



Chronic fatigue syndrome

The patient centred clinical method – a guide for the perplexed

BACKGROUND Chronic fatigue states are common in general practice and over the past 20 years there has been considerable worldwide consensus developed on the criteria for chronic fatigue syndrome (CFS) also commonly known as myalgic encephalomyelitis (ME). Chronic fatigue syndrome is an illness characterised by the new onset of disabling fatigue, accompanied by cognitive, musculoskeletal and sleep symptoms. There are no specific diagnostic tests or biological markers and the diagnosis is made by ruling out other causes of fatigue. The pathophysiology of CFS is still unclear.

OBJECTIVE This article discusses the application of the patient centred clinical method to the diagnosis and treatment of CFS.

DISCUSSION There is no new breakthrough in the diagnosis or management of CFS in spite of much research and controversy. There is considerable evidence that the best place to manage CFS is in primary care under the care of the patient's own general practitioner, but it has been suggested that doctors feel unable to deal with the problem. The patient centred clinical method offers a constructive guide to management. The author considers that the best hope for sufferers is self management guided by a supportive and helpful health professional, preferably the patient's own GP.

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An unsolved problem in suburbia

It is June 2001 and Raylene is really 'stuffed'! Raylene O'Hanlon is a 25 year old mother of two children who lives in a suburban area of a large Australian city. She is married to Shane who is also 25 years of age and a pillar of the local football club. Raylene and Shane have never been sick but have their general practitioner, Dr Cynthia Swale, who looks after the health of them and their two children, Lara aged three and Conroy aged one (one of Dr Cynthia's deliveries). In September 2000 Raylene decided to stop breastfeeding Conroy then aged six months. Not long after, she began to feel tired and had frequent headaches and pains all over. She felt 'really weird' and drowsy all day and when she went to bed she couldn't sleep at all. Looking after the children became very difficult and Shane's mum tired of continually having to come over and help her out. Shane himself didn't stay home much and things came to a head one night after he got home from the football club and found Raylene lying helpless in bed with the children wet and screaming in the next room.

'You'll have to get down to the doctor!' he slurred as he changed Conroy's nappy and, sure enough, she was the first patient on Dr Cynthia's list the next morning.

Dr Cynthia takes a careful history and does a full examination. Everything appears normal and her differential diagnosis is limited. However, Raylene has had no problems before so she decides to send her off for a few blood tests including a full blood count, C reactive protein, liver, renal and thyroid function tests, Epstein-Barr and cytomegalovirus virology. All tests come back 'normal'. Six consultations later there is a rapidly fattening file with reports all bearing the same message – that Raylene is 'normal' – but Raylene still feels 'stuffed'! This visit Shane is with her and pretty angry. 'A woman in the health shop said she's quite sure Raylene's got ME, whatever that is. What do you think, doctor?'

So what do you think, doctor?

Cynthia is probably reflecting on how nice it would be if she were a specialist who could either pronounce some specific diagnosis or tell the patient that any possible diagnosis was ‘out of my field’. She has gone through six years of medical school, a further five years of internship and general practice training and she has sat in this office for 15 years, but she is falling into a big black hole of unknowing. Now if Cynthia were sensible, she would enjoy that big black hole, but after a lifetime of instruction, she sees it as shameful. She falls with her unopened parachute through the stratosphere of her ignorance

Table 1. Making a diagnosis of CFS ^{4,5}
Type of fatigue – chronic fatigue lasting more than six months which is: <ul style="list-style-type: none">• Clinically evaluated and unexplained• Persistent or relapsing• With a definite onset• Not the result of ongoing exertion• Not substantially alleviated by rest• Results in a substantial reduction in previous levels of occupational, educational, social or personal activities
Symptoms – Four or more of the following should be present <ul style="list-style-type: none">• Substantial impairment of long term memory or concentration• Sore throat• Tender lymph nodes• Muscle pain and tenderness• Multijoint pain without swelling or redness• Headaches of a new type, pattern or severity• Unrefreshing sleep• Postexertional malaise lasting more than 24 hours
Exclusions <ul style="list-style-type: none">• Any medical condition that may explain chronic fatigue• A pre-existing diagnosis of cancer or chronic infection• Any present or past diagnosis of major psychiatric disorder• Alcohol or substance abuse within two years of the onset• Obesity with a body mass index of 40 or greater

and stretches out for phrases that might excuse her ignorance such as: ‘snap out of it’ or ‘you’re doing too much, what do you expect’, or ‘do you think you are depressed?’ or ‘are you getting on with Shane?’ Back to the health shop Raylene and Shane go and ask if anyone knows a decent doctor. At her monthly Balint group, Cynthia and her colleagues discuss the ‘heartsink’ patient and wonder who could persuade Raylene to have cognitive behaviour therapy (CBT) rather than her choice of electroacupuncture according to Voll (EAV.)

The thesis of this paper is that Raylene needs neither CBT nor EAV. In turn her doctor does not need to go to courses in either. What Raylene needs is a good doctor, and in order to become a good doctor Cynthia needs a method, a clinical method, a patient centred clinical method.

McWhinney in his introduction to the textbook on this method' draws attention to the historic struggle between Raylene and Cynthia – Raylene wants the doctor to understand her experience while Cynthia wants a disease to recognise in Raylene. The root of the current flight from evidence based mainstream medicine to alternative unproven therapies lies in the criticism that doctors are only any good if you’ve got something recognisably wrong with you. How could a new method help?

The patient centred clinical method

There are six interactive components of the patient centred clinical method and we will apply each in turn.

Exploring both the disease and the illness experience

The difficulty is that the scientific training of clinicians has resulted in a dominance of disease and diagnosis over symptoms and suffering. One of the

Table 2. Minimum clinical and laboratory evaluation of CFS
<ul style="list-style-type: none">• Full clinical examination• Urinalysis• FBC, ESR/CRP, autoantibodies• Thyroid function tests• Fasting morning cortisol• Epstein-Barr virology including nuclear antibody

major problems that Cynthia faces is that she has been carefully taught that a diagnosis must be made before treatment is delivered. The problem for Raylene is that chronic fatigue syndrome (CFS) is not yet universally accepted as a disease by doctors like Cynthia, so her suffering may be ignored while a diagnosis acceptable to both parties is sought. Is there any other explanation for the fact that in one series there was an average of two years between the onset of symptoms and diagnosis of CFS? In the introduction to a recent United Kingdom report into CFS, Sir Kenneth Calman² wrote:

I recognise chronic fatigue syndrome is a real entity. It is distressing, debilitating, and affects a very large number of people. It poses a significant challenge to the medical profession.

The fact is that diagnosis is not necessary for management to proceed, indeed in important areas of management it is dangerous to wait for the luxury. The problem that led to the development of advanced trauma life support (ATLS)³ was that patients died while doctors puzzled. Similarly people like Raylene have petitioned parliaments because doctors could not make the diagnosis of CFS.

Second, family doctors can make a diagnosis of CFS according to internationally agreed criteria that are outlined in Table 1 by applying a minimum evaluation as outlined in Table 2. Of course, where indicated, further investigations should be ordered.

So Dr Cynthia ought not to be confused. She can listen and believe in the fact that things are not right with Raylene's body and she can arrive at a diagnosis. The strict application of the criteria is helpful because there is now a rapidly increasing evidence base that gives helpful markers of incidence and treatment. Community studies demonstrate a prevalence that makes CFS a much more common women's health problem than was formerly recognised.⁶ Recent evidence suggests however, that only one-third of patients presenting to their general practitioner with unexplained fatigue lasting six months or more have a diagnosis of CFS.⁷ The same study indicated that the diagnosis was helpful in that it identified a group with more severe outcomes and comorbidities such as depression. However, this diagnosis is not the endpoint but only the beginning of a journey for healing.

Understanding the whole person

When patients and doctors meet, the question:

'what' will often be asked, but we also need to ask the question 'why'. Why Raylene, why now? We are always very keen to discover the specific entity that has caused her fatigue but less willing to explore some very good reasons why Raylene's pregnancy, lactation, maternal instincts, relationships with a demanding and potentially abusive husband may have produced conditions which made her a 'sitting duck' for a potentially innocent passing virus. There is a 'truth about Raylene' that is still elusive in our story. For example, did she want this pregnancy, did she want the last one and why was she at the health shop in the first place? Knowing about the life cycle transitions experienced by Raylene and the social context in which she lives could help Cynthia to understand the meaning of her present illness. She might have loss, abuse or hopelessness in her story that could help her to understand why she is ill and give her hope to suffer the current problem.

Finding common ground

This is probably the most important issue in dealing with patients like Raylene. Since 1983, I have dealt with many people with unexplained chronic fatigue, and I can say that the most common reason for referral is failure to find common ground with their own doctor. The disturbing thing is, most of the doctors have been reliable GPs to these patients for many years. The first step is giving a name to the problem. In a classic description of a country doctor, Berger⁸ makes the point:

Patients are inordinately relieved when doctors give their complaint a name. The name may mean very little to them, they may understand nothing of what it signifies, but because it has a name, it has an independent existence from them. They can now struggle or complain against it. To have a complaint recognised, that is to say defined, limited and depersonalised, is to be made stronger.

The second step is establishing common ground and there is no doubt that this is the doctor's professional responsibility. There is a need for common ground to be expressed in terms of problems, goals and roles (Table 3). Raylene and Shane should be able to walk out of the first consultation with an agreed description of what is going on, with an outline of what management goals and treatment options are available, and a good idea of what they and the doctor can and cannot do.

Table 3. Finding common ground in CFS

Issue	Patient	Doctor	Common ground
Problems	What is wrong?	God only knows!	Let's find out
	Muscle pain	It's not cancer	Cause discussed
	Sleep problems	Common in CFS	No hypnotics
	Going mad?	Depression	Trial of drugs
Goals	Is there a cure?	Most recover	Symptom diaries
	Return to work	When you are ready	Certification
	Exercise	Graded only	Referral/review
	Alternative medicine?	Naturopathy may help	Offer to observe
Roles	Lead investigator	Assessor	Review
	Sufferer	Encourager	Provide refuge

Incorporating prevention and health promotion

There is now a vast literature on CFS and it is clear that, not only is it a distressing and disabling disorder, but it leaves the individual susceptible to depression and physical deconditioning. Nor does the illness confer immunity from other diseases and there is very definite risk that the worsening of symptoms such as fatigue and anorexia may be attributed to a recurrence of CFS and delay in diagnosis may result.

Enhancing the doctor-patient relationship

Before all this happened, Cynthia and the O'Hanlons thought they knew each other pretty well. Now Cynthia's heart has a sinking feeling every time she sees Raylene's name on her consultation list. The term 'heartsink patient' has entered the medical literature but it should be remembered that the 'heartsink' is in the doctor, not the patient, and there is evidence that our doctoring style may attract the patient who induces anger, frustration and despair in us."

Chronic fatigue syndrome is an illness that lasts a long time and the chosen doctor of a patient like Raylene is going to see her a lot. The doctor is going to need to exhibit compassion, continuity and constancy if healing of the patient is to result. In short, if we wish to continue this relationship we have to make sure that we enjoy it. Making enough time is perhaps the first priority and there is considerable skill in recognising that these patients are often disconnected and vulnerable and lack control of their own destiny. It is important to take time to explore with the patient the fact that inside them is a sick

person whom they despise and a well person whom they have lost but desire to return. Other useful tools in this most difficult task are the judicious use of humour. Perhaps the most useful manoeuvre I have ever used is to get the patient to role play the doctor dealing with a person with CFS.

Being realistic

Given the prevalence of CFS, it is reassuring to remember that the prevalence is 420 per 100 000 and that each Dr Cynthia is likely to have less than five such patients in her practice at any one time. While it is difficult to predict how things will go, in my experience most people with CFS recover gradually over a period of 1–3 years. Perhaps the most important issue is to be clear about what is possible and what is not and that it will be impossible to please all of the people all of the time.

Feeling a little better in suburbia

It is June 2003 and Raylene is back for a final visit to Dr Cynthia. 'Now that I'm moving down to the coast, I just wanted to thank you for all your support over the past two years. I feel a whole lot better but I still get the odd day when I can't do much. The counsellor has helped a lot and I've been able to work through lots of issues. It's been difficult breaking up with Shane but he's never grown up and his family are so controlling. Looking back I still feel unsure what caused it all. Was it a virus, something to do with the pregnancy, stopping breastfeeding, or was it all the stress of being in a difficult relationship? Anyway, thanks for being there when I needed you, I will always be grateful'.

Conclusion

Research over the past 20 years has removed much of the mystery from CFS but the devastation in people's lives has not lessened. The cost of this illness has recently been computed in the UK¹⁰ where the total three month costs were on average AUD8787 and over 90% of the cost was accounted for by care provided by friends and family members and by lost employment. These facts are not greatly different from what we knew 20 years ago;¹¹ we seem merely to be confirming the facts. General practitioners are still asking the question: 'Does CFS exist?' and individuals and families are still suffering, consulting quacks, losing money and each other. However, there is a way back from the disaster and it lies in a quote from the book by E F Schumaker, *A Guide for the Perplexed*¹² which became a watershed for me as I struggled to look after patients with CFS in New Zealand.¹³

When the level of the knower is not adequate to the level of the object of knowledge, the result is not a factual error but something much more serious: an inadequate and impoverished view of reality.

'Adequate' knowing will not come from the scientific clinical method alone, we need this method to be patient centred. It is time for general practice to give patients with CFS the type of treatment they deserve, and perhaps in doing so we might find a new and unique role for ourselves in modern medical practice.

Conflict of interest: none declared.

SUMMARY OF IMPORTANT POINTS

- CFS is characterised by the new onset of disabling fatigue accompanied by cognitive, musculoskeletal and sleep symptoms.
- There are no specific diagnostic tests or biological markers for CFS.
- Diagnosis is not necessary for management to proceed.
- Establishing common ground between doctor and patient is necessary for management of CFS to be successful.

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Further reading

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