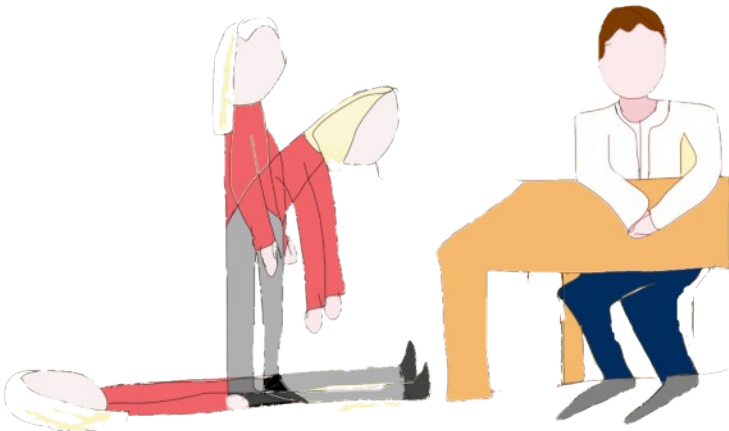


The doctor's dilemma

Dr John L Whiting



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Open Your Eyes

In the darkness ... I sleep?

If only I could. I weep

For those who have no arms

Why is it that power's charms

Fail to ease the pain unseen.

Are they asleep? Perhaps so, I say

Their sleep is eternal, come what may

Their dream like images of earth and stars

Match nothing we know, is and ours

Divided we stand but we will not fall

What writing is there on the wall?

Look, look hard and then you will see

Yes, it is, my goodness, it is about you and me!

by John L Whiting

An Urgent Message

AS YOU KNOW, TYPHOON Yolanda has caused massive devastation and hardship to many parts of the Philippines. Our goal is to help.

My wife and I set up a foundation to help the medical situation for the poor and needy called iHope earlier this year. THIS WAS in AUGUST 2013. See Hambilanon Ako on Facebook.

<https://www.facebook.com/search/results.php?q=Hambilanon+Ako&init=public>

<https://www.facebook.com/groups/1382683738628303/>

<https://www.facebook.com/groups/hambilanonako/>

<mailto:hambilanonako@groups.facebook.com>

Our cries for help secured funds from around the world. The delivery of medical supplies to the Island of Hambil, also known as Carabao Island, was micromanaged by us and we had success to the degree that none of the donation monies were wasted on administration fees.

ALL OF THE FUNDS REACHED THEIR TARGET
WITHOUT WASTE

NO CORRUPTION

We are confident that we can do this again so that we can guarantee that none of your donations will be wasted or fall into the wrong hands. Everything will be accounted for.

We have set up a bank account in Australia for the single purpose of providing food supplies in the form of rice, noodles

and sardines to the people of Hambil. A large portion of its population is now homeless.

THOSE WITHOUT FOOD ARE CERTAIN TO DIE IF WE DO NOT HELP. This is the second wave of devastation that the typhoon is going to deliver if nothing is done.

It is for this reason that my wife and I are driven to use our prior successes in such matters. We are using an Australian Bank Account to SPECIFICALLY create the primary resource post from which we can operate our assistance missions. The following are the account details,

Teresita Whiting

Commonwealth Bank of Australia

BSB 064173

Account Number 10598726

SO PLEASE HELP NOW. TIME IS RUNNING OUT.

Any donation will be duly noted and recorded for transparency purposes. We will inform all donators about where and what their hard earned incomes will have gone. There are no middlemen, so we can guarantee that your good wishes do not vanish into the aether. Volunteer police officers in Hambil will guard all food deliveries. Each delivery will be blessed by the local priest and photographic documentation will be there to record each event.

Thanking you in advance,

Dr and Mrs John L Whiting

FRACP

INFECTIOUS DISEASES AND INTERNAL MEDICINE

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Introduction by Greg Crowhurst

It is very rare indeed to encounter a doctor who understands Myalgic Encephalomyelitis (ME), never mind Severe ME. I am immensely proud to introduce the ground-breaking “Doctor’s Dilemma” by Dr John L Whiting; an extraordinarily detailed, powerful, challenging, passionate plea for doctors to take ME seriously; it is exactly what the ME community are crying out for.

In this extract from “Severe ME”, Dr Whiting urges doctors to be creative, to “dig deep” into their medical experience, in order to find solutions for people with ME, who currently, he writes, live lives of “utter misery and deprivation.”

Some of Dr Whiting’s patients report that it is “easier” to have breast cancer and chemotherapy” than to have ME. Dr Whiting sets out to tackle the “epistemological and phenomenological” fallacy that automatically misrepresents ME and leads to tragic universal neglect.

Dr Whiting outlines a practical way ahead and in the process gives us a new language to express the hidden and denied; its potential is staggering.

I leave the last word to Dr Whiting himself:

“When I think of it, my chapter is all about getting past first base. It is hard for me to believe that so many don’t get past this. How can treatment advances be made when so many care givers still have this ‘caveman’ status where nothing is happening except fire gazing? ”

The doctor's dilemma by Dr John L Whiting

THE AUDIENCE I AM principally addressing in this chapter are doctors and other medical practitioners who look after patients with severe ME. The goal in this chapter is to explain what it is like to have ME, and particularly to describe what it is like for a person to have severe ME. In this way, I am hoping that the patient's doctor will be better equipped to empathise with such a patient in a meaningful and substantive manner.

I will begin, for the sake of practicality, by defining severe ME as ME where a carer is necessary or should be present to look after affected individuals.

Having said this, some of the patients I look after do have severe ME, and yet are devoid of the care from another close to them, and truly do live lives of utter misery and deprivation. If such is the case, then the doctor of this patient has the essential responsibility to correct this situation in a manner that is in keeping with the special needs of this patient. These special needs should not only be acknowledged as real, but also respected by the doctor as being of sufficient importance to motivate the doctor into taking corrective action in whatever way is feasible and practical.

These actions should be in the best interests of the patient so that they remain sympathetically consistent with the nature of that patient's illness features and challenges. Given that so little research into this area currently exists, it behoves the doctor to be both creative and to dig deep into his or her medical experience

and knowledge to find solutions to such problems as they present themselves in any given severe ME patient. This, in part, is the Doctor's Dilemma.

In the context of this definition of severe ME, the need for a carer requires descriptive and definitional elaboration. This definition of severe ME excludes patients where the carer's primary role is one of watchfulness and mindfulness of a patient's mistakes and correcting them if the need arises. Certainly this is an important carer's role, but such a role is not necessarily essential for the patient's hard core health and survival needs. Protectively watching a patient in case he or she might forget to do something or need a helping hand now and then, is not what I have in mind here as part of the definition of severe ME.

Instead, severe ME cases are those people who clearly require, as ESSENTIAL to survival, ongoing assistance in a range of different possible ways in order to do things that they cannot do on their own, which include being safeguarded from accidents, assistance in walking steadily, wheelchair pushing, feeding assistance, maintenance of the home environment and the like.

According to this line of thinking and the difficulties that arise as a result of defining severe ME, I believe that it is now more than appropriate at this point to consider the value of introducing our minds to a more heuristic system of severity grading of ME. This lends itself to a number of useful functions and goals. For the sake of simplicity, within the context of ME, I recognise four grades of illness severity. With this new idea now in our minds, it is worth noting that currently there is NO DISTINCTION made between ME individuals along ANY lines of illness grading within current definitions. This, I believe, is a gross error. I have encountered a number of mindsets that lead me to hold this opinion.

By not having a grading system of illness severity, inaccurate assumptions are often made about ME as a whole, and also, about ME in individual cases.

Seen apart and even unrelated, neither Grade 1 ME nor Grade 4 ME can alone be held up to represent the prototypical ME case. Actually, the whole idea of prototypical ME itself is problematic, as my idea of ME grading demonstrates. While, to the trained eye, the core problems within each grade are essentially the same, each grade presents to the doctor very different clinical challenges.

Current definitions of ME do not allow for this epistemological and phenomenological fallacy. Thus, ME is automatically misrepresented, independent of other definitional accuracies and inaccuracies.

Consequently, the public image of what ME is, will be distorted as a matter of course. Not only is this not helpful in general terms, but doctors too will buy into this aberration of a single image, and treat all patients as if they are the same, which of course they are not. This is not just a matter of semantics. Thus, for example, treatments which may be helpful for Grade 1 ME, may not make any overt difference whatsoever to the wellbeing of Grade 4 ME sufferers, DESPITE certain qualitative similarities in symptoms between both Grade 1 and Grade 4 sufferers.

The heuristic value of a grading system is immense. With a grading system that works, doctors can immediately impart important information about a patient to another doctor who works in the same field, without the need to elaborate in detail about all aspects of a patient's condition. This would be a big step forwards in the field of medicine in general, and in the field of ME in particular.

ME Severity Grades

Now for the hard part. I have already alluded to some differences between severe ME and and less severe forms of ME, but creating a grading system that is valid and holds itself up against the test of time, is much more challenging. Below, is a first attempt at this task of describing rather than defining these four illness grades.

Grade 1 (G1)

Patients within this grade may go unnoticed altogether or for many years by their peers, family and friends. Their illnesses may blend in readily with the sores and scars of a normal busy life. There are, however, subtle differences that makes Grade 1 sufferers a pathology as opposed to a phenomenon of life. Much of this has to do with how well sufferers 'excelled' prior to becoming ill (see below). This is actually true for all four severity grades of ME, but is especially relevant to Grade 1 sufferers who may both unwittingly and effectively disguise their illnesses even beyond their own conscious awareness.

More often than not, however, such individuals do have a significant, noticeable and relatively sudden drop in their abilities, but not necessarily to the extent that this drop overtly impacts on their performance in general. Phenomenologically, variations in their abilities and other symptoms are no different from those with more severe grades of ME. This means that they too experience classical ME phenomena which vary, in seemingly unpredictable ways at first, with the occurrence of good days and bad days, post exertional malaise, and so on.

What we often fail to realise is when healthy, we rely on reserve capacities, particularly in the cognitive realm, that get us to where

we want to be. Healthy individually, when pushed, still have even more to call upon, when it comes to shove. In Grade 1 ME sufferers, these unrecognised but nevertheless essential additional 'higher' skills, functions, and somewhat undefinable social, cognitive and physical abilities, are all, to varying degrees, undermined.

These 'extras' can no longer be relied or called upon, under the challenges of normal life. Extra effort replaces the easy flow of natural functions in this Grade of ME.

In modern life, we all exist as high performance individuals, whether we realise it or not. The complexities of life demand this to be true. We need these immeasurable extras. These extras, or reserve capacities, or whatever we choose to name them, allow us room to breath, allow us to flow and allow us time to rest. Take these extras away, and what were previously autopilot functions in many respects, now demand deliberated vigilance in order for ME sufferers to achieve what healthy people usually take for granted. Consequently, Grade 1 sufferers can appear normal, but at the cost of greater effort than before their illnesses struck. At this Grade of Illness, the need to look normal and to live a stable life under these circumstances, so as to be as fast or as creative or as powerful as they once were, all demand greater effort in all realms of being, if indeed these goals are achievable.

The catch also is that this is not short term effort I am talking about. Instead, I am talking about determined effort that goes on and on. To not know what the problem is and whether or not it will ever stop, is a major source of stress to both sufferer and family alike. Big changes in the dream are called for, if one is brave enough to face them.

Adaptive behaviour can play a role in maintaining normalcy and holding one's position in what are deemed priorities in life. These subtle changes in lifestyle may allow much of this loss in function

to go undetected by those who know Grade 1 sufferers, but not well enough. Grade 1 sufferers may socialise less, be less available to others than before, restrict themselves to more of the essentials in life, go to bed earlier, and use their time better, but ... to others, these are not taken as a reflection of illness. They survive despite knowing that they are not themselves. They know it and are usually very frustrated by it.

As an aside, whilst the focus of this grading system has been on functional disabilities with respect to what outsiders and especially carers may be aware of, there is still huge world of other symptoms tagged onto these disabilities.

The word 'fatigue' is such a disservice to the illness, because the problem is so much more than that. Not only this, but fatigue can label a person as lazy, weak of spirit and not worthy.

Subconsciously, I believe that because our ancestors saw fatigue as a tribal liability, we still view 'fatigue' as an unacceptable personal and social phenomenon, not to be spoken of unless it is as a consequence of something heroic. Fatigue is an anathema written into our genes. Not only did the lions eat you, but your peers may have helped in providing them dinner. This simple, curious but very real observation deserves its own deep scientific enquiry by the whole body of existing humanities, independent of any other enquiries into ME.

Similarly, 'bizarre' symptoms, that biological science has hitherto yet to find adequate pathological underpinnings to (a system failure), do, in the meantime, provide meat for philosophers and psychologists to speculate on using 'old' theories, and of course now, 'new' interpretations of impersonal, statistical, population derived data. This can all happen without the thinker ever encountering a single case of ME. This, in turn, allows such

symptoms to be explained in what I view as contrived, self serving ways by various ignorant members of society who have biased, shallow understandings of this illness.

This is the polar opposite to my firm position that ME is a legitimate, biologically based disease. The evidence for this position really does exist for interested and well meaning doctors who can then judge the whole matter for themselves.

This is not the place to discuss such matters in detail. My purpose is to remind the reader of additional morbidity that accompanies the functional disabilities described herein. These so called bizarre symptoms are gradually being explained by state of the art technologies.

Until now, to the unknowing public, these symptoms were merely representations of the neurotic mind, ripe for social ridicule. For me, I am optimistic that ME sufferers will find the respect that once was lost or taken away from them, and that they will rejoin society as heroic survivors of an isolating tormented existence.

Finally, and returning to theme, in Grade 1 cases, there is a need to conceal these inner changes that at first are alarming and later confronting: for many good reasons. In Grade 1 disease, 'going public' on these symptoms was like adding petrol to an otherwise kindling fire. For example, if their worlds are competitive ones, the last thing these people want to do is to expose their newly developed weaknesses to their predatory counterparts. Above all, these individuals strive to remain reliable citizens, and go to great lengths to control their lives to maintain this illusion.

The magnitude of the adverse consequences of Grade 1 illness cannot be overstated. What is at stake includes the integrity of one's family, more than any other issue, at this Grade of Illness.

This is where divorce occurs for 'no apparent reason' other than the ME sufferer is not who he or she used to be, despite all the effort, concealment, and life adjustments that have, by necessity, occurred. How sad it is that, through forced silence, the treasure of family itself is an additional victim of this horrid illness, one of many indictments against regarding Grade 1 ME as being less serious than higher phenomenological grades of illness.

Grade 2 (G2)

This grade of ME merges in with both grades 1 or 3, and depends on both illness severity position at baseline, to what degree the illness varies (frequency and extent), and circumstances in life at work, at home, or whatever.

Effects on work performance are more obvious and are one of the bigger issues in G2 illness. Alternatively, roles in various capacities are now under greater threat. This might include the role of mother to her children or as social entertainer as useful examples to consider. These problems are not unique to ME.

What is unique to ME though is the problem of illness validation. One might wish compassion and empathy towards the ME sufferer, but this fails to come. Indeed, the opposite is more likely. Once treasured friends, such people begin to move away from the ME patient. It is a peculiar observation but it is nearly always true.

Several of my ME patients have independently stated to me that it was easier and strangely heartening to have breast cancer and chemotherapy and its own set of problems than it is to have ME. They claimed that the public rallies to the side of the breast cancer patient, as do the doctors whose support team of care giving staff and nurses, all know what the patient's experience is and why.

There is no comparison between what it is like to have breast cancer as opposed to ME. I am not belittling the seriousness of breast cancer here. What I want to emphasise is that there is no dignity or social acceptance in having ME. Furthermore, it is hardly the illness that any malingerer or attention seeker would choose to have.

Another important feature of this increase in illness grading is the appearance of stress intolerance. I do not believe that this is what drives friends away, but it certainly would enhance this abandonment.

Stress intolerance is an often neglected and misinterpreted subject in public discussions of ME. What is not generally recognised is that there are real physiological reasons for this problem.

The failure to recognise these pathophysiological underpinnings will naturally cause premature conclusions of primary psychopathology. Both the burden of symptoms of illness on stress tolerance in general, and the direct effects of some of these symptoms (for example, sleep loss) can negatively impact on stress tolerance, but there are also pathophysiological considerations that can be brought to bear on why stress intolerance is a common experience amongst ME sufferers.

We know with confidence that endocrine and neurotransmitter dysregulations occur in ME, and that appropriate treatments can diminish or even abolish stress intolerance in most cases. Without such treatment, it would be hard to see how benefits from interventions for other ME related symptoms could be optimally achieved.

Stress intolerance undermines life in general as well as the ability to learn how to adapt positively to the phenomenology of ME. It is not surprising therefore, that A SENSE OF LOSS OF CONTROL

is so common amongst ME sufferers, beginning particularly at this Grade of Illness. Consequently, patients focus on many matters as if their lives depend on this behaviour (which it may well do) in order to protect themselves in advance on matters they will not cognitively have answers for in the moment. 'Obsessive' planning and logistically challenging 'just in case' preparations come into play, even to just leave the house. Outsiders will view such actions as over-controlling and over the top. It is not surprising that unwitting psychoanalytical assessments might draw the wrong conclusions from these observations.

Transitions back to function, involving new, tempering, and adaptive behaviours in response to the physical illness, take time and discipline to develop for patients and friends alike. Making excuses for not showing up for a loved one's wedding or for similar significant occasions can be embarrassing at the very least for the patient, and hard to explain to a non-empathic-to-ME person. This kind of social standoff is common in Grade 2 illness.

Once beneficial transitions (ideally) have taken place, in terms of acceptance by others as well as of themselves by these patients, life can become less stormy and more settled. Whilst the illness is still the same, it is now easier to see the wood for the trees. Problems can be more clearly identified and described, and hence, taken more into consideration when making plans.

The energy envelope is visible or at least, is clearer than it once was. There is a degree of predictability and it becomes somewhat easier to cope with the bad days that follow certain activities. Random bad days occur all the same, but the more overwhelming and frequent they become, the more one might be looking at G3 ME.

Real reductions in those Grade 2 sufferers contributions to society must be tolerated by others as much as possible, and allowances made for errors in judgement brought about by ME-induced cognitive dysfunction, temperament, and other ME specific symptoms. This means that backup behaviours by others may be necessary to cover and fill in for these patients unreliabilities.

This is necessary so that whilst patients are not 'perfect' in the ways they used to be or want to be, they are still allowed to remain useful contributing members of society, albeit to a much lessor degree, both qualitatively and quantitatively.

Part time work, particularly work carried out in an forgiving environment where deadlines and other pressures are minimised, create the optimal circumstances for Grade 2 sufferers to thrive. Unfortunately, these ideal circumstances are rare.

Grade 3 (G3)

This grade of illness marks a greater loss of independence of the individual sufferer. Indeed, my grading system highlights 'independence' versus 'dependence' as a key factor on how a patient's illness is graded. The emphasis on the carer also increases with each grade. In parallel, compensatory behaviours become increasingly stringent and critical to illness stability, such that features like sound reduction, special diets, limited exposure to physical, cognitive and emotional challenges become much more prominent aspects of the patient's life in Grade 3 illness.

With Grade 3 illness, some semblance of normal life is not possible without a carer and in fact, a carer becomes a necessity to the extent that a live-in carer or a readily available carer becomes a medical and social survival issue. Much of the contents of the rest of this chapter refers to either this grade of illness and to Grade 4 illness.

Grade 4 (G4)

Here, in this illness grade, we find not only a house bound patient but primarily a bed bound patient by necessity. Movement is difficult. Standing or walking are near impossibilities. Confrontations cannot be coped with, as the bodily turmoil that always follows, goes beyond description.

What comes as a surprise to many medical practitioners is that even at this level of illness severity, blood tests and other so called standard investigations, reveal very little about the illness to the 'average' doctor, and nothing whatsoever to the ME skeptic. This is a medical tragedy writ large.

I mention elsewhere in this chapter how hospitalisation may be detrimental to the wellbeing of ME sufferers, but is especially true for Grade 4 sufferers. These patients more likely will die at home, and the medical profession at large will be none the wiser for it.

What describes Grade 4 sufferers best is the degree of specialised hands on and hands off care that these patients must have (and not just need). More of the body's homeostatic mechanisms are dysfunctional at this grade of illness. Acute awareness of a patient's real idiosyncrasies must be firmly understood and abided by the carer.

Illness idiosyncrasies are very prominent at this level of disease. Almost all patients, that is from G1 to G4 disease, have their own set of personal pathophysiological flavours, nuances, and 'special' symptoms and complaints. Some of these are merely mild nuisances in G1 disease. With G4 disease, these idiosyncrasies may be amongst a patient's worst symptoms. They do not belong to any standard description of ME and whilst they are potentially classifiable, the sheer number of them, of which I have encountered hundreds of variations, make this task a daunting

one. In G4 disease, it is as if the body's systems have no means available to moderate such symptoms, which no medical text book has descriptions of (in one volume and place), let alone answers for.

The body itself almost takes on a personality of its own. Previous adaptive behaviours become less reliable in bringing even more ME-typical symptoms and complaints under control, which themselves now behave idiosyncratically. Life becomes a day to day problem with no way of knowing what the next day will bring.

The carer takes on the role of a medical professional, a nurse, a physiotherapist, a dietician and many other roles, especially the patient's only advocate. This is a huge responsibility for a single carer to manage. And yet it is still possible to achieve an overall state of peace and equanimity despite all of this. On the other hand, suicide amongst patients seemingly occurs not only because of the patient's own long term torments but may arise as a seemingly humanitarian act to the carer too. These patients can still remember who they were and are, and are acutely aware of the burden their illnesses impose on their loved ones. Survival instincts, strong for so long, gradually dwindle away as total exhaustion and sleep deprivation slowly take their toll. But it is much more than exhaustion and sleep deprivation that take their toll on the patient. There is often immense pain and unimaginable physical suffering beyond endurance. The problem is so much more complex than this however, as I have already alluded to above.

Grade 4 illness is NOT what the public sees as the prototypical ME sufferer, even though it does fit the commonly stated "tired all the time" description. The most severely ill are either completely unknown to medical circles or are seen as the "rare" exceptions to the rule. It is my belief that without appropriate

intervention, the G4 state would be much more common than it presently is. Just like Multiple Sclerosis, there is a form of ME that is slowly progressive, which makes proper research into this disorder an even more serious matter than it presently is to the outside world.

It should be emphasised that there is no such thing as mild ME or a "touch of ME". ME is always a dreadful illness to have. Grade 1 ME deserves medical and public respect too, even if the chances of functional improvement (relative to before), might be better at this illness grade with good medical interventions compared to other grades. Why should anyone with ME have to conceal their illnesses, solely based on social stigma and ridicule?

Also, Grade 1 can become Grade 3 for a time and then return to a Grade 2 over time, so that a grading designation is not necessarily a fixed entity. Overall, I do not believe that this Grading System is a special entity in that similar principles do apply to illnesses other than ME. In a study on quality of life of patients with ME-like illnesses, many patients scored reductions that brought them in line with patients with terminal cancer and AIDS. We grade cancers, so why not ME too?

Function is one measure of illness severity. However, maintenance of or improvements in an ME sufferer's quality of life, in my mind, is where the focus of treatment should lie most, especially in Grades 2 to 4 ME. This is not achieved by standing idly by but by looking at the disease, doing proper tests, looking more carefully at what are the underlying physical dysfunctions, and everything else that modern medicine can and should offer for any common illness, including ME.

Whilst my perspective as a doctor in this field is one of a specialist physician, that which I have learnt in my 26 years of practice

dedicated to helping patients with ME is also generally applicable to any doctor who might encounter a patient with ME of any level of severity, especially one for the first time. Firstly, I will discuss matters relating to all ME sufferers, and then focus in on the additional skills required to care for the very severe ME sufferer.

Before I proceed further, and applicable to the care of all cases of ME, I must emphasise that the most important message I can give you the doctor is to DO NO HARM.

In my career, I have had the opportunity to observe patients who have been referred to me soon after the onset of their illness and to compare them with those patients who have done the rounds of seeing general practitioners and other specialists before they find their way to me. The difference in the behaviour, state of mind, and overall attitude towards themselves and their illnesses between these two groups is enormous.

In the latter group, time and time again, I find broken souls, a finding which is a vastly different behaviour set from those patients who see me or another ME friendly practitioner first or relatively early on. I conclude from this and thus maintain that many patients have unfortunately undergone various degrees of abuse at the hands of medical professionals (not necessarily deliberately), but also not unlike battered wives or equivalent forms of subjugation. This complication in 'management' only adds to the patient's misery, and this is not something that anyone, and especially a stress sensitive severe ME sufferer, can cope with.

Consequently, one encounters two very different forms of patient, whose care has differed from the very outset, regardless of illness severity. On this basis, our endeavour as doctors should be to try to not be one of those who might contribute to the patient's woes and thus, to try not to be the creator of the second type of patient I speak of here.

All of the patients I see are by referral. These patients, more often than not, are much more illness affected than those who do not necessarily need to see me as a specialist. These patients see me because they are all concerned about their futures, not only because they need medical care, but also because their careers or marriages or schooling are on the line. Plainly and simply put, these people ARE worried people. How could they not be? So, these patients should not be criticised for being anxious.

The subject herein is much bigger than the space I have to write, so I need to speak in generalities and hope, in so doing, that which I do present will then act as a working platform to which any caring doctor can add his or her own personal skills, and thus fill in the blanks. I am going to present various rules of thumb that I have learnt over these many years to assist any interested medical practitioner to follow or to at least consider.

Firstly, most of what you the doctor has learnt in medical school in term of standard history taking and interpersonal reciprocity will not apply neatly to the doctor patient exchange required here.

It is different and perhaps threatening for some doctors to change their approach at the risk of compromising previously well trusted methodologies but if they realise, in so doing, they actually do help the patient and most importantly, do not make the situation worse, this itself is a big achievement. Sometimes, the patient is the expert and the doctor the student, a role reversal that many doctors find disempowering and unacceptable.

Indeed, I advocate a team spirit in the doctor patient relationship. There are many good and easy to understand reasons for this. I will go through these later, one by one. Having said this, this switch is not one devoted to pampering per se, or aiding and abetting and hence, creating or enhancing abnormal illness

behaviour. Indeed, the opposite effect occurs, when the approach is correct, a fact that may come as a surprise to many medical and non medical purists.

I have yet to arrive at the care of the more severely affected ME sufferers, which is the purpose of this chapter. This is because certain principles must be understood and accepted first. Indeed, there are principles a sufferer should also follow in order to be a 'good patient'. First and foremost, you the doctor will need to keep an open mind because you are about to encounter some strange and challenging symptoms that medical school has not prepared you for. Moreover, you will have to accustom yourself to handing more control than usual over to the patient during the first few visits, within certain limits of course, until you have the gist of what the patient is about. I accept that the diagnosis of ME does not come stamped on the patient's forehead, and it could be that you will not have prepared yourself for the necessary switch when you first see the patient.

However, when a severe ME patient presents, this predicament will or should not arise, if you read what I have to say. Sadly, many doctors are unlikely to read this chapter, or will openly refuse to.

Alas, a paradigm shift in thinking in any walk of life often requires a full generation of time to pass. No doctor can be forced to read what he already disbelieves or misconceives. Be warned too that a very human phenomenon known as CONFIRMATION BIAS pertains here, whereby information that confirms and conforms to a particular mindset is noticeable and therefore notable to the receiver, and information that does not conform to this mindset can be AUTOMATICALLY dismissed, ignored or not even perceived consciously at all.

Indeed, I believe it is morally or ethically wrong for someone, anyone, and especially a doctor, to dismiss this illness on merely hearing its name, without reading what might be important piece of information to the patient.

Openly putting a document of this kind into the bin in front of the patient during a consultation is not only insulting but it is an act beyond wrong, and doctors who do this deserve to have a full enquiry into their conduct as registered professionals. Sadly, this kind of act happens far too often, and even worse, is condoned behind closed doors, by many of a doctor's peers.

Why is it necessary to change the standard method of medical history taking?

In a doctor's training, a standard structure exists in how a medical history is taken, which has been developed over the last century, to encourage an orderly approach to acquiring the pertinent clinical information from a patient. Years of practice as a student go into perfecting this methodology. It is thus very difficult, uncomfortable and perhaps, dare I say it, stressful for the unaccustomed doctor to find that this effective strategy does not work when collecting information from an ME patient, especially from a severely affected ME patient.

Why is this so, and how will the average doctor react to such a predicament?

I believe that this disharmony in communication is at the crux of much of the breakdown in understanding on both sides of the fence, ultimately leading to mutual animosity between parties, and the development of erroneous preconceptions of the nature of ME.

Beware also that doctors often reach such a high level of knowledge in many other medical subspecialties that again, they become naive to the possibility that other common illnesses could exist that they have no training in. It is not surprising that words like "I am the doctor", "I am the one who has the medical training", "You don't know what you are talking about", and the like are used when the doctor is on the defensive.

Communication

On the other side of the coin, naive patients also exist. Pseudo-medical jargon is like poison to many a doctor's ears. Stating factually to a doctor, without good supporting evidence, that "I am allergic to so-and-so" when in truth, the patient should say "I seem to be intolerant or reactive to this substance", shows the doctor that these patient are not being careful enough in how they express themselves to the doctor, eliciting red flags in the doctor's mind. Similarly, statements such as 'brain pain' are annoying to many doctors, because pain receptors in the brain do not exist. A good doctor will explain such errors to the patient so there is some clarity of communication and understanding between parties.

This kind of mutual 'to and fro' approach, when applied respectfully, makes an enormous difference in building a strong and yet good boundary setting medical relationship, which is often one of the main hurdles many ME patients face.

What follows next is the common circumstances that arises between a between a doctor and the patient at each consultation, bearing in mind that time constraints on the doctor's consultation exist:

Patient's perspective:

What do I (the patient) want the doctor to know and is the doctor able to or knows where or how to find the help that I need?

Doctor's perspective:

What do I (the doctor) want to know or need to know of the patient's complaints, and how can I format it in the manner I can work with and am accustomed to, as well as placing the problems in some order of relevancy, urgency and priority?

*In this dynamic mix is ONE ADDITIONAL QUESTION:
Does this doctor believe in ME?*

This latter question deserves some discussion, as the question itself is fundamentally flawed. Firstly, is ME a belief system? If it is, how much does it differ from any religion, or from any cult for that matter? Science has no place in such a system. Instead, we would potentially be dealing with converting non-believers into believers as a matter of faith, and not on evidence. A doctor who says "I don't believe in ME" is equally culpable of the same unscientific thinking. More than likely, such a doctor is a victim of gossip and propaganda and has not taken the time to personally evaluate all aspects of existing scientific publications on the subject. Peer pressure not to do this kind of reading is widespread, and it takes a brave doctor to stand up against the flow of the existing buddy system. In conclusion, the decision to "believe" or "not to believe" is an irrational and unscientific position.

The question therefore should be reframed: has the doctor done his homework on the state of the art, valid research on ME and related disorders?

There are thus two dilemmas in the doctor-patient dialogue: The Patient's Dilemma and The Doctor's Dilemma.

The Patient's Dilemma

The patient's perspective is more complex than he or she realises or can communicate. This is The Patient's Dilemma.

What are the origins of The Patient's Dilemma and what is its nature? When is this dilemma most prominent?

The answers to these questions are actually quite simple: failures in communication and understanding. These are basic to The Doctor's Dilemma as well. What then are the specific strengths and weaknesses of each party?

One of the obvious basics about ME is its chronicity. The problem doesn't go away on its own and persists, evolves, fluctuates in a variety of ways, and either lessens (rare) or progresses and even transforms over time. I have had the opportunity to witness all of these phenomena over many many years, and some of my patients have been seeing me for over 20 years.

The point I am making is that the patient gains experience as much as I do over such vast periods of time, from Day 1 onwards. Some of this experience a patient gains revolves around seeing doctors, and many other professionals for that matter.

The importance of this is that the patient through experience with other doctors, learns more about the art of communication on ME-related matters, whilst the doctor with a single ME patient experience, may not know how to engage in any useful conversation with one ME patient let alone, another or new ME patient.

At the beginning, this is not so true. The patient has very little structure in what is told to the doctor. This is not just because the patient is not a doctor (usually) but because the patient's illness has directly interfered with the cognitive wherewithal to do so. This too is not always true, but certainly in the severer forms of ME, this is much more likely.

At one end of the spectrum, patients have very little to say and can hardly describe to the doctor what their problems are. One of my patients was next to mute for some months, invariably saying "I dunno". On the other end of the spectrum is a long, imprecise, multidimensional ramble that is packed with so many different subjects at once that it is like the proverbial Gordian knot. Patients vary and this ranges from having so little to say, to so much to say, and finally to too much to say.

Amongst other things, there is a distinct absence of succinctness and a high level of digression and distractibility. These features could be attributable to many things, but given the way that these issues subside over time in the right doctor's hands, strongly leads me to conclude that they are features of the illness itself. In summary to this aspect of the patient's difficulties in effective communication with the doctor, much of this may relate to their cognition, which at times can verge onto or into overt dementia.

Remember, the patient has a huge need to communicate as well. In long term illnesses, isolation becomes increasingly prevalent and relevant. This is so so true in ME. To be held back from doing so is terribly distressing for the patient, even if some or much of what is said may not be so important in other people's eyes to the big picture. Being free to communicate, unrestrained and unashamed, and being honestly listened to and understood, has enormous healing powers of its own.

Validation, and I mean genuine validation of even the strangest of symptoms, releases the patient from a nightmare of self doubt. I have seen the moment of validation in many of my newer patients after their years of travel to find someone who knows. Tears flow, as relief from inner loneliness and dogged determination to keep going, finally have paid off. In summary, part of The Patient's Dilemma is to how to get the story out there to someone who will receive the story without judgement and ridicule and who truly knows what it is like to have ME and can relate readily to the story as a whole as well as the multitude of details within.

The third and final aspect of The Patient's Dilemma is the cost of seeing a doctor. This cost can be measured in three ways, and is especially pertinent to patients with severe ME. I will talk about the least recognised cost first as, in many ways, it is the most important, and should be the most obvious. The physical, cognitive and emotional costs of attending a consultation, before during and after the event, can be enough to deter the patient from further visits. A cost benefit evaluation is therefore a fitting way to look at such things.

It really is a big ordeal for a severe ME patient to see or be seen by a doctor.

Behaviour differs between the severe and the very severe ME patients. There is thus a micro spectrum of severity. There are also subtypes within this realm of the very severe, or even mixtures of subtypes. These are not classification subtypes but subtypes dictated by what symptoms and complaints dominate these patients lives. On the one hand, we might find severe memory, planning problems and other features of a major higher cognitive brain disorder. Alternatively, we might find upright time measured in seconds and not minutes, so that the patient's life exists primarily in the supine position. We might even find

starvation issues through food or even gastric filling intolerances. These have nothing to do with an psychiatrically based eating disorder, but gastrointestinal symptomatology and other symptoms that make the act of eating itself, unbearable. Finally, and what probably puts many patients into the 'strange category' are the sensory intolerances. Sound, light, smell, taste and touch sensitivities can be such that even the thought of exposing themselves to a given trigger elicits the same severe distress as the exposures themselves. Interestingly, such intolerances would not seem so strange in the setting of pregnancy, for example. Such intolerances lead to increasing levels of isolation (as do the other symptom categories above) and increasing dependency on a care giver. All of these problems lend to the description or definition of severe ME.

The above are mammoth considerations that patients have to mindfully address in advance of seeing a doctor. So much preparation is involved, ranging from choosing the best time of the day to go to the doctor, to cataloguing what has been happening so that the patient has ready resources available to remember by, to what subjects will be discussed and documented in advance, and are all daunting tasks that terrify many already exhausted individuals. They may decide that they are not up to the task and won't see the doctor after all. For example, they may not feel up to the challenge of getting ready, travelling by car, 'sitting' too long in the waiting room or elsewhere, or talking to anyone at all or for too long. Then, of course, there is also the challenge of the trip home to consider.

Finally, and most importantly. The energy conservation behaviours that Grade 2-4 ME patients have taken to enable them to see the doctor are not enough to protect them from the pay back symptoms they know they will have for days or weeks afterwards. None of these speaks out to the naïve doctor, who has no clue as to the nature or extent of the patient's ordeal.

Most of my severe ME patients do make it to my consultation room. But I do recognise the compliment they have given me in putting in a huge effort, in order for them to manage to do so. I recognise THE COST to their health that they have 'paid' so that they can come to see me.

The second cost is measured in terms of time. Given that each visit to me lasts an hour, the typical severe long term patient I have has spent somewhere between 50 to 100 hours over the years. This is a lot of time. If it weren't useful time, they would not come. The point though is in making it useful. If it weren't useful, it would be an enormous waste of time. How does one measure one's life, when it is devoted to medical attendances ? Time is only a cost when it is spent visiting doctors who have no clue. THE COST is measured instead in terms of frustration, anger and an overall sense of futility, and dare I say it, helplessness. As an aside here, please note that even in good hands, the journey forward is long. All patients need to know this. Imagine how many 10-15 minute consultations with a doctor would be required to reach a total visit time of 50-100 hours, and then one gets an idea of the extent of the problem, and the deficiencies in the system.

Finally, monetary costs deserve a big mention. It is not my place to discuss this matter in detail except to say that every penny and every cent spent should count - not necessarily right away, but eventually.

Experiencing the ME Patient.

The purpose of this chapter is to provide insight both to doctors and about doctors in regards to ME patient management issues. I have already provided some contextual information in regards to this endeavour. Severe ME (Grade 4 disease), as already stated, have little representation in terms of published literature on the

subject, and this places patients and their doctors in a very awkward, unsettling, and most importantly, uncertain position. Uncertainty in this particular setting is too stressful for many Grade 4 patients who, on these grounds alone may choose NOT to see a doctor, for many years in many instances, in my experience.

Most doctors are good, honest and hard working people. They are also very busy.

I can remember my own first encounters with ME, some 30 years ago. I was very diligent in taking a history for the first time, and to this day, I remember thinking to myself, when will this history ever stop?

How could any illness fail to fall in line with other conditions I could readily recognise so that I could then cut to the chase? I assume that this early personal experience is likely to be a typical one for most doctors, even today. It never ceases to surprise me that medical school has neglected ME to such a degree that at worst, it is not on doctors medical maps, and at best, could best be described as uncharted territory. That is why I believe that 'unexposed' doctors will ask themselves the same questions that I did so many years ago. The only difference is that a greater number of better informed patients prevail than formerly was the case. These informed patients will react differently, depending on the kind of doctor they see. My patient was the last hospital admission for the day, and so I spent over two hours recording her problems in detail. I was none the wiser at the end of this. Had time allowed, I could have spent even more time with this lady, who I remember was so relieved to be able to tell her story. However, I found it hard to fit her story into anything I knew before, and it was such an unrecognisable story too. Later, with other similar patients, I anticipated this time consuming process, and would attempt to shorten it and condense it if I could, and endeavour to try to focus in on what the 'real' problems were. I

had to present these patients to my consultant the next day, and do so in only a few minutes during ward rounds that usually lasted a couple of hours. This was no easy task and was tremendously stressful and often futile. Moreover, it was not uncommon even then for senior staff to commiserate with me that I had fallen for what many believed was a phoney illness.

The same challenges are still faced by well meaning doctors to this day. Only now, there is much less time available to them.

Technology in so many areas has advanced since the day I entered medicine as a young 17 year old. At that time, the patient's history and examination were all important. We didn't have CT scans at the ready, or echocardiograms to help us make a definitive diagnosis. Endoscopies were also in their infancy. Gastric surgery for peptic ulcers were the norm, and women were allowed to suffer labour for days and days. Pathology was everywhere, with rheumatic fever and its complications as commonplace phenomena. There were central iv lines, but to find someone who knew how to insert one was another matter altogether. Whilst we may retrospectively have seemed to have been in the dark ages at that time, what we did learn was how to more fully listen to our patients, a talent that perhaps is not so sharp now amongst new doctors as it was way back then.

Nowadays, patients exist in a technological age, and if possible, are processed speedily and efficiently through the system. Patients expect more, as advances in all realms claim new possibilities. This is modern medicine, and now, evidence rather than good clinical judgement is demanded. Evidence based medicine has become technology driven.

I have deliberately set the scene for what it is like to be a doctor in the 21st century.

So, you the doctor, may still find ME to be a very 'suspicious' illness, just as I was informed it to be many years ago.

Technology does not identify or validate it. The histories are too long to listen to, and in the absence of credible physical evidence, there is a large mismatch between abbreviated, uninformative clinical histories and what profit driven, affordable technologies are capable of showing. Given this challenge, doctors, pressed by patients for answers, will do their best to avoid ME patients. No amount of history taking will bring the doctor closer to a technologically legitimate illness, and the doctor will be left frustrated and drained. Syndromes are a thing of the past, except in psychiatric settings. Medical triaging, these sorting patients out into categories, does not put ME into its proper box. ME was once appropriately placed into the neurological box, but as technology development is designed to help most of the people most of the time, ME has fallen through the cracks.

Technology has empowered much of medicine, but at a cost to technologically unexplainable or unfixable diseases and symptoms. A complaint as simple as tinnitus, or ringing in the ears, has no reliable test to confirm or explain it or even cure it. The list of such common phenomena where technology has 'failed' is amazingly large. Today's doctors are challenged or even charged to find the most acceptable and creative ways to minimise such complaints. "Its old age", or "it's just a virus" are very familiar minimisers, and they usually work.

What happens when such minimisers fail to work? ME patients are one good example of these weaknesses of modern medicine.

It is not surprising that you, the doctor, will not be able to cope with an ME patient, as neither your training, available technology, or your repertoire of minimisers will help you here. It only takes

one ME patient to show that the Emperor has no clothes, and that is you. You might be able to cope with one such patient. However, it feels far easier and more convenient to pass such ME patients on to some other doctor, almost as if these patients are like hot potatoes in your hands. You can justify your actions because you have many other patients who you are very competent in helping and through which you can readily and publicly demonstrate your expertise, skills and training. Here, you DO feel confident. Here, you truly do help MANY people in need, and your skills and training are on show for all to see. I get that, and most people get that too.

Let me assume that you encounter someone you know very well who falls ill with ME. You may ask yourself how is it possible that a patient can change so much? You find it almost unbelievable. Their symptoms don't make any sense to you. Nor does the patient make much sense. If you listen, you feel like you are being sucked in. Normally, you set boundaries and control the interview with panache. But here, with ME, the danger in listening is to lose control of the dialogue and it will be a long conversation. Allowing free reign for the patient to ramble about matters that don't fit the norm, is as if you are giving the patient too much latitude to express himself and cause you to conclude that he does not sound credible. It is hard to see the wood for the trees when you first encounter such a patient.

You feel overwhelmed. The symptoms are either weird full stop, or they aren't symptoms that modern medicine has ready answers for.

You know about vertigo and dizziness and tinnitus, but even if these were the only problems, you still aren't in a position to fix them in the same way as you might suture someone's head gash and close up. If these symptoms aren't enough, the patient is also complaining of pains all over, and headaches, and fuzzy heads,

and migraines, and stomach bloating. All the tests you've done aren't demonstrating anything unusual, so either these symptoms aren't as bad as the patient thinks they are, or there is some other motive. You don't see how all these symptoms tie together.

There is patient driven urgency emerging. Now, your long term patient is threatened with losing his job: time to refer the patient - as the heat is rising quickly.

So, what are the problems that can be identified by examining such an engagement? Knowledge, time, expertise, and money are the problems.

Firstly, medical training has provided no prior information to familiarise you with this type of problem. It feels alien, uncomfortable, and beyond your knowledge base. Basically, you feel helpless, and that's not good.

Secondly, the system doesn't allow you to spend enough time with problems of this kind. Ten to fifteen minutes in and out barely scratches the surface of your history taking. And if we assume 3-4 hours is what's needed to get a good history, then that is not going to happen.

Thirdly, you don't think the problem is psychiatric, as you know the patient well enough to realise this. So, who do you have to come to your assistance, even if you do suspect ME? There is no body of MEDICAL Specialists to refer the patient to, which is what your goal might be, but can't.

Why aren't there more ME Medical Specialists, aside from training issues? I personally find this specialty very rewarding, but not to my pocket. Earlier, I spent 14 long years to just to begin to make a proper living. My peers make 5-10 times my own earnings. Expertise exists but is not formally recognised by any regulatory body and is not reimbursed in accordance with one's knowledge

and wisdom. So, I don't have any financial incentives to choose this line of expertise over many other options.

There is one exception to all of the above, and this itself implies that in a different society, things could be different. Independent Medical Officers (IMO's) working on behalf of Insurance Companies, are often very knowledgeable on ME matters. This implies that Medical Expertise in ME is not some strange aberration arising purely for humanitarian or idiosyncratic reasons. If these semi-retired physicians put their experience into helping rather than hindering the patients they evaluate, then the medical work force would easily reach an adequate number of ME informed medical specialists to not only be available for referral and more effective care, wisdom and creative therapeutic thinking, but a stronger lobby group would exist to safeguard the interests of ME patients. Understanding specialists do exist but they work, for financial reasons I believe, 'for the other side' (insurance companies, that is). So, it seems that only financial gain blocks the way forward, not ignorance.

In an ideal world, how would or should a severe ME patient be cared for and humanely catered for? As I have already indicated, I have much to say about this. In this ideal scenario, ME should be a legitimate subspecialty for both general practitioners and medical specialists, who are financially rewarded accordingly. Proper training would then follow naturally from such a change.

Once a critical mass of interested medical personnel exists, then creativity between fellow doctors who don't necessarily live half way round the world, would be generated.

Future Potential, Solutions to the Doctor's Dilemma.

The Patient's Dilemma is a genuine component of the dilemma most doctors face in terms of general patient management strategy. If the Patient's Dilemma were to be adequately understood, a greater rapport between parties would be engendered. Rapport is the first step in any effective communication process. Without rapport, no genuine long term gains are achievable.

Most experienced clinicians should have well developed rapport building skills, no matter what the circumstances are. So why is this a problem with ME?

A clinician with good communication skills may have no problems with an ME patient during the first few consultations. This initial success has more to do with the doctor's general ability to put all patients at ease, regardless of diagnosis. Experienced patients will be trying to put their best foot forward too, at this time, hoping that more meaningful discussion will eventually follow. There are multiple well recognised stages of engagement that need to be passed through in order to create any productive relationship. None of this is new, but are not always explicitly and formally developed as skills, even for doctors. In the case of ME, only the first few stages of engagement are passed through uneventfully and are often then followed by relationship collapse because certain clinical skills and knowledge milestones are missing

A human relationship is an engagement between two or more individuals. A healthy relationship includes mutual respect. This is what the patient aspires to, but in order to achieve this, an ME patient has to overcome a number of obstacles. Rapport is number one in this endeavour. As already mentioned, many clinicians have this capacity as a general skill. Other clinicians will have this,

but choose not to use this skill for any ME patient whatsoever; the message being that the clinician is either uncomfortable with ME, has no ME management skills, or at worst, detests ME patients as a rule.

The Patient's Dilemma involves these presets of the doctor's mind. In a new doctor encounter, the patient has to actually triage the doctor's attitude towards ME. This is quite an unusual and unacceptable situation as far as medicine as a profession is concerned. Nevertheless, it is real and therefore, deserves to be catalogued as a problem, which is what I am doing here.

Clearly, there are many 'structural' combinations of patient-doctor relationship that can be encountered in the context of ME that would not be an issue with any other medical condition that I know of. What is more unusual is the fact that very little is being done by health authorities to improve or at least publicly admit to the very existence of this anomaly. It is therefore not surprising that ME sufferers have little confidence in their Health Authorities and are suspicious of any initiative that potentially might undermine what few rights ME patients do have.

The relationship structures I am referring to can range from

(A) A recent onset ME sufferer presenting to a caring, genuine and trustworthy doctor who knows nothing whatsoever about ME, but unfortunately recognises the illness not as ME but instead, as primary or a chemical depression (as perhaps one of the most common "adverse outcomes"). The trusting patient accepts this diagnosis, as does the family of such a patient, and innocently embarks on years of antidepressant therapies, all of which are ineffective. The patient is then labelled as treatment resistant depression. I have looked after many such patients.

One of my successes in this field relates to a lady who at the time was in her mid-30's and had annual admissions each of three months duration to a psychiatric facility for whatever was the next new breakthrough antidepressant, but which also included a series of ECT sessions in a vain attempt to break the 'depression'. By chance, at her 5th or 6th annual visit to hospital, I was consulted to review what then was considered to be a permanent depression. Multiple aspects of this lady's condition were highly consistent with ME. She was treated accordingly, and since 1994, has not had a single episode of clinical depression or had the need to be admitted to hospital.

Her well-being and quality of life have improved enormously, and she now has the capacity to be an effective mother and work in a worthy position on a part time basis ever since.

(B) A recent onset patient may similarly accept graded exercise and cognitive behavioural therapy, again by a well meaning and caring doctor, only to find that instead of keeping her job position, her condition has been aggravated to the degree that she might be removed from the work force and dismissed by her insurance company, despite perfect compliance with her doctor's recommendations.

(C) A long term ME sufferer has raised the bar and recognises that the GP lottery is a failure. Such a patient has moved passed the rapport trickery phase and actively seeks something beyond the GP's CBT and GET reflex responses that just about everyone can roll off his or her tongue as the only 'responsible' and respectable thing to do in this setting. Insurance companies and others will say "if you have not had CBT or GET yet, then you have not been adequately treated".

By the way, these challenges that are aspects of the Patient's Dilemma, are pervasive and affect even G1 ME patients. Imagine the problems that a G4 ME patient faces.

(D) To demonstrate the worst relationship structure would be to consider a G4 ME patient's encounter with a totally dismissive clinician, with a rigid mindset and an obsessive belief that ME is entirely psychiatric. It is no wonder that adult ME sufferers are so fearful of doctors. Not only are such patients special needs disregarded, but they are deliberately hidden from view by the patient, out of fear of being labelled as having strange symptoms. What awaits them is ridicule at best, and institutionalisation at worst. No doubt, many ME sufferers in years gone by suffered the latter fate - an awful thought to even consider, however true it might be.

Addressing the Doctor's Dilemma and Severe (G4) ME together

As alluded to in preceding paragraphs, the ME patient's position in the Doctor-Patient relationship, by and large, is out of balance. In its current form, the G4 ME patient is deprived of basic needs, and the carer is the patient's only life line. This is untenable and yet, it persists. How might this be changed for the better?

The purpose of describing matters from the patient's point of view is to inform those doctors who do care, but don't know how to. Ideally, this type of information should be basic to any doctor's training, but I have seen violent reactions to even this relatively benign idea. To accept ME into basic medical training, as I understand it from such unexpectedly vigorous responses, clearly must be threatening the system as it presently exists.

It is hard to pinpoint what exactly is being threatened, but it is clearly there somewhere. The most simple speculation I have is that to accept ME as a legitimate medical condition calls for a major overhaul in medical thinking as a whole.

One might think that medicine is complex already. Maybe, but to experienced doctors, it is not so complex. It currently feels so neat and tidy, with diagnoses and factory line procedures at one end, and the hands on art of medicine and carefully crafted therapies, helped along by the pharmaceutical industry and the like, at the other end. I personally don't see how ME would upset matters to any extreme degree, but I have had plenty of time to adjust.

Much of what I rely on requires knowledge that medical students do understand, but which is usually deemed irrelevant once one enters real medicine. I assume it is the latter that creates the greatest consternation amongst seasoned physicians whose knowledge of the basics has waned considerably. I know this because doctors readily admit it once a discussion on ME gets underway. Doctors quickly lose the thread of basic biochemistry in particular. A rare few are not so academically compromised by the years, and have remained passionate towards all things medical.

These people are the gems that an ME patient at present should seek.

A word of caution is required before proceeding further. It is hard for a doctor to be both a clinician AND an academic at the same time. Very different skill sets are involved: population facts versus probabilities of the same in a given patient; rapport skills; an intellectually enquiring mind that spots exceptions to rules and asks why and seeks to find answers, not only in populations but also in individual patients. These are some of the qualities of the

pioneers in this field who will make the problems of today become things of the past in tomorrow's medicine.

How is it that G4 ME should be so 'difficult' for today's doctors in matters that are as basic as rapport and communication? Much has to do with medical culture as it exists and has existed for so long. Technology and the pharmaceutical industry have made large inroads, but this culture otherwise remains largely the same.

In regards to change, it is a curious fact that at one time only a dozen physicists understood Einstein's Theory of Relativity and were capable of recognising its legitimacy. If these physicists all been killed in a plane crash, the story would have ended there. It took a certain kind of necessity to bring this theory into the realm of reality and become a significant driving force in shaping today's society. What forces would have to come into play to bring about real changes in medical culture accepting of ME as having physical legitimacy as one of the building blocks within the edifice of medicine? (In the same way that Einstein's bizarre theory was pushed into reality by critical circumstances.)

I fall short in terms of the usual forces that drive significant change. An idea grows when the time is ready. These humble ideas should be the beginnings of what I fail to say. There is nothing special about the approach to a severe ME sufferer. What stands in the way is a reluctant mindset that cannot embrace doctors with the uncompromising desire to understand what severe ME is about and how to mindfully ease the complaints that literally surround the patient.

Our medical culture is more tuned to objective explanations than ever before. Many doctors are culled from the 'Western' work force for failing to adhere to the strictest application of doing only that which is precisely supported by available scientific evidence. Strangely, and somewhat paradoxically, if this approach was truly

valid under all circumstances, a minority of illnesses could be managed by robots and the rest, including all patients in underdeveloped countries, would not receive any medical help of any degree of sophistication, at all.

What I am proposing is simply for the doctor to relate to the patient, as one human being to another. This is not rocket science and yet, a majority of doctors faced with a severe ME patient, are so indoctrinated that they are incapable of doing so.

Being able to thoroughly relate to a severe G4 ME patient does indeed require skill, but a basic premise to this process is empathy. This comes naturally to doctors when seen under other circumstances and with other diagnoses. In the case of severe ME, empathy requires additional factors to be in play. I feel I am addressing a first year medical student as I write this, but this is place where I believe it is necessary to go to make contact with the receptive few doctors out there willing and ready to reach out to what is truly a medically yet undescribed disease level existing right in front of us. Existence is indeed the appropriate word here.

I am building up to something, but have to create so much context to get to not much. I skirt, just as severe ME patients skirt about, in case what they have to say will be received with total disbelief.

One of the most influential books on neurology I have ever read is Oliver Sacks best selling and ground breaking book cleverly entitled 'The man who mistook his wife to be a hat'. The book is a collection of case studies, describing various logically 'impossible' twists in functional perception due to well documented objective neurological deficits. Dr Sacks has written other books, again relying on his incredible prose, to compellingly document what it is like to have this neurological disorder or that. The mind is a curious thing, and not all curiosities are figments

of the mind, as we ordinarily view them. A pathophysiological basis exists for the figments described in Dr Sacks choice of case presentations, and there is no reason to believe that the list of objectively based cognitive anomalies is complete.

At one time, reality was once considered to be within the bounds of computability. This has unanimously been shown not to be true. No amount of data and computation could account for why a man should mistake his wife to be a hat.

I will take an aside and describe another story I believe is of some relevance to my commentary. The Boeing 737 is an incredible plane with sophisticated technology under its hub. However, despite this, no amount of prior research could have anticipated a previously unbelievable failure of its PCU's dual servo valve deflecting the plane's rudder in the direction OPPOSITE to the pilot's input, until three crashes took place in the 1990's. Thermal shock was eventually discovered as the likely cause, after millions of dollars were spent in the investigation of these crashes.

The point here is strange things really do happen for legitimate reasons, sometimes taking years to finally explain them. This I believe to be also the case for the phenomena experienced particularly in severe examples of ME, a neurological disorder.

How does one explain a doctor's logical brain cutting out at the mere mention of ME? This is a psychological phenomenon. My hope is that this psychological barrier, once breached, will enable doctors to listen more closely to the patient, to discern cognitive dysfunctions and autoregulatory sensory failures and other hitherto poorly documented symptoms and functional challenges a severe ME patient and carer face on a daily basis.

Patterns of dysfunction abound in severe ME, and to the trained and skilled eye, nuances in body language can indicate problems accurately without the need for the patient to

communicate them verbally. Bizarre is a harsh and inappropriate adjective to apply to the complaints, as they have yet to be put together and studied in a systematic manner, as were the cases of Oliver Sacks and the Boeing 737 rudder failures.

The Patient's Dilemma would be understood by the doctor and effectively managed by some very simple, empathetic gestures. The list of such gestures might include the following (but of course, this list is by no means complete):

- taking steps during consultations to ensure the patient can lie down if needed, have a glass of water
- being seen without shame during both a patient's good days and bad days, and so on.
- the patient's problems being so familiar to the doctor that any subtle unspoken nuances in a patient's body language are immediately and intuitively recognised for what they really represent.

A mutually respectful partnership between doctor and patient would become the norm. Brainstorming for solutions would be ok, and not be experienced as a threat to the doctor's position.

Hospital care would become a specialty in itself for those who are not coping at home. This care would be just as demanding on staff as someone in any Intensive Care Facility. Patients would not have to live in fear of hospital care.

Respite services for carers would be available to those whose carers meet the criteria for severe ME

Consider what I have spoken of, as only the the beginning of much more to come once the dilemma is overthrown.

I have put together a polite and relatively light reading letter to highlight some of the behaviours and symptoms that I believe might be useful introductory reading for a caring and eager doctor regarding a severe ME case coming soon to the doctor's office.

A letter from an experienced doctor to a more junior doctor with less experience.

Dear Doctor,

I am writing to let you know that I understand your problems in managing the medical complaints of Mrs X.

Allow me to provide you with some friendly advice about your new patient.

I appreciate your frustrations and how challenging your patient might seem to you. I know that she rambles on, and you have trouble taking notes for your records. May I suggest that you record what she says in no particular format and write things down as they are first explained to you during her first few visits to you. Later, after these visits, you can rearrange this information, or highlight what, in your view, you see emerging as the key features or most important features of her history and also what seems to be the most important problems FOR HER.

They are likely to differ, but sooner or later you will be able to talk to her about your own thoughts on the matter. For now, just listen. If she speaks too fast, that's because she has so much to say, and she knows how valuable your time is and how short your available consultations times are. It's ok to say to her "just wait one moment while I write what you have just said down". She will understand, but you may need to remind her a few times before she gets that you are truly interested in her case and you want to take good notes.

Remember too, she hasn't had someone who has listened to her like you do for some time, so she might be a little bit overexcited. In some of my own patients, they get wired up as they talk, and just can't help themselves, and pay for it later with several days in bed after they have seen me. Your patient may also have the same problem.

I think you will find it beneficial if you invite her husband along at each visit. He can act as her eyes and ears, and will probably remember more about her consultations than she does. Also, she won't have to attempt to explain to him everything that went on between you if he is already there.

If you are agreeable, might I also suggest that you invite Mrs X to bring a tape recorder along with her so that she doesn't have to keep track of everything you say at the consultation. She can listen to the tape later at her own pace. This will alleviate her from the pressure of taking everything in in one go, so that her mind won't fog up too early in the consult. That way, she has more space to listen and absorb at least some of what you say. If she knows you are taking good notes, she won't feel pressured in having to repeat herself at her next visit.

By the way, don't feel overwhelmed by the lists of symptoms she brings in. She just writes down whatever occurs to her at any given moment, not necessarily in any particular order. You might ask her which symptoms are bothering her the most at the moment. It's possible though that at her next visit, other symptoms are causing her more grief. Also, and I don't know why, but she may leave her most important questions till last. Of course, you won't have the time to answer them there and then, as your next patient no doubt will be already waiting to see you. Just jot down her final words and promise to bring these up first at her next visit.

She does seem a bit obsessive, doesn't she? I think she behaves that way because its the only way she can survive.

I once witnessed a patient with a well documented bilateral hippocampal brain injury who behaved very similar to this lady. My patient had to write everything down, not only about what he had just done, but also what he was doing and what he was planning to do. He had post-its stuck all over the house. He even kept a record of his thoughts as if his autobiographical memory was poor.

Don't be fooled into thinking that your patient's memory seems just fine. She probably has spent days getting her thoughts together in preparation for her visit to you. She may know much of her history off pat, but don't rely on her remembering the details of what her family is doing next week because she is barely able to keep track of her own problems.

Her husband may have a completely different view of things than she does. May I suggest that both versions are correct, and that this difference is only a matter of perspective.

You are probably wondering where to start with this lady. If you get an idea on how she spends her day and why, then you soon will be able to identify what is holding her back the most. She may not even know how to articulate her most important problems, as she has had to endure them for so long that she only notices the changes and the background truths are 'ignored' by accident.

I hope you find this brief letter useful to you.

All my regards,

Dr

PS Her husband has been looking after her from some time. Check him out and see how he is coping, because he may need a break of his own. Some R&R would really help him to sustain his own health and keep this loving couple together.

The above letter aims to illustrate in gentle terms some of the doctor's misunderstandings that underlie The Doctor's Dilemma. Once enforced by a colleague, they won't necessarily seem so out of line to a budding ME doctor.

Additional 'unusual' doctor's behaviours might include:

1. Finding a place for the patient to lie down while waiting, be it on a couch, a spare bed, on the floor, or outside in the car. The receptionist can go fetch the patient from the car when his turn has arrived. Similarly, it is not uncommon for an orthostatic intolerant patient to need to lie down throughout a consultation, and the doctor should enquire of the patient if this is the case.

2. Paying attention to subtle changes in a patient's body language. These changes are very likely to be relevant and should not be dismissed. What might be happening is the patient, in an effort to be polite, is refraining from mentioning that he or she is:

- too cold or too hot in your office
- in great need for a glass of water to drink
- finding your perfume or aftershave is making the patient sick in the stomach
- suddenly exhausted and needs to cut the visit short
- has gone into a brain fogged state and really can't focus on his or her thoughts coherently and has no clue as to what the doctor is saying

I say that these are unusual doctor behaviours because more often than not, they actually don't happen in the context of an ME naive doctor. This is not meant to be an insult or a suggestion that the doctor is not caring, but that the doctor does not yet know what it is like to have ME.

Similarly, but in the opposite direction, ME opponents dislike the fact that patients wear masks, dark glasses, strange attire, ask too many questions, waste their time, are burdensome, use vitamins and supplements, have different opinions, use the Internet for information, belong to networks and self help groups, and so on. This is just the way some doctors are at this moment in time. Consequently, it is up to ME sufferers to live them out if they can. In some countries, unfortunately, the doctor the ME patient has, is the only patient that the patient can attend. I have no personal solution to this situation, but I do pray for better times ahead, especially in terms of public awareness of ME and better medical training.

Finally, some cautionary words.

(1) ME patients who are so sick that they cannot leave their own beds at home do not necessarily find answers to their needs by admission to general hospitals. Such patients have such stringent special needs that a general hospital will be unable to cater to them. This will include wake up times, day time naps, special diets, precise physiotherapy methodologies, knowledgeable nursing staff, showering and bathing practices, noise reduction, closed curtains, room temperature adjustments +/- fans or air conditioning, adequate fluid intake and output monitoring, and so on.

(2) Very sick ME sufferers are often so exhausted that they are too tired to care. This can be mistaken for the apathy of depression, rather than the apathy of fatigue. Indeed, when the apathy of

fatigue lifts in the course of effective management, this is not uncommonly replaced by a sense of frustration and despair because the realisation of the situation for what it is comes flooding back.

In a sense, ME patients can be so so ill that they are too tired to be depressed. Conversely, the return of a depressed mood can actually be one of the first signs of improvement.

(3) The carer-ME sufferer relationship is often a long term one and habits and routines develop. The ME patient must rely on the carer, and the carer sacrifices a great deal. A good ME doctor should watch out for the consequences of a change in this dynamic in the course of any improvement the patient might have. As the patient gains or recovers a degree of control, the carer may feel that his or her role is being undermined. This is when the doctor should step in and assist the carer in this delicate transition. The patient wants more space and the carer may interpret this as rejection. If everyone is aware of this possibility in advance, then a smooth upward trend is made more available to all.

Unfortunately what might be available is presently not guaranteed, even in the best of hands. Nevertheless, sustained validation, sustained love, the human touch and any release from isolation can uplift a patient's quality of life when medications cannot.

And on a better note, even my sickest patients can laugh and show great spirit. I encourage that always. We are a team and we know it.

(DR WHITING IS A SPECIALIST CLINICIAN IN GENERAL MEDICINE, INFECTIOUS DISEASES AND CHRONIC FATIGUE DISORDERS, BASED IN BRISBANE, AUSTRALIA.)