

CONSIDERATIONS FOR CLIENTS WITH CHRONIC FATIGUE

Drawing from her personal experience of trial and error, writer for holistic therapists and story massage practitioner, **Katy Lassetter**, demonstrates how chronic fatigue can affect clients in a myriad of ways, and how practitioners can alter their treatment to help...

WORDS KATY LASSETTER

“We suffer disbelief daily and it is wearing to continually explain ourselves. All we need is a lot more understanding and a little more consideration”

News headlines of celebrity struggles with related conditions have provided a small contribution to the knowledge gap around Chronic Fatigue Syndrome (CFS)/ Myalgic Encephalomyelitis or Encephalopathy (ME). Stories about *Love Actually* actress Martine McCutcheon’s long-term battle with ME and Lady Gaga’s painful battle with fibromyalgia come to mind. Likewise, Jennifer Brea’s 2017 Sundance award-winning documentary, *Unrest*, caused a stir. This eye-opening personal journey, from patient to advocate to narrator, provides unsettling but necessary insight of living with CFS.

And, in October this year, over 2000 readers told *The Guardian* about their long-Covid fight. As Clea Skopeliti, who compiled readers’ letters, reported: “The chronic condition has an array of physical and neurological symptoms, but most remain misunderstood. From overwhelming fatigue to brain fog that makes it impossible to complete daily tasks, long-Covid is having a devastating impact on people’s lives around the world.” These symptoms are all too familiar for those who have lived with CFS/ME for many years.

Whether it is long-Covid or CFS/ME, the affliction is real. But with around 2.3 million people experiencing long-Covid symptoms in the UK* and ME afflicting around 17 million people worldwide**, we are still not in a

place where people with chronic fatigue and associated issues feel seen.

AWARENESS AMONG HEALTHCARE PROFESSIONALS

General practitioners do not know enough about these related conditions. I was first diagnosed with CFS, through a process of elimination, by my GP in 2006. My treatment options were Cognitive Behavioural Therapy (CBT), graded exercise and taking painkillers as needed. None were suitable long-term, and physical activity/exercise programmes were even advised against by The National Institute for Health and Care Excellence (NICE) last year.

In 2022, UK charity Action for ME wrote: “Within the NHS, a diagnosis of CFS or CFS/ME is often given. This can make it confusing for many... Action for ME uses the terms ME, CFS and ME/CFS... We recognise that it is quite possible that ME/CFS may be an umbrella term for a number of illnesses. Therefore, it is critical that there is more biomedical research to further investigate and validate our understanding and increase knowledge of the different sub-groups (phenotypes) of ME and/or CFS.”

After some research, I turned to complementary therapies. At different times, I have tried combinations of aromatherapy massage, Indian head massage, reiki, physiotherapy, the MELT method and



acupuncture. I am now into my second year of Perrin Technique™ treatment, designed specifically for those with ME. I have learned many lessons from therapists' couches on a journey towards quelling fatigue, muscle aches and poor sleep, and there is plenty they can do to give their CFS/ME clients the best possible care.

HOW CFS/ME MAKES ME FEEL

In a NICE guideline for ME, it stated that: "[Professionals should] recognise that people with ME/CFS may have experienced prejudice and disbelief and could feel stigmatised by people (including family, friends, health and social care professionals, and teachers) who do not understand their illness." Below, I have listed some ways CFS/ME has made me feel, and how practitioners can combat these feelings:

■ Exhausted and excluded

Fatigue is not tiredness, it floors you. It is like having the exhaustion that comes with flu most of the time. Where there is a choice, a downstairs treatment room and the lowering of the bed is always preferable.

As driving is often too taxing, we may rely on someone to bring us to appointments. I rely on my partner, who does not get home until late on weekdays. Also, I cannot work after a treatment as it wipes me out. This means evening and weekend appointments are my only option. As they are in high demand, consider putting a few suitable appointment times aside for clients with exhaustion.

Rigid block booking is rarely suitable for many with CFS/ME. Fixed days and times are not inclusive for people with immune-system abnormalities who are more likely to be ill and forced to miss appointments they have paid for. For many unable to work full time or at all, funds are low too. This makes paying for block bookings unattainable for those with CFS/ME.

■ Sensitive – in every way

There are so many sensitivities associated with CFS/ME and it is not unusual for all senses to heighten. My skin is particularly sensitive and my face regularly flares up with a malar rash, so I need to stick to natural, hypoallergenic products.

Smells play havoc with my wellbeing, especially artificial ones. A burning candle, air freshener or alcohol-containing antibacterial spray can cause a tight chest and nausea. For some, paint fumes weeks after the decorators have gone can be a trigger. Airing out the room before treating someone with CFS/ME is best, as is sticking to natural products and essential oils wherever possible.

Light sensitivity is another common problem. Spot lighting not only gives me a headache but also makes me sweat. Even natural lighting can hurt my eyes. Consider softer lighting where practical and introduce an eye mask or pillow to cut out glare when brighter lights are needed.

One of the defining symptoms of CFS/ME are pain points. Certain

IMPROVING THE TREATMENT EXPERIENCE

1 Prepare

CFS/ME often comes with many symptoms and related issues so a longer consultation may be required. It can make us feel like hypochondriacs when listing them all out so please be patient. Consider the extra requirements we may need as mentioned previously.

2 Adapt

My symptoms, feelings and sensitivities change daily. What worked for one treatment might not work for the next so a little tailoring is often needed.

3 Communicate

Make sure you check in more, with pressure and temperature changes especially. As relaxation often triggers feelings of guilt and laziness, I like reminders to relax and untense. It helps me be more mindful and makes the treatment more beneficial.

4 Understand

Listen carefully to needs and try not to question or judge them, we suffer disbelief daily and it is wearing to continually explain ourselves. All we need is a lot more understanding and a little more consideration.

parts of my body are so sensitive the lightest pressure can be uncomfortable but other parts of the body are fine. For hands-on treatments, get to know your client's regular pain points. Alternatively, adapt the treatment to avoid causing potential discomfort.

Overwhelm caused by noise is not uncommon either. I find background noise (people chatting outside the treatment room/building) as stressful as "relaxing" music that has been turned up too loud.

■ 'Befuddled' with brain fog

CFS/ME brain fog is a frustrating forgetfulness that leaves you searching for words mid-sentence if you do not forget what you were saying or doing completely. Although I always note appointments in my diaries, a text the day before really helps me remember.

And when it comes to self-care, any recommended gentle exercises are much better received as a handout or link to an online video. Trying to remember the simplest routine is likely to be as unsuccessful as it is stressful.

*As of September 2022, according to Office for National Statistics

** As of October 2022, according to Action for ME. **TWR**

Katy Lassetter is a writer based in Chichester, West Sussex. Living with ME for over 15 years and PIC (a rare eye disease) for over 10 years has provided Katy with experience using many alternative therapies to manage her own health as well as the empathy required to write for and about others receiving treatments for similar symptoms and conditions. To contact Katy email katy@chichestercopywriter.co.uk or visit chichestercopywriter.co.uk.