



When asked to reflect about what Phyllis Tuckwell means to them, the couple said: *“People don’t realise how much Phyllis Tuckwell has to offer. Most people think it’s a place to come and die. If anyone is apprehensive about coming to the Hospice, I would say give it a try or you will be missing out, big time.”*

Costas adds: *“Phyllis Tuckwell has kept us sane. Because of our jobs perhaps, we were used to the dog-eat-dog environment of the corporate world. It is so heart-warming to have met such wonderful and caring people. **We can trust everybody at Phyllis Tuckwell, and trust is such a delicate and valuable thing.**”*

Koula’s mind is as sharp as ever; it keeps her active and she still works for Oracle UK from home. When she feels well she is so productive. Koula is phenomenally strong emotionally and has a very stoic approach to her disease. She lives in the present, has no anxieties about the future and doesn’t dwell in the past. She lives for today and that is the best tactic against this enemy.”

We are privileged to care for people like Koula 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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support@pth.org.uk

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Our patients are inspiring...

**“Phyllis Tuckwell
has kept us sane.”**



Living
Well

Koula’s Story

Day Hospice, occupational therapy and support for carers

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

Koula's Story



It was whilst on holiday that Koula, 57, first noticed the early symptoms of what would be diagnosed as Motor Neurone Disease (MND).

Koula regularly visited her native Greece to see her parents and it was on one of

these trips in 2010 that her symptoms began. Whilst hanging out some washing, Koula found her middle finger was not responding as she tried to work the pegs. She didn't think too much of it at the time, but by June that year her other fingers began to be affected.

In August 2010 Koula visited her doctor and was referred to Guildford Hospital where various tests were carried out. Although Koula and her husband Costas knew straight away that Koula had MND, it was officially confirmed on 14th March 2011.

"To be told that Koula had MND was a traumatic experience to say the least." Costas remembers. "It was like being in a room full of fog with hidden obstacles in the way, and we kept falling on those obstacles. We were all very anxious and were not prepared for something like this. This was the sort of thing that happens to other people."

Early in 2011, Dr Wren at Frimley Park Hospital referred Koula to Phyllis Tuckwell Hospice Care.

Koula recalls that she was completely fearful of the Hospice and it took a few months of gentle persuasion to convince her to visit. *"My sister died in a hospice from cancer so I felt that it was just a place that people go to die."*

"It took us quite a while to convince Koula. I nagged her enough for her to say 'let's just go and have a look'," says Costas.

When Koula eventually visited the Hospice late in 2011, she was pleasantly surprised and very impressed with the environment and the people. Since then she has attended Day Hospice every Wednesday.

"The people we met were unbelievable – absolute angels," says Costas. *"It soon became that neither of us could wait for our visit there each Wednesday."*

At the Hospice, Koula sees complementary therapists, physiotherapists - who have given her exercises to aid her mobility - and once a month has an appointment with her Frimley Park Hospital doctor as well as Phyllis Tuckwell's Dr Dando.

It's wonderful that she can access all of these services on the same day and at the same place."

Koula enjoys receiving massages and taking part in relaxation sessions at the Hospice. She also makes use of the Levo powered wheelchair that enables her to stand up and stretch out – *"an awesome piece of kit"*.

As well as attending Day Hospice, Koula also visits the In-Patient Unit for a week of respite care every three months, a service which the couple refer to as *"priceless"*.

"To see Koula returning from her Hospice visits beaming with happiness is wonderful. To know that I am sending my wife somewhere where she is being looked after means I don't feel guilty about having time for myself," says Costas.

The couple have received Home Support, which means a trained volunteer can be with Koula for

a few hours at a time while Costas goes out to run errands. This time out enables Costas to continue with his basketball coaching.

Costas attended the very first *'What About U?'* – a course designed for carers to talk with others in a similar situation and to also find out more about the services which Phyllis Tuckwell offers. He has also had regular sessions with a Clinical Psychologist.



"I am not a carer by nature - I had to do this. I had a lot of issues with my identity as I was no longer running multi-million pound projects; I became a carer and a house husband. The psychologist helped me through all of that, and I still see him every two to three weeks. The emotional support we've received has been fantastic."

We have benefited from many great Hospice Care services, but the most life-changing has to be the support from the Occupational Therapy (OT) and Patient and Family Support team. In the early days, in particular, what we really needed were practical, financial and logistical solutions.

When the OT team took on a job, things happened. *They often managed to get people together from Phyllis Tuckwell, social services and the MND Association to get things done.*

We wish we had gone to Phyllis Tuckwell Hospice Care for help sooner. *It was our fault that we didn't want to get involved at the start when we would have benefited from so many hints, tips, ways of doing things and places where we can get help."*