

Our patients are inspiring...

“PTHC has made a huge difference.”



We are privileged to care for people like Paul 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:

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support@pth.org.uk

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Paul's Story

Support for those living with MND

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

Paul's Story



In January 2006, Paul was diagnosed with Motor Neurone Disease (MND), a degenerative disease which leads to the weakness and wasting of muscles, loss of mobility and difficulties with speech, swallowing and breathing.

Paul's first symptoms of MND were cramps in his right thumb. *"Having played professional football for Aldershot FC for 12 years, I was used to cramps in my legs, but not in my thumb,"* he quips!

After retiring from football, Paul continued spending his time running the window cleaning business which he had set up when he was just 19. *"In my days as a professional footballer, I would be finished on the training field at 1pm, then out cleaning clients' windows. We didn't get paid the huge salaries that footballers get today."*

After several months of increasing pain in his thumb, Paul went to see his doctor, who referred him to a consultant at Frimley Park. He underwent several tests and had to wait weeks for the results.

"I was very apprehensive," he remembers. *"When I was given the diagnosis, I was really scared and upset, and so were my family. My wife had been researching my symptoms on the internet and her fears had now become a reality. I have four daughters and had my first grandchild on the way. I didn't know what MND was or what having it meant for me. The consultant said I only had two years left to live."*

At first, Paul's symptoms were fairly minor and he was able to continue living his life as normal. *"I had really strange muscle movements in my arms, which I had no control over,"* he remembers. *"It looked like little aliens under my skin making it move."* He carried on working for as long as possible, but in 2009 the pain in both his arms became too great for him to continue carrying out the practical side of his job and he was forced to give up work.

When Paul's GP received the results of his tests and his diagnosis, he spoke to Paul about a referral to Phyllis Tuckwell.

*"At first, I thought 'I'm not dying, so why do I need Phyllis Tuckwell?' But after my first visit, I realised **the Hospice is a place that can add more living to my life and help me manage my symptoms, as they will inevitably get worse.**"*

On his first visit to the Hospice, Paul saw a physiotherapist and occupational therapist, and received reflexology treatment.

*"**The great thing about coming to the Hospice was being able to talk to others who were also suffering from MND and finding out how the disease affects them, as it's very different for each person,**"* he says.

Paul started to volunteer at the Hospice on a weekly basis and helped a fellow patient, Ashley, who was suffering from a brain tumour. Paul and Ashley supported each other through their respective illnesses and worked together to keep fit. Sadly, 18 months later, 28 year old Ashley died.

"As an ex-professional footballer, I know how important it is to keep your body in shape, which is why when Ashley asked me to help keep fit with him, I jumped at the chance. It was rewarding to give

something back and I really enjoyed my time with him. It's very upsetting that he is no longer with us."

For Paul, MND has had the greatest impact on the use of his arms, but swallowing food can also be problematic. *"When we go out for meals now, I choose very carefully,"* he says. *"I had a very stressful situation recently when eating steak; I couldn't swallow it and I nearly choked."*

As Paul's symptoms have progressed, he has tried to remain upbeat and stay positive, and his family and friends have really helped him in this. He is still in touch with his old teammates at Aldershot FC and was given a lifetime season ticket by the club. *"Everyone there treats me like I'm normal,"* he says, *"and they've been a great help in fundraising for Phyllis Tuckwell, as have my family. My son-in-law has been running the Lion Brewery music festival for the last 27 years and has recently used that to raise money for Phyllis Tuckwell, and my sister runs a weekly raffle in her pub in Hull, for Phyllis Tuckwell."*

With the support of Judith, his wife of 38 years, and his four daughters who keep him on his toes, Paul is looking forward to living the remainder of his life to the full.

"After I was diagnosed, I set myself some goals some of which revolved around my first granddaughter, Maddison, who was born in November 2006. I wanted to be able to take her to playschool, which I did, and I was also able to take her to Infant school". Paul now has three more grandchildren, Charlotte, Paul and Lexi.

"It costs Phyllis Tuckwell a lot of money to provide their Hospice Care services, and without the donations from supporters they wouldn't be here. For me and my family it has made a huge difference - without it, my illness would have got the better of me."