

Our patients are inspiring...

"They give me help and advice."

regarding council funding for a shower chair and ramp, which Claire will soon need. Claire has also bought herself a rollator, which she describes as "a walking frame on wheels" and has had a stairlift installed.

"My best purchase was my wheelchair, though" she says, smiling at her black and purple motorised wheelchair, accessorised with its pink cupholder, purple bag and umbrella. "My eldest daughter, Kate, got married in September, and I wanted to get a wheelchair to help me through the weekend. It's a tilt-in-space state-of-the-art chair. Now I can take the dog for walks, recline right back so I'm lying down - which takes the pressure off my lungs and helps me breathe more easily - and I can even raise the seat so I'm at eye level with people who are standing up - to help me kiss the taller men," she winks!



When asked about the future, Claire is determined. *"I want to get to January. Alex is getting married in January and I want to be there, even if they have to wheel me in! Anything more than that is a bonus."* And her advice for anyone faced with MND is equally resolute. *"Act now"* she says. *"Don't wait til you're tired. Do it all now. Get ready; be one step ahead. And delegate everything but the breathing. Then you can still be a mother, daughter, partner, neighbour, best friend. That's all you need to do. That and breathe."*

We are privileged to care for people like Claire and her family, at probably the most difficult time in their lives, but we can only do this with the generosity of our local community.

We have to raise over £20,000 every day in order to provide care, free of charge, to our patients and their relatives.

For further information about how to support Phyllis Tuckwell Hospice Care, contact our Fundraising team on:

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Living Well

Claire's Story

How occupational therapy can help those living with MND

**Phyllis Tuckwell®
Hospice Care**

...because every day is precious

Claire's Story



Five years ago, Claire's daughter Alex graduated from university. Claire had always been conscious of her posture, so when they posed for photographs she was surprised to hear Alex telling her to stand up straight. "I can't," she replied. "I can't straighten my spine any more than this!"

Alex had just spotted the first of many symptoms which would lead doctors to diagnosis Claire with Motor Neurone Disease, a progressive disease which attacks the nerves in the brain and spinal cord, stopping messages from reaching muscles, and leading to muscle weakness and wasting.

When Alex had started university, Claire had helped her to carry her bags out to the car, but she now found herself leaving them for someone else to take. In her job as a primary school teacher, she also found that she was opting out of the physical work, and was having trouble standing up after sitting on the small chairs in her classroom.

After a summer away from school, Claire found herself facing the approaching new academic year with less enthusiasm than usual. *"I used to be raring to go each September, ready for a new term, but that summer I just felt exhausted. One of the other teachers asked me if I was ok – she said I didn't seem myself."* Prompted by her friend, Claire went to the doctors, where she was tested for bone density, iron deficiency, thyroid deficiency and the menopause.

"The weight was falling off me by that time," she remembers. *"And I became breathless whenever I walked up an incline."*

However, Claire's test results came back as negative. Her GP advised her to increase her calorie intake, but didn't mention MND.

That Christmas, Claire's husband Richard suffered a massive heart attack and died at their house. When the start of the

January term came around, Claire found herself wondering whether she ought to go back to work at all. She was still convinced that something was wrong, and felt that she needed time to work out what it was. She resigned from her job and spent the following few months doing up her house - replacing the old boiler, putting in a new staircase, updating the bathrooms and having the electrics rewired. *"I knew there was something wrong, something physiological, and I had to make the house suitable for my changing needs,"* she explains.

At the end of January, Claire saw another doctor who told her that she suspected the problem was neurological. She sent Claire for two more tests: one to test her muscles, to rule out muscle disease; the other to test her nerves, to confirm MND.

By this time, Claire had spent so much time trying to find out what was affecting her body, that a diagnosis of MND was actually something of a relief. She was told that her weight loss was due to muscle atrophy. The disease had now reached her lungs, and was starting to affect her breathing and speech, and her mobility was compromised.

"MND sneaks up on you," she says. *"It's not common in a woman, or in a 50 year old. There were lots of other things which my symptoms could have been due to. That's why it took so long to diagnose. It's hard to detect. But once your muscles begin to atrophy, there's no way back. It's a steady downhill decline – the occasional plateau – but no recovery."*

Because Claire's diagnosis came so late in her illness, she had lost the three-five year prognosis which most MND sufferers are given, and was told that she only had 14 months left. However, once she had her diagnosis, things suddenly started moving and she was quickly able to access the appropriate help. Her consultant referred her to the Motor Neurone Disease Association (MND), as well as to a respiratory specialist at Frimley Park Hospital, who could help her with her breathing, and to Phyllis Tuckwell, where she was able to access a range of services.

"I come to the Hospice once a month, to see my doctor," Claire says. *"A volunteer driver picks me up, and after*

my appointment I see the Occupational Therapist and the Physiotherapist. I haven't been to Day Hospice yet, but I know I will be invited if I need to come – when my condition deteriorates, or if I need to get out of the house more. I fill in a form every now and then, so they can assess my mood. They're keeping good tabs on me." Claire has also seen a dietician and a speech & language therapist at the Hospice, and her occupational therapist has helped her manage the practicalities of life, and pace herself.

"It's like running off a very small battery," Claire explains. *"I don't have that much energy anymore, not like other people in their fifties. You have to delegate. Your only objective is to breathe. Everything else can be delegated."*

Claire's friend Denise stays over at Claire's house three nights a week, so that Claire has some companionship in the mornings and evenings, and the knowledge that someone is there if she needs help in the night. She also has a carer who comes to her house three days a week, loading and unloading the washing machine and tumble dryer while Claire has a bath, safe in the knowledge that someone is there if she needs help. But she is aware that she will need more help soon, as her arms are starting to tire more and more, and she will soon need help dressing.

"I've had seven of my 14 months," Claire says. *"I've sorted out the house and I've got plans to install a downstairs shower room – one which can be fitted quickly and easily. I can turn the dining room into a bedroom, and I'm going to get a ramp fitted in the garden, so I can get my wheelchair in and out of the house. My Occupational Therapist has advised me on what length it needs to be, and how it could fit on the patio, to lead up to the house. I know I'll need my wheelchair indoors before too long. It's Phyllis Tuckwell which has given me the courage to do all this. The care and services they offer are custom-built for each person. They tell me I'm doing the right thing, and give me help and advice."*

Claire's Occupational Therapist has helped in acquiring Claire a raised toilet seat, so that she can use the bathroom more easily, and has supplied Claire with a pressure relieving mattress topper, to prevent pressure sores, and a perching stool for the shower. She has also co-ordinated discussions with Surrey Heath Council