

# 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.



**S**ylvia, 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.

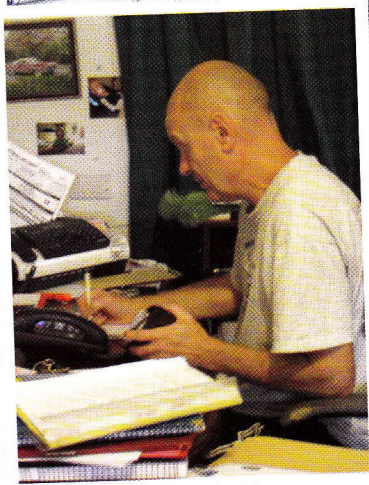
## What is daily life like for me now?

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.



Steve hard at work