# Anaesthesia and M.E.



Myalgic Encephalomyelitis (M.E.) is a debilitating neurological disease which has been recognised by the World Health Organisation (WHO) since 1969 as a distinct organic neurological disorder. It can occur in both epidemic and sporadic forms, over 60 outbreaks of M.E. have been recorded worldwide since 1934.

What defines M.E. is not mere 'fatigue' but a specific type of acquired damage to the brain (the central nervous system) caused by a virus; an enterovirus. Myalgic Encephalomyelitis is an *acutely acquired* illness initiated by a virus infection with multi system involvement which is characterised by post encephalitic damage to the brain stem; a nerve centre through which many spinal nerve tracts connect with higher centres in the brain in order to control all vital bodily functions – this is always damaged in M.E. (Hence the name 'Myalgic Encephalomyelitis')

So although M.E. is primarily neurological, symptoms may be manifested by virtually all bodily systems including: cognitive, cardiac, cardiovascular, immunological, endocrinological, respiratory, hormonal, gastrointestinal and musculo-skeletal dysfunctions and damage. Symptoms are also caused by a loss of normal internal homeostasis - the body/brain no longer responds appropriately to certain levels of: physical activity, cognitive exertion, sensory input and orthostatic stress.

M.E. is an infectious neurological illness which affects all races and socio-economic groups and has been diagnosed all over the world with a similar strike rate to multiple sclerosis. Children as young as five can get M.E., as well as adults of all ages. M.E. can be extremely disabling. 25% of M.E. sufferers are severely affected and housebound and bedbound. In some cases Myalgic Encephalomyelitis is fatal. M.E. is similar in a number of significant ways to illnesses such as multiple sclerosis, Lupus and Polio.

This is not simply theory, but is based upon an enormous body of mutually supportive research and clinical information. Confirmation of this hypothesis is supported by electrical tests of muscle and of brain function (including the

subsequent development of PET and SPECT scans) and by biochemical and hormonal assays. Newer scientific evidence is increasingly strengthening this hypothesis. M.E. is not 'medically unexplained.' If all tests are normal, then a person does not have M.E.

**In addition to physical activity, cognitive activity and orthostatic stress patients with Myalgic Encephalomyelitis are also very likely to relapse with anaesthesia and need extra care during all stages of surgery. This is well-documented.** The articles below give more information on many of the different issues to be aware of regarding anaesthesia/surgery and M.E. In summary:

- Surgery for the M.E. patient should be avoided if at all possible
- M.E. patients must advise their anaesthetist and doctor of the problems M.E. patients face with anaesthesia (and that their body will not react normally to it in a number of ways) so they can be prepared for this (and educated about it)
- M.E. patients may also want to make their doctors aware of the characteristics (and severity) of M.E. generally (see: What is Myalgic Encephalomyelitis?)
- Patients should also inform the doctors about their orthostatic problems so doctors can avoid placing them in positions which will negatively affect their blood pressure and heart-rate during and post surgery. Patients should also advise doctors of any other relevant problems eg. Known chemical or drug allergies or intolerances etc.
- The M.E. patient should be hydrated prior to surgery and additional saline administered as needed
- Less anaesthetic will often be required than normal for M.E. patients. Doctors/anaesthetists should start with a smaller dose than usual and then add more only if needed
- Caution is required with muscle relaxants and M.E. patients
- M.E. patients may need higher doses of pain medications
- Certain drugs may need to be avoided by those with M.E. (eg. histamine releasing drugs, adrenaline in dentistry)
- Certain common drugs may be replaced by other drugs that are more suitable. For example, adrenaline containing anaesthesia in dentistry can be replaced with adrenaline and preservative free Prilocaine HCL
- Respiratory functions of M.E. patients should be carefully monitored during surgery, along with cardiac function (these are the two areas most likely to be problematic in these patients)
- Magnesium and potassium supplementation may be required prior to surgery, and supplements such as high-dose vitamin C may be of use before and after surgery (though avoided the day of surgery)

- Patients should tell their doctors about all herbal medicines they are taking, as well as prescription medication as some of these can adversely affect surgery/anaesthesia
- Longer recovery time should be planned for with M.E. patients as relapse caused by surgery and anaesthesia is common. In some patients this relapse will be very severe and prolonged (perhaps also permanent in some cases; the previous low level of health is never regained)
- M.E. patients may want to consider wearing a medic alert bracelet in case they require emergency surgery and nobody is available to inform the doctors of their M.E. and the extra care that must be taken with regards to surgery and anaesthesia

See the articles below for more information on anaesthesia and Myalgic Encephalomyelitis.

To read more about all aspects of M.E. (and to view the references for the introductory text) see: What is Myalgic Encephalomyelitis? This fully referenced paper can also be downloaded in Word and PDF formats.

Doctors or other hospital staff caring for M.E. patients are also encouraged to read the following papers on this topic:

- Hospital or carer notes for M.E.
- Why patients with severe M.E. are housebound and bedbound
- The importance of avoiding overexertion in Myalgic Encephalomyelitis

Before reading this text, please see the notes below for more information on the terminology of M.E. and ‘CFS’ and why these are anything but synonymous terms.

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**A brief introductory note on terminology and definitions:**

It is important to be aware that Myalgic Encephalomyelitis and 'CFS' are not synonymous terms and should not be used interchangeably, and that 'fatigue' is not a defining nor even essential feature of M.E. M.E. is defined by a variety of serious (testable) neurological, cardiac, cardiovascular, metabolic and other abnormalities - not by mere 'fatigue.'

Myalgic Encephalomyelitis is a distinct, scientifically verifiable and measurable, acute onset, organic neurological disease. ‘CFS’ in contrast, is not a distinct disease. ‘CFS’ doesn’t exist. Every diagnosis of CFS – based on any of the CFS definitions – can only ever be a *mis*diagnosis.

CFS was created in the 1980s in the US in response to an outbreak of what was unmistakably M.E., but this new name and definition did not describe the known signs, symptoms, history and pathology of M.E. *It described a disease process that did not, and could not, exist.* The fact that a person qualifies for a diagnosis of 'CFS' (a) does not mean that the patient has Myalgic Encephalomyelitis (M.E.), and (b) does not mean that the patient has any other distinct and specific illness named 'CFS.'

The bogus disease category of 'CFS' has undoubtedly been used to impose a false psychiatric paradigm of M.E. by allying it with psychiatric fatigue states and various unrelated fatigue syndromes for the benefit of insurance companies and various other organisations and corporations which have a vested financial interest in how these patients are treated, including the government.

When the terms CFS, CFIDS, ME/CFS, CFS/ME, Myalgic Encephalopathy or ME-CFS are used what is being referred to may be patients with/facts relating to any combination of:

1. Miscellaneous psychological and non-psychological fatigue states (including somatisation disorder) 2. A self limiting post-viral fatigue state or syndrome (eg. following glandular fever/mononucleosis.) 3. A mixed bag of unrelated, misdiagnosed illnesses (each of which feature fatigue as well as a number of other common symptoms; poor sleep, headaches, muscle pain etc.) including Lyme disease, multiple sclerosis, Fibromyalgia, athletes over-training syndrome, depression, burnout, systemic fungal infections (candida) and even various cancers 4. Myalgic Encephalomyelitis patients (despite the fact none of the CFS definitions describes M.E., many M.E. sufferers are given a 'CFS' misdiagnosis by default).

The terminology is often used interchangeably, incorrectly and confusingly. However, the DEFINITIONS of M.E. and CFS are very different and distinct, and it is the definitions of each of these terms which is of primary importance. *The distinction must be made between terminology and definitions.*

**Chronic Fatigue Syndrome** is an artificial construct created in the US in 1988 for the benefit of various political and financial vested interest groups. It is a mere diagnosis of exclusion (or wastebasket diagnosis) based on the presence of gradual or acute onset fatigue lasting 6 months. If tests show serious abnormalities, a person no longer qualifies for the diagnosis, as 'CFS' is 'medically unexplained.' A diagnosis of 'CFS' does not mean that a person has any distinct disease (including M.E.). The patient population diagnosed with 'CFS' is made up of people with a vast array of unrelated illnesses, or with no detectable illness. According to the latest CDC estimates, 2.54% of the population qualify for a 'CFS' (mis)diagnosis. Every diagnosis of 'CFS' can only ever be a misdiagnosis.

**Myalgic Encephalomyelitis** is a systemic neurological disease initiated by a viral infection. M.E. is characterised by (scientifically measurable) damage to the brain, and particularly to the brain stem which results in dysfunctions and damage to almost all vital bodily systems and a loss of normal internal homeostasis. Substantial evidence indicates that M.E. is caused by an enterovirus. The onset of M.E. is always acute and M.E. can be diagnosed within just a few weeks. M.E. is an easily recognisable distinct organic neurological disease which can be verified by objective testing. If all tests are normal, then a diagnosis of M.E. cannot be correct.

M.E. can occur in both epidemic and sporadic forms and can be extremely disabling, or sometimes fatal. M.E. is a chronic/lifelong disease that has existed for centuries. It shares similarities with MS, Lupus and Polio. There are more than 60 different neurological, cognitive, cardiac, metabolic, immunological, and other M.E. symptoms. Fatigue is not a defining nor even essential symptom of M.E. People with M.E. would give anything to be only severely ‘fatigued’ instead of having M.E.’ Far fewer than 0.5% of the population has the distinct neurological disease known since 1956 as Myalgic Encephalomyelitis.

The only thing that makes any sense is for patients with M.E. to be studied ONLY under the name Myalgic Encephalomyelitis – and for this term ONLY to be used to refer to a 100% M.E. patient group The only correct name for this illness – M.E. as per Ramsay/Richardson/Dowsett and Hyde, and the more than sixty outbreaks of M.E. recorded worldwide, and so on – is Myalgic Encephalomyelitis.

M.E. is not synonymous with CFS, nor is it a subgroup of CFS. (There is no such thing as a subgroup of CFS; there is no such disease as "CFS.’) M.E. is not a primarily fatiguing condition, nor is it a wastebasket diagnosis or ‘medically unexplained’ as ‘CFS’ is. There is no such disease as ‘CFS’ – that is the entire issue. The vast majority of patients misdiagnosed with ‘CFS’ do not have M.E. The only way forward, for the benefit of society and all patient groups involved, is that:

1. The bogus disease category of ‘CFS’ must be abandoned completely.
2. The name Myalgic Encephalomyelitis must be fully restored (to the exclusion of all others) and the World Health Organization classification of M.E. (as a distinct neurological disease) must be accepted and adhered to in all official documentations and government policy.

For more information on why the bogus disease category of 'CFS' must be abandoned for the benefit of all the patient groups involved, (along with the use

of other vague and misleading umbrella terms such as ‘ME/CFS’ ‘CFS/ME’ 'CFIDS' and 'Myalgic Encephalopathy' and others) see: What is Myalgic Encephalomyelitis?

**Before reading these quotes below and documents linked to below, please be aware of the following facts:**

1. Myalgic Encephalomyelitis and ‘Chronic Fatigue Syndrome’ are not synonymous terms. The overwhelming majority of research (and articles) on ‘CFS’ or ‘CFIDS’ or ‘ME/CFS’ or ‘CFS/ME’ or ‘ICD-CFS’ does not involve M.E. patients and is not relevant *in any way* to M.E. patients. If the M.E. community were to reject all ‘CFS’ labelled research/articles as ‘only relating to ‘CFS’ patients’ (including those which describe those abnormalities/characteristics unique to M.E. patients), however, this would seem to support the myth that ‘CFS’ is just a ‘watered down’ definition of M.E. and that M.E. and ‘CFS’ are virtually the same thing and share many characteristics.

A very small number of ‘CFS’ studies/articles refer in part to people with M.E. but it may not always be clear which parts refer to M.E. The A warning on ‘CFS’ and ‘ME/CFS’ research and advocacy paper is recommended reading and includes a checklist to help readers assess the relevance of individual ‘CFS’ studies to M.E. (if any) and explains some of the problems with this heterogeneous and skewed research/advocacy.

Note that the inclusion of a link to an article on this site does not necessarily denote support for all parts of the article it was taken from, or support for the terminology used in this article, nor total support for all articles created by this author.

In future, it is essential that M.E. research again be conducted using only M.E. defined patients and using only the term M.E. and that M.E. activism also focuses entirely on M.E. The bogus, financially-motivated disease category of ‘CFS’ must be abandoned.

2. The research and articles referred to on this website varies considerably in quality. Some is of a high scientific standard and relates wholly to M.E. and uses the correct terminology. Other studies are included which may only have partial or minor possible relevance to M.E., use unscientific terms/concepts such as ‘CFS,’ ‘ME/CFS,’ ‘CFS/ME,’ ‘CFIDS’ or Myalgic ‘Encephalopathy’ and also include a significant amount of misinformation. For more information see A warning on ‘CFS’ and ‘ME/CFS’ research and advocacy and the more detailed paper Putting research and articles on M.E. into context.

**So you are going to have surgery?** Advice on anaesthetics and pain control for those with M.E. by Dr Dowsett (Word format)

M.E. results in widespread neurological changes throughout the body, which may deteriorate in the older age groups (for example, some 20 to 30 years after onset of their illness). Patients and carers should always take responsibility for informing, reminding, or carrying printed material to G.P.'s other doctors surgeons and dentists involved in planning surgery or making referrals. The best person with whom to discuss this will be the anaesthetist on the team. In case of emergency surgery make sure that relatives or friends accompanying the patient are aware of these problems and can speak to the surgical team. This includes dentistry, orthodontic treatment, day stay or inpatient procedures.

**1. Sedative analgesic drugs**

These control pain but not inflammation, e.g. codeine and morphine. M.E. patients are nearly always very sensitive to these due to their effects upon the central nervous system, especially the Reticular Activating Spinal Network. This is responsible for maintaining wakefulness and alertness but is frequently damaged especially in young people at the onset of the illness. Side effects: may include drug dependency, which is not as common as thought when used in a controlled fashion to prevent severe pain, respiratory depression, postural hypotension, dizziness and fainting and possibly the need for increasing dosage as tolerance develops.

**2. Non Sedative analgesic drugs**

These include agents such as Paracetamol and several other drugs freely available over the counter (OCT). They control pain but not inflammation and can have serious side effects if taken in excess, especially upon the liver, and interfere with other drug therapy.

Non Steroid Anti-inflammatory Drugs - e.g. aspirin and Neurofen are sold without prescription but also have serious side effects such as allergy, bleeding, e.g. gastric haemorrhage and interference with other prescribed drugs.

**3. Muscle Relaxants**

These may be required for general surgery and abdominal operations. They work by blocking nervous transmission to muscles. The effect in M.E., where muscles may be weak, wasted or otherwise damaged is much greater than in normal people.

**4. Pain**

This is always a serious problem in M.E. and additional or alternative methods of anaesthesia maybe required, e.g. spinal anaesthetic or local nerve block.

**5. Dysfunction of the Autonomic and Enteric Nervous Systems**
The former may be associated with a rapid or irregular pulse and problems with blood pressure control and the latter with gastrooesophageal reflux and vomiting.

**6. Respiratory problems**
These can be due to weakness of the diaphragmatic and chest muscles, or to asthma and chronic obstructive airways disease, especially in smokers. The anaesthetist may need to order tests of respiratory function well in advance of any operation.

**7. Muscle, Joint and other Orthopaedic Problems**
These, together with muscle weakness, may affect the correct support of the patient and the positioning of limbs on the operating table in order to avoid damage to superficial nerves.

**Summary**
The patient with M.E., compared with a normal person, requires less anaesthetic and caution with muscle relaxants, e.g. half the dose at onset with careful increments during operation, more painkillers, but caution with sedative analgesics and more time to recover. Day surgery may be inappropriate and the need for home support after discharge must be considered. Local anaesthetics, e.g. in dentistry, dermatology, and accident departments should be adrenaline free.

[This article is recommended as a good brief overview to print out for your doctor. Dr Dowsett has treated literally thousands of individual patients with the illness and has over 20 years experience in studying M.E. This is probably the only article here that we can be sure relates 100% to actual M.E. patients. See the notes at the top of this paper for more information.]

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**Dr Paul R. Cheney, MD, PhD, on anaesthesia** in1992

"I would recommend that potentially hepatoxic anesthetic gases not be used including Halothane. Patients with Chronic Fatigue Syndrome are known to have reactivated herpes group viruses which can produce mild and usually subclinical hepatitis. Hepatotoxic anesthetic gases may then provoke fulminate hepatitis. Finally, patients with this syndrome are known to have intracellular magnesium and potassium depletion by electron beam x-ray spectroscopy techniques. For this reason I would recommend the patient be given Micro-K using 10mEq tablets, 1 table BID and magnesium sulfate 50% solution, 2cc IM

24 hours to surgery. The intracellular magnesium and potassium depletion can result in untoward cardiac arrhythmias during anesthesia. For local anesthesias, I would recommend using Lidocaine sparingly and without epinephrine."

[Dr Cheney has treated literally thousands of individual patients with the illness and has over 20 years experience in studying M.E. Unfortunately there is some mixing of M.E. and 'CFS' and the terminology used is of 'CFS.']

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**Patrick. L. Class, MD Ask the Doctor, Summer 1994, The CFIDS Chronicle, page 82.**

"I have used the following anesthesia with success during surgery on CFIDS patients. First, I perform skin tests for all the agents I am considering with the patient. With CFIDS patients, I recommend Diprivan (propofol) as the induction agent; Versed (midazolam), fentanyl (a short-acting narcotic) and droperidol (an anti-nausea agent) during the anesthetic; and a combination of nitrous oxide, oxygen and isoflurane (commonly called Forane) as the maintenance agent.

In contrast to the above agents, there is a group or commonly-used anesthetic agents which are known to be histimine releasers and are probably best to be avoided by CFIDS patients. This group includes the thiobarbituates such as sodium pentothol, which is probably the most common induction agent, but is a known histimine releaser. In addition, there is a broad group of muscle relaxants in the Curare family, namely Tracrium and Mevacurium, which are also potent histimine releasers and should be avoided by CFIDS patients.

Since so many of these histimine releasing agents are commonly used during emregency surgery, it would be advisable for you to wear a medical alert bracelet in the event you are unconscious and would have to have an anesthetic. I would mention on the bracelet that you cannot receive any histimine releasing drugs."

[Note that no other part of this site is necessarily recommended. The term 'CFIDS' is not supported by this site, and note that this term should not be considered synonymous with M.E.]

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**Preoperative considerations in a patient with orthostatic intolerance syndrome** 2000

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**CFIDS and anesthesia: what are the risks?** by Elisabeth A. Crean in The CFIDS Chronicle, Winter 2000

[Note that no other part of this site is necessarily recommended. The term 'CFIDS' is not supported by this site, and note that this term should not be considered synonymous with M.E.]

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**Enhanced sensitivity of the peripheral cholinergic vascular response in patients with chronic fatigue syndrome** MERGE

'The results of this study show enhanced cholinergic activity in the peripheral microcirculation of patients with ME/CFS. This enhancement was specific for acetylcholine. We could not determine why the patients have acetylcholine supersensitivity in the skin microcirculation. However, many of the symptoms of chronic fatigue syndrome, such as temperature sensitivity, gastrointestinal difficulties, problems with sleep, and orthostatic intolerance, are consistent with altered cholinergic activity, and the findings might have important implications for features of chronic fatigue syndrome that involve vascular integrity.'

[Note that no other part of this site is necessarily recommended. The term 'ME/CFS' is not supported by this site, and note that this term should not be considered synonymous with M.E.]

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**CFS Patent** Gow et al.

'Previous reports have hypothesised that CFS is a form of channelopathy - a disorder of membrane ion channels. There are several reports in the literature which we believe strengthen the hypothesis that the vacuolar H+ATPase plays a pathogenic role in CFS.

Local anaesthetics, which are known to act on ion channels, have an adverse effect on patients with CFS/ME. It has been demonstrated also, that in some patients with CFS/ME, there are morphological changes to the red blood cells. Remarkably, a study by Nishiguchi et al, has demonstrated that the local anaesthetic lidocaine can induce reversible morphological transformation of human red blood cells and that this change is mediated by the activation of vacuolar H+ATPase. In addition, Li et al have shown that the gene is involved in iron binding in red blood cells.

The ion channel gene is a member of the vacuolar H+ ATPase proton transporting gene family. This family of genes is directly involved with the phosphocreatine-dependent glutamate uptake by synaptic vesicles. The gene is responsible for vesicle docking/exocytosis during neurotransmiter release and is a major constituent of synaptic vesicles associated with intracellular membrane structures. We have demonstrated, using H MRS that there is a perturbation of the choline/creatine balance in the CNS. This finding has been corroborated by Puri et al. As stated above, this type of gene is directly involved in the creatine pathways. We have previously demonstrated that patients with CFS have low body- potassium levels. Bailey et al have shown a relationship between potassium depletion and up-regulation of H+-ATPase.

As stated above, viruses have often been associated with CFS. Virus entry into cells may be mediated by H+ATPase. In addition to viral infection affecting neurotransmitter function, there is a large body of evidence to show that the vacuolar H+-ATPase is also invoked.

[This is the only part of this paper relevant to anaesthesia. Note that no other part of this article is necessarily recommended]

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**Chronic fatigue syndrome: a disorder of central cholinergic transmission**. Chaudhuri A, Majeed T, Dinan T, Behan PO. Journal of Chronic Fatigue Syndrome 1997; 3(1): 3-16.

[This is cholinergic defect is relevant to problems with anaesthesia in M.E. patients. Note that no other part of this site is necessarily recommended. The term ‘CFS’ is not supported by this site, and note that this term should not be considered synonymous with M.E.]

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**Herb Cures add to Risk of Surgery** from "Metro" Wednesday 11th July 2001 (on 25% M.E. Group)

Commonly used herbal remedies could cause serious complications for patients undergoing surgery, experts warned yesterday. Dangers included bleeding, heart problems, low blood sugar and dangerous reactions with conventional drugs.

Researchers said doctors should obtain a complete history of any herbal medicines their patients were taking before booking them in for operations.

They studied the effects of eight popular preparations – echinacea, ephedra, garlic, ginko, ginseng, kava, St John's wort and valerian.

Direct effects including bleeding from garlic, ginkgo and ginseng, heartbeat irregularities from ephedra and low blood sugar from ginseng. Reactions to drugs involving kava and valerian included increasing the sedative effect of anaesthetics. Among possible risks associated with St John's wort was a rise in the potency of a range of drugs used during operations.

See more articles on this topic:
Virtual Anaesthesiology Textbook
The Virtual Anesthesiologist
Herbal Medicine & Anesthesia
Herbal Medications and Anesthesia: Another Study Warns About Problems
Herbal Agents and Anesthesia

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**ME and Surgery from the 25% M.E. Group**

'I have had severe ME since 1992. In 1998 I had a general anaesthetic which affected me very badly, leaving me extremely weak and totally bedbound. I learnt to stand and walk again with the help of a community physiotherapist who came twice a week. It was 11 months before I could walk to the bathroom and two years before I began to pick up again, but I am still not able to walk as far as I could prior to surgery.

The dilemma I now find myself in is that my Consultant has suggested a further operation. I'm wondering if anyone else has had any experience in which they fared better, perhaps their anaesthetist was aware of the potential effects of anaesthesia on severely affected ME patients. Alternatively, has anyone been adversely effected at their first operation and faired better the second time around?

If anyone would like to contact this person, please email the Web Team on webmaster@25megroup.org '

[This article is included to illustrate the potential severity of relapses caused by surgery. Relapses from anaesthesia (as well as physical activity) may be long term or even permanent; the previous level of health may never be regained in some cases.]

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**Recommendations for Persons with Chronic Fatigue Syndrome (or Fibromyalgia) Who Are Anticipating Surgery** by Dr. Charles W. Lapp, MD
January 8, 2008

Intracellular magnesium and potassium depletion has been reported in CFS. For this reason, serum magnesium and potassium levels should be checked pre-operatively and these minerals replenished if borderline or low. Intracellular magnesium or potassium depletion could potentially lead to cardiac arrhythmias under anesthesia.

Up to 97% of persons with CFS demonstrate vasovagal syncope (neurally mediated hypotension) on tilt table testing, and a majority of these can be shown to have low plasma volumes, low RBC mass, and venous pooling. Syncope may be precipitated by cathecholamines (epinephrine), sympathomimetics (isoproterenol), and vasodilators (nitric oxide, nitroglycerin, a-blockers, and hypotensive agents). Care should be taken to hydrate patients prior to surgery and to avoid drugs that stimulate neurogenic syncope or lower blood pressure.

Allergic reactions are seen more commonly in persons with CFS than the general population. For this reason, histamine-releasing anesthetic agents (such as pentothal) and muscle relaxants (curare, Tracrium, and Mevacurium) are best avoided if possible. Propofol, midazolam, and fentanyl are generally well-tolerated.

Most CFS patients are also extremely sensitive to sedative medications - including benzodiazepines, antihistamines, and psychotropics - which should be used sparingly and in small doses until the patient's response can be assessed.

Herbs and complementary and alternative therapies are frequently used by persons with CFS and FM. Patients should inform the anesthesiologist of any and all such therapies, and they are advised to withhold such treatments for at least a week prior to surgery, if possible. Of most concern are:

1. *Garlic*, *ginkgo*, and *ginseng* (which increase bleeding by inhibiting platelet aggregation);
2. *Ephedra* or *ma huang* (may cause hemodynamic instability, hypertension, tachycardia, or arrhythmia),
3. *Kava* and *valerian* (increase sedation),
4. *St. John's Wort* (multiple pharmacological interactions due to induction of Cytochrome P450 enzymes),
5. *Echinacea* (allergic reactions and possible immunosuppression with long term use).

The American Society of Anesthesiologists recommends that all herbal medications be discontinued 2 to 3 weeks before an elective procedure. Stopping kava may trigger withdrawal, so this herbal (also known as awa, kawa, and intoxicating pepper) should be tapered over 2 to 3 days.

HPGA Axis Suppression is almost universally present in persons with CFS, but rarely suppresses cortisol production enough to be problematic. Seriously ill patients might be screened, however, with a 24-hour urine free cortisol level (spot or random specimens are usually normal) or Cortrosyn stimulation test, and provided cortisol supplementation if warranted. Those patients who are being supplemented with cortisol should have their doses doubled or tripled before and after surgery.

**Summary Recommendations**

1. Ensure that serum magnesium and potassium levels are adequate.
2. Hydrate the patient prior to surgery.
3. Use catecholamines, sympathomimetics, vasodilators, and hypotensive agents with caution.
4. Avoid histamine-releasing anesthetic and muscle-relaxing agents if possible.
5. Use sedating drugs sparingly.
6. Ask about herbs and supplements, and advise patients to taper off such therapies at least one week before surgery.
7. Consider cortisol supplementation in patients who are chronically on steroid medications or who are seriously ill.
8. Relapses are not uncommon following major operative procedures, and healing is said to be slow

[This article is one of the worst there is for supporting the myths of ‘CFS’ and mixing a small amount of M.E. information with psychobabble about ‘CFS.’ This ‘CFS’ site is not recommended.]

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**Illustrations of Clinical Observations and International Research Findings from 1955 to 2005 that demonstrate the organic aetiology of Myalgic Encephalomyelitis / Chronic Fatigue Syndrome** by Malcolm Hooper Eileen Marshall Margaret Williams, 12th December 2005 174 pages.

**Anaesthetics and ME**

A Consultant Anaesthetist (Dr F.L.M of the McNeil Centre for Research in Anaesthesia Philadelphia)

***Meeting Place, Journal of the Australia and New Zealand ME Society: 1988:30:29-30***

"When there may be neural involvement by a disease, spinal or epidural anaesthesia is not recommended because of the risk of worsening symptoms" "Normally, a depolarizing muscle relaxant is used, (but) in persons with neuromuscular disease such as demyelination, which has been decribed for (ME), this drug has a known risk of causing potassium release from muscle, which can lead to cardiac arrest" "Because of chronic muscle weakness, breathing may be impaired (and) muscle weakness increases the risk of respiratory failure" "More care than usual is appropriate in the case of (ME)".

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**Caesarean Sections** by ME/CFS Parents

'Whether you are considering an elective cesarean or are just aware that an emergency section may be necessary there are several issues surrounding c-sections that are of particular interest to ME/CFS sufferers.'

[Note that this is not necessarily a recommendation of any other part of this site, and is not a recommendation of the term 'ME/CFS']

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**Anesthesia & Procedure Preparation Information** The Northern Virginia CFS Support Group

Factors to consider for anesthesia include speaking to the anesthesiologist ahead of a procedure about your blood pressure and heart rate variabities, choosing the type and dosage of anesthesia to minimize symptoms during and after, and even what positions your body will be in and for how long while under anesthesia and how that will affect your [illness]. Preparations include adjusting medications and supplements to decrease bleeding time, increasing supplements that promote wound healing if you have good experience with them, and adding in guided medidation for a successful outcome.

**Our short answer**

Our one minute answer for this complex topic is: ask for non-histiming releasing anesthetics and ask for a lower than normal dose if you are drug sensitive. Give overseers permission to add more in needed, better to add more later than start too high. Ask for your blood pressure and heart rate to be monitored extra carefully since you might have a very sensitive autonomic nervous system. If you have pre-medicated with antibiotics before for procedures, check the latest guidelines. If possible and appropriate in your case, ask for the IV fluid to have potassium in it. (Ringer's Lactate solution has both

calcium and potassium in it and was very good for my home IV rehydradtion approach. Plain saline was too stimulating. -Elly.) For more in depth discussion, keep reading...

**You have valuable experiences to consider**

Consider your past experiences with surgical anesthetics, dental anesthetics, prescription pain medications, and over the counter pain relievers. Also, think about any herbs, supplements, drugs, and foods that are known to dilate or constrict blood vessels. Anything unusal in your history could be a good clue for determining how to best proceed. Maybe you can spot a pattern about classes of drugs. Perhaps you can remember if you had something before that worked well and track down its name.

**IV difficulties: Spasming blood vessels, being too upright**

In a great MVPS/Dysautonomia video, Al Davies, MD, of Mediscene, spoke of how many people have their blood vessels go into spasm, making it very difficult to properly insert a needle or catheter. Keeping up our treatments that help our other kinds of spasms, electrolytes (calcium, magnesium, time-release prescription potassium) and using calming techniques (guided imagery, focusing on being there for help, distracting yourself) can help. Just letting the nursing staff know you go into spasm and extra patience is required on everyone's part may help everyone relax and succeed.

Ask the staff if you can lie down when they insert the IV needle in preparation for any procedure last week. You may not have needed to in the past, but if you are doing worse, this may help you get through a long stressful procedure. You may have to ask days in advance of procedure, and then again the day before, and then the day of. You may have to ask your doctor to write a note about it with the referral for the procedure. Inform nurses about any vasovagal syncope (fainting) reactions you've had in similar situations. Report tendencies to feel faint often, especially when dehydrated or hungry/fasting.

**Fasting**

Many procedures require fasting. Many of us don't do so well if we get too hungry. If this is true for you, insist upon or ask for your doctor's help in getting the earliest possible appointment in the day that makes sense for you. Some people get more nauseated and weak from having not eaten and they can't make it through a procedure. Ask if food really affects the results, how much, and if the choice is to relapse and not make it through the test vs eating a little because you need to complete it if they will make an exception.

**Blood Volume, Hydration**

Often there is giving blood for tests beforehand, taking your fluids, electrolytes,

plasma and all those other goodies in blood. Just drinking water or water and electrolytes is not going to replenish you enough, and probably not fast enough. Ask if can do any of the blood work longer in advance so they can take less closer to the procedure. Tell them if you usually feel worse after giving the blood for blood tests. Sometimes they take large amounts of blood -- and don't really expect it could have an effect on someone, even if they know you suffer from dehydration. Spell it out, calmly repeat it, write it down for them, put it on a medical alert document.

Staying hydrated, keeping the water and electrolytes intake is great, but it can be overdone. That water has to go somewhere and there may be no opportunity once procedure starts to use a restroom. Always use the last chance they offer to empty your bladder. If you need a wide open IV, you may need a urinary catheter so you won't be so uncomfortable. Consider a moderate, but steady amount of oral fluids or a slow but steady IV drip instead.

**Go without**

Several procedures can be done with less or no anesthesia! Perhaps you don't need any or the same kind most people get. Dentists can do small to medium fillings with no anesthetic. For some surgical procedures that most people get general anesthesia, it is possible to ask for a local and stay conscious.'

Medical ID, Wallet Cards

Sometimes, just having a medical ID shows you've gone to the trouble of putting this information in one place and feel it important enough to show and that can get you some respect. Until you can set one up, carry some index cards or a page of information in your wallet or purse to refer to or hand to someone if you can't talk. You may need one approach for general and one for emergencies.

Having a wallet ID card or an medical condition identifcation dog tag or such is one thing, knowing what to put on it is another! Sometimes it can be better to just say the simplest of things on the ID, and keep updating a file elsewhere. Some suggestions from our members have been drug sensitivites, complicated history, heat sensitivity, needs IV fluids, dehydrates easily, sensitive to anesthesia, orthostatic intorance, postural tachycardia, wheat and dairy sensitivity, administer Ringer's lactate, reclining recommended.

[Note that this is not necessarily a recommendation of any other part of this site]

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**David S. Bell, MD, FAAP, Published in Lyndonville News,** September 2001

Patients with CFS struggle with anesthesia. If a CFS patient has surgery, there is the additional burden of recovering from the surgery on top of [the symptoms of the illness] to start with. While this is an over-simplification, I think the concept works.

Years ago, I had expected CFS patients to be dropping like flies during surgery, surgeons not understanding the illness, anesthesiologists using the wrong anesthesia and an already fragile state to begin with. But it hasn¹t happened. So, general advice for a patient with CFS would be, Don't have surgery if you don't need it, but if you have to have it, have it and expect to feel even more [ill] for a while afterwards. Somehow this statement does not seem very elegant.

There has been concern that the type of anesthesia is critical. My personal feeling on this is that the type is not so important, but the amount of fluid support is going to determine how [ill] you feel afterward. I have heard some patients say that with an extra liter of saline they seemed to recover quite well. So I would advise the anesthesiologist not to be stingy with the saline unless there were clear indications to cut back on fluids. This area could be studied if there were interest among physicians, but so far it has not been.

[Note: Dr Bell does not seem to be aware of the serious/life threatening cardiac and respiratory problems which can occur during surgery in patients with M.E. Nonetheless, they do exist and are well documented. One can only assume that Dr Bell does not see very severely affected patients perhaps, or even that he no longer sees M.E. patients AT ALL but instead treats various fatigue patients misdiagnosed as CFS. Bell's most recent work on 'fatigue' and 'CFS' makes this hypothesis seem very likely. He seems to have abandoned studying M.E. and is now focused solely on various fatigued patient groups, sadly.]

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**Tips on Anesthetics and Hospitalization for People with Multiple Chemical Sensitivities** by Susan Beck

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**Hospitalization For The Chemically Sensitive** Selene Anema, RN.

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**Summary of Anesthesia Issues for Post-Polio Patients**

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Read Dr. Calmes' article, **"Anesthesia Concerns for the Polio Survivor,"** from the Spring 1997 issue of *Polio Network News* (now *Post-Polio Health*).

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## Two case studies of 'CFS' anaesthesia from India

[This article on anaesthesia mixes primarily 'CFS' information with a small amount of M.E. information. The patients involved may have 'CFS' or M.E., it is impossible to tell from the information given. This article reinforces many harmful myths about M.E. and its link to 'CFS.']

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## NCF Anesthesia protocol for 'CFIDS/ME'

The protocol recommends that any anesthesia avoid using the sodium channel.

[Note that this site is not recommended. The site, including this article on anaesthesia mixes primarily 'CFS' information with a small amount of M.E. information.]

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**Surgery** Compiled by Melissa Kaplan

(This first section is paraphrased from the site, by M.E. patient Lesley)

ANAESTHESIA
- potentially hepatoxic anaesthetic gases should not be used (Cheney) (also Lapp)
- anaesthetic with adrenaline (epinephrine) should not be used (Cheney)
- histamine releasers, including sodium pentothol, should not be used (Patrick Class)(also Lapp)

DRUGS
- muscle relaxants in the Curare family, such as Tracrium and Mevacurium, should not be used (Patrick Class)

WOUND HEALING
- wound healing in ME patients may be abnormally slow

POSSIBLE PROBLEMS DURING SURGERY

- ME patients may have intra-cellular magnesium & potassium depletion, causing cardiac arrhythmia under anaesthetic. Patient should be given magnesium & potassium before surgery (Micro-K using 10mEq tablets, 1 table BID and magnesium sulfate 50% solution, 2cc IM 24 hours to surgery) (Cheney) (also Lapp)
- catecholamines, sympathomimetics, vasodilators, and hypotensive agents should be used with caution on ME patients (Lapp)
- ME patients should be hydrated prior to surgery (Lapp)

Surgeons, anesthesiologists and support staff need to be aware of the following anomalies:

- neurally mediated hypotension (NMH) or orthostatic hypotension (OI)
- low red blood cell count
- low blood plasma volume
- hypercoagulation (thick blood - a low sed rate [0-5] is often seen)
- alkalotic (urine pH < 6, venus blood ph > 7.4)
- drug and food sensitivities
- chemical sensitivities, including plastics, vinyl, disinfectants
- poor absorption of nutrients in the gut
- leakage out of the gut ("leaky gut") of non-assimable particles
- abnormally low (up to 50% below normal) oxygen release from red blood cells
- 80+% chance of severe herxheimer effect from some antibiotics
- many supplements act as blood thinners and anticoagulants
- low NK levels, or abnormal numbers of immature NK cells, coupled with hyperactive Th2 immune activity

[Note that this is not necessarily a recommendation of any other part of this site]

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**Informal notes on the issue of funding biomedical research into ME/CFS**
Margaret Williams, 17th July 2006

Some local ME groups have already generated and run small-scale projects in conjunction with local universities, but are in need of central financial support to replicate their findings (which are important in helping to manage the day-to day problems that are seen in ME/CFS). Some of these studies have involved identifying key features of ME/CFS, for example, in conjunction with the University of Sunderland, the local ME group identified a hypersensitivity to adrenaline in local anaesthesia used in dental practice, which, because of the induced cardiovascular responses, has immediate value and ought to lead to a broader study. Taking care not to use adrenaline makes a big difference to

patients' well-being and safety, not to mention to the stress levels of dental practitioners Other local group findings relate to pain control, for instance, the study of the slow infusion of lignocaine carried out by a consultant rheumatologist, with promising results. Unfortunately, the rheumatologist in question is about to retire and his replacement is refusing to continue with the study. Surely the practical implications to the enhanced well-being of those with ME/CFS of such studies deserve the relatively modest financial support that is needed?

[Note that the term 'ME/CFS' is not supported by this site, and note that this term should not be considered synonymous with M.E.]

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**Allergic responses during Anaesthesia: methods of detection.** *Anaesthesia Review 1985:2:49-62*

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**Some anaesthetics may pose a risk to sensitive people.** Article. *Green Network Feb 1997.13*

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**CFIDS and anaesthesia: what are the risks?** EA Crean. *CFIDS Chronicle, Winter (January) 2000:11-13*

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The HUMMINGBIRDS' FOUNDATION for M.E. (HFME)
Fighting for the recognition of Myalgic Encephalomyelitis based on the available scientific evidence, and for patients worldwide to be treated appropriately and accorded the same basic human rights as those with similar disabling and potentially fatal neurological diseases such as Multiple Sclerosis.

**A one-page summary of the facts of M.E.**


Taken from www.hfme.org

- Myalgic Encephalomyelitis is a disabling neurological disease that is very similar to multiple sclerosis (M.S.) and poliomyelitis (polio). Earlier names for M.E. were 'atypical multiple sclerosis' and 'atypical polio.'
- Myalgic Encephalomyelitis is a neurological disease characterised by scientifically measurable post-encephalitic damage to the brain stem. This is always damaged in M.E., hence the name M.E. The term M.E. was coined in 1956 and means: My = muscle, Algic = pain, Encephalo = brain, Mye = spinal cord, Itis = inflammation. This neurological damage has been confirmed in autopsies of M.E. patients.
- Myalgic Encephalomyelitis has been recognised by the World Health Organisation's International Classification of Diseases since 1969 as a distinct organic neurological disease.
- Myalgic Encephalomyelitis is primarily neurological, but also involves cognitive, cardiac, cardiovascular, immunological, endocrinological, metabolic, respiratory, hormonal, gastrointestinal and musculo-skeletal dysfunctions and damage. M.E. affects all vital bodily systems and causes an inability to maintain bodily homeostasis. More than 64 individual symptoms of M.E. have been scientifically documented.
- Myalgic Encephalomyelitis is an acute (sudden) onset, infectious neurological disease caused by a virus (a virus with a 4-7 day incubation period). M.E. occurs in epidemics as well as sporadically and over 60 M.E. outbreaks have been recorded worldwide since 1934. There is ample evidence that M.E. is caused by the same type of virus that causes polio; an enterovirus.
- Myalgic Encephalomyelitis can be more disabling than MS or polio, and many other serious diseases. M.E. is one of the most disabling diseases there is. More than 30% of M.E. patients are housebound, wheelchair-reliant and/or bedbound and are severely limited with even basic movement and communication.

- *Why are Myalgic Encephalomyelitis patients so severely and uniquely disabled?* For a person to stay alive, the heart must pump a certain base-level amount of blood. Every time a person is active, this increases the amount of blood the heart needs to pump. Every movement made or second spent upright, every word spoken, every thought thought, every word read or noise heard requires that more blood must be pumped by the heart.

  However, the hearts of M.E. patients only pump barely pump enough blood for them to stay alive. Their circulating blood volume is reduced by up to 50%. Thus M.E. patients are severely limited in physical, cognitive and orthostatic (being upright) exertion and sensory input.

  This problem of reduced circulating blood volume, leading to cardiac insufficiency, is why every brief period spent walking or sitting, every conversation and every exposure to light or noise can affect M.E. patients so profoundly. Seemingly minor 'activities' can cause significantly increased symptom severity and/or disability (often with a 48-72 hour delay in onset), prolonged relapse lasting months, years or longer, permanent bodily damage (eg. heart damage or organ failure), disease progression or death.

  If activity levels exceed cardiac output by even 1%, death occurs. Thus the activity levels of M.E. patients must remain strictly within the limits of their reduced cardiac output just in order for them to stay alive.

  *M.E. patients who are able to rest appropriately and avoid severe or prolonged overexertion have repeatedly been shown to have the most positive long-term prognosis.*

- Myalgic Encephalomyelitis is a testable and scientifically measurable disease with several unique features that is not difficult to diagnose (within just a few weeks of onset) using a series of objective tests (eg. MRI and SPECT brain scans). Abnormalities are also visible on physical exam in M.E.

- Myalgic Encephalomyelitis is a long-term/lifelong neurological disease that affects more than a million adults and children worldwide. In some cases M.E. is fatal. (Causes of death in M.E. include heart failure.)

For more information, and to read a fully-referenced version of this text compiled using information from the world's leading M.E. experts, please see: What is M.E.? Extra extended version. Permission is given for this unedited document to be freely redistributed. Please redistribute this text widely.