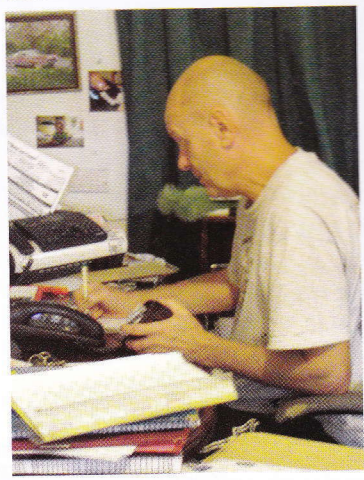




What makes my life work now? *by Sylvia Wright*

Sylvia Wright's MS is now so bad that she has had to move into the living room downstairs and be looked after by her husband Steve and paid assistant Salmoon. Here, she says what practical things help make her life work.



Steve hard at work

Sylvia, 39, was diagnosed with MS when she was 23. She lives in Sheffield with Steve and their seven-year-old son Marcus.

It's been a very difficult twelve months; around a year ago I really started to struggle as I was having more and more trouble swallowing. This meant I wasn't getting enough food and was losing

weight – I went down to six stone, then when I couldn't swallow at all I was sent to hospital.

In hospital I had a PEG fitted (percutaneous endoscopic gastrostomy, given to people who cannot swallow food. A PEG tube is passed into the patient's stomach to provide a means of feeding). This saved my life. I now get my nutrition directly through a PEG feeding tube, so I don't have to swallow.

When I first came out of hospital I was in for a double emotional blow – first my granddad died and then two weeks later my father died.

What is daily life like for me now?

I am in bed most of the time in my room downstairs which Steve, my husband, had built last year along with a wet room next to it.

I need lots of help

I have needed and still need a lot of help, mainly from Steve. But on six afternoons a week I have my fantastic personal assistant Salmoon, who sometimes I think knows me better than I know myself. He takes a lot of the pressure off of Steve. Also, my brother Matthew often helps out on a Sunday. Without their help my life would simply not work.

I also couldn't manage without friends and family. I'm still able to talk to many different people who come to visit. I find talking to my Mum helps a lot, but I do miss my Dad's words of support.

I totally rely on the PEG to help me stay alive. Not only do I get my soya-based feeds through it, but also ground-up medicines. However, I am now able to swallow drinks and enjoy eating soft fruit (when Marcus hasn't eaten it all!). Swallowing liquids helps keep my throat and voice box moist.

I have Botox injections in my knees which help to loosen the muscles and increase their flexibility. This makes the spasms less painful and makes it easier for whoever has the task of stretching my legs.

I take Wormwood, which helps kill off the Candida and thrush and prevent urinary tract infections (UTIs). This means I am not always fighting infections.

Then there's my wonderful big bean bag! I sleep better when my legs are in a tower over it.

When I don't have much energy I watch a lot of TV, but I have recovered enough that I often want to do more than that. Currently I'm also listening to music, teaching Marcus cockney rhyming slang and recording tapes about my life as I'm planning to write a book about it.

I'm also starting to ask Salmoon to take me out into the local community

more as I miss meeting and talking to people in places like the local library. I have to be carried from the bed to the car, or use a wheelchair.

Life can be a struggle, but I'm convinced I delayed being this bad by ten years through my earlier regime of diet, nutrition, exercise and getting sunshine. I still avoid dairy and sugar.

One thing I will never regret is having Marcus, now seven – my 'not so little boy anymore' miracle. I'd do all the same again if I had the choice.

My positive outlook is starting to return and you will be able to keep up to date with me, Steve and Marcus at www.livingwithms.co.uk which my brother is in the process of updating and will keep up-to-date for me.

All the best to everyone,

Sylvia Wright



TOP: Sylvia's son Marcus
ABOVE: Sylvia with personal assistant Salmoon

"My positive outlook is starting to return."

BELOW: The big bean bag helps Sylvia sleep

