



## **ME/CFS and Sleep: Managing a Free-Wheeling Brain for Needed Repair**

by Dr. Sarah Myhill, MD\*

April 14, 2010

"Often ME/CFS patients get into a bad rhythm of poor sleep at night, which means they feel ill for the day, which means they get another bad night. They are half asleep by night and half awake by day. Furthermore, their natural time for sleep gets later and later. They go to bed late and if they have to get up at the usual time, chronic lack of sleep ensues."

### **You Must Sleep - Time for Service and Repair**

All animals, even bacteria, need a time to shut down normal metabolism for the processes of healing and repair. All higher animals do this during sleep. If you get insufficient sleep, your health will gradually ratchet downhill as there is more time for damage to take place and less time for healing and repair.

Humans evolved to sleep when it is dark and wake when it is light. Sleep is a form of hibernation when the body shuts down in order to repair damage done through use, to conserve energy and hide from predators. The normal sleep pattern that evolved in hot climates is to sleep, keep warm and conserve energy during the cold nights and then sleep again in the afternoons when it is too hot to work and hide away from the midday sun. As humans migrated away from the Equator, the sleep pattern had to change with the seasons and as the lengths of the days changed.

### **Get the Hours of Sleep**

People needed more sleep during the winter than in the summer in order to conserve energy and fat resources. Furthermore during the summer humans had to work long hours to store food for the winter and so dropped the afternoon siesta. But the need for a rest (if not a sleep) in the middle of the day is still there.

Therefore it is no surprise that young children, elderly and people who become ill often have an extra sleep in the afternoon and for these people that is totally desirable. Others have learned to 'power nap', as it is called, during the day and this allows them to feel more energetic later. If you can do it then this is an excellent habit to get into – it can be learned!

The average daily sleep requirement is nine hours, ideally taken between 9:30 pm and 6:30 am, i.e., during hours of darkness, but allow for more in the winter and less in the summer. *An hour of sleep before midnight is worth two after* – this is because human growth hormone is produced during the hours of sleep before midnight.

To show how important the balance of hours of sleep and rest are, divide the day into 12 hours of activity and 12 hours of rest. If you have one extra hour of activity (13 hours), you lose an hour of rest and sleep (11 hours). The difference is two hours!

### **Sleep When It Is Dark**

Light on the skin prevents the production of melatonin, which is the sleep hormone essential for a good night's sleep. Therefore, the bedroom should be completely blacked out and quiet in order to give the best chance of quality sleep. Even people who are born blind still have a day night rhythm – it is light landing on the skin which has the effect – just closing your eyes will not do it!

A study done in 1907 before electricity was available showed that people went to bed when it got dark and rose when it got light. On average through the year they got 9 hours sleep, more in winter, less in summer. Nowadays we average 7 and a half hours of sleep – we are losing on average 550 hours of sleep a year!

Loss of sleep is a major risk factor for heart disease, cancer and degenerative conditions. We damage our cells during waking hours, and heal and repair during sleep – get the balance wrong and one ratchets downhill with time with not enough time to heal and repair the damage created during wakeful

hours!

### **Sleep is Essential for Life**

After the First World War a strain of Spanish 'flu swept through Europe killing 50 million people worldwide. Some people sustained neurological damage and for some this virus wiped out their sleep center in the brain. This meant they were unable to sleep at all. All these poor people were dead within 2 weeks, and this was the first solid scientific evidence that sleep is as essential for life as food and water. Indeed all living creatures require a regular "sleep" (or period of quiescence) during which time healing and repair takes place.

You must put as much work into your sleep as your diet.

### **Understand the Phenomenon of Sleep Waves**

The desire for sleep does not come up and up slowly through the evening. It comes in waves. We get a sleep wave every 90 minutes. Work out from when you do drop off to sleep when your wave occurs. For example, if you drop off now at 11 pm, you have missed the 9:30 wave.

Once you start to look for the wave it is very obvious!

Again, if you nod off in front on the TV at 8 pm, that tells you when your sleep wave has come. Get into bed before the sleep wave, recognise it, lights out, then "ride the wave" with your sleep dream.

### **First, Get the Physical Essentials in Place**

We are all creatures of habit and the first essential is to get the physical essentials in place.

- A regular pre-bedtime routine - your "alarm" should go off at 9 pm, at which point you drop all activity and move into your bedtime routine.
- A regular sleep time so you ride the sleep wave.
- Learn to recognise the sleep wave.
- A busy day with the right balance of mental and physical activity.
- Not having a bed fellow who snores.
- Small carbohydrate snack just before bedtime (such as nuts, seeds) helps prevent nocturnal [hypoglycemia \(low blood sugar\)](#), which often manifests with vivid dreams or sweating or waking in the night. [And could be the cause of menopausal sweating.]
- Perhaps restrict fluids in the evening if your night is disturbed by the need to pee.
- No stimulants such as caffeine or adrenaline inducing TV, arguments, phone calls, family matters or whatever before bedtime! Caffeine has a long half life – none after 4 pm.
- Dark room - *the slightest chink of light landing on your skin will disturb your own production of melatonin* (the body's natural sleep hormone). Have thick curtains or blackouts to keep the bedroom dark – this is particularly important for children! Do not switch the light on or clock watch should you wake.
- A source of fresh, preferably cold, air.
- A warm comfortable bed - we have been brainwashed into believing a hard bed is good for you and so many people end up with sleepless nights on an uncomfortable bed. It is the shape of the bed that is important. It should be shaped to fit you approximately and then very soft to distribute your weight evenly and avoid pressure points. Tempur® mattresses can be helpful (if expensive), as are water beds.

### **Address Other Factors Known to Disturb Sleep**

1. If your sleep is disturbed by sweating, then this is likely to be a symptom of *low blood sugar*.
2. Another common cause of disturbed sleep is *hyperventilation*, which often causes vivid dreams or nightmares. (See "[Hyperventilation, makes you feel as if you can't get your breath](#)"). This can now be tested for by measuring a red cell carbonic anhydrase. However

I often use a benzodiazepine [a "minor tranquilizer"] such as diazepam 2-5mgs at night which reduces the sensitivity of the respiratory center.

3. If sleep is disturbed by *pain* then one must just take whatever pain killers are necessary to control this. Lack of sleep simply worsens pain.

4. If one wakes in the nights with symptoms such as asthma, chest pain, shortness of breath, indigestion, etc. then this may point to *food allergy* being the problem, with these withdrawal symptoms occurring during the small hours.

5. Some people find *any food* disturbs sleep and they sleep best if they do not eat after 6 pm.

If you do wake in the night do not switch the light on, do not get up and potter round the house or you will have no chance of dropping off to sleep. Learn a "sleep dream" to train the subconscious to switch on the sleep button!

### **The Commonest Cause of Disturbed Sleep in the Night is Hypoglycemia**

Once the [Stoneage Diet](#) is established, this often helps considerably with sleep, but in the meantime have a snack last thing at night (e.g., nuts and seeds with a small piece of fruit) and if disturbed maybe eat again in the night.

### **Recognize the Sleep Wave**

Actually sleep does not gradually creep up on us during the evening – it comes in waves. There is a sleep wave about every 90 minutes and you will get to sleep most efficiently if you learn to recognize and ride the sleep wave.

Often there is a lesser one earlier in the evening when people drop off to sleep in front of the telly, or they jump and make a cup of tea to wake themselves up because "they are not ready to go to bed" – actually they are!

My sleep wave comes at 9.20 and I like to be in bed reading well before this – it is immediately recognizable now I have learnt to expect it!

### **Get the Brain Off to Sleep**

Getting the physical things in place is the easy bit. The hard bit is getting your brain off to sleep. I learned an astonishing statistic recently - which is that throughout life, the brain makes a million new connections every second! This means it has a fantastic ability to learn new things. This means it is perfectly possible to teach your brain to go off to sleep, it is simply a case of pressing the right buttons.

*Getting off to sleep is all about developing a conditioned reflex.* The first historical example of this is Pavlov's dogs. Pavlov was a Russian physiologist who showed that when dogs eat food, they produce stomach acid. He then "conditioned" them by ringing a bell whilst they ate food. After two weeks of conditioning, he could make them produce stomach acid simply by ringing a bell.

This of course is a completely useless conditioned response, but it shows us the brain can be trained to do anything.

Applying this to the insomniac:

1. Firstly, he has to get into a mind-set which does not involve the immediate past or immediate future. That is to say if he is thinking about reality then there is no chance of getting off to sleep - more of this in a moment.
2. Then he uses a hypnotic medication (see below) which will get him off to sleep.
3. He applies the two together for a period of "conditioning." This may be a few days or a few weeks.
4. The brain then learns that when it gets into that particular mindset, it will go off to sleep.
5. Then the drug is irrelevant.

However, things can break down during times of stress, and a few days of drug may be required to reinforce the conditioned response. But it is vital to use the correct "mind-set" every time the drug is

used, or the conditioning will weaken.

I do not pretend this is easy, but to allow one's mind to wander into reality when one is trying to sleep must be considered a complete self-indulgence. It is simply not allowed to free-wheel. Treat your novelty seeking brain as you would a naughty, recalcitrant, undisciplined child.

### Find a Sleep Dream that Suits You

Everyone has to work out their best mind-set. It could be a childhood dream, or recalling details of a journey or walk, or whatever. It is actually a sort of self hypnosis. What you are trying to do is to "talk" to your subconscious. This can only be done with the imagination, *not with the spoken language*. [For a step-by step explanation, see the final section of this article - "Self Hypnosis - Like Learning To Drive With A Clutch" - which offers excerpts from a book on self hypnosis.]

### Use Medication to Reinforce the Sleep Dream

I instinctively do not like prescribing drugs. However, I do use them for sleep, in order to establish the above conditioning and to restore a normal pattern of sleep, after which they can be tailed off or kept for occasional use.

Indeed, viruses can cause neurological damage (for example polio) and this could involve damage to the sleep center. CFS patients often get into a bad rhythm of poor sleep at night, which means they feel ill for the day, which means they get another bad night. They are half asleep by night and half awake by day. Furthermore, their natural time for sleep gets later and later. They go to bed late and if they have to get up at the usual time, chronic lack of sleep ensues. There is now evidence that the biological clock is dependent on normal adrenal function - and we know this is suppressed in CFS.

So often some medication is needed to facilitate sleep.

### The Personal Sleep Support 'Starter Pack'

Most CFS patients react badly to drugs in normal doses. I like to use combinations of low dose herbals, natural remedies and prescribed drugs to get the desired effect. Everybody works out his or her own cocktail which suits. This may have to be changed from time to time. I like to supply a "starter pack" which has a selection of hypnotics to try [as outlined below, the supplements melatonin and valerian root, and the over-the-counter sedating antihistamine Nytol®].

Please note that I am only able to prescribe the sleeping drugs, and any other medication listed in this booklet to my patients and not members of the public. But anybody can purchase and use melatonin, valerian and Nytol.

I am always asked about addiction. My experience is that this is rare, especially if drugs are used as above to develop a conditioned reflex. One has to distinguish between *addiction* and *dependence*. We are all dependent on food, but that does not mean we are addicted to it. We are all dependent on a good night's sleep for good health and may therefore become dependent on something to achieve that. This does not inevitably lead to addiction.

Addiction is a condition of taking a drug excessively and being unable to cease doing so without other adverse effects. Stopping your hypnotic may result in a poor night's sleep but no more than that. This is not addiction but dependence.

### Beginning With Natural Preparations to Help Sleep

These all work differently and so I like to use low dose combinations until you find something that suits. Choose from the following, and start with:

- **Melatonin** 3mgs (one tablet) at night. Some people just need 1mg. CFS patients have a poor output of hormones from all their glands - namely the hypothalamus, pituitary, adrenals, thyroid and also the pineal gland. The latter is responsible for producing melatonin, the natural sleep hormone. It seems logical to me therefore to try this first. One or two of my patients have become depressed with melatonin, so be aware of this. On the container it also states melatonin should be avoided in autoimmune disorders, but I can find no reason why this should be so.
- **Valerian root** 400 mg 1-4 capsules at night. This is an herbal preparation which is shorter acting and can be taken in the middle of the night.
- **Nytol (diphenhydramine)** 50mg. This is not a supplement, but a sedating

antihistamine available over the counter. This is longer acting – don't take in the middle of the night or you will wake feeling hung-over. [It is "potentially dangerous" taken with alcohol.] **Nytol Herbal** is a different product that includes hops, valerian and passion flower.

My standard herbal "starter pack" consists of:

- Nytol Herbal one a night (8 tablets)
- Melatonin 3 mgs (20 tablets)
- Valerian complex (30 tablets)

### Prescription Drugs, Starting With Sedating Antidepressant

If there is no improvement with a combination of the above, or if there are intolerable side effects, then I would go on to a prescribed drug. I usually start with one of the sedating antidepressants such as:<

- **Amitriptyline** 10mgs - 25mgs. I would start with 5mg initially. Most CFS patients are made worse and feel hung-over with "normal doses".
- I do not prescribe **dothiepin** now because a study suggested that this had an increased risk of cardiac dysrhythmias compared to other tricyclic antidepressants.
- **Surmontil** 10-30mgs at night.
- **Short acting temazepam** 10mgs. This is useful but recently has been made a controlled drug so doctors are understandably twitchy about prescribing it. It is controlled because some drug addicts were taking the gel and injecting it into themselves. Nowadays I tend to use instead **zaleplon (Sonata®)** or medium acting **zopiclone (Zimovane®) 7.5mg**.
- **Diazepam** is helpful if sleep is disturbed either because of hyperventilation (it reduces the respiratory drive) or for muscle spasms (it is a good muscle relaxant).

Different people will respond to different combinations of hypnotics. For example, one person may take a melatonin and two valerian at night, plus a zaleplon when they wake at 3.00am. Somebody else may be best suited by 10 mg amitriptyline at night with a Nytol. Don't be afraid to try combinations - there are no serious side effects that I am aware of with any of these used in combination. However, *don't change more than one thing at any time* otherwise you (and I) will get confused!

One of my patients has found [a wrist band that presses on the acupressure point on the wrist] very helpful.

### If You Find Your Dose Creeping Up...

If you find your dose of hypnotic is gradually creeping up, then this may be because you have become less disciplined about establishing the conditioned reflex. Go back to the basics as above.

The deal is that every time you take a tablet for sleep you must work hard on the self hypnosis methods in order to condition yourself to sleep! We all are given the gift of sleep as babies, then unlearn it! It is perfectly possible to relearn sleep!

When your normal sleep pattern has been restored you can begin to reduce or tail off completely your hypnotic medication, but only if good quality sleep can be maintained. Use the hypnosis "sleep dream" techniques every time you try to go to sleep, even when your sleep is disturbed by the need to pee – eventually your brain will learn! If your sleep begins to suffer, you must go back on the medication that worked before because the need to sleep is of paramount importance in CFS patients.

Every time you have a bad night you "unlearn" how to sleep. It is vital to keep working on the sleep dream every time you go to sleep.

### Other Causes of Poor Sleep: Get the Right Hormonal Balance

**Hypoglycemia** is the main cause

**Menopausal sweating** - I am increasingly coming to the view that this is a symptom of low blood sugar – see Hypoglycemia.

**High levels of DHEA** mean low levels of melatonin. Check this with an [Adrenal Stress Profile](#) (salivary)

**Hypothyroidism** - can certainly present with insomnia

**Hyperventilation** – “Makes you feel as if you can’t get your breath”

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**Self Hypnosis** – “Like Learning To drive With a Clutch”

The following is lifted from a book on self hypnosis which works for some:

"We know that the hypnotic state is characterized by extreme responsiveness to suggestion. You can use this information for conditioning yourself in self hypnosis. Here is a standard procedure to follow.

1. Lie down in bed, ready for sleep initially with your eyes open (the room needs to be dark). Mentally give yourself the suggestion that your eyes are becoming heavy and tired. Give yourself the suggestion that as you count to 10 your eyes will become very heavy and watery and that you will find it impossible to keep your eyelids open by the time you reach 10. If you find that you cannot keep them open and have to close them, then you are probably under self- hypnosis.
2. At this point deepen the state by again slowly counting to 10. Between each count mentally give yourself suggestions that you are falling into a deep hypnotic state. Give yourself suggestions of relaxation. Try to reach a state where you feel you are about to fall asleep. Give yourself the suggestion that you are falling more deeply down into sleep. Some may get a very light feeling throughout the body; others may get a heavy feeling.
3. Let us assume that your eyes did not become heavy. Then repeat the procedure. You can count to 100 if you need this period of time to assure an eye closure. The closing of the eyes is the first sign you are in a receptive frame of mind. Let us assume that you get the eye closure. Take a longer count to get yourself in the very relaxed state. Once you achieve this you should be able to respond properly. The difficult bit is not allowing your brain to wander off into other areas. You must work hard at concentrating on the counting and the responses that achieves.
4. If you respond properly, give yourself the “post-hypnotic suggestion” that you will be able to put yourself under later by counting to three, or using any specific phrase you desire.
5. Continue using it every day and give yourself the post hypnotic suggestion every time you work with it, that at each succeeding session you will fall into a deeper state and that the suggestions will work more forcefully with each repetition.

Each time that you work towards acquiring the self-hypnotic state, regardless of the depth that you have achieved and whether or not you have responded to any of the tests, give yourself the following suggestions: “The next time I hypnotize myself, I shall fall into a deeper and sounder state.” You should also give yourself whatever suggestions you desire as though you were in a very deep state of hypnosis.

You may ask "If I'm not under hypnosis, why give myself the suggestions?" You do this so that you will begin to form the conditioned reflex pattern. Keep at it. One of the times that you work at achieving self-hypnosis the conditioned response will take hold... you will have self hypnosis from that time on.

It is like learning to drive a car with a clutch. At first you must consciously go through the process of putting your foot on the clutch and shifting gears. Usually there is a grinding of the gears and you feel quite conspicuous about this, but gradually you learn to do this almost automatically and you gain confidence in your driving ability. The same is true of hypnosis. As you work at your task, you gradually get the feel of it and you achieve proficiency in it.

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\* Dr. Sarah Myhill, MD, is a UK-based fatigue specialist focused on preventive healthcare, nutrition, and patient education. This material is reproduced here with kind permission from pp. 49-53 of Dr. Myhill’s free downloadable book *Diagnosing and Treating Chronic Fatigue Syndrome* (28th Edition, March 2010) which can be found at her newly redesigned patient-information website ([www.DrMyhill.co.uk](http://www.DrMyhill.co.uk)) - © Sarah Myhill Limited, Registered in England and Wales: Reg. No. 4545198.

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