

My struggle to hold on to happiness as I live daily with MS

By Helen Fowler

I'M sitting on the grass watching my elder daughter learn to play tennis. As the lesson ends she begins skipping over to where I'm enjoying the early summer sunshine. I get up to go and meet her.

I try to walk down the sloping path. I... can't... do... it. I can't seem to get my balance. My legs have done their usual and turned to cotton wool. I find myself grasping at thin air for support. For a moment or two, sat in the sunshine, I'd managed to forget about having multiple sclerosis (MS).

I call out for help, trying to hide my panic as I do so. My younger daughter rushes over and takes my arm. I can't lean on her, she's only seven years old. As I topple, the fencing catches me. I'm grateful to be spared the humiliation of yet another fall.

I'm not alone in my struggle with MS, a chronic neurological condition that affects around 10,000 of us here in Scotland. We're a global blackspot for the illness, with a higher prevalence than almost anywhere else in the world. Around 188 out of every 100,000 of us have the disease.

Nobody is quite sure why so many more of us Scots suffer from MS than other groups. Lack of sunshine, and the resulting shortage of vitamin D, might be one reason. Good old genetics might be another. Getting certain viruses, including Epstein-Barr, might be another explanation.

Teams of scientists here in Edinburgh are working around the clock to fathom out how we acquire MS in the first place, and what can be done to stop and repair its ravages, which can include permanent blindness, paralysis and memory loss.

I go for regular check-ups at the Anne Rowling Clinic at the Royal Infirmary in Edinburgh where scientists are working for a cure. The clinic is named after JK Rowling's mother Anne, who suffered from MS. It reassures me to be reminded that the famous writer is the daughter of somebody who suffered like me and, in some way I can't quite pin down, it makes me feel slightly better about having the illness.

The pills I'm on for my MS only became available in this country just over 18 months ago, a few weeks after my diagnosis. Steroids helped me recover from the attack that led to my eventual diagnosis. But, up until a year or so ago, staying off attacks meant relying on regular injections.

I take comfort from the intensity of research into MS. At this rate, we may even have a cure before too long. But I'm not counting on it. Nobody really even knows yet what causes it.

Following my diagnosis I've started to meet other people with the disease, mostly women. It's not a coincidence – more than twice as many women as men have MS. Some people I wouldn't even have known were sick – many of us look deceptively normal. You have to see how we struggle to remember the day of the week, or watch us attempting to walk or stand, before you see the problem. I don't remember much about my diagnosis. A cocktail of cognitive damage



Facing up to MS: Edinburgh mother Helen Fowler

I've most needed to feel part of a wider community.

Becoming ill when my younger daughter was just a few months old meant I was forced to skip the parent and baby groups I had attended for my first daughter. Energy was so limited. I was frightened, medicated and badly shaken. Perhaps as a result, my younger daughter is more home-loving than her sister.

I still keep thinking about the cellist Jacqueline du Pré. She had a worse form of the disease than me, known as primary progressive which gets steadily worse from the onset. Mine is the kind where attacks come and go. Her husband, musician Daniel Barenboim, had an affair with another woman as du Pré became progressively more disabled.

FOR years after the initial episode of blindness, I couldn't get thoughts of du Pré out of my head. The haunting Elgar cello concerto for which she is famous seemed to follow me wherever I went. It doesn't seem to matter how often my husband tells me he loves me, that he's not going anywhere. I still fear abandonment. In darker moments, I can't say I'd blame him if he did leave.

Whenever I mention this to my husband, in a forced attempt to sound casual, he reminds me of our marriage vows – that bit about 'in sickness and in health'. I never really thought the sickness bit would come along so soon or be quite so devastating.

Marriage with MS as the third partner has not been a barrel of laughs. As the months have gone by, the tears and anger following the initial diagnosis have given way to something else – sorrow. A simple sadness about never being able to run again or walk further than a couple of hundred yards. Sometimes I just feel bleak, and all the anti-depressants in the world can't change that.

Simple things are hard. Walking up and down stairs is an ordeal. I cling on to the banisters and pause on each step before putting a foot on the next one. For some reason going downstairs is harder. Wrestling an over-sized atlas out from under the bed is impossible these days. I wanted to show one of my daughters the location of the world's rainforests to help her with her homework, but I can't lift something that heavy any more.

The arrival of MS has changed my thinking on all sorts of things. I no longer imagine old age as an idyllic, sun-lit time. I cry a lot more often. But MS has at least forced me to focus on what really matters – my family.

Sat in the spring sunshine this morning, having my breakfast and listening to birdsong, the depression, frustration and anxiety slipped away. Instead, I was absorbed in watching a pigeon collecting twigs for its nest. It was a brief moment, but gave me a glimpse of a reality where MS and happiness can co-exist.

and tranquillisers means I don't even remember telling my kids I had MS either. I'm not sure it meant that much to them. They were more worried that I couldn't see and was unable to walk.

My elder daughter has asked if me having MS means she is likely to have it, too – words that fill me with horror. I tell her medication will be much better by the time she is a grown-up. There may even be a cure.

AS the initial horror of the diagnosis has begun to subside, I have started to re-think my past. The supposed 'sciatica'. The 'slipped discs' that wouldn't get better. The years of depression – with no obvious explanation. The 'shingles' that left me unable to walk. The 'pelvic dysfunction'.

The first sign something was really wrong came when I went blind in my right eye eight years back. But it was a further six years before the eventual diagnosis. The blindness led to countless medical appointments, sat in packed waiting rooms with people (again,

mostly female) in wheelchairs and dark glasses. This episode ended with the consultant telling me it wasn't multiple sclerosis 'at the moment'.

I didn't take in what his emphasis meant. Maybe I didn't want to hear it. I'd just had a baby, my younger daughter. It was only later that I learnt that the three months following the delivery of a baby are among the worst for women with MS.

My daughter came to some of the early medical appointments with me, her face a reflection of the same forlorn terror I felt myself. My husband came with us, telling me he wouldn't stop loving me, even if I did have MS. Not daring to believe him, I hid my fear and terror in anger. Better not to trust anyone when life can turn on you without notice.

My children have seen me collapse a few times, but I still pick them up from school every afternoon. Fellow parents are aware I'm struggling, and treat me with a special kindness. These women have watched my kids for me while I have gone to medical appointments, counselled me and listened. They've been here for me when

TINY TWEAKS

START your day with two cups of coffee, not one. Older people given caffeine tablets – the equivalent content of two cups of coffee – scored higher in tests of their attention skills and reaction times, than when they were given lower-dose caffeine pills. Researchers from the University of Bristol say the results could offer hope in the search for new treatments for dementia patients.



DOZY POSES

HOW the way you sleep can affect your health. This week: The recovery position for acid reflux



KNOWN as the recovery position because it's similar to the posture used in medical emergencies, this involves half lying on your stomach, half on your side: with the arm on that side under your head for support and the other resting on the bed in front of your stomach.

It's thought to help stop stomach acid splashing up the oesophagus and triggering pain. The key to this is to sleep on your left side.

In a study of heartburn patients at the Graduate Hospital, Philadelphia, doctors found that sleeping on the right side meant that leaked stomach acid took longer to drain out of the oesophagus compared with sleeping on the left – it's not clear why.

If sleeping in this position doesn't help your indigestion, prop up the head of your bed slightly, so that the upper body is higher than the stomach.

DO THIS

VISIT an art gallery to de-stress. Researchers at the University of Milan studied 100 people during a visit to an art gallery and found that their stress hormone levels were 60 per cent lower after the trip, according to saliva tests.

DIET DESTROYERS

HEALTHY FOOD: Wholegrain bagel

WITH around 220 calories each, wholegrain bagels are a tasty alternative to sandwiches at lunchtime.

Better still, studies show that people who eat more wholegrains find it easier to control their weight, mainly because wholegrain foods contain fibre and so are more filling than the more processed varieties.



UNHEALTHY EXTRA: Peanut butter

PEANUT butter is made from crushed peanuts that are often combined with a small amount of oil, sugar and/or salt.

Peanuts themselves are high in fat and calories.

So there are no surprises then that a tablespoon (15g) of peanut butter has 95 calories – roughly the same as a single Milky Way chocolate bar – as well as 8g of fat.

Light cream cheese is a far better option in terms of calories – just 23 – and has less than 2g of fat.