



Megan Arroll  
Bruce Arroll

# Chronic fatigue syndrome

## A patient centred approach to management

### Background

Chronic fatigue syndrome (myalgic encephalomyelitis) is a diagnosis that can attract feelings of stigma in the patient due to the lack of a definite diagnostic biomarker. To ensure that the patient firstly understands the diagnosis, and subsequently is comfortable with the treatment suggested, a patient centred approach is advised within the consultation.

### Objective

This article presents a hypothetical case and uses this to give guidance on methods for negotiating the diagnosis and treatment of chronic fatigue syndrome.

### Discussion

It is important to reassure the patient that negative investigation results and the suggestion of treatment options that are also used for depressive illness (eg. antidepressants and cognitive behavioural therapy), does not mean that their illness experience is fabricated or that they are being treated for depression. Once red flag features are ruled out and any exclusory illnesses identified, a multidisciplinary pragmatic rehabilitation program can be implemented. This includes strategies for increasing social support, liaising with employers and graded return to activities in a 'What matters to you?' approach.

### Keywords

chronic fatigue syndrome; communication; doctor-patient relations; rehabilitation



### Case study

A woman, 42 years of age, presents with complaints of exhaustion that seem unrelated to her activity levels. She has a range of other symptoms such as unrefreshing sleep, muscle aches and difficulties in concentration. She has tried resting but this does not appear to alleviate the fatigue. Her symptoms have been stable over the past 5 months.

Review of the patient's medical notes reveal that her previous general practitioner had thoroughly examined her, completed the recommended investigations for such a presentation (Table 1) and had diagnosed chronic fatigue syndrome (CFS) (myalgic encephalomyelitis) when these investigation results were normal.

The patient was offered amitriptyline and a course of cognitive behavioural therapy (CBT), the latter of which she knew was a treatment for depression. After investigating amitriptyline on the internet and seeing it was an antidepressant, the patient became very disillusioned and did not seek medical advice again until now. She told her partner and family of the diagnosis and felt stigmatised, as many did not believe this to be a 'real' illness and made comments such as: 'Oh yes, I get tired too, perhaps I have this chronic fatigue syndrome?'

During the consultation the patient states quite strongly that she does not feel depressed and does not wish to be treated for depression, but finds the diagnosis of CFS hard to come to terms with following the negative interactions with family and friends. Her current major concern was that she has used up all her sick leave through having days off to rest, and that her supervisor had expressed exasperation at the frequent absenteeism. Her previous GP also suggested she try to exercise, so she joined a gym. But after a relatively vigorous introductory session with a trainer, she had to take time off work to recover. She has not been back to the gym and her activities are now severely limited.

### Examination

The patient says her weight is steady and she does not snore or have breathing pauses when sleeping (making sleep apnoea less likely).<sup>1</sup> Examination reveals no lymphadenopathy, no signs of inflamed joints, and no other 'red flags' such as localising focal or neurological signs or signs of cardiorespiratory disease.<sup>1</sup> She answers 'no' to two depression screening questions: 'During the past month have you often been bothered by feeling down, depressed or hopeless?' and 'During the past month have you often been bothered by little interest or pleasure in doing things?'<sup>2</sup>

**Table 1. National Institute for Health and Clinical Excellence recommended investigations for chronic fatigue syndrome<sup>1</sup>**

- Urinalysis for protein, blood and glucose
- Full blood count
- Liver function
- Thyroid function
- Erythrocyte sedimentation rate
- C-reactive protein
- Random blood glucose
- Serum creatinine
- Screening blood tests for gluten sensitivity
- Serum calcium
- Creatine kinase
- Serum ferritin levels (in children and young people only)

## Negotiating the diagnosis

Following the examination, it is reconfirmed that the patient meets the criteria for CFS. At this point it would be beneficial to explain to her that this is a diagnosis of exclusion and explore her own understanding of the diagnosis. Communicating to the patient that CFS is an incompletely understood condition with no single clear biomedical cause, and that there is now evidence to suggest that a triggering event (such as a viral infection<sup>3</sup> or traumatic life experience<sup>4</sup>) may lead to this chronic condition,<sup>5</sup> can be helpful for acceptance of the diagnosis. It is essential not to deny her symptoms and to avoid giving the impression that negative results indicate that there is ‘nothing wrong’<sup>6</sup> as this can lead to feelings of ‘delegitimation’.<sup>7</sup> It is worth stating to her that there is no agreement on the cause of CFS but there is a lot of research interest in the topic.

## Negotiating the treatment

It is essential to work in partnership and discover what is most important for the patient by tackling this consultation in terms of, ‘What matters to you?’ rather than, ‘What’s the matter?’<sup>8</sup>

It would be worthwhile to discuss the treatments offered by the previous GP and explain that amitriptyline can be used for pain management and sedation in low doses as well as for depression in higher doses. This honesty will further engender a trusting relationship between patient and doctor. The patient may then wish to try this medication (or similar)

in a low dose to help with sleep and pain control, particularly as these were reported as predominant symptoms.

Next, it may be explained that CBT can help people to cope with the distressing symptoms (including fatigue) of a number of illnesses, including multiple sclerosis and rheumatoid arthritis<sup>9–11</sup> and is not just a treatment for depression. While CBT has been shown to be effective in CFS,<sup>12</sup> it is important to work with the patient to find an acceptable treatment plan. As this patient feels stigmatised by the offer of such therapy, even when considered in light of other, less controversial conditions, it should not be presented as the only option.

## Suggested treatment program

Considering the patient’s narrative and experiences, pragmatic rehabilitation may be the best treatment program for her.<sup>13,14</sup> This type of treatment has been shown to be effective in short-term randomised control trials conducted in primary care, using a model of a nurse delivered program of graded return to activities, designed collaboratively by the nurse and the patient.<sup>13</sup> In this study, sleep patterns were regularised and relaxation exercises offered to address the somatic symptoms of anxiety. Supportive listening as a therapeutic strategy was not shown to be effective, suggesting that keeping the focus on activities (and the future) may be more important once an empathic relationship has been

established. Social support is also important in this condition,<sup>15</sup> particularly for coping with negative interactions with family and friends.<sup>15</sup> It could be suggested that the patient discuss the stigma that she’s experienced and how to manage interactions with loved ones. A discussion about liaising with her employer or occupational health services at work may also be beneficial, given the stress felt about days taken off. Given her condition is mild and not yet adversely effecting her work situation, it is reasonable to monitor her progress in general practice. With a new clinical team she may improve sufficiently to not warrant referral. The British National Institute for Health and Clinical Excellence recommends referral after 6 months for mild cases<sup>1</sup> and a decision about referral would need to be made jointly with the patient.

## Concluding the consultation

Having heard the patient’s story, conducted a physical examination and negotiated pragmatic rehabilitation, there would be no more time to discuss further options in this consultation. Before concluding, it would be worthwhile to use the ‘teach back’ technique to ensure that what has been discussed was delivered effectively.<sup>16</sup> A possible question to check understanding would be: ‘Just to ensure that I have communicated clearly with you, what will you say to your family about what we discussed when you go home?’

The patient would then be asked to make another appointment to develop the specifics of treatment and explore any further concerns/questions that she may have after considering this alternative treatment approach.

## Authors

Megan Arroll PhD, FHEA, CPsychol, CSc, AFBPsS, is Director of Research, The Optimum Health Clinic, Research Department, London, England. drarroll@theoptimumhealthclinic.com  
Bruce Arroll MBChB, PhD, FRNZCGP, FNZCPHM, is Professor in General Practice and Primary Health Care, Faculty of Medical and Health Sciences, University of Auckland, New Zealand.

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correspondence [afp@racgp.org.au](mailto:afp@racgp.org.au)