn't prevent me [from having sex]. Sex is worth the pain." - Participant 12

"Even if I don't feel like [sex] I still do it… Sex is part of your relationship and you have to try the best that you can to have a good sexual life with your partner…" – Participant 18

1.

ENGAGEMENT IN SEX DESPITE FM

4.

"[My husband] would make me literally cry at night saying 'you know important sex is to me' and 'you know that was part of the deal when married' and 'now you're just pretending that you can't [have sex] an because your losing interest'… so I would suffer through it." – Particip

- A proportion of women with FM are willing to engage in sexual activity
- Women who experience FM-related changes to their sexual lives do no
- Clinicians can help individuals and couples adjust to FM by encouraging communication training, recommending changes to the sexual script).
- Engagement in valued activities despite pain is an essential component pain acceptance.

Activity Among Partnered Women With Fibromyalgia

hapelle[1], Pablo Santos-Iglesias[2], & E. Sandra Byers[1]

k [2]Department of Oncology, University of Calgary

RESULTS/DISCUSSION

d experiencing changes in their sexual lives as a result of FM (e.g., pain, fatigue, depression, medication side-effects, negative body image)[1-3].
valued activity for some women, but not others.
espite FM, while others described **little to no willingness to engage in sex**.
ts to accommodate FM by changing the timing, duration, location, or nature of their sexual encounters.
ip conflict as a result of the sexual impacts of FM.
ual values, lower levels of personal distress and interpersonal conflict were reported:
te FM
y held value
r values, higher levels of personal distress and interpersonal conflict were reported:
activity due to their illness
of reducing conflict or out of fear of losing their relationship

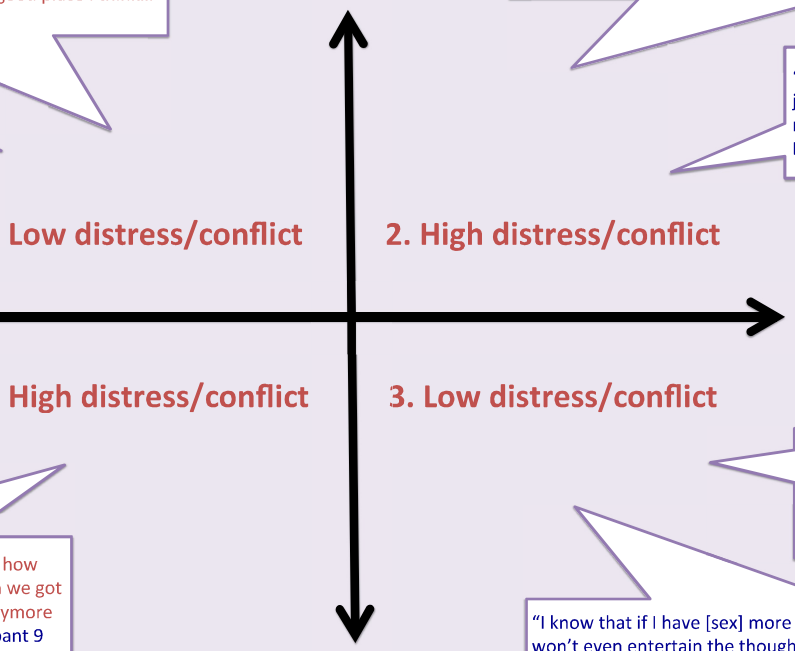
ell him 'Hey, my
t this way' and it's
cipant 4

good place I think...

"I would get angry and frustrated [when FM got in the way of sex]. It's like FM has affected so many aspects of my life, can't I just have one thing that it doesn't affect...." – Participant 13

"I feel like I've let [my husband] down" – Participant 7

"[Our sex life] lacks when I have a period of really not feeling well. I just keep telling myself 'I'm going to feel better in a few days'..., but right now it hasn't gotten any better and we still aren't having sex." – Participant 11



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"Lots of time you don't feel like being touched. Especially when you have a flare-up... Sex is the last thing on your mind for sure. With us [lack of sex] is not too bad... I could see other couples, it impacting them for sure... fighting about it or whatever but we've been very fortunate... The two of us are okay with that." – Participant 1

"I know that if I have [sex] more frequently I'm going to be in agony, so I just don't... I won't even entertain the thought [of having sex] even if I am aroused." – Participant 5

"Although [sex] is enjoyable for both of us, it's not as important [to us] as it may be for some people." – Participant 14

IMPLICATIONS

despite their condition, indicating that for some women, sex is worth the pain.
t necessarily experience personal distress or interpersonal conflict if their sexual behaviour is consistent with their sexual values.
g patients to clarify their sexual values and, if sex is a strongly held value, assist them in finding ways to engage in sexual activity despite FM (e.g.,

t of chronic pain acceptance, therefore a woman's willingness to engage in sexual activity despite FM may be an indicator of more general chronic

honest, not everyone has or even wants a partner in their life but, according to Dr. Stosny, we all have that basic human need for intimate contact.

Alternatives to Intercourse

When a person is in a committed relationship and sex is no longer an option, life can look very bleak. I worked as a facilitator in the Stanford Chronic Pain Self-Management program offered in Kingston, Ontario, a few years ago. During classes, someone invariably expressed a deep sense of futility and frustration caused by the lack of sex due to the chronic pain, which in some cases was associated with illnesses such as Fibromyalgia. Statements such as "My life is over because no one will ever want to have sex with me again" or "I can't have a normal life because I can't have sex now", expressed the deep sense of fear and rejection caused by their perceived inability to have intercourse.

Depending on a couple's ability to perform intercourse, sometimes, those problems can be overcome by exploring alternate positions. There are many books on the subject and with a bit of creativity and willingness to explore, a position that works for both people in the relationship can be discovered. Courage and communication are key. Just the exploration of the topic and the discussion of alternatives can help achieve a state of arousal or play leading to a state of arousal, which will help move the couple toward a successful sexual encounter.

Another option that can be explored if traditional sex is no longer possible, is oral gratification. In lieu of penetration and ejaculation, orgasm can be induced through foreplay and mutual oral stimulation.

In a similar manner, sex toys and aids can be used to create arousal leading to orgasm and sexual release. Some of the devices available today are technological works of art! It's a topic worth exploring. The staff at Adult Stores are always very willing and able to find exactly what you had in mind or even guide you toward alternatives. If you are not comfortable or don't have access to a store, then online shopping might be the answer to your needs.

The Importance of Touch

My mother once said, "I feel weird when I go for a long time and no one touches me." She was a widow living with my husband and me at the time. Now that I'm a widow living alone, I genuinely understand what she meant. When no one touches me for long periods of time I feel "spacey" for want of a better word… or perhaps "ungrounded" explains it better. It's like you're floating or disconnected from reality. For me, touch resolves that problem instantly. Whether it's something as simple as a warm, heartfelt hug or a hand on my shoulder, it brings instant relief. An "ahhhhhhhh" and physical let down or relaxation. It's amazing that such a simple gesture can bring so much relief and provide a sense of connectivity and intimacy, which may not even be sexual and often isn't.

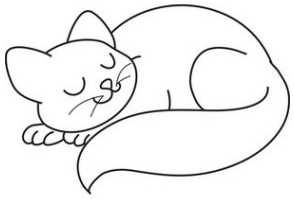
Living alone, I've found that it's not just humans who can provide that sense of belonging and connectedness that touch provides.

According to an article in US Today, written by Adrianna Rodriquez, pet owners live longer. They quote:

"Keith C. Ferdinand, professor at Tulane University School of Medicine, said … dogs address multiple factors that contribute to cardiovascular diseases, including mental and physical health. Having a family pet may assist a person with managing stress, increasing activity and decreasing isolation and loneliness"

I know that when snuggling with my pups, the rhythmic action of petting them as we watch TV is very soothing and helps me to relax – let go. It distracts me from my chronic pain and loneliness. Is it the same as the release provided by sex? Definitely not, but that simple act of touching connects me and improves my quality of life. It is a different form of intimacy, which although not sexual in nature, provides that intimate contact that Dr. Stosny referred to in the earlier quote.

In conclusion, it is important that everyone have their needs of intimacy met. Sometimes, it takes moving beyond the obvious to find answers that will enhance our personal experiences and improve our quality of life, even when we live with all the chronic pain and symptoms of Fibromyalgia.



NEW Post-Retirement Disability Benefit

Several people called us about the same issue. Each had found, when they were around 60 years old, that they were struggling at work. Each chose to retire early and signed up for CPP early retirement monthly payments. Each later received a diagnosis of ME/FM and realized that they could have applied CPP-Disability monthly payments (which are higher that CPP early retirement monthly payments) from the time they left work until they turned 65. And each found out that they could not go back and apply for CPP-D benefits because the rule said that if you are on CPP retirement benefits for more than 15 months, you can't apply for CPP-D benefits. Both thought it was extremely unfair not to be able to apply.

The rule changed somewhat in January 2019. You still can't apply for regular CPP-Disability payments, but you can apply for the "post-retirement disability benefit" which gives you extra income every month ($496.36 in 2019). People who think they could have qualified for CPP-D when they started their early retirement benefits or became disabled shortly afterwards can apply.

Note that you will receive these benefits for the period before you turn 65. Note also that this benefit was introduced in 2019 and no payment will be made for disability before 2019.

Goliath Won – Lessons Learned from Applying for Long Term Disability (LTD)

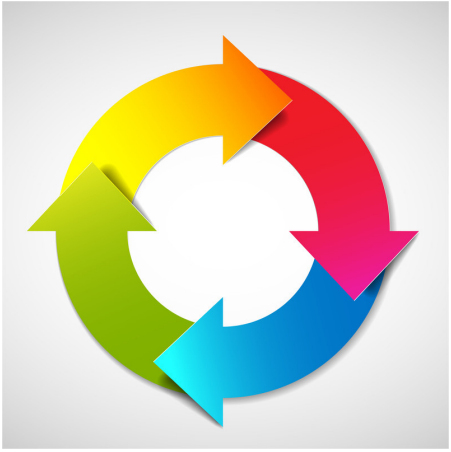
By Dolores Griffin

I was hoping this article was going to be one where I could share tips from a LTD application process which had a positive outcome for the applicant. Unfortunately, the outcome was in favor of the Insurance Company but I believe the lessons learned are still worth sharing, perhaps even more so. This case involved a person 62 years of age with multiple health conditions including Fibromyalgia, severe anxiety and a back issue causing limited mobility.

Here is what I learned:

1) Not all insurance companies are created equal.

   Some companies are more restrictive and difficult to deal with than others. Most of us do not get to choose the company as our employer has that right.



   But if you are going to buy a plan on your own, do some homework and check out on the internet the reviews and comments of others who have dealt with a particular company.

2) Your age plays a factor.

   Too young is not good but too old is no better. I erroneously thought that if one applied nearing retirement age it would go in one's favour (fewer years for the company to pay out). Not so, insurance companies have the idea that people are looking for easy way to retire early.

3) No consideration is given to the fact that conditions worsen as one ages.

   The company's agent actually said to the applicant, "well you worked all those years with the same conditions, why can't you continue to do so". When evidence was given that the multiple conditions had deteriorated and the applicant was no longer able to function at work, the company responded, "take more frequent breaks and get up and move around a bit". Being stoic and holding out in applying until one's disability is severe is not the answer.

4) Work closely with your family doctor.

   Hopefully you will have built up trust with your family doctor especially if you have been a patient for several years. Your doctor is required to complete a physician's report as part of the initial application process. He/she may not be fully aware of all your work functions nor the impact on your home life. You can assist with that in a number of ways such as preparing a document outlining your work and home responsibilities in detail and then how your health condition(s) impact on your ability to do each of those functions. You can save your doctor time by completing those portions of the Physician's Report where you are capable of doing

so, such as list of medications, list of hospitalizations, etc. Be sure to book an appointment with your doctor to review the Physician's Report before it is sent to the insurance company and keep a copy for your records.

5) Request a copy of your medical and hospital file.

   You have a legal right to review or get a copy of your medical and hospital file. It is your information. Your doctor may charge a fee to copy the information. During an appeal process, it is important to request a copy of your complete file held by the insurance company. It will contain all the information used by the insurance company to make a decision on your claim, including the third party medical review of your application, as well as your Physician's report in case you did not get a copy.

6) Medical evidence in the form of tests, specialists reports, etc. are critical.

   While strong evidence from one's family doctor is important, specialist reports are critical. In this particular case, the company said "if your conditions are so disabling, your family doctor would have referred you to specialists." Even with specialists reports, there is no guarantee, especially if there is nothing that can be done to help the patient. Timing becomes an issue on appeals (generally you have 4-6 months to provide evidence for an appeal). Getting a referral is often difficult to obtain and wait times for specialists are usually 1-2 years.

7) Letters of support from family, friends, neighbors, pastor, employers.

   While not given a lot of weight, they do add support to one's case, especially if they come from an employer or co-workers.

8) Seek advice and help in preparing one's application or appeal.

   Seek out people who have experience in working with medical reviews or compensation claims, or who recently been through the LTD process. Your local Legal Information Society may be able to provide information – they also have a lawyer referral process where you can get approximately 30 minutes with a lawyer for a minimal cost (+- $25). There are several levels of appeal. Also remember at any time, you can hire a lawyer and seek to settle the claim. However, one must weigh the cost of a lawyer who often works on a contingency basis (meaning it will not cost you upfront but if you win they will take up to 50 – 60% of the settlement) against the actual value of your claim.

9) Keep a record of all contact with the insurance company.

   Document the date, time, contact person and summary of all telephone calls. Keep a copy of all emails, texts, etc. Be careful in what you say in any contact with the insurance company. If you are not sure what to say, ask the company to send you their question or request in writing – this will allow you time to formulate a detailed and complete response. Often they will ask you to describe a typical day, or how does your condition impact your ability to work. Be ready for these questions.

10) Do not underestimate or exaggerate your ability to work.

    Frequently, applicants do not fully consider the overall impact of their condition on their ability to work or function at home. As well, insurance companies often work on the assumption that applicants will exaggerate the extent of their condition(s). To this end, it is not uncommon for insurance companies to secretly videotape applicants as they go about their daily routine in order to refute their claims on their application.

11) Do not give up or become frustrated with the process.

    It is a time consuming and tedious process meant to challenge the average person - it is no small undertaking. Insurance companies rely on the fact that most people will find it too complicated, get discouraged and give up – that is why many applications are initially denied, forcing one to appeal. Get help with the process and take your time in preparing your application and/or appeal.

You paid your insurance premiums in good faith that coverage would be there if and when needed – do not be hesitant to make a claim.

Dr Amir Landi and Judy-Anne Wilson were interviewed by Global News in a report on CIHR funding for the new ME Research Network.

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