CHRONIC DISEASE MANAGEMENT – CHRONIC FATIGUE SYNDROME

A patient's experience of overcoming chronic fatigue syndrome and engaging with clinicians faced with medically unexplained symptoms

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SUMMARY

Whilst debate continues around the aetiology, classification and treatment of chronic fatigue syndrome (CFS), the authors report on a successful case of chronic disease management during a time in which little clinical evidence on the most effective methods of treatment was available; question whether this protracted, and polarised, debate may have had a detrimental impact upon sufferers of this condition; and also advocate a more holistic approach to the treatment of medically unexplained symptoms in general.

INTRODUCTION

A situation where a patient presents with a disease of unknown origin, with an uncertain treatment plan and an uncertain prognosis raises a number of dilemmas for clinicians working within both the primary and secondary care sectors. The main dilemma may be in the form of a lack of a solid evidence base on which to build a suitable treatment plan, or the manner in which medically inexplicable and clinically baffling symptoms present a challenge to rational scientific thinking and medical training. Medical debate can arise regarding the intrinsic cause and treatment for such symptoms, the psychosomatic or physical nature thereof, and, in the absence of a firm consensus of opinion, differing opinions can become polarised, leading to a situation where patients may feel alienated by the experience. This paper seeks to give clinicians, from all specialties, an insight into what this situation can be like from the perspective of a patient who experienced these difficulties first hand and sought to overcome such a situation, and also from the perspective of a General Practitioner (GP) involved in treating such medically unexplained symptoms in the context of CFS.

THE PATIENT'S PERSPECTIVE

Background, symptomology and diagnosis

In May 1990, almost 12 years before the Chief Medical Officer (CMO) for England and Wales endorsed the recent report of the CFS/myalgic encephalomyelitis (ME) Independent Working Group,[1] and formally recognised CFS/ME as a chronic illness[2] I was diagnosed, at the age of 22, as suffering from ME by a consultant physician. This followed a period of over six months during which my general state of health had deteriorated considerably following the contraction of what could perhaps be best described as a virulent strain of influenza which, for whatever reason, my body had been unable to recover from and which left me feeling fairly unwell. During this initial period of ill health I continued with normal work and social activity (including vain attempts to sweat the after-effects of the virus out of my system through a variety of sporting activities), and I underwent a range of blood tests in order to eliminate diseases such as glandular fever which the GP whom I had been consulting at the time had speculated could perhaps have been the cause of the symptoms which I was presenting with (profound fatigue following, and exacerbated by, exertion; severe muscle pains in my arms and legs; recurrent sore throat; short term memory loss and a slurring of speech). Given that I had also suffered recurring bouts of tonsillitis in the preceding year, and required courses of antibiotics for this, it was suggested to me that a possible cause of my symptoms could have been a mild form of post viral fatigue which had been exacerbated by either another infection or by 'overdoing things' (as I had not been abroad or been exposed to any infectious diseases that I was aware of).

The gradual deterioration in my health continued until April 1990 when I collapsed at work and was referred to a consultant in infectious diseases for a specialist opinion. This referral was made following the negative results of earlier investigations carried out by my GP and also in immediate response to the profoundly debilitated condition which my body was in at that time – the earlier symptoms had intensified and I had great difficulty walking, or even standing up, and also in carrying out 'simple' tasks which I had taken for granted, such as holding a pen or combing my hair. In addition to experiencing this profound exhaustion and muscle pain I had started to present with a variety of additional symptoms including sensitivity to light, severe headaches, blurring of vision, altered taste, sensitivity to sound, profuse sweating, trembling muscles and dizziness, to name but a few.

Following a clinical examination and a detailed taking of my case history by the consultant, a diagnosis of ME was given. For those readers within the general medical

audience of *The Journal* who may not be familiar with this clinical area I should, perhaps, point out that as there was not, and is still not, a specific diagnostic test for this disease, the diagnosis made was a diagnosis of exclusion (which involved the exclusion of diseases such as HIV/AIDS and a variety of neurological disorders). The consultant who made this diagnosis was very helpful in explaining that a number of patients experience varying forms of post viral debility following certain infections and that the lack of clinical knowledge and evidence in this area, coupled with the individual patient's particular circumstances and symptoms, meant that an accurate prognosis would be very difficult to give. It was further explained that whilst the most effective treatment for ME was also unknown, the most appropriate form of therapy, in the meantime, would be to combine short periods of rest with normal activity ('not exceeding 50% of (my) available energy') and that the vast majority of patients suffering from ME made good, if not full, recoveries within a relatively short period of time. In my case, the opinion was also expressed that my particular form of post viral debility had hopefully peaked, although this was also another unknown.

Reaction to diagnosis

Upon receiving the diagnosis I experienced a mixture of emotions ranging from relief to confusion. In the main, I felt relief that someone seemed to know what was happening to my body; that my symptoms had not been due to anything more sinister; and that I had not been imagining my symptoms.

The term 'myalgic encephalomyelitis' was not, at that time, well known to me and I was only vaguely familiar with this illness through occasional sensationalist media articles in which it had been referred to as 'yuppie flu' and which had portrayed sufferers as being either over-achievers who had 'burnt out' or as being work-shy, depressed malingerers. (Fortunately, I was completely unaware, at that time, of the protracted medical debate which would continue to unfold regarding the nature of this illness and what the precise clinical definition of this should be. For the purpose of writing this paper I have simply opted to use the clinical diagnosis originally given, of ME, but will comment on the debate regarding this definition later in this paper.)

Whilst the slightly controversial 'public' nature of the diagnosis was a little unsettling, it was not as unsettling as finding myself in the position of receiving a diagnosis, but no firm indication as to how to treat my illness or, indeed, to receive a firm prognosis based upon this diagnosis. This confusion bordered on disillusionment when I attended a follow-up appointment with my GP, and it started to become abundantly clear that there was very little information available to GPs on how to manage and treat ME at that time and that, ultimately, the responsibility for recovering from this unknown illness had been left with me as the patient.

Early attempts to devise a treatment plan

Following diagnosis, my (then) employers were very supportive and agreed for me to return to work part time so that I could manage my energy levels by balancing periods of activity with periods of rest during what I believed would be a short period of recuperation prior to regaining full health. During the periods of rest I used any available energy to further my understanding of what was happening to my body in order to hasten my recovery. This simple act of seeking to gain more information was quite empowering and came naturally, as my work, at that time, had primarily involved general research.

Through a process of trial and error I managed to source some very informative papers and texts including two books[3, 4] written by clinicians in the UK who had been diagnosed with ME themselves, and which served to provide a useful introduction to the subject matter. Given that there was a variety of 'self help' books on this subject appearing on the market, I believed that clinically authored books would offer a greater element of quality assurance with regard to the content and would also offer further sources of reading material. At first the information was a little overwhelming as, out of necessity, the information covered mild to very severe cases of the illness, but this did not distress me greatly as I did not see myself as fitting into the severe, longer term cases. I was also interested in the fact that these clinicians had similarly found that conventional medicine had very little to offer for these medically unexplained symptoms and that some conditional credence was given to a variety of complementary therapies which other patients had reported some benefits from trying.

My initial attempts to act upon this new information were, however, short lived, as I contracted another 'virus' in September 1990 which left me bedridden for about six weeks. In hindsight, it was clear that my illness had not peaked, as had been hoped and my health deteriorated considerably during the next 18 months as my apparently lowered general immunity left me unable to fight off simple cold viruses and infections. These infections, in turn, triggered relapses which put me back in bed for many weeks at a time and greatly intensified all of my symptoms. During these periods of relapse I had great difficulty in reading and had to wait for spells of lesser exhaustion and greater lucidity during which I could focus my energy on reading the earlier papers and books which I had sourced and, in turn, on developing a treatment plan which would assist my recovery.

Disease management: managing the unknown

At the outset of my illness there was very little in the way of medical treatment available for ME. Whilst I was not necessarily expecting there to be a 'magic bullet', I did

have a number of discussions with my GP regarding possible pharmacological treatments which might have been of assistance in alleviating my symptoms, but since general medical opinion, at that time, was split between the causes of ME being physical or psychological, any pharmacological interventions were limited to analgesics and antidepressants.

Over a period of months I experimented with a variety of prescribed analgesics, including paracetamol, aspirin, co-proxamol and dihydrocodeine. This experimentation highlighted a dilemma in that the more powerful analgesics helped to reduce some of my muscle pain to a more tolerable level, but served only to exacerbate my exhaustion due to their sedative effect, resulting in my having to opt for large doses of aspirin which, whilst helping a little, only served to slightly reduce my muscle pain which, by this time, was preventing me from sleeping at night.

Similar experimentation with antidepressants had been ruled out as it had not been believed, during my original diagnosis by the consultant or, indeed, during follow-up discussions with my GP, that I was depressed. After a few months, however, the GP I had been seeing suggested that I take advantage of a pilot exercise in which a psychiatrist was attached to the general practice I was attending in order to get a more expert opinion on whether or not I might benefit from being treated with antidepressants. Given that my symptoms had worsened after contracting a couple of further viral infections I viewed this suggestion with an open mind and agreed to undergo a psychiatric consultation. This consultation confirmed the view that I was not suffering from depression; that, in the opinion of the psychiatrist, my symptoms were the result of a physical illness (albeit unexplained); and that I would not benefit from being prescribed antidepressants. The psychiatrist further volunteered the opinion that I was in the top five to ten per cent of patients in terms of how I had responded to my ill health and that I was actively seeking to manage this situation.

What became clear to me, during this period of time, was that the wide array of symptoms which I was presenting with could not be treated in a simple manner. Instead, it was a question of attempting to reduce the physical stresses on my body in order to enable me to gain more energy with which to build up my strength and aid my recovery.

Combining conventional and complementary medicine (in the absence of evidence)

In parallel to this exploration of conventional treatment options I had started to conduct further reading on complementary medicines. I was not naturally drawn to experimenting with such therapies as, if I am honest, I was fairly cynical and sceptical about what they could offer. This type of experimentation may also seem alien or, indeed, irresponsible to readers of *The Journal* who may be more used to practising evidence-based medicine and who may be bemused by the increasing level of patient interest in such therapies (the clinical effectiveness of which may be unknown). I was, however, in a fairly strange position which compelled me to explore alternative methods of alleviating my symptoms – I had been presenting with a variety of debilitating and painful symptoms, varying in severity, which, after consultation with both a consultant physician and a psychiatrist, had been confirmed as being physical in origin and the only form of conventional medicine available to assist with this situation was mild analgesics. When coupling this situation with my further deteriorating health I felt that, if I was to assist my own recovery, I had no option but to try experimenting with a combination of conventional and complementary medicine whilst attempting to keep my body, and my muscles, as active as possible during relapses.

I was also aware that I was in a vulnerable position, given my state of debilitation, and that it would be all too easy to end up spending large sums of money on treatments which might not work and, even worse, could possibly have an adverse effect upon my health. For this reason I sought to investigate what I saw to be the more 'established' complementary therapies, such as homeopathy (and did so by consulting a highly respected, medically qualified GP who was also a trained, and qualified, homeopath), whilst embarking upon further in-depth reading related to less established therapies, keeping my GP apprised of precisely what I was doing. Over time I experimented with a variety of complementary therapies including homeopathy, acupuncture, reflexology, hypnotherapy and meditation in addition to experimenting with new clinical and pharmacological therapies which were being tested by clinicians throughout Scotland and whose early results had indicated that they might be helpful in treating aspects of ME.

Whilst much has been written over the years about the conventional medical view of complementary medicines merely providing a placebo effect, I would have to question this broad assumption based upon my own personal experiences. I fully understand that personal experiences only provide anecdotal evidence and that some readers of *The Journal* may believe the inclusion of such comments to be completely inappropriate for a peer-reviewed journal. In defence of these comments, however, I would argue that I am not presuming to evaluate the published evidence in this area within this paper, but merely to report my experiences as a patient in an area where there was little clinical evidence and, where it did exist, was contradictory.

It could be argued that I could easily have been psychologically influenced in experimenting with treatments which I ultimately hoped would alleviate my

symptoms, but I would counter such suggestions with the following points: I do not perceive myself as being easily influenced or open to suggestion; I experienced a considerable amount of scepticism when experimenting with some of these therapies; and there were times when I will admit that I clearly willed therapies to work and there was no response, and other times when I did not really believe that a therapy would work and was staggered by the results. This was never more noticeable than in the way in which prescribed homeopathic remedies such as nat mur and baptisia assisted me to overcome colds and other infections which had been the main barrier to my recovery due to prolonged relapses triggered by infections, and for which I could not be prescribed antibiotics for clinical fear of exacerbating my condition.

I acknowledge that such experimentation was completely unscientific and may seem abhorrent to proponents of evidence-based medicine, but would suggest that the scientific rigour of evidence-based medicine may, in itself, further complicate the matter of dealing with medically unexplained symptoms. Whilst, in an ideal world, I would have been more comfortable using treatments which were evidence-based, what do we do in the absence of evidence or even a consensus of opinion? Evidence naturally has to begin somewhere in order to stimulate interest in conducting trials, and there will not always be the funding, or interest, with which to embark upon the large scale clinical trials of treatments which are currently seen as being 'alternative' and which may not fit in with the research agendas of pharmaceutical companies whose priorities may lie in developing more lucrative pharmacological treatments. This leads to a situation whereby there can be an inequity in the quality of evidence presented – this is not the same as saying that a particular treatment is less effective (to do so would require an equity of investment, and interest, in comparable clinical trials). There were, undoubtedly, some complementary therapies which I tried that had no therapeutic benefit whatsoever, so it became a question of using selected complementary therapies in their truest sense in order to complement the gaps in conventional medicine at that time.

By removing one physical stress on my body at a time I was slowly able to make some progress with my recovery and to follow a loose exercise programme during which I gradually built up my strength. This was not, by any means, a fast or smooth process and I experienced a number of further (although lesser) relapses during the following years which were triggered by more infections or, indeed, by exceeding my physical capabilities by over-exercising – a constant problem encountered when making rehabilitative progress and, in particular, when frustration creeps in.

Phased recovery

Whilst the first two years of ill health followed a pattern of deterioration, an optimistic pattern started to emerge during my third year of ill health in which I would make some slow progress and then reach 'plateaus' whereby, even if I relapsed, I did not go back to being as ill as I had been before having reached that level of recovery. Upon reaching each new plateau I effectively had to re-educate my body and judge the very fine line which existed between making use of my new-found energy and overdoing things to the extent where I risked relapsing and had to rest for a number of days to prevent this from happening, and in making the most of my recovering position.

During this recovery phase I developed a flexible exercise programme which was loosely structured. It included physical targets which I had set for myself (such as increasing walking distances) but was also flexible enough so as to allow for longer rest periods, if required, in order to enable me to reduce the likelihood of further relapses by listening to my body, recognising when it was in danger of relapsing, and taking appropriate preventative action. Progress was not always fast, at times following a 'one step forward, two steps back' pattern, and was not without its lighter moments, such as being overtaken by elderly ladies with walking sticks whilst out walking. In order to counteract the frustration which easily built up I logged all of my physical activities and plotted these on graph paper in order to remind myself of the progress which had been made over a period of time, but which was not always apparent due to the slow rate of improvement on a daily or weekly basis. I also closely monitored the success or failure of any new treatments which I tried.

Doctor/patient relationship

Prior to becoming ill I had experienced good health and, as a result, did not tend to visit a particular GP within the practice. Instead, I had tended to arrange an appointment at short notice, when required, with whichever GP was most likely to be available – these tended to be locums with whom patients had not yet built up a relationship, or new partners. When faced with attempting to manage a chronic illness, however, I realised that this arrangement was not ideal and that it would be more beneficial to identify a GP with an interest in this area with whom I could develop a constructive long-term clinical relationship.

After consideration, I arranged an appointment with one of the partners in the practice I was attending who had demonstrated a clear interest in my symptoms when called out one weekend when a sudden intensity in muscle pain had required more powerful analgesics to be administered to me. During this subsequent consultation we had a wide ranging discussion about my illness during which the GP openly admitted that he did not know much about this area, but was interested in

finding out more about it and would be happy to work with me, as a patient, in learning more about, and managing, my condition. From a patient's perspective I found this admission to be both refreshing and empowering. Through time, a very positive relationship developed during which this GP would happily read and consider any papers relating to potential new treatments that I had obtained and was interested in considering experimenting with; similarly, he informed me about any papers which he had sourced.

Whilst I suspect that this GP did not condone all of my experimentation with complementary forms of medicine – nor would I have expected him to – a mutual respect developed where it was recognised that I was exercising informed choice and, wherever possible, in conjunction with medically qualified practitioners (as in the case of the homeopath whom I was consulting). Through a protracted period of trial and error I had identified two complementary therapies which seemed to work for me and helped to alleviate some of my symptoms, these therapies being homeopathy and meditation (the latter of which I used to great success in managing the anger and frustration which can become manifest when experiencing chronic ill health, and which can ultimately become counterproductive if not managed effectively). In continuing to use these therapies I did not encounter any prejudice for so doing, but instead received positive support in seeking to manage my illness.

This positive relationship and mutual exchange of ideas also had a significant impact upon efforts to alleviate the severe muscle pain which I experienced throughout my period of ill health and which I still suffer from today (but to a lesser extent). By considering the situation and combining and alternating dosages of a straightforward analgesic (co-codamol) with a non steroidal anti-inflammatory drug (NSAID), ibuprofen, we discovered a more effective form of pain relief which enabled me to become more active.

A further positive example of treatment generated by this relationship was our experimentation with a selective serotonin reuptake inhibitor (SSRI), paroxetine. Whilst I had enquired about experimenting with a mild antidepressant in order to assist me with a short, temporary, spell of associated depression, caused by the frustration of having been chronically ill for a period of about four years, there seemed to be a strange, clinically unexpected side-effect in that I experienced a slight increase in energy at around the 5 mg daily mark (a very low dosage not generally recognised to have therapeutic benefits). Whilst this was unexpected it should not be a great surprise given that a number of pharmacological therapies that have been developed to treat specific diseases, during the last century, have been discovered to have had unexpected therapeutic benefits for additional unrelated diseases (such as antihystamines and tricyclics).[5]

Other forms of support

Throughout the period of my illness I was extremely grateful to have the strong support of my family, close friends and my now wife, whom I met during this time, all of whom without which this experience would have been even more horrific and my recovery may have been slower. Whilst I firmly believed that I would recover from this illness, and would not be ill for a long period of time, from the outset, I suspect that there must have been times when my family and friends questioned this given the severity of my symptoms which effectively reduced my family's relationship with me to that of carers and my friends' to that of 'visitors of the sick'. For my family's sake, as much as my own, I was determined to remain optimistic, even when this was difficult, and with my friends I deliberately cultivated the role of providing a 'listening ear' in order to prevent these friendships developing into an unhealthy patient/visitor relationship.

The importance of the strong support, and belief, of family, friends and employers (who held my post open for four years in the hope that I would be able to return) when faced with a debilitating chronic illness of this nature cannot be overestimated. In addition to maintaining and enriching these support networks it is also, in my experience, important to cultivate additional external support networks, such as links with voluntary sector organisations and support groups who can provide much needed support and understanding. Whilst I did not avail myself of the assistance of local support groups to a great extent (for a variety of reasons such as wishing to feel part of 'normal' society rather than a categorised subgroup, and wishing to avoid becoming too inward-looking and absorbed with my illness), I do recognise that such groups have an important role to play, particularly in supporting people who do not have the strong support of family and friends. National support groups can also be extremely helpful in providing literature and advice when required.

Returning to 'normality'

In total I was physically unable to work for a period of eight years as my health, at first, continued to deteriorate over a period of 18 months before levelling out, and the protracted recovery process commenced. During this time I had undergone numerous medical examinations by GPs, consultants, a psychiatrist and a number of medical advisers employed by my employers and the Department of Health and Social Security (who for a period of time classed me as being severely physically disabled).

Following a recovery programme, as described throughout this paper, I was keen to engage in some therapeutic work which would enable me to gradually ease back into working life and which would also convince prospective employers that I would be a viable employment prospect despite having been out of the

workforce for such a long period. I decided that voluntary work would be the most effective manner of doing this, as the severity of my symptoms was still fluctuating and such work would allow the flexibility to choose what hours I would work. I was, however, keen to ensure that I could put my previous skills to use, so I selected a leading voluntary environmental organisation and offered my services as a researcher. After undergoing a formal interview process, I was offered a voluntary position as a general researcher and started working a few hours each week.

Over a period of months I gradually increased my hours and became closely involved in researching an emerging public health issue which required me to establish links with scientists, researchers and public health professionals internationally. I continued to increase my working hours as my strength increased, and was offered a part-time paid contract as a researcher. During this contract I raised awareness of the work in which I was involved within Scotland and the UK, involving considerable contact with the media, politicians and the public in addition to the professional groups already mentioned. This work led to my being invited to address a conference in the House of Commons, to present oral evidence to the Scottish Parliament and to an independent expert group before ultimately achieving legislative change in Scotland.

My contract within the voluntary sector was time-limited, due to ever-present funding constraints, and I was offered a contract (initially part-time and then full-time) with another Medical College before taking up employment with this College.

Closing observations on the controversy surrounding ME/CFS

Since being clinically diagnosed as suffering from ME 12 years ago I have been bemused by the prolonged, and polarised, public medical debate which has taken place surrounding the aetiology, classification and treatment of this disease. I would further add that the diagnosis given was not one which I had sought, in any manner, nor was it a disease which was known to me.

This protracted debate has concentrated on two specific areas – whether this is a physical or psychological illness, and on the classification of the disease (which has involved a variety of 'preferred' labels, including post viral fatigue syndrome (PVFS), ME and CFS).

Whilst some encouraging progress was made with the publication of the report of the Royal Colleges' joint working party, which recognised that this disease does 'not fit neatly into the conventional view that disease is either physical or psychologial',[6] it has more recently been observed that ingrained attitudes regarding mind/body dualism (the 'physical or psychological' debate) 'are as prevalent among the medical profession as among the general public'[7] and are, in turn, still proving to be a barrier to treating medically unexplained symptoms. This, however, is not unique to this disease and can apply to any situation where a patient presents with medically unexplained symptoms which, due to their biologically unexplained state, 'provide challenges to the rational order'[8] or challenge scientific thinking, resulting in a situation where it may be easier, either consciously or subconsciously, to blame patients for their illnesses rather than accepting that some things are not known.[5] From a patient's perspective it is all too easy to feel marginalised by such academic debates, and in the absence of a more positive move on the part of the medical profession towards starting to accept and talk about the existence of medically unexplained symptoms and the practical difficulties experienced in dealing with such symptoms (without reverting to 'physical or psychological' debates), I believe that the medical profession runs the risk of alienating affected patients or turning them into 'heartsink' patients – a situation that no one would wish to see happen, particularly given the latest prevalence estimates (0·2–0·4% (England & Wales)[1] and 0·7% (Scotland)[9]).

With the benefit of hindsight I have a great deal of sympathy for clinicians faced with dealing with this disease. Within the last decade a large number of medical papers and reports have been published on this clinical area. There has, undoubtedly, been some progress in identifying some treatments, such as cognitive behavioural therapy,[10] which has been shown to help some symptoms in some patients, but the contradictory nature of the overall published conclusions reached still offers a challenge to clinicians. In order to quantify, simply, the scale of the task facing a clinician wishing to read the published research for his- or herself today, to assist in an understanding of the nature of the evidence behind these conclusions, a brief search of the PubMed database was carried out at the time of writing this paper which highlighted a total of 2,260 papers on this clinical area.[11]

In recognising the difficulties faced by clinicians I do, however, also believe that more recognition has to be given by clinicians to the difficulties experienced by patients. The recent independent expert group's report and the government's response would appear to be taking a step in the right direction in terms of reconciling clinical and patients' views. Whilst clinicians may not believe that ME is the most scientifically correct classification of the disease,[6] and there have been reports of dissatisfaction with some aspects of the expert group's report,[12] I would urge for some restraint to be exercised in challenging the group's suggested new classification of this disease as 'CFS/ME' (for reasons explained within the report[2] with which I would concur. Whilst I have no particularly strong feeling about which classification is ultimately used, I do believe that the term 'chronic fatigue syndrome' erroneously conveys an impression to clinicians and the

public alike that sufferers are simply overtired. Fatigue, whilst a prominent feature of this disease, is but one of a multitude of symptoms which patients can present with.) There are times when we can all, patients and clinicians both, get sidetracked by issues, and the priority has to be ensuring that patients diagnosed with this disease receive the best quality of care which can be provided given the current state of knowledge rather than, after 12 years, still getting bogged down in a debate regarding the classification, or labelling, of this disease.

Where do we go from here? The government's response to the expert group's report is again to be welcomed, in terms of its asking the Medical Research Council (MRC) to develop a broad strategy for advancing biomedical and health services research on CFS/ME, and in its consideration of whether the report should, in time, be referred to the National Institute Of Clinical Excellence (NICE) for the development of national guidance on the management of treatment of CFS/ME and also integrated into the two National Service Frameworks (NSFs) under development for children's services and adults with long-term conditions. Until such time as further research has been carried out and national clinical guidance is available, it is hoped that papers such as this may help in some small way to educate and inform clinicians and psychiatrists alike about patients' experiences, and that this will further clinical knowledge in line with the Department of Health's (DOH) 'Expert Patient' initiative.[13]

And as for my current state of health? Whilst I have not regained full health, I am able to work full-time and have recently become a father for the first time. I may not, yet, be able to engage in sporting activities, and am still on medication, but am continuing to regain my health. I have, admittedly, lost a large chunk of my life but, on reflection, I am lucky that my personal condition was recoverable – a luxury which patients with terminal or degenerative diseases do not have.

'To receive the gift of a future is, indeed, an unforgettable delight.'[14]

THE GENERAL PRACTITIONER'S PERSPECTIVE

The management of patients with unexplained physical symptoms challenges the GP and our NHS. Mr McAlister's thoughtful and articulate account of his personal struggle with CFS touches on a number of aspects of this challenge which I will reflect on from the perspective of my experience gathered over 20 years in general practice.

There are various evolving changes in our health care system in the early twenty-first century which may make us less good in meeting the challenge. These include:

- growth of evidence-based medicine;
- increased specialisation; and
- reduced continuity of care.

Growth of evidence-based medicine

Voltaire saw medicine as 'The art of amusing the patient whilst Nature heals the disease.'

Whilst Voltaire's view may understate the role of the physician, for centuries it was certainly true that medicine was as much an art as a science. Suddenly, over the past few decades, we have been armed with powerful weapons, the progeny of science. Now, science is also being brought to bear in our 'weapons guidance systems'. We work in a new world dominated by formularies, protocols, guidelines and guidelines to the guidelines.

Whilst there was certainly a need for medicine and, particularly, general practice to become more scientific, there is a risk that we may become infatuated with our shiny new weapons and forget our traditional skills as family doctors – skills based more on the 'art' of general practice than on modern science. The 'art', for example, of effective communication, of building therapeutic alliance and of supporting the suffering with compassion but without fostering over dependence. I fear that consultations where we 'just' talk to our patient will increasingly require justification to our peers and auditors.

Modern, 'scientific', evidence-based GPs may feel threatened, perhaps even impotent, in the presence of patients with seemingly inexplicable symptoms and see them as a 'heartsink' rather than as a challenge. Yet such patients are common and may account for a quarter of GP consultations.[7]

Increased specialisation

The controversy over the name to be given to this illness reflects the unhelpful polarisation which exists within medicine between 'mind' and 'body'. Such polarisation is disappointing when we are increasingly aware of the subtle links between physical and psychiatric morbidity. We know that serious physical illness will inevitably have psychological spinoffs and will often be associated with important psychiatric comorbidity, and yet liaison psychiatry remains a 'Cinderella' service and clinical psychologists are rarely seen inside a general hospital.

Conditions with unexplained symptoms, such as CFS, cry out for a holistic approach, but such an approach is increasingly hard to find within our health service. In my earlier years in general practice, when I did not know what was wrong with a patient, I could refer to a wise general physician such as Dr J.F. Munro at the Eastern General Hospital. Now the generalist has almost vanished and, unless I have a diagnosis, it is difficult to know which specialist to select.

Patients with CFS suffer not just from their illness but

also from the fact that, in an increasingly specialised medical world, they occupy a kind of 'no man's land'. They may enjoy an occasional flirtation with a specialist in infectious diseases, neurology or psychiatry, but in many areas of the UK they are unlikely to be embraced by any hospital clinic, let alone one specialising in their condition.

Emerging from the trends towards evidence-based medicine and increased specialisation is an even greater threat to the patient with unexplained symptoms. The threat that, if there is no evidence of a cost-effective specialist intervention for the patient's problem, then the specialist will not be prepared to accept a referral. This threat has already become a reality with respect to mental health care in Edinburgh. Previously, in trying to support a patient with severe and persisting psychological distress, perhaps an abuse victim whose life is being ruined by self harming behaviours and damaging relationships, I could have drawn on the multidisciplinary skills of our locality mental health team for help and support (for me as well as the patient). This option is no longer open unless the patient currently has a defined psychiatric disorder, such as clinical depression, where there is evidence in favour of a specific therapy.

As Mr McAlister points out, absence of evidence that a treatment works is not the same thing as evidence that it does not work. Conditions with vague symptoms, which do not clearly belong to any specialty and which do not attract the interest of the pharmaceutical industry, are clearly at a massive disadvantage in the research arena.

Reduced continuity of care

Patients who complain of multiple vague, puzzling or inexplicable symptoms are difficult to manage within the constraints of the typical GP consultation where little more than five minutes is available for talking, history taking, explanation, reassurance, dealing with questions (often numerous) and giving advice. Lack of time to deal adequately with our many patients who do not present a clearcut physical problem is one of the greatest stresses facing the GP. Small wonder then that patients with unexplained symptoms do not always elicit a positive response when they consult.

What are the consequences of a hurried or unsatisfactory consultation? Patients whose symptoms do not have a clear physical basis are likely to be wary of 'bothering' their GP. In addition, their self esteem may well have been damaged by their illness. Such patients will be easily put off by the doctor who appears busy or disinterested. They may retreat with even greater feelings of hopelessness or they may seek help elsewhere. The notes of patients with CFS, or other causes of unexplained symptoms, are characterised by 'doctor hopping', multiple negative investigations and attendance at a number of hospital clinics. All at great cost to the patient and the NHS.

Whilst the move from single handed to group practices has had many advantages, it has had the major disadvantage of reducing continuity of care.[15, 16] It is all too easy for patients with difficult problems to ricochet around the various members of a practice team with no one person 'grasping the nettle' and taking clinical responsibility. Balint spoke of the 'dilution of responsibility' that occurs with referral to a specialist.[17] Now this is a major issue within expanding general practice teams, much to the disadvantage of the patient with a chronic and disabling illness.

Success in CFS

Chronic fatigue syndrome denotes severe disabling physical and mental fatigue, exacerbated by minimal exertion and unexplained by conventional biomedical diagnosis. It is typically accompanied by other symptoms such as myalgia, sleep disturbance and mood disorder.[18] Various operational definitions have been published which generally require disabling functional impairment for at least six months accompanied by a number of other characteristic symptoms (Figure 1).

The prevalence of patients fulfilling the criteria for CFS outlined above is about 0·5%.[6] In contrast, fatigue as a symptom is extremely common, with one survey of 15,000 patients revealing that 18% had experienced substantial fatigue for six months or longer and, on average, 13 out of 1,000 patients will present to their GP each year with fatigue as the main symptom.[19, 20] In consequence, it is important that the GP is most cautious about diagnosing CFS, particularly in the early months of debility.

Not surprisingly, given such a loosely defined and variably managed illness, the published figures regarding prognosis differ greatly depending on the source and it is almost impossible to provide the sufferer with any helpful indication of what to expect. A systematic review of published studies suggests that the overall prognosis of CFS is poor.[21] It seems that a substantial percentage will be significantly disabled after five years and a small minority will remain so at ten years.

Whatever figures are taken, it is apparent that CFS causes a great deal of suffering and, in many cases, long-term disability. Of the small number of patients whom I have known with unequivocal CFS, Mr McAlister has made by far the best recovery. The factors that contributed to his success can be considered under two headings:

- patient's resources; and
- relationship with GP.

Patient's resources

Mr McAlister's exceptional personal strengths and resources are evident from his account and I would concur with the opinion of the psychiatrist who assessed him, that he was in the top five to ten per cent of patients

	CDC-1994*	UK**
Principal symptoms	Severe disabling fatigue not relieved by rest	Severe disabling fatigue affecting physical and mental functioning
Minimum duration	Six months	Six months
Functional impairment	Substantial	Disabling
Cognitive or neuropsychiatric symptoms	May be present	Mental fatigue required
Other symptoms	Four required	Not specified
New onset	Required	Required
Medical exclusions	Clinically important	Known physical causes of chronic fatigue
Psychiatric exclusions	Melancholic depression	Psychosis
	Substance abuse	Bipolar
	Bipolar	Eating disorders
	Psychosis	Organic brain disease
	Eating disorder	

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* Fukuda K, Strauss S, Hickie I *et al.* The chronic fatigue syndrome: a comprehensive approach to its definition and study. *Ann Int Med* 1994; **121:**953–9.

** Sharpe M, Archard L, Banatvala J *et al.* Chronic fatigue syndrome: guidelines for research. *J R Soc Med* 1991; **84:**118–21.

FIGURE 1
Case definitions for chronic fatigue syndrome.†

in terms of how he had responded. A crucial factor was the positive way in which he adapted to his changed life and strove to rehabilitate himself. He was also fortunate in the support he received from his parents and friends and, unusually in my experience, from his employers.

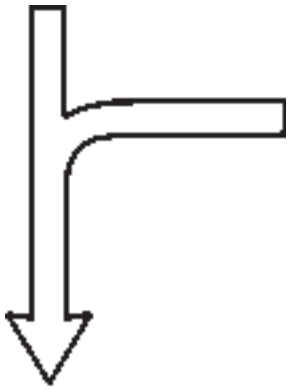
Relationship with GP

Although the GP contribution to Mr McAlister's recovery was relatively small, it included some important positive features, particularly continuity of care, complete acceptance of the severity and reality of his illness, allocation of adequate consultation time and the creation of a working relationship based on mutual respect where management decisions were taken jointly.

For patients with unexplained symptoms, particularly when they are chronic and disabling, a key factor determining outcome is the willingness of a GP to grasp

Predisposing factors identified in fatigue generation:

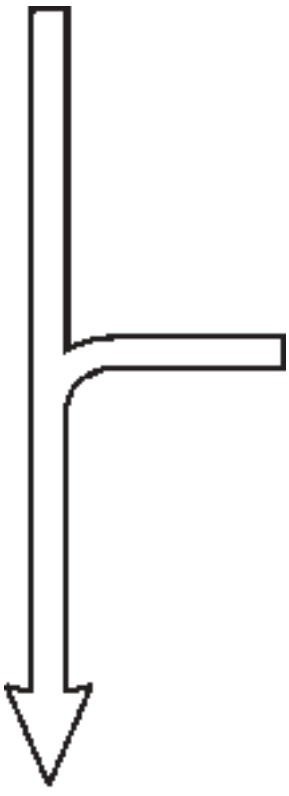
Past psychological illness
Somatic attributional style
Early experiences of illness
History of fatigue



Precipitating factors identified in fatigue generation:

Serious viral illness (Epstein-Barr virus, Q fever, viral meningitis)
Life events
Operative stress
Over training
Depression/anxiety

ACUTE OR SUBACUTE FATIGUE



Response to fatigue	• prolonged bed rest or time off work • fixed somatic attribution of cause • demoralization, depression, anxiety
Effects of inactivity	• fatigue • physical deconditioning • biochemical changes in muscle
Response of doctor	• issuing sick note • imprecise diagnosis • evident disbelief
Cognitive factors	• loss of control • belief that exercise will cause damage or worsen fatigue
Biological factors	• reduced cortisol levels • hypothalamic disturbance • circadian rhythm and sleep disruption • increased central 5-ht receptor sensitivity
Social factors	• reinforcement by others • work related problems

CHRONIC FATIGUE OR CHRONIC FATIGUE SYNDROME

Reproduced with kind permission from the Royal Society of Medicine Press Ltd. *A Research Portfolio on Chronic Fatigue*. Edited by Robin Fox for the Linbury Trust. London: Royal Society of Medicine Press Ltd; 1998.

FIGURE 2
Cleare's schema: there will be much interaction between factors.

the nettle, to take responsibility for clinical care and to give consistent and continuing support. We have all had moments of hoping that a 'difficult' patient will book to see somebody else next time. Simply undertaking personally to review the patient again at an agreed interval rather than leaving the patient to play lucky dip with the practice appointment system may be a vital step. Mr McAlister achieved unusual continuity of care from early on in his illness.

In any chronic disabling condition, and particularly in one such as CFS where our health service may offer little in the way of formal therapy, it is crucial that the patient is encouraged to believe that he or she is leading the rehabilitation team and that their efforts will be the most important ones. The GP must seek to create a 'therapeutic alliance' whereby the patient is empowered to take charge of his or her own destiny. If this does not happen, the patient may become passively dependent on their doctor or engage in a fruitless search for some doctor or therapist who will deliver the magic bullet.

Patients with unexplained symptoms may suspect, sometimes with good reason, that their GP does not entirely accept that they are ill. Frequently with such patients the intimation of further negative investigation results will elicit a response along the lines of 'so you think it's all in my mind, then?'. In seeking to establish a working relationship I try hard to convey to the patient that I fully accept the reality of their illness. At the same time I try not to get drawn into debate about aetiology and what the illness should be called, but shift the emphasis onto what we can do together to get the patient well again. I try to keep my investigations to the minimum necessary to reassure the patient, and myself, that we are not missing some treatable physical factor. Arranging another investigation, or even another referral, may be a way of closing a difficult consultation, but such a closure risks moving the emphasis back towards the magic bullet and away from patient self-reliance and autonomy.

In discussing the management of CFS with the patient I find it helpful to talk in terms of 'predisposing', 'precipitating' and 'perpetuating' factors as outlined by Dr A.J.Cleare (Figure 2).[22] My emphasis is on how to tackle and diminish the 'perpetuating' factors. For example, 'reinforcement by others' may be a crucial 'perpetuating' factor, particularly if the sufferer is a child.

Giving a name to this type of illness is of great importance to the patient and what that name is has considerable implications. I personally prefer CFS, since this name makes no assumptions about aetiology or pathology and therefore encourages a more open minded, holistic approach to management. At the same time I fully accept Mr McAlister's observation that 'fatigue' does not adequately convey the malignant exhaustion associated with this condition, nor does CFS convey the constellation of other unpleasant and disabling symptoms which are likely to accompany the 'fatigue'.

Chronic fatigue syndrome is a great challenge to GPs. It tests our traditional skills as family doctors in ways that few other conditions do. Chronic fatigue syndrome and other conditions with unexplained symptoms challenge us to apply both art and science in a way that is unique to general practice. Not least, CFS challenges our humility. The humility to admit that we do not have all the answers, and to accept the kind of role reversal, illustrated by Mr McAlister's account, where the patient may know more about their own condition than we do, and where the patient is the leader of their own therapeutic team and we are in a supporting role. Long may we continue to embrace such patients within general practice.

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