



Bob's Story

A2: BOB'S STORY

▶ 2.27 mins

I've been retired for just on twelve months now. I was diagnosed with motor neurone disease and because I was a sparky it was just too dangerous for me to keep on working. My wife and I didn't know what motor neurone disease was, but the neurologist we went to referred us on to the MND association. That was pretty confronting at first. They gave us some brochures that were very frank about what happens; it's a cruel disease. I was really angry for a few weeks and you immediately think 'why me', 'why now'. I didn't take it very well, I really took it out on the family. Everyone's different of course but you've just gotta do what's best for you. I found others that were coming to terms with issues like 'what it's like to not be the bread winner anymore' and you know that sooner or later you're going to have to relinquish some of your responsibilities, but you just can't do everything. These were some of the hardest adjustments I've had to make, but it's hard when you think people just aren't listening to what you want. Everyone seems to be an expert on what you should be doing.

A4: THREE MONTHS LATER

▶ 1.09 mins

Occupational therapist: I just wanted to go over some of the plans we discussed last time I saw you, and see how you're managing with some of the equipment that I brought over, and also the modifications to the house that we discussed.

Bob: Well the chair over the shower is making showering a lot safer and the wheelchair makes it easier if we go out shopping. But I still like to walk though.

Occupational therapist: Have you heard when they're coming to change the bathroom around?

Bob: Well, that's a bit of an issue. I know when you came over and we spoke it seemed like a good idea at the time. But I think it's a lot of expense and bother changing everything around, just to make it easier for me to get in the shower.

Occupational therapist: I guess they're just suggestions and whether you get them done or not is really up to you and Margaret. At the moment you're obviously coping with the shower in the bath but further on down the track you may find it a bit more difficult to use. So maybe what we'll do is reassess as things change.

A7: EXPLORATION

▶ 1.39 mins

Occupational therapist: How is your strength in your arms and legs at the moment?

Bob: The legs are a lot stronger than the arms and I'm a lot better in the mornings than I am in the afternoons.

Occupational therapist: Last time we talked about the tasks you need to do across the day.

Bob: I do try to do that. But some days I just can't do things that I want, when I want and I get angry because I just can't do as many things as I could do last year.

Occupational therapist: What sort of things help you deal with your concerns?

Bob: Well I guess I still really enjoy the friendship of some old blokes I know. But I don't want to be a burden on anyone.

Occupational therapist: Are you managing to get out and maintain some social contact?

Bob: I'm been very self-conscious that my walking is starting to look funny. and if we go any distance and take the chair, you know people look at you. I much rather stay at home. I'm embarrassed to eat in front of anybody other than Margaret. My coordination is bad, sometimes I cough.

Occupational therapist: Are you having trouble swallowing? Is that why you cough?

Bob: Some food just seems to stick.

Occupational therapist: Now might be a good time to see a speech therapist and a dietician then.

Bob: My GP said that this may become necessary.

Occupational therapist: Well it's very individual and it doesn't necessarily mean that you can't continue to eat. It's just very important that you do so safely.

Bob: Okay.

A9: HIS ILLNESS PROGRESSES

▶ 5.14 mins

Doctor: So Bob, how are things at the moment?

Bob: I've been getting very weak. If I have to go any distance I have to use the chair. I can walk a bit, but I'm very slow and my arms are very weak. But its Margaret I'm worried about, look at her. Some days it breaks my heart to see what this is doing to her.

Doctor: Yes. Margaret how are you managing?

Margaret (Bob's wife): It's been very hard. I know I should be stronger but I can't.

Bob: I wonder as I get worse, it's going to be harder for people to understand what I want and I'm going to be totally dependent on them. When I was in the palliative care unit for a few weeks it gave Margaret a rest, and I realised that while you're at home that there's someone there all the time. But in the palliative care unit and in the hospital it's not always going to be like that.

Doctor: It is very hard to adjust to but there are people there twenty-four hours a day whereas Margaret has got to have some sleep at some stage. And they'll never let you get into any real trouble.

Margaret how did you find it when Bob was in respite?

Margaret: Well In some ways it was a real break, especially at night. However Bob didn't like it and he's not keen to go back. I don't know how much longer we can keep going at home.

Doctor: Yes. Bob, what do you think about staying at home?

Bob: Naturally I want to stay at home as long as I can. I know the time will come when I might have to go to the hospital and back to the palliative care unit.

Doctor: Do you think you're getting enough help at home at this stage?

Margaret: There is a constant stream of people coming to our house so I don't know if we need any more. I mean they all want to help. But you do lose your sense of privacy don't you?

Doctor: It does sound like both of you are under a lot of pressure at the moment and I think we need to do something to try and help. I wonder if it might be time to get the OT to come back to your place and just reassess how things are and whether they can provide any extra support for you to might make things easier. Bob how would you feel if we did arrange more time in respite to help Margaret? And Margaret it is very important that you to get some rest so that you can provide help for as long as you possibly can.

Bob: What you think Margaret?

Margaret: I'll keep it in mind, but I'm okay at the moment.