

ME

Background Reading

This booklet is designed to be used in conjunction with your appointment with Dr Mason Brown.

Understanding ME and Laying the Foundations for Getting Better

BY

Dr David Mason Brown

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This booklet has been prepared to enable you to get the full benefit out of your appointment with Dr Mason Brown, whether this is a face-to-face consultation or a telephone appointment.

This booklet is designed for reference only and any questions should be directed to Dr Mason Brown when you see/speak to him at your appointment.

Warning: We are unable to accept responsibility for any symptoms resulting from the use of this document. Any action you take as a result of reading this document is at your own risk.

Appointments can be made in 2 ways:

1. **Face-to-face consultation:** This can be arranged by calling 0131 225 5656. Appointments are held at Medicalalternative, Waterside House, 19 Hawthornbank Lane, Edinburgh, EH4 3BH
2. **A half-hour telephone consultation:** This can be arranged by calling 0131 476 7183

Please do not try to contact Dr Mason Brown by any other means.

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How to use this Booklet

You will get the maximum benefit from this booklet if you follow these guidelines:

- Read this booklet thoroughly before your first appointment with Dr Mason Brown
- Note down any specific queries so that you can make the best use of your appointment time
- You can obtain supplements in advance of your consultation with Dr Mason Brown, however, please do not start taking them until your appointment so that Dr Mason Brown can check the exact dosages that you would require
- Refer to this booklet in between appointments to remind yourself of Dr Mason Browns approach
- Remember that apparent lack of progress usually stems from failing to follow the guidelines and protocols precisely, and in the most ill, the temporary release of excess toxins

Main Principles of this Approach

- You must act to lay the foundations for getting better both physically and mentally
- Taking personal responsibility for getting better is the key to the recovery process
- Dr Mason Brown will provide the method and the tools for getting better, but you have to apply them with conviction to make progress
- You must acknowledge the stage you are at with the illness and resolve to pace the recovery process appropriately
- The process of getting better must be gradual and in sequence
- If you have acquired what psychologists call “learned helplessness” from years of suffering without hope of recovery, you must pay particular attention to the mind-body aspects of this approach
- Action based on the belief that you can succeed increases the feeling that you are taking some control of your life

Introduction

Understanding and getting better from this condition is a very complicated business, especially with the most ill patients. It has to be done in a sequence. You can't do everything at once, it won't work. So this is why we are introducing you to the main concepts now, Dr Mason Brown will cover additional areas gradually as and when you are ready.

In this booklet we're going to be looking in detail at the first stage of getting better. The priority here is improving the brain circulation and the body's circulation, so that you have a transport system that works, to take the oxygen and the nutrients where they're needed, and any medication where it's needed. Good circulation is also necessary to start removing some of the toxic waste products. It is vitally important for you to understand that for your long-term health and well-being, mastery of this stage is the first step.

This condition has been known about for a long time. As far back as 1934 it was referred to in the United States as Atypical Poliomyelitis because of its similarity to Polio. Before the days of immunisation there were a great many cases of Polio during the hot summers in the United States. Polio could start with the symptoms of the common cold. However, if the child or adult was to rest at that point they could minimise the increase in the virus and recover. An important principle to recognise is that when suffering from any viral infection one of the worst things anyone can do is to overdo it physically or mentally. This can cause even low-grade viral infections to increasingly incubate and spread throughout the body. Real polio has a wide range of severity as the symptoms can vary from that of a common cold to muscle paralysis or even death in extreme cases.

In CFS/ME there is also a range of severity. What many doctors look upon as CFS is really a form of burnout where people have been working too hard and have had too many pressures or demands on them. They may have temporarily depleted their immune systems with all the pressures they've had, and then they get a viral infection as well.

Those individuals who have it mildly may be back to work within a year or two. Unfortunately many doctors who lack information on this condition, take the view that if the person does not get better within two years, then they must have an underlying mental illness. Through no fault of their own they are not aware of the more severe versions of the condition. Unfortunately, those who have the more severe forms of ME and have had it long-term (15 years or more in some cases), know only too well what it can be like.

It is important to understand this tremendous range of severity. Some people may have it mildly, others moderately and some may have had it severely for many years. But everyone suffering from this condition can apply the

knowledge that is now available, and can be helped. For example, a student with ME being able to get back to university, finish their degree, and go on to have a normal professional life. A child not only getting back to doing school lessons, but also getting back to school full-time and ending up completely healthy, or a middle-aged doctor being able to return to work full-time after having been bedridden.

It would be wrong to suggest that this always happens, but with those who stay the course and perform the actions in the right sequence it happens more and more often. Many of Dr Mason Brown's patients, especially if seen early in their illness, have been able to get back to health, stamina and good quality of life within a reasonable period of time.

The most ill, the people who have had it the longest time, have the most toxicity in their body and will take longer to treat. It takes longer and has to be done much more gradually and with great care. Also, people who have had it very severely for a long time, reach a stage where they may feel they cannot get better.

If you are in this position, you are not alone, and it is not surprising that you feel this way. Much of the literature from the medical establishment reinforces this negative belief. It does take time, but you can make progress, and many of you will make very significant progress toward better health and quality of life. However, it cannot be emphasised enough at this stage, that to make real progress it is essential that you follow the advice in this booklet carefully and don't get ahead of yourself. You must tackle the underlying problems in the right order, and you must pace yourself.

Because of the wide range of severity it is very difficult for relatives, friends or doctors to understand the type of tiredness and myriad other symptoms that come with the illness. There is a spectrum of severity and many different ways the condition can manifest itself.

For the technically minded, ME and other related illnesses are covered by the clinical term 'Psycho-neuro-immuno-endocrinitis', which means:

- *Psycho* – the mind, the way we are able to mentally function. A typical example with ME is brain fog.
- *Neuro* – the nervous system in the brain and body.
- *Immuno* – The immune system is a key factor in the causes of ME
- *Endocrinitis* – When there is decreased blood circulation to the lower part of the brain the hypothalamus and the pituitary gland, the trigger hormones that need to be sent out into the bloodstream to trigger the various glands of the body (including the sex glands) may not be produced in sufficient quantity. So, occasionally, someone with ME is

found with decreased thyroid function, decreased adrenal function, or decreased sexual gland function.

Common Symptoms of ME

- Circulation to the brain can be impaired severely affecting cognitive and physical function exacerbated by neurally mediated hypotension- this can cause you to collapse
- Difficulty sequencing thoughts, i.e. putting them in order
- Low motivation, lack of volition, procrastinating
- Poor co-ordination, disturbed balance
- Disturbance of glucose function- many people need the amino acid L-glutamine to help to correct this in the brain.
- Lack of energy
- Dropping things
- Arms or legs suddenly jerking
- Difficulty writing
- Sometimes a secondary or reactive depression can be a symptom
- Sudden dizzy spells
- Sleep disorders- dream disorders
- Endocrine dysfunction- Natural killer cell dysfunction
- Cognitive dysfunction- easy distraction, decreased concentration
- Seizures

N.B. Reactive Depression is exactly what it says. It is a reaction to significant life events, the degree to which one feels not in control of one's life, and the frustration one may feel for not being listened to or not being treated. When you get the ME better most of the reactive depression just goes.

For those who have recovered enough to read and for family members Dr Mason Brown suggests buying *The Power of Now* by Eckhart Tolle, published by Hodder & Stoughton (further details in booklist).

Note: These symptoms are likely to vary minute to minute, hour to hour, day to day.

ACTIONS IN STAGE 1

- **Motivating Yourself**
- **Pacing Yourself**
- **Understanding and Prevention of ME**
- **Improving Blood Circulation**
- **Supplements for Stage 1**

In using this booklet you are starting on a journey to increased wellness followed by increased fitness over time. If you have suffered from this condition severely and over a long period of time this journey to wellness may take longer. However others have managed to do it, so you could too!

Motivating yourself

You must learn to live the principles of expectation psychology. At the end of the day there are only two basic motivators: fear and desire. Fear is all too often used as a motivator with disastrous results. Fear is negative and a drainer of energy and is most effective when we want to encourage inaction and stagnation. On the other hand motivation through desire is much more powerful and effective.

Desire stimulates positive emotions, which generate energy and a passionate will to succeed. Think about this from your personal experience, how have you reacted in the past when someone has attempted to motivate you through fear. How did you feel? Were you inspired, enthusiastic, energised? Of course not! You probably felt resentful and angry, with negative emotions that sapped your energy and interest in the task at hand.

Dr Mason Brown is passionate about the use of desire as a motivator. He has succeeded where others have failed by inspiring patients to dream of what they desire. Part of your job in getting better is to fill your mind with what you want to happen. Spend time daydreaming of how you will spend your time once you are better, see yourself doing more and more as your body heals. Imagine yourself in the future rewarding yourself for your recovery, sensing how clear your thinking is, how comfortable your muscles feel.

This is so important as mind-body medicine has proved without any doubt that you cannot help but gravitate towards what you think about. Psychologists have completed thousands of studies and experiments to prove the benefits of positive thinking and placebo effects. You can use relaxation to help you to habitually think about a future you desire.

Think of the time you spend relaxing as a treat you allow yourself for all the hard work and effort you are putting in to getting yourself better. Allowing yourself to drift into the healing state will help you to focus on what you desire, lift your mood and improve your attitude.

ME is a condition of remission and exacerbation. At times, we plateau. If you follow this booklet and the advice that Dr Mason Brown gives you, you should find that the remissions become longer and longer and the exacerbations shorter and shorter and less severe. This is Dr Mason Brown's experience from working with hundreds of ME patients over the last 10 years. If you plateau you ask yourself why, and work out the next step forward.

Remember famous examples from history. Edison was told by his fellow scientists that it was impossible to make an electric light bulb as the heat generated would destroy any filament. He persevered and the light bulb was invented.

Look at America's decision to land a man on the moon by the end of the 1960s. It started in the imagination and became reality. There is an old saying 'imagination rules the world'. There is another saying 'by the inch it is a cinch, by the yard it is hard.' With ME you heal yourself gently, you learn to be kind to yourself. You learn to love yourself instead of being hard on yourself. Do not let anyone chuck guilt or stress at you.

COMMITMENT BOX

I will fill my mind with positive thoughts and only think and dream about a future I sincerely wish to come true.

I will enjoy entering the healing state and resolve to make relaxation a regular part of my daily routine.

Signed

Date.....

Pacing Yourself

Why Pace Yourself?

At this stage, there are 2 areas where pacing is important, the dosages of medication and the amount of activity you do. Pacing is a key attitude in getting better.

Medication and Supplements

No two people with ME are the same and as a result, the correct dosages of medicine and supplements will be different for each person. A key part of getting better is learning to listen to your body and act according to what it is telling you rather than blindly following a strict dosage.

The section on improving circulation explains how to use pacing in order to get the correct dosage of nimodipine for your body. Similarly with the other supplements mentioned in this booklet, if you feel that you are taking too much you should go back to the previous dose until you feel able to increase it again. It is understandable that when you have had ME for a long period you feel frustrated and will want to push on with the various stages as quickly as you can. However, this can have a negative effect. Try to see this as a process which you must go through at a pace you feel comfortable with. Just like running a marathon, if you sprint in the first few miles you can exhaust yourself and may not be able to finish!

Activity

Pacing your activities is an integral part of getting better. You may find yourself in situations where you feel duty bound to push yourself when you know that you are too tired and should really be taking a rest. Getting involved in activity at these times is not at all helpful to your long-term health.

Learning to pace yourself effectively often involves a major change in attitude. It is important to make a commitment to yourself that getting better is your main goal. If you feel tired at a certain point, no matter if it is inconvenient or doesn't fit in with your plans you must take rest. It is not always easy to recover when you have pushed yourself too hard as you are probably very well aware. You must be focused on your long-term goal of getting better. It is better to lose a battle occasionally so that you can win the war.

How to make Pacing work for you.

Learning to pace yourself is a crucial part of your actions. Your body will send you signs as to whether it is coping or not and one of the most important things to learn in any treatment is that your body knows what it likes and what it doesn't like. You must learn to listen to your body.

Before starting a task it may help to ask yourself questions like:

Pacing for medication and supplements

- How do I feel today?
- What signs is my body trying to give me?
- How am I physically?
- How am I mentally?

Pacing for activity

- Why do I feel that this is more important than my health?
- Do I really need to do this?
- Am I having a good day?
- Do I feel well enough for activity today?
- What can I do to make the most of this energy that I am feeling right now?

It is important to remember that ME affects each person differently. A key to pacing yourself effectively is having the ability to recognise the signs which are specific to you.

Here are some examples of symptoms which could result if you have not been pacing yourself:

- Fight-flight symptoms are a sign that you are pushing yourself too hard.
- Heart beating faster
- Brain fog
- Going pale
- Neurally mediated hypotension

If you feel you have pushed yourself too much physically, you may need to stop and take a rest before doing anything else. With medication it may be a case of reverting back to the previous dosage and building up again when you feel you are able.

It is also important to pace your recovery, only going on to the next stage when you feel you are ready.

Please note:

If you have been severely ill for a long period of time, pacing yourself for activity may mean something as small as sitting upright in bed for 5 minutes a day initially. Pacing is important for everyone, but you can only start from the point that you are at at the moment.

Another important point about pacing is that in the same way as you have to adapt your medication and supplement dosages depending on how you feel, pacing means listening to your body, not rigidly sticking to a routine, for example, you may try to go to bed at the same time every night, however, if you are feeling particularly tired or you know you are going to be doing something which requires energy, go to bed early or before the event.

COMMITMENT BOX

Getting better is my main goal. When I feel better I can tackle the other areas in my life. Right now I want to prioritise to get better. I will NOT overdo it! I will Always Pace Myself. It takes practice to get the right balance: if I do too much I will get an exacerbation, do too little and I will slow my recovery.

Signed

Date

Understanding and Prevention of ME

Although understanding ME is important, the key area here is working towards minimising the effects of these potential causes and moving towards long term prevention.

All of the following potential causes can be and are often interlinked:

- Unique genetic inheritance
- Pollution and toxicity
- Stress and significant life events
- Infections
- Nutritional deficiency
- Electromagnetic factors

Unique Genetic Inheritance

The implications of genetic inheritance are often underestimated as a contributory factor in M.E. All individuals are born with strengths and weaknesses in body and mind. The example of organophosphates mentioned in the tape demonstrates the fact that genetic inheritance can link with other factors such as pollution and toxicity. Some people are able to be in contact with the organophosphates for years with no negative effects whereas others have contact once and become ill.

Minimising the effects

Obviously there is nothing you can do about the genes you are born with. However there are things you can do to reduce the damage that any genetic weaknesses may cause. You can become an expert on yourself by increasing your awareness of your genetic weakness and taking appropriate action when necessary. For example if you know that you have a tendency to get a cold when you feel stressed, look after yourself during stressful periods, build relaxation into your day, and make sure you are eating a healthy diet.

If you are aware of a particular genetic weakness that you have, mentally or physically, work out a way to protect yourself from it. Take extra care to avoid getting into an environment that you are sensitive to.

Pacing yourself is relevant here. If you are aware of being in a situation which can cause you problems, take things at a pace you feel comfortable with. Remind yourself that not pacing at these times could be very detrimental to your health.

If you have ingested a substance that you are genetically sensitive to then drinking plenty of water can help this as well as detoxification. Dr Mason Brown will talk to you about detoxification products at your appointment when you are ready to use them.

Pollution and Toxicity

Human beings have never been exposed to so many toxic elements before. This has a direct effect on our health as our bodies constantly have to deal with new substances.

We are potentially affected by what we breathe, by what we eat and drink, and by what we put on our skin. It is important to pay attention to air, water, food and nutrition quality. Household products, including detergents, cleaners, personal care products, and cosmetics are all man-made substances that can be toxic.

It is also important to remember that we are affected by our own negative thoughts and emotions, and also by the negative emotions and behaviours of those around us. These negative thoughts can also be described as a type of pollution.

Please note pollution and toxicity are dealt with in detail at a later stage in the treatment.

Minimising the effects

There are things you can do to control some of the effects of pollution and toxicity. A water filter can remove some of the toxins from tap water before you drink it. If you are genetically sensitive to certain pollutants e.g. organophosphates then make sure you cut out any foods containing them from your diet. Avoid substances that you know to be toxic such as artificial sweeteners etc.

Stress / Significant life events

Although we cannot say that stress causes ME, it is a very important contributory factor and certainly makes the illness worse once you have it.

To enable us to respond to stressful situations we unconsciously trigger our fight-flight response. This involves a number of physiological and hormonal changes in the body that are designed to maximise our ability to run from, or fight, the threat we perceive. We all use our fight-flight occasionally with no harmful health effects. However, if we start to use it on a regular daily basis an unfortunate side effect is that it gradually weakens our immune system.

If you have ME you are more likely to have to call on your fight-flight response on a chronic basis. This is because you have less energy and are under more stress than the average healthy person. This weakening of the immune system makes you more susceptible to viral infections and other health problems. In exceptional circumstances when we are exposed to excessive pressure for long periods this can lead to the eventual 'collapse' of our immune system.

Stress is a very personal phenomenon and only you will know what stresses you the most. You will also be aware that what stresses you does not necessarily stress others and what stresses others does not necessarily stress you. However, there is no doubt that there are increasing levels of stress in today's fast moving, ever changing society.

Sadly, for many of us, the stressors in our lives can easily become chronic. We never really switch off or relax. In the presence of chronic stressors we can be experiencing an almost perpetual low-level fight-flight response with excess release of adrenaline and cortisol. It is not therefore surprising that disturbance, and indeed damage, to our immune system occurs.

Stress is part of life and we cannot avoid it, but we can take action to learn skills and adopt healthy habits. These habits can minimise our use of the fight-flight response and its harmful effect on our immune system.

Common Symptoms of the Fight-Flight Response The Body's Arousal Reaction

Initial Biochemical Reaction: The brain sends a biochemical message to the pituitary gland, which releases a hormone, which triggers the adrenal gland to release adrenaline. This in turn leads to:

Physical Reaction: Pupils dilate.

Symptom: Headaches, dizziness, blurred vision.

Physical Reaction: Mouth becomes dry.

Symptom: Difficulty swallowing.

Physical Reaction: Neck and shoulders muscle tense - large skeletal muscles contract ready for action.

Symptom: Aching neck, backache.

Physical Reaction: Breathing becomes faster and shallower, supplying more oxygen to muscles.

Symptoms: Over breathing, chest pains, tingling, palpitations, asthma.

Physical Reaction: Heart pumps faster and blood pressure rises.

Symptoms: High blood pressure.

Physical Reaction: Liver releases stored sugar to provide fuel for quick energy.

Symptoms: Excess sugar in blood, indigestion.

Physical Reaction: Digestion slows down or ceases as blood is diverted away from the stomach.

Symptoms: Nausea, indigestion, ulcers.

Physical Reaction: Muscles at opening of anus and bladder are relaxed.

Symptoms: Frequent urination, diarrhoea.

Physical Reaction: The body cools itself by perspiring: blood vessels and capillaries move close to skin surface.

Symptoms: Excess sweating, blushing.

Minimising the effects

Many of the mind-body techniques, which Dr Mason Brown will introduce, will greatly help to reduce your stress. If you practise them regularly you will:

- Be able to switch off and relax better, conserving your energy
- Improve the quality of your sleep
- Reduce the strain on your immune system
- Improve your mood
- Boost your confidence and self-esteem
- Think more positively

Becoming more aware of your own specific stressors will enable you to plan to avoid them, or, if this is not possible, take all possible actions to minimise their affects on you.

The section on pacing can help you to minimise your reliance on your fight-flight response. For example learning to say no may be a key strategy in pacing your activities and managing your stress.

Infections

Like all contributory causes of ME, 'infections' are linked to the other causes. For example, in the previous section it is explained that stress can depress the immune system and lower defences. This allows viruses and other infections to take hold when normally they would be fought off.

There are basically four types of infections that are implicated as potential causes and as associated effects of ME:

- ***Viral infections***
- ***Bacterial infections***
- ***Parasitic infections***
- ***Fungal infections e.g. Candida and Thrush***

Although by definition you may have already suffered from these infections, it is important to understand ways to avoid re-infection in the future. This section looks at each cause and what can be done to minimise the chance of becoming infected in the future. Although there are infections all around us, someone with a healthy immune system is much less likely to become infected. If you have a weaker immune system, then you are more likely to become infected.

Individuals with chronic catarrh, asthma, or smokers are much more likely to have respiratory infections as the particles you inhale stick to the lining of their lungs instead of being breathed out. In smokers the situation is much worse due to the tar in their lungs acting like miniature fly paper to viruses, bacteria, dust, pollens, and pollutants.

Viral infections

Viral infections play an important role in ME. It is unlikely that they are the sole cause, but they can certainly be a contributory factor. The body may have been 'under stress,' for some time. It is the virus that takes the body beyond coping into what can be described as a 'de-compensated' state – a state of exhaustion and burnout.

Minimising the effects

Looking after your mental and physical health generally reduces the likelihood of contracting viruses. Make sure you are eating a healthy diet. If you know you are going through a particularly difficult period make sure you are using stress management techniques, going into the healing state and taking plenty of rest. If you are aware that you may be vulnerable for some reason, try to avoid places where there is likely to be infection.

Bacterial infections

As someone with ME looks back at how their health has deteriorated, they often realise they have had increasing bacterial infections e.g. upper respiratory infections, sinus infections, stomach upsets. The individual's resistance to bacterial infections had gone down, and often this results in using antibiotics.

Regular use of broad-spectrum antibiotics not only kills the bad bacteria, they also kill the good bacteria (especially in the gastro-intestinal tract). That is,

although antibiotics may kill an infection in the short term, they may compromise our immune system in the long term, lowering our defences. One antibiotic which many ME sufferers seem to be particularly sensitive to is Augmentin.

Minimising the effects

Good personal hygiene is a key factor in preventing bacterial infections. Brushing teeth properly night and morning reduces the likelihood of bacteria cultivating. If you think you may have been exposed to an infection, gargle with mouthwash.

Good cooking practices are also important here. For example, separating any cooked meat from raw meat, cooking meat thoroughly and eating fresh foods within 'best before' dates.

Prime Directive (mentioned in the supplements section) replaces the good bacteria killed by antibiotics.

Parasitic infections

In ME there is particular concern with microscopic airborne parasites. These can be picked up easily, for example through aircraft ventilation systems. Microscopic airborne parasites are very difficult to detect. If someone has a recurring chest infection which keeps coming back, despite repeated treatment with antibiotics, microscopic parasitic infection could be a cause.

Minimising the effects

Similarly to bacterial infections, proper cooking and good hygiene are important in minimising the risk here. Gargling is effective in killing infection when it first enters the body. Parasites are often picked up abroad. It is important to be cautious about what you eat, locals can build up an immunity to parasites which you may not have.

Fungal infections e.g. candida and thrush

Too much sugar in the diet is a major cause of fungal infections. Sucrose, the simple sugar, which is absorbed very quickly into the blood is the problem here. People are often very unaware of just how much sugar they are actually eating in all the different foods that they take. One example of this is the can of cola, which contains about 8 spoonfuls of sugar. It rises quickly in the bloodstream and creates a perfect environment for candida. Fungal infections are also made worse by regular use of broad-spectrum antibiotics.

Minimising the effects

Mentioned in the supplements section, Prime Directive replaces the good bacteria lost through use of antibiotics. You may feel that antibiotics are the only option to get better from a particular condition. If this is the case make sure you take Prime Directive to replace the good bacteria.

Often the symptoms of candida and thrush are so overpowering that it is difficult to imagine trying to treat the CFS/ME at the same time. If this is the case, starting on the Prime Directive alone initially can help to control the symptoms of candida, and when you feel more able you can start on the other treatments at your own pace.

Reducing the amount of sugar you eat has an instant effect on the sugar levels in the bloodstream.

Aloe Vera is very good for fungal infections and this is mentioned in the supplements section. Personal hygiene is also important here. Avoid going barefoot in public, damp areas such as swimming pools.

Nutritional Deficiency

For the body to process sufficient nutrients, several factors must exist:

Healthy Diet

Our diet must be healthy, with the foods we consume containing sufficient quality nutrients.

Gastrointestinal Tract

Our own gastrointestinal tract must be able to take the nutrients into the body and deal with them properly, absorbing the nutrients required by the body.

Cells and Body Systems

Individual cells and body systems receive the nutrients and must be able to make use of them.

Potential Problems:

Healthy Diet

There is a distinct lack of minerals in soil, which has been farmed for many years. This results in food grown in this soil also lacking in minerals. Also, pesticides can have a negative effect on the quality of the food produced.

Gastrointestinal Tract

If the gastrointestinal tract has become blocked at parts by various toxins and pollutants, or antibiotics have been used for a long period, absorption

from the gastrointestinal tract deteriorates. As a result nutrients are not absorbed effectively.

Cells and Body Systems

Where the brain circulation and the body's transport system are not functioning properly (as in the case of ME) nutrients are no longer transported effectively to the cells in the body where they are required.

Minimising the effects

Eating organically grown foods is particularly important with individuals who are genetically sensitive to pesticides, in particular the organophosphates.

As mentioned previously Prime Directive restores the good bacteria. Some of these good bacteria help cleanse the bowel lining allowing improved absorption. The importance of bowel cleanliness is demonstrated by the temporary improvement in energy levels and absorption, which occurs after colonic irrigation. Prime Directive is much better for this and Dr Mason Brown does not recommend colonic irrigation.

L-Glutamine is an essential supplement for the small intestine and the brain. It also helps to prevent muscle breakdown and fatigue (see supplements section).

Deficiency of L-glutamine causes leaky gut syndrome, where minute undigested particles of food get into the peritoneal cavity, producing food allergies. This is an important supplement for the small intestine and it also helps to prevent muscle breakdown and fatigue.

Proper mineral replacement, especially Magnesium, Zinc, and Selenium (see supplements), and trace elements need to be replaced.

Electromagnetic Factors

Today in our modern civilisation, we live in a very strong *artificial* electromagnetic environment. We are surrounded by radio waves, television waves, radar etc. Electromagnetic pollution is a very real issue at the present time, where information and communication technology are developing rapidly.

Until recently, people were used to living in the normal electromagnetic environment of the earth's magnetic field. However, electromagnetic equipment like a television set or a computer gives out positive ions into our atmosphere, which causes a change in the balance of ions. These positive ions have many effects including making us tired.

Various particles in the air such as bacteria, viruses, pollen, or bits of dust become charged. These particles 'stick' to the lining of your mouth, nasal passages and lungs, rather like a balloon will stick to a wall after being rubbed on your jersey. This is another reason why infections breed rather than being exhaled back out as they would be for someone with a healthy immune system.

Minimising the effects

Good quality ionisers in the most used rooms will change the charge in the room to negative. You can usually buy a good quality ioniser from large department stores and chemists.

Good ventilation is also important, making sure that there is a constant flow of fresh air in the area where you are. If you are spending a lot of time in electromagnetic environments, make sure you make opportunities to get out in the fresh air at regular intervals.

COMMITMENT BOX

I will listen to my body and become an expert on its individual needs and vulnerabilities.

I will raise my awareness of all events and circumstances which may disrupt my progress towards getting better, and plan to minimise their effects.

Signed **Date**

Improving blood circulation

Why are we doing this?

We need to improve our blood circulation as it acts as the body's transport system. Improved circulation will remove neurotoxins from the brain and other toxins from the rest of the body allowing nutrients and supplements to reach the parts of the brain and body where they are required.

Actions which improve blood circulation:

- Taking a controlled course of nimodipine tablets
- Taking Ginkgo Biloba
- Drinking the right amount of water every day

Nimodipine

Background of the use of Nimodipine for ME

Anyone who wants to understand more about the physiology of the brain in ME should buy and read Dr Goldstein's book, *Betrayal By The Brain*. It explains the use of nimodipine as well as having seventy pages of research references. It was published in 1997, and has the ISBN number 1-56024-981-1. There is also a simpler version for GPs and patients (see book list at back of this booklet). It is also important to remember that nimodipine has been used for brain circulation for so many years that it is now out of patent.

Dr Mason Brown's nimodipine protocol has been developed over the last ten years and is designed for maximum safety and ease of use by patients, preferably with the support of the general practitioner. Dr Mason Brown will talk about this at your appointment. Patients who follow the protocol carefully should avoid side effects, by ensuring the safe low release of trapped neurotoxins. Once the toxins have been released nimodipine can be used rather like an angina patient uses their spray or an asthma patient uses their inhaler.

The only side effects we are aware of have resulted when doctors have prescribed too much nimodipine, not taking account of the build up of neurotoxins in the brain over the years. When these neurotoxins are flushed out too quickly, it is their effects that give the side effects. These are not produced when the protocol is properly followed.

Nimodipine is a calcium channel blocker. It works by improving blood circulation in the brain, especially through the smallest vessels. It also works by relieving areas of localised vessel spasm in the brain decreasing the vascular headaches sometimes associated with ME.

In ME there can be reduced blood pressure due to the neurally mediated hypotension found in many patients. Neurally mediated hypotension is where the blood drains from the head causing parts of the brain to have inadequate circulation. This is why 'brain fog' often occurs.

The combination of the decreased brain circulation and low blood pressure produces the characteristic facial pallor seen in many individuals.

Please note: Dr Mason Brown will go over the protocol with you at your appointment.

If in the meantime you are looking for further information on nimodipine and its use in ME you can do a search on the internet.

Here are some links to information on the internet:

<http://www.immunesupport.com/chronic-fatigue-syndrome-teitelbaum.htm>

<http://www.immunesupport.com/library/showarticle.cfm/ID/3346>

<http://alnelson.tripod.com/48jun01.html>

<http://www.infoaging.org/d-stroke-14-ref.html>

<https://www.endfatigue.com/home.nsf/0/6154701cd458943785256857006fa45f?OpenDocument>

Obtaining Nimodipine

Nimodipine has been used for many years in NHS hospitals to treat a form of stroke called a subarachnoid haemorrhage. The dosage used in the case of a subarachnoid haemorrhage is 8 tablets per day for 3 weeks to restore brain circulation.

However, the list of drugs that GPs are allowed to prescribe on NHS prescription has become increasingly limited. There is an official list which some local prescribing bureaux stick rigidly to. In these areas, a GP prescribing any medicine that is not on the limited list may be asked to pay for it out of his or her own pocket. In other parts of the country an increasing number of GPs, having seen the effects of nimodipine are starting to insist on prescribing it on the NHS. This is part of what is called postcode medicine where certain services or treatments are available in some parts of the country and not in others.

If you are lucky and live in a non-rigid area and have a helpful doctor, they may, after reading the information, or seeing your initial progress, be willing to

prescribe nimodipine on the NHS. However, it can also be obtained by your doctor writing a private prescription.

You can obtain a private prescription from Dr Mason Brown at your appointment/ after your telephone consultation.

Ginkgo Biloba

Dosage

The dosage varies according to the product used. For example, Goldshield's Ginkgo Biloba 400mg capsules of powdered leaf, starting at one capsule a day. There are other forms of Ginkgo Biloba, for example, tincture. Whatever form you use, **use the smallest dose of that company's range. Do not use high strength ginkgo biloba products.**

You should start the ginkgo biloba at the same time as you start the nimodipine for the best effect. However, it is **not** necessary to build up the dose of ginkgo biloba in the same way as you do with the nimodipine, stay within the guidelines on the supplement you are taking.

If you suffer from extremely cold hands and feet and this is still present after two weeks of taking 400mgs of ginkgo biloba once a day, you can increase your dose of ginkgo biloba to 400mgs twice a day. This dosage level is extremely safe, **but if you experience any bruising stop taking the ginkgo biloba.** In 5 years Dr Mason Brown has had one person with a previously undiagnosed clotting disorder, but this is extremely rare.

Caution: you will see advertisements for very high dose Ginkgo. These can too easily decrease the blood clotting mechanism too much. Always check that the preparation you are buying is the lowest dose in that range.

Purpose

Doctors in Germany, Sweden and France have been using Ginkgo Biloba for fifteen years to prevent strokes, and heart disease, to treat arm and leg circulation, angina, impotence, macular degeneration, cochlear deafness, tinnitus, chronic dizziness and asthma. Ginkgo is needed to ensure that the whole body circulation and especially the peripheral circulation to the arms, legs, hands and feet improves.

Ginkgo Biloba and nimodipine, in combination with drinking 8 glasses of water daily, are probably the two most important treatments for decreased brain circulation in ME. The Ginkgo Biloba works by countering the viscosity produced by excess production of Platelet Activating Factor (which thickens the blood).

Every time a patient with ME does too much physically or mentally for their present state or level of recovery, they can only keep going by using their fight-flight response. This response includes the release of Platelet Activating Factor, PAF, which, if one is wounded in the genuine Fight-Flight situation, can help prevent bleeding to death.

However, the inappropriate use of the fight-flight response in ME means that all that happens is that the blood becomes thicker as platelets stick together. This causes the circulation in various parts of the brain and body to get worse and worse.

At the present time, the best source of the specific antidote is found in the leaf of the Ginkgo Biloba tree, which contains Platelet Activating Factor Inhibitor, PAFI.

Excess release of PAF is also caused by feeling any negative emotions or having any negative stressors chucked at you by someone else, for example at work. Also apprehension or fear about the future or frustration or resentment about your illness or how you may have been treated, can produce excess PAF. One can also reduce the occurrence of the Fight-Flight response by using relaxation techniques on a regular basis in order to learn the relaxation response.

Obtaining Ginkgo Biloba

Goldshield 365 capsules (reference SS273) Tel 08708877000. Ginkgo Biloba can also be obtained at your local health store or quality chemist. Please remember to check that you are buying the lowest dosage in the range.

Water

It is critically important that you drink enough water and we recommended that you drink 8 medium size glasses of high quality water a day (approx 4 pints). When we say high quality water, we are talking about bottled mineral water or filtered water. Chlorine in tap water is potentially very toxic. Leave tap water in an open glass bottle to allow chlorine to evaporate. Water is needed to flush out the toxins from all parts of the body, from wherever they have been trapped. If insufficient water is drunk the toxins just remain rather than being flushed away. This can be compared to trying to shower under only a trickle of water when covered in mud.

Another consequence of the decreased circulation to the brain is that the thirst reflex can also decrease causing dehydration. Up to 30% reduction in total blood volume can occur in patients with ME. As half of our blood consists of cells which are solid matter and the rest are liquid, if we are dehydrated it makes the blood much more solid, it just can't flow so well. By drinking water we also help the flow of the blood.

Progress you should expect from improved circulation

Although you may have experienced some nausea when learning the appropriate dosage of nimodipine, you should also start to enjoy some of the following benefits:

- Be able to think and do things you haven't been able to do for some time
- Find the quality of your thoughts and emotions improving
- Feel emotionally more relaxed and able to concentrate more easily
- Your coordination and balance should improve
- Your ability to read, listen and remember things should improve

COMMITMENT BOX

I will follow the dosage protocols for nimodipine and Ginkgo Biloba precisely and with patience, as instructed by Dr Mason Brown.

I will temporarily reduce the dosage of nimodipine if necessary.

I will drink 8 glasses of water every day.

Signed **Date**

Supplements for Stage 1

Please note: In this section supplements which are essential for everyone to take at the start of treatment are marked ESSENTIAL. Those which relate to particular symptoms which you may or may not have and are therefore not essential for everyone at this stage of the protocol are marked NOT ESSENTIAL

- L-Glutamine
- Evening Primrose Oil
- Prime Directive
- Weleda Gargle/Aloe Vera
- Calcium, Magnesium, Zinc, Boron and Selenium

Please note: Details of supplements are correct at time of writing. Please check with Dr Mason Brown at your appointment.

L-GLUTAMINE - ESSENTIAL

Dosage

The dose for the first month or six weeks is one 500mg capsule 3 times a day. Then take 500mg twice a day for a month, later 500mg should be taken daily as maintenance.

Glutamine is also available in powdered form. It is used more often in this form in the United States although it is becoming more widely available in the UK. If you buy it in powder form it is essential that you buy *pharmaceutical grade*. The powder itself has no taste and can be sprinkled onto food. The important thing to remember is, if you use it on your food you must only put it on the food *after* the food is prepared or cooked. Do not put it on the food and then put it in a microwave or cook it, as you would then destroy the glutamine.

Purpose

The amino acid glutamine is used by the brain for energy. By supplementing with glutamine, regulation of the level of glucose is improved. This helps intellectual and cognitive behaviour, and the functioning of the whole of the rest of the brain. These are areas that are often affected by ME, so it is important to try to improve by supplementing.

It has been found that people under stress or recovering from illness and injury, lose lean muscle mass very quickly even when given twice the calories and protein they normally need. When we're under stress, the free glutamine in muscle is released to go where it is most needed; the brain, the intestines,

the immune system and the liver. Unless the individual has enough unbroken down glutamine in their diet, the muscles will continue to lose glutamine to other tissues, becoming weaker and more wasted. Please remember that glutamine is broken down by cooking.

Researchers have discovered that if a stressed person is given glutamine, the breakdown and wasting of muscle is prevented. This has implications for anyone who is under stress mentally or physically. Taking supplemental glutamine at these times could help maintain the body's glutamine stores and prevent muscle breakdown and fatigue. This is very relevant in ME as muscle breakdown and fatigue are often very severe.

Glutamine also works on our stomach, the large bowel, and especially the small intestine. The small intestine is the only part of the body that solely uses glutamine for energy. Lack of glutamine leads to 'leaky gut syndrome', as mentioned in the section on 'nutritional deficiency'. By using glutamine over a period of up to six months, these allergies can decrease.

Glutamine is found in eggs, poultry, fish and red meat, but the problem is that it is destroyed by cooking. This is why we need to supplement the body directly with glutamine.

Obtaining L-Glutamine

Manufacturer: Solgar
Name: L-Glutamine 500mg capsules

The Solgar capsules are not made of gelatine and are therefore suitable for vegans. Please note strict vegans have been found to not recover from ME unless they supplement with glutamine.

Manufacturer: Holland and Barrett
Name: L-Glutamine 500mg tablets

Manufacturer: See Local Chemist
Name: Pharmaceutical grade L-Glutamine powder

A new product from Australia is Glutamine complex 500. this also includes zinc, magnesium, chromium, and Vitamin B6.

Manufacturer: Orthoplex (contact Safe Remedies on 01289 332 888 to order by credit card)

Name: Glutamine complex 500

EVENING PRIMROSE OIL - ESSENTIAL

Dosage

500 mg capsule 4 times per day

Purpose

Evening Primrose Oil (EPO) contains a high amount of gamma-linolenic acid (GLA). GLA is an important constituent of prostaglandin E1, which is used to relieve inflammation and decrease pain in ME. It especially helps the brain and those with the worst muscle symptoms.

Obtaining Evening Primrose Oil

Goldshield 365 capsules (reference SS300)
Tel 08708877000

Evening Primrose Oil is also found in good health food shops and chemists. (Starflower oil can be used instead and is also available from Goldshield and other suppliers)

PRIME DIRECTIVE - ESSENTIAL

Dosage

Half a teaspoon in water or orange juice once a day, on an empty stomach, either in the evening or before going to bed. The most ill patients may only manage a quarter teaspoon or less whereas the least ill patients may be able to work up to as much as 4 teaspoons a day. The sign of having taken too much Prime Directive is feeling extremely tired, due to toxin release. You should increase the dosage in a slowly controlled fashion, listening to your body and depending on how you are feeling. If you become particularly tired and think you may have taken too much prime directive, have a break for a couple of days and then restart it when you feel you are able.

Purpose

It has been found that in societies where people have not taken antibiotics each person has about 4 pounds of bacteria in their gut, as covered in the section on infections. These bacteria are responsible for many important functions that maximise gastrointestinal function and nutrient absorption.

As mentioned previously, many ME sufferers have taken antibiotics and other medication over the years that have killed these 'good' bacteria. By taking Prime Directive you can replace these bacteria. Prime Directive also contains the nutrients that are required for these 'good' bacteria to grow. The nutrients also help increase energy levels, as digestion is the most energy consuming function of the body. Prime Directive also reduces symptoms of irritable bowel syndrome, indigestion and candida and thrush.

Obtaining Prime Directive

Contact Safe Remedies on 01289 332888 to order by credit card (Quoting Equilibrium)

OTHER SUPPLEMENTS

The following supplements can be used for particular symptoms. You do not have to take them if you don't want to, it is up to you to decide whether you require them for your particular symptoms.

WELEDA GARGLE – NOT ESSENTIAL

Dosage

Gargle 3 times per day

Purpose

Mouth Ulcers are a common problem when the immune system is depleted. Many patients with ME suffer from them. Weleda gargle has been found to be very effective by many ME patients in the treatment of mouth ulcers.

Obtaining Weleda Gargle

You can buy Weleda Gargle at most good chemists and pharmacists.

ALOE VERA – NOT ESSENTIAL

Dosage

20mls liquid twice a day

Purpose

Aloe Vera is used to reduce inflammation to stimulate healing and detoxification at the cellular level. It can be taken orally or applied locally.

Obtaining Aloe Vera

You can buy Aloe Vera from any good quality health food shop or pharmacy. Many patients use the Forever Living brand, especially the Berry flavour.

Additional Supplements- NOT ESSENTIAL

Minerals and other nutrients will be dealt with later. After the circulation has been restored and the toxins have been removed is the best time to properly restore all the minerals and trace elements. However, the following supplements can be taken at this stage. As your health improves, absorption should increase. It is up to you whether you wish to start on these supplements at this stage – initially absorption may be limited, however when absorption improves, if you are already taking the supplements they will be quickly absorbed. Alternatively you can wait until the absorption has improved after a month on Prime Directive.

CALCIUM

Patients who have been very ill, had long periods in bed or had little physical activity lose calcium. Some females, especially around the time of the menopause can develop osteoporosis. Osteoporosis is more common in some families. If you are in this category and are not dairy product intolerant, then you must drink enough milk and eat enough cheese. You can also supplement with various over the counter calcium supplements, especially if you have dairy product intolerance. If there is an osteoporotic history or tendency your GP may prescribe calcium and vitamin supplementation on the NHS.

MAGNESIUM

Magnesium deficiency is very common in Britain due to it being deficient in our soil. Magnesium deficiency leads to increased muscle spasm, a greater tendency to palpitations or irregular heartbeat and, in women, to more painful periods due to uterine muscle cramping. Enough magnesium can greatly diminish muscle pains as you start to exercise more. It is best taken in chelated or colloidal form.

ZINC

Zinc is a crucial element in an effective immune system, especially in resistance to infection. Zinc is best taken in chelated form.

BORON

Women can be deficient in boron and it is believed by some doctors that boron deficiency increases the likelihood of needing a hysterectomy. If there is a family history of hysterectomy, boron supplementation might be helpful.

SELENIUM

Selenium is another mineral, which is deficient in British soil and is an essential trace element, especially for people with ME.

Dosage for all of the above supplements:

Whatever is advised as the maintenance dosage on the pack.

Please note: There is generally reduced absorption of minerals in ME.

Obtaining Supplements

The above supplements can be obtained at your local health store or good quality chemist or mail order.

BOOK LIST

Please note you can buy any of the books below from the links on our website www.cfs-me.com

The Sickening Mind

Paul Martin

Publisher: Flamingo

ISBN: 0-00-655022-3

Betrayal By the Brain

(Subtitled: The Neurological basis of CFS, Fibromyalgia Syndrome, and related Neural Network Disorders)

Dr. Jay A. Goldstein

Publisher: The Hawthorn Medical Press (1997)

ISBN: 1-56024-981-1

Comment: Dr Goldstein uses nimodipine and works on the brain function as well as the whole body. This book has 76 pages of medical references.

The Companion Volume to Dr Jay A Goldstein's Betrayal By the Brain for Patients and their Physicians

Katie Courmel

ISBN 0-7890-0119-5

Comment: This book includes a list of all the medication used by Dr. Goldstein. It is still a bit complicated to understand.

The Power of Now

Eckhart Tolle

Published by Hodder & Stoughton

ISBN 0 340 73350 0

The Clinical and Scientific Basis of Myalgic Encephalomyelitis- Chronic Fatigue Syndrome

Edited by Byron Hyde

Publisher: Nightingale Research Foundation

ISBN: 0-9695662-0-4

Comment: This is the definitive A4 sized 740 page book from 1992 with contributions from eighty specialists covering all aspects of CFS/ME. Even today, it is still the bible for those working in this field.

Dr. Mason Brown also recommends joining Action for ME, and receiving their magazine Inter Action. Their contact telephone number is: 01749 670 799.