

# Ann and Peter's story

When Ann and her husband, Peter, were planning their retirement, she hoped to volunteer for Farleigh Hospice. Instead, she has been supported by this charity after being diagnosed with motor neurone disease. The couple explain how Farleigh's occupational and physiotherapy teams are helping them continue to live their best 'normal' life.



**Ann in the bedroom specially adapted by Peter**

Ann, 70, had been a nurse for over 50 years. Her career included intensive care, paediatrics and adult cardiothoracic care and she worked in the post-anaesthetic recovery unit at Broomfield Hospital before she retired. Peter, 62, a retired teacher has always enjoyed renovating houses so, after he stopped working full-time, he began fitting kitchens and bathrooms for people. The couple live with their son, Oliver, who is 29.

Just under a year ago, Ann was told that she has motor neurone disease (MND), which is a life-limiting condition that affects the brain and nerves. It is caused by a problem with the body's motor neurone cells that gradually stop working, causing weakness that gets worse over time.

From her nursing experience, Ann knew her health would deteriorate and she would eventually need the support of Farleigh, so she asked her doctor for a referral to the hospice's MND service.

Peter said, "I always associated Farleigh with end of life care, so my first thought was why is Ann being referred now? I wasn't aware of all the services and support that they offer or the helpful advice they could give us on what resources are available as Ann's needs change."

One of the couple's biggest concerns was what would happen when Ann could no longer climb the stairs in their house.

Ann said, "Farleigh's occupational therapy team had the expert knowledge and experience that we needed. They gave us practical

advice on adapting our home to make it a suitable environment as my condition develops."

Peter explained, "We were trying to work out how we could continue to live our best 'normal' life amongst all this. Rather than going to the expense of transforming upstairs, we were advised that Ann would need to live downstairs in the longer-term, so we should consider adapting the garage. That was an emotional time for us both - there were tears."

They decided to follow the occupational therapist's recommendation and convert the garage into a bedroom and a wet room for Ann. Farleigh referred them to a housing occupational therapist in the Adult Social Care department at Essex County Council. She promptly visited their home and gave them advice on their plans which they shared with the architect. She also guided Peter on how to make the best use of the space for a wheelchair user.

Peter added, "The rapid deterioration of Ann's condition and the impact this has had on her mobility has been quite a shock but, with this extra help and support, the conversion is now complete. The new bedroom has a hospital profiling bed and hoist and the wet room includes a shower and body dryer and washer/dryer toilet. We know we can discuss further adaptations and equipment with Farleigh when Ann needs more help."



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Maggie Humphries, Farleigh's Clinical Specialist Occupational Therapist, explained, "At Farleigh, we know how MND progresses and we use this experience to give our patients the best level of care. We also gently guide them through the other services that are there in the community to support them when they are ready. Ann and Peter have been very receptive to our advice."

Farleigh Hospice has also helped Ann to get a wheelchair and a wheelchair accessible vehicle (WAV). Maggie referred her to the mid Essex Wheelchair Service who visited her at home to find something suitable.

Ann said, "The first time I got a call about having a wheelchair, I had driven to the garden centre and remember walking around thinking 'I don't need one!'. You are reluctant to see what's ahead, but Farleigh has the experience as they have trodden this path with other people. Now, I would be a prisoner within my own home if I didn't have a wheelchair."

Peter added, "Ann's electric wheelchair has been a revelation! It can easily be manoeuvred in small spaces and elevates her to reach

items inside the house and out in the garden. She can get around our home independently without relying on me to push her and she can continue to do the things that are important to her."

Ann and Peter are very grateful to Farleigh's occupational therapy team for their advice and know that Farleigh's other care and support will be available to them as Ann's symptoms develop.

The couple have been invited to Farleigh's MND peer support group which has given them the opportunity to meet with other local people who are in a similar situation to them.

Peter said, "With MND, you understand where it is going but you just don't know which parts are going to affect you and when. You can't really talk to family and friends about certain things as it's almost a burden on them, so you need someone you can open up to. We can offload with Farleigh and this group is also really useful. Hearing their stories has helped to put things into perspective and, hopefully, sharing our experiences will help the other members of the group too."



**Ann attends a neuro support group at Farleigh**

"My earlier perception of Farleigh was that hospice care was about 'booking a bed' and just going into a hospice to die. I realise now that it's a totally different experience and not just a terminal situation. It's recognising that it's important to get the support that you need now as well as in the future. If you wait, you would miss out on so much – it is all about living a better quality of life."

Ann adds, "The best thing that has happened to us since I've been diagnosed with MND is being part of the Farleigh family. It has opened up a whole load of emotional and physical support that is very much tailored to me. I can't imagine where myself and Peter would be without Farleigh and I feel reassured that they will also be there for our son, Oliver, when he needs support."

"Farleigh Hospice is helping us to look ahead and the strength that gives you is so important - if you just stood alone you would fall over. It's like having a first-class ticket for this difficult journey that we're on. Farleigh are always there and are always positive. They are just incredible."

You can help Farleigh Hospice to care for more people like Ann by fundraising for us. For more information visit [farleighhospice.org/events](http://farleighhospice.org/events) or call 01245 457411.



**Ann in her garden with occupational therapist Maggie**