

Philip's Story

First Email – August 2010

Forgive this epic email. Having first exhibited symptoms of a TIA, after exhaustive tests my husband has been diagnosed with Functional Weakness by consultant neurologist. Never before hearing the term, I this evening Googled it and found your research overview/direction page.

If I may, I'd like to give you a potted background history and ask if you have any guidance for me (or dare I say, the consultant).

Philip, a chatty, personable 76 year old, has had a traumatic few years: he had pains in his legs and scans revealed he had an abdominal aortic aneurysm for which he had elective surgery.

July 2009 he was diagnosed with oesophageal cancer and was told he would have surgery to remove it Dec 16 after course of pre-op chemo. During pre-op heart function tests (Dec 11) he was told that he had previously unknown heart disease (another shock!) and was therefore unable to have the surgery.

Referred back to oncologist and Jan 2010 started course of radical combined radiochemotherapy. His attitude throughout was "I will beat this." His stoic determination was an inspiration not only to us, his family, but to other patients on the oncology ward.

Post treatment scan was 'inconclusive' due to radiotherapy scarring. July 2 he had a gastroscopy/biopsy and it was clear. He had, indeed, beaten this killer cancer and we rejoiced.

July 4 he was admitted to hospital; he dropped to the floor with what seemed symptoms of a TIA and admitted to the stroke ward. He had a multitude of tests (incl MRI) which showed nothing worse than severe osteoarthritis - but 6 weeks later with physio 5 days a week, he is still there, unable to stand.

Apart from physio sessions, he sits in a wheelchair. He is frustrated, highly emotional, depressed, easily distracted, finds it hard to concentrate - all traits alien to him. He has been started on Sertraline. He was convinced he'd had a stroke - he'd ask why else do his legs give way - and it has been hard to convince him otherwise.

But even using a standing machine with physios on either side of him, he cannot/will not put weight on his legs (left weaker than right). I should mention that in the weeks prior to his admission, he had experienced some problems with his left knee giving way but he was still going out for long walks which he enjoyed.

The hospital team has been very patient, giving him every opportunity and extending his stay in the hope that he will show signs of progress (i.e. stand unaided) so they can recommend him to a follow-on rehab unit to get him to walk again. To no avail..... tho' he insists he's trying.

So now they are reluctantly planning to discharge him once a home care package is arranged. The alternative was a care home which we would not consider.

I asked the neurologist if it was not medical, could it be a form of post traumatic stress and perhaps should be referred for some form of psychotherapy/counselling but she said that it would be

detrimental to his mindset to be passed on to the mental health unit which is not part of the hospital and hence there are no doctors in that field 'on site'. Only today did she put a name on the condition: "Functional Weakness".....

Second Email – November 2010

I thought you may be interested in this update on my husband about whom I contacted you (see below). He stayed in hospital for 8 weeks and on discharge end Aug. was still unable to stand or walk and had lost all self-belief.

The symptoms listed in your Functional Weakness leaflet could have been written just for him. The neuro-ward physio who was used to dealing with stroke patients said he wasn't trying - although it was obvious to me that he was. He refused to recommend him for a stay in rehab unit as he 'didn't have potential' and I was told that I should consider a home care package or a residential care home.

I fought long and hard and managed to get Collaborative Care (NHS) as it was my firm belief that Philip needed encouragement to do things for himself, not have others do everything for him. At first, he needed the assistance of 2 to use a glideboard to get from wheelchair to bed etc. and a slidesheet to move him up the bed as he had no upper/lower/core body strength, muscles had gone to flab and couldn't use legs (left worse than right).

They have been amazing, and under the direction of a young physio attached to the team (who took the trouble to research the condition and believed in him!!) he started walking - dragging left foot as described in leaflet - but now, 10 weeks after discharge has progressed from a zimmer frame to a quad-stick to a walking stick and can walk short distances with normal gait.

He has regained his positivity and independence (loves being able to shower again!) - it's truly amazing. I hope this info. is of interest and may give hope to others.

Third email – November 2010

.....When he was eventually diagnosed, to be totally honest, I thought 'Functional Weakness' was a 'get-out-of-jail' diagnosis just to get the neurologist off the hook; but when I read the description on the neurosymptoms.org website, I thought it could have been describing ALL that Philip was going through and when I printed it off and showed it to him, it in itself, helped with his recovery: just knowing that he was no longer the 'mystery man', that he was believed and not 'making it up'.

Full marks to his neurologist who put a name to it in his case. I do wish that you could make specialists in other fields aware of the condition. Even his oncologist and cardiologist hadn't heard of it. It needs to be publicised so patients are not written off.

Best wishes,

Carol