



25% M.E. Group
Support for Severe M.E.

A Tribute to Dr Byron Hyde, Canadian ME Expert who has helped thousands of ME Patients around the world

Dr. Byron Marshall Hyde studied pre-medicine in the Faculty of Medicine, University of Toronto followed by a degree in Chemistry and Nutrition in 1961. His first medical employment was as an immunological research chemist at the Roscoe B. Jackson Laboratory, Bar Harbor, Maine – a leading world laboratory in immunological & transplantation research. He then became Chief Technician in charge of the Electron Microscope Laboratory at the Hospital for Sick Children in Toronto.

Dr. Hyde returned to the University of Ottawa and graduated from the Faculty of Medicine in 1966. After an internship at Montreal's Hotel Dieu and residency at the St. Justine Paediatric Hospital and the Ottawa Civic Hospital, he opened a family practice in Ottawa that continued until 1984 when he started the full time study of post infectious Myalgic Encephalomyelitis. For five years he had travelled extensively around the world investigating the epidemics of M.E. in the USA, the UK, Australia, New Zealand and Iceland and spent the next several years being instructed by previous researchers of these epidemics. Only then did he start to investigate patients who had M.E.

In order to widen resources to investigate these patients, in 1988, he founded the Nightingale Research Foundation, obtaining charitable organization status in the same year. Nightingale is dedicated to explore, understand and treat the patients disabled with Myalgic Encephalomyelitis (M.E.), fibromyalgia-type illnesses and post-immunization injuries. In its early years, Nightingale became a critical vehicle providing technical assistance to other medical practitioners and researchers worldwide and outreach and informative publications to help and encourage thousands of North Americans who were patients or had family members disabled by M.E.

“What Doctors can’t Diagnose and what tests should be considered”

**Dr. Byron Hyde, Founder & Director of the Nightingale Research Foundation,
Ottawa, Canada,**

Dr. Hyde's Background

Several incidents early in Dr. Hyde’s life shaped his capacity for empathy. In the eighth grade, he developed polio, which he felt gave him an advantage compared to other doctors. He was unable to go to school, and while at home he became a prolific reader. After a year he was able to return to school but he learned first-hand what it was to be disabled.

He also has suffered with migraines since he was a young teen. While studying at the University of Toronto, during one of his last exams in history, a subject in which he was getting excellent grades, he was unable to take the final because of a migraine. The physician did not believe him; and this doctor’s response led Dr. Hyde to affirm he would always believe his patients when he, himself, became a doctor.

Dr. Hyde explained that physicians do good work and make excellent diagnoses in about 90% of their patients. However, in the remaining 10%, which would include Myalgic Encephalomyelitis (ME) and Fibromyalgia (FM) patients, physicians do not have enough understanding or time to make a complicated diagnosis, and instead make what Dr. Hyde called the “Educated Guess Diagnosis”. He suggested that doctors rarely look for multiple causes of illness. Dr. Hyde, in fact, has rarely found just one cause in a complicated illness.

Dr. Hyde divided his lecture into a section on ME and then Fibromyalgia, though some topics were addressed simultaneously..

What piqued Dr. Hyde’s interest in ME?

Having been trained as a forensic physician, Dr. Hyde put his curiosity to work asking the questions “why?” and “what is behind ME?” He believes that the acute onset of ME/CFS is caused by an injury to the brain and it can be seen as a diffuse encephalopathy.

Unfortunately, Dr. Hyde thinks most neurologists miss this diagnosis because it does not show up with traditional neurological testing. He said that is due to the fact that the symptoms reside in the vascular system.

Diffuse encephalopathy, however, does show up on SPECT, PET (with the proper software) and BEAM scans (electronic computer-driven EEG), but a physician has to have enough knowledge of the tests to order them.

In an effort to improve medical efficiency

In an effort to improve medical efficiency, many physicians now run between multiple examining rooms, see patients between 6–8 minutes, and whether conscious of it or not, limit patient questions and dispense with time-consuming, proven patho-physiological diagnosis.

It takes too much time to counsel patients rather than prescribe a pill. Some physicians have limited the number of complicated patients and/or decreased procedural referrals such as EEG, Brain SPECT, transcranial doppler, tilt table test, CAT scan and MRI testing.

Many physicians use templates in their notes such as SOAP— S. subjective: history of present illness; O. objective: prior diagnosis, new examination; A. assessment: diagnosis; P. plan: tests, referral, advice or treat. As Dr. Hyde pointed out, this is part of the educated-guess diagnosis.

In the 1890's, another Canadian, Dr. William Osler, became the chief of John Hopkins Hospital, Baltimore, MD. Osler's technique was to find the cause of the illness and then treat it specifically, which was regarded as being revolutionary at that time.

Doctors to this day rarely look for the causes of illness. Dr. Hyde emphasized that he himself has never had ME patients with only one thing wrong with them; instead, patients can have 10 to 20 underlying problems.

ME/CFS breakthroughs—or maybe not

In September, 1990, Drs. Elaine DeFreitas, David Bell, and Paul Cheney were pictured on the cover of The CFIDS Chronicle because they were on the forefront of ME research at the time. People believed that Dr. DeFreitas had found a retrovirus associated with the illness and her work was promoted as a research breakthrough.

Drs. Bell and Cheney, each having found themselves in the midst of an epidemic outbreak, began treating numbers of their patients. These doctors were well known and lent credibility to the illness.

Dr. Hyde, with his forensic background, explained that researching the cause of a virus in an outbreak can only be done if you go to the epidemic and look for viruses in everyone. Otherwise, there is no way to tell what caused an outbreak because healthy folks carry around so many viruses that don't make them ill—scientifically, this research did not have the significance implied.

Though it proved to be quite challenging, Dr. Hyde was determined to find out how research funds earmarked for ME had been spent by the National Institutes of Health (NIH), Bethesda, MD. After many calls to NIH, he was told he would have to call each department individually to inquire where the money was directed.

Much of it went to a study on alcoholics who were thought to be fatigued. More was spent on cancer patients who were thought to be fatigued. The misspending of research funds also occurred at the CDC, a circumstance that was eventually made public by a whistle-blower, the head of the CFS research programs at the CDC.

Dr. Hyde stated that he felt Dr. Stephen Straus, who headed up the ME/CFS research at NIH, was “the bane of the problem”. Dr. Hyde then laid out his case for his statement explaining that in a time-line, the term CFS was first employed by Dr. Straus in 1986. In 1987, Straus believed CFS was caused by Epstein Barr Virus (EBV). In 1988 his term CFS was used to label the new CFS Working Case Definition. Keep in mind that ME was an established illness in other parts of the world. Dr. Straus maintained a very poor attitude towards ME/CFS and given his position at the NIH, this had a negative outcome on patients and research for many years.

Dr. Hyde discusses how some players in the ME or CFS field were just making money on unproven lab tests, as was corroborated with the downfall of the XMRV theory. He discussed how researchers, laboratories and pharmaceutical companies would put more effort into a project if it proved money-making as in the case of utilizing something with a patent on it. ME or CFS progress suffers when research is steered by power or towards profit or when results are overplayed.

Enterovirus in ME

According to Dr. Hyde, there have been multiple epidemics, since 1946 to the present, in which an enterovirus has been recovered and associated with development of ME. An enterovirus has a certain structure/mechanism, but there are many types included in enterovirus group (i.e., polioviruses, non-polioviruses, coxsackieviruses, echoviruses). These outbreaks have been reported from around the world and a majority of them seem to occur in institutional settings such as schools, hospitals, residences and after congested travel or being in close quarters.

Dr. Hyde has personally researched all the outbreaks for decades. In discussing what may cause ME, he brought up the fact that in 1992 The Nightingale Research Foundation had sent 100 blood samples (from 60 gradual and 40 acute onset ME patients) to Drs. Galbraith and Nairn at Ruchill Hospital, Glasgow for enteroviral studies.

50% of acute onset patients were positive for chronic enterovirus infection, but three years later few patients were positive. None of the gradual onset patients were positive.

Dr. John Chia, an infectious disease specialist and Assistant Professor at UCLA in Los Angeles, CA has been finding enterovirus in the biopsied stomach mucosa of ME patients in 82% of the patients. Currently, there are no significant treatment options for enterovirus, but Dr. Chia is currently testing out some medications.

Dr. Hyde mentioned he had recently spoken with pharmaceutical companies about medications for enteroviruses, but there seems to be nothing currently in the pipeline. He also believes some of the problems lie with the fact that there are no patents on enteroviruses, and therefore no financial motivation.

If by chance you, as a patient, had a stomach biopsy, and it was stored in a paraffin block, not a fixed specimen, you may be able to get 3 slices and have it sent to Dr. Chia for testing. You would have to contact Dr. Chia for information. Specimens stored in a paraffin block will last forever, according to Dr. Hyde.

Medical refugees

Dr. Hyde drew a contrast and similarity between refugees and ME patients. He showed pictures of 2 women from Iran with similar names. The first one was killed and images uploaded to the internet. However, Iran went after the second woman, thinking they were one and the same and attempted to murder her. She was a university English professor, who was forced to flee for her life from Iran. She escaped from being killed, but wound up in a refugee camp in Germany and wrote "Every day in such a place is torture, not just for me but for all those refugees. Some had been there for 10 years. You give up on your own destiny. You have to submit to whatever the system decrees. In my society I had achieved so much and now I had nothing—I was in a drawer, a folder labeled 'refugee'." Her name is Neda Soltani. Dr. Hyde made the comparison of her plight and that with patients who feel pretty much the same way.

1934 Los Angeles ME epidemic

Dr. Hyde had the opportunity to examine two physicians who had become ill during the 1934 polio epidemic outbreak at the Los Angeles (LA) County Hospital. According to Dr. Hyde's slide, 198 healthcare workers, who were immunized with sera from recovering patients, fell ill with ME, but not polio.

He believes in this case that the combination of an immunization and viral infection triggered their ME. The two doctors sued the hospital and the city of LA and received about 2 million dollars each.

Dr. Hyde's hypothesis is that this was a wake-up call for insurance companies to dismiss the illness and from then onward, anything resembling ME was mocked. There were times then, and even now, where ME patients were put into psychiatric hospitals and labeled as crazy (plus they were given drugs that made them sick). So, when CFS came along, it seemed to follow the same pattern. Same illness, different name, same outcome.

Pseudo-Diagnoses are non-scientifically-testable diagnoses

In explaining what he meant by pseudo-diagnosis, including anything with the word "syndrome" or "disorder" after the name, Dr. Hyde said that the following syndromes are diagnosed on symptoms alone without any available diagnostic laboratory tests:

- CFS, CFIDS
- Fibromyalgia
- IBS (Irritable bowel syndrome)
- Non-major depression
- Anxiety-neurosis
- Hysteria, conversion or somatization disorder

His analogy was akin to having a headache but not knowing if it was caused by a migraine, brain cancer, or perhaps an injury to the neck, but the only thing the headache did was indicate something was wrong and should be evaluated. He emphasized that anything with the name "syndrome" or "disorder" means it is something that should be looked into.

Conversion Disorder is a situation where the patient has physical symptoms with no organic cause. It affects motor & sensory functions.

Somatization Disorder affects the gastrointestinal, nervous, cardiopulmonary, or reproductive systems.

Disorders with hysteric features typically begin in adolescence or early adulthood.

Immunizations and ME and FM

Dr. Hyde emphatically states that "immunizations save lives, and are better than all the doctors in the world put together", but cautioned that doesn't mean they are problem-free. His concern centered on two: recombinant hepatitis B immunization and the rubella immunization.

Dr. Hyde also spoke to the issue of contaminated immunizations around the world and how they can possibly trigger ME/FM illnesses.

Recombinant hepatitis B immunization

He has personally seen some very ill, bed-ridden patients as a result of the recombinant hepatitis B immunizations, causing disautonomia—the disconnect between the brain and the ability to maintain normal pressure in peripheral arteries.

Rubella immunization

Dr. Hyde explained how the rubella immunization can cause rheumatoid arthritis. If a pregnant woman has not had the vaccine, she cannot receive it while pregnant because it will cause harm to her unborn child.

When Dr. Hyde started in practice, the current wisdom of the day then was to give the immunization immediately after childbirth to both the mother and child. If the mother was breast-feeding, a sensitivity to, not immunization from rubella would develop in the child.

If the child was a boy, nothing happened to the child. If the child was a girl, and she received a booster for that vaccine in grade 8 (in Canada), she could go on to develop an internal auto-immune reaction which then could develop into rheumatoid arthritis. Dr. Hyde pointed out that this is 12–14 years after the initial insult to the body.

Contaminated Immunizations

Dr. Hyde discussed some of the issues around immunizations that have been contaminated and still go to market. For example, during 2004–2005 some batches of the flu vaccine manufactured by Chiron Labs in England became tainted with *Serratia Marcescens*.

The US and Canada bought vaccines made in England because they were cheaper. Even though the company informed the buyers about this contamination, the US and Canada continued to use the immunizations for 6 more months. Dr. Hyde feels many people probably got ill with ME after this.

Immunization and travel start date

Dr. Hyde emphatically states that when preparing for travel abroad, particularly following and during trips to third world countries, “NEVER get an immunization and then travel immediately. Always allow 30 days between the injection and the travel plans to allow the immunization to take effect.”

He explained that if, by chance, you got on a plane the week following the immunization, and sat next to someone with a minor virus, your immune system may not be able to fight it off and you could end up becoming chronically ill with ME.

A virus plus an immunization do not mix well. He reiterated that acute ME is usually not detectable by routine examination and only a SPECT, BEAM or PET scan can pick up the encephalopathy.

What questions should a doctor be asking?

Dr. Hyde shared his thinking that all doctors should be asking themselves the questions “what makes the symptoms worse, what makes them better and how did it start,” having learned these basic skills in medical school.

Other questions to ask are if there was any injury to the physiological system, could it be proven which organs were injured and in what manner?

The theory is that if a patient is ill, there must be proof of it.

However, the physician has to be thorough enough and ask the right questions to determine which tests to run and how to interpret them. This is where many ME and FM patients fall through the cracks.

Above all, Dr. Hyde stressed that it is absolutely important to capture a patient's genetic history, beginning from their infancy to the present. Before he does anything, he will spend the first visit (which usually takes 1 1/2 days) gathering patient background information.

Dr. Hyde’s protocol of taking a patient history and work is as follows:

- Genetic History
- Historical Illnesses & Traumas
- Immediate Prior Illnesses or traumas
- Trigger (any combination of infection, immunization, medications, trauma, surgical procedure, transfusion, severe emotional injury)
- System Injuries or Pathophysiological Injuries
- Multiple Organ Injuries

Myalgic Encephalomyelitis vs Chronic Fatigue Syndrome

Dr. Hyde stated that he did not think ME and CFS were the same thing and the names should not be used interchangeably. He noted that he did not agree with the effort in the U.S. to combine them.

He also made a distinction between the gradual onset of ME and the sudden onset of ME. Dr. Hyde felt that patients with a gradual onset were easier to treat, as there usually was an identifiable cause and treatment.

In contrast, those with a sudden onset were much more complicated and showed the encephalopathy in the brain. He concentrates on sudden onset of ME.

Dr. Hyde's definition of ME

Take the term apart and it means: My: muscle; Encephalo: brain; Myel: spinal cord; itis: inflammation. ME is a measurable, diffuse, patchy, chronic patho-physiological brain injury. He defined ME as:

A previously well individual who has developed a new incapacitating, chronic cognitive, intellectual and physical illness. Characterized by rapid onset and persevering cognitive and physical exhaustion following normal physical, intellectual, sensory, or emotional exposure or stressors. Patients are frequently women, healthcare workers, teachers and students.

He stated that classical ME cannot be seen on an X-ray, but can be caught on a SPECT scan. Dr. Hyde explained that when sent for the scan, the patient should be exhausted and at their worst so the test will see the brain at its worst.

In contrast, the MRI is an anatomical map of the body while the SPECT scan is functional (meaning how the brain is actually working). This diffuse injury destabilizes the central nervous system control of many body functions.

There are slides included in Dr. Hyde's medical text book, authored in 1992. The scans done by Xenon SPECT (the Xenon machine is no longer made) of a 37-year old female ME patient showed abnormal resting SPECT; post-exercise SPECT that still shows abnormal findings; and a 24-hour post-exercise SPECT also showing abnormality even though the patient had not exercised since the initial time. So the brain continued to show a break-down of functioning.

These findings were demonstrated by Drs. Jay Goldstein and Ismael Mena at UCLA in 1989. Dr. Hyde found it unbelievable that even today the SPECT test is not widely used.

Dr. Hyde made clear that the SPECT scan showed exactly what an acute onset of ME in the brain looks like if caused by encephalomyopathy. What was so interesting was how he explained how most patients would perceive the situation—they may think they just have a headache with no idea they have an encephalopathy. Only a SPECT scan or spinal tap would show it at the time of onset.

A slide of a 10-year old child's ME brain showed marked (50%) decreased blood perfusion in the right frontal and right posterior parietal and occipital lobe. (Slide courtesy of Drs. Michael Goldberg & Ismael Mena of California.) Dr. Hyde presented another slide — this time of a basal ganglia in the brain. A second slide, taken two years later, showed the left side of the basal ganglia just starting to return.

After following patients for decades, Dr. Hyde noticed a correlation between male patients that had ME for almost 25 years & an increase of Parkinson's disease. Although he does not know what the connection is yet, he thinks there is a relationship between ME & Parkinson's.

Missed diagnoses

In explaining some of the various other diagnoses he found in “diagnosed” ME patients, Dr. Hyde listed quite a number, driving home the point that doctors **MUST** really examine these patients. Some of the missed diagnoses included but were not limited to:

- Central Nervous System Vascular disease
- Carotid/Vertebral disease
- Coronary & Heart disease
- Peripheral vascular disease
- Autonomic diseases
- POTS, Ehlers Danlos, Marfan
- Clotting Factor disease
- Endocrine system disease
- Malignancies
- Multiple Sclerosis
- Diabetes
- Renal & Hepatic disease
- Syphilis, Lyme, Brucellosis, TB
- Von Economo-like
- Metal & chemical & medication poisoning

Dr. Hyde mentioned that he has found type-1 diabetes and blood malignancy in some of the patient’s family members from the outbreaks and thinks family members should be further studied. Dr. Hyde has authored another book titled **Missed Diagnoses**.

Patient population

The majority of Dr. Hyde’s patient load came from students, teachers and healthcare workers. He said the worst affected group was the respiratory therapists, who were coughed on all the time. He stated that 60% of post-viral ME occurs in the above population as well as folks following or during trips to third world countries.

Most epidemics occur in institutional settings such as schools, hospitals, residences and after bus or air travel in close quarters. Some ME cases are associated with immunizations, which he already covered.

Dr. Hyde's definition of FM

FM used to be called Fibrositis, a non-articular muscle pain. Arthritis affects the joints. A patient can have both FM and arthritis. Fibromyalgia is non-articular muscle pain. Arthritis is articular (joint) pain. If you have pain in the joints, in the bones, inside your chest or abdomen or pelvis, that is not fibromyalgia. Fibromyalgia is muscle pain.

Dr. Hyde's view is that Fibromyalgia is a vascular pathology — a pathological, hyper-elasticity of the peripheral vascular system or anything that causes this pathological expansion. Translated it means a problem in the muscles of the blood vessels.

At this point he asked everyone in the audience if they could touch their tongue to their nose. If so, it was evidence of the hyper-elasticity of the interstitial tissue called Ehlers Danlos Syndrome. In explaining its meaning, he said the ascending aorta can become flabby and have problems pumping blood. It was suggested that anyone who can meet this test should ask his/her doctor for an echocardiogram looking specifically to check the ascending aorta.

What makes FM worse

There were several answers to this question. Dr. Hyde started by explaining that a patient can expand his/her vascular system simply by eating salty potato chips and drinking beer. If the patient feels worse, it is a good chance they have FM. That is because as the vascular system expands in the arms and legs, it causes increased pain to the patient.

If, however, the patient feels better after ingesting the chips and beer, Dr. Hyde said they may have dysautonomia. Dysautonomia (autonomic dysfunction) is a broad term that describes any disease or malfunction of the autonomic nervous system.

This condition is common in ME patients resulting in Neurally Mediated Hypotension (NMH), Orthostatic Intolerance (OI), or Postural Tachycardia Syndrome (POTS) diagnoses. Most FM patients do not drink alcohol because of their negative response to it. Dr. Hyde suggested an even better way to worsen Fibromyalgia is to do a Persantine Myoview Stress test. This is a chemical stress test which instantly expands the blood vessels causing significant, even intolerable pain in FM patients.

A physician who administers this test has a drug that reverses its effect. Sometimes the patient has immediate relief, and sometimes it might take a week or so for the patient to get back to pre-test baseline.

Causes of FM

A better question is, “What causes this condition?” Dr. Hyde offered 3 suggestions:

- Central Nervous System (CNS) injury of the arterial messenger system
- Genetic disease
- Autoimmune or chemical injury to the arterial wall’s succinyl choline receptors.

In diffuse encephalitis, the brain, which produces the hormones that tell your blood vessels to contract, has been injured by the kind of encephalopathy that ME-type patients or acute onset ME patients have.

Dr. Hyde thinks FM is a central nervous system injury to the arterial messenger system.

CNS injury to arterial messenger system as an FM cause

It is also possible to have secondary Fibromyalgia, which can be caused by injury to spinal vertebrae and its appendages. Nerve endings for the entire body come out of the posterior tracks of the spinal cord.

Dr. Hyde thought it is very important for FM patients to have an X-ray of their entire spine, not just the anterior and posterior views, but also the oblique views. His reasoning was the patient may not have FM even though they have all the symptoms of FM, but instead have an injury to the nerve endings in the spine that pick up pain as they exit the spinal column.

Dr. Hyde went on to say that this could be genetic, but it could also be delayed injuries from an auto accident. In a seemingly minor motor vehicle accident, the neck can become hyperextended, causing the spinal cord to hyperextend and cause all the small capillaries that feed the bones in the spine to be ripped out.

Insurance companies want to settle quickly, especially if there are no broken bones. Dr. Hyde said “You should never give up your rights to sign away claims. What happens is that 5–10 years later there can be disintegration of the micro-arterial capillary system of the spinal bones, which causes arthritis and also FM.”

Genetic and auto-immune diseases as FM causes

Dr. Hyde raised the issue of genetics and why it is important. For example, HLA B27 is simple blood test, which when positive, indicates an increased risk for development of certain illnesses. HLA B27 is associated with Ankylosing Spondylitis and with Psoriasis, with or without arthritis. Dr. Hyde even went on to further say “that if family members have psoriasis, and you don’t, you stand a very good chance of developing Fibromyalgia.” He feels genetics definitely play a part. The reason it is so important to have a good family history of the patient is because illness that develops 10–20–30 years later could possibly be traced back.

Auto-immune disease

Some auto-immune causes of disease are Lupus Erythematosus, Sicca syndrome (the milder form of dryness of eyes and mouth) and Sjögren's syndrome that has chronic drying of the eyes, mouth and vagina. In the most severe cases, Sjögren's can be a serious rheumatoid-like illness and it can cause death. Raynaud's disease, rheumatoid arthritis and Rubella immunization have already been mentioned. Dr. Hyde did not speak for every auto-immune illness, but touched on the most common causes of what he believes to trigger FM.

In his earlier discussion about immunizations, Dr. Hyde described how the rubella immunization, more specifically, the booster shot could trigger an internal autoimmune reaction in females and lead to serious rheumatoid arthritis. Often, the initial insult to the body can occur a decade or two earlier, but doctors only sometimes make the connection.

Pharmaceutical causes

Dr. Hyde isolated the medications/worst offenders that can cause pharmaceutical injuries to muscle, its innervations and its constituents:

- Statins
- NSAIDs
- Persantine
- Quinolones (Cipro), Minocycline
- Loss of or stopping of estrogens
- Thiazide diuretics
- Multiple Herbal Medications: Alfalfa

Side effects of many medications can cause illness. Dr. Hyde feels that both the physicians and the pharmaceutical companies share some responsibility in this happening. The pharmaceutical companies want to sell product and the doctors want to prescribe.

He says Lupus-like symptoms being caused by a drug. He said that logic would indicate that if you stop the medication, the Lupus symptoms would go away. However, Dr. Hyde cautioned that has not always been his experience. A small number of the hundreds of medications are known to cause side effects triggering FM or FM-like illness.

Cipro and Minocycline

Cipro and Minocycline are antibiotics. And although Cipro is an effective medication, Dr. Hyde said "Cipro should never be taken longer than 30 days, and, it shouldn't be given to children because it will rupture their tendons." Long-term use of the drug in adults can cause the same issue. He felt Minocycline would not burst the tendons, but can cause FM.

Statins

Dr Hyde believes Statins are one of the biggest causes of FM symptoms”. Statins are an anti-cholesterol medication, and will usually melt the muscle, a process called rhabdomyolysis. One of the well-known side effects of statins is muscle pain. Anyone on statins should have a creatine phosphokinase (CPK) blood test every 3 months, as it will show any signs of inflammation.

A scale showing the percentage of symptoms in normal, non-ME/CFS & FM patients on statins shows:

- 13% will have muscle pain
- 10% joint pain
- 8% headache
- 5% asthenia

Over 50% of ME patients on Statins have severe side effects including rhabdomyolysis.

NSAIDS

NSAIDs—non-steroidal anti-inflammatory drugs. Many physicians prescribe NSAIDs for treating spinal trauma, FM itself, fracture, arthritis etc. Dr. Hyde said, “NSAIDs are one of the biggest causes of Rheumatoid-like Arthritis known to God and man. It kills people.”

He further describes what happened to a patient he inherited too late. She was given NSAIDs for trauma from an automobile accident and she stayed on them continuously for over 8 months. During that time, she became deaf, chronically constipated, and ultimately died.

Dr. Hyde explained that long-term use of NSAIDs can destroy muscle, cause inflammation of the arteries, and kill the blood vessels. His patient had developed the chronic constipation because the arteries going into the intestines and kidneys were killed off, the deafness was caused by the NSAIDs, and by the time she came to him as a patient, there wasn't too much he could do for her.

Over the years, many of the ME & FM specialists have mentioned that NSAIDs may make the symptoms worse. Dr. Hyde just clarified why.

Estrogen

Estrogen was widely used by many women for years then was stopped because of the concern over breast cancer. Dr. Hyde thought there was more of a risk eating a lot of chicken because they were loaded with estrogen, than taking the estrogen pill. He casually commented that if a man was having trouble performing, it could be due to too much estrogen, usually from a food source.

Thiazide diuretics and alfalfa

Thiazide diuretics and that they, along with alfalfa, which is in many medications and used in herbal preparations, can cause symptoms. Patients should ask for a referral to a physician who knows a good deal about medications and interactions, most likely a psychopharmacologist. If at all feasible, the amount of medications taken should be reduced.

Dr. Hyde believes that patients can always have their list of prescriptions and over the counter pills checked by their pharmacist for interactions. The pharmacists have access to a special computer program of drug interactions that many physicians do not have.

No doctor could possibly know all drug interactions. Dr. Hyde made clear that FM is not a disease, but can be any of the above conditions as well as many not listed.

Questions & Answers

Q1) Thoughts on any of the following treatments that I read about that some people are trying: Imunovir, low dose naltrexone, antivirals?

A: You have to investigate the patient thoroughly to find out why they are ill and know what you are treating.

Q2) Is an annual flu shot a good idea or a bad idea for an adolescent with ME/CFS?

A: For an adolescent, the dosage of mercury alone every year is really, really additive and can cause brain injury in some people. Folks over 65 years old don't usually seroconvert to flu. It is given to everyone, especially in nursing homes, to prevent the spread of flu but it doesn't help the patient. Almost any immunization given to a person over the age of 65 won't seroconvert, meaning they won't build up antibodies adequately. A few people might, but not sufficiently. I'm not one for flu immunization. I've seen too many bad things.

Q3) US groups are trying to combine ME & CFS and code them the same—what do you think?

A: They are not the same. Chronic Fatigue Syndrome was invented by Stephen Straus who thought he had Chronic Fatigue Syndrome when he had a brain tumor. You have to examine these people. I think the only way you can diagnose ME is you do a brain SPECT when the patient is tired. It is as simple as that. If their brain looks perfect, something else is causing their fatigue. It's not a brain injury. ME is only diffuse brain injury. Chronic Fatigue Syndrome can be anything up to 100 things or more. When I am doing a report for disability insurance, even though everyone has free medical in Canada, I never mention the word ME. I never mention the word Chronic Fatigue Syndrome. I never mention the word Fibromyalgia because the lawyers who are working for the insurance companies have all these experts who come and say, "Oh, everyone knows that Chronic Fatigue Syndrome is a minor psychiatric disease and the people can really work." So, you never mention that and you go to the heart of the matter and you go and say what is really wrong with these people.

Q4) If acute onset of ME causes brain damage, what type of treatments might help?

A: Well, I've mentioned that Dr. Chia, has had good success in finding the enterovirus in the stomach mucosa of CFIDS/ME patients. We're just starting to use treatments that Dr. Chia has been using. That's skeptical at the moment. I just don't know. All I know is there is no good anti-enteroviral medication in existence at the moment. There are a lot of things I don't know how to treat. One thing I have noticed in ME is people with money get better faster. And it is not because they have access to physicians. What it is— they have a cushion. I've had a lot of doctors come down with severe ME and diffuse brain injury after that epidemic period, and those with insurance stopped working, were able to relax, had money coming in, were able to live a healthy life, weren't under any stress, their mortgages weren't being taken out from underneath them, their spouses didn't run away, everybody was happy, the kids were happy, and they got better. Not everyone, but most of them to some degree. None of them became 100% better. The doctors who were saying "Oh, God, I'm only 35. What do I need health insurance for, disability insurance" and didn't get insurance, and they'd just graduated [from medical school] and they came down with that epidemic, not one of them, not one of those doctors is working today. Several of them committed suicide—they didn't get better. After you fall ill, the ability to do nothing except relax and live a healthy life, gives the body a chance to fix itself. There is no better physician than the body.

Q5) What is POTS?

A) Postural Orthostatic Tachycardia Syndrome is one of the classic dysautonomias. We see it most commonly after the recombinant hepatitis B immunization. We have 200 patients I mentioned earlier with POTS. What is POTS—your heart rate, which should be running around 60–80 beats per minute, should drop to 45 beats per minute when sleeping. What happens with POTS people when they're sleeping, is that their heart rate may drop down to 55–60 beats per minute and then when they awake, and try to move or do anything, their heart rate rises to over 100 beats per minute, which is tachycardia, or close to it in the 90's. If they get excited or if they try to do anything their heart rate may instantly go up to 150 to 200 beats per minute. If you put them on a treadmill, their heart rate can go up to 300 and you have to stop them. POTS is a major consequence to several other conditions. One is a brain injury, and injury to the system regulating the pressure in the blood vessel. I spoke about it earlier, I just didn't use the word POTS.

Q6) I had acute onset of ME 1990 after a bout of pneumonia—had years of recurring infections. Now, in 2012, diagnosed with Sjögren's (via positive salivary gland biopsy), joint enlargement deformity/pain—worsening of dental issues with tooth loss. Do I have autoimmune disease replacing ME? Both?

A: Of course you do. Forget about the names ME, CFIDS & FM. Ask what is causing this real symptom. You can't run off and have a test. You have to have a total body examination.

Q7) How do you do a workup?

A: I'll try to send to your group my working profile and you may even want to publish it. It will give you an idea of how extensive my exam is. We do Skype interviews with patients for 2 hours and sometimes we can help them.

Q8) Is a TB test a good idea?

A: We do a tuberculin skin test on every patient. We have picked up 5 cases of TB among people who think they have CFS. And it is so simple to do. It is a little skin test, costs nothing, put a little bleb underneath the skin. If the next day you have a big red reaction, you may have TB. You could have other diseases which could blow up.

Q9) I have very high heavy metal toxicity after EDTA & DMPS chelation. I have become much worse with my ME & FM. Your thoughts on this?

A: This treatment really doesn't work. I don't know a treatment that works. The idea of chelation has made a lot of people rich in Canada and the United States. What happens with heavy metals toxins is it goes in the brain. We had some serious injury to farmers when I was working in Glasgow for a short period of time. The doctor was doing every test he could on these farmers. We found exposure to different kinds of pesticides, herbicides and metals, but nothing special. They put them through chelation and all sorts of things. There was nothing we could really prove until they died. When they died, we got their brains and the brains were so solid with mercury, pesticides and herbicides that I phoned the Mounties, our national police force, like your FBI and CIA combined, and asked, "If you wanted to murder your husband with a nice milkshake of herbicides and pesticides could you tell?" They said, "We can't."

Q10) How does POTS contribute to CFS?

A: It doesn't contribute. POTS patients have it the worst. The POTS and autonomic nervous dysfunction people are so terribly ill—those are the ones that are not usually here. The better POTS patients might be here, but the serious ones are home in bed right now. They don't even know there is any organization to help them.

Q11) What can you tell us about the relationship to gender and CFS/ME?

A: What you are looking at with women is that they have a very different immune system. 80% of the all of the ME type patients are women. 80% of all of the MS patients are women. 80% of the RA patients are women. They have an immune system that is organized so that when they get pregnant they don't reject the baby as an autoimmune reaction. Their immune system shuts off as part of their natural reproductive ability to develop and build a healthy child. They already have an immune system which shuts off and starts on its own, so they are more vulnerable to any autoimmune disease and most of the ME sub groups that we have talked about are highly related to the autoimmune system.

Q12) Are women who had children more likely to get ill?

A: I don't know. I've never done the statistics on that. The last time we did statistics was around 15 years ago when we were looking at patients after the epidemic period of 1984 and that is one question we didn't ask, and that would have been a really useful question.

Q13) What's the difference between acute ME gradual onset?

A: ME is a diffuse brain injury that is measurable. If you can't measure it you don't have ME. ME depends on whether the onset is acute or gradual—if acute, it can be a combination of genetics, immunizations, medication, viral infections, things you can't always prove, trauma, brain injury. It can be a combination of things.

Q14) Can you explain more about gradual onset?

A: Gradual onset patients are one of the most interesting sub-types of ME because it almost always is something which is building in the patient. Those patients are the ones we find cancers in, those are the ones we find organ injury in, but those are the ones that are often best treatable. But you have to find out why.

Q15) What's the difference between acute and chronic?

A: Some people who have acute onset ME get better. If they are not better within a year, they lapse into what we would call chronic. And very few of those people get better. On their own, probably 25 % of that group does get better. But that still leaves a large percentage of patients that don't get better. You have to ask what is causing my ME and FM. That is absolutely essential. If you can answer that question you have a chance of curing the patient.

Q16) Did you have the polio vaccine before getting polio?

A: I fell ill in grade 8 so I must have been around 11–12 years old and that was 1948. The vaccine came out in 1954–55. But even before the vaccine was introduced in 1954, it had been tested on people in the island of Newfoundland and in the island of Granada, and it killed pretty well everyone they gave the immunization to. So the vaccine was withdrawn and retooled. It was reintroduced somewhere else and it didn't kill the people and ever since it has been the safest immunization known to God and man. It was a wonderful invention.

There had been a high risk of having your child die from polio. You hear about all the paralysis, but not about the deaths. Most of these kids died. It was also mainly women who died, not kids, but you didn't hear about those statistics because there was no research money for women in those days. Money was easier to get if children were being studied. I don't know if any of you remember Little Jimmie, the March of Dimes advertisement. Even then, women would give money for the study of children. Only later did the advertisers bring in a girl.

Q17) Is medical cannabis an option for replacing other meds?

A: I was on the medical committee in Canada, the LeDain commission, which looked at the safety of drugs. The LeDain commission came out showing that marijuana was not dangerous at all. Medical cannabis depends if you are taking it by a pill form, inhaling it from a cigarette or taking it internally as in the wild stuff. All my friends who grow cannabis are as ill as can be physically. And they smoke it all the time. Does it help you sleep? Yes, it does—so does cocaine. So does morphine. Do you get good sleep? Anything you inhale into your lungs is causing you major, major damage. I'm not one for cannabis.

Q18) Do you win when you go up against American insurance companies?

A: We almost always win. It is not because we're good; it is because of what we do.

Q19) How do you afford to practice medicine?

A: I make an average of \$40,000 a year in medicine. Every now and then I buy a property and sell it at a ridiculous price 5–10 years later and make a couple of million dollars. It is easy to make money but it is boring. But in medicine I just like to try to figure out what is wrong with people and that is a lot of fun. We charge a lot of money to see American patients, about \$10,000. But then we do all the testing in Canada which costs about \$6–7,000. The Canadian patients are only charged about \$3–4,000. However, it still takes us 18 months to investigate them and we do a better job than any of the big American clinics.

Q20) How do you win against insurance companies?

A: Insurance companies are really easy to beat if you know what is wrong with the patient, and these patients are seriously ill. We have done about 2000 patients since 1984 and most of them were in the early years. Now we take much longer per patient and only take about 20 new patients a year. They are easy to win because the patients are so ill. The cases never go to court because the insurance companies settle.

Learn more

You can learn more about Dr. Hyde at www.nightingale.ca

You can learn more about Dr. Chia at the Enterovirus Foundation

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