

me,” he says. “The first time I only stayed a few days then went back home, but the second one I stayed a week and the third one as well. The third was really helpful as my wife had a knee operation, because she suffers from rheumatoid arthritis, so I was able to come to the Hospice while she had the operation.”

“Hospice care means the world to me,” he concludes. “It’s great. They’re lovely people, they know what they’re doing and are very skilful. **I would recommend it to anyone.** I know what to expect from MND now, it just depends how my disease progresses; it might be very slow, it might be fast - there’s no way of telling. If I was speaking to someone who had just been referred to Phyllis Tuckwell I would tell them to come and try it, and they will love it. They’ll wonder why they didn’t come here before!”



We are privileged to care for people like Vimal and his 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:

01252 729446
support@pth.org.uk

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Our patients are inspiring...

“Hospice care means the world to me.”



Vimal's Story

Day Hospice, respite care, physiotherapy and occupational therapy for MND patients

Phyllis Tuckwell[®]
Hospice Care
...because every day is precious

Vimal's Story



Vimal's first symptoms of Motor Neurone Disease (MND) came over ten years ago, in July 2005, when his speech started sounding slurred.

"Everyone thought I was drunk," he says, "but I've never touched

alcohol in my life!" The disease, which causes degeneration of the motor neurones, leading to the weakness and wasting of muscles, had affected Vimal's throat and mouth, making him unable to talk clearly.

A range of tests, including swallowing tests, led to a diagnosis of MND. Vimal was just 44 years old. "I didn't think much of it," he says. "I'd never heard of it." He returned to work and told his HR manager about the diagnosis, who told him that it was very serious. "We made a family appointment with the consultant," he continues, "and that was when it hit me. We all came out crying because it's so very serious."

The symptoms which Vimal was experiencing at that time were restricted to his speech and hadn't progressed to the rest of his body – and he took advantage of this. He was given a year off work and spent the time doing all of the things which he had always wanted to do, visiting places he had always one day planned to go to, such as America, Russia and the Mediterranean. "We did a few cruises – it was lovely," he remembers, smiling.

Once back home, Vimal was referred to Phyllis Tuckwell and began to attend weekly Day Hospice sessions.

"I felt a bit negative," he admits. "I hadn't had any contact with or experience of a hospice before. But my doctor recommended it. **When I first came in it was lovely, and since then I've loved it.** I think it's the best thing anyone can do. All the staff, all the volunteers, they're wonderful."

Vimal is cared for by many people at Phyllis Tuckwell, but his main contact is Day Hospice nurse Caroline Brooks. Having had MND for over ten years now, he is the longest MND patient PTHC has cared for, but this brings with it its own problems. "The normal life expectancy for an MND patient is two to three years," he explains, "so I've beaten that. But I think the longer you stay the more it gets to you. I've noticed my hands and fingers are bending and I can't hold anything. My wife feeds me sometimes because I can't hold the spoons, but I still try. All these things are very hard. I still try to do the things that I want to do; in my mind it's still there. I tried standing up, and there have been a few falls. I loved jogging and running, travelling, which I can't do anymore. Even a cruise is very hard."

When his condition worsened to the point where he began to fall over quite frequently, Vimal accepted that he needed a wheelchair. "It's been a really slow progression," he says, "but from there it continued into my hands, arms and legs." At Day Hospice he can access physiotherapy sessions, and has



hand, back and feet massages to relieve muscle pain and aid relaxation. **"The services are out of this world,"** he says, "they help a lot." Our Occupational Therapists have also helped him by prescribing equipment for his home and by referring to and working alongside specialist teams who have provided adapted computer access, an environmental control system at home and a bespoke powered wheelchair. He also benefits from meeting other MND patients at the Hospice, and enjoys spending time in the Hospice gardens, accessing them easily in his wheelchair through the new large concertina doors of the recently extended Dove Lounge.

"I wish I had a lovely big garden like this at home," he laughs.

Because he cannot drive anymore, Phyllis Tuckwell volunteers collect Vimal and take him to and from Day Hospice. "It lets my wife have a break too," he says of the weekly sessions, which run from 10am to 3pm and include lunch. "She is wonderful and I feel sorry for her; I don't like being a burden, and I do feel like a burden. I have a wonderful family - two grown-up sons, a sister and three brothers, nieces, nephews. They all help me. They stay in touch by email and telephone, and they come to visit me, but I think my wife needs a break more than anyone."

As well as visiting Day Hospice, Vimal has stayed at the Hospice In-Patient Unit for three periods of respite care, where staff were able to look after him round the clock for a whole week, while his wife and family could take a longer break than Day Hospice can provide. "All the staff are wonderful and look after

