

# Real Life

## My MS journey

**Sylvia Wright** recounts her life with MS which lead to her writing a book

I've had multiple sclerosis (MS) since I was 21. It began with numbness, dizziness, tingling and fatigue. At 23, just after graduating from Sussex University in Chemistry with European Studies (German), I was at long last diagnosed with MS. It was a big relief in a way to know that I wasn't just going mad, but I still felt devastated. MS was always there, progressing, and I felt like it was whispering to me, "You are living on borrowed time you know."

Whenever the MS progressed, I was given quick-fix steroids to put me back onto my feet. I responded well, however, they didn't fix the problem, just bought me a little more time. I felt I had no choice as I knew of no alternative.

By 24, my mobility began to deteriorate visibly. I could no longer run away or hide the MS, so I decided to tell the world by jumping out of an aeroplane at 13,000 foot! I wanted to give people something to really talk about.

Through my tandem sky dive I met some wonderful new friends who have played a crucial role in helping me to help myself.

I consulted a good nutritionist. Together we set out a diet and vitamin plan to give me the best possible chance in stabilising my condition.

### Falling in love

MS even brought a wonderful man into my life (when I wasn't looking - that was the last thing

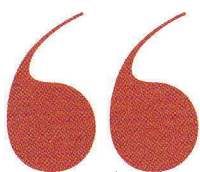
it anyway.

An additional bonus was that Steve owned a property in the Florida Keys where I could soak up sunshine for two to three months each autumn.

### Getting published

I've now written a book called *My Crazy Brain*, because it comes from my crazy brain. You can find it at [livingwithms.co.uk/book.html](http://livingwithms.co.uk/book.html)

The first part of the book contains poems I have written



I actually met my Mr Right when he sold me my mobility scooter

on my mind!). I met Steve Wright (my Mr Right!) when he sold me my mobility scooter.

It was Steve's love that made me really believe in my new regime of diet, nutrition, exercise and sunshine. It is amazing how self-belief, and a feeling of self-worth can boost one's health, especially when you are taking actions that help

through my life. Each poem has an introduction as to how that poem came to be written and what it means to me.

**The themes covered are often intertwined, they include**

- 1 Love
- 2 My feelings of self-worth, or lack thereof



- 3 My family and what they mean to me
- 4 How the progression of MS has affected me.

They reflect my life. The second part of the book contains jokes and riddles, some I have heard, but a lot I have made up myself, in *My Crazy Brain*, since I have become bed-bound due to MS. I like riddles and jokes and telling them to people I meet – this part of the book reflects this part of my personality.

Feedback on the book has been positive. Some friends have said that some of the poems have emotionally touched them. I am glad they are seen as meaningful. As for the jokes and riddles, well, personal taste, not unexpectedly, dictates most people's reaction.

I am now looking to make it into an audio book, though this will probably just be the poems section.

## Life now

My life is now very restricted by MS. I need carers to help me with everything as I can't physically control anything beyond moving my head. I can ask Alexa to play music and so on, but need others' help for everything else.

I am fortunate to have carers funded from first thing in the morning until late evening. This helps me stay positive as does my son, Marcus, who has just finished his GCSE exams. I was born with a bicornuate

uterus, half of which was taken away when I was a teenager, which made the birth of my son even more special.

Family and friends help me stay positive too despite hospital stays, nowadays primarily for complications linked to infections caused by kidney stones, something extra serious due to me only having just one kidney.

Staying positive has been more difficult since Steve passed away, due to non-Hodgkin's lymphoma in August 2020, but I am still managing it and getting my book published has helped me a lot.

Steve also helped me travel the world to places like the Galapagos Island, Iguassu Falls, Machu Picchu and Angel Falls, where Steve proposed to me. My trip to the Galapagos Islands was actually featured in an old issue of *New Pathways*.

These trips confirmed me in my belief that life isn't measured by the number of breaths you take but by the number of moments that take your breath away.

