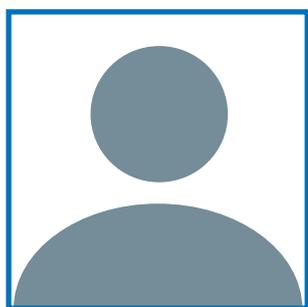


Patient experiences



“ Despite my fears, despite my anxiety, despite my belief that things weren’t going to get better, as time went on getting better is exactly what happened. ”

Patient E

I arrived at the NICPM with severe ME and had been suffering from it for the past 13 1/2 years. I fluctuated between being housebound and bedridden. I endured periods of time where I had to be spoon fed and needing a commode next to my bed. I have to rely heavily on my partner to care for me. Most things in life like being able to speak, sit up, or watch TV, I either severely struggled with or nine times out of ten I simply couldn’t do.

The most prominent symptom I had was the extreme pain and discomfort in my head. All the way throughout my illness there has been some sort of pain and discomfort, and most of that was either severe or moderate. I forgot what it felt like to have a clear pain free head.

Life was hell for me, life was hell for my partner, life was simply unbearable.

When I got referred to hospital I was extremely anxious about going. Even though it was hell at home it was my comfort zone, and the thought of going to hospital absolutely scared me. I started stressing about silly little things like how far away is the bed from the sink? Is the bed positioned in the same way as my house with the wall being on the right hand side of the bed? Will I be able to deal with the different type of smell there is in hospital? What happens due to the pain and discomfort in my head (I’m not able to speak to them, and they can’t do anything with me)?... Why should these people be any different to all the other professionals I’ve seen over the years, in and outside of the NHS? I have put my faith in people before and I’ve got let down so badly. So how can I put my faith and trust in these people? What’s so different about them?... And the list went on and on.

“ They really do know what they are doing. ”

For me going to hospital felt like it was the last chance of me getting better. There was nowhere else for me to go, and there was no one else for me to see. The thought of not getting better in hospital was just too unbearable to think about.

When I arrived at hospital all these little things I was stressing about just sorted themselves out. There was no need to stress about them, but anyone who is in the same situation knows that that it is easier said than done.

I arrived there being full blown bedridden, and needing a commode next to my bed. I could just about sit up a bit for eating my meals, but even that was difficult and I was only able to talk for extremely short periods of time and that was it. My hair was all matted as I hadn't been able to wash it for about 18 months, and I was no longer able to brush it. And my body was full of dirt spots and dry skin as I was no longer able to wash myself and it was too much for someone else to wash me.

The first couple of months or so was extremely difficult for me in hospital. I felt overwhelmed by the interactions I was having with people as I was used to being in a quiet house on my own a lot of the time. There were lots of “blood, sweat and tears”, and more tears, and at first it felt like I wasn't going to get better here, because what they were suggesting seemed too much for me and I believed that it was the wrong way to go about it. They kept reassuring me, saying they knew what they were doing, and that they were experts with this, and that they have had years of experience. Even though they were saying this to me I still had a belief that they were wrong and that it was just all too much for me.

Despite my fears, despite my anxiety, despite my belief that things weren't going to get better, as time went on getting better is exactly what happened. Everything they said was right. They really do know what they are doing. And their expertise is exceptional and they really do get results. All the staff on the ward are such wonderful amazing people. And you really do get a feeling that everyone there really does want you to get better, and they will do anything they can to make this happen.

After eight months stay in hospital I got discharged, by then my quality of life had drastically improved and what I was able to do was just unbelievable. I was showering myself stood up every day. I was walking about, and going off the ward every day, which is one of the things they encourage later on as

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part of the rehab programme. And with it I was walking quite a fair distance, doing bits of shopping and even going out for something to eat.

When I was getting close to discharge and was on one of my home leaves I came back on the train on my own. I had gained a decent slice of independence back and it was absolutely amazing. I couldn't have wished for anything more.

I came back home a totally different person. I came back home being the real me.

My advice to anyone who is considering or has been referred to the NICPM is to say that if you go there you will definitely be in the right place to get better. The only reason I got as well as I did is because I took on board everything they said, even though I questioned it time and time again. They really do know what they are doing and trusting them, no matter how hard that may be, is my best advice.

I would like to take this opportunity once again to thank the team at the NICPM for the wonderful and amazing work they did with me. They gave me my life back, and I'm now continuing the rehab journey back at home fully equipped.

I wish you the very best of luck. And I hope that you go on to get your health and life back too.