

NHS Expert Patients Programme

Experience and research have shown that whatever our condition, the things that we all have to deal with on a day to day basis are similar. Such as: fatigue and pain.

The course gives you the opportunity to put into practice the skills that are learnt, with the support of others who are facing similar challenges.

In the dark traumatic days, after I had been suffering severe symptoms for well over a year, without any progress in diagnosis and treatment or apparent focused attention from my then GP, I came across a leaflet advertising the ***NHS Expert Patients Programme*** in the waiting room of my GP's surgery.

I was desperate, extremely depressed, haggard, stressed, exhausted and pulling my hair out with frustration. I am sure that you get the idea, as with M.E., you have probably experienced some of this yourself.

At the time, this was all that I had as a potential pathway, **which was within my control**, in order to try to get some way of appropriate attention within the **NHS**, and consequent potential recovery from the symptoms of my ill health. Without any medical opinion of any kind, I was still unaware that my symptoms were anything other than a temporary short illness, from which I hoped to recover, if only I could receive treatment.

When I attended, I became aware that many people came away each week, with many varying degrees of success in effect. I feel that is not actually down to the programme, which is well structured, but probably, more greatly influenced by the attitude of mind and openness to take in and try something new, of the participants. Obviously, the more open minded that one is, and prepared to consider new ideas, in spite of health, then the greater the gain. By the same token, the more that one puts in

and contributes in the group, the more that one will go away with.

Basically, it is a lifestyle management programme, that gives ideas and routes as to how one can live and enjoy a better quality of life, working with one's health condition, rather than fighting it, and then suffering the boom and bust consequences. It is of benefit, even for those that may have had a long term chronic condition for some time, as we look at our patterns and practices and re-evaluate them as to their effects and how they may be revised to good benefit.

Before attending, one of my biggest gripes was the state of cleanliness and tidiness of my home. Interestingly, it still is. I am not obsessive, but my home could be cleaner. I am a man. Say no more! However, it is improving.

Most people that I know with M.E., have a similar gripe about their homes. We often joke about who hasn't washed the dishes for the most days. If you haven't the energy, it's a fact of life, so why get worked up about it.

Back to the ***NHS Expert Patients Programme***. Before attending, I found the vacuuming a real bugbear and impossible. It had never before crossed my mind that I did not need to do it all in one go!

Why not break the activity down into easily manageable and completed chunks! This also does wonders for morale!

Why not do a bit a day, and instead of then replacing the cleaner in the cupboard and coiling up all hoses and cables, leave it where it is, ready for the next day, or if enthusiastic, later that day, therefore, also saving on the energy of each time, getting it out and putting it away.

All my available energy was then available for the direct job in hand of actually vacuuming the floors.

Incredibly simple! Why had I never thought of that before?

I also went and purchased a very light rechargeable battery operated carpet sweeper that can be used for those bits of floor that aren't worth getting the vacuum cleaner out, but are still in need of a clean.

Problem sorted! (Well, most of the time).

Over 2 years after attending the course and where it was originally suggested, I have now taken the next leap, that I always knew was going to happen. I swallowed my pride and have hired local cleaners to come in for 2 hours each week. You have no idea how nice it is not to feel weighed down by seeing dirt that I need to clean, or to be exhausted by cleaning efforts that others are more capable of. It really has brought joy back into my home.

It was also a revelation to me to discover that when a GP is presented with a list of symptoms (such as M.E. may provoke), the GP may only note 2 or 3 of them and only focus assessment and treatment on those.

Are you outraged? I was! It explained a lot of the history of the 20 months of my suffering and maelstrom of trauma!

I also found out about **PALS**, the **NHS Patient Advisory Liaison Service**, and was advised that in the light of my experience (or lack of) of **NHS** care, that I should be making contact with them.

The **NHS Expert Patients Programme** was the first step on my pathway of many steps, in managing my life and finances, to where I am today. This pathway never ends, it just continues.

At the time of writing, in Hampshire, regular courses are held throughout the county. As the organisers are well aware that people are not in the best of health and capability to attend them, they are held at satellite venues, when a sufficient

number of people have registered an interest to attend in a particular area.

In addition, in order to best assist the attendees, the courses are not held on any set day of the week or time of day.

To date, courses have been run at accessible community venues, such as:

Alton Community Centre, Alton
Cowes Medical Centre, 200 Newport Road, Cowes, Isle of Wight
Emsworth Division, St John's Ambulance, Convent Lane, Emsworth
Gosport Discovery Centre, High Street, Gosport
Oak Farm School, Farnborough
Fenwick Hospital, Lyndhurst
Winton House Centre, 18 High Street, Petersfield
Portchester Parish Hall, Castle Street, Portchester
Millbrook Community School, Green Lane, Maybush, Southampton
Swaythling Community Centre

The above is not an exhaustive list, but merely gives an example of how willing the organisers are prepared to be in presenting a course near to you, the patient.

Registering for a course assists the organisation and preparation of them. Places are limited to a maximum of 16 attendees. Any special needs may also be taken into account. When there is sufficient demand and interest registered in a particular community area, the organisers then contact the patients concerned in order to finalise dates, times and location of the next course.

Unfortunately, these courses may not be sufficiently appropriate for those of us that are bed bound and very severely affected.

It also helps to confirm to the organisers that you are serious about attending. As we all know, many people do take the **NHS** for granted and book appointments that they then fail to attend. Not only does this waste resources, but it also deprives another patient of the much needed time and increases waiting lists. So please help the **NHS** to help us.

Please contact them for the nearest and next available course and register for it. I feel sure that you will come away with some benefit.

Also, I would suggest that you visit the website for more up to date information.

NHS Expert Patients Programme - Hampshire

Expert Patients Programme Co-ordinator: Tina Coulter
Fareham & Gosport NHS Primary Care Trust
Unit 180, Fareham Reach, 166 Fareham Road, Gosport, PO13 0FH
Tel: 01329 226 110
Email: tina.coulter@ports.nhs.uk
Web Site: www.expertpatients.nhs.uk

NHS Expert Patients Programme – Southampton & Isle of Wight

Expert Patients Programme Co-ordinator: Bev
Newman
Southampton NHS Primary Care Trust
Unit 418a, Solent Business centre, Millbrook Road West,
Millbrook,
Southampton, SO15 0HW
Tel: 02380 777 608
Email: beverley.newman@nhsepp.org
Web Site: www.expertpatients.nhs.uk

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