

# Long JOURNEY HOME

When Patricia Ingle contracted a rare brain infection in 2008 it was the start of a three-year battle, first to survive and then to get the support she needed to return home from hospital. *Joanna Marsden* travelled to Limerick to meet Patricia and her parents, Pat and Annette, at their home, and to find out more about the family's struggle and about how telling their story has helped them come to terms with their experience

**Patricia at  
Glenstal Abbey,  
near to her  
home in Murroe,  
Co Limerick, in  
March**

Photo by Alan Place



“I want to tell other people, ‘Don’t give up,’” says Patricia Ingle. “I was on my last legs but I survived and eventually got home. And that’s thanks to my family for not giving up on me.”

It’s a windy, wet February afternoon and I am sitting with Patricia and her parents, Pat and Annette, in their family home in Murroe, Limerick. Patricia is explaining why she wanted to tell her story in her recently published book, *I am Free*.

“Patricia loves hearing her story,” says her father, Pat. “She doesn’t remember much from the early months and she likes us to tell it to her again and again.”

“It sounds like a different person,” says Patricia. “It doesn’t feel like it was me that went through all that. But it is part of my life so it’s good to fill in the blanks. Until our ghost-writer, Mary Malone, helped us put it all on paper and I heard it read back, I never realised how sick I was. I was amazed that a person like that survived – and that that person was me.”

Patricia Ingle’s difficult journey began on 19th August 2008, when she was 19 years old. “It all started with headaches, and it went very bad. I was

eventually sent to Cork University Hospital. I had cardiac arrest and I couldn’t move or speak.”

Patricia, as she would find out years later, had contracted a rare airborne brain infection while working in her job in a pet shop. For many weeks, her condition was misdiagnosed, and by the time the seriousness was realised, she required neurosurgery to relieve the pressure on her brain. Pat says, “We had awful moments. She was critically ill and had a grave prognosis.”

After surgery, Patricia remained in a coma. Pat and Annette, and Patricia’s sisters, Melissa and Kiera, stayed beside her bed, sleeping on chairs and washing in the hospital toilets. Pat says, “Patricia was in a locked-in state. The doctors didn’t know what activity there was in her brain. Seeing our Tricia lying there bloated with her head shaven was very hard.”

After two months they began to see Tricia’s eyelids flickering. Eventually she began to open her eyes, but her tear ducts were not working and at first her eyes blistered. In the months that followed, Patricia learned to communicate a little through blinking her eyes – once for yes, twice for no. Then she progressed to mouthing words.

Annette recalls a day when the doctors asked Patricia if she could identify her family members in the room. Patricia looked at her sisters and mouthed their names, then the word ‘Dad’. But when she got to Annette, she stared blankly. “I burst into tears and ran out the room,” says Annette. Suspicious, Pat stared at Patricia and eventually she smirked. The joke cheered them all up because they knew that her mischievous spirit was intact.

In early 2009, after four months in Cork, Patricia was transferred back to Mid-Western Regional Hospital, Limerick. She was now considered clinically stable, and by March 2009, for the very first time, “the magical word ‘discharge’ was mentioned”.

At that point the family had no idea of the obstacles that would have to be overcome before that discharge could happen. The first obstacle was the family home in Ballinacurra, Weston, Limerick. Annette explains, “It took a year to sort out the house. We had been living in a small terraced house with a narrow front door and hallway, so we had to sell and find somewhere more accessible.” Pat lobbied doggedly and eventually Limerick County Council offered the family a bungalow in Murroe.

The family also pushed for a dedicated rehabilitation programme to be put in place. While they waited, they did everything they could to keep Patricia’s spirits up – putting up photos around her bed, making sure she was changed out of her pyjamas and into ordinary clothes each day, and organising a 21st birthday party for her in the ward.

**“It doesn’t feel like it was me that went through all that. But it is part of my life so it’s good to fill in the blanks”**



**Patricia outside the hospital with her sisters, Melissa and Kiera, on the day she finally went home**



**Patricia with her parents, Pat and Annette, at Glenstal Abbey**

The NRH in Dun Laoghaire could not take Patricia because she was ventilator-dependent, but in September 2009, Patricia was flown in an Air Corps plane to the Lane Fox Unit at St Thomas' Hospital in London for a five-day review. Annette describes how on the first day a doctor there put a speaking valve into the circuit of Patricia's ventilator. "After more than a year of not speaking, her first word was 'Finally!'"

Patricia nods. "I was so glad to go from being mute to actually talking."

The attitude of the staff at the Lane Fox Unit left a lasting impression. "We saw nurses taking groups of patients up to Westminster Bridge with oxygen cylinders – just because they wanted to give them the opportunity to look at the river. The mind-set over there was to try everything."

Patricia and her family returned to the hospital in Limerick full of hope, only to face two more years of frustration as they tried to get the right treatment and an appropriate support package. Pat says, "We tried all routes – asking for help from politicians, the advocacy route, fundraising, and finally the legal route."

Pat adds, "We weren't intending to go the legal way, but when we heard they were thinking about a nursing home as a long-term solution for Tricia, we had to look at all options. Our local solicitor referred us to a practice in Cork, and the solicitor there, Susie Elliott, heard our story and thought we might have a case against the HSE and Patricia's employer."

Annette says, "When something like this happens, everything changes. Trust is gone, particularly trust in medical people, and you question everything. Before all this we had great faith in professionals, but they let us down badly."

While Patricia was regularly updated on the legal case, she says, "I didn't focus on what had been done wrong. I had to focus on the funny side of situations and on getting better."

She pauses, "If you become angry, anger might engulf you, take over. Then where do you go? Yes, I'm in a wheelchair and I'm on a ventilator, but what's the point of dwelling on it?"

"I did the anger thing for a while," admits Pat.

"He was a lunatic," jokes Patricia, throwing her eyes to



**Patricia at her family home in Murroe**

the ceiling. “But his anger did achieve things. It helped me get out of hospital in the end.”

While the legal and advocacy work continued, Pat and Annette were all the time learning skills related to Patricia’s peg-feeding, medicines, ventilator and suctioning. As their confidence increased, they started transferring Patricia into a wheelchair and taking her out for a couple of hours. “Our first significant trip out of the high dependency unit was to the Skyfest in Limerick in March 2010,” says Patricia. “In the photos I am wearing sunglasses,

**“She always had to be back to the ward by midnight and it was heart-breaking bringing her back to the hospital. She would be crying going in”**

because I hadn’t been outside in three years.”

They progressed to visits to the family home. Annette says, “She always had to be back to the ward by midnight and it was heart-breaking bringing her back to the hospital. She would be crying going in.”

The family’s long campaign, which is documented in detail in Patricia’s book, came to a dramatic end in June 2011 at Dublin High Court, when she received the largest interim settlement in Irish history. The interim nature of the settlement means that she will receive a further award every two years, ensuring that her care needs will always be met. “Susie was fantastic and fast-tracked our case. We are forever grateful,” says Patricia.

Arrangements for Patricia’s homecoming could at last be made, and on 5th August 2011, after 1,069 days in hospital, Patricia finally came home to Murroe. “The first thing we did was have a huge party to make up for all the birthdays and Christmases I had missed,” says Patricia. “I dressed up as Cinderella to celebrate the fact that I didn’t

have to go back to the hospital at midnight for the first time.”

Soon after, Patricia chose to go to Oxford for six months of intensive rehabilitation. “I went to this fantastic place called the Centre for Enablement.” Being there enabled Patricia to progress significantly and reduce her medication, and it also gave her and her family confidence about the risks they were taking on a daily basis. “When we went shopping in Oxford we always saw lots of people with ventilators – you don’t

see that in Ireland. Of course you think, what if it pops off? But if I want to live my life, I have to take risks.”

Annette says, “We’ve got to the stage now where we just treat Patricia like normal when we’re at home. But we’re trying to venture out more and more.”

Patricia explains that she loves shopping, cinema, going for walks at nearby Glenstal Abbey, and staying at the Gibson Hotel in Dublin in order to attend concerts at the 3 Arena.

She says, “When I got out of hospital I had three big goals. The first was to have a party, the second was to turn my story into a book, and the third was to build a home of my own. I’ve done the first two, and I’m now working on the third.” Patricia recently bought a site a hundred yards down the road from her parents’ home, “with a beautiful big tree centre-stage”, and she is now in the final stages of planning. “Obviously I want my new home to be spacious and accessible but I’d also like it to be fun. I always wanted a VW camper van, so hopefully we can take design inspiration from that! And when I get in, I’ll be getting a couple of dogs. I’m so happy to have my freedom. I have lots to look forward to, lots to keep me going.” ■

**ABOUT *I am Free***

Patricia Ingle’s book, *I am Free*, is an account of the traumatic experience Patricia Ingle and her family went through. Her parents’ and sisters’ lives were torn apart along with Patricia’s, but they pulled together and fought. Every page of the book brims with honesty and warmth, and it will resonate with anyone who has gone through serious illness or trauma, or who has supported a family member in dealing with this. Available to buy from O’Mahonys ([www.omahonys.ie](http://www.omahonys.ie)) in O’Connell Street, Limerick; from selected Easons book stores; or by contacting Annette on 087 906 2669.

