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Dr. Jeff Sherkey

It is with great sadness that we have to inform you of the passing of Dr. Jeff Sherkey Sunday morning, June 20th, 2004. The service was at Benjamin's Funeral Home at 2401 Steeles Avenue West, Toronto (near Dufferin and Steeles Avenue) at 1:30 PM.

Dr. Sherkey has been mostly comatose for the last two weeks. However, there was one day that he was conscious within this period and his wife read him cards that M.E./CFS and FM patients had sent to him and he smiled.

Thank you so much for sending cards to him. They brought him much happiness in his final weeks. He will be greatly missed by all.

If desired, donations may be made to the Dr. Jeffrey Sherkey Memorial Fund c/o The Benjamin Foundation, 3429 Bathurst Street, Toronto, ON M6A 2C3 (416) 780-0324.

Brain Problems in ME/CFS – Is There a Simple Explanation? The "Too Many Symptoms" Syndrome

E.G. Dowsett, MB ChB. Dip. Bact.

It may be that people with ME/CFS are so commonly and unfairly accused of hypochondriasis because they have too many symptoms to permit credibility. Alternatively, the casual observer may not have had time to listen, does not understand brain function or finds neurological research boring because it seems incomprehensible. This is a tragedy for all concerned. The sick person faces cruel disbelief, the casual observer seems unkind and the research worker lacks recognition for a fascinating and important study which might produce an adequate research grant.

Heart-Sink Patients

ME/CFS is primarily a NEUROLOGICAL illness which may or may not be accompanied by complications affecting skeletal and cardiac muscle, liver, endocrine and lymphoid organs. While most of these can be accepted by the average television viewer as interesting and understandable parts of routine medical and veterinary practice, the problem of belief pertains to the neurological' background and its attribution to psychological causes in humans, if not in animals. We therefore have to revise our scanty knowledge of brain function and its variation in disease before making a hasty judgment. Obstacles in the way of improving our knowledge (which is essential for doctors as well as for sufferers) include the fact that the brain is an enclosed organ, sequestered from the rest of the body, devoid of visible movement and not readily accessible for investigation without invasive, expensive or scarce equipment. For centuries philosophers and physicians have debated its functions, the earliest suggestions ranging from the casket of the soul to a device for cooling the blood. Yet, despite four hundred years of technological progress since the invention of the microscope and the current status of molecular biology, biochemistry and brain imaging, we still encounter well educated people prepared to manipulate their observations according to their beliefs. As a result, we have 2 separate camps in modern society - those who do and those who do not "believe" in ME/CFS. Unfortunate sufferers, who have no choice of listeners to their myriad symptoms, gain the inevitable reputation of being "heart-sink patients" - an appellation referring only to the doctor's sinking heart at the sight of a large medical file and the prospect of too frequent clinic attendances. Recently a group of research psychiatrists active in supporting a psychological origin for ME/CFS has been awarded a generous grant of £190,000 to relieve the NHS of "heart-sink " problems by the same route'.

Using Our Eyes – Anatomical Investigation of the Brain and Its Effect Upon "Belief"

Apart from organisms which are permanently static and do not require a brain to organize purposeful movement, all animated creatures have a brain with the same basic structure Although its component parts vary greatly in size and proportion in adaptation to the lifestyles of different species, the ground plans invariably include a thick stalk (BRAIN STEM) tapering below to a tap-root like extension (the SPINAL CORD from which a number of paired SPINAL NERVES emerge) and bearing the above,- two hemispherical outgrowths (the cerebrum or CEREBRAL HEMISPHERES) covered by a convoluted sheath of un-insulated nerve fibres (the CEREBRAL CORTEX, an extension of the brain's GREY MATTER). Two similar outgrowths (the little brain or CEREBELLUM) are borne at the base of the brain stem. Although some specific functions can be ascribed to special anatomical sites (e.g. SPEECH to the CEREBRAL CORTEX, lying below the left temple) there are intricate nerve fibre connections to "association areas" such as the PRE-FRONTAL CORTEX, which enable the brain to function as a whole and may permit connected and undamaged nerve cells to restore or take over some function of others, lost because of accident, stroke or infection.

Naked eye examination of the brain at post-mortem, which could reveal scar tissue in Multiple Sclerosis, for example, is unlikely to disclose damage affecting function in ME/CFS, where the changes are more subtle. Investigations require the use of radio-imaging in life - (e.g. SPECT scans)[2] or of molecular techniques to amplify viral genetic material (by PCR)[3] at post mortem. Though deaths from complications such as heart or pancreatic failure, may be officially recorded,[4] the lack of attribution to ME/CFS as the underlying disease, encourages insurance companies to "believe" that it is a benign illness and deny pension rights. It is a sad fact that the generosity of many sufferers wishing to donate organs for research is not matched by funding for appropriate scientific investigation.

Can Analogous Studies of the Brain in Poliomyelitis Lend Credibility to Sufferers of ME/CFS?

Using light microscopy and the available histological techniques for studying post mortem material from patients in 1948, BODIAN[5] demonstrated that the main impact of polio virus infection was upon the BRAIN STEM, an area through which almost every important neurological message must pass. A more recent development has been the re-discovery in 1982, of the post-polio syndrome (first recorded in 1875) indicating that survivors of acute polio virus-infection, despite apparent stability for some 40 years, may present with <u>new</u> symptoms of incapacitating fatigue, muscle pain and cognitive disturbance, often indistinguishable clinically from ME/CFS. A remarkable series of research papers from 1983 onwards by BRUNO[6] and colleagues," using modern investigational techniques in both illnesses, provides strong supportive evidence of similar abnormalities of brain function leading to movement disturbances, anomalies of hormone and neurotransmitter function and of the electrical and chemical activity of the brain (suggesting a central- cause for fatigue) as well as of cognitive function. These studies, which link the seemingly bizarre and unconnected symptoms reported by sufferers, should not only revolutionize preconceptions about patients previously considered to be hypochondriacal but encourage, them to keep a careful record of all symptoms which can be used as evidence at social benefit tribunals.

How Does the Brain Process Information?

The brain has often been likened to a computer. However there are fundamental differences in its essential function of processing, comparing and storing information. This is highly developed in humans, making us uniquely creative and better adapted to our environment than any animal. The brain, relies upon specialized cells designed for the reception and transmission of information (nerve cells or NEURONS) which are always electrically active, registering either a low voltage RESTING POTENTIAL or, after rearrangement of positively and negatively charged ions within and without the insulated CELL MEMBRANE, capable of generating a higher voltage ACTION POTENTIAL down its main nerve fibre (AXON). At the axon tip, chemical transmission (via NEUROTRANSMITTERS, released from the axon) bridges the gap (SYNAPSE) between axon and .the receptors (DENDRITES) of the receiving cell. These are spider like out growths from the cell body which are simultaneously in contact with axons transmitting from other neurons. Unlike a computer, which can be switched on and off and is programmed to give set answers to a single question, the chemical transmitter bridging the synapse introduces a variability into the on-going message and "NEURONAL PLASTICITY" into the receiving/transmitting network. It has been shown that similar modifications in response may be induced by virus infection[7] and that a change in behaviour may be the only indication of this subtle effect; The brain contains-some 100 billion neurons connected to some 10,000 relay stations and this enormous electrical activity creates a massive need for energy, using up 20% of the entire body's demand for oxygen and glucose. Recent studies of the brain stem by SPECT scan, indicate hypo-perfusion and low metabolic activity in subjects with ME/CFS. It is worrying that so many of these patients still smoke and adopt "sugar free" diets, further diminishing supplies of oxygen and glucose.

In order to avoid slowing down the incoming electrical impulses, chemical transmitters must be removed rapidly from the synapse and returned to cell metabolism. However, many drugs are designed to inhibit this process (e.g. selective serotonin re-uptake inhibitors such as PROZAC). Despite the manufacturer's disclaimer and the belief of the patient in chemically manipulated happiness, such drugs can impair the natural production of neurotransmitters, and lead to recurrence of the very symptoms for which they have been prescribed[8]. Most ME/CFS patients realize that, in view of their pre-existing brain dysfunction, potentially addictive drugs are better avoided unless used, as advised in the British National Formulary, only for brief periods.

Movement Disorders

The brain is continuously bombarded by incoming signals each of which, after information processing and co-ordination, will initiate an appropriate muscular response (however small). However, there is no single "movement centre" and incoming signals will either be directed via the brain stem to the spinal cord, undergoing processing on the way from specialized centres such as the cerebellum (the brain's autopilot) or the THALAMUS and BASAL GANGLIA beneath the cerebral hemispheres, all of which act as subsidiary control areas, relieving higher motor centres in the cerebral cortex for more intricate muscular action. Thus, semi automatic movements (e.g. swimming) co-ordination of movement with visual and sensory input, determination of balance and the mediation of individual limb movements, will pursue a devious pathway, while <u>direct</u> connection is made between the higher motor cortex and muscles requiring exceptionally fine co-ordination such as those of the hand, face and mouth - an arrangement appropriate to the evolutionary tool making, and communication skills of humans. Such muscles are allotted an especially large share of the motor cortex and, when a motor impulse reaches the nerve end plate e.g. in finger muscles, it is allocated to a few individual fibres rather than being spread over large areas, as in the leg. Modern research indicates disturbed metabolism in many areas essential to motor control in the brain stem of patients with ME/CFS, the majority of who have evidence of uncoordinated muscle twitching after slight exertion. Difficulty with balance and with fine motor control is often overlooked in medical assessments (especially in children). If patients can be persuaded to send a handwritten letter or children to produce a school notebook, evidence of a marked deterioration in fine motor control compared with previous proficiency or a deterioration in handwriting from one page to the next, can be a valuable aid to diagnosis.

Sensory Disturbance and Pain

The human brain possesses a degree of skill in parallel processing not yet matched by modern computers. Of the five senses (touch, vision, hearing, taste and smell) all pursue devious pathways to various sites in the cerebral cortex for interpretation as well as being linked in parallel processing. Thus, an individual watching television while eating, if examined by SPECT Scan, would demonstrate several areas of the brain simultaneously activated by touch, taste and smell, possibly coordinated with vision and hearing. Since vision can only be interpreted in the visual cortex any damage in the intermediary pathway involving the THALAMUS for example, will lead to visual disturbance despite a normally functioning eye while distortions of taste and smell may arise from disturbance in the same or adjacent areas of the mid brain through which the signal has passed for interpretation in the SOMATOSENSORY CORTEX. It is not unusual for subjects suffering from ME/CFS to complain of distortions in taste or smell and to ascribe these to allergy while auditory and visual hallucinations may be experienced by individuals where certain neurotransmitters (such as dopamine) are produced in excess. It is important that these patients should record and report seemingly inexplicable symptoms of this type without fear of being disbelieved. Aberrations of touch, pain, pressure and temperature sensation, initially transmitted from skin receptors, are common in ME/CFS and many patients suffer severely from a generalized pain syndrome which may arise from damage to the Thalamus. There is no specific pain centre in the brain but the sensation of pain is normally controlled by natural production of neurotransmitters such as encephalin which, like synthetic opiods, does not so much remove the pain as render the sufferer indifferent to it. Pain control is difficult in ME/CFS and, if simple measures do not work, it has to be remembered that prolonged use of morphine analogues may reduce natural production of encephalin. Acupuncture acts to increase local enkephalin production and, together with pleasurable activities which can "gate" pain sensation temporarily, as well as intermittent use of appropriate drugs, these patients may be made more comfortable. However, referral to a specialist pain clinic is often necessary

Hormone Disturbance

Hypothalamic function is often disturbed in ME/CFS. The HYPOTHALAMUS is a central relay station for collecting and integrating signals from diverse sources (including the THALAMUS, LIMBIC SYSTEM and RETICULAR ACTIVATING SYSTEM in the brain stem and mid brain) and for producing hormones which affect kidney function and lactation before funneling them into the dependent PITUITARY GLAND, as well as inhibiting or promoting the release of pituitary hormones. In this fashion it has a major influence on specific reaction to stress, thyroid function, weight, appetite and control of glucose metabolism, as well as regulation of female sex hormones and the circadian sleep/temperature rhythm. Most of these hormones are neither difficult nor expensive to measure and there is no case for self medication with thyroid hormones (for example) without accurate laboratory monitoring. Children and adolescents suffer more severely than adults from symptoms of sleep and appetite disturbance as well as from difficulty with emotional control. They should be relieved of school stress as far as possible until their condition stabilises.[9] Unfortunately, because of the hormone dependence of this illness, it is more common and more severe in females in the childbearing years and almost three times as common as in men, who have a more stable hormone profile throughout life.

The Growth of the Brain, Development of Memory and Effect Upon Education

A child's brain, at birth, is no larger than that of Ancient Man and must grow rapidly in the 18 months before the skull bones close to adapt to modern life. Multiplication of neurons, whose axons reach out in random fashion, occurs initially but, unlike a computer, neuronal connections are not irrefutably fixed and can adapt in later life. Neurons which do not achieve connection within the increasingly complex network die off. In childhood, it is a case of "use it or lose it" and a baby born with a squint will lose visual perception in the "lazy eye" unless nerve connections are made before the age of 5 years. From 11 to 16 years, when the multiplication of new neurons ceases, there is a *5%* increase in brain size following which, growth in the complexity of neuronal networks proceeds throughout life. Although young people are quicker to learn, an adult gains in experience and judgment well into healthy old age. These facts underline not only the importance of play and human communication in childhood, but also the devastating effect of educational disadvantage, in the peak learning years of puberty and adolescence, suffered by young people with ME/CFS. At this stage of neuronal growth and increasing complexity of nerve pathways, language function, for example, may never be laid down. Studies of identical twins indicate that experience and memory capacity has a more dramatic effect on neuronal growth and complexity of connections than genetic inheritance.

A good memory demands normal functioning of almost all areas of the cerebral cortex, the basal nerve centres of the mid brain (e.g. the THALAMUS and HIPPOCAMPUS) and their interconnecting pathways through the brain stem. Fluctuations of the metabolic activity in these areas (often made worse by physical and mental exhaustion) have been reported in SPECT SCANS of patients with ME/CFS[2], the vast majority of whom complain of difficulty with short term memory, though higher intellectual functions are usually preserved.

Normal functioning of the Temporal lobe and other areas of the cerebral cortex is required for:

1. Short Term Memory - laid down, for example, by uninterrupted repetition of telephone numbers and lasting for ½ hour. It is not "hard wired" by further processing to link with other memories, and resembles the free floating unassociated thoughts characteristic of dreaming and certain abnormal mental states.
2. Memory for Simple Facts - unrelated to time and space.
3. Implicit Memory- for automatic sequential repetitive movements appropriate to driving or sports.

Sufferers from ME/CFS may experience some of-these problems and be well advised to carry shopping lists, limit long distance driving and seek alternative hobbies.

Normal functioning of the entire cerebral cortex is required for:

1. **Memory for Events**: personal and unique to an individual.
2. **Explicit Memory:** which fixes special and personal events in time and space.
3. **Temporary Memory Storage** for 2 years or more in a "scaffolding;" of nerve connections in the mid brain
4. **Long Term Memory Storage**: Memories are retained as increasing experience modifies the nerve connections and, although it is still not quite clear how long term storage is finally accomplished, it depends upon a series of overlapping nerve circuits involving the entire cerebral cortex. A good memory is the corner stone of the human mind and deprivation of special educational provision in their most formative years is the greatest disability-inflicted on young people with ME/CFS.[2]

Summary

Patients with ME/CFS cannot be compared with a programmed robot. Damage to vital brain centres (albeit temporary in some cases) may lead to a wide range of apparently unconnected and bizarre symptoms. These are invariably exacerbated by physical exhaustion and mental stress, leading to misinterpretation by the casual observer. Time taken to listen and to examine carefully (aided by a simple scoring chart to assess severity) will do much to prevent patients, who are so often courageous and uncomplaining despite serious disability, from the final indignity of becoming a statistic in "Heart-sink" research.

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I am deeply indebted to the following authors upon whose work this entire paper is based: GREENFIELD SUSAN (a) Journey to the Centre of the Brain. Royal Institution of Great Britain Christmas Lecture, BBC Education 1994. (b) The Human Brain - a guided tour. London Weidenfeld & Nicholson. 1997
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The Student with ME/CFS in the Ontario Public School System

Margaret Parlor, Advisor on Youth Issues

This article is based on work of The Myalgic Encephalomyelitis Association of Ontario.

Introduction

To meet the clinical definition for ME/CFS, one has to have a significant degree of physical and mental fatigue that substantially reduces activity levels, generally by 50% or more. Another criterion of ME/CFS is post-exertional malaise or fatigue, meaning that if people with ME/CFS over-extend themselves their symptoms will worsen. Since a typical young person is active 12 to 14 hours a day, to be diagnosed with ME/CFS a young person will be active 6 or 7 hours a day at most. Subtract the time needed for tasks of daily living and transportation to and from school. School is around 6 1/2 hours a day and a rule of thumb for homework is 10 minutes times the grade level each day. It is obvious that a young person with ME/CFS will not have the stamina to maintain a regular school program. People with ME/CFS also experience cognitive difficulties such as confusion, impairment of concentration and short-term memory consolidation, disorientation, and difficulty with information processing. This makes getting an education even more challenging. Other aspects of the condition may further complicate the student's education.

A diagnosis of FMS is based on a history of widespread pain and the existence of tender points. The clinical definition of FMS states that most people with FMS have additional symptoms which need to be considered when assessing the total illness burden. These can include persistent fatigue with reduced physical and mental stamina, and cognitive difficulties such as impaired concentration and short-term memory consolidation, impaired speed of performance, inability to multi-task, easy distractibility, and cognitive overload. Thus, a young person with FMS can face similar and serious challenges in accessing an education.

We estimate there are several thousand students in Ontario (and thousands more across the rest of Canada) whose education is being significantly disrupted by ME/CFS and/or FMS at any point in time.

With conditions as frequent and as disruptive to education, you would think that the education system would be primed to deal with these cases. Instead, there is legislative confusion that is left to individual boards and schools to sort out. This leads to inconsistent service.

The Education Act

The Ontario public school curriculum is flexible enough to handle a variety of students. However, some students are exceptional in that the regular system does not work for them and special accommodations have to be made. Section 8(3) of the Education Act states that "the Minister shall ensure that all exceptional children in Ontario have available to them... appropriate special education programs and special education services without payment of fees...."

After this promising start, Section 1 defines an "exceptional pupil" as "a pupil whose behavioural, communicational, intellectual, physical or multiple exceptionalities are such that he or she is considered to need placement in a special education program..." This definition is further detailed in the Ministry's Standards for School Boards' Special Education Plans in a way that ties in with the classic special education categories such as hearing impaired, vision impaired and developmentally delayed. There is no category that clearly includes ME/CFS or FMS, no category along the lines of "other health impaired" found in the US Individuals with Disabilities Education Act (IDEA).

The fact that ME/CFS and FMS are not clearly included as exceptionalities in Ontario has ramifications when it comes to developing accommodations for these students.

1. It sends the message that these are not serious educational disabilities. Thus, educators are inclined to underestimate the difficulties the student faces and to underestimate the educational planning and support required.
2. It raises doubts whether students with ME/CFS and/or FMS are entitled to use the "IPRC" (identification, placement and review committee) process. It appears that some school boards require that the student be formally identified as exceptional before accommodations are made, while others are prepared to make accommodations without identification. We would hope that the categories of exceptionality would be given a broad interpretation, and we are aware of one case where an Ontario student was identified as exceptional based on ME/CFS.
3. The Ministry and school boards develop plans based on the categories of exceptionality. Each school boards is required to prepare an annual special

education plan showing the range of placement options available for each exceptionality. Consideration is therefore given to programs for students with the classic educational disabilities, but not for those with ME/CFS and/or FMS. They are simply slotted in existing programs like home instruction (visiting teacher), alternative schools or correspondence courses and are expected to adapt. There are aspects of all these programs that can be problematic for students with ME/CFS and/or FMS. For instance, home instruction programs are often designed for fixed-term absences not involving cognitive challenges. We are encouraging the province to consider different possible programs for these students. Particularly interesting is a program for homebound students developed in Warwickshire England based on an internet classroom supported by visiting teachers.

4. As long as these conditions are overlooked as exceptionalities, inadequate consideration will be given to the costs of serving the students.

The Ontario Human Rights Code

Section 10 of the Ontario Human Rights Code defines "handicap" in a very clinical manner and it is not obvious whether ME/CFS and FMS are included. However, the Ontario Human Rights Commission has made it clear in its Policy and Guidelines on Disability and the Duty to Accommodate (2000) that the conditions set out are "merely illustrative and not exhaustive". The document specifically identifies chronic fatigue syndrome, back pain and environmental sensitivities as examples of "non-evident" disabilities. FMS is not mentioned but clearly implied.

The Myalgic Encephalomyelitis Association of Ontario wrote the Ontario Human Rights Commission asking about the educational rights of young people with ME/CFS under the Ontario Human Rights Code. The Association received a quick and supportive response from the Chief Commissioner who made it clear that the Code puts an obligation on educators to address the educational needs of these young people:

> "Regardless of whether students have been formally identified as "exceptional", they are still entitled to protection from discrimination in the educational context under the provisions of the Ontario Human Right Code (the 'Code'). Under the Code, individuals have the right to equal treatment in services, including educational services, without discrimination because of disability. Education providers also have a duty to accommodate students with disabilities up to the point of undue hardship. The Commission's Policy and Guidelines on Disability and the Duty to Accommodate specifically includes chronic fatigue syndrome as an example of a disability that, while non-evident in nature, has full protection under the Code."
>
> "In determining the type of accommodation that a student will receive, education providers are to evaluate each student and each situation on an individual basis."

Unfortunately, not everyone looks beyond the narrow words of the Code itself. Take one example. The recent Ontarians with Disabilities Act requires each school board to prepare an annual plan to improve access to educational services for those with disabilities. This would be an alternate route to draw attention to the challenges faced by students with ME/CFS and/or FMS in accessing the education system. In the guidelines to school boards used in the first planning cycle, section 10 was quoted but there was no mention of the wider interpretation. Instead, it was assumed that the categories of exceptionality under the Education Act adequately covered the gamut of disabilities. As might then be expected, there was no reference to issues affecting access to educational services for students with ME/CFS and/or FMS in the guidelines.

Working for Change

Imagine the scenario where a student has ME/CFS and/or FMS and the education system understands the educational implications, knows how to dialogue with the family, and responds with the appropriate accommodations.

The Myalgic Encephalomyelitis Association of Ontario, the Ontario Fibromyalgia Society, and the National ME/FM Action Network jointly contacted the Ontario Minister of Education in early 2003 to point out the gaps in service -- the lack of awareness, the lack of coherent policies and procedures for dealing with students with ME/CFS and/or FMS and the resulting inconsistent service. Subsequent dialogue has taken place with the Ministry of Education, the Ontario Human Rights Commission, and the Ministry of Citizenship and Immigration (which has overall responsibility for Ontarians with disabilities). The Minister of Citizenship recently asked the Attorney-General to look at the situation as well. So far there has been little to see for these efforts and young people continue to fall between the cracks.

While service to students depends a lot on the policy framework in place, it also depends very much on the sensitivity and creativity of the educators involved. Therefore it is important to make individual educators aware of the issues surrounding ME/CFS and FMS Thanks to the efforts of the ME/FM community, the conditions are becoming better known and Teach-ME document has been made available to numerous schools and boards across Ontario.

The ME/FM Action Network, provincial associations and local groups are available to provide information and support to students with ME/CFS and/or FMS as well as to their families and schools.

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PLEASE HELP: The **National ME/FM Action Network** would like to hear about the school experiences of young people with ME/CFS and FMS, good or bad, from all across Canada. Your information will give us a more detailed picture of the educational issues young people face which will help when dealing with government policy makers. Please indicate whether you have ME/CFS and/or FMS, as well as your school, city and province. The information will not be shared with others in a way which might identify you without your knowledge and consent.

Young People – We Would Like to Hear From You

Our website **http://www.mefmaction.net** has a Youth Site.

Study Tips From Youth: If you have found something that helps you at school or with your homework and would like to share your tip with others, please let us know.

We're always looking for original poems or stories by young people with myalgic encephalomyelitis /chronic fatigue syndrome or fibromyalgia syndrome. You can tell how you feel about being ill and not be able to do many things your friends can do. Your poem or short story does not have to be about your illness. You can write about things you have learned, what you like to do, or hope for in the future. Sometimes being ill makes you learn to appreciate and value things that you took for granted before. Have you changed your perspective on life or discovered hobbies or talents you might not have pursued if you were not ill? Have you found some way of helping others?

We primarily present non-fiction. However, if you are not yet a teenager, we may consider a short fictional poem or story. If brain fog is a problem but you would still like to contribute, we're happy to edit your article for you. Please indicate this when you send your article. If you wish, you can indicate your age and let us know if you want us to include that after your name. Visitors to our site would love to read about your experiences and ideas!

Please email your article or poem to **Marj van de Sande** at **mvandes@shaw.ca**
If you have a website of your own; please give us the URL in your email so we can link to it from your article.

Help for Parents and Educators: Our Youth Site also has helpful information for parents and educators to assist young people with ME/CFS and FMS.

National ME/FM Action Network Granted Intervener Status by the Court of Appeal for Ontario

The **National ME/FM Action Network** applied for and was granted Intervener Status in Lowe v. The Guarantee Company of North America. The outcome of this case will affect our members' rights to sue a DAC (Designated Assessment Centres) doctor. We hope that the results will also impact on future cases where a client may wish to sue a negligent I.M.E. (Independent Medical Examination) doctor.

We are asking you to please make a generous donation to our organization towards the legal costs of this intervention which will be approximately $10,000.00.

Please see below a letter from our Counsel, **Mr. Hugh R. Scher** of Scher & De Angelis, regarding the importance of this intervention:

Lowe v. The Guarantee Company of North America
(Court of Appeal for Ontario, Court File No. C40670)
Hearing Scheduled for December 1, 2004

An Appeal from the Order of Mr. Justice Lane, made September 2, 2003 disentitling the Plaintiffs to pursue an action for negligence and bad faith in the exercise of a statutory duty by a DAC assessor.

Why is it so Important for the National ME/FM Action Network to Intervene in This Court Case?

For the first time in its history, the **National ME/FM Action Network** has been granted standing as a friend of the Court. On June 24, 2004, **Chief Justice Roy McMurtry** heard arguments from the Network's counsel, **Hugh R. Scher** of Scher & De Angelis, Barristers and Solicitors in Toronto and granted the Network's standing to submit a written argument and to make oral submissions before the Ontario Court of Appeal when the Lowe case comes before it on December 1, 2004.

Importance of the Case

This appeal is fundamentally about the appropriate remedy for wrongs committed by DAC assessors in the unlawful and bad faith exercise of their statutory duty under the Ontario Statutory Accident Benefit Regulations.

This appeal will resolve the issue of whether or not an injured party can sue a DAC assessor for injuries including lost entitlement to benefits, arising from a DAC assessment which is conducted in a manner that results in opinions which are dishonest, biased, incompetent, negligent or in bad faith and where an injured party is deprived of benefits as a result of this wrong done to them by the assessor's unlawful and bad faith exercise of their statutory duty.

It is the Network's position that an injured party should have the right to sue in these circumstances and that justice demands that the law provide an appropriate remedy for the injuries caused by the wrongs of the DAC assessor. The Association submits that the proposition that a remedy should flow from the damages caused by the wrongs of a DAC assessor is deeply rooted in the basic principles of tort law and is supported by the statutory regime which governs the DAC assessment process and imposes on DAC assessors a duty of fairness, good faith, neutrality and professional competence.

The Network notes that people with disabilities, including those with Chronic Fatigue Syndrome and Fibromyalgia are amongst the most vulnerable members of society. They are often exposed and subject to discrimination in the insurance context, and are particularly vulnerable at the point in time when their disability occurs.

The hardship faced when a person becomes an injured victim of a car crash would be compounded by immunizing DAC assessors from liability for wrongs committed by way of unlawful, incompetent, biased and bad faith exercise of their statutory duty.

The Network will argue that the statutory duty of DAC assessors set out in the SAB regulations ought to be interpreted in a manner consistent with the equality provisions within the *Ontario Human Rights Code* and the *Charter of Rights and Freedoms* so as to ensure that the common law develops in a manner consistent with these principles and does not evolve in such a way as to threaten and undermine an injured victim's sense of self worth, dignity and just entitlement to benefits by virtue of their disability or the unlawful exercise of a statutory duty which denies injured and disabled people their just entitlement to insurance benefit.

The implications for the decision of the Ontario Court Appeal in this matter are significant both for the community of people with Chronic Fatigue Syndrome and Fibromyalgia who are injured in car crashes and for the legal profession who represents this community to secure their just entitlement to health, rehabilitation and income replacement benefits as well as to fair and appropriate compensation for tortious wrongs done to them by third parties.

About the Case

The case arises from injured victims of a car crash who were required to attend a DAC assessment to determine the appropriateness of the healthcare treatment plan proposed by their family physician. Based on the opinions expressed in the DAC assessment, which was conducted in bad faith, in a biased and incompetent manner, the injured victim was deprived of health and rehabilitation benefits to which they would have been entitled but for the negligence and bad faith in the exercise of their statutory duty by the DAC assessor.

The Initial Judgment

The motion was originally brought by the respondent by way of a Rule 20 Summary Judgment Motion but was converted by Justice Lane into a Rule 21 motion to determine whether or not the pleadings raised a reasonable cause of action.

Justice Lane ordered that the plaintiffs' claim failed to raise a reasonable cause of action in that the nature of the relationship as between a DAC assessor and a plaintiff was not one that created a duty of care, or a fiduciary duty and further ordered that the DAC report was absolutely privileged and subject to witness immunity because it forms part of the litigation process.

The Urgent Need for Appeal of the Court Decision

In response to the court's decision, the plaintiffs appealed to the Ontario Court of Appeal on the basis that the purpose of the DAC assessment is to determine treatment and rehabilitation in order to promote recovery and not to gather evidence for future litigation.

It is also argued that the relationship as between the DAC and an injured party is governed by the statutory duties set out in the Statutory Accident Benefit Regulations which include a duty owed by a DAC assessor to be neutral, free of bias, professional and to act in good faith.

It is submitted that the nature of the relationship does give rise to a duty of care under basic tort principles and that this duty is not limited in circumstances where a DAC assessor acts in bad faith, dishonestly or in a negligent or incompetent fashion in the context of a DAC assessment and its report. This reasoning is supported by a parallel decision of the Ontario Superior Court of Justice which did hold a DAC assessor liable for damages to a third party healthcare provider who was denied the opportunity to provide healthcare services based on a dishonest, bad faith and incompetent DAC assessment.

The Urgent Need for Intervention by the National ME/FM Action Network

The Network feels compelled to intervene in this matter in order to ensure that those of its members who are victimized by unlawful DAC assessments have a mechanism in order to seek and recover damages resulting from the breach of the statutory duty and bad faith giving rise to injuries suffered by them. It is submitted that an injured party should not be left without a remedy to address the wrong done to them by the DAC assessor especially where the statutory regime contemplates, or at least does not preclude such an action.

This case raises significant issues of concern to the community of people with Fibromyalgia and Chronic Fatigue Syndrome and the Network requires your financial support in order to make sure that these are adequately addressed at the Ontario Court of Appeal.

PLEASE SUPPORT THE NATIONAL ME/FM ACTION NETWORK IN ITS WORK OF FUNDAMENTAL IMPORTANCE TO THE COMMUNITY OF PEOPLE WITH CHRONIC FATIGUE SYNDROME AND FIBROMYALGIA.

Yours very truly,
SCHER & DE ANGELIS PROFESSIONAL CORPORATION
Per: **Hugh R. Scher**, Counsel for the National ME/FM Action Network – Tel. **(416) 515-9686** or <**hugh@sdlaw.ca**>

Forensic and Demonstrative Evidence for Insurance Claims – March 27, 2003

Reflection of the Role of the Expert Witness

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Introduction

In *R v. Abbey*[1]*,* Dickson J. held:

> **Witnesses testify as to facts. The judge or jury draws inferences from facts. With respect to matters calling for special knowledge, an expert in the field may draw inferences and state his opinion. An expert's function is precisely this: to provide the judge and jury with the ready-made inference which the judge and jury, due to the technical nature of the facts, are unable to formulate. An expert's opinion is admissible to furnish the court with scientific information, which is likely to be outside the experience and knowledge of a judge or jury.**

As science and technology have become more complex, the role of the expert witness has become increasingly more important.
The selection and preparation of the expert witness has been and will prove to be at the cornerstone of much successful litigation.

The Ikarian Reefer

The British decision commonly referred to as *The Ikarian Reefer*[2]*,* a 1993 decision of Justice Cresswell, has been referred to in a number of Canadian decisions as providing certain guidelines for expert evidence and as setting out certain duties of the expert witness.

The first two duties referred to by Justice Cresswell are as follows:

1. Expert evidence presented to the court should be, and should be seen to be, the independent product of the expert uninfluenced as to form or content by the exigencies of litigation; and
2. An expert witness should provide independent assistance to the court by way of objective, unbiased opinion in relation to matters within his expertise.

The courts tend to be way of an expert who assumes the role of an advocate or advances a self-serving viewpoint. Expert testimony that appears objective and well-balanced is likely to be accorded more weight and is more likely to be relied upon by the trier of fact.

In *Perrlcone* v *Ba1dassatra*[3]*,* a decision on a motion brought pursuant to s.266 of the *Insurance Act* Macdonald J. stated that:

> **[I]f the person rendering the evidence assumes the role of advocate, he or she can no longer be viewed as an expert in the legally correct sense; instead, he or she must be viewed as advocating the case of a party with the attendant diminishment in the credibility of the report. Expert opinions guide the court but they do not determine the matters which are to be determined by the court.**

In *Fellowes, McNeil* v *Kansa General International Insurance Company Ltd. et al*[4], Macdonald J. once again referred to *The Ikarian Reefer* and the duties of the expert witness listed above, and ruled that a proposed expert in a solicitor's negligence action did not qualify to give expert evidence because of his early involvement as an advocate for Kansa.

In *Fellowes, McNeil,* Macdonald J. reiterates that:

> **Experts must not be permitted to become advocates. To do so would change or tamper with the essence of the role of the expert, which was developed to assist the court in matters which require a special knowledge or expert is beyond the knowledge of the court.**

In Toronto-Dominion Bank v. E. Goldberger Holdings Ltd.,[5] it was stated that:

> **[E]experts must conduct themselves as objective neutral assisters of the court and, if they fall to fulfill this function, their testimony should be ruled inadmissible and therefore Ignored after they have been eviscerated.**

The duty to remain impartial and objective and the value of finding experts who can fulfill this duty has become increasingly more important, particularly with the proliferation, in recent times, of "professional expert witnesses" - people who have little, if any, clinical practice, but who spend the majority of their time testifying as experts.

Experts must always be reminded of their primary role, which is to assist the trier of fact. After all, this forms one of the bases for the admissibility of expert evidence by the courts, as set out in the Supreme Court of Canada decision in ***R v. Mohan*[6].**

The next duty of an expert witness mentioned by Justice Cresswell in ***The Ikarian Reefer*** is as follows:

> **An expert witness should state the facts or assumptions upon which his opinion is based. He should not omit to consider material facts which could detract from his concluded opinion.**

It is logical that, in order for a court to evaluate an expert's opinion and compare and contrast competing opinions, it is necessary to have knowledge of the facts and assumptions which underpin those opinions. It is therefore incumbent upon counsel to carefully evaluate the opinion of his7her own expert and that of the opposing expert as this can provide fertile ground for examination and cross-examination.

In this regard, the disclosure requirements contained in the ***Rules of Civil Procedure*** are particularly useful in providing counsel with an opportunity to evaluate the potential expert testimony and canvass issues and controversial areas with his/her expert in advance of a trial. This is particularly important in personal injury actions where the evidence can become very complex and technical. The input of the expert is essential in focusing both the lawyer's and the expert's attention on potential strengths and weaknesses in the expert's testimony and the testimony of competing experts.

The fourth duty of expert witnesses expressed by Justice Creswell in ***The Ikarian Reefer*** is as follows: "**An expert witness should make it clear when a particular question or issue falls outside of his expertise.**"

The Supreme Court of Canada in ***R v. Mohan***[7] stated that in order for expert evidence to be admissible, such evidence must, ***inter alia,*** be presented by a witness who is properly qualified: in other words, a witness who is shown to have acquired special or peculiar knowledge through study or experience in respect of the matters on which he or she undertakes to testify.

In ***Kozak v. Funk***[8] a decision of the Saskatchewan Court of the Queen's Bench, Klebuc J., referring to the decisions of *R* V. *Kuzmack* and *R v. Howard,* states that:

> **Whether a person qualifies as an expert varies with the circumstances and thus no all-encompassing definition is possible. Nonetheless principles have evolved to control the testimony of proposed experts. An expert is limited to testifying to matters within his or her area of expertise. Experts are not to consider or comment on facts that are not subject to his professional expert assessment.**

Freiman and Berenblut, in their book, The Litigator's Guide to Expert Witnesses[9] state that:

> **The test of expertness is the skill in the field in which the expert opinion is sought. Before the expert witness may be permitted to testify, counsel must qualify the expert witness's knowledge of the subject matter....Counsel calling the witness must demonstrate to the court, by examining the expert on his or her qualifications, that the witness has special knowledge, experience or expertise in the area in which he or she proposes to testify. Once the expert witness has been qualified in a particular field, he or she may testify about matters falling within that field.**

The corollary to this is that it is incumbent upon the expert witness to make it clear when a question or issue falls outside of his or her expertise.

In *The Ikarlan Reefer,* Justice Creswell also suggests that the expert witness has a further duty which is that:

> **If an expert's opinion is not properly researched because he considers that insufficient data is available, then this must be stated with an Indication that the opinion is no more than provisional one.**

Once again, this goes to the role of the expert in assisting the trier of fact. Particularly where an expert is testifying on a complex and technical issue, the judge needs to know the factual bases and assumptions underlying the expert's testimony in order to fully understand the testimony and to question the expert should this prove necessary.

It is equally vital, therefore, that the expert conveys to the judge that his testimony, or a report prepared by him, is deficient as a result of there being a paucity of information or data for him to evaluate and that he requires further information in order to provide a more comprehensive opinion. Failure to do so could mislead the court and be detrimental to the case in the long run.

The last two duties mentioned by Justice Creswell in ***The Ikarian Reefer*** echo the emphasis placed by Canadian courts in recent years on the importance of pre-trial disclosure. These duties are that:

> **If after the exchange of reports, an expert witness changes his view having read the other side's expert's report or for any other reason, such change of view should be communicated (through legal representatives) to the other side without delay and when appropriate, to the court; and Where expert evidence refers to photographs, plans, calculations, analyses, measurements, surveys, reports or similar documents, these must be provided to the other party at the same time as the exchange of reports.**

The purpose of exchanging information is to enable the parties and the experts to evaluate opposing opinions in an attempt to narrow the issues and possibly canvass settlement where the experts appear not to be very far apart. It may, however, also result in the experts and the parties realizing that they may be required to obtain further information to bolster the expert evidence that they intend to present to the court.

Conclusion

Although it is a decision of the British courts, ***The Ikarian Reefer*** and the duties of the expert witness enumerated by Justice Creswell have been applied in a number of subsequent Canadian decisions, and the decision provides a useful roadmap to counsel on how to deal with expert testimony. Counsel should consider the principles espoused in ***The Ikarlan Reefer*** and the Canadian cases applying those principles, when preparing or assisting an expert witness to prepare for trial.

References

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A Special Thank You

We wish to thank and are deeply grateful to **Mr. Richard Bogoroch** who was kind enough to give us the funds we needed to buy a computer and printer for Mary Ellen. Her computer had crashed so many times that it was not feasible to get it repaired again.

Over the years, Mr. Bogoroch has been very supportive to our organization and has assisted us anytime we have asked for help.

In addition, he has helped many ME/CFS and FM people who were having legal problems.

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