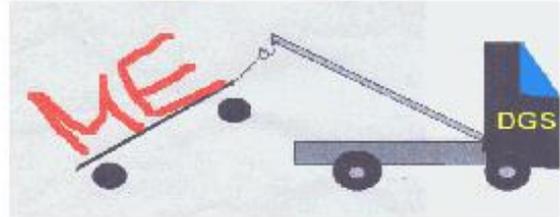


ME/CFS—YOU CAN GET BETTER

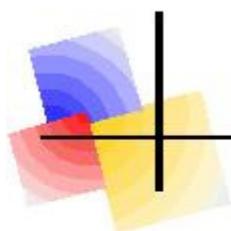
GET WELL GUIDELINES



These recovery guidelines have been developed and used
by
Dr David Smith, M.B., Ch.B., B.Sc. for over twenty-five
years while treating patients, on the NHS, at his Essex
based clinic.

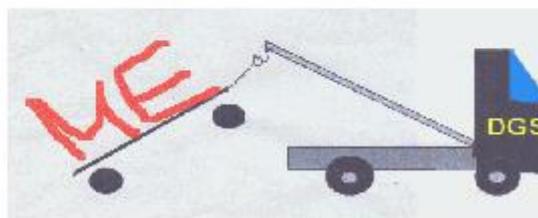
It is recommended that you consult your GP regarding
medication.





ME/CFS—YOU CAN GET BETTER

GET WELL GUIDELINES



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Before you Start

At all times you should feel comfortable while undertaking this recovery programme. Timings do not have to be SO precise to the absolute second, nor should your expectation of how you would like to feel become a ball and chain making you tense. Trying to accept each day as it is will be a helpful aid to a relaxed attitude and you may find a little Mindfulness Meditation in rest periods beneficial. This would particularly apply to those of you who are perfectionists and like to strive to do well in all things.

Step One

Stabilising your illness

Modify your Physical Activity

The foundation to recovery is to develop a modified activity programme containing mental and physical activity (especially mental). You should not vary the amount of activity by very much because this will lead to a boom and bust situation, which is not good. By doing slightly less than you can achieve you should find that your sleep pattern will improve. **After repeating the same amount of activity every day for two weeks you will know whether you can do it every day.**

Your marker to know you can do it every day is that when you go to bed, you sleep well and wake refreshed, or relatively so. You can add other things, after two weeks.

If you wake un-refreshed you are doing it wrong. As you will have noticed, if you do too much you sleep badly and wake un-refreshed the next day; then on a bad day you do less, you tend to sleep a little better and then you wake up feeling good or less unwell, and again you do too much, which leads to this continuing

boom or bust approach

You should not over-potter. **On a good day don't do any more. Consistency is the key.** Your marker is sleep quality. All informed opinion knows that the problem lies in your brain and all peripheral symptoms are centrally derived. There is nothing wrong with your body, muscles, heart, etc. The illness is biochemical, i.e. one of brain cell dysfunction, not psychiatric. It is the loss of central regulatory mechanisms that cause physical symptoms and loss of cognitive intellectual performance that is the cause of your brain symptoms.

Activity Physical and Mental

It is very important that your total mental and total physical energy output is the same every day and should be LESS than you can achieve.

Your day should be started in an organised and clearly defined programme. The more you can stick to this the better and where you can legislate for something make sure you do; most things can be planned.

You should wake up at the same time and go to bed at the same time. Your day starts at the same time and finishes at dinner approximately 6pm. (See Regularise your Day). During the day you should do the same quantity of

physical and mental activity and you should apply it every day. If, for some reason, you are feeling bad you don't have to do things. However, if you have a good day, don't do any more. You should find by doing this that your general wellbeing will improve and, even if it doesn't appear to improve quickly at the beginning, you will find that your days will be more uniform and the boom and bust, the good days and bad days, tend to even out.

First, you determine how much physical activity you can do in one day. Something inside you will be able to tell you whether or not you can do something and how much. For example, just picking a random distance, you might ask yourself whether you can walk, say, a mile (about 1.5Km), but that is not the whole question. The question is 'Can you walk a mile every day?' You should be able to do whatever you decide to do for two weeks before you know you can do it every day because there is this lag effect with physical activity. If you do overdo it, it will tend to catch up with you as time goes by so, if you know you can't walk a mile, you shouldn't try. You might ask yourself whether you can walk half a mile. The answer might still be 'No' but then if you ask yourself whether you could walk one hundred metres the answer may well be 'Yes' but, of course, this depends upon how ill you are. Walking as far as the front gate might be all you can do, maybe even less.

It is impossible to be prescriptive about how much physical activity any one person can do because only they know that; there is no point in being told to walk a mile every day if you can't do it. You can just make things worse and that might even apply to one hundred metres a day if you are very unwell and almost chair bound. It would certainly be too much if you spent a lot of time being bedbound although, for-

tunately, this is not common. The question of how much you do is up to you.

Should you decide that you will try to go for a walk you will have to decide what distance it will be (taking into account the return journey) and I would recommend that you do less than you can achieve or less than you think you can achieve to start with. So if you know you can walk one hundred metres but you are not sure about two hundred metres then stick to the one hundred. Indeed you might even try fifty metres twice a day rather than one hundred metres once a day. You will be able to do that more easily and, by doing less more often, you get more out of yourself in the long run. Once you decide upon how far you can walk you might then say, 'Can I go for a ride in the car or even drive the car?' and the answer will be the same. How much you drive depends upon how long you think you can do it and then try and do a little less but make sure you do it every day. **If you can't do it every day don't do it at all.** So, you can see the general advice would be to potter.

I think most people will understand what is meant by pottering but, in essence, it is doing little bits of activity or small tasks or just a few minutes of a longer task without using too much effort to do it. Pottering would mean going to the greenhouse and potting up a couple of geranium cuttings, it might mean going out in the garden for five minutes deadheading roses, it might mean rinsing a cup and saucer, a couple of plates or tidying out one shelf of the fridge or a cupboard; just bits and pieces. Mix them up with rests in between so these are not particularly planned. If you have something more constructive to do like the ironing, make sure you do a couple of shirts and put the iron down, turn it off but leave it there and come back to it later. If you have some particular bills to pay or an e-mail to send then of course you would

make that a time based activity and plan it.

Don't do things too quickly or do things for too long. You wouldn't stand at the sink for an hour and a half washing up. That would be too much. If you do too much it will stop you and then you have to sit in a chair for the rest of the day resting and wasting that time, so by doing less and resting a little bit here and there you will find that you can do more. So it is do a bit, stop, start, do a bit, rest, do a bit more and, as you do more, make sure you change the modality, which is the actual thing you do. So if you do a little bit of vacuuming you wouldn't then do a bit of polishing because that would be using the same muscles for the same purpose. So you would mix your physical pottering and your mental activity up in small aliquots.

How much mental activity?

If you can sit down and think about what things you find are difficult mentally and put them in a list in order of difficulty, you will probably find that using your computer will be the thing that you notice most and reading a book would come second. Even if you don't do either of those things you do a lot of mental processing all of the time. The more you need your brain to do something the more difficult you will find the task; the less intellectual something is the easier it is to do. So, initially, I suggest that you remove as much mental function, concentration and intellectual cognitive thinking as possible and the more difficult things are the more that advice applies. **If you need a brain to do it, avoid doing it.** This is not to say that you mustn't do it; it is just that if you **do** do it you should only be doing it, when necessary, for a few minutes at a time..

Eliminate Visual Input.

Avoid the Computer and Books.

Most informed opinion will tell you that regularising your activities in the day needs to be controlled and you mustn't do too much but my long observation of this illness finds that advice given by other medical opinion does not include curtailing visual activity. **You should almost totally avoid using your computer and reading books.** Having said that, if you want to spend a minute, or so, on your computer just to send an e-mail that would be fine but, on the whole, I find that if people use their computer for more than five to ten minutes per hour they will encounter difficulties and will continue to make their illness worse. This advice is not universally available. **Very few advisers tell people not to read and not to think intellectually, not realising that the consequences of these activities are as bad as trying to walk a mile when you are only able to walk one hundred metres.** It is easier to recognise a physical activity that makes you worse and less easy to realise that sitting down and playing with a computer or watching television is just as bad. This is simply because mental activity drains so much more energy comparatively than going for a few hundred metres walk. The more difficult the mental function is the more a time limit should be advised so at the beginning of any programme it is important to remove all mental function as much as possible. **Other visual intellectual processes such as embroidery, jigsaw, Sudoku, crosswords, cross-stitch should also be avoided.**

Television is not good for you either.

All patients with chronic fatigue syndrome will express the fact that their short-term memory is not good, their concentration is poor, word finding processes are difficult, long conversations are tiring and they have difficulty concentrating on a book. However, they have not worked out that watching television for too long (beyond their visual concentration span) is just as bad for their illness and their brain as is walking too far or going out in the garden and doing too much. People work out the fact that they can't do too much physically but they don't see a connection between chronic fatigue syndrome and visual processing. **Therefore, at the beginning of any programme to stabilise your illness it is important to minimise visual intellectual processing and, as it is very difficult to work out exactly where you are at the beginning, my advice to everybody is not to do any visual processing.** In other words, cut out reading, cut out computers and cut out the television completely and do other things. Often, my advice to a patient is that if you need to think about it and if it requires using your brain don't do it; particularly at the very beginning. These things can be introduced later as you improve and begin to recover.

It is not suggested that these things must not be done; it is just that they are more tiring mentally than pottering around physically. When people are very unwell they tend to sit in a chair and not do very much. If they are doing anything at all you will find that most people gravitate to watching daytime television, without realising that this is just as bad as going out and digging the garden. That is not to say that you

should close your eyes and not do any visual processing; looking at magazines and pictures is fine. You don't need a brain to look at Cosmopolitan or OK Magazine but I wouldn't sit down and have a game of chess, play Bridge or any card game as you will find it very difficult to do and it easily makes your illness process worse.

After you have removed these visual processing activities for a couple of weeks you will then start to notice how much your illness process has been affected. Your cognitive capabilities become much more obvious if, after a period of time, you inadvertently spend too much time on the computer or start reading a book.

You might find that there are things that you can do that cause you no ill effect and therefore you would do more of those things than the things that make you unwell. Again, if you do too much mentally you will find that your sleep pattern will become worse and you will start to wake unrefreshed.

Remember, chronic fatigue syndrome does not have a life of its own, despite what you might believe at the beginning i.e. that it is unpredictable. It is, in fact, exactly the opposite; it never gets worse by itself, doesn't fluctuate by itself and it is totally predictable.

At the beginning of a programme, mental function might be to do a little art and crafts, to do some painting or drawing (but not fine detailed work involving intense concentration), write a short letter, send a postcard or to have a short conversation with your friends; and telephone calls which you should also limit to approximately

ten minutes. **All of these early mental activities should be limited to only one activity within any one hour.** You should never continue any activity, either physical or mental, for such a length of time that it forces you to stop; you should always stop before it stops you. If for example reading makes your brain bad then you shouldn't read at all or, if you do, just make it a page or a paragraph at a time. The more you can do without it making you feel bad the more you can continue doing it. Don't forget all intellectual brain function such as talking, hearing, listening, thinking, socialising have their limitations.

Never do any one thing or collection of things that will make you suffer tomorrow for what you do today. The rationale behind that is that if you do too much today and suffer for it for a day, or even two days, then you not only make your problem worse it actually affects your recovery time. Every time you suffer for one day it is another day on the end of the illness for every year you have been ill. Put another way; if you have been ill for three years and you overdo it and suffer for two days then you multiply three years by two and put a week, roughly six days on the end. The longer you have been ill the more that is multiplied so it is important to get it right. Learn by pragmatism; if you are not sure try it and see what happens.

Try one thing at a time. Don't try two or three because you won't know which of those two or three produced the bad result. If you are not sure, do half of it and see what happens but if you know you can't do it without suffering don't do it at all. If something has to be done, such as going to the dentist,

then of course you would minimise your visits, minimise the time and the difficulty of getting there as much as possible. If you know you are going to suffer for that then you would cancel the activities for the next day. This is not to be advised but sometimes it is unavoidable.

Anything that you know you can do without causing any ill effect you can do again with less control. It is important to try and do things that are good for you or make you happy, such as going to get your nails or your hair done; or you might wish to go to the gym. That is not to suggest that you should be doing heavy exercise but the act of going to the gym and sitting in the hot tub for a short time or going for a short, gentle swim might be good for you; although this might not include powering up and down length after length, but just simply sitting in the shallow end and going for a float.

Your marker to know you can do it every day is that you sleep well and wake refreshed or relatively so. If you wake unrefreshed you are doing it wrong.

Regularise your sleep pattern

Regularising your sleep and waking times is very important. It doesn't matter what time you go to bed or what time you wake up as long as you do it consistently for the same time every night. It is better to try to adopt a lifestyle of sleeping and waking which is similar to what you might have been doing when you were well. If after a few days or weeks you find that your going to bed time, or your waking time, is ei-

ther too early or too late then, of course, you can alter it again but having altered it you should then 'lock it in'. Let us say, for example, that you go to bed at 10pm; you will take your tricyclic antidepressant (*See Medication below*), if appropriate, approximately an hour beforehand but it is also important to 'dumb down' for at least two or even three hours before you go to bed. So you do nothing mentally stimulating; no long conversations, no visual input, no TV, no DVDs, no computer games and no reading. Gentle pottering around, listening to the radio, music, talking books etc. are very good.

It is very important that you should not sleep in the day. (*See Rest*) It is also almost as important not to lie down during the day but if you have to rest then recline on the sofa. Don't lie down, close your eyes and go to sleep as it alters the sleep patterns, perpetuates fatigue and alters diurnal variations and circadian rhythms. The sedative tricyclic antidepressants (*See Medication*) act as sleep regulators and hopefully you will wake in the morning feeling better.

If you consistently overdo things and try to press forward you will continue to wake unrefreshed and, in fact, this can make your illness worse so it is important at the beginning of the programme not to allow yourself to run away with things when you are feeling a little better. It is important to have a slow disciplined approach to your programme and if you have been ill for say two years it might take a couple of months or even more to get your programme right and you may feel that you are not making any progress but when you look back you will start to see that you are feeling a little

better over a longer period of time.

Please do not feel discouraged or that you are a failure if it takes longer than anticipated to get your programme right. Each sufferer can vary widely in what type and amount of input and output they can tolerate and the length of time you have already been ill can also have a bearing on this. There is no predictable timescale for recovery although, roughly speaking, if you have been ill for two years it will take you as long to get better. The more unwell you are and the longer you have been unwell the longer it takes to get better and it is very difficult to stick to programmes for long periods of time.



Medication

Using various medications to improve your sleep is essential. Once you have your programme right you should try **sedating antidepressants to treat your sleep.** People with CFS, whether they sleep too much, too little or keep waking, wake unrefreshed. There is almost certainly a tricyclic antidepressant which will suit you. The lowest dosage that works is the one for you, e.g. 10mg Amitriptylene or 10mg Trimipramine. They are available in drops. **They are not addictive but don't try stopping them quickly.**

How long are you going to be taking these? For as long as you are ill. The dose cannot be prescriptive. How much Amitriptylene or Trimipramine depends upon what dose is best for you. Start with 10mg increasing by 5mg per week or fortnight until you get the required response; e.g. you go to bed at, say, 10pm, you take Amitriptylene one hour before, sleep by 10pm, sleep all night, and wake, by alarm, at the same time every day, say 8am. You may feel a little groggy every morning but this should wear off after 20 minutes or so. If you wake refreshed and better you are getting the programme right.

Once you have your programme right and you are waking refreshed, then other medications can be added as well. I would recommend Fluoxetine Syrup 20mg/5ml starting off with a very small dose of 1 or 2 mls (4 or 8mgs) which, at the start, will be almost nothing but, as you increase the dose, it lifts your mood and decreases fatigue. **Fluoxetine should be taken in the morning.** Don't forget that

Amitriptylene and Fluoxetine are very good painkillers and good for the neurogenic pain of CFS. This dose of Fluoxetine or Citalopram should be increased slowly, i.e. 1ml per fortnight in the case of Fluoxetine until you get to a therapeutic dosage of 20mgs (5mls or one capsule).

Fluoxetine Hydrochloride was probably one of the very first SSRIs ever to be discovered, nearly 30 years ago, and, initially, used as an antidepressant. It has been extremely useful and there are a few properties that Fluoxetine Hydrochloride possesses that other SSRIs are not quite so good at doing and one of them is to reduce fatigue.

Fluoxetine reduces fatigue, lifts mood, probably increases intellectual functioning and makes people feel quite happy. It has a 'laissez faire' capacity i.e. it can make people feel uninhibited. Most of these are beneficial to patients with chronic fatigue syndrome although there is no doubt that there are some side-effects that make people unhappy to continue with it. Firstly, the direct side-effects of the medication are those of headache and nausea and it can produce gastrointestinal side-effects. These may stop people using it. I think that probably headache and nausea occur in about 5% of the patients that I have seen and the vast majority can tolerate Fluoxetine Hydrochloride quite well. I have come across people in whom it has produced some quite undesirable side-effects. It can make you angry, it can make you agitated, it can produce tremor and anxiety.

My advice, always, is to start taking Fluoxetine Hydrochloride in small amounts. It comes in a syrup preparation (20 mg in 5 ml) and if you start

off with 1 ml this is equivalent to 4 mg of Fluoxetine Hydrochloride. You should take this for, say, a week or 10 days and then increase to 2 mls and then 3 mls at approximately 4 intervals; so it will take you 10 weeks to get to 5 ml (20 mg) of Fluoxetine Hydrochloride and then you can swap it for one 20mg capsule. Fluoxetine hydrochloride comes in 20 mg capsules. If you can tolerate 20 mg without any problem you are unlikely to develop any problems taking 40 mg or 60 mg and I suggest that you try taking as much as you can tolerate (within prescribing guidelines) without producing significant side-effects. **You should always take Fluoxetine Hydrochloride in the morning because it does tend to keep people awake at night and, therefore, you shouldn't take it after 12 o'clock midday.** It takes about four weeks for it to work so take it easy, take it slowly and be careful.

My advice here, and elsewhere, is that medication will never, ever work if you are making your problem worse when you're taking medication of this nature. You should always be sticking to a program, you should always be adhering to the mantra that says 'If you sleep well and wake refreshed you're doing it right; if you sleep badly and wake unrefreshed you doing wrong.'

There's no doubt that medication will help and you should take Fluoxetine Hydrochloride and Amitriptyline, if at all possible, if you've been ill for two and a half years. You can get better without medication if you've been ill for a year or so but, if you been ill for two and a half years, medication is probably necessary, although not essential. As I said before, medica-

tion won't work if you're not sticking to a program. Medication will not make things better if you are making it worse. As I'm sure you will appreciate, if you take Paracetamol for a headache it won't work if you're banging your head on the wall; heart medication won't work if you're making yourself ill by smoking; in diabetes, insulin can't work if you're eating too much carbohydrate, so getting better from chronic fatigue syndrome using medication takes careful patient c-operation.

One final piece of information, and a warning: If you do badly overdo it and, therefore, make yourself ill while on medication you have nowhere else to go with chronic fatigue syndrome.

If you become ill, having made yourself worse, without medication you are always in a place from which you can recover. The same cannot be said if you're taking drugs to make you better and then you abuse them. It doesn't work like that.

/Continued

Regularise your Day

It is also important to regularise your day. Once you've got up at, say, 8am I would encourage everybody to get washed and dressed, sit down and have a leisurely breakfast and then to plan your day. Your day might start from 9:30am or 10:00am and I usually ask people to finish their day when they have their dinner in the evening at, say, 6:00pm. Then, after dinner, until you go to bed, you do nothing intellectual at all and nothing too demanding; just chill, relax and the usual going to bed type of things. So, whatever your programme is going to consist of it should be done between the hours of 10:00am and 6:00pm.

It is impossible to be prescriptive about physical content and the intellectual content of any programme. It depends upon you as a person as to what you want to do, what your hobbies are, what your likes and dislikes are and you can put anything into your programme that you enjoy doing or that needs to be done. Tasks should be done slowly and the activities should be broken up into small sections of time.

My suggestion is always that you shouldn't do anything for too long.

As a random guess as to what too long might be I suggest fifteen minutes (it may be even less for you) so if you are going to tidy the kitchen as the first thing at 10:00am then you should tidy it for ten to fifteen minutes; not until it is finished but by time. Then you might sit down, have a rest and then you might do something else such as go for a short walk, a ride in the car; you could go round the garden but whatever

you do you split it up into small sections of time. In other words, do a bit, stop and rest, have a cup of tea, do a bit more, stop, listen to the radio, do a bit more, and stop and so on. You break your day up into small sections and try not to spend too long on any one activity. You should certainly not do anything for a length of time that would make you stop. **You should always stop before it stops you.**

Then change the activity into something else and do things on a rota. **You wouldn't do two things that are the same back to back.** For instance, you would not listen to the radio and then go and have a telephone conversation as they are the same thing; you are listening. However, you could listen to the radio and then go and do a little gardening and then come back in, rest a little, and do a little cooking.

As long as the things you choose are as different as you can make them you will find that you can get more out of yourself. By breaking things up during the day you will also find that you can do more. If you were able to walk for, say, four hundred metres it would be better to go for a walk round the garden for one hundred metres four separate times than it is to do one walk of four hundred metres. **By doing less more often you will find that you are able to do more.**

It is also important to do single level processing. In other words, you do one thing at a time. So if you are cooking you should not wash up at the same time, if you are washing up you are not listening to the radio, if you are listening to the radio you are not having a conversation with your children or your spouse.

How long it takes you to stabilise your illness process is extremely variable but, as I

have indicated elsewhere, your marker to guarantee that things are getting better is that you sleep well and wake feeling better after your sleep and the more refreshed you wake up the better your improvement will be.



Rest

It is important that you do rest, where appropriate, and as much as is necessary for your programme. You can't keep going all day because otherwise you wouldn't be ill. Rest does mean reclining. It doesn't mean sleeping. **You shouldn't sleep in the day.** In fact, you shouldn't lie down. If you have to rest then sit in an armchair; and putting your feet up, if you wish, would be fine. It is most important not to over rest. If you want to do absolutely nothing that is also fine but it might be good just to sit down in a chair and listen to Radio Four, a talking book, Women's Hour, a little light music or whatever. Remember when you are resting you shouldn't be doing anything too active or thinking about doing things or making your brain churn over; that is not good either. It is good to sit down and listen to mood music, relaxation tapes, de-stress yourself. Try and plan your rest. **You shouldn't sit down because you have to; it should be because you choose to.**

So, it is a mixture of doing things mental and physical and resting. Later on, as you improve, you would increase the physical and mental activity at the expense of your rest, maintaining your day from 9am or 10am to 6pm as much as possible. You should also do things evenly during the day. You shouldn't try and do all of your physical and mental pottering in the morning and then not have any energy left to do things in the afternoon. So, by evenly spreading it out during the day means that by the end of the day you should have used all of your energy up but no more and no less.

/Continued . . .

Because chronic fatigue syndrome is almost invariably a stress related condition the most important thing you should avoid is the thing that makes it bad and that is stress. If you know something is going to stress you just don't do it.



Food Intolerances

ATOPY: the literal translation of atopy is something that is out of place.

In the medical sense it is a true antibody mediated immune reaction usually presenting in the form of hayfever, rhinitis, asthma and eczema. It occurs in the Western world and probably in 10% of normal people, this being hayfever or "seasonal rhinitis". There is no doubt that it is more common in the Western world, where hygiene is more practised than in the East. In the Third World countries where people are more exposed at younger ages to all sorts of allergens they do not develop anywhere near as much reaction to these allergens as we do in the West.

I have seen a lot of suggestions that in chronic fatigue syndrome the association between this illness and allergy is much more than the normal population and, indeed, a lot of people believe that ME/CFS is caused by allergy. I do not believe that to be the case. Over many years I have seen a great number of people and I do not believe that the incidence of atopy or food intolerance or allergy is any more than I would expect to find in the normal 10% of population. I have done at least two large surveys and written previously about this elsewhere and the incidence of atopy in my cohort of patients is less than 10%.

Having said that, it is undoubtedly true to say that where atopy exists it is always made worse by stress reactions and as I believe, indeed I know, that chronic fatigue syndrome/ME is associated with a significant set of premorbid stressful factors, then patients that do have eczema or asthma often find that their condition is worsened

during the phase when they are suffering from their ME. This will also be the case in patients who have psoriasis.

Food Allergy

It is the same for food allergy as it is for atopy. Patients frequently come along and say that they're allergic to things such as food, chemicals, perfume, deodorants, diesel and other fuels. In fact, the patient here is misinterpreting his symptoms because, when you test for true atopy, by doing analysis of the blood looking for IgE antibodies to these substances, they are invariably not there. In fact what the patient is describing is food intolerance.

I think during the whole of my career I have only come across three people who have been shown to have a true food allergy and which they knew about before they became ill. One of those was towards fish and the other two were peanuts. Food allergy is not a problem associated with or a causative factor in CFS/ME.

Food Intolerance

When looking at food and chemical intolerance there is, indeed, a very large association with food intolerance, which they didn't have before, but which becomes a problem after the patient becomes ill with CFS/ME and a classic example would be that of intolerance to alcoholic drink.

Most of the patients that I see are social drinkers, a very few are teetotal, and none

would have an association of being ill with large alcohol intake. If their alcohol intake history is significant and where one might consider a diagnosis of alcoholism, then you can't make a diagnosis of chronic fatigue syndrome. I have seen this couple of times, maybe more, and sent them elsewhere for treatment.

As I said, the majority of people that I see are social drinkers. One or two units a day or a few glasses of wine at the weekend would be normal for this group. When they go down with their chronic fatigue syndrome it is more than likely that they will develop an intolerance to this amount of alcohol intake. The patients often says they have never had a problem before but now they can't drink one half glass of white wine, red wine or a brandy or whatever without being ill. Particularly, the next day it makes them feel they have quite a hangover, they have a headache, they can't think straight, maybe for whole day or 48 hours after, what for them, would be a minute amount of alcohol intake. They are affected to such an extent that they stop drinking altogether.

I know of no other illness where the patient will voluntarily stop drinking alcohol after they become ill. I know a lot of people with other illnesses might be told by their doctor that they must not drink alcohol because there would be an interaction with the tablets that they are on, but in something like 70% of patients that I see, they stop drinking alcohol of any kind because it makes them have a bad reaction.

I think that probably every doctor who has any working understanding of chronic fatigue syndrome/ME has found the same and, as far as I can see, the majority of doctors working on chronic fatigue syndrome use alcohol intolerance as a significant

observation. I have found that many doctors will make a diagnosis of chronic fatigue syndrome on the basis of a patient's symptoms along with the fact that the patient doesn't drink alcohol. I have had at least one patient referred to me, having been told he did not have CFS/ME because he was able to tolerate a small amount of alcohol. Some doctors seem to use alcohol intolerance as a diagnostic test and this is very unreliable.

Like these other doctors I came to understand this problem many years ago and I set up a little experiment. I wrote off to be licensed Victuallers Association and asked them to tell me what chemicals might be found in a typical bottle of Chateau-neuf Du Pape .A few days later I was surprised to receive a small booklet of approximately 20 pages and on each page were 50 organic chemicals that consisted of alcohols of different composition, esters, aldehydes, ketones etc, etc.

You will understand that if you can find something that makes patients ill and if you could analyse what that was, you might be able to give them something to stop that happening and make them better. However, there would be no way that I would be able to test all of these compounds; it would just be too much. What I did do, however, was to obtain some pure ethyl alcohol; after all it is probably the major component of an alcoholic drink that gives you the feeling of being happy and slightly drunk. I gave each of a group of my patients, numbering about 20, a sterile plastic bottle containing 20 ml of ethyl alcohol 90% proof. I suggested to them that they mix it with something to dilute it and give it some flavour, say, Ribena or orange juice. This is what they did and not one of them was made unwell, although all of them experienced that little alcohol glow. This means that ethyl alcohol is not the chemical

that makes any sufferers ill but it is probably one of the other 5000 flavour compounds.

If you look at the chemical structure of all of these 5000 flavour compounds they are all closely related (and some of them almost identical) to the neurotransmitter substances that you have in your brain. On taking an alcoholic drink, it is absorbed into the bloodstream, crosses the blood brain barrier and interferes with your brain function. So, in a CFS/ME sufferer with a slightly abnormal brain dysfunction the alcoholic drink makes that worse, as you know. I argue that chronic fatigue syndrome is purely centrally based in the brain and so people with alcohol intolerance should probably not drink at all as it will make their already diminished brain function worse and perpetuate their chronic fatigue syndrome.

In relation to food the same discussion will apply. Take cheese intolerance and Gorgonzola as an example. Gorgonzola is made from milk which, is then fermented for quite a long time, and fermentation produces hundreds, probably thousands, of different short chained chemical molecules, many of which are probably similar, if not identical, to those in an alcoholic drink. You eat the cheese, these chemicals are absorbed into the blood and will quickly make you unwell. This exploration can be extended to pretty much all foods so patients with chronic fatigue syndrome find that they are quite often, maybe 30 to 40% of them, intolerant of certain foodstuffs. My advice here is to try and find what they are, what these foodstuffs consist of, and exclude them from their diet if this is practical.

When it gets down to looking at food exclusion diets I will not put myself forward as

being an expert. If patients with chronic fatigue syndrome feel that they have chemical intolerance then I would suggest that they seek further professional advice.

Beware. When you seek this sort of advice please try and go to a medical practitioner. If you go to the alternative field you can end up with some very strange suggestions.

In my experience, food intolerance is also closely associated with irritable bowel syndrome.

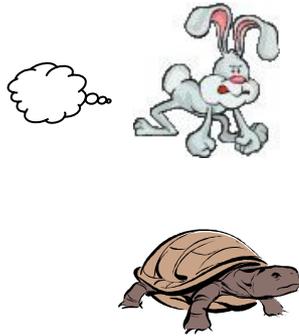
Irritable Bowel Syndrome (IBS)

Your bowel is controlled by your brain, via the Vagus nerve, which also is a nerve that controls lots of other things, and when the brain isn't working properly the Vagus nerve control is not as good and you can often end up with irritable bowel syndrome, This again, is a stress related condition. However, there is no doubt that if you have IBS and food intolerance then your IBS is going to be made that much worse.

Other Chemicals

Finally there are other allergens that patients find they can't tolerate, such as chemicals, deodorants, car fumes, etc. The same explanation exists here. The chemical is airborne, you breathe it in through your nose or mouth and it then goes to your

lungs, is absorbed into the bloodstream and ends up in your brain. These irritants can make people ill very quickly, in just a matter of seconds, and I don't know what you can do about them other than avoid those situations.



Step Two

Moving Forward

At the beginning of any programme the advice is to do less than you can achieve. You do the same thing every day or the same quality and quantity of physical and mental activity but slightly less than you can achieve and on a good day never do any more. Depending upon how ill you are and how long you have been unwell you should be able to recognise that, after a few weeks, maybe longer (say, a couple of months or so) you feel a little better and would like to start moving forward. **You shouldn't try to move forward until your sleep pattern has got you to a point where you are consistently waking up in the morning feeling refreshed from your night's sleep.**

At this point I suggest you purchase an anno-planner, which can be bought from WH Smith for under £5. This is a one year calendar on which each day is represented by a small rectangle. If you also buy some coloured stars or dots and some felt tip pens you will then be able to keep a visual progress log.

If you go to bed and wake feeling very ill or unrefreshed you might put a black star on your chart. If you wake in the morning not feeling good but not as bad as black then it might be a grey star. An encouraging sign is to go to bed and wake a little bit refreshed and you might use a silver star. If you go to bed and sleep extremely well and wake up feeling 'Full of the joys of spring' it is a gold star - and you don't need

any prizes to know what is best for you – the gold star!

At the end of each day you can also enter onto the chart a score from 1 – 10 of how you have felt generally during the day; ten being very good and one being very ill. You could also put a brief note about what you have done. You will then start to see the correlation between feeling good and sleeping well and waking refreshed with the fact that you are improving and able to do more.

The visual representation is much easier to see and more encouraging than keeping a diary. For example, you might go shopping for two hours around Tesco and wake up the following day feeling 'Grey star'. You will see that your sleep is less good if you overdo it. Overdoing it makes you very tired and exhausted when you go to bed, your sleep pattern is less good and you wake unrefreshed. Therefore this anno-planner should have something to teach you; that you learn by pragmatism not to do certain things that make you feel bad. If you start feeling a little bit better and getting some silver stars or gold stars and you do that consistently for, say, two weeks then you can start thinking about moving forward.

'I would recommend however that you don't increase activity at intervals of time of less than two weeks.'

There are lots of ways in which you can do this but the best is to leave your daily structure as before, e.g. starting at 9.30 or 10 am and ending at dinner at 6pm. It is suggested that you have a one hour rest in the middle of the day, say from 1 – 2 pm. So what you do in the day would simply be to do a little bit more and you would

plan one activity. How much to move forward and how much to increase your programme is quite difficult to answer but in general **you would increase your activity by doing increments of approximately ten per cent.** As you gradually recover this percentage can be increased but, here again, trial and error is the key. Don't try and double your activity; that would be too much. Don't be afraid to move forward – you can't get better just by feeling well. That means that as you increase your activity your symptoms will increase but that shouldn't worry you. **You can suffer today for what you do today as long as you don't suffer tomorrow.**

As you increase your mental and physical activity you will find that some of your symptoms will get worse during the day. That does not matter as long as you are sleeping well and waking refreshed.

If you find that you are doing too much and it is beginning to tell on you, you will notice that you wake unrefreshed in the morning and feeling bad. You are suffering the next day for what you have done the day before. In this event you would cut back a little until refreshed sleep is re-established and you have identified what it was you did too much of. Then you can try and move forward once more.

Physical Activity

As a random example, let us say that you are walking 50 paces twice in the morning and once in the afternoon and you want to increase that. I suggest you increase it

by a small percentage, say 15% - 20% (10% - 15% or five paces if you have been very unwell) You increase the walk, not by increasing the distance that you walk but by increasing the number of times that you do it; so now you might do 50 paces twice in the morning and 50 paces twice in the afternoon.

As you progress with increasing this activity you will get to a point where it is more practical to have one walk in the morning and one in the afternoon. This is where you can double your amounts to make one morning walk but make sure you can tolerate one longer module for two weeks before you link up the afternoon modules.

At the same time you might want to increase a little bit of what you do at home. You start doing a little bit of washing-up again. It shouldn't be for a long period of time; you should break it up. You might rinse the dishes, put them in the sink and come back and wash them two hours later or in the afternoon; just at a pottering pace. Whatever you choose to increase you should do it on a regular basis. If you do it consistently everyday, you should do it everyday for two weeks before you know that that is successful because, as you will realise, there is a lag effect of suffering if you do too much in one day. If you do just a little bit too much on one-day, you will suffer for it the next day . You might not notice that you suffer as a result of that for two or three following days down the line as it has an accumulative effect. So as I've already said you should do it for two weeks before you know you can do it. Having ascertained that you know you can do it you don't have to then do it everyday and then you can choose to increase your program by doing something else.

Further on, you may want to do a little cycling. You're still doing 50 paces walking

twice in the morning and twice in the afternoon but you might get on your bike as well, as an additional activity, and cycle 100 metres. Then you would do that again everyday for two weeks and, all being well, then you would increase it to 100 metres twice a day and then you might want to increase it to hundred metres three times a day after another fortnight and then again to 100m four times a day. From this you can see you would gradually increase the numbers of times you do things rather than the distance or the amount. This clearly has a natural limit. You don't want to start going out on your bike hundred metres 12 times a day so I suggest that once you are doing it four times a day then you can increase the actual distance, by gradually doubling the modules, rather the number of times you do it.

As I have said many times before, your one marker to guarantee that you will get better is to sleep well and wake relatively refreshed in the morning. If you overdo your program by doing too much or just a little bit too long then you will find your sleep pattern is not as rewarding and you've just set yourself back. You should be able to identify this before moving on again. If you do start sleeping less well, now would not be the time to increase your programme. What you do is try and identify why you are sleeping badly or less well and cut back a little bit on that aspect of activity.

Once you are confident with your gradually increasing physical programme you then might put in a plan of increased mental activity, along similar lines.

/Continued

Mental Activity

Introduce one mental activity at a time. Only add another when you are confident the previous one is not causing problems.

Now you should try an experiment. After you slowly increase what you're doing physically you might find that your day is busy just pottering around and you would like to change the way in which you increase your program. Now might be the time to start doing a little mental work such as a little bit of television; something simple, not too aggressive. I always suggest watching something like *The World About Us* by David Attenborough or one of these travel films which are not too intellectually or emotionally stimulating and are easy to watch. In this case I would watch television for about 15 minutes twice in the morning and 15 min twice in the afternoon. This is where a DVD player, Sky+ or similar service is handy.

I would still try to avoid reading unless it's something fairly simple. If you do want to read then I would limit it to a page at a time, one page twice in the morning, one page twice in the afternoon. You should be able to identify whether doing that is difficult and it makes you more tired than other things; so that is the time not to push things too hard. If you are unable to cope with reading at this point, try introducing another mental activity. Again continue to monitor your sleep. You can, in fact, introduce anything you are able to do, as long as it makes you suffer just for today but not tomorrow.

Don't try to increase your program too quickly. If you do you may set yourself back and you will have to cut back and get stable before moving on again.

Returning to use of the computer

At the very beginning of developing a modified activity program I have advised you to exclude visual intellectual processing, reading, writing, computer, card games and other things. However, because using a computer as a way of keeping in touch with your friends, social networking and buying things is an everyday event and pastime for virtually everybody the chances of my getting people to stick to non-use of a computer is probably impossible and one must always compromise. **I would advise no computer use but I'm perfectly aware that people will use it a little and, therefore, I suggest probably less than 2 – 5 minutes a day just to send a quick e-mail and answer your post.** However, some people manage it and when you are feeling better you can reintroduce intellectual processing very slowly.

I usually start off by asking people to read a book for a short period of time to get used to using their brain again and a little bit of television, also in small amounts a few times a day. These are, usually, a prerequisite to using a computer for the first time. **The computer is probably the most difficult thing to use because it involves multi-tasking.** You are studying the screen, you're looking

for information on it, you may well be listening to some text (via a text reader) or music and you're using both hands typing commands. So, this is either three or four level processing and, consequently, should be the last thing to be introduced for very small periods of time. **I would suggest no more than 5 minutes two or three times a day to start with and, during this time, you should probably exclude reading and television, and see what happens.** You could, of course, do a bit of television one-day, a bit of reading the following day, and a bit of computer the day after that but probably not all three at the same time.

As with other things, once you've got a baseline and you know you can manage it you should introduce it slowly by increasing the number of times that you do it; up to, say, eight times in one day before you actually increase the length of each time that you spend at the computer. I am, of course, aware that the majority of jobs, occupations and careers have some, if not a large, degree of computer based work and it seems more than likely that you will have to be able to do 15 min per hour six times or eight times in one day before you are able to consider returning to work. If a computer is a significant component of your work, however, you will be able to find that out for yourself. **If you do too much computer work you will undoubtedly end up with a fuzzy, foggy brain and a headache as well as fatigue.** It has to be up to you to judge when you've had enough and, again, don't progress too fast. Slow and sure is best.

You will find that, because chronic fatigue syndrome lies purely in

the brain and is an intellectual cognitive dysfunction, increasing your physical activity is actually easier to do than increasing your mental activity.

As discussed elsewhere, you should be taking some medication during this period. I would certainly advise you to do so if you're been ill for more than 2 1/2 years. You will need something like Fluoxetine hydrochloride in the morning and Amitriptyline at night, in order to help you improve. They do work, but by the time you get to be about 50% of how you used to be then you will find that the medication is working against you and, at this stage, you should then start to reduce very slowly. I have talked about that elsewhere.

As you increase your activity you will reach a point where you should find that you can increase it again by the same amount as long as you continue to feel well the next day. **Increasing any activity is bound to increase symptoms and you might find that you feel unwell a lot of the time most days but, as long as you are sleeping OK and waking refreshed, that doesn't matter.** Then you will see that as you increase your activity you don't necessarily feel any better but if you are not feeling worse and doing more then you must be improving. Bear that in mind. If you do have a bad day then you don't have to do anything on that day. You could pull the plug on everything and just take a day out, sit in a chair, listen to the radio a little bit, but don't do anything much and hopefully you will recover the following day.

Once you get the confidence to be able to increase things you will get a feeling about what you can add into and increase your programme with some degree of confidence. **I would recommend, however, that you don't increase activity at intervals of time of less than two weeks.** Everybody is different and individual; you are the only one who can find your own level of progress. Doctors can't tell you by how much to increase your programme; indeed, they can't in fact write a programme for you because what you want to do with your day is not what I would want to do with mine. It is good to get a hobby or at least it is good to get a project to do. For instance, you might wish to decorate a room and you would start off by just doing a couple of square feet of emulsion on one wall and leave it at that and come back tomorrow and do a bit more. As you improve you can increase what you do.

There is a learning curve as well. You will find that a lot of things are easier to improve and to increase than others and, therefore, you continue to push forward on the things that you get away with at the expense of things you don't get away with. If you don't get away with it this week you might try doing it again in a couple of weeks or three weeks' time to see if it is any better. The one thing you wouldn't do is to reward yourself with a trip to the local cinema and go and watch a film for two and a half hours. You will find that that will blow your brains. But if you wish to go out and have a nice quiet restaurant meal that would be fine or, surprisingly, a visit to an arts festival would be OK. I have seen people not suffer after going to a play as long as it is a play that doesn't need an enormous amount of thinking about and one that is not too long. A short musical would be OK as well, but not the cinema. Going to London and seeing a show would undoubtedly be too much but some-

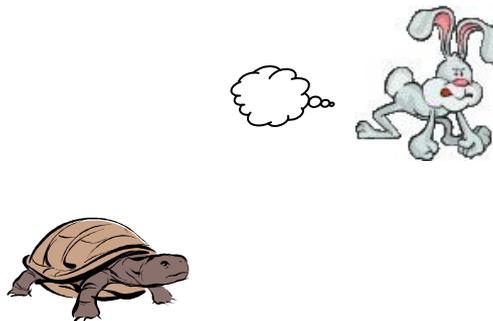
times, although it is not recommended, it is good for your soul to go and do something that is enjoyable as a one off knowing that you are going to suffer for it; but don't do that too often. It does buck the spirits up.

When you are about 50% well there comes a time when you can start to relinquish this modified activity program. By now you should be able to start doing things a little bit more spontaneously and not the same everyday. You should find that you can push forward a little bit harder. The best way of doing this would be to pick a particular day when the sun is shining and it is nice outside and go for a walk or a short cycle ride on the flat. For example, instead of being 300m you might try 800m, come home, have a rest and see what happens the following day. You should find that you suffer the next day less than you thought. If you do suffer a day or so for it with aches and pains and fatigue wait until that wears off, stick to your program for a bit and then do it again. The next time you do it you may well find that you don't suffer as badly or as long and you start getting away with overdoing it. So you begin to push your program a little bit harder. You can push physical things more easily than the mental side of it.

As you can increase your mental activity as well, start reading a little bit more, start doing crosswords and puzzles to get your brain back to work. **I would not recommend pushing forward with an increase in mental activity the same time as a physical activity as the cause of any adverse effects will be harder to pinpoint.**

Reducing Medication

By now you will have been improving with your programme for approximately a year and your medication is coming down slowly. If you have been taking Fluoxetine and Amitriptyline for a year or more then you should come off it at such a rate which will take you about a year. In other words, to get off both of them you need to go back to the liquid preparation and come off drop by drop, at fortnightly or three weekly intervals, reducing each one alternately. You can't stop these drugs too quickly as you'll get a bad ride!



Viruses and colds in chronic fatigue syndrome

It is common, if not usual, for the patient who is suffering from chronic fatigue syndrome to have an initial illness that suggests they had some kind of virus. Usually it consists of a series of symptoms that are readily identified by the sufferer as being a virus, namely those of headache, malaise, fatigue, aches and pains, hot and cold sweats, sore throat, possibly a cough and similar symptoms. The symptoms, whilst varying in their intensity, tend to persist to a greater or lesser extent throughout the whole of the period of time that the patient suffers from Chronic Fatigue Syndrome/ME. Blood tests taken at the start of chronic fatigue syndrome are usually unhelpful. Sometimes a low lymphocyte cell count in the blood test will suggest the possibility of a virus. Furthermore, because these symptoms persist for months, if not years, at varying levels, it can be very, very difficult to tell whether you have got a new virus, a new infection or a new problem. It is also true that if the sufferer does too much mentally or physically they will exacerbate their symptoms, which may suggest to them that their virus has come back. So how do you tell?

When I see patients for the first time, often they will have misinterpreted the recurrence of their symptoms as being another virus, but when I point out to them that they probably have just caused the return of their symptoms by overdoing it they can begin to see the problem more clearly. So, once you have got your symptoms under control with the programme outlined in a previous chapter, you will find that you cannot afford to overdo things to a point whereby you retrieve all of the symptoms of a virus, or you may be under the impression that overdoing it produces the symptoms of a new virus. This is almost certainly not the case. So, if you do get a

worsening of the symptoms that you have had you may well be able to start to see that this was caused by something that you actually did to bring the symptoms back. This is especially true if the symptoms that come back are those that are very familiar to you, that you had on many occasions before and there is nothing to suggest that they are new.

On the other hand, if you haven't overdone it and your illness process is stable and you get new symptoms that are not so familiar to you, it is likely that you have a new infection, especially if somebody in the family or friends have had the same thing and you can justify having caught a problem from them. It is also true to say that, when patients find their familiar symptoms have intensified they may feel that they are hot and cold but, if they actually take their temperature, they will invariably find their temperature is either normal or, in fact, slightly low. Whereas, if it's a new infection it is likely that you may have a raised temperature

If, however, you have been " good" and you haven't done too much and you get new symptoms that you don't recognise, and nobody around you has had a cold, other virus or any other kind of infection, it may be appropriate for you to ask your doctor if he could just run a full blood count and white cell count just to make sure that nothing else is going on.

So the symptoms to look out for in a new infection are:

1. Raised temperature
2. New or unfamiliar symptoms
3. You have stuck to your program

4. A blood test indicative of a new infection.

5. There was a lot of it about!

If you are not quite sure, then the best advice I can give you would be to pull the plug on your program, and take the day off, lounge around the house, don't do much and wait and see what happens. **If it does turn out to be a new virus or new infection of some kind it will make itself fairly apparent. In this case you should adopt the following advice.**

You pull the plug on everything.

Take two Paracetamol, go to bed and allow yourself the indulgence of being ill. Normal, healthy people fight viruses by tending to be rather stoical. This doesn't help when you've got chronic fatigue syndrome; it's only going to make it worse.

Apart from the new symptoms that you will get with a new virus, such as a very sore throat and cough, phlegm, more aches and pains, it is going to exacerbate all of your other symptoms as well. **You will get a major setback, but don't worry; it will go away.** It will gradually improve but probably more slowly in you than in a normal healthy person; probably about twice as long so, if your spouse or child suffers for a few days or a week, you are likely to suffer for two weeks.

When your symptoms start to improve, then you should get out of bed and start

moving about, and you should get back to where you used to be fairly quickly. Don't forget that if you go to bed for too long you will find the symptoms of fatigue and malaise becoming prolonged simply because you rested too much. It's okay to go to bed when you are ill but don't stay there. Try to get up and maybe recline on a chair or the sofa; don't sit and indulge yourself with television. Be prepared to take your anti-inflammatories, Paracetamol or aspirin, drink plenty of fluids and it will get better.



Returning to Work

Returning to using your brain will be a slow process and going back to work will be even more difficult so it's important for you to be doing a little bit of your work at home before you actually try to return to the geographical location of your work. Most of us have to travel some distance to work so, before you consider returning to work, it would be advisable for you to get in the car, drive there, meet your, colleagues and your boss, so that they can see you are still alive and hoping to come back soon, spent half an hour in the office showing your face and then leave and drive home again.

If you work in London then you will probably have to get on a train and go up there, introduce yourself, have a cup of coffee and go home. When you feel that you are able to do a small amount of work, say half to three-quarters of an hour, then I would suggest you travel up to London or to your work in the late morning, do your half an hour's work, have lunch with your colleagues and then go home. You should do that two or three times a week for approximately two weeks before you know that you are comfortable with it and that you can actually do it. Then you should try doing it every day for a couple of weeks and get your confidence back again; and it is a matter of confidence.

If you've been ill for two and a half years, which is the average length of time for most of my patients, it'll take you probably a month to progress from just half an hour everyday and of course that's not taking into account that you might have a small setback such as a mild cold or you have to go to the dentist or something else might interfere with your return.

It is important to break up the time that you work whilst you are there so, if after a month you feel you can increase the time to an hour and a half, you might try three quarters of an hour in the morning before lunch and three quarters of an hour after lunch then, as you increase that, after another month you might split the work in the morning so you may go in at 11, work half an hour, rest for half an hour or have a coffee until 12 AM, another half an hour of work, have an hour for lunch and repeat the process in the afternoon doing half an hours work at one o'clock, half an hour's coffee break, another half an hour until two o'clock and then go home.

So as you can see, you should split it up, do a bit of work, do a bit of rest. Then you can go to work for a longer period of time but actually filling the extra time with longer rests but then as you continue to improve you gradually work into the rest periods at the expense of the resting time. It may take you a couple of years to build your return to full-time work and you shouldn't push it too hard, especially if you are in a screen-based occupation.

I find that the vast majority of employers expect you to be able to go back to work full-time and on a time scale that is completely impractical. They might say they want you to do an hour for a couple of weeks and then two hours and so on and that they expect you to be full-time after 2 to 3 months. If you've been unwell for two and a half years, as my example suggests, it'll take you two years to get back to full-time work, and that's if everything goes well, so you need to sit down and talk to your HR Manager, your boss or your line manager and make sure that they understand this is going to be slow. You might need several letters of support from your physician, who is trying to help you make clear to them that if you do have a cold or you have

to go and have a local anaesthetic for a dental appointment or you need a minor operation, it's going to set you back.

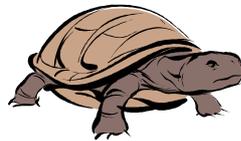
You should never push too hard; taking control is the most important thing. It may be that your employer will not be so helpful or understanding and insist that you return more quickly. In this case, you may be faced with the choice of going back to work quicker or losing your job and I always find it very difficult to say that you shouldn't try it, especially if your job is on the line. However, be aware that if your sleep pattern starts to deteriorate and you start waking up unrefreshed you will be heading downhill. In these circumstances, my advice would be that you stop, no matter what your employer is trying to make you do. You are nothing without your health!

It may be that you can't go back to full-time work, that after a period of time you find that you are only able to do four hours, or you can't go back as quickly as your boss would like. Therefore, you might have to compromise with them. You may suggest that you try job sharing or you move to another part of the office and do something else that you think you can handle.

It is very difficult to get back to full-time employment especially if it was actually the full-time employment that caused your problem of stress in the first place. For example, if you are a teacher and it was the appointment of a new head teacher who came into the school with 'a new broom' and, as a result, expected more out of you than you were able to give and, consequently, caused your stress I would suggest that it would be very difficult, if not impossible, for you to go back into the same

situation without expecting to become unwell again.

If the stressful factors were something to do with the family, family health, bereavement, marital difficulties or something else that you can resolve and that is in the past, and not job related, that made you ill, then I would hope and expect that you can get back to doing your occupation again. However, going back into the same situation that made you ill is extremely unwise; you are going to walk into the same wall and bang your head just as hard – don't do it!



Returning to School

Before I actually discuss the mechanisms of the best way to return to school I would suggest that, even though you might be very unwell and confined to a chair or your house most of the time, **it is very important for young people to keep in contact with their friends.** As you know, I don't suggest that you do a lot of computer work, which is bad for you, but I do understand if you want to spend 10 minutes four to five times a day on 'Facebook' to keep in touch with your friends. This would be something I would not recommend, and probably the best way is to keep in touch by phone for, say, ten minutes once an hour. I do appreciate that your friends will be at school and therefore you can't phone them during the actual school day but you could talk to them, maybe, at lunchtime or in the early parts of the evening. Try not to spend too long as it can be very tiring. It is probably better to use a hands free option, if you have it, in which case you can probably spend 15 minutes per hour (provided you can cope with this amount). Whatever you do, don't spend an hour talking - it will make you worse. You can also control your calls by using an answering machine or the 1571 facility, in order to preserve your rest periods.

When you are a little bit better, whilst you may not be well enough to start returning to school, it would be my suggestion that you go into school, if you can, stay 10 min during break time or go in for lunch to meet your friends and keep in contact. I know this is important, otherwise your peer group can forget you even exist, they find new friends and move on, and you'll find it very difficult to get back in. I have noticed

this, particularly, with young girls of fourteen to fifteen years old, when the people that were thought to be friends start to ostracise you. It can be very destructive, so keep in contact, perhaps going once a week for lunch so you can stick your face around the door and say, "Hi, I am still alive!"

When you are ready to go back to school, I would suggest you just try one lesson on Monday, Wednesday and Friday. Even though it might not be a lesson that you actually want to attend, it would be the one that you have just before lunch. It should be at about 11:45am or something like that. Go in for the one lesson, have lunch with your friends and then go home.

As you continue to improve you go in for one lesson before lunch, stay for lunch, and then one lesson after lunch on a Monday and Wednesday and Friday. When you are feeling a little bit better make it one lesson before and after lunch on Monday through to Friday. Do it very slowly. Continue to carefully monitor your sleep pattern and if you find that things are not going well in your sleep pattern and it starts to get disturbed again or you have other difficulties, then you pull your programme back a little bit until your sleep has re-stabilised and then go forward again. It is important not to try do too much too quickly.

I would not increase the rate at which you try to return to school by intervals of time of less than, say, a month so you would introduce one lesson and then, if you're doing well, another lesson at the end of a month. **Do it slowly; make sure your sleep remains good; that is your one**

marker that will tell you whether you're doing it right or not.

It is fairly certain that you will have lost quite a lot of time at school and so people start to make noises about repeating the year. Then your peer group move on and you have to drop back. That can be very upsetting for the patient and something that most people will find unacceptable, and I tend to agree. I have known a lot of people struggle and they go back a year lower; they seem to be the odd fish in the pond which can make stress worse and exacerbate your ME. In this situation I have advised people to try and stay in their year and I have gone to see the headmaster or headmistress of the school or of the year involved, to see whether we can negotiate a reduction in the curriculum for the following year rather than drop a whole year. This can be most important when you're going into year 10 (the beginning of GCSEs) so maybe, then, you should stick to the core subjects of English, Maths, Science and, maybe, a couple of other subjects that are not so important but that you enjoy such as Art, IT or something like that.

Obviously, this advice is very difficult and can only be done on an individual, tailor-made basis but going into Year 10 with five subjects does work quite well. **Even if you do improve more, you shouldn't then try to increase your subject list. Try to spend more time at school and get better grades. You can always get GCSE subjects later. The most important thing of all is your health; whilst I accept that education comes a very close second, it is second only to your health.**

When you go to school it is often a good idea to make sure that you have a discussion with the staff to see whether they can give you photo copy notes or allow you to take into school a tape recorder or a computer with a recorder and to produce your work using a voice recognition program, like Dragon, which works extremely well. You can compose essays for English this way as you don't have to sit and stare at the computer screen; you can actually do it quite easily with your eyes closed and then get another member of the family to just read it through to check that the grammar and the punctuation is okay. If you've got an automatic spellchecker you shouldn't have problems or, at least, they would be minimised.

Exams

If, unfortunately, you continue to be unwell when the examination period is coming up you can always get your Doctor to write to the school and ask for extra time during the examination period for mental rest. If the exam was to be one and a half hours long you could expect to get a 20 min break, halfway through, have a rest by closing your eyes in an easy chair, and then return to your second part of the exam. Of course, this will mean that you will need to be separately inviolated. If, unfortunately your ability to concentrate and write has been diminished, you can also ask for a scribe to help you write it out, or they may allow you to do it with a voice recognition program such as I have advised above and use that. After all, examinations are supposed to be a test of what you know and are able to do, rather than trying to find out what you can't do.

Also, get your doctor to write to the examination board and point out the fact that you've been ill for 12 months, or three years, or whatever, and then you can have

this taken into account when marking. This can be especially important if you been struggling with your S or A-levels and want the right grades to apply to University. If you get a couple of decent passes and a B, or an A plus a B, or something like that, you write to the University and, along with your personal statement, you get a doctor's letter saying that you have missed a lot of your education, and they will take this into account.

Okay, it may not be possible for you to do a first-class honours degree at Cambridge but you can get some very good university places and there are one or two that I know of that are, actually, chronic fatigue syndrome/ME friendly and you can get a lot of educational support such as computer and voice recognition programmes as a result. Also, there are disability grants available. I have used these frequently and to good effect, and I have helped a good number of people get back to University using these approaches so, whilst chronic fatigue syndrome can be and often is a devastating illness, with the right management and the right help, approach and attitude of mind, you can do well.



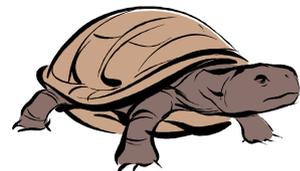
Recovery Point

It would be really nice if I could feel that all of the patients that I have seen have got better to a point at which they would have said they had fully recovered. However, I'm afraid that I can't do that. Getting better, from my point of view and my definition, would be that the patient would be able to say that they have got to a level of function that they are happy with and was probably nearly as good as it was before they became unwell. So let us see whether we can unpick this.

You are on this program, you are doing physical activity, mental activity, watching television, playing with your computer, doing the things that make you happy, going back to work, or back at school, University or doing whatever it is that you would like to do that makes you feel you have recovered. So the end point of recovery is whatever you want it to be and, having adopted the program that I have suggested, you have reached that point. If you want to be able to run five miles then you have to build it up gradually from a few metres to then, say, half a mile, one mile and so on until you get there and you progress by doing it in slow increments that you are comfortable with, bearing in mind that the one guaranteed marker of recovery is that whatever you do doesn't make you suffer for more than today, that you sleep well and wake relatively refreshed. If you wake unrefreshed - you're not recovered.

The same applies to what ever you want to do, whether that's to watch a film, or play with your computer for three hours. If it makes you feel bad and you suffer for it tomorrow you are not well; you're not in a position to say that you're happy with what you're doing. The most difficult thing to increase, as far as I can see over my

years of experience, is the intellectual, visual processing. The most difficult thing to do would be to return to a University academic career involving a lot of screen work, or to go back to work in a high pressure job and spend all day on a screen and answering the telephone.



How to avoid being ill again

This very much runs alongside what I have said above. Chronic fatigue syndrome/ME is a stress related condition, 99.9% of the time, and if you ever return to a stressful situation similar to that which made you ill in the first place, I can promise you that it is almost certainly likely to make you ill again. So, in order to remain well you have got to put yourself in a place where you are not exposed to a similar situation.

Stress levels are very individual; some of us can take more than others and we react to stress in different ways. As I have mentioned elsewhere, stress can cause migraines, headaches, eczema, asthma, irritable bowel syndrome, anxiety, depression and panic attacks. One can cope with only so much - it's whatever floats your boat. However, having been made ill with chronic fatigue syndrome once and, having exposed yourself to that particular stressful situation that made you ill in the first place, I will warn you now not go down that road again. If you see stress coming, you do not have to go there. Having been made ill once with chronic fatigue syndrome, I know from experience that it would take less stress to make you ill a second time, than it would have done the first time, so my advice to everybody is to avoid stress. You will now turn around and ask the question, "How on earth do I do that?" If I knew the answer I would be a millionaire!

However, here are a few indications as to what you should avoid, if at all possible. If you have a problem that is causing you stress the most important thing to do is to

resolve the problem, get rid of the stress. You are in control and it won't bring your chronic fatigue syndrome or ME back. I would sit down at the end of every four, five or six weeks and ask yourself, your partner, your husband or your family "Am I coping with my problems well enough? Do we need to resolve issues, sort things out, or address difficulties?" Don't carry them around with you. They are a burden that you do not need. If you are well and you haven't had a problem before then we can all cope with more stressful factors than we would like to but, when these factors have made you ill once, they will make you ill again.

I have given this advice to so many people and I must admit that, to my great disappointment, a lot of people come back to me, not once but even twice, having put themselves in the same situation, exacerbated their symptoms and made themselves ill again.

Chronic Fatigue Syndrome/ME never comes back by itself. Chronic Fatigue Syndrome/ME does not have a life of its own, is totally and absolutely predictable - 100% money back guarantee. If you do not expose yourself to what made you ill in the first place it will never come back.

If you do put yourself in a stressful situation, you will react to that stress with fatigue; not necessarily going back to as bad as it was in the first place, (at the beginning of your illness process), but there's no doubt you will get fatigue and your sleep pattern may start to deteriorate. These are your warning signs; these are the things you should avoid at all costs. If you wake refreshed, you're okay; wake up unrefreshed and you're heading for problems. **However, if you find yourself in a**

stressful situation do not panic. Don't think that you mustn't get up the next day, imagining that you are back to the point that made you feel bad originally and go worrying about the whole thing coming back again. It doesn't quite work like that. If you find yourself in a stressful situation for a day, a week or something like that, then you should take account of what's happening, try to reduce the situation you're in, remove the stress and don't push it.

The most difficult thing of all is to manage this if the stress lies within you, if you're a worrier or you have an anxiety level that is more than the average person would expect to have. If you're a worrier, you get stressed and you get headaches then you should do something about that. So, it's having to look at yourself and trying and resolve the issue that's more difficult. So it is my suggestion that you try to develop some self-awareness and try one of the coping with stress strategies that are currently available.

Remember the Hare and the Tortoise ?



And who won in the end!

