Chapter 16

Treatments and Hazards

Drugs

M.E. patients need to be very cautious about taking medicines for various reasons: so many sufferers become hypersensitive to drugs, and in some there may be a problem, if the liver is at all affected, in breaking down and disposing of a drug. Also drugs affecting the nervous system may produce quite bizarre effects, sometimes the opposite of what is intended.

A good rule is to discuss with your doctor any medicine you may be prescribed. You need to know exactly what it is - its name and purpose, the symptoms it is supposed to treat, how to take it, and for how long. Report any possible side-effects as soon as possible. Various self-medications that can be bought at a chemist's, and which for you were once harmless, may now cause side-effects or allergic reactions if you have M.E. Beware of medicines or pills that have colourings which cause a reaction, and be aware that many cough medicines also contain sugar or alcohol.

Drugs to be Avoided (Unless Essential)

Tranquillizers

Tranquillizers include drugs such as Valium, Librium, and Ativan. These can be addictive, can make depression worse, and do not do anything to correct underlying brain disturbance.

Antibiotics

Broad-spectrum antibiotics in particular should be avoided. Ideally, proof of a bacterial infection should be obtained first, such as by a urine culture or throat swab (for suspected urine or throat infections); if an antibiotic is needed, hopefully your doctor will prescribe one specifically for that infection, for a limited length of time. The sensible M.E. patient who develops an infection will take measures to help his or her body's natural resistance, such as taking extra vitamin C, zinc, and vitamin A, and getting extra rest and plenty of fluids.

If you require a course of antibiotics, take the complete course; a half-hearted course leads to more trouble as the germs may come back, and may develop resistance to that antibiotic. Restore the friendly bugs in your gut, which will have been depleted by the antibiotic, by taking probiotics for at least two weeks after the antibiotics are finished.

Steroids

If you are already taking cortico-steroids, i.e. cortisone, prednisolone or similar, *do not stop taking them,* but consult your GP or specialist about the need for them. Steroids may cause temporary improvement of symptoms in many conditions, including asthma, multiple sclerosis, arthritis, ulcerative colitis and fibromyalgia.

However, this dramatic improvement happens because the body's own supply of cortisone is boosted artificially; this can dampen down the symptoms which result from allergic reactions (e.g. asthma), or from autoimmune diseases. Short-term benefits are outweighed by the longer-term effects of steroids: laziness of the adrenal-cortex glands in making one's own cortisone, which leads to poor response to stress and infection, and to increasing dependence on the steroid drug as the source of cortisone. Suppression of symptoms does nothing to correct the underlying problem which produced them, a problem with many drugs. It may also mask other serious conditions, such as TB or cancer. Natural cortisone levels fluctuate during 24 hours, and this natural response to the body's needs cannot be duplicated by regular pills. Other side-effects can be high blood-pressure, fluid retention, loss of calcium from bones - leading to osteoporosis - muscle weakness, stomach ulcers, and mental symptoms of depression or euphoria. Also any Candida yeast infections flare up.

A person who has been on steroids for more than a few weeks must not suddenly stop them. If long-term treatment is to be stopped, the dose has to be lowered very gradually over a period of time, and under medical supervision.

There *are* conditions where steroids save lives, and for some people life-long replacement steroid therapy is essential. However, steroids are *not* recommended for people with M.E., as the side-effects strongly outweigh any short-term suppression of symptoms.

Oral Contraceptives

'The pill' was hailed as the ideal contraceptive. However, certain long-term problems from its use have become recognised. Female hormones are related to cortisone in their chemical structure, and artificial levels can have some of the effects of steroids - weight gain, mental changes, and Candida yeast overgrowth.

Oral contraceptives also lead to depletion of zinc, and raised copper levels. There is increased tendency to allergies, migraines, blood clotting, high blood-pressure, and depression. Some of the mental symptoms may be due to the disturbance of B-vitamin metabolism by the pill, and to the change in the zinc/copper ratio. So women with M.E., who may have enough problems with depression, thrush, and blood-sugar, should not create further problems by taking the pill.

There is evidence to show that the long-term effects of being on the pill for several years include a greater risk of allergies and less resistance to infections, indicating some changes in immune response.

Anaesthetics and Surgery

All anaesthetic agents are drugs with powerful effects on the central nervous system. Any after-effects may be more severe for an M.E. sufferer. I know of two cases where the effect of a muscle paralysing drug (routinely used in anaesthesia after you have gone to sleep, to allow a tube to be safely passed down the airway) has taken an abnormally long time to wear off after the operation. Since in M.E. there appears to be some disturbance of the neuro-transmitters between nerve cells, and also some disturbance of muscle function, it is not surprising that a routine anaesthetic may cause problems. Obviously there are occasions when surgery is essential; you would not wish to delay operating on acute appendicitis or a broken leg.

If surgery is really needed, it is important that you tell the anaesthetist you have M.E., and describe any problems you may have with muscles, walking, coordination, and brain symptoms. Then he or she can make adjustments and use the most appropriate drugs, in lower doses if necessary.

Of course, any operation is stressful and may bring on some kind of relapse. If it is unavoidable, then try to make provision for extra care and rest in the convalescent period, and take extra vitamin C, zinc, vitamin A and all B vitamins for a few weeks after surgery. Allow yourself plenty of time to recover. Non-essential surgical procedures should be postponed until the M.E. is better, or is stable, which may be well before your turn comes upon the waiting list! Remember that hundreds of people with M.E. do have operations safely each year.

Local Anaesthetic

Many M.E. sufferers report increased sensitivity to local anaesthetic. It may be a reaction to the adrenaline which is often combined with the anaesthetic, and it is wise to ask the surgeon to use a local that does not contain added adrenaline. Several instances have been recorded of M.E. people collapsing or losing consciousness after local anaesthesia for dental procedures. On the other hand, many muscle biopsies have been performed on M.E. patients, with no ill effect from the local anaesthetic. So the reactions experienced in the dentist's chair may be partly due to stress caused by 'dentist phobia', or to the dose used, or to the site of injection being closer to the brain.

Whatever the reasons, non-urgent dental treatment, apart from scaling and cleaning, is probably not a good idea while you are unwell with M.E. Candida often lurks in the mouth and in gum crevices, so good preventative mouth and gum hygiene is extremely important. You may find that your gums' health improves after improving your diet and increasing your vitamin C intake. But tooth abscess or any chronic mouth sepsis must be treated, with penicillin and dental surgery if needed, as any septic focus in the body damages health and will worsen M.E.

Mercury Toxicity - Is it Relevant?
Talking of dental treatment, another reason why some M.E. patients report a relapse following dental work involving fillings may be to do with mercury sensitivity. This is a very controversial topic. Although the use of mercury amalgam is being abandoned in some European countries, there is a reluctance in the British dental profession to look closely at mercury's hazards.

What Are the Facts?
We know that mercury is extremely poisonous. It is used in a mixture with silver, tin, copper and zinc, containing about 50 per cent mercury. Once the amalgam has been installed in a tooth, there is no proof that some of the mercury does not escape in the form of vapour and enter the body. When the fillings are ground, as is done when chewing, some mercury does escape as vapour, and this can enter the saliva and be swallowed, and can be converted into methyl mercury by the action of bacteria in the mouth and in the gut. Methyl mercury is much more toxic than elemental mercury.

Because there is more than one metal in the mouth and there is liquid in the form of saliva, a small but measurable electric current is continuously generated in the mouth. This is something that gradually corrodes the amalgam, together with foodstuffs and chemicals and physical wearing away by chewing. All amalgam fillings gradually deteriorate, some have to be replaced after five to ten years. So where has the mercury gone?

The electric potentials between teeth and their surrounding saliva can be measured using a *milli-ammeter.* Some of the symptoms possibly due to the electric current in the mouth, which has been measured as 900 mv or more, include a metallic taste in the mouth, increased salivation, irritability, pins and needles or pain in the face, and severe depression. The roots of teeth, particularly in the upper jaw, pass close to main nerves, and the impulses passing along nerves can be affected by local electric currents.

Research has demonstrated that mercury can affect central nervous system functioning, and also has a bad effect on the immune system. It was demonstrated in 1984 that removal of amalgam fillings resulted in a rise in circulating T lymphocytes, whose numbers fell when the amalgam was reinserted. This may be due to hypersensitivity to amalgam fillings. There is certainly plenty of documented evidence of the undesirable results of having such a toxic metal in the mouth. I am not suggesting that mercury toxicity is a *cause* of M.E. or CFS, but it may contribute to damage to the immune system and increase susceptibility to developing immune dysfunction diseases. For those who would like to pursue this matter further, I recommend the book *The Toxic Time Bomb,* by Sam Ziff.

The problem for someone who has been diagnosed as having M.E. or CFS, who is getting worse and has a lot of old amalgam fillings, is this: Do you ask your dentist to take them all out, and replace them with one of the newer metal-free fillings?

There are several snags about this:

1. The replacement is not available on the NHS, and will therefore be costly.
2. You need to have evidence first that the amalgam is causing trouble, which is hard to find. However, it is possible to have tests done which show if the mercury is leaking out, and if you are allergic to it. These tests are only available from a few dentists, however.

3. The process of removing amalgam causes a great release of mercury, and usually the patient feels much worse for some days, maybe longer. In other words, it may induce a severe relapse.
4. The removal needs to be done by a dentist who is aware of the hazards, with special precautions taken to minimise swallowing and inhaling the amalgam. The fillings need to be removed in a particular sequence, depending on which ones are causing the greatest reaction.
5. Some of the replacement materials may cause problems. Ideally the patient needs to be tested for sensitivity to different substitute materials beforehand.
6. Because it is a procedure which causes worsening of symptoms, it is essential to take extra immuneboosting supplements (vitamins A and C, zinc, and calcium pantothenate) before and for several weeks afterwards.

There is an urgent need for more research into the connections between mercury amalgam fillings and immune functioning, the nervous system, and indeed the whole physiology of the body. There are no figures to show if the percentage of people with amalgam fillings is significantly different between M.E. patients and healthy controls.

In the meantime, the advice to M.E. patients about changing dental fillings is this: *Do not rush into having your amalgam fillings removed,* especially if you are really ill. If you start to get better, and feel you would like advice about it, contact the Dental Society for Clinical Nutrition.

Immunizations

An immunization is a procedure in which the body's immune system is stimulated to produce an antibody to a specific infection; so that if the virus or bacteria causing the infection enters the body at a later date, the white blood cells will recognise it and produce lots more antibodies very quickly. The antigen which stimulates antibody production is usually a form of virus or bacteria which has been killed or changed to make it harmless. When smallpox immunization was given, a modified relative, called cowpox, was used.

The question of immunization for an M.E. sufferer arises in these circumstances:

- Before foreign travel - e.g. a typhoid, cholera, yellow-fever, or polio booster.
- To start or boost protection against tetanus, for going abroad, for gardeners and agricultural workers, or when there is a penetrating wound.
- Schoolchildren with M.E. who would normally be at the age to have BCG (for TB), rubella (only girls need this), or any booster vaccine.

Practically all M.E. people will have had childhood immunizations to protect against tetanus, diphtheria, polio, smallpox, BCG (for TB), and possibly measles, mumps and rubella.

If tetanus protection is advised because of a risky wound, this must be done, because tetanus is lethal. Tetanus toxoid is not derived from live germs, and therefore should be less likely to produce a reaction.

The main occasion when you may consider having an immunization is before going abroad. Unless it is obligatory before entering the foreign country, the advice to M.E. patients is *don't have immunizations.*

Typhoid and cholera (commonly given together as *TAB/cho)* immunizations cause some reaction in all healthy people, and may lead to a severe reaction, a relapse, or possibly to no reaction at all in someone with M.E. The lack of any reaction may mean that no immunity develops, yet the person, unaware of this, will eat and drink contaminated food in the belief that he or she is protected. It is better not to go to countries where there is a high risk of contracting enteric diseases; if you go, though, be scrupulously careful about hygiene: boil water before you drink or cook with it, and do not eat uncooked food in cafes. Anyway, typhoid and cholera injections do not protect against dysentery and hepatitis, which are just as easily picked up in many countries.

Immunizations are intended to stir up the immune system, but if the immune system is not functioning normally, one can end up with hypersensitive reactions, or incomplete immunity.

Some Useful Drugs

Ideally, it would be best to do without any drugs at all; however there are occasions when certain medicines can help tide one over a bad patch, and assist in dealing with troublesome symptoms. It is important to reduce pain, and also insomnia, as both of these are stresses that hinder recovery.

As you have probably found out, much of living with M.E. turns out to be based on compromise. I do not agree with purists who say that all conventional drugs are wrong; nor with narrow-minded doctors who prescribe drugs with possible side-effects, but condemn all 'alternative treatments' (usually through ignorance) which in general are safer and gentler than drugs. The rigidly obsessive M.E. patient whose life is dominated by strict rules is not going to be open to trying various therapies, nor to be aware of what suits him or her.

Sleeping Pills

If these are needed and other measures don't help, then one of the short-acting hypnotics is best, such as Temazepam or Triazolam, starting with a small dose. Some people worry about dependence on them, but to use them to achieve healing sleep is more sensible than nights of wakefulness followed by days of feeling exhausted. As you get better you can do without them. But sleeping pills may be less effective than tricyclics (see below).

Antihistamines

In small doses such as 2-4mg twice daily, an antihistamine such as *Piriton* (chlorpheniramine) can be very helpful if there are many allergic symptoms, particularly the chronic explosive sneezing and streaming nose experienced by some sufferers. It causes a little sedation, but if taken at night, this is no disadvantage. Some newer antihistamines are nonsedative.

Nalcrom (Sodium Cromoglycate)
This may be helpful to prevent reactions in severely food-allergic patients, if they are in a situation where they cannot control their diet. One or two 100 mg capsules are taken before meals, either whole, or dissolved in water.

Painkillers
Avoid aspirin and compounds containing aspirin. Many people are sensitive to salycilates, and aspirin is now known to cause allergic responses and may be implicated in a hypersensitivity illness in children called Reye's syndrome. It is also irritating to the stomach. All the non-steroid anti-inflammatory drugs (e.g. ibuprofen) have the potential for stomach irritation, and should be taken with food.

Ibuprofen (Brufen) is an anti-inflammatory that can be used for headaches, joint pain and period pain.

Paracetamol has fewer side-effects than aspirin. Again a small dose should be tried, such as ½ or 1 tablet, instead of 2 tablets.

A good remedy for pain is vitamin C, 500 mg every hour. It has anti-prostaglandin effects similar to those of aspirin and anti-inflammatory drugs, and is much safer.

Antidepressants
Tricyclic antidepressants are closely related (chemically) to antihistamines. Although a controlled trial of tricyclics in treating M.E. is still awaited, the drug does seem to help some patients. The main benefit is improving the quality of sleep, probably by correcting the disturbance in non-REM sleep. A dose that is much less than that used to treat severe depression seems to help not only sleep, but also:

- Other brain functions - cognition, concentration, memory
- Muscle power (also reduces muscle spasms)
- Emotionallability (also reduces depressive symptoms)
- Some allergic reactions e.g. asthma, sneezing, as reported by some patients

As so many M.E. symptoms may result from disorder in neuro-transmitters (the chemical messengers between nerve cells), especially those that influence hypothalamic functions, it is not surprising that tricyclic drugs work in many patients. They work by increasing the level of certain brain peptides, such as serotonin.

I want to emphasise that these drugs do *not* suit *all* M.E. people, nor do they effect a cure for the majority who benefit from them.

Many M.E. patients do not tolerate tricyclics, often because the initial dose prescribed is too high. A tricyclic that has been tested on patients with 'fibromyalgia syndrome' (thought in the USA to be possibly identical to the myalgic form of CFS) is amitriptyline. When prescribed at only 10 or 20 mg nightly, it improves sleep and muscle pain and tenderness in fibromyalgia syndrome. There is more about tricyclic drugs in Chapter 10.

Tested Treatments *Essential Fatty Acids*

In a trial in Glasgow (Behan, 1990), it was found that EFA supplements have beneficial effects on M.E.

The levels of essential fatty acids in the blood, which were abnormal at the start of the trial, returned to near normal after three months. EFAs have been shown to inhibit the production of cytokines and replication of viruses. The authors of the trial noted that no patients were cured, but that they could increase their activities and felt better.

Intravenous Immunoglobulin Therapy

In Australia (Lloyd et al., 1990), 49 patients with CFS were given either intravenous infusions of immunoglobulin (2 gm/kg/month) or a placebo for three months. After assessment, 43 per cent who had received immunoglobulin had improved, compared to 12 per cent of those given the placebo. At the start, 82 per cent of the patients were found to have abnormal cell-mediated hypersensitivity and/or reduced T-cells. In many of those who improved on Ig therapy, these abnormal immune test results returned to normal.

In another immunoglobulin trial, in the USA (Peterson et al., 1990), patients received either IgG (1 gm/kg) or a placebo every month for six months. In this trial there was no significant improvement in any patients, and side-effects occurred in a fifth of patients. The dose used was less than that in the Australian trial.

There seems to be a contradiction in the results of these two trials, and intravenous immunoglobulin is not yet recommended treatment, perhaps unless there is evidence of reduced levels of circulating IgG in the patient.

Treatments Used or Being Tested in the USA

Calcium Channel Blockers

These are already used to treat angina, high blood pressure and migraine. When used to treat CFS they are thought to improve blood flow in the brain.

Ampligen

Ampligen is double-stranded RNA, which mimics the RNA in the immune system. It has both antiviral and immune-modifying effects, and may remove some block in the immune system which prevents it from recognizing virus.

A controlled trial of Ampligen, using 200 patients, was completed in July 1991. The results showed that Ampligen was an effective treatment for the severely debilitating form of chronic fatigue syndrome. Ampligen improved both the physical debility and the cognitive dysfunctions. There was no significant toxicity from Ampligen. Symptoms of low-grade fever and muscle and joint pain tended to improve with the treatment, and were probably due to the disease and not to Ampligen.

Unfortunately, in spite of this promising result, Ampligen is not yet a licensed drug in the USA. Hopefully further trials will convince the authorities there that this is a worthwhile treatment. Ampligen is not available for use outside clinical trials in the UK or other countries.

The Physician's Forum, issued by the CFIDS Association of USA, gives an overall account of all treatments in use or under trial for CFS in the USA.