Guildford M.E. Support Group

Newsletter

Winter 2007

Welcome back Hilary

We are pleased to announce that one of the founding members of the group, Hilary Adams, is re-joining the committee as a General Factotum. Hilary has had M.E. for over ten years, has a professional background in law and is a mother of two. In the short time Hilary has re-joined the group she has already raised £180 in support of the collaborative workshop at Southampton General Hospital, details of which are included on the next two pages.

New local Perrin practitioners

We are hoping that osteopaths/chiropractors from Dorking, Haslemere/Headley Down and Godalming will soon be trained and qualified in the Perrin Technique. If anybody is interested, please ring Alison Wallis on after 1st February 2008, when we should know who has completed the course and be able to provide associated contact information.

Future events

Afternoon meet - Friday 1st February – 3-5pm
The Seahorse, 52-54, The Street, Shalford, Guildford, Surrey, GU4 8BU
Shalford is about 1½ miles south of Guildford on the A281 (signposted as Horsham).

Collaborative workshop – Tuesday 12th February (time on ticket)
Southampton General Hospital
An overview of the collaborative workshop is provided on the next two pages.

Morning meet – Thursday 28th February – 10.30am

Morning meet – Wednesday 12th March – 10.30am
Mair Ellis has kindly offered to host a coffee morning for the group at her house.

Evening meet – Thursday 23rd April – 7.30pm
The Bridge Barn Pub, Bridge Barn Lane, Woking, Surrey, GU21 1NL
(Please refer to the summer 07 newsletter for directions)

Annual General Meeting - Friday 18th April – 7.30pm

Time for a change ?

Unfortunately, ME/CFS is still largely a mystery to modern medicine. “Due to a lack of knowledge of and research into the illness in the UK it exists somewhere between the schools of psychology and neurology. At present the only treatments are symptomatic and psychosocial” **

“There are 3 psychosocial therapies commonly used to treat CFS/ME in the UK” **. Cognitive Behavioural Therapy, Graded Exercise and Pacing. At best such therapies help a sufferer to manage the illness. At worst undue exercise makes the illness worse.

“It was estimated by the Chief Medical Officer’s Report in 2002 that there could be anything from 100,000 to **250,000** people suffering from CFS/ME in the UK.” ** “We do know that the £8.5 million ring fenced by the Department of Health for treating CFS/ME has been used to establish 13 treatment centres nationally. These new services expect to see **21,000** patients annually when working at full capacity” **.

A better way ?

There are a number of professors/doctors that have researched ME/CFS and have found significant biological findings and success at improving the lives of ME sufferers. The UK Government is working with such professors/doctors through the ‘2006 Gibson parliamentary report on ME’, however, it is unknown if/when services for the UK ME community will improve.

In an attempt to:
- improve awareness of the biological reality of ME; and
- explore accessible ways to help sufferers ‘today’;

a number of these professors/doctors are holding a workshop for GPs, Healthcare Professionals, Patients. Carers, Academics and lay people at Southampton General Hospital on Tuesday 12th February 2008 between 9am and 5pm.

A list of professionals/doctors is included below, and the official advert (with order form) is included on the following page. Ticket pricing is included on the order form and includes a buffet lunch. In addition to the listed speakers we have recently confirmed that Dr. Sarah Myhill (20yrs NHS and private practice) and Dr. Raymond Perrin (Osteopath and CFS specialist) will be participating.

Please show this information to your GPs and other such healthcare workers. It is most important to get health professionals to this significant event

SPEAKERS

Professor Martin Pall, Professor of Biochemistry – Basic Medical Science Washing State University	Converging mechanisms in the pathogenesis of ME/CFS and related conditions
Dr. Jonathan Kerr, Senior Lecturer, St George’s Hospital	New insights into ME (gene expression)
Dr. Russell Lane, Consultant Neurologist, Charing Cross Hospital	Peripheral components of ME (mitochondrial malfunction)
Dr. Byron Hyde, Founder of Nightingale Foundation, Canada	An understanding of ME/CFS through 20 years of clinical experience
Dr. Estabiliz Olano-Martin, Bilbao, Spain	Genetic profiles in aggressive forms of ME and Fibromyalgia
Professor Malcolm Hooper, Professor of Medicinal Chemistry, Sunderland University	Multiple chemical sensitivity
Dr. Adhihit Chaudhuri/Dr. Federico Roncaroli	A view of the neuropathology of ME/CFS
Professor Hugh Perry, Professor of Experimental Neuropathy, Southampton University	Systemic Inflammation of the brain
To name but a few…	

**** 2006 Gibson parliamentary report on ME**

Hampshire Solutions

The Alliance for Fibromyalgia, Myalgic Enchephalomyelitis and Chronic Fatigue Syndrome

An Invitation to Patients, Carers, GPs and Healthcare Professionals

Hampshire Solutions and Professor Stephen Holgate

(MRC Professor of Clinical Pharmacology, Southampton University)

Invite you to a

Collaborative Workshop

Seeking solutions for ME/CFS, FM and related conditions

A colloquium to raise awareness of recent research and
new approaches to diagnosis and management

'Putting the Patient at the Centre'

Tuesday 12th February 2008
Southampton General Hospital

- The aim of this event will be: to update, comprehend and explore the biomedical nature of ME/CFS, FM and related conditions.
- This groundbreaking event will be hosted by the world renowned immunologist **Professor Stephen Holgate** (BSc. MD. DSc. FRCP. FRCPE. FIBiol. FRCPath. FMedSci.)
- The conference is based on the recommendations from the Gibson Parliamentary Report of 2006 on ME and related conditions. Dr. Ian Gibson has a PhD in Genetics, MP for Norwich since 1997 and was Dean of the School of Biological Science UEA from 1991-1997.
- There will be world authorities in the field who have specialised in researching the nature of these conditions.
- If you are interested and would like to attend, please complete the booking form attached and return to the address below with the appropriate registration fee. Further details will be sent to you on receipt of this application.

CPD Validation/Accreditation (TBC)

Complete the form below and return to Fiona at
The Point of Health, 106 Winchester Road, Chandler's Ford, Eastleigh, Hants,
SO53 2GJ Tel: 023 8026 0227
Please make cheques payable to Alliance for FM, ME/CFS (Hampshire Solutions)

Collaborative Workshop (Solutions for ME/CFS, FM)

Tuesday 12th February 2008

Name: ……………………………………………………… Tel: ………………………………………………………

Address: …………………………………………………… Fax: ……………………………………………………..

………………………………………………………………. Email: …………………………………………………...

Please specify your area of interest: ………………………………………………………………………………...

Please specify any special dietary requirements: ……………………………………………………………………….

Please tick:
GPs and Health Care Professionals £50
Academics and Interested Lay People £35
Patients and Carers £20
Students free

The Point of Health, 106 Winchester Road, Chandler's Ford, Eastleigh, Hants, SO53 2GJ Tel: 023 8026 0227

Perrin Technique lecture

On Wednesday 21st November, at the Guildford Institute, Dr Raymond Perrin provided a lecture about his unique treatment for M.E. – ‘The Perrin Technique’. The following overview of the lecture is not intended to be a comprehensive representation of the lecture but rather an insight for those who were unable to attend. A more in-depth understanding of the technique is available from Dr. Perrin’s recent book - “The Perrin Technique: How to Beat Chronic Fatigue Syndrome/ME”.

1. How it all began

18 years ago a top cyclist in the northwest of England had to give up cycling because he was struggling with both M.E. and back problems. Dr. Perrin, as an osteopath, treated the cyclist’s upper back and found that over the course of a few weeks the cyclist’s M.E. was also improving. A few months later the cyclist told Dr. Perrin that he was recovered from his M.E.

Over time Dr. Perrin noticed that many of his patients that had M.E. also had upper back/thoracic spine problems. Dr. Perrin knew that problems in the upper back may affect the sympathetic nervous system which is situated along the spine. The investigation into M.E. had begun.

2. Background information

In order to explain M.E. and the Perrin Technique certain background information is important to understand. As such, Dr. Perrin provides an overview of:

- the sympathetic nervous system;
- cerebral spinal fluid;
- the cribriform plate;
- the lymphatic system; and
- the hypothalamus.

2.1 Sympathetic nervous system

In order to explain the sympathetic nervous system, Dr. Perrin used the analogy of a power station. Before a power station can deliver energy to electrical appliances in a house it must first use a transmission station to direct the energy where it is needed. In the body the power station is represented by food and oxygen, electrical appliances are muscles and internal organs and the transmission station connecting the two, is the sympathetic nervous system.

Power station (food and oxygen)

↓

Transmission station (sympathetic nervous system)

↓

Electrical appliances (muscles and internal organs)

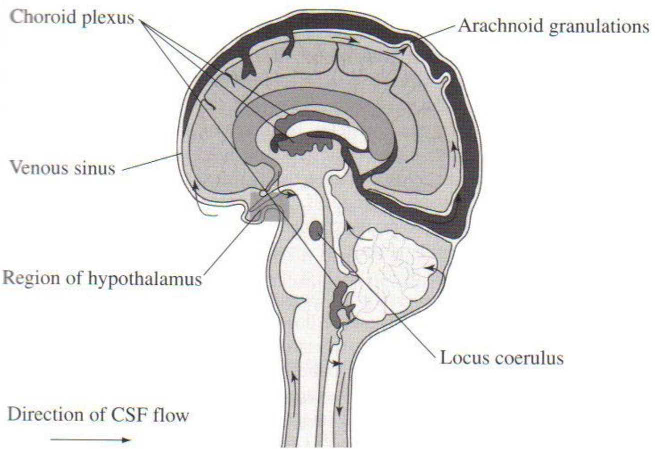
As illustrated above, the job of the sympathetic nervous system is to control the level of energy for muscles and internal organs. In M.E. the process is unregulated and, as a result, the M.E sufferer experiences bodily functions that are out of balance e.g. (too hot, too cold, too sweaty, not sweaty enough, cold feet but warm hands).

2.2 Cerebral spinal fluid

Cerebral spinal fluid is a protective layer of fluid around the brain and spine that provides nutrients to, and removes toxins from, the brain and central nervous system.

The diagram to the right uses small arrows to indicate the flow of the cerebral spinal fluid.

The fluid goes up and down the spine and around the brain and drains through the venous sinus into the blood.

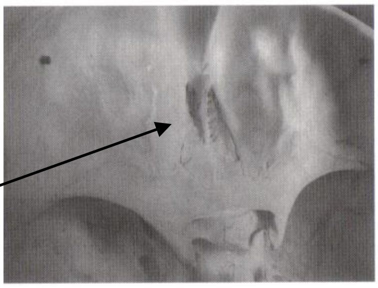


Although most doctors would be unaware of it, there is another drainage which is in to the lymphatic system through the spine and blood vessels of the optic, trigeminal, auditory and olfactory nerves.

The primary lymphatic drainage is via the blood vessels of the olfactory nerves which go through the cribiform plate.

2.3 Cribriform plate

The cribiform plate is a perforated part of the skull situated above the nose that allows passage of olfactory nerves which transmit the sense of smell to the brain from the nose. The blood vessels of the olfactory nerves allow drainage of cerebral spinal fluid into the lymphatic system.



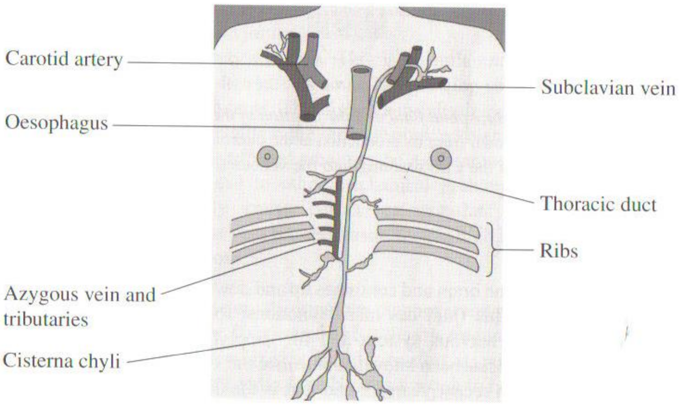
Cribiform plate

2.4 The lymphatic system

The primary system for collecting toxin from around the body and delivering it to the liver, for processing, is the blood. It is the fine veins of the body called the capillaries that collect the toxin. Capillaries are particular about the type of toxin that they collect. By filtering the collection of toxin the capillaries ensure that only toxin with small molecules is collected. It is the function of the lymphatic system to collect toxins with large molecules. The lymphatic system is a network of tubes throughout the body similar to that of the veins. The core of the lymphatic system is the thoracic duct, as shown in the diagram below, which travels from about waist level to the collar bone.

The thoracic duct delivers the body’s lymphatic fluid and large molecule toxins to the blood system at the subclavian vein. The lymph fluid and toxins then travel via the heart to the liver where the toxins are broken down for disposal from the body.

The thoracic duct has a thin wall of muscle that pumps the lymph fluid at four beats per minute to the subclavian vein.



2.5 The hypothalamus

The hypothalamus is part of the brain that controls the sympathetic nervous system and hormones of the body. To be able to control the hormones of the body the hypothalamus uses ‘biofeedback’ where the levels of hormones in the blood are tested. Because of the requirement to access the blood, to test hormone levels, the hypothalamus is the only part of the brain not protected by the blood brain barrier. As such the hypothalamus is a weak point of the brain where toxins can enter, which means that it is particularly affected by toxicity in the body.

3. What goes wrong

3.1 Drainage of cerebral spinal fluid is poor in the spine and cribriform plate.

With the condition known as M.E. the suffer has poor drainage of cerebral spinal fluid in both the spine and cribiform plate. The poor drainage may be due to localised injury or deformity of the drainage areas.

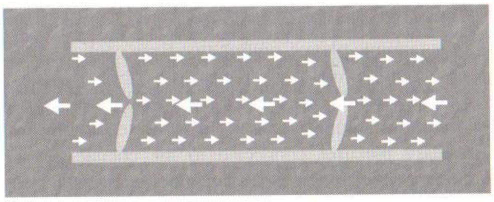
As a result of the poor drainage toxins are present in the brain at un-natural levels which, due to its biofeedback mechanism as described in section 2.5, affects the hypothalamus in particular.

Also mentioned in section 2.5, the hypothalamus controls the sympathetic nervous system (section 2.1) which in turn controls the thoracic duct (section 2.4). Therefore as the hypothalamus’ function deteriorates with the toxic build up in the brain the pumping action of the thoracic duct malfunctions.

The thoracic duct malfunction means that lymph fluid and toxins are no longer being delivered to the blood for expulsion from the body but instead build up in the body. The build up of toxins affects the hypothalamus further resulting in a cycle of dysfunction.

Evidence of the thoracic duct malfunctioning is seen by sufferers experiencing varicose lymphatics. Normally lymphatic tubes in the body have valves that only permit travel of lymph fluid in one direction.

In varicose lymphatics the backflow caused by the thoracic duct pumping incorrectly breaks the valves causing them to allow lymph flow in both directions, as depicted on the right.



In extreme cases the swollen varicose lymphatics can be seen with the eye. Typically, the varicose lymphatics can be felt by a professional beneath the skin.

3.2 Sensitivity to stress

As mentioned above, an M.E. sufferer experiences a build up of toxins in the brain which particularly affects the hypothalamus. Because 80% of the sympathetic nervous system function is sensory, receiving information from the body, as the body experiences stress (emotional, physical, chemical, pollution) it affects the hypothalamus via the sympathetic nervous system. Both good and bad stress affects the hypothalamus. Often, for example, M.E. sufferers are very symptomatic after the Christmas period.

3.3 Cytokine toxicity

As a normal process of the immune system when a virus, for example, invades the body chemicals called cytokines attach to the viruses as markers for the antibodies of the immune system. Once the virus has been destroyed the cytokines need to be decommissioned otherwise they will cause the immune system to damage healthy cells. Because cytokines are large molecules they need to be decommissioned by the lymphatic system. In an M.E. patient the lymphatic system is not draining properly so the cytokines end up in the brain and spinal cord where further damage is done.

4. Treatment

The Perrin Technique treatment is a combination of massage and osteopath techniques that help to drain toxins away from the brain and spine and stimulate the healthy flow of lymphatic and cerebrospinal fluid. The technique reduces strain on the sympathetic nervous system helping to reverse the M.E. condition.

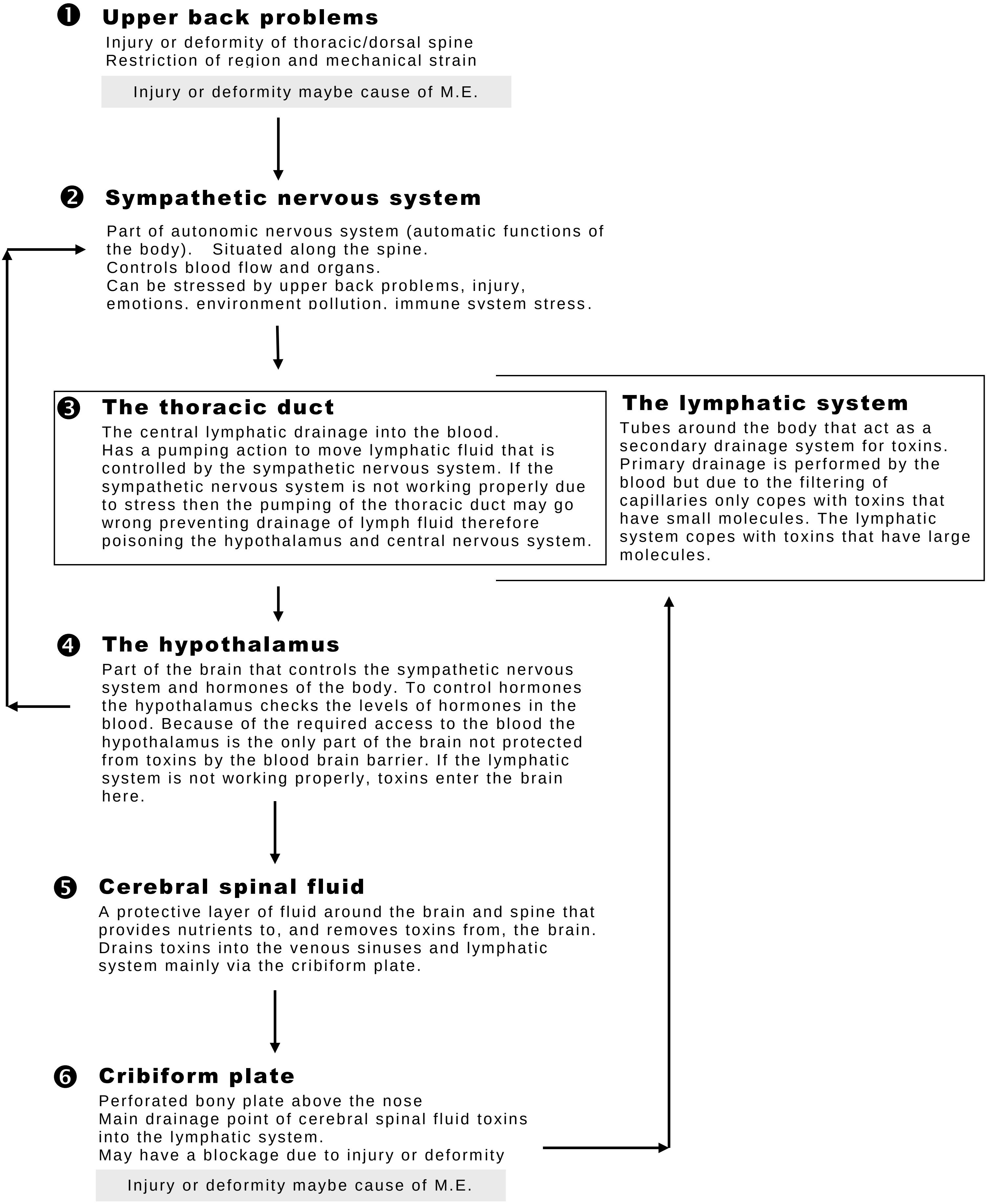
5. Further information

A diagram that attempts to explain Dr. Perrin’s concept of M.E. is included on the following page.

For a more comprehensive and in-depth understanding of The Perrin Technique please read Dr. Perrin’s recently released book “The Perrin Technique: How to Beat Chronic Fatigue Syndrome/ME” which is available from general book stores. The book price on amazon is £11.49 + postage.

Please also refer to the Perrin website: www.theperrinclinic.com

Diagram 1 – The Perrin M.E. concept



❶ Upper back problems

Injury or deformity of thoracic/dorsal spine
Restriction of region and mechanical strain

Injury or deformity maybe cause of M.E.

❷ Sympathetic nervous system

Part of autonomic nervous system (automatic functions of the body). Situated along the spine.
Controls blood flow and organs.
Can be stressed by upper back problems, injury, emotions, environment pollution, immune system stress.

❸ The thoracic duct

The central lymphatic drainage into the blood.
Has a pumping action to move lymphatic fluid that is controlled by the sympathetic nervous system. If the sympathetic nervous system is not working properly due to stress then the pumping of the thoracic duct may go wrong preventing drainage of lymph fluid therefore poisoning the hypothalamus and central nervous system.

The lymphatic system

Tubes around the body that act as a secondary drainage system for toxins. Primary drainage is performed by the blood but due to the filtering of capillaries only copes with toxins that have small molecules. The lymphatic system copes with toxins that have large molecules.

❹ The hypothalamus

Part of the brain that controls the sympathetic nervous system and hormones of the body. To control hormones the hypothalamus checks the levels of hormones in the blood. Because of the required access to the blood the hypothalamus is the only part of the brain not protected from toxins by the blood brain barrier. If the lymphatic system is not working properly, toxins enter the brain here.

❺ Cerebral spinal fluid

A protective layer of fluid around the brain and spine that provides nutrients to, and removes toxins from, the brain. Drains toxins into the venous sinuses and lymphatic system mainly via the cribiform plate.

❻ Cribiform plate

Perforated bony plate above the nose
Main drainage point of cerebral spinal fluid toxins into the lymphatic system.
May have a blockage due to injury or deformity

Injury or deformity maybe cause of M.E.

You Know You Have M.E. When . . .

You know you have M.E. when you realize that caution is the only thing you care to exercise.

You know you have M.E. when getting lucky means you found your car in the parking lot.

You know you have M.E. when you're sitting in a rocker and you can't get it started.

You know you have M.E. when you wake up with that morning-after feeling, and you didn't do anything the night before.

You know you have M.E. when you know how to spell gastroenterologist, chiropractor, etc.

You know you have M.E. when you have to sit down to brush your teeth in the morning.

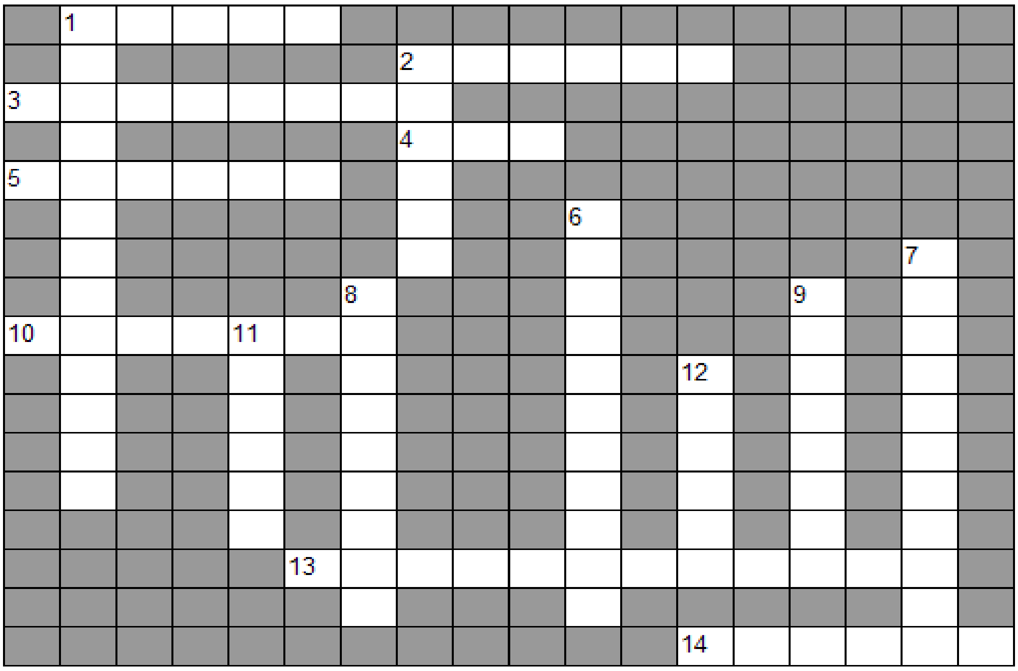
You know you have M.E. when you can't finish a conversation, because you don't remember what you were talking about.

You know you have M.E. when you boil the kettle dry three times to get one cup of tea.

You know you have M.E. when you feed the dog twice, because she has learned how to trick you into thinking you forgot.

M.E. is having a choice of two temptations and choosing the one that will get you home earlier.

M.E. crossword



ACROSS

1. a popular energy supplement for ME
2. a massage type technique for ME
3. a particularly frustrating symptom of ME
4. another acronym for ME
5. a supplement for ME that helps with brain fog
10. the main symptom of ME
13. a painful version of ME
14. affected by ME that may cause undue repetition

DOWN

1. can cause onset of ME symptoms difficult to maintain
2. a popular strategy for ME
6. a UK ME charity
7. name of a virus suspected as a cause/trigger of ME
8. helps with sleep
9. an ME symptom that can cause anxiety
11. often swollen during ME
12. nickname given to the CDC criteria for a CFS diagnosis

Answers will be included in our Spring newsletter

Caring for a person with M.E.

A carer is someone who, without payment, provides help and support to a partner, child, relative, friend or neighbour who could not manage without their help.

Caring for a person who has M.E. can be a difficult job. Just as the person with M.E. has to come to terms with their illness and limitations, so the carer suddenly has to face their own limitations and how to cope. Taking on a caring role can mean loss of freedom and choice, frustration, isolation and financial difficulties. M.E. can be one of the hardest illnesses there is to cope with, both for the sufferer and the carer. The illness itself is very variable and while some may be able to work for several hours a day, others can be very seriously affected and need full time care. The problems you face as a carer will also vary, and for each carer they will be different.

Caring isn't just about providing physical help but involves emotional support and encouragement as well. Your life may be very different for quite a while. In addition you may find that your relationship with the person you care for has changed. You are now their carer as well as a partner, sister, brother, mother or father. So how do you stay sane and manage the stress of caring? Very often, the first step is in recognising that it is actually okay to have needs. Becoming a super carer isn't always the best route in the long run, and investing in your own care is vital if you want to be a well and contented carer.

It will really help if you can try to:

- keep your own personal networks going and take time out to enjoy them;
- ask for help when you feel you need it;
- take each day as it comes – good or bad;
- look for help and support services locally such as social services, carers support organisations and local support groups; and
- stay as positive as you can.

It is important to get the support you need as a carer. Make sure that you:

- Tell your GP that you are a carer and ask them to write the details on your notes. Your GP should make sure that you have a regular health check. A good GP can be the gateway to getting all kinds of help, such as counselling, other medical services and referrals to your local Social Services.
- Turn to family and friends for support. It is important that you do not cope alone, as this can impact on your own health. Speak to them and make sure that they know the extent of your caring role. Many family members and friends may not realise the level of care that you are providing, they may be embarrassed or don't want you to think that they are interfering. Other people may be reluctant to ask if you need help in case you get hold of the wrong end of the stick and think they are saying that you can't cope. Sadly, some people don't know how to react to illness or disability and they find it awkward, so the onus might be on you to make the first move.
- Ask your GP to refer you to your local Social Services or you can call them directly and speak to them about your role as a carer. Social Services are a part of your local council and provide a range of services to carers and people with disabilities. As a carer you are entitled to a carer's assessment, which looks at your needs and how you, as a carer, can be supported. They can provide replacement care to give you a break, help with aids and adaptations to make life easier or simply be a back up in an emergency. They can also give you cash to sort things out yourself (this is called a Direct Payment). Even if you choose not to have a carer's assessment, it is advisable to let Social Services know that you are a carer, should a time arise when you need urgent assistance.

- Make sure that you claim your entitlements. The benefits system is complex and many people who are new to caring are unsure what they should be claiming. Many people are put off claiming by means testing or complicated forms, but the benefits system is there to help and you are entitled to claim. There are a number of benefits available to carers and one of the most important things is to ensure that you have the relevant information. You may be able to get Council Tax reductions or help with prescriptions as well.

If you are new to caring for a person with M.E. it will help if you understand M.E. itself and how a person with M.E. may be feeling…

- M.E. is a disabling illness although the visible signs and restrictions that people normally associate with being disabled are sometimes absent
- Some people with M.E. often look well
- M.E. can be characterised by severe fatigue that is made worse by minimal physical or mental exertion
- The severity of M.E. varies between people. The symptoms a person with M.E. has can vary from day to day and indeed throughout the day.
- M.E. can, on occasion, vary quite suddenly from near normal to sheer exhaustion. The onset of other symptoms can come on just as suddenly.
- Both physical and mental activity can bring on symptoms.
- The physical symptoms of M.E. vary between sufferers.

You may be asking yourself how can you best help a person with M.E.? Should you encourage activity or rest? How hard or kind should you be? How best can you express sympathy or understanding?

Try to understand how the person with M.E. is feeling both emotionally and physically. Showing a person you understand can help them enormously. It is important with M.E. to understand the limitations of the illness. This can be difficult because the symptoms of M.E. can vary from day to day and throughout the same day. Encouragement to do a little but not too much is best, watching for signs of fatigue. Pacing is very important – a little activity and a little rest. If a person overdoes things then the symptoms may not show up for a couple of days, or the symptoms can worsen very quickly – almost like switching a light off or pulling a plug out.

It is best to discuss between you what kind of help is needed. Sometimes, it can be good to ask "Shall I help?" or "If that feels a little much for you, have a rest and I'll help you finish it later".

There may need to be very different strategies if the person with M.E. cannot manage very much at all physically. Just some reassurance that you are there to help and will understand when they cannot do any more or are getting too tired, is often enough.

Where a person with M.E. hasn't been used to asking for any assistance in the past, it may be difficult for them to accept help now. They may resent having to rely on you and you may find it is hard reorganising your life around them. This is where the importance of agreeing help between you both comes in. Equally importantly, you must look after yourself. If you become exhausted, frustrated or depressed, you won't be able to give your full support.

For some people with M.E., it may be that short gentle strolls are possible but not a day's walking in the hills. Life will change – small amounts of energy may be possible, perhaps only once or twice a day and certainly with rest breaks built in. However, for those who are more severely affected, it is likely to be difficult (or impossible) to plan even a small stroll. For some, holidays and social events may become a thing of the past for a while or they may need careful planning with an understanding that sometimes planned events may need to be cancelled.

Those who are severely affected with M.E. may need full-time care. This can be a very difficult task and it can turn your lives upside down both physically and emotionally. Whatever you are feeling is likely to be normal and very understandable. It is easy to give up hope when someone has been ill with M.E. for several years and becomes convinced that they are never going to get better. Even so, many people do improve, sometimes after quite a long period of ill health, and gradually return to a more normal way of life.

You may like to read “The Selfish Pig’s Guide for Carers”. Although Hugh Marriott’s wife has Huntingdon’s disease and not M.E., the book is about ‘caring’. About how it feels, how to cope and how to forgive yourself when you feel selfish or guilty. The author does not pull any punches and tells it ‘like it is’ but with some humour. Hugh Marriott looks at the advice he would like to have been given when he was struggling.

Finally, do remember that talking to friends, family and other carers can be very helpful. It is important to express the loneliness, isolation, frustration and sometimes anger you may feel. Talking to the person you are caring for can really help too. Try to share your anxieties and difficulties and remember that although life may be very different for a while, there can still be happiness and laughter between you both.