

**Foundation Degree in Integrative Counselling**  
**Literacy Test Example**

The four questions below are based on the following article: Driffill, R. (2019) 'Working therapeutically with chronic fatigue syndrome', *Therapy Today*, Vol. 30, Issue 1, pp. 26-28.

Please read the article and then answer the following four questions as fully as you can.

1. What are the current recommended NICE Talking Therapy guidelines for clients presenting with Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME)?
  
2. What does Driffill (2019) suggest about how we can learn from a client whose presenting issue is CFS/ME?
  
3. What does Driffill (2019) suggest about how to work with unhelpful relational patterns in client work with individuals whose presenting issue is CFS/ME?
  
4. Under Driffill's (2019) list of 'don'ts' in relation to client work what point is the author making about belittling the client's fears about her condition worsening?

# Working therapeutically with chronic fatigue syndrome

**Rosie Drifill** explains how counselling can be useful to people with chronic fatigue syndrome

*I have a client who has recently been diagnosed with chronic fatigue syndrome (CFS). He suffered a bereavement not long ago and then was very ill with a virus, which he said he has never really recovered from. His GP told him that the CFS was probably triggered by these events and advised that he should seek counselling to help him deal with any emotional issues that might be perpetuating his condition. I feel I've been tasked with the job of "curing" his illness.'*

This vignette encapsulates a common dilemma for counsellors when a client presents with CFS, and the counsellor is absolutely right to be questioning their role here, particularly in light of the GP's comments. CFS (also known as myalgic encephalomyelitis or ME) is, according to leading CFS/ME charity MEAction, 'a systemic neuroimmune condition characterised by post-exertional malaise (a reduction in functioning and a severe worsening of symptoms after even minimal exertion), which causes dysregulation of the immune, nervous, and energy metabolism systems'.<sup>1</sup> Its effects can be devastating: some 25% of people with this diagnosis are housebound or unable to leave their bed, and all those with the condition experience a substantial loss of physical or cognitive functioning across a spectrum of severity.

Medically, CFS/ME has recently been reclassified as a 'neurological' condition on the SNOMED CT system - the clinical vocabulary used by NHS doctors to categorise patients' conditions when creating an electronic health record. Previously it was classified as 'psychological'. Nevertheless, many medical practitioners continue to regard CFS/ME as psychosomatic and there are frequent reports of patients being disbelieved by their doctors when they say their illness is physiological.

So, it's important when working with someone with a diagnosis of CFS/ME to avoid presenting it as something that can be resolved with talking therapy. There is currently

no known cure for CFS/ME (although the national (NICE) clinical guidelines recommend CBT as helpful for people to manage their condition<sup>2</sup>). However, ME Association medical adviser Charles Shepherd makes an important distinction between chronic fatigue and CFS/ME: 'It may well be that there are some people with a general fatigue state resulting from stress, emotional or psychological problems who could benefit from a "mind over matter" retraining approach... Such fatigue states are a separate entity and not to be confused with ME/CFS' (emphasis added).<sup>3</sup>

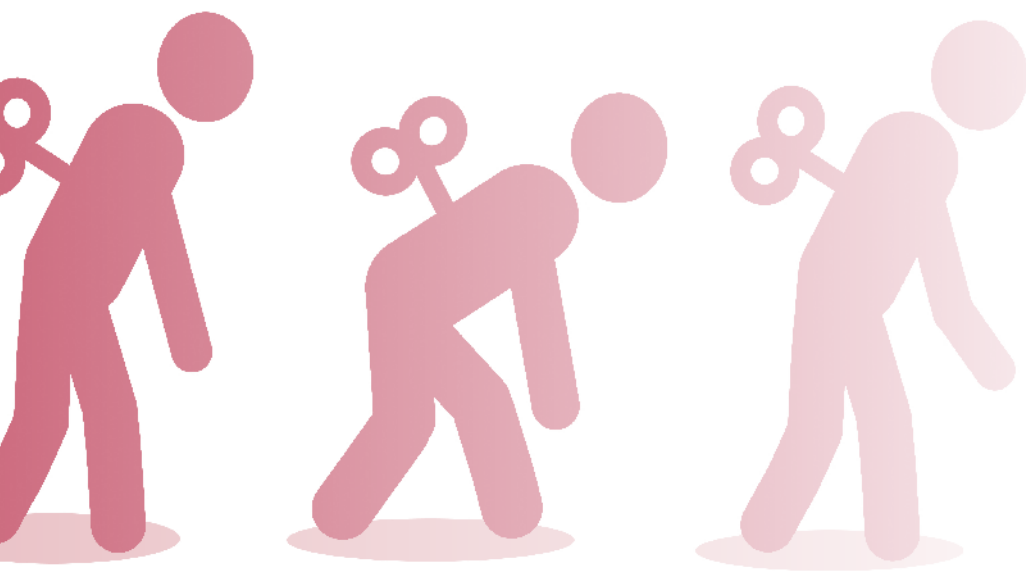
That said, the therapist needs to meet the client where they are. It may be that your client believes that having counselling for any underlying emotional trauma will help him in his recovery. Indeed, because of continued inconsistencies in understanding and attitude towards CFS/ME among medical professionals, not all clients may understand it as biomedical - that it is, essentially, a physical illness. They may have been told or choose to believe there is a psychosomatic element, resulting from their lived experience, and this may be an important element of their recovery path. You may have to

walk a fine line between being respectful of your client's perspective and working with how they conceptualise their condition while, at the same time, being honest about the limitations of therapy. Try not to collude with any notion that therapy will in some way 'cure' CFS/ME, just as you wouldn't claim that therapy will help someone recover from flu or heart disease; at the same time, however, share with your client what therapy can help with.

Indeed, clients with CFS/ME are likely to bring a range of issues to therapy: most notably, a sense of hopelessness arising from the chronic nature of their condition and its impact on their sense of self (who they once were, often characterised by what they were able to do) and fear that their condition will worsen and their quality of life will be further impaired. The therapist should be prepared to work with loss and grief. It may be helpful to consider models of grief, such as Kubler-Ross's stages of grief<sup>4</sup> and Stroebe and Schut's dual process model,<sup>5</sup> and be aware that clients may move between different ways of reacting and coping, depending on the severity of the illness and/or how recently they were diagnosed.

Clients may also be locked into relational patterns that hinder self-compassion and self-care, particularly if they are used to being a caregiver and find it hard to attend to their own needs as a result of entrenched relational

*"Try not to collude with any notion that therapy will in some way "cure" CFS/ME... however, share with your client what therapy can help with"*



and attachment dynamics. It is important that therapists use supervision to reflect on how their own courage and hope for their client might be affected by the intensity of the client's experience, and that they identify and work through any prejudices, assumptions and blind spots related to the illness. Supervision is also a place to consider the degree to which the therapist is communicating empathy in relation to the depth of hopelessness and uncertainty the client might be experiencing.

I have summarised below some suggestions specific to working with a client with CFS/ME. The charities ME Association, Action for ME and MEAction also have a wealth of resources on their websites. I can also recommend Jen Brea's TED Talk, 'What happens when you have a disease doctors can't diagnose',<sup>6</sup> which offers an arresting insight into the devastating effects of CFS/ME and how it has been dealt with by the medical profession.

## DO

### ... learn from the client, and be open about what you do/don't know

CFS/ME is surrounded by controversy and false assumptions, so allow yourself to be educated by the client and be willing to add to what you already know about the condition. In the spirit of congruence, it's OK to be honest about not knowing a lot about a client's illness, but you should express a willingness to learn from them and to conduct some further research. It communicates that you do not hold

rigid ideas about ME/CFS. For someone with the condition, this in itself can be a new and refreshing experience.

### ... contract with the client and conduct regular reviews

Clients with CFS/ME may come to therapy for all sorts of different reasons. They may need support with coming to terms with their illness, or they may want to use the sessions for more practical reasons, such as problem solving or prioritising activities to allow for their reduced energy levels. Be clear about what you as a therapist can offer and signpost them to alternative sources of support if needed. Regular reviews can be helpful, as they enable you and the client to revisit the aims of their therapy and whether they are being met.

### ... look out for potentially unhelpful relational patterns

As you would with any client, particularly those with a chronic health condition, support them to recognise their relational patterns and identify any that might be having a negative impact on their health. This could range from trying too hard to please others to denying their illness through shame or fear of exclusion. Equally, a client may have very high expectations of others and worry that they are disliked or forgotten if friends and loved ones don't always fulfil promises or come up to their standards. Notice if a client finds it hard to say 'no' and, once trust is built, work with them to consider how that affects them.

### ... consider the counselling environment

Many people with CFS/ME experience sensory processing difficulties and may be unable to tolerate environments that are too hot, cold or bright. Ask the client about how they experience the therapy room and, indeed, the waiting room, in the first session and be led by them as to what adjustments you could reasonably make, if necessary.

Clients may not always be able to attend sessions, as CFS/ME flare-ups can sometimes interfere with speech and mental processing, as well as physical strength. You could acknowledge that possibility in the first session and work out a system whereby the client can alert you in good time if they can't attend a session and what to do about last-minute cancellations. Be cautious, however: unless the client brings it up themselves, talking about cancellations could come across as reprimanding, and a client who may once have prided themselves on being reliable may feel that they are now experienced as an unreliable person. Tailor your approach to the quality of relationship you feel you have with the client and assure them that you understand that having to sometimes cancel and put self-care first is OK.

### ... remember that pro-recovery may not be the best attitude

Few people make a complete recovery from CFS/ME. Most people with the diagnosis tend to manage their condition by pacing themselves and taking on less than they used to. The CFS/ME community recommends a therapeutic approach that aims to help a client accept the illness and come to terms with the loss of their former self, with a focus on what they can do. Many who have endured the illness for years find that an emphasis on recovery, although intended to be positive, feels unrealistic and unhelpful. Often people with the condition have to put a vast amount of energy into persuading close friends and family members that accepting their illness is not being pessimistic; it is simply realistic. So, try to walk alongside the client on their path to acceptance, as you would any grieving client, if that is where they lead you. On the other hand, if the client hopes to make a full recovery, be alongside them in that journey, too. ▶

### ... support a client to come up with metaphors

If a client reports that they struggle to describe the fatigue and/or pain they experience, you could work with them to come up with helpful metaphors. If the client finds something that really encapsulates their illness, it can help them explain their condition to close friends and family, especially if others try to draw comparisons with their own feelings of 'tiredness', which can be very frustrating for those with CFS/ME.

### DON'T ... belittle the client's fears about the condition worsening

CFS/ME symptoms can sometimes get worse, although the ME Association advises that this is rare. However, a client's concerns about doing something that might make their condition worse are absolutely valid. A desire to 'rescue' the client by talking down their fear and assuring them that their condition won't worsen can suggest an unwillingness on the therapist's part to fully accept the realities of the illness and risks losing the client's trust.

For instance, a client expressing trepidation about doing something they previously enjoyed for fear that it will make them worse should not necessarily be met with an encouragement to go for it on the therapist's part. A more nuanced approach might be to validate their anxiety and explore past experiences of similar activities and their effects on the client. Support them to weigh up the pros and cons so they can decide for themselves the balance between the potential positive impact on their wellbeing from their enjoyment of the event/activity and the payback they may experience later. People who have had their diagnosis for longer tend to be better-versed in the patterns of their illness and more cautious about what they do; those in the early stages can be less cautious or more optimistic and may not necessarily recognise their triggers.

### ... blame the client

The causes of CFS/ME are still unknown, although extreme stress and/or trauma can be implicated. Some clients may find it helpful to explore what might have brought on their illness, but, unless they raise it themselves, they may experience the therapist prompting such an exploration as holding them responsible for their

'Try to avoid any implication that psychosomatic factors either caused or are perpetuating the condition'

illness. Psychological factors such as stress are known causative factors in many illnesses, yet a therapist would be unlikely to explore causation with a client with cancer or recovering from stroke. While stress may be involved in the onset of CFS/ME and stress management techniques may be helpful in managing the condition, they are certainly not going to 'cure' ME/CFS.

Try to avoid any implication that psychosomatic factors either caused or are perpetuating the condition, unless the client wants to explore this. Clients will vary in the extent to which they regard the mind and body as connected. If a client with a diagnosis of CFS/ME takes a mind-over-matter stance, perhaps as a result of their own beliefs or what they've been told about their condition, it would be therapeutically detrimental to trample on that. At the same time, foisting a mind-over-matter approach on a client who stresses the physiological nature of their illness will not help, and could add to their sense that they are not believed.

To summarise, CFS/ME is a very real, potentially severely disabling condition with a neurological basis. People with CFS/ME may seek help from a counsellor and it is important that practitioners are well versed in the condition and its effects, as well as the history and controversies surrounding its diagnosis. Their role is likely to be one of helping the client manage the condition and adjust their lifestyle and expectations, as well as deal with their grief and loss and the expectations and attitudes of others. The main CFS/ME charities offer sound, evidence-based advice and information about the condition, but the real expert is always the client: be open to their experience, knowledge, beliefs and understanding and be willing to travel with them on their journey of recovery, whatever form that takes. ■

#### REFERENCES

1. MEAction. What is ME? [Online.] MEAction; undated. [www.meaction.net/about/what-is-me](http://www.meaction.net/about/what-is-me) (accessed 30 November 2018).
2. NICE. Chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy): diagnosis and management (CG53). London: NICE; 2007.
3. ME Association. Lightning Process and SMILE trial in young people with ME/CFS. [Online.] Press statement. London: ME Association; 19 September 2017. [www.meassociation.org.uk/2017/09/me-association-statement-lightning-process-and-smile-trial-in-young-people-with-mecfs-19-september-2017](http://www.meassociation.org.uk/2017/09/me-association-statement-lightning-process-and-smile-trial-in-young-people-with-mecfs-19-september-2017) (accessed 30 November 2018).
4. Kubler-Ross E. On death and dying. London: Routledge; 1969.
5. Stroebe M, Schut H. The dual process model of coping with bereavement: rationale and description. *Death Studies* 1999;23(3): 197-224.
6. Brea J. What happens when you have a disease doctors can't diagnose. [Online.] TED Talk; June 2016. [www.ted.com/talks/jen\\_brea\\_what\\_happens\\_when\\_you\\_have\\_a\\_disease\\_doctors\\_cant\\_diagnose](http://www.ted.com/talks/jen_brea_what_happens_when_you_have_a_disease_doctors_cant_diagnose) (accessed 30 November 2018).

#### USEFUL WEBSITES

The research data on which this article is based are taken from the following websites:  
[www.meassociation.org.uk](http://www.meassociation.org.uk)  
[www.meaction.net](http://www.meaction.net)  
[www.actionforme.org.uk](http://www.actionforme.org.uk)  
[www.counselling-directory.org.uk/chronic-fatigue-syndrome](http://www.counselling-directory.org.uk/chronic-fatigue-syndrome)



**Rosie Driffill**  
About the author

Rosie is a counsellor and freelance writer based in Yorkshire. She has worked with clients with chronic illnesses, including ME/CFS, and has a research interest in the intersection between physical and mental health. Rosie uses her own experience of chronic illness as a basis for her website, which brings together humorous anecdotes, campaigns and support for friends, family members and therapists caring for someone with a long-term illness. [www.diagnosischronic.co.uk](http://www.diagnosischronic.co.uk)