

# 'I kept my terminal illness a secret from my husband for 10 years. When he found out he left me'

Naima Chakkour



Naima knew something was wrong when she began dropping things  
Heathcliff O'Malley for The Telegraph

I first realised something was wrong when I struggled to tie my three-year-old son's shoelaces. My fingers had been gradually getting weaker and I'd started dropping things. At first I put it down to clumsiness but then started worrying that I was suffering from something much worse like a stroke. Being unable to tie Adam's laces shocked me into seeing my GP, who reassured me that was highly unlikely as I was far too young. Initial tests by a neurologist at Westminster and Chelsea Hospital also showed nothing abnormal. But

my symptoms continued, and I even had to wrap cellotape around my car key so I could grasp it.

At the time, in 1993, I was a busy 33-year old mother, with four children aged between seven and three. We lived in a two-bedroom flat on the fifth floor of a building in Victoria. My husband was managing a member's club and was rarely home, so I just had to keep going. There was no one else to take care of the children or drive them to school.

## The diagnosis

Within a year, my speech began to get slow and slurred and walking became difficult as my limbs grew weaker. By then, I was having trouble writing and even signing my children's school books. Sometimes, my fingers would not work at all.



Naima with her daughters Sawsan and Sabrina before the diagnosis

I returned to the same neurologist for an MRI and lumbar puncture tests, which again revealed nothing. But then, in March 1995, I got a second opinion from another neurologist, Dr Guiloff at Charing Cross Hospital. He diagnosed me with **motor neurone disease (MND)**. Life expectancy, he said, was usually five years – and I had already suffered it for two. I was shaking in terror, but couldn't even tell my dear friend, Habiba, who waited for me at the reception. Collecting my children from school afterwards, I thought, I have to fight for them.

## My weakening body

With MND the body gradually closes down because of the gradual death of motor neurons, which are the nerve cells in the brain and spinal cord which control movement. Gradually, the muscles stiffen and waste away, and it can become difficult to walk, talk, eat or even breathe. There is no cure for this illness, nor any way to slow it down or treat the symptoms. But as a Muslim with a deep faith in God, along with my love for my children, I had the determination to live as long as I could. While other terminally ill people have bucket lists of experiences and projects to fulfil, my only wish was to see my children grow up safe and happy. Even as my body grew weaker, I concentrated on raising them.

## The impact on my family

I went into denial, telling no one about my diagnosis, not even my husband. We had never been close, having had an arranged marriage in Morocco before we settled in London. He took little interest in my wellbeing, and began to spend more time at work, staying at his club. Having no other family in Britain, I had no one to confide in and felt so frightened and alone. I struggled to sleep at night.



Naima and her brother Ahmed outside the White House in 2012. Ahmed was one of the victims of the first wave of Covid-19 in 2020

It was only after four years, when I was no longer able to walk unassisted, that I finally told my beloved older brothers, Abdeslam and Ahmed, the truth. Fortunately, they were very successful hoteliers (sadly, Ahmed passed away in 2020), and they ensured I had all the material support needed. Habiba became my full-time carer and more support arrived as my illness progressed. Two other carers now assist Habiba in helping me. I have seen leading medical specialists – but to no avail.

### **Telling my husband**

Six years after telling my brothers, in 2005 I finally told my husband about my diagnosis. His reaction was to leave. He thought the illness was contagious. Though I did not regard him as someone to depend on, I was still shocked that he abandoned us. When I married, I believed it was for life.

### **The divorce**

In 2006, I decided to divorce him. Still, he showed no sympathy, asking the court not to allow my daughter Sarwan to translate for me. By this time, my speech was badly impaired and only she could understand me. Thankfully, the judge ignored him.

### **'The nail in the coffin of our 17-year marriage wasn't a blazing row or an infidelity'**

Over time, my ex-husband did reflect on his behaviour. In 2019, we learnt he was dying of cancer and wanted to see us. We had not met since the divorce and my anger towards him returned upon seeing him again. But I put these feelings aside. We went to a café – I was now confined to a wheelchair – where he took my hand and, full of emotion, said, “Forgive me. I am so sorry about the past.”



Today, Naima still enjoys going out and looking her best

I cannot bear holding onto bitterness, and he spent his final year living in our family home in Tangier, where our children were as devoted to him in his illness as they have been to me. It was difficult to see him suffer, and he died in 2021. Forgiveness is complicated, but far better than holding onto hate and resentment.

### **Living with MND today**

I am now completely immobile but for a little neck movement. Lying down is extremely painful because my muscles have wasted away such that any pressure is excruciating. I sleep on a water bed and my carer turns me over several times during the night. I dread the nights, and when falling asleep, I dread waking up to the pain. That is when the dark thoughts come, and I do take antidepressants to cope with them. My nine-year-old granddaughter has recently moved into my apartment, she is a great comfort.



Naima sleeps on a water bed with an oxygen mask and is turned over by her carers several times per night

I've been living with **this disease for 31 years now** and I am the longest living case of MND, but no one knows why. The younger people are diagnosed with it, the longer they tend to live. **Stephen Hawking**, for instance, was diagnosed at 21 and lived until he was 76. My current specialist thinks that my present condition is stable and puts no time-frame on it – I could live for a long while yet.

I live in South Kensington with my carer, and even though I cannot drive any more, I travel everywhere in

London using the buses, which are very accessible to wheelchair users. I love Indian food, and sometimes go to Southall to eat and look in the fabric stores. I still love shopping for clothes, having my hair and make-up done, and looking my best.



Naima and her daughters, Sawsan and Sabrina, who help care for her in London

My daughters live close by and are a constant help, while my sons live in Morocco. I split my time between them. I am blessed to have their support, and cannot imagine having this illness without such assistance. My family and my faith are the source of all my hope.

### **Bringing up my children**

Despite my illness, I was a very strict, hands-on single-mother of teenagers, and without my illness, I might have been even stricter. My parenting seems

to have paid off. They have grown into wonderful and successful adults, and I now have four grandchildren who cheer me up immensely.

Sawsan has a Masters in international relations from New York University, and has worked for JP Morgan and on Hillary Clinton's election campaign, while Sabrina also has a Masters from Cass Business School and is both a mother and businesswoman. My sons are also graduates and businessmen in Tangier. Their education was paramount to me, and it was amazing to attend all the ceremonies and watch them receive their degrees.



Naima and her sons Adam and Mehdi on the beach in Morocco

I still laugh a lot and find joy in the midst of all this. I have made many friends online who have MND, one of whom we invited to have an amazing stay with us in Morocco with her husband and daughter. My speech is now extremely weak, but I have a gadget that helps me to type with my chin and use the internet as well as text and email my friends and family. This was how I was able to write my memoir. I wrote it so people can understand the reality of this cruel disease and hopefully bring more compassion and assistance to those who do not have the support I have had.

Most of all, I want people who are well to appreciate life. I get so angry when I hear people being upset about small things. You still have your health and your body. Be thankful for what you have, and be happy.