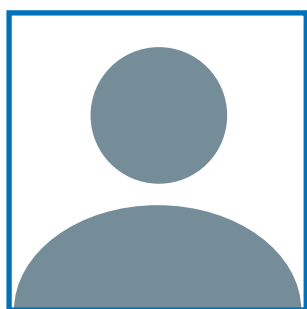


Patient experiences



“ Since being discharged from the service a few years ago I have got back in touch with friends and family, and have successfully completed an Occupational Therapy degree. ”

Patient C from Lancashire

I had been ill with CFS/ME for almost seven years when I arrived.

I was bedbound, unable to tolerate any light or noise, unable to talk or listen to more than a few words from others or have them in the room. I was also unable to feed myself, my hair hadn't been washed or brushed for 18 months and I couldn't even be physically washed by others or have my pyjamas changed.

Despite completing a music degree in the past I had become unable to carry out any mental tasks, and I hadn't been left alone in the house for over two years due my emotional state of complete fear, anxiety, frustration and anger.

Overall I was in a state of utter desperation and just wanted to get better... but didn't know how to.

Fear

This was immense and indescribable, I hadn't been out of the house in over three years and knew that after the journey to Leeds I would feel so much worse, but at that time I had no option, as what was the alternative?

Trust

For me this was the key to me sticking to the program and its ultimate success. Having been told that many things would “cure” me in the past I was extremely sceptical and it took quite a while for me to trust the team. Gradually they kept opening the blinds in the room more and more, and I realised that I was able to tolerate more and more light.

“ ...the benefits far outweigh the struggle along the way. ”

I held onto this thought and then started to believe that if they had been successful with this aspect of the treatment, then the rest of it might just work too. They understood what I was thinking, and I gained confidence from then on that they knew exactly what CFS/ME entailed, although I was still not completely confident that they could treat/cure it.

Confidence

I had to gain confidence in the whole team and this took time as there were hurdles along the way, both physical and emotional. My advice would be to concentrate on the small tasks of the rehabilitation one at a time and gradually everything comes together and you start to get your life back. This is so difficult when you are in such an anxious and fatigued state, but eventually it does become possible.

Worry

I had worrying thoughts about everything! The cognitive behavioural therapy (CBT) that you receive is excellent in dealing with these and helping you to challenge them. Over time your worries diminish and as this happens your energy levels begin to increase, you are able to carry out more day to day activities and focus your attention on these rather than worrying...eventually breaking the cycle.

Patience

Rehabilitation takes time. Focusing on what you can do, however little, and not on what you can't, helps you to get through. Frustration is still a factor, but keeping determined, with your goals always in mind, helps...as well as a good cry every now and again!

Medication

For me the medication helped a great deal, even though I was extremely reluctant to take it. The consultant knew exactly what to do and introduced very tiny amounts at first, as I was sensitive to it. There is an element of trial and error, but I was glad that I persevered.

Hard Work and Determination

The entire journey was the hardest thing I have ever done. The whole process took sheer determination and strong will, but the benefits far outweigh the struggle along the way.

“ I will be eternally grateful to the NICPM and its commitment to helping people with chronic fatigue syndrome. ”

My Life Now

Since being discharged from the service a few years ago I have got back in touch with friends and family, and have successfully completed an Occupational Therapy degree. I now work four days a week as an occupational therapist and am currently thinking of teaching clarinet privately as well.

I have been on active holidays abroad, and I also attended personal fitness sessions for 18 months to improve my strength and fitness. I met my husband and we now have a baby daughter and a very happy life together. I do give thought to planning and pacing my activities, and there have been a few ups and downs along the way.

However, the only relapse I have had was after giving birth, which was a 33 hour labour followed by eight weeks of breast feeding! Since then, after several weeks of being back on the programme, I now lead a normal and enjoyable life.

I will be eternally grateful to the NICPM and its commitment to helping people with chronic fatigue syndrome. The whole process was a joint effort between me, the team, and family/friends. Although it was difficult, I am so glad that I persevered to get my life back.