President’s Message:

While I will miss the warmth of summer, I love the changing colours of fall. After a summer of well-deserved rest, the Board of Directors for the M.E. Society of Edmonton will begin a new season. We look forward to the input from some new Board members and are grateful for their desire to serve the ME/CFS community with us.

Our September issue covers a couple of very important topics. If surveys and statics are not taken and measured, we never know the extent and severity of a problem. Without this information problems never get addressed. We have highlighted a couple of studies to illustrate the prevalence of ME/CFS around the world and in Edmonton. This shows not only the number of people affected but who they are. Those of us with ME/CFS know that our illness is not due to a lack of sleep. The Sleep Survey Results on page 6 provide some interesting insight into how sleep affects our symptoms.

Until the source of ME/CFS is discovered, each of us will continue in our journey of trial and error to find what relieves our unique symptoms. I hope you will find within these pages some helpful information, encouragement and a laugh.

Diane Ching
Events

Support Group Meetings

Everyone is welcome to our Support Group Meetings: patients, family, friends, supporters, Society membership or not. These meetings are free, and you do not need to sign up or register, just drop in and join us for the afternoon.

Now held the 3rd Saturday each month!

Support Group Meetings are held monthly on Saturdays at the Central Lions Senior Recreation Centre. This facility at 11113-113 Street is handicapped accessible and has plenty of free parking. Please refrain from wearing scented products.

Saturday, Sept. 19 (1-3 pm)
Support Group Topic: Open Discussion

Saturday, Oct. 17 (1-3 pm)
Support Group Topic: Coping with brain fog

Saturday, Nov. 21 (1-3 pm)
Support Group Topic: TBA

Volunteers Needed

Our casino fundraiser is Nov. 7 - 8 at the Baccarat casino (10128 - 104 Ave.) We still need volunteers for the following positions:

- Chip Runner: Sunday, Nov. 8th from 9:30 AM - 5:30 PM
- Banker: Saturday & Sunday, from 6:30 PM – 3:30 AM
- Alternate General Manager: In case one of our General Managers cannot work.

Please ask your family and friends if they would be willing to help us out!

There is free parking and meals/snacks are provided.

For more information contact Kristine in the general office at general.info@mesocietyedmonton.org or (780) 944-0809.

Disclaimer: Our newsletter is published by the M.E. Society of Edmonton. It is a cooperative effort of volunteers. The Society’s executive, board of directors, and newsletter editors do not accept responsibility, legal or otherwise, for the opinions and content of articles printed in their newsletter. We do not endorse any healthcare professionals, products, or medical treatments that may be mentioned in any of the articles and personal stories in our newsletters or at our meetings. They are provided to demonstrate the wide range of treatments that individuals have tried. Every individual has unique health concerns. It is recommended that anyone wishing to start/stop treatments mentioned in our newsletters do so under the close supervision of a healthcare professional.

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Please submit articles or feedback for the newsletter to Ed: newsletter@mesocietyedmonton.org or contact our office. Deadline for the next newsletter: October 15, 2015.
Who’s With M.E.?

Having M.E. can be very isolating, and lonely. Sometimes it may feel like no one understands what M.E. is, or what it’s like to have it.

Yet recent reports have confirmed that M.E. is actually quite common, as chronic illnesses go. The feature articles on the next two pages highlight the prevalence of M.E./CFS in Canada, based on Statistics Canada survey results, and examine the incidence of M.E. in Norway, based on medical code use in a national medical database.

Surveys of people by census, or phone calls followed up by medical evaluation of prospective CFS cases, tend to capture the greatest proportion of people with M.E./CFS; usually reporting about 2.5% of adults having M.E./CFS.

Studies of the prevalence, or incidence, of M.E./CFS based on doctor’s records (like the one from Norway) tend to report much fewer M.E./CFS cases, typically about 0.35%.

Part of the reason for this difference is the attitudes of medical professionals. In fact, one such study in the Netherlands, found that only 51% of GPs of adolescents accepted CFS as a distinct diagnosis, and only 43% had actually identified an adolescent patient as having CFS (even though their numbers and distribution of patients suggest they all should have).

So what do these results mean for us, here in Edmonton? Edmonton has*:

- 22,600 people with M.E./CFS.
- 7,000 males vs 15,600 females.

- 3,400 consider themselves active, 3,800 are moderately active, but 14,000 (two-thirds) are inactive.
- 28% (6,300) are employed (full or part time), working an average of 26 hours/week.
- Less than half are married (10,400) while a fifth are single (4,300) and the remaining 7,800 are widowed, separated, or divorced.
- By age, 10,500 are 60+, 8,500 are 40-59, and 3,600 are 12-39.

Edmonton has about 800 school-age children with M.E./CFS (based on studies of prevalence in Australia and the UK).

On average, one Edmontonian will be diagnosed with M.E./CFS each day. In Edmonton this year, it will be diagnosed in**:

- 70 youth (school age)
- 160 young adults (20-39)
- 80 middle-aged adults (40-54)
- 20 older adults (55+)

* Based on the Stats Canada survey prevalence of 1.4%, applied to the estimated Edmonton metro area population of 1.328 million (July 1, 2014), rounding to the nearest hundred.

** Based on incidence rates by age group from the study in Norway, and Edmonton 2014 census data by age.
PHAC JOURNAL FEATURES ARTICLE ON CFS AND FIBROMYALGIA (FM)

Excerpts from an email March 26, 2015 by Margaret Parlor, President, National ME/FM Action Network:

A peer-reviewed article on CFS and FM called Chronic fatigue syndrome and fibromyalgia in Canada: prevalence and associations with six health status indicators was published in March.

The study was a collaboration between the researchers at Public Health Agency of Canada (PHAC) and the National ME/FM Action Network.

It was based on data from the 2010 Canadian Community Health Survey. The CCHS is a survey of a sample of Canadians and is conducted by Statistics Canada. Among the questions, the survey asks if the respondent has been diagnosed with CFS or FM.

The study found:

- Diagnosed CFS and FM are reported by 1.4% (1.3%-1.6%), and 1.5% (1.45-1.7%) respectively, of the Canadian population age 12+ years in 2010, with comorbid CFS and FM affecting 0.3% (0.3%-0.4%) of the household population.

- Prevalent CFS and/or FM were more common among women, adults aged 40 years and over, those with lowest income, and those with certain risk factors for chronic disease (i.e. obesity, physical inactivity, and smoking). It is not clear whether the correlation between these factors and CFS and/or FM is causal or the result of having these conditions.

- After controlling for differences between the groups, individuals with CFS and/or FM reported poorer health status than those with neither condition on five indicators of health status, but not on the measure of fair/poor mental health.

- Having both CFS and FM and having multiple comorbid conditions were associated with poorer health status.

The survey data shows that people with CFS and/or FM report worse general health, worse mental health, more impairment, more pain, more activity limitations, and more need for help than the rest of the population. However, that could be due to the number of different conditions that people with CFS and/or FM have, their age, gender etc. After taking these factors into account using mathematical techniques, people with CFS and/or FM still report worse than usual general health, impairment, pain, activity limitations and need for help, BUT the indicator for mental health is what would be expected under the circumstances.

Thanks to the Public Health Agency of Canada for their interest in CFS and FM and for the sensitive way they handled the sensitive issues!
Study Suggests Hormones, Autoimmunity and/or Viruses at Work in ME/CFS

By Cort Johnson

The full version of this article originally appeared on Health Rising December 15, 2014; excerpts reprinted with permission.

A Norwegian study of ME/CFS patient records that found two age peaks in Chronic Fatigue Syndrome, one starting from ages 10-19, the other from 30-39, could tell us something about the disorder.

It wasn’t as if people of other ages didn’t come down with Chronic Fatigue Syndrome – many people in other age groups did – but the numbers of ME/CFS cases spiked in these age groups.

The least likely times to come down with ME/CFS were at the two ends of the age spectrum: from 5-9 and after the age of 55.

Just 121 cases were reported from ages 5-9, but after the age of nine the incidence of ME/CFS spiked up sharply with almost 700 cases reported from ages 10-14 and 15-19. From 20-29 it dropped about 30% with about 500 cases reported, and then zoomed up again to about 700 cases from ages 30-39. From ages 40-44, 45-49, 50-54 declined until at ages 55+ the incidence was very low indeed.

That’s in contrast to many disorders which get more prevalent as we age.

As in other surveys, young female and adult women in their most productive years were much more likely (75%) to come down with ME/CFS than men.

What does it all mean?

The high rate of females with ME/CFS combined with the unusual pattern of incidence points a finger directly at female hormones. Three periods of major hormonal fluctuations occur in women; during puberty, during pregnancy and during menopause. Spikes in ME/CFS incidence occurred during two of these; puberty and when women often get pregnant, but not during menopause...

Hormones, or the lack of them, may very well be a contributing factor to getting ME/CFS, but the spikes in incidence also point a finger at two other factors: viruses and autoimmune disorders.

The increasingly late exposure to the Epstein-Barr virus found in the Western world could contribute to the spike in ME/CFS prevalence in adolescence.

Exposure to EBV in infancy, when cytotoxic T-cell levels are at their highest, is usually hardly noticed, but a first exposure to EBV in adolescence often results in a severe illness such as infectious mononucleosis/glandular fever – which appears to trigger ME/CFS in about ten percent of patients.

Attributing the spike in ME/CFS prevalence in from 30-39 to EBV activation is a bit more difficult. Pregnancy in combination with the stress of child rearing could help explain it, however...

A similar age-related incidence pattern is also found in some autoimmune disorders. Lupus is most commonly diagnosed between the ages of 15-35. Multiple sclerosis (MS) is most commonly diagnosed in people between the ages of 20 and 50 years. Sjogren’s Syndrome typically begins in the same “middle adult” years that ME/CFS spikes are seen in.

The age spikes found in this study suggests chronic fatigue syndrome shares features with several other disorders. Similar patterns of incidence in IBS, multiple sclerosis, lupus and Sjogren’s Syndrome, and high rates of female predominance also occur in some autoimmune disorders (systemic lupus erythematosus (SLE; females:males – 9:1), autoimmune thyroid disease (8:1), scleroderma (5:1), rheumatoid arthritis (4:1) and multiple sclerosis (3:1)).

Determining what the spikes mean will take time and much in the very complex interactions involving hormones and the immune system. The evidence suggests that a constellation of factors, perhaps involving hormones, immune activation, central nervous system excitation, and in some cases viruses play a role in producing ME/CFS. This study highlights “danger points” when women may be particularly vulnerable.

The reduced incidence of ME/CFS and autoimmune and pain disorders in men, on the other hand, may reflect the protective effects male hormones provide.
The Chronic Fatigue Syndrome and Fibromyalgia
Sleep Survey Results

by Cort Johnson.

The full version of this article was posted on Health Rising, December 13, 2014. Excerpts reprinted with permission.

Poor sleep has been long held to be synonymous with ME/CFS and FM, and indeed the survey found that fairly poor (40%) and really poor (27%) sleep was common. However, about a third of the survey participants stated their sleep was OK (25%), pretty good (6%) or excellent (1%). Poor sleep is clearly not a necessary part of the diagnosis.

On the other hand, unrefreshing sleep is. The vast majority of respondents said they woke either exhausted (44%) or unrefreshed (42%). Eleven percent said they felt “so-so”, and only 2% said they felt “fairly good” or better upon awakening. The survey suggested that even people who felt their sleep was OK were still generally waking up feeling beat up for the most part.

As expected, given the alpha intrusions documented in fibromyalgia, interrupted sleep was very common, with most people (53%) waking up between 2-5 times a night and over thirty percent stating they wake up 5-9 times a night. A fairly large (11%) and quite unfortunate group that is apparently getting very little deep sleep stated they wake up 10 or more times a night.

Insomnia is not often mentioned as a major sleep issue, but it emerged as a very prominent issue with no less than 42% of respondents stating it was a “major” problem and 36% stating it was a “moderate” problem. Only 8% of respondents stated it was “not a problem”.

Going to sleep very late can be a cause of poor sleep and fatigue because it throws your circadian rhythms out of whack. Most people went to sleep before midnight (73%), but a significant portion (23%) go to sleep after midnight and 9% stated they usually go to sleep after 2 am.

Early wakening was also a common theme with 20% of people stating they usually woke before 5 am and 29% between 5 and 7am. The percentage of late-wakening folks (10% waking after 11 AM) lined up well with the 9% that went to sleep after 2 am.

Almost half (48%) of the respondents reported they believe they get less than 5 hours of sleep a night with 7% stating they get less than 3 hours a night. About half (48%) reported they get relatively normal amounts of sleep (6-10 hours) and just 4% stated they get more than 10 hours.

Factors that negatively affected sleep, and treatments

About two-thirds of the people taking the survey stated they had “greatly improved” their sleep. The fact that most people still did not feel they had OK or good sleep suggests, however, that some people who had experienced real improvements still had significant sleep issues.

Greatly improving sleep had a moderate to great improvement for about 30-50% of patients with regard to any symptom. Clarity of thought was the symptom most often improved while pain was the least affected. Most people (50-70%), however, reported either small improvement or no improvement on their symptoms after “greatly improving” their sleep – a surprising finding that underscores the fact that ME/CFS is much more than a sleep disorder.

The modest impact “great” sleep improvement had on fatigue, pain, and other symptoms for many suggests sleep therapies are, like most treatments, band-aids that are helpful but don’t begin to get at the causes of ME/CFS or FM. To really fix the possibly unique set of sleep problems found in ME/CFS and FM, you need to fix ME/CFS or FM.

No home runs were found in the sleep treatments. A small percentage (<10%) of people do experience great relief from drugs, supplements or other means of helping sleep, but when help comes for the vast majority of people it comes in smaller bites. The good news is that from 30-50% of the people trying almost every treatment found that it was at least “somewhat helpful”. The bad news is that from 50-70% of responders found the treatment was not effective or made them worse.

The fact that many factors were at least somewhat effective suggests that putting a variety of factors together – say, good sleep hygiene, a drug or supplement that works, investing in a good mattress, raising the head of the bed – might end up with greatly improved sleep.

Chronic fatigue syndrome and fibromyalgia are clearly, however, much more than about poor sleep. While improving sleep can be helpful, until the core issues of these disorders are addressed, most people with the disorders will have significant troubles with fatigue, pain, as well as other issues.

[For more information, check out other articles on Health Rising such as: "Deconstructing Sleep in Fibromyalgia and Chronic Fatigue Syndrome" and “When It’s Not All ME/CFS/FM”]
Health and Lifestyle

Thanks to our readers for comments and suggestions for our newsletter! We're happy to pass along these suggestions for ways to help with entertainment and sleep, and remind everyone that none of these is universal, and depending on the severity of your symptoms, may seem trivial or extreme.

Keeping entertained while lying down …

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<td>Crafts</td>
<td>Savoring smells and tastes</td>
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<td>Fireplace gazing</td>
<td>Playing board/card games</td>
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Sleep solutions

Ensure your sleep environment is creating the conditions for quality sleep:
- Reduce light as much as possible
- Invest in the right mattress, and pillow, for you
- Keep electronics away
- Make your sleep space comfy and inviting

For more ideas:
- Get tips from the National Sleep Foundation
- Take a sleep quiz
- Keep a sleep diary
- Learn about sleep disorders, and sleep apnea
In the news:

A Simmaron Research article explains the startling discovery of a lymphatic system for the central nervous system: "Medical Game-Changer" To Shed New Light on Neuroimmune Diseases.

The ME Association summary for the latest results of the ongoing Norwegian study of Rituximab.

A series of four articles on ME/CFS was published in the June 16, 2015 Annals of Internal Medicine http://annals.org/. Two were reviews of the literature prepared for the Pathways to Prevention (P2P) process by the US Agency for Healthcare Research & Quality. The topics were Diagnosis of ME/CFS and Treatment of ME/CFS. The third was the final report of the P2P panel charged with reviewing NIH research. The fourth was an editorial by Dr Komaroff tying together recent developments in ME/CFS. He concludes with the following statement:

> These reports from the IOM, AHRQ, and NIH demonstrate how much we have learned about ME/CFS and how much we still do not know. We do not understand its pathogenesis, and we do not have a diagnostic test or a cure. However, these recent reports, summarizing information from more than 9000 articles, should put the question of whether ME/CFS is a "real" illness to rest. When skeptical physicians, many of whom are unaware of this literature, tell patients with ME/CFS that "there is nothing wrong," they not only commit a diagnostic error: They also compound the patients' suffering.

Videos:

Understanding & Treating Myalgic Encephalomyelitis/Chronic Fatigue. Dr. G. Kaplan. Three parts (19 min; 18 min; 11 min)

MECFS Alert Episode 74: Dr. Mady Hornig. Two parts (12 min; 19 min)

Dr. Alan Light compares fatigue in ME/CFS to conditions like cancer, MS, depression, and fibromyalgia in episodes 61 (14 min) and 62 (7 min), and discusses mental fatigue in episode 63 (8 min)

Invisible Illness – Stories of Chronic Fatigue Syndrome (12 min) – includes the story of the son of Ron Davis (PhD) whose story was also featured in news coverage in Palo Alto CA:


http://paloaltoonline.com/news/print/2015/07/10/whitney-dafoe-when-i-crash

Meetings:

IIMHL/IIDL 2015 Leadership Exchange

International Initiative for Disability Leadership

Information is available for Leadership Matches at: www1.iimhl.com/IIDL/Meetings/Themes.asp?msstat=2

Registration is free, but spaces are limited. September 21-22, 2015.

The two matches hosted in Edmonton are: "Rotary Employment Partnerships" and "Inclusive Post-Secondary (Tertiary) Education".
On the Lighter Side

"But First" Syndrome

I have recently been diagnosed with the "But First Syndrome." You know, it’s when I decide to do the laundry, I start down the hall and notice the newspaper on the table. OK, I’m going to do the laundry....

BUT FIRST I’m going to read the newspaper. Then, I notice the mail on the table. OK, I’ll just put the newspaper in the recycle stack....

BUT FIRST I’ll look through that pile of mail and see if there are any bills to be paid. Yes, now where’s the checkbook? Oops.....there’s the empty glass from yesterday on the coffee table. I’m going to look for that checkbook....

BUT FIRST I need to put the glass in the sink. I head for the kitchen, look out the window, notice my poor flowers need a drink of water. I put the glass in the sink, and darn it, there’s the remote for the TV on the kitchen counter. What’s it doing here? I’ll just put it away....

BUT FIRST I need to water those plants. Head for door and.........Aaaagh! Stepped on the cat. Cat needs to be fed. Okay, I’ll put that remote away and water the plants....

BUT FIRST I need to feed the cat....

End of day: Laundry is not done, newspapers are still on the floor, glass is still in the sink, bills are unpaid, checkbook is still lost, and the cat ate the remote control.... And, when I try to figure out how come nothing got done all day, I’m baffled because....

I KNOW I was BUSY ALL DAY!!

I realize this condition is serious, and I’ll get help!...

BUT FIRST.... I think.... I’ll check my E-MAIL!

DespicableMeMinions.org (reprinted with permission); author of “But First Syndrome” unknown
Resources

M.E. Society of Edmonton
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2015 - 2016

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Vice President – Florence
Secretary – Vanessa and Christopher
Treasurer – Judy-Anne

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Lynn
Doreen
Kathleen

Resource Centre Administrator-
Kristine

New Board and committee members are welcome at any time. If you have an interest and a little time, and would like to join in our endeavors, please contact our office or speak to any board member.

The Board meets the first Saturday of every month (except holidays) from 1 – 3 pm.

Members of the ME Society of Edmonton and the general public are invited to attend our monthly Board Meetings. Besides business, our meetings are filled with friendship, support and fun!

Feeling hopeless?
Thinking about suicide?
Help is available 24hrs/7d a week

Crisis Support Centre Distress Line: (780) 482-4357
Crisis Response Team: (780) 342-7777

Annual Memberships

Memberships can be purchased at any time, especially for newcomers!

Thank you for your support.

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