25% Severe ME Group & Stonebird

Do Not Mess with Severe ME :

provide a proper medical service

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Greg Crowhurst August 2012

Introduction :

Imagine the gap that exists between the person with Severe ME and you. In their world, there are breaks to contact that are invisible , without insight and knowledge. That which seems near and accessible is still beyond reach , no matter how apparently close or easily possible it may seem to a well person :

- There are breaks to communication.
- There are breaks to physical function.
- There are breaks to every single ordinary things that make the world difficult to impossible to be in and access.
- There is cognitive dysfunction that impacts upon comprehending conversation, remembering information, focusing, concentrating, understanding, connecting with another person, answering questions, providing information, processing information.
- There is pain : muscle, gut ,nerve and head pain , which is indescribable, multi-layered, may be constant and often untreatable, severe to extreme and unimaginable to someone without ME.

- There are fine and gross motor control issues, which may make it impossible to hold anything, to co- ordinate, to function, to perform any daily living task or activity, to walk even.
- There is extreme and profound physical exhaustion, which impacts every single aspect of living, even breathing, moving, thinking.
- There is a post- exertional impact that simply has to be factored in to any encounter as it can result in massive deterioration and potential harm.
- There is malaise which means the person may feel constantly ill and this level of malaise is incapacitating in itself from any normal thing.
- There is noise sensitivity, which can be so extreme that the person is tormented and literally damaged, resulting in increased exacerbation of other symptoms such as pain and paralysis, breathing, by any noise at all, no matter how insignificant or irrelevant it might appear from the outside.
- There is muscle dysfunction and this can impact all physical action making it difficult to impossible, including swallowing, moving, walking, holding.
- There is light sensitivity, which can be so painful that people live in darkened rooms and can impact communication, use of computers, reading, everything requiring vision.
- There are complex gastric issues which affect eating, digesting , swallowing, vomiting and diarrhoea/constipation.
- There is a massively increased hypersensitivity to the environment which again impacts every aspect of health and life. Chemical sensitivity may mean the person needs to live in a chemical free perfume free zone. Exposure to chemicals can be distressing, and damaging yet the person living in the normal world may not even be aware that their laundry detergent, perfume, deodorant or moisturiser can make a person with Severe ME very sick.
- There may be transient paralysis and or facial palsy.
- There may be an inability to be upright, to move, to function.

- There may be shaking spasms, which are uncontrollable and worsened by physical contact or exposure to stress.
- There may be irritability and emotional lability as a result of the physiological processes going on in the body.

Every single issue is severely disabling; added together you have an incredibly complex situation , in which the person can be easily harmed by any service not firmly based upon the central truth , that ME is a neurological disease

Careless use of the words "management" and "fatigue" for example, can easily deny the person's physical reality if they are not qualified ; in a medical framework :

Post- exertional and muscle fatigue becomes tiredness, a mental health issue.

The need for a medical service is met by a psychiatric psychosocial approach.

Treatment becomes misrepresented as therapy.

So far, there is no formal safe medical pathway for ME, no formal safe treatment protocol. People with ME do not even have the safety of knowing

that they have been diagnosed accurately , or if they have been properly diagnosed, whether their diagnosis will be respected and understood.

In this document we seek to outline the importance :

1. of identifying ME, what it is and what it is not
2. the need to create a safe medical service, by separating ME from CFS and re diagnosing CFS - labelled patients accurately
3. the development of new medical pathways based on honesty and the truth of Severe ME

The need to separate ME from CFS

Despite the difficulties of working with people with Severe ME, their need is great ; the chronic neglect of these patients must not continue, however the dangers of

getting involved with a person with Severe and especially very Severe ME are colossal and must be recognised, understood and taken into account.

Severe ME needs to be taken seriously . It is essential to ensure that no harm is done through ignorance, unawareness or denial.

People with Very Severe ME are vulnerable.

They are frail.

They are extremely physical ill (please see Appendix 4).

They are fragile.

Through the current lack of separation between neurological Myalgic Encephalomyelitis and generalized fatigue conditions- because of the use of the label CFS or CFS/ME , people with neurological and Severe ME are easily open to being :

- Abused
- Misrepresented
- Mistreated

It is unlikely that anyone , apart from people with Severe ME and their carers , really knows what life is like for the most severely affected, who are house and / or bed bound, unable to interact in a normal way .

There are few clinicians, who are well informed on Severe ME. Virtually no studies or research have been carried out.

ME , an organic neurological disease, is classified under WHO ICD G93.3; it can be fatal . "CFS", on the other hand, defined through the Oxford and CDC/Fukuda Criteria , describes no distinct patient group :

- Patients assessed using the Oxford or CDC/ Fukuda definition may or may not have ME as the definition is too loose. They may equally have a mental health issue or some undiagnosed illness, but not ME

- The recent PACE Trial was supposed to study ME (labelled as "CFS/ME"), however the Pace Trial authors were forced to admit that their multi million pound funded trial into CFS, did not study ME. but CFS defined simply as a principal complaint of fatigue that is disabling, having lasted six months, with no alternative medical explanation (Oxford criteria)"; yet funding for the trial was granted on the basis that the disorder being studied was "CFS/ME", not "fatigue or a synonym". (Professor Malcolm Hooper 2012 http://www.meactionuk.org.uk/Update-on-the-PACE-Trial-110712.htm)

- .In day-to-day use "CFS" does not define a neurological illness; there is no CFS definition that includes viral or bacterial triggers.

It is important to be clear that using the label "CFS" leads to :

- a lack of clarity and confusion

- a misrepresentation of CFS as being the same as ME, whereas in reality it may or may not be; the person may or may not have ME.

- allows psychiatric therapies to charade as treatment, because some people in the CFS community may be helped by them - however even this is debatable given the PACE and FINE trial test results."In practice, the clinically useful difference (of CBT/GET) is so small as to be imperceptible in general living and it is questionable as to whether it does in fact represent a "clinically useful" difference." (Professor Malcolm Hooper 2012) http://www.meactionuk.org.uk/Update-on-the-PACE-Trial-110712.htm

'ME/CFS' is not formally acknowledged or classified by the WHO; it has no ICD Code.(LK Woodruff (2010 http://www.rescindinc.org/mecfs_and_cfsme_do_not_exist.htm).

The WHO ICD-10 code as used in UK, Australia, Europe and other countries, has 'CFS' in the index only, indexed to G93.3 ;'CFS' does not appear in the Tabular list, i.e. the main body of the classification listings, at that code.

In ICD-10 'CFS' is not the same as 'Fatigue syndrome,' which is classified at F48.0 Neurasthenia under "Mental and behavioural disorders " (Lesley Ben (2009

http://www.hfme.org/Word/WHO_ICD_ME_and_CFS_Long.doc but coding - in the real world, frustratingly does not always override definition. CFS, despite the WHO classification, is not widely recognised by clinicians in the UK, as identifying a neurological disease, rather it is treated as Chronic Fatigue - enabled by the application of loose definitions ; the boundaries have become hopelessly muddied.

Any effort to create a proper medical service for ME must not be compromised away or lost because of a wrong identification or association with chronic fatigue.

There is no evidence anywhere in the world, that adopting the psychiatric-driven convention of linking ME and loosely defined CFS together , has led to improvements in research, diagnosis or recognition ; it only leads to misunderstanding of neurological ME. Only the International Consensus Criteria (please see Appendix 3 for an overview) should be used to identify patients with ME specifically because the ICC Crieria separates them from patients with chronic fatigue or general fatigue conditions .

The CDC/Fukuda Criteria help to justify a fatigue service - inappropriate for ME patients, but possibly beneficial for other less clearly defined patients ,who do not have neurological ME. There is no reason whatsoever to use the CDC or Fukuda Criteria, to underpin service provision , which are so wide as to be almost useless; the vast majority of those selected under the CDC criteria do not have ME, resulting in people with ME having their physical health needs neglected or down played and overlooked.

An ME aware service , one that conforms to the International Consensus Criteria (Carruthers et al 2011 http://onlinelibrary.wiley.com/doi/10.1111/j.1365- 2796.2011.02428.x/abstract) is essential to protect these patient's health needs; every step must be thought through.

(*Please see Appendix 1 on Risk Assessment*.)

Severe ME Service Provision

Unfortunately, with loose definition and wide diagnosis, it becomes not enough to say "I want a specialist" for people with ME.

Sadly it is not even enough to say " I want a biomedical specialist", without also stressing the need for the right clinician , one who :

- Is aware that fatigue and post- exertional fatigue are different and does not consider ME to be just another sort of fatigue illness.
- Comprehends the reality of Severe/Very Severe ME
- Is abreast of current physical research and open to new tests and treatments and is in a clinical environment where they are supported to recommend and offer them.
- Can relate any suggestion they might make to the person's physical reality, factoring in risk and health impact.
- Genuinely understands Severe / Very Severe ME and who will not make the person wrong when/ if any suggested intervention fails, is required.
- Will have the humility to realise, if they get it wrong
- Has the integrity to understand that Severe ME is so complicated that people can be harmed, long term even permanently and even die from wrong treatment.
- Clearly understands and factors in the post- exertional impact of any interaction. The subtlety of interactional impact is profound in Severe ME. Placing any extra physical demand upon a person with Severe or Very Severe ME can cause irreparable damage.

The Five Essential Components of a Severe ME Service :

- **Tests**
- **Research**

- **Understanding**
- **Treatment**
- **Hope**

People with ME should be able to feel safe; they certainly are not safe right now .They do not , however, need to be taken over as a "cause "by people who :

- do not represent them
- do not respect the experience of genuine Severe ME
- do not understand the severity of illness
- call it a fatigue illness
- downplay the symptoms of neurological ME so that it will appear to fit into a fatigue service or fatigue regime.

ME services need to be about ME. Nothing else.

Keep your fatigue clinics if you will, but they are not for Severe ME. Let us not confuse illnesses. Let us not confuse treatments for ME with psychosocial misrepresentation. Rehabilitation techniques services should be for just that ; BUT treatment is required first. People with ME need new medical tests and treatments .

Lives and health are at stake.

Establishing the wrong service, or bringing in the wrong Consultant could have horrific consequences for people with Severe ME ; it could not be more serious.

New services for Severe ME

New services are needed : new biomedical tests and treatments for neurological ME. New hope. A new way is required. (See Appendix 2 for a Brief List of possible ME Tests) :

- As a basic starting point , alongside provision of an aware medical consultant, proper use of ICC criteria to identify patients accurately and adequate ME

tests and possible treatments, paid for by NHS, while there is not one definite test for ME, many tests may indicate abnormalities , the following, at least, should be in place, for people with Severe ME :

- A specific medical service for ME separated from CF.
- Specialist ME tests and treatments , paid for by NHS.
- A full health report outlining physical dysfunctions.
- The proper diagnosis of patients already labelled with CFS , using the ICC criteria to distinguish patients , so that they know if they have ME - or something else.
- A commitment to look at all the person's symptoms and offer complete medical support not just palliative care .
- An wholistic view of ME and an wholistic treatment approach.
- A safe, educated dental service with informed dentists about how to work with severe ME and the risks to health . Awareness of the potential dangers of mercury fillings in ME. The provision of white fillings, awareness of implications of various anaesthetic. Ability to respond quickly to need and be flexible with times. Minimise chemical exposure and perfumes.
- Awareness and monitoring by someone who knows and understands about numbness of limbs.
- Dietary input and support /advice
- Physiotherapists with specialist knowledge relating to the physical dysfunctions , educated in neurological issues in ME, particularly understanding the problems of transient paralysis and muscle fatigue and how it affects people who have it in their daily living.
- Special aids and equipment provided and developed especially for sound sensitivity/light sensitivity. Knowledgeable practitioners able to make appropriate recommendations.

- Specialist wheelchair knowledge , regarding the difficulties caused by acute hypersensitivities and sitting upright, in Severe ME.
- Domiciliary medical service from a knowledgeable Consultant , flexible and willing to communicate in ways that do not cause harm , who does not wear chemicals/perfumes and is aware of the risks and dangers
- A comprehensive Risk assessment for any involvement/ interaction.(Please see Appendix 1)
- Education of all clinical and support staff that ME is a physical disease .

Do not mess with people with Severe ME . Let the Severely Affected be represented by people who know about it: the Severely Affected and their carers. No one else can possibly have a clue.

Appendix 1 : Risk Assessment :

A risk assessment ensures that all steps are taken not to harm the most vulnerable particularly, it requires empathy and understanding of the disease and its impact : the ability to enter into the person's experience and relate what you have been told by the person, about their symptoms and experience, to any interaction, possible interaction or procedure that you are going to recommend, forms the core of any Severe ME risk assessment.

You cannot come in and impose anything on the person with Severe ME, without looking at the context of their physical illness experience and the potential impact and likelihood to do harm . In particular you need to understand what the person can tolerate, if anything , how they communicate and what is the likely post-exertional impact of any interaction or intervention.

In brief the following components are required:

R.I.S.K A.S.S.E.S.S.M.E.N.T :

Respect - of the person with Severe ME 's experience and physical illness.

Insight - into the great potential to damage the person with Severe ME as well as to help.

Sensitivity - to the hypersensitivity of the person.

Knowledge- of the ICC Criteria, the correct WHO Classification , the reality of Severe ME and the risks involved.

Awareness- Personal Awareness, Awareness of the Environment, Awareness of the Person and their illness and Awareness of any Post -Exertional response upon the person.

Sincerity- in your interaction with the person and sincerity about your knowledge or lack of knowledge.

Stillness- you need to be very still in your being because your energy will affect the ill person; you need to take the time to be with the person to try and understand.

Empathy- you must be able to relate to the person's experience and reality and show it.

Sharing- the person must share their experience and the practitioner must share their knowledge and views. Helping is a two way process, not just you imposing your will.

Sensible- in your practice; above all going out of your way to make it safe.

Mindful- aware of your interaction , the impact of it and the potential future impact of any recommendations.

Experience - in working with people with Severe Myalgic Encephalomyelitis .

Non-judgemental - understanding the physical difficulties the person experiences and not blaming them for any failure on your part to get it right.

Together - you have to work things out together, not impose your will. Really listen and proceed with caution.

Caution is always required when interacting with a person with Severe ME. It is never straight forward.

The practitioner must always aim to see the person's reality - and therefore be less likely to risk inadvertently harming the person.

Nothing is obvious ; the key is to expect and try to comprehend the post- exertional impact of any intervention and minimise it - also to be prepared for any outcome.

Any physical contact, any auditory input, any cognitive demand, any expectation of activity, even moving a leg, an arm, a finger, has to be considered within the context of safety. However simple and minimal it might seem from the outside, to the

practitioner, it could easily be too much for the person with Severe ME to tolerate , possibly leading to an extreme deterioration.

An aware and considered risk assessment should always take into account the minutiae of detail :

1. The impact of the practitioner - their voice, posture, energy, timing, communication.

2. The environmental impact of chemicals, sound, physical contact, sound-sensitivity, light.

3. The impact of the person's symptoms , please ask yourself : have you studied, do you understand, are you fully aware of the multitude of physical symptoms, that the person from Severe ME is likely suffering from and the risk if they deteriorate ?

4. The likely impact of any intervention upon the person's health.

5. A response plan for issues and problems that might arise.

Appendix 2 : A brief listing of some possible ME tests and investigations :

Do not forget , when you are in the presence of someone who has Severe ME, you are potentially with someone who is as seriously ill as a Cancer patient. Although , as with lupus, multiple sclerosis and ovarian cancer for example, there is no medical test available to confirm a diagnosis of M.E, it is absurd to claim no objective or quantifiable abnormalities can be found in patients with Svere ME . (Bassett 2006) Bassett J (2006) Testing for Myalgic Encephalomyelitis : Introduction, Hummingbird. http://www.ahummingbirdsguide.com/testingforme.htm

Here is a list of the most popular current tests :

37kDa 25A RNase L immunoassay: protein, activity, PKR cleavage, & elastase activity assays. (Red Laboratories, Belgium (http://bit.ly/QoF8ef)

From January 2007 International Conference on ME/CFS summary of immunological abnormalities: Anthony Komaroff (Professor of Medicine, Harvard) summarized the immune abnormalities that have been demonstrated in ME/CFS. These include activated CD8 (T cells); poorly functioning Natural Killer cells; novel findings -seen only in ME/CFS -- of abnormalities of the 2-5A pathway (RNase-L ratio); cytokine abnormalities (pro-inflammatory dysregulation); increased TGF, and 27 times more circulating immune complexes than in controls.

Allergies or sensitivities? Lung function testing? Liver function: CPK and liver function

Chronic orthostatic intolerance: Use tilt-table test or monitor the pulse and blood pressure while standing. Note: This monitoring must be done with caution and someone standing beside the patient.

Postural orthostatic tachycardia syndrome (or POTS) is a condition of orthostatic intolerance in which a change from the supine position to an upright position causes an abnormally large increase in heart rate, often, but not always accompanied by a

fall in blood pressure. Patients with POTS also have problems in maintaining homeostasis when changing position ie moving from one chair to another or reaching above their heads. The syndrome was identified as such by Schondorf and Low in 1993. Similar symptoms were collectively described as "idiopathic hypovolemia" by Fouad in 1986. A comprehensive historical account is given by Grubb (2002). Symptoms include an abnormally large increase in heart rate upon standing, lightheadedness, extreme fatigue, nausea, headache, chest pain, exercise intolerance and impaired concentration. Patients may exhibit mild hypotension while standing, but most do not experience fainting. Patients with POTS may frequently be misdiagnosed as having panic attacks, chronic fatigue syndrome or chronic anxiety disorder (Grubb, 2002). POTS patients are usually significantly debilitated by their symptoms. Cardiac Dysfunction: 24-hour Holter monitoring - Specifically ask to either view the results yourself or to report repetitive oscillating T-wave inversion and T-wave flats. This pattern is typical of many ME/CFS patients but may not be reported.

Cardiopulmonary Exercise Testing: AMA Guide for Evaluation of Permanent Impairment. Lower cardiovascular and ventilatory values at peak exercise help determine functional capacity, and peak oxygen consumption levels determine disability categories (http://bit.ly/QoMz5d)

This test is mentioned in the book Disability and CFS: Clinical, Legal and Patient Perspectives with this comment by Dr. Daniel Peterson: "One objective and reproducible technique for determining and measuring functional disability that should be used consistently is Cardio-Pulmonary Exercise Testing with measurement of VO2 max, anaerobic threshold, and maximal heart rate and respiration. The test is well established, sedentary and ill norms are published and the technology is relatively inexpensive and quite available. Approximately 1700 patients [as in 1997] have been tested over the past 10 years and the test is now used on the initial visit to screen patients, to direct rehabilitation, and adjunctively to determine disability."

Legal and Scientific Considerations of the Exercise Stress Test (http://bit.ly/Qoyp3W), Ciccolla, Stevens, Snell, Van Ness, ©2007 The Haworth Press "This article examines the legal and scientific basis on which an exercise stress test can provide

medically acceptable evidence of disability for the (ME) patient." This research group's excellent work proves the post-exertional disability that (ME) patients suffer, much worse on average than heart failure and COPD patients." Computer Science and Application (CSA™) Actigraph is a small device that measures frequency and intensity of activity in one minute intervals for up to 22 days. Typically, less intense and shorter activity peaks followed by longer rest periods are identified. It is helpful to have the patient keep a daily diary of activities during this period and/or wear a speedometer. CNS, ANS: Romberg test? nystagmus test (may fluctuate from positive & negative throughout the day)? altered sympathetic modulations? subnormal and/or fluctuating diurnal body temperature.Cognitive performance: decreased processing speed, working memory, information learning, etc.

Endocrine testing: CT scans may show reduced adrenal gland size? thyroid hormone levels with attention to bioavailability of T3 & those with reduced level should be checked for selenium as it regulates conversion of T4 to T3? reduced HPA function.

Th1/Th2 Imbalance - There are two general branches (Th1/Th2) of the immune system. Some patients appear to have an over activation of the anti-inflammatory (Th2) branch and an under activation of the pro-inflammatory (Th1) branch of the immune system. This could cause increased rates of allergy and sensitivity on the one hand and difficulty fighting off pathogens on the other. Further explanation from Dr. Cheney: Balance the Th1/Th2 Immune System (http://bit.ly/QoWJTf)

Hypercoagulability: flow cytrometry fibrinogen, thrombin/anti-thrombin complexes, etc. Increased 5HT neurotransmission

Mitochondrial Dysfunction (http://bit.ly/QoNaDI)

From 2007 IACFS/M. E. Conference: Dr Jonathan Kerr from London stated that his gene expression studies are finding three main abnormalities in ME/CFS patients: these involve the immune system, mitochondrial function and G-protein signaling. There are seven genes upregulated in ME/CFS - those associated with apoptosis, pesticides, mitochdonrial function, demyelination and viral binding sites. Kerr

mentioned three genes in particular: gelsolin, which is involved in apoptosis and amyloidosis; one that is upregulated by organophosphates, and a mitochondrial gene involved in the demyelination of nerves.

Mitochondrial abnormalities in the postviral fatigue syndrome. - Behan WM, More IA, Behan PO Department of Pathology, University of Glasgow, Scotland. Acta Neuropathol 1991;83(1):61-5 :

"We have examined the muscle biopsies of 50 patients who had postviral fatigue syndrome (PFS) for from 1 to 17 years. We found mild to severe atrophy of type II fibres in 39 biopsies, with a mild to moderate excess of lipid. On ultrastructural examination, 35 of these specimens showed branching and fusion of mitochondrial cristae. Mitochondrial degeneration was obvious in 40 of the biopsies with swelling, vacuolation, myelin figures and secondary lysosomes. These abnormalities were in obvious contrast to control biopsies, where even mild changes were rarely detected. The findings described here provide the first evidence that PFS may be due to a mitochondrial disorder precipitated by a virus infection."

Ocular test: slowed and marked jerkiness of saccades? difficulty with and slowed changing of visual fixation, constricted peripheral fields? low and/or incomplete blinking? small pupils? light hypersensitivity, tear film abnormalities such as low tear breakup time, inadequate production of the oil or mucus layer in tears, rose Bengal corneal staining? visual midline shift.

PET scans may reveal decreased glucose metabolism in the right mediofrontal cortex, and significant hypoperfusion and hypometabolism in the brain stem. MRI brain scans: Elevated numbers of punctuate lesions, particularly in the frontal lobes and subcortical areas, suggest demyelination or edema. Do spinal MRI for disc herniation and minor stenosis.

Brain imaging shows that, amongst other abnormalities, ME patients have reduced blood flow to the brain (especially to areas that are involved in autonomic nervous system functioning and in sleep, concentration and pain, including the pre-frontal cortices, the anterior cingulate and the cerebellum); altered patterns of brain

activation; reduced grey matter volume; altered serontonergic neurotransmission and reduced acetyl-carnitine uptake.

The remarkable similarity in the brain images of patients with ME and multiple sclerosis has been noted.

Positive tests for fibromyalgia syndrome and myofascial pain syndrome should be noted.

qEEG brain topography: Elevated EEG activity in theta and beta frequencies and increased intracerebral electrical sources in left frontal region delta and beta frequencies in eyes closed condition may be identified. Reduced sources in right hemisphere (beta) may be noted during verbal cognitive processing.

Skin conductivity and skin temperature: The combination of a lower ability of the skin to conduct electrical current in response to visual and auditory stimuli, and a higher skin temperature of fingers indicate a down-regulation of autonomic sympathetic tone. Sleep studies may indicate that there is insufficient time spent in the deeper stages of sleep, and alpha wave intrusion into delta waves within non-REM sleep.

Testable Major Sleep Dysfunction: This can include all forms of sleep dysfunctions. All or any of the following may be present: (a) impaired sleep efficiency, (b) significant fragmented sleep architecture, (c) movement arousals, particularly if there is an associated pain syndrome, (d) absence or significant decrease of type 3 and 4 sleep, (e) abnormal REM sleep pattern (f) changes in daytime alertness and (g) sleep reversals

SPECT scans may reveal significantly lower cortical/cerebellar regional cerebral blood flow frequently in the frontal, parietal, temporal, occipital, brain stem and throughout the cerebral cortex. (http://bit.ly/QoMSNi)

SPECT Imaging of the Brain: Comparison of Findings in Patients with Chronic Fatigue Syndrome, AIDS Dementia Complex, and Major Unipolar Depression," Richard B. chwartz, Anthony L. Komaroff, Basem M. Garada, Marcy Gleit, Teresa H. Doolittle, David W. Bates, Russell G. Vasily, B. Leonard Holman; American Journal

of Roentgenology, Vol 162, 943-951, Copyright © 1994 by American Roentgen Ray Society. Summary :

"This study shows that CFS (ME) shares some similarities on SPECT imaging with AIDS Dementia Complex - acute changes in radionuclide uptake in the younger population may be caused by inflammatory processes at the cellular or micro vascular level .... the findings in CFS (ME) face are consistent with the hypothesis that CFS (ME) ... results from a viral infection of neurons, glia or vasculature .....viral infection can provoke neurological dysfunction by interfering with intra-cellular mechanisms or membrane transport systems .... or by cerebral hypoperfusion due to vasculitis".

Other immunological markers: NK cell levels and function per cell for low NK cell cytotoxicity? CD4CD8 ratio? ANA? activated immune complexes - IgG sub-fractions including IgG1 and IgG3, circulating immune complexes IL2 & IL4? Th1 -Th2 response to mitogen stimulation (high levels of Th2 indicate autoimmunity), flow cytometry for activated/elevated lymphocytes? antilamin antibodies may indicate autoimmunity and brain cell damage (lamin B antibodies are evidence of autoimmunity)? humoral autoimmunity for polypeptides of the nuclear envelope (NE)? antibodies in neuronal cells MAP2 (kinase regulators) (Red Laboratories, Belgium, UNEVX (http://bit.ly/QoFCkl)

Natural Killer (NK) and T-cell Dysfunction - NK and T-cells are two other components of the immune response to pathogens. A set of ME patients have been shown to have reduced NK cell numbers and poor NK and T-cell functioning. These problems also could interfere with the ability of the immune system to find infected cells and kill them.

Urinary markers: 24hour urine free cortisol elevated amino-hydroxy-N-methyl-pyrrolidine correlate with quantity of symptoms. IAG - tryptophan metabolite, is usually positive and indicates a leaky gut, which in turn is indicative of a leaky blood brain barrier? urinary creatine & other muscle metabolites. Virology, etc: viral antibodies, including Coxsackie B? bacteria, including HHV6? mycoplasma, etc. (Wisconsin Viral Research Group (http://bit.ly/QoED3T) RNase-L was found to correlate with HHV-6 infection in ME/CFS and that RNase-L protein is a marker for

active infection. Info on HHV-6 testing at The HHV-6 Foundation (http://bit.ly/MKB0t0)

Adapted from :

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: A Clinical Case Definition and Guidlines for Medical Practitioners (http://bit.ly/QoD1qE) ©2005 Carruthers, van de Sande

TOP 10 TESTS for MYALGIC ENCEPHALOMYELITIS & CFS LABELED PATIENTS by Steven Du Pre © 2008 [updated 2012] http://www.name-us.org/MECFSExplainPages/TestAbnormalities.htm

Appendix Three : an overview of the International Consensus Criteria (ICC) for ME (2011)

The new biomedical ME International Consensus Criteria (ICC), an attempt to identify the unique and distinctive characteristic symptoms of ME (Carruthers et al 2011), uses the original clinical term of Myalgic Encephalomyelitis , in stark contrast to the prevailing vague, fatigue-based Oxford and CDC criteria which dominate at the moment.

To be diagnosed as having ME , a patient has to meet the criteria for :

Postexertional neuroimmune exhaustion :

Marked, rapid physical and/or cognitive fatigability in response to exertion, which may be minimal such as activities of daily living or simple mental tasks, can be debilitating and cause a relapse.

Postexertional symptom exacerbation:e.g.acute flu-like symptoms, pain and worsening of other symptoms.

Postexertional exhaustion may occur immediately after activity or be delayed by hours or days

Recovery period is prolonged, usually taking 24 h or longer. A relapse can last days, weeks or longer.

Low threshold of physical and mental fatigability (lack of stamina) results in a substantial reduction

They also have to have at least one symptom from three of four neurological impairment categories :

Neurocognitive impairments :

Difficulty processing information: slowed thought, impaired concentration e.g. confusion, disorientation, cognitive overload, difficulty with making decisions, slowed speech, acquired or exertional dyslexia.

Short-term memory loss:e.g. difficulty remembering what one wanted to say, what one was saying, retrieving words, recalling information, poor working memory.

Pain :

Headaches:e.g. chronic, generalized headaches often involve aching of the eyes, behind the eyes or back of the head that may be associated with cervical muscle tension; migraine; tension headaches.

Significant pain can be experienced in muscles, muscle-tendon junctions, joints, abdomen or chest. It is noninflammatory in nature and often migrates. e.g. generalized hyperalgesia, widespread pain (may meet fibromyalgia criteria), myofascial or radiating pain.

Sleep disturbance :

Disturbed sleep patterns:e.g. insomnia, prolonged sleep including naps, sleeping most of the day and being awake most of the night, frequent awakenings, awaking much earlier than before illness onset, vivid dreams/nightmares

Unrefreshed sleep : awaken feeling exhausted regardless of duration of sleep, day-time sleepiness.

Neurosensory, perceptual and motor disturbances :

inability to focus vision, sensitivity to light, noise, vibration, odour, taste and touch; impaired depth perception

Muscle weakness, twitching, poor coordination, feeling unsteady on feet, ataxia.

Neurocognitive impairments, reported or observed, become more pronounced with fatigue.

Overload phenomena may be evident when two tasks are performed simultaneously. Respiratory:e.g. air hunger, laboured breathing, fatigue of chest wall muscles

Loss of thermostatic stability:e.g. subnormal body temperature, marked diurnal fluctuations; sweating episodes, recurrent feelings of feverishness with or without low grade fever, cold extremities

Intolerance of extremes of temperature.

Abnormal accommodation responses of the pupils are common.

Sleep disturbances are typically expressed by prolonged sleep, sometimes extreme, in the acute phase and often evolve into marked sleep reversal in the chronic stage.

Motor disturbances may not be evident in mild or moderate cases but abnormal tandem gait and positive Romberg test may be observed in severe cases.

At least one symptom from three **immune/gastro-intestinal/genitourinary impairment categories** :

Flu-like symptoms may be recurrent or chronic and typically activate or worsen with exertion.e.g. sore throat, sinusitis, cervical and/or axillary lymph nodes may enlarge or be tender on palpitation

Susceptibility to viral infections with prolonged recovery periods

Gastro-intestinal tract:e.g. nausea, abdominal pain, bloating, irritable bowel syndrome

Genitourinary: e.g. urinary urgency or frequency, nocturia

Sensitivities to food, medications, odours or chemicals.

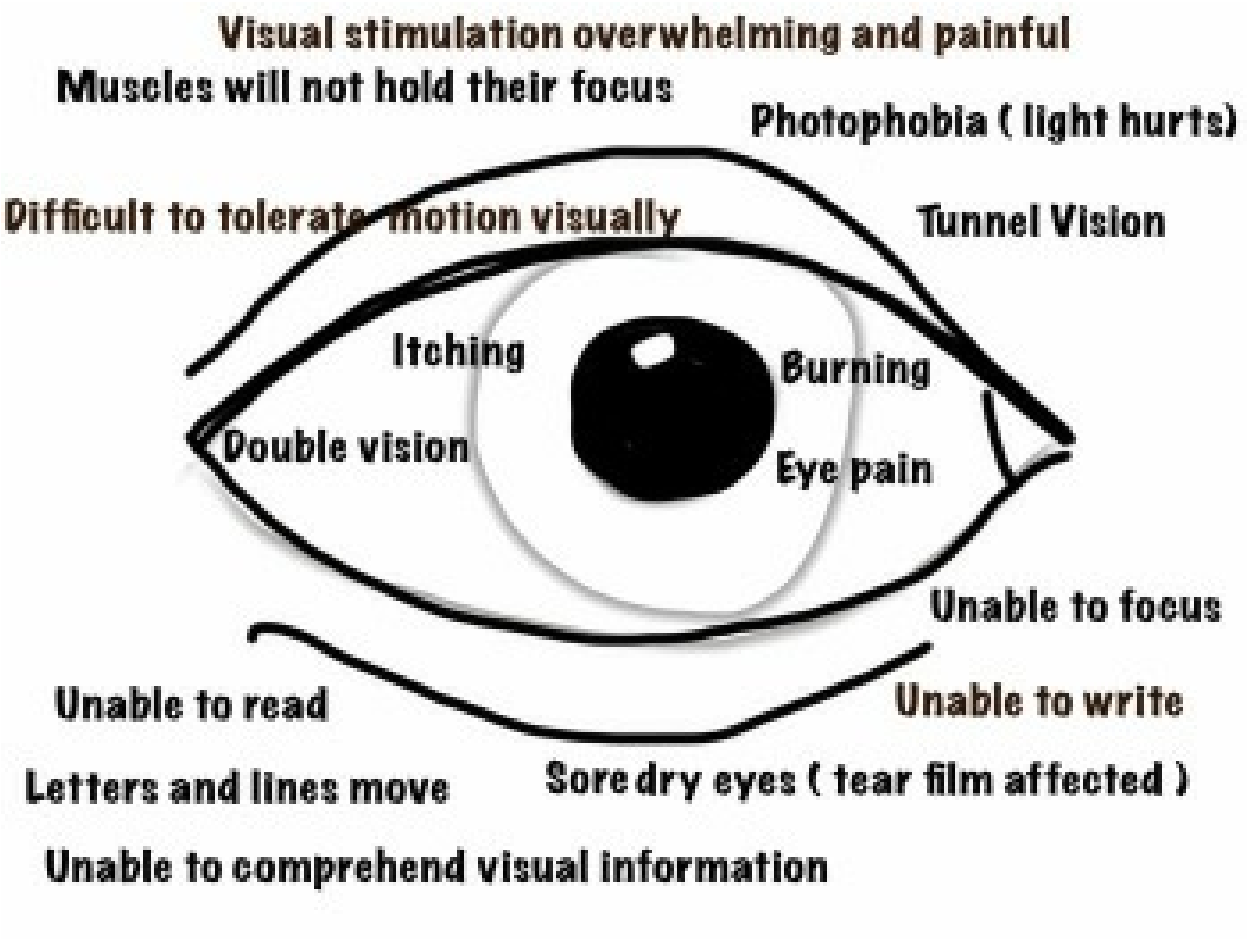
At least one symptom from **energy metabolism/transport impairments :**Cardiovascular:e.g. inability to tolerate an upright position - orthostatic intolerance, neurally mediated hypotension, postural orthostatic tachycardia syndrome, palpitations with or without cardiac arrhythmias, light-headedness/dizziness.

The International Consensus Criteria provide a framework for the diagnosis of ME that is consistent with the patterns of pathophysiological dysfunction emerging from published research findings and clinical experience.

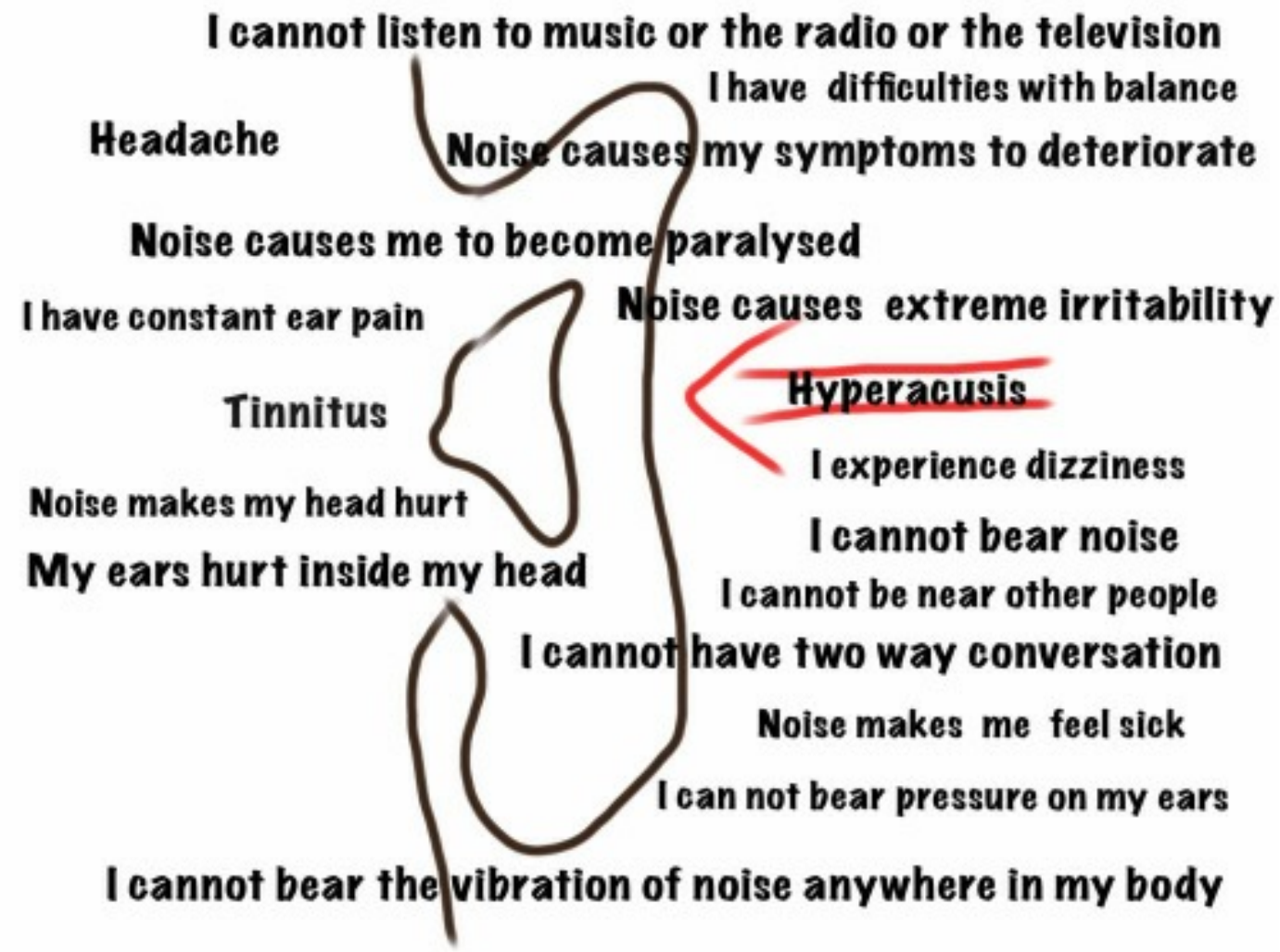
(Carruthers et al 2011

Myalgic Encephalomyelitis: International Consensus Criteria, Journal of Internal Medicine, 20 July 2011 http://www.meassociation.org.uk/?p=7173

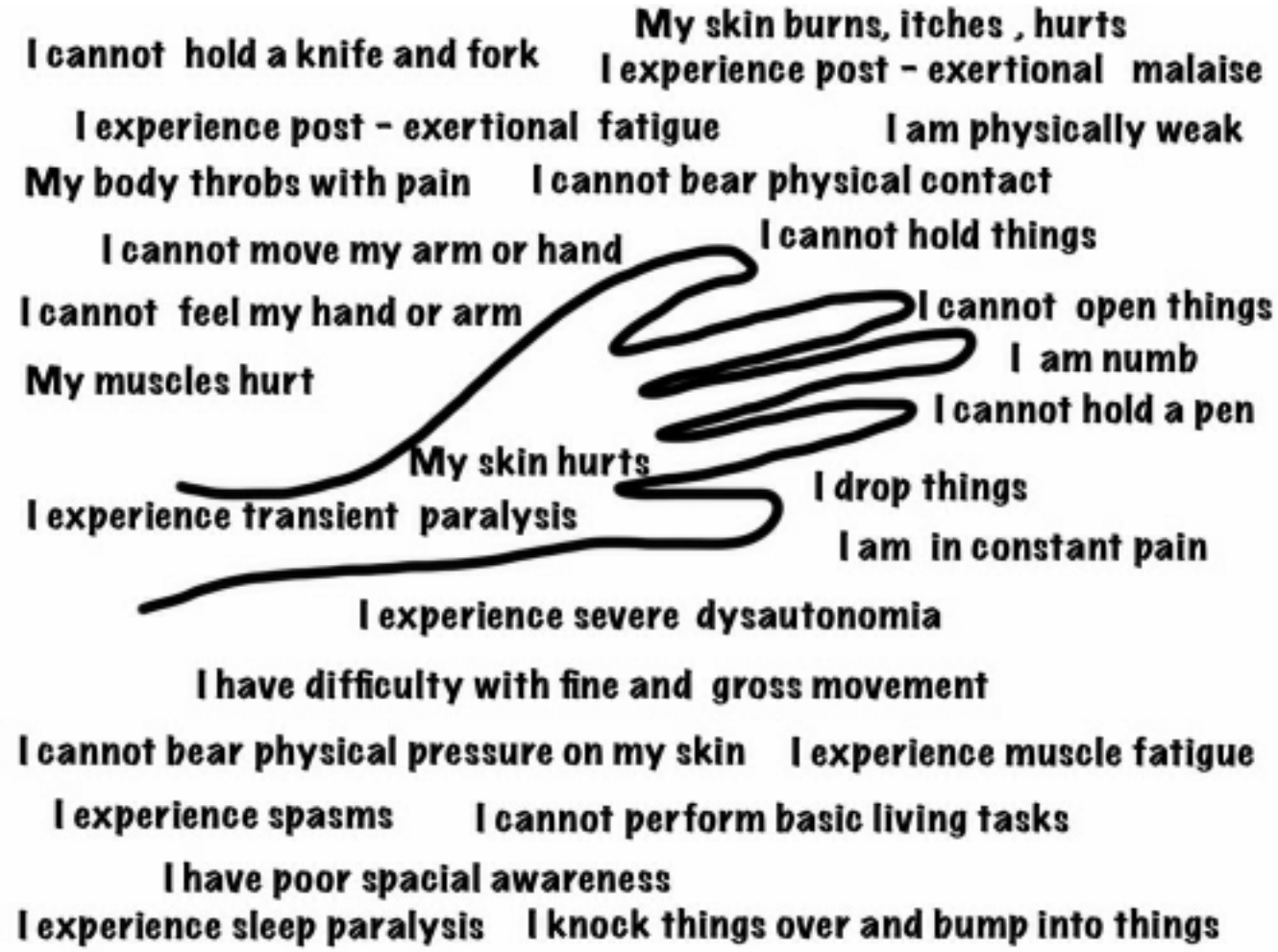
Appendix Four : The physical experience of Severe ME :


Visual stimulation overwhelming and painful
Muscles will not hold their focus
Photophobia (light hurts)
Difficult to tolerate motion visually
Tunnel Vision
Itching
Burning
Double vision
Eye pain
Unable to focus
Unable to read
Unable to write
Letters and lines move
Sore dry eyes (tear film affected)
Unable to comprehend visual information

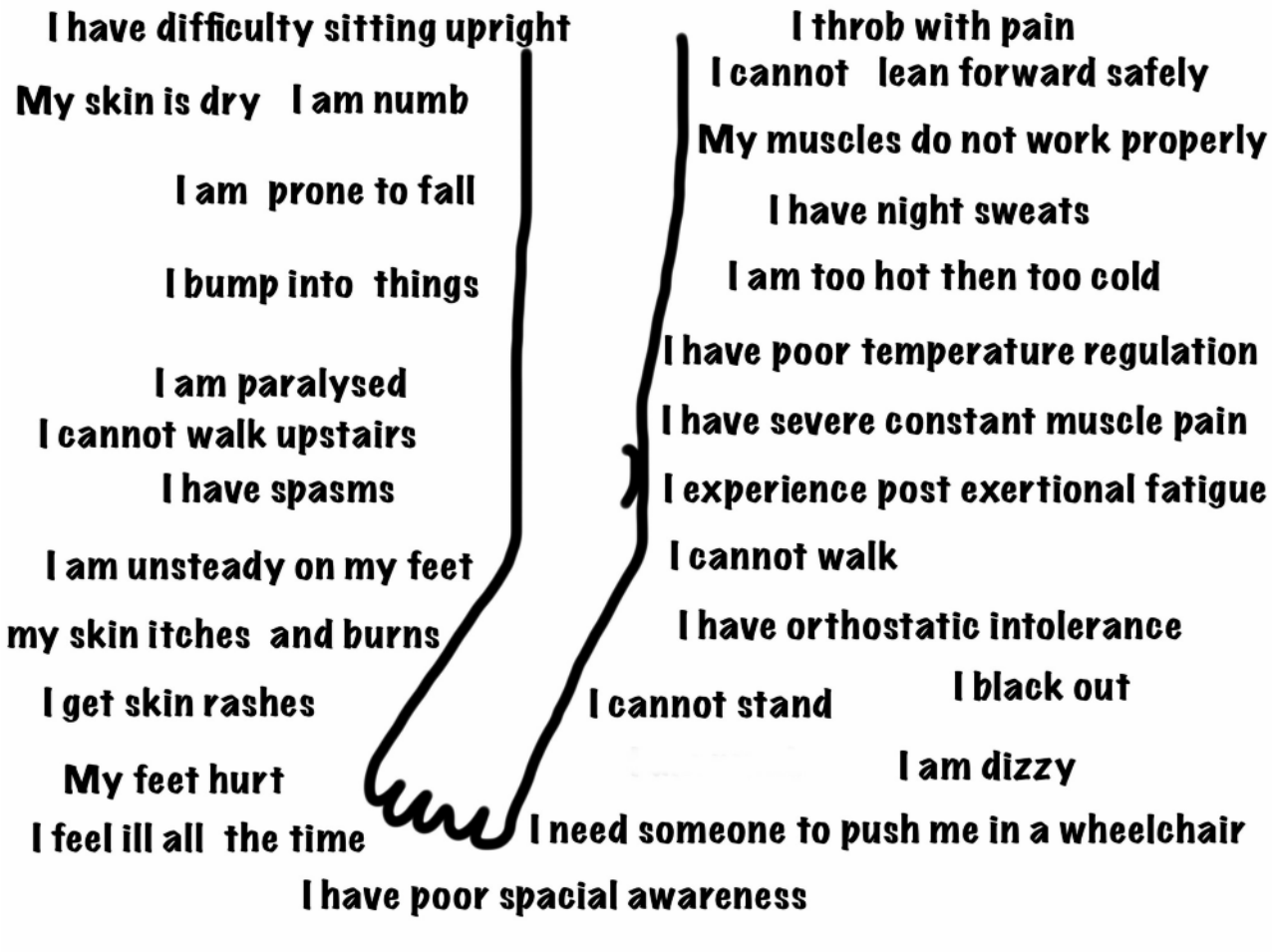
Eye


I cannot listen to music or the radio or the television
I have difficulties with balance
Headache
Noise causes my symptoms to deteriorate
Noise causes me to become paralysed
I have constant ear pain
Noise causes extreme irritability
Hyperacusis
Tinnitus
I experience dizziness
Noise makes my head hurt
I cannot bear noise
My ears hurt inside my head
I cannot be near other people
I cannot have two way conversation
Noise makes me feel sick
I can not bear pressure on my ears
I cannot bear the vibration of noise anywhere in my body

Ear


My skin burns, itches , hurts
I cannot hold a knife and fork
I experience post - exertional malaise
I experience post - exertional fatigue
I am physically weak
My body throbs with pain
I cannot bear physical contact
I cannot hold things
I cannot move my arm or hand
I cannot feel my hand or arm
I cannot open things
I am numb
My muscles hurt
I cannot hold a pen
My skin hurts
I drop things
I experience transient paralysis
I am in constant pain
I experience severe dysautonomia
I have difficulty with fine and gross movement
I cannot bear physical pressure on my skin
I experience muscle fatigue
I experience spasms
I cannot perform basic living tasks
I have poor spacial awareness
I experience sleep paralysis
I knock things over and bump into things

Hand


I have difficulty sitting upright
My skin is dry
I am numb
I am prone to fall
I bump into things
I am paralysed
I cannot walk upstairs
I have spasms
I am unsteady on my feet
my skin itches and burns
I get skin rashes
My feet hurt
I feel ill all the time
I throb with pain
I cannot lean forward safely
My muscles do not work properly
I have night sweats
I am too hot then too cold
I have poor temperature regulation
I have severe constant muscle pain
I experience post exertional fatigue
I cannot walk
I have orthostatic intolerance
I black out
I cannot stand
I am dizzy
I need someone to push me in a wheelchair
I have poor spacial awareness

Foot