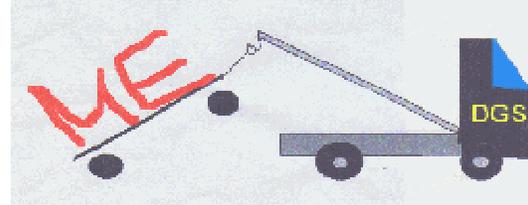


# ME/CFS—YOU CAN GET BETTER

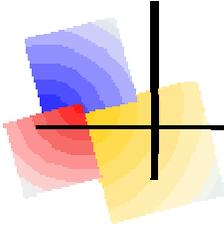
## **GET WELL GUIDELINES**



This is a PDF Copy of the full contents of Website [www.me-cfs-recovery.co.uk](http://www.me-cfs-recovery.co.uk)

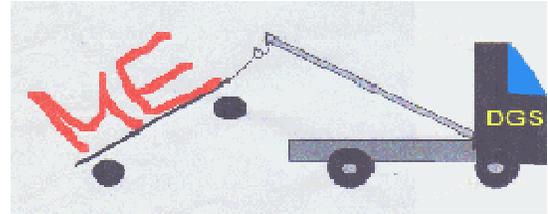
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## ME/CFS—YOU CAN GET BETTER

**GET WELL  
GUIDELINES**



## Recovery Plan for ME/CFS Sufferers

### Welcome

This website is intended to help those suffering from ME/CFS to help themselves recover from the illness, which IS POSSIBLE. Whilst the site has been split up to cover aspects indicated by the general headings on the links on the left, it is arranged in a logical order which can be followed through by using the "Next Page" links.

The Authors would not presume to claim that the programme referred to represents a universal cure, but we do know that it has worked for our son (who thankfully has made a full recovery) and for many many others. A study (by Dr David Smith and others), of treatment of children under the age of 18, based on these principles, was published in the October 2003 Edition of Archive of Diseases of Childhood - a British Medical Journal publication. < <http://adc.bmjournals.com/> > This gives evidence of an 80.6% success rate. It is acknowledged however that there are some who cannot tolerate the medication or the discipline of the regime that is required. Inevitably, there will be others for whom, for whatever reason, it does not work. We simply want to share these notes with those of you who would agree with us that it is a soundly based programme which is definitely WORTH A TRY.

This is no "quick fix" method of recovery; it involves self-discipline, patience and perseverance. Ideally it will also involve plenty of support from family, friends and other carers. Often it is this support, particularly in the form of dealing with the day to day practicalities of life, which make it possible to stick to the programme.

**We do hope you will find it helpful and if you have any comments at all to make, or any experiences to share, do please use the Feedback Form on the final page.**

**These notes have been produced in consultation with Dr. David Smith and reflect the general principles of the programme he prescribes for recovery.**

**With the help and support of a sympathetic GP there is good reason to be optimistic. Your Doctor may find helpful reference to Dr. Smith's Website:- [www.me-cfs-treatment.com](http://www.me-cfs-treatment.com)**

# Golden Rules

## The Golden Rules of the Recovery Program



1. **At the start of the programme all activity should be less than you can achieve.**
2. **Nothing should be put in the programme that cannot be done every day, seven days a week.**
3. **If you cannot do it every day do not do it once.**
4. **The programme should be moved forward by small increments. You should not suffer tomorrow for what you do today. On a good day never do any more.**
5. **It is widely believed by specialists in this field that this illness is in your brain - not in your body. (That is NOT the same as saying it is "all in the mind"). It is a biochemical, (i.e. one of brain cell dysfunction), not psychiatric (mental) illness. However, you may suffer some depression, anxiety and some psychiatric problems as components of the illness. (Follow this link for an article "Lets Knock the Stigma" reproduced from a Get Well Club Newsletter)**
6. **The use of anti-depressants is essential to treat sleep dysfunction. A mixture of antidepressants, in low dosage, is recommended. For example, a general prescription might be 10mg. Amitriptyline, Doxepin, or Trimipramine at night (THESE ARE NOT SLEEPING TABLETS), and 1 or 2mls of fluoxetine syrup (Prozac) or Paroxetine (Seroxat) in the morning. These dosages can be increased gradually to achieve the desired effect, but it is important to start at the lowest levels so that any possible side effects or sensitivities may be picked up. IT IS IMPORTANT that your prescribing doctor has an opportunity to read Dr.Smith's notes on this combined prescription. You can find them on his medical website <<http://www.me-cfs-treatment.com>> under the heading 'Management of AoPVS in Adults'. Antidepressants are not addictive.**

# Make Yourself Well

Readers may find it helpful to refer to 'Management of AOPVS in Adults' on Dr.Smith's website when reading these guidelines.

Basically, with the support of anti-depressants you have to MAKE YOURSELF WELL

This is essentially a slow, strictly disciplined approach and for a long time you may feel you are making no progress but, suddenly, you will look back and realise how much better you are.

There is no set time scale for recovery although roughly you will take as long to recover as you have been ill.



Regularise your sleeping and waking time - precisely, and stick to it. NEVER sleep during the day.

A self-help step you can take is, first, to quit work and lock up the TV, computer and games machine. Any visual input involving close concentration, such as reading, embroidery, jigsaws, games or detailed painting should be avoided until the programme is established, sleep pattern restored and symptoms are stable. (For guidelines on reintroducing these activities see Moving Forward).

# ACTIVITY

## ACTIVITY - PHYSICAL & MENTAL

Your day needs to be organised into a clearly defined programme in order to keep all activity under control in a manageable way. This should cover the time from after breakfast to your evening mealtime and should apply to every day of the week.



First, assess how much PHYSICAL ACTIVITY you can cope with per day, without being ill, (i.e. initially less than you can achieve), undercut the total and divide it by the number of hours over which your daily programme will run. If, for example, this undercut, maximum total works out at thirty minutes take a two and a half minute walk, every hour for ten hours, or two and three-quarter minutes for nine hours, each followed by five minutes or up to half an hour rest, (depends on how much YOU need). If this still proves too much, cut down more. After a period of time, maybe six to eight weeks your symptoms should be more settled (i.e. the same every day) and you should only feel a general tiredness, which will continue until you reach the recovery marker.

The same is done with MENTAL FUNCTION and split into hourly slots. There are many things, which can make you feel ill, (they vary from person to person) and they might not be immediately obvious so trial and error or keeping a diary might help.

The best way to assess your mental function capacity is to see how long you can read a book, as concentration is involved in most of the other things you do with your brain.



If, for example, reading knocks you out, you ration it as above but if it doesn't make you ill you can read more. The same applies to talking, hearing & listening, thinking, socialising, even watching the world go by. Test them by re-introducing them one at a time and monitor your response.

Never do things today that will make you suffer tomorrow

Anything that can be done without making you ill can be done with less control, although anything done to excess will make a 'well' person tired. Things that fall into this category can be incorporated into leisure time at the end of the day.

# REST

**REST should mean just that - resting mind and body but NOT sleeping.**

**However, DON'T OVER-REST - just gently 'potter'.**

**Do one thing at a time - e.g. don't talk and cook at the same time. Single level mental processing is important so you don't overload the brain.**



**In the early stages, when trying to stabilise your illness, it may be beneficial for some of your daily rest time to take the form of four half-hour rests of, literally, just sitting quietly, doing nothing. This can be an opportunity to practise relaxation techniques.**

**As you begin to move forward, these longer rest periods will decrease as your mental and physical activity periods increase.**

**DO NOT do anything which you know causes you stress.**



# FOOD

## FOOD INTOLERANCES

**Some people find that, after dealing with the mental and physical functions, they are still experiencing some symptoms.**

**It is possible to develop food intolerances with CFS/ME and if you suspect that this may be the case try eliminating certain types of food, one by one, to see if this makes any difference. Common culprits can be wheat and dairy products containing lactose. Once again, trial and error is the key.**



# Moving Forward

After some time (weeks, possibly even a few months), at the foregoing baseline level of activity, your symptoms should level off. If they are still acute you are still doing too much and need to cut back further. All you should feel at this stage is tired. Your sleep should have stabilised, i.e. you should begin waking up in the morning feeling refreshed (not shattered) and the bad dreams should gradually be ceasing. You can then start increasing your mental and physical activity slots, starting with about 10% increments per slot. You will eventually reach a point where it is practical to double each activity slot and rest periods and work within two-hour spans but it may be wise to work these in gradually.



**DO NOT INCREASE AT INTERVALS OF TIME OF LESS THAN TWO WEEKS.**

Everyone is different and you have to find your own level of progress. If symptoms (which may briefly reappear after an increase in activity) haven't disappeared within three days of an increase, the increment may be too much and you can stop, cut back to where you were before for about two weeks or so (may be less, may be more) and then have another go with a smaller increment.

**DO NOT DO ANYTHING WHICH CAUSES YOU STRESS**



Think of your energy levels as a bank account. When you are bankrupt you have to save up to a certain balance before you can start regular spending again. After a while you can start spending in small amounts and you can only become a big spender when you have a full account to fall back on.

**INTRODUCING READING, TELEVISION AND COMPUTER**

**WATCHING TELEVISION** Once you have started to sleep well and wake feeling refreshed, you can start doing some very limited visual processing. This should come within the structure of your mental processing slots in the programme. For instance, if you particularly want to watch television then it is suggested that you use a DVD/Video Recorder and then watch ten minutes per hour. The more mentally demanding the television programme the shorter the period of time it should be watched. If you have done ten minutes of television then, of course, you can't do any reading or any computer within that next hour.

**READING.** If you want to read then it is suggested that you start with just one page of a book, (or even less if your visual concentration begins to deteriorate), and progress gradually from there.

**and COMPUTER** If you are on broadband it is suggested that you leave it booted up and linked to the internet all of the time and then your time slot is not wasted on technicalities. If you want to do a bit of computer work, then it is suggested you start with two minutes per hour right from the word go. This allows you, at least, to print off an e-mail and, maybe, write an e-mail of one or two lines in reply. However, if you use the computer for a couple of minutes per hour (say up to five minutes maximum) then you can't read or watch television. If you read, then of course, you can't watch television or play with the computer - it is simply one thing at a time. In order to simplify this it is suggested that you should have a television day, a computer day or a reading day so that you don't get bogged down with different activities confusing one another.

It is suggested that all three of the foregoing activities are enjoyed between breakfast and your evening meal. After your evening meal no visual processing of any kind should be done during the period of winding down before going to bed.

# FRIENDS

## KEEP IN TOUCH WITH YOUR FRIENDS

If possible, keep control of your social life while keeping in touch with your friends. Explain what you are trying to do and invite them to encourage you - maybe help with shopping, or a lift somewhere would be welcome. Get an answering machine so they can keep in touch with you and encourage you but YOU phone them back as your programme permits. Also, do things which you enjoy doing and are nice for you but not necessarily serious work. You may even discover new skills or talents you didn't know you had.



# VIRUSES

**If you get a cold or other virus while recovering you stop doing everything until you begin to feel the acute stage is over and then, gradually, over a few days or a week build your programme back up to the level at which you were before the virus. Some viruses take longer than others but a ME sufferer will be affected for up to twice as long as a 'well' person.**



# Returning to School

## Back to School

When you reach a daily level of mental activity equalling about one and a half hours (the equivalent of two average school lessons) a return to school or college can be considered. It would be desirable to have a break between the two lessons attended so a lesson either side of morning break or either side of lunch break might be envisaged. The idea, then, is to build up the third lesson period to be attended by adding on a daily work slot at home, after school, of say ten minutes, increasing to twenty minutes the second week and thirty minutes the third week, the fourth week attending school for the extra lesson.



It is important to get the Headteacher and subject tutors on your side while doing this as they cannot expect complete preps to be handed in after each lesson attended. Make sure at the start that they understand exactly what you are trying to do and how you plan to go about it. It may be a good idea to regard one's attendance at school for the current academic year as merely 'therapy', so there is no pressure, and be prepared to repeat the year once up to full steam. Games periods, which tend to be 'doubles' can be introduced by, perhaps, a half period to begin with.

All the foregoing falls under the guidelines outlined earlier. Trial and error is the key and no two people will move forward at the same pace or in the same increments. A return to school, after a long absence, can be stressful as it can mean rejoining peer groups with whom contact has been broken or it may mean joining a new school. Just remember, that there is more to life than exams.



## Returning to Work

Returning to work should, initially, be discussed with your employer. If you work in an office it may be helpful to just attend for a couple of hours, daily, just doing the filing or some other non-demanding role. If this is not possible, consider getting a voluntary job for a few hours each day. It may be possible to do a little voluntary work, if your Doctor will vouch for it being 'For therapeutic purposes' without losing any Benefit you may be receiving, but you should discuss this with your Benefit Office.



Once again, it is important to explain to your employer what you are trying to achieve and how you plan to go about it. If it was your job that caused the stress in your life may be this is the time to downshift.

# Medication

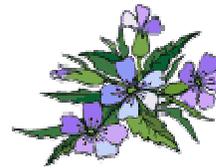
## Withdrawing Medication

**This is encouraged at about 50-75% level of recovery. It is advisable to do this under the guidance of your GP as it has to be done very, very slowly. i.e. about 5mg/0.5ml per week, fortnight or three week period. Some people may find they need a small maintenance dose for a while, until they have regained some confidence but, once again, everyone is different.**



# RECOVERY

## Recovery



**THE MARKER OF ME RECOVERY** is when you recover from a cold or other viral infection in the normal time span. You will still feel an underlying tiredness until you are 60% to 70% well.

If you have a day when you feel particularly good **DO NOT** roar off and do more than your programme dictates because the **GUARANTEED** result will be a relapse which can take a week or more to recover from.

Never be afraid to take a whole day off, occasionally, and do nothing but be lazy and do not feel guilty about it.

**REMEMBER THE HARE**



**AND THE TORTOISE-**



.....**AND WHO WON IN THE END...!!**

# Testimonials

## *The Recovery Room*

*Welcome!*

This page contains stories of recovery from some of Dr.Smith's patients and others.

(Their names have been changed to protect their privacy)

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### *The one that says it all*

(a letter received recently by David Smith accompanied by some flowers)

- the text reads as follows in case it is not clear -

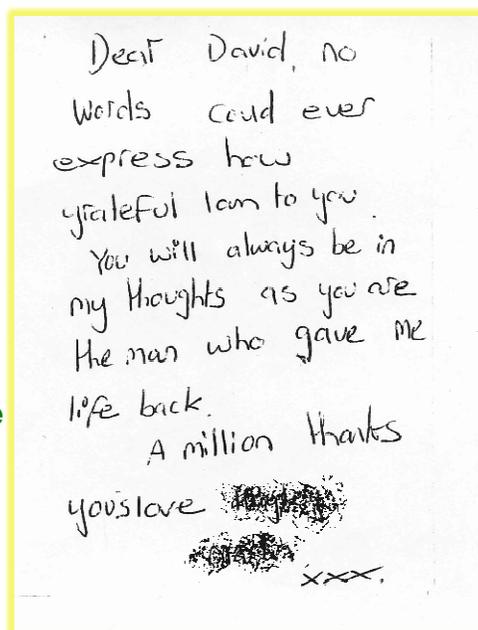
" Dear David, no words could ever express how grateful I am to you. You will always be in my thoughts as you are the man who gave me life back.

A million thanks

yous love

xxx"

---



**Richard** was eight years old when he suffered a severe attack of tonsillitis. He recovered after a week of antibiotics but the infection returned for 24 hours. Over the next few months he experienced an increasing amount of time off school with sore throat, tummy ache, nausea, dizziness, severe physical exhaustion and nightmares which left him sweating and disorientated. Over a period of two years this worsened to the point where Richard could only manage two lessons in school for a couple of days a week. I pressed our GP for a referral to a Paediatrician, who, coincidentally, had recently been to a lecture by Dr. Smith.

Dr. Smith had Richard assessed by a Psychologist to determine the damage to his cognitive function. This turned out to be quite severe. A small amount of antidepressant was prescribed. We embarked upon a programme of mental and physical activity and had the services of a Home Tutor from the local EA until, seven months later, Richard returned to school for two lessons a day. In our case, this is the point at which Richard's recovery slowed down. We later discovered that this was because he was being subjected to mental and physical bullying by his peer group. We had asked him if he wanted to change schools at the time of his return but he was quite sure he wanted to stay put. We eventually parted company somewhat acrimoniously from his prep school and sent him to a co-ed school. By this time Richard was attending school full time but his confidence had taken a hammering. He took a year to settle in his senior school and so repeated Year 9 but since that time he hasn't looked back.

Richard is now nineteen, has seven GCSEs and two A levels, has been in his school's soccer First Team, has a full and lively social life and is about to go to College. He has suffered no adverse effects whatsoever from taking antidepressants. We could not have reached this stage without Dr. Smith's expertise and tremendous support. We have had to fight some battles with school personnel along the way and Dr. Smith has been right behind us every time. We shall be eternally grateful to him.

September 2002

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**Jane** had gained a Degree in Chemistry and, in 1994, had started studying for a PhD when Chronic Fatigue struck following a virus.

"I was very fortunate to meet David Smith at the end of 1995. For most of 1996 I lived my life with a stopwatch, gaining control over the CFS so that I could start to increase my daily activities. By January '97 I had made enough progress to be able to start working as a volunteer for my local Citizens' Advice Bureau (CAB) for two hours a week. I gradually increased my hours and, at the beginning of May '97 when the admin assistant left, I job-shared for an adviser, working initially for ten hours a week and increasing to twenty.

"After a couple of months, to test how my brain power had improved, I started a computer course in the afternoons, to brush up on my skills. Once I'd finished that I started to train to be a CAB adviser and took on a City and Guilds Stage 1 in Adult Teaching. In March '98, when I had finished my adviser training and basic teaching, the CAB decided to increase my hours to thirty. By July '98 I was working for four days a week for the CAB and one day a week as a freelance IT consultant for our local National Association. In April '99 I had a promotion and now work full time as Administrator/Technical Adviser for my local CAB. In summer 2002 I have gained a Diploma in Management Studies.

"I've told you all this because, when I started seeing Dr. Smith, I was only able to concentrate on the computer for ten minutes at a time and could only cycle for two and a half minutes. I am now living a normal life. The first stage of recovery was relatively slow but I hope you can see that from June '97 my recovery started to take on a much faster rate. So if you are at the bottom end of the curve trying to control your illness and slowly increase your boundaries the motto is -

"Things can only get better!"

September 2002

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**Anna** had been ill for ten years before being diagnosed with CFS.

"For most of that time I had led a 'normal' life, even though I couldn't plan ahead very much as we never knew if I would be up to it by the time the day arrived!

I was very up and down – it seemed that about every six weeks I would get glandular fever symptoms (it was glandular fever that I had suffered with right at the beginning) which would clear up after one or two weeks' rest.

Then I went on holiday to Kenya and had a few vaccinations, which were required, as well as taking anti Malaria tablets. Big mistake! I didn't feel quite right while we were away and felt much worse once we had returned to the UK.

The following year was spent visiting various Doctors and feeling dreadful. I was away from work more than I was there!

Finally I got to see Dr. David Smith who told me I would be up and running again within two years if I committed myself to his programme.

It took a few months to get my CFS under control and I found it very frustrating limiting everything I did, but as the months unfolded we began to see an improvement. Soon I was able to take a bath every day – as long as someone helped me to wash and dry my hair. I began spending less time in bed during the day, a little longer chatting to friends, a bit more reading, a bit more music and soon a year had passed. I began to improve very rapidly then and I found it really difficult to hold myself back! Twenty paces from the front door turned into a five minute walk, soon building up to a whole twenty minutes. I began pushing my wheelchair around the shops (and loading it up with purchases – good for my self-esteem, not so good for my finances!)

Two years have now passed since my consultation and I am a different person. I have started working again – part time and local. I watch a whole TV programme at once with no ill effect. I have bought a house with my boyfriend, which we keep fairly tidy (!) I've even helped with the decorating. We have bought bikes. We only cycle for ten minutes at a time but I will soon build that up. And best of all, I have been on a Girls' Night Out to a pub, then on to a night-club where I danced for a whole two hours, arrived home at 3.00 am and suffered no repercussions!



**Barry** was a busy schoolboy at the local Grammar School in October 1987.

"I was in the choir, three orchestras, Captain of the school shooting team and, oh yes, studying for eleven GCSE's. In the half-term I got the flu' and struggled back to school after about three weeks, but the more I tried to catch up the worse I felt. I got a bit better over the Christmas

holidays and put all my energy into my mock exams, which went surprisingly well considering my three-month absence from regular school. After that I went downhill quite badly, spending most of the day sleeping in bed and feeling absolutely awful. My condition worsened for the next two years. In this time my parents tried pretty much everything from healing to acupuncture. Most helped for a short time but the symptoms persisted.

I went to Dr. Smith after being unwell for nearly three years. I followed his advice in building a personal program to slowly increase my mental and physical activities, week by week.

I had a physics tutor who came in once a week and I learnt to walk again with the aid of riding lessons with Riding for the Disabled, to strengthen my wasted leg muscles. This program progressed for a year until I was ready to go back to study for my GCSE's at the local Sixth Form College (who were absolutely terrific). I only did six in the end but the next year I fulfilled the ambition I had had for a long time.

Firstly, I managed to get into the Sixth Form, at last - four years too late but better late than never! Secondly, I got my Private Pilot's Licence! The Civil Aviation Authority insisted on no less than nine thorough medicals before I was allowed to fly solo. It had been my ambition to become a commercial pilot since the age of seven and I had joined the RAF as a cadet before becoming unwell. Despite everything it remained my ambition to beat my illness and to achieve my dream, although at times there did seem to be little hope.

After my A Levels, I went to Cardiff University where I gained a BSc.(Hons) in Business Administration and took part in many extra-curricular activities which also included starting my own society to visit places and organising walking and canoeing trips from as far apart as Swansea to Amsterdam. Oh yes, a certain amount of going out and one or two drinks were consumed along the way! In my final year, I applied for sponsorship from a few airlines and, after some tough interviews and aptitude tests, I was offered a sponsorship by KLM (UK). This included becoming a flying instructor for two years at Biggin Hill. I have now been at Biggin Hill for the last six months and have been the busiest flying instructor for a couple of them. At present, I am on a trip to Holland, where I am writing this, but so far I have visited France, Spain, Morocco and Wales as well !!

So, how did I get here? Well, I believe there are two reasons. Firstly, I had terrific support, especially from my mother, so when I needed to rest I could do so; my only commitment was to myself to get better. Secondly, I had a goal. I'd never heard of anyone getting better but I was determined not to be beaten by my lot. I aimed for a job where I

didn't just need to be ok - I needed to be healthy and well and I could not afford to have a 'bad day' or a relapse.

So, am I fully recovered? Yes, but I have had to learn to adjust my lifestyle wherever appropriate. The real test for me was my first term at University when I became quite unwell and I picked up every cold and virus around. I realised that I couldn't continue that like and I found my level by eating sensibly, working sensibly (well, a bit anyway) and playing sensibly. If I did go out all night I couldn't go in next morning. I *had* to get a good night's sleep. It is now the same at work. I do make sure that if I have had a busy week I have a quiet weekend to catch up with myself - but that's normal isn't it?!

---

**Robert** writes:

"I've just come across your website after one of my regular checks on David Smith's Website. My daughter, Sally, suffered from ME/CFS from the age of 10 and it wasn't until she was 14 that we came across David Smith via the father of one of his patients on the internet. I had a look at the website and was interested.

"Simultaneously, the consultant paediatrician treating Sally went to one of Dr. Smith's lectures and was keen to try the treatment. We jumped at the chance because nothing else we'd tried had come remotely close. Sally's consultant put her on the antidepressants and then prozac. After only 18 months she completely recovered, and in the meantime carefully integrated herself back into school slowly but surely.

"Now 18, she has just received her A level results and is set to train as a doctor in London. Needless to say we are over the moon!"

August 2002

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**Cherry** was fifty-eight when she became very ill. Glandular fever led to hepatitis and jaundice, eventually leaving her with ME.

"Luckily my doctor referred me to Dr. Smith after only a few months of being ill. My first visit lasted 45 minutes. He said I should stop working; this was easier said than done as my husband and I were running our own pottery school and we were working all hours, teaching up to seventy students a week.

"At first I tried to carry on as normal until I realised I had to stop completely before I would start to get better. I was put on tablets to make me sleep at night and I started to delegate jobs. I couldn't hold a conversation, answer the telephone let alone do a days work. Eventually Dr. Smith said I could start taking Prozac - I had heard such terrible things about the drug so I was worried. Dr. Smith reassured me it could be taken in liquid form and is carefully regulated. As the Prozac was increased I was able to do more. With my ME I had a pain over my heart. Dr. Smith said 'Work until you have the pain' - that was my warning not to do too much. "Over a year I completely altered my life style and cut my workload and I responded to the treatment.

"At last Dr. Smith said I could start decreasing the Prozac by two drops a month (as far as I can remember) and it was by this method one could reduce the medication by such a little that the body didn't notice.

"I was still told to work until I got my pain but gradually I found I could do more. It took months to be weaned off the Prozac but I'm sure this method of medication was the reason for my successful recovery.

"I am now 66 and retired. We have an acre of garden to look after and we walk on Exmoor. I can easily walk six miles. My lesson was not to try and do at 60 the things I could easily do at 30! If I do too much I occasionally get my pain and I have been left with shaky hands."

October 2002

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**Carol** didn't quite make it. An 'A' grade student, Carol gained a place at Oxford to read History. During her first year she caught 'flu but kept studying. By the end of the year she could study no longer, suffering the classic symptoms of CFS. She moved out of her parents' home

after finding the pressure from her workaholic father to 'keep on doing' too much to cope with. After two years of illness she was referred to Dr.Smith.

Living in a top floor flat with, sometimes, noisy neighbours, Carol found it difficult to stabilise her illness and it was several months before she was able to start increasing her activities. After some considerable time she was well enough to enrol at the local college to take an 'A' level, which was eventually to be her undoing. Fired with determination to do well she spent too long trying to perfect essays and got into panics if they were not up to scratch. She found her symptoms returning with a vengeance and eventually had to give up her college course.

Carol then contracted Shingles, which laid her low for several months and in between an increasing number of subsequent minor viral infections she managed to climb back up again to be able to do a voluntary daily half hour stint helping in a local infants' school. After over a year doing this and being unable to increase further the time she spent 'at work', Carol left. Her Landlord then decided he wanted to sell her flat so she moved back in with her parents. The last we heard she was working a few hours daily in a local delicatessen.

September 2002

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***A visitor to the website from the Southern Hemisphere writes***

.

My name is Ross and I live in South Africa . 15 years ago I had a severe case of ME and was off work for several months. It took me years to regain my health . Last October I had a serious relapse and feared being boarded from work . Searching the Internet desperately

I was more than prepared to be a guinea pig and took a six months course. The effect was unbelievable and within two weeks I was so much better nobody (particularly my GP) could believe it . I was advised to carry on for the full six months which I did and have never looked back. I have friend in New Zealand who has suffered for very many years and suggested that she try the treatment . She

has been on it for a while and I am told has benefited greatly. I am extremely grateful to Dr Smith for putting the info on the net It is so well explained and all makes so much sense.

I am very happy to supply more details to anybody who is interested. My E-mail address is [pak03541@pixie.co.za](mailto:pak03541@pixie.co.za)

November 2002

***Yvonne*** was referred to Dr Smith in 2001.

"The good news is that, 2 years on, I am doing really well. I'm not exactly 100% back back to my old self yet (and I'm still not working), but I'm able to enjoy a full life again and I have lots of exciting plans for the future."

"I've just completed a part-time teaching course to gain a qualification in teaching English as a foreign language. I'm engaged to an Italian guy and I'm finally feeling well enough to make the long awaited move to Italy. I'm hoping to leave the UK early next year - the exact timing depends on how long it will take me to get my house packed up and rented out. I'm going to be taking this at a much slower pace than I would have attempted before my CFS!! We have the wedding planned for May 2003 so I have lots to organise on that front too! It will be a busy time and a good test of my new health and what I have learnt about how to keep it!"

September 2003

### ***A Cautionary Tale from Margaret***

Twelve years ago, I was diagnosed with CFS.

People sometimes ask me if I am completely better now. I used to tell them -

*"Yes - and no. Yes, I am vastly improved: this week, I wrote an article, worked on a screen play, helped out at a friend's theatre*

*performance, attended a writer's circle and went to a birthday party. But I can't do what I used to be able to do"*

That is what I used to tell them until a thought struck me: very possibly, nobody is able to do what I used to do – and live.

I am a 'do-er.' Before I got ill, if something needed doing, I was up doing it. If a child in the street dropped its rattle, I would be the one to rush over and pick it up. I got a huge kick out of 'doing.' Then I got ill.

For three years, I couldn't go out in a wheelchair unless it had a head and foot rest.

Then I saw Dr Smith and began my slow but steady recovery.

So if you are a do-er, remember that you may have a will of iron but you have a body of flesh and blood. Respect it. Look after it. And it will look after you.

Margaret

December 2003

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**Nel** writes

I had been ill for approximately eighteen months before I was referred to Dr. Smith. I came down with Glandular Fever in January 2001, although looking back, I had already been experiencing the first symptoms of fatigue a few months before that. I was completing the final year of my 'A' Levels so stress was rife! My condition gradually deteriorated to the extent that, although I was able to complete my exams and gain the necessary grades, I had to postpone going to University.

In the following months, before I had even heard of Dr. Smith, my activity declined to days of lying horizontally in front of the television and crying in desperation when it was necessary to leave the house. In July 2002, however, my luck and indeed my condition was about to improve, as I was referred to the respected expert in Essex.

Dr. Smith's recovery programme came as a great shock to me, as I had never heard of any such cure for this condition. I followed his

advice and with a great deal of encouragement and support from him during the following months of hardship, of having to give up almost every thrilling aspect of one's life, I am now fully recovered. I followed his regime for a little over a year and was discharged from his care last November. Since then I have been cementing my recovery.

I returned to my (amateur) dancing classes and can now enjoy the full two hour dancing lessons. The school recently put on a charity dance event, for which I learnt several dances, ranging from tap, ballet and contemporary. It was a great success with the whole school of about a hundred dancers, (including our teacher), of ages ranging from five through to fifty, taking part. Furthermore, I now have an active social life, do a few days voluntary work within the offices of Crisis (a national charity for the homeless) and am looking forward to beginning my study of English Language and Linguistics at Sheffield University in September.

Dr. Smith not only taught me how to recover from CFS: he equipped me with the invaluable knowledge of where the illness originated inside me. Therefore, I left feeling confident that it would never return. It's been an interesting few years, for which I certainly had not planned, but with Dr. Smith's help I now have never felt so alive!

October 2004

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### ***Esther's* mother writes:**

Esther was treated several years ago. At that time she had been diagnosed for around 3 years but was receiving no treatment or help whatsoever. She was no longer able to attend school and was about to take her GCSE's, having been receiving 4 hours a week home tuition.

She is about to graduate from the University with a B.Sc. (Building Surveying) and is aiming to return next term to commence her Masters in Facilities Management. She has achieved this on a day release basis and has been working for the past two years.

Prior to acceptance at University she spent two years at a local college and obtained a National Diploma in Construction.

**She has travelled to Australia and New Zealand (twice), the West Indies and Canada - a trip in the car used to tire her for days.**

**None of this would have been possible but for Dr. Smith, his treatment and the kindness and compassion that he showed towards both her and her family.**

**She has learnt to pace herself, to prioritise her workload and social life - like Scarlett O'Hara, "Tomorrow is another day - I can't afford to think about that today".**

**So, I will say Thank you, Thank you, Thank you.....**

**July 2005.**

# News and Links

## News & Links

### 8th February 2004 Chronic Fatigue Syndrome in Children - a Cross Sectional Survey

A peer reviewed Study, by Dr. M.Patel, Dr.D.G. Smith, Dr.T.Chalder and Prof.Simon Wessely, showing the success of Dr.Smith's recovery method was published in the BJM publication, Archives of Diseases of Childhood, October 2003 edition, Vol.88 P.894-898. Follow this link to view a full copy. <http://adc.bmjournals.com>

The data needed for the Study was obtained by sending eligible patients a battery of standardised questionnaires by post. Further data was later obtained from the clinical notes and a follow up telephone call.

The Study involved thirty six children between the ages of eleven and eighteen, who were all treated by Dr.Smith at his secondary referral clinic in South-East England. Using Cognitive Behaviour Therapy, graduated activity and low-dose antidepressants (Tricyclics and SSRI's) these children have shown that recovery is possible.

Initially the children were screened for anxiety and depression and subjected to standard clinical investigations. After close discussion with parents and child a personally tailored programme of modified activity was devised for both mental and physical activity. The children followed their regimes in their home environment, supported by their families, and were monitored monthly by Dr.Smith in the early stages. Gradual return to school was encouraged as soon as was practically possible and treatment appeared to double the number of children actually attending school. Return to normal health or significant overall improvement was reported by 29 of the 36 subjects (80.6%).

Dr. Smith has been treating children and adults, with considerable success, for over ten years and, working within the NHS, has contracts with several Local Area Health Authorities. This Study shows that whilst Chronic Fatigue Syndrome entails significant suffering for children the prognosis is generally good and indeed better than that reported elsewhere.

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Dr Smith's own website which is rather more "in depth and technical" and which has previously been published at [www.stantonm.addr.com](http://www.stantonm.addr.com) has now been rewritten and republished. All new material can be found at [www.me-cfs-treatment.com](http://www.me-cfs-treatment.com) which in future will be his main site. (Webmaster 28/7/05))

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The Report of the CFS/ME Working Group to the Government's Chief Medical Officer was published on the 11th January 2002. This can be found at:

<http://www.publications.doh.gov.uk/cmo/cfsmereport/index.htm> from where it can be printed off together with "Annexes" to the document. It is a substantial report and those interested may find it easier to download it to their computers and read or refer to it at their leisure, rather than trying to take it all in whilst online.

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We have included on the site an article entitled "Lets Knock the Stigma" reproduced from the Summer 2002 edition of the Get Well Club Newsletter. [Click here to read the article](#)

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*The MEACH Trust* is a new Charity formed to provide specialised residential accommodation and care for patients suffering from severe and chronic ME.



“There is nowhere in the country that provides long-term specialised residential care for ME sufferers. Ordinary Nursing Homes cannot cater for the needs of people who experience heightened sensitivity to stress and external stimuli, who are allergic to a variety of chemicals and who cannot tolerate light or noise. In addition, sufferers’ ability to concentrate, to communicate, even to more, can vary dramatically from day to day, which increases significantly their need for specific understanding of the condition.”

The above is an extract from their brochure.

Do have a look at their website at [www.meach.org](http://www.meach.org) and support them if you can

**Get Well Club Comment:**

*This is something that is much needed. Feedback from the Get Well Website reveals many people who would love to try Dr.Smith's recovery regime but cannot because they live alone and are so isolated or surrounded by unsympathetic 'friends' that restricting their level of activity would mean they would need help to do shopping, cooking and other basic day to day things. What would, also, be useful is a nationwide 'buddy' system whereby someone in the early stages of recovery can have a mentor and guide to support them and, perhaps, do shopping and help in other ways until they are able to do these things for themselves.*



**This is an informative and interactive site for ME/CFS sufferers and carers, bringing Christian encouragement to lonely people and promoting creativity.**

Click picture or go to address - [www.menotalone.com](http://www.menotalone.com)

Also, within the site there are "Latest updates" at [www.menotalone.com/updates.html](http://www.menotalone.com/updates.html) and "Reflections and Meditation at [www.menotalone.com/reflections.html](http://www.menotalone.com/reflections.html)

**At present this site does not appear to be working which is a shame. However, we have left the link here in the hope that the site may be restored soon. (Webmaster 28/7/05)**

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*Claridge House* A Centre for Healing Rest and Renewal

We have recently heard about about Claridge House, a retreat centre in Lingfield, Surrey which is run by the Quakers in association with Friends Fellowship of Healing. Their philosophy is based on spirituality, not religion, and, primarily, is to provide individual rest, convalescence and healing in an atmosphere of understanding and love.



On looking at their website it looks an ideal place for a short countryside break. It is under the flightpath for nearby Gatwick Airport but we do know that planes are not very low at that point and are usually incoming. Also, on checking this out for ourselves, we do not believe that this aspect will be significantly intrusive. Full board works out at £50 per day although there is a midweek break package for only £98, out of season. Bursary help is available. All rooms have wash basins and drinks making facilities and there are four of these on the ground floor, two of which are specially equipped for disabled guests. There are two lounges as well as a quiet room. There is no television but there are activities and courses available if you should want them. The menu is vegetarian and special diets can be accommodated with prior notice.

Check out their website on [www.claridgehouse.quaker.eu.org/](http://www.claridgehouse.quaker.eu.org/) or telephone 01342 832150.

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### "MIND-BODY HEALTH AND STRESS TOLERANCE"

is the title of a recently published book by David Jameson. As a former CFS/ME patient who has now recovered, David has brought together much of the research that has been done into this illness and the result is this very interesting book. Not only does it outline how the illness develops as a result of stress and burnout, but it also carries very useful advice as to how one can prevent it recurring after recovery.

More information about the book, and how to obtain a copy, can be found on David's own website at [www.mind-body-health.net](http://www.mind-body-health.net)