

I'm Anita and two weeks before my seventieth birthday I was diagnosed with motor neurone disease.

I always thought I was going to be that old lady of a hundred that you always read about in the paper, that's parachuting out of a plane. That was my idea of myself.

### **Diagnosis**

I prided myself on being fit and healthy, and I'm vegetarian. I've always watched what I eat, very careful about eating the right things, taking exercise, having my greens, never smoked... drink a little bit but [laughs] just occasionally [laughs].

### **Interviewer: Tell me what then happened.**

I needed to get some cash from a cash machine, and I put my card in and the thing bleeps and it says please take your card. I went to take my card out and my fingers didn't work. I couldn't pull that card out of the slot. Nothing I could do would grip it. Uh then I found that I couldn't reach things on high shelves in the kitchen. So uh I eventually went to the doctor, I think it was the following February and said about this, and she referred me to a neurologist who I saw at the end of May.

They told me I'd got motor neurone disease. And I just could not believe this. I just said, are you sure? I said are you sure?! Me? Um I just said well can you tell me something, what's going to happen, and the neurologist looked at me and she said well judging by your current progression you will be in a wheel chair in two years time.

Of course then I started reading up about motor neurone disease and found out what was really going to happen to me.

**Interviewer: What did you discover, Anita?**

Well it's not, not a pleasant disease. The progression is that your muscles go gradually and in the end you can't move any part of your body. Then you lose your voice. Then you're unable to swallow. Swallowing is also a muscle, and in the end you're unable to breathe. So you are, your brain remains the same, but you are lying there in a body that doesn't work at all and totally dependent on other people to do everything for you.

**Interviewer: How long, did you ask them how long you had?**

Uh the average is three, three to five years after diagnosis. Some people live longer. Some people are gone within six months.

Coping mechanisms - being positive

My life isn't about motor neurone disease.

**Interviewer: What's it about?**

It's about going out and having fun [laughs].

**Interviewer: Good for you [laughing].**

That's what it's always been about you know, as best as I can without hurting anybody. I just want to live every minute of my life to, to its utmost.

There's no point in me being miserable about it, because if I've got a short time left to live then it's even more important that I make the most of every day and be happy every day.

I've only got so much time to live. I can't sit here and be distraught. I've got to get on with it. Therefore you go out and do it. Okay I, I've been scared, scared to do things, but I've had to push myself to do it.

I feel so lucky in everything I've, in my life that I've had, the fact that I've got to seventy-two years old before I got before I got diagn-, seventy anyway before I got diagnosed with motor neurone disease. I've had a wonderful life and I'm still managing to squeeze a bit more out of it [laughs]. So yeah that's what's makes me happy.

Interviewer: Is there anything about knowing that you're got a limited amount of time left that you think is a positive?

Oh there's lots of positives [laughs]. That means I can make plans for my end, um that I can sort all my affairs out. I know that it's going to happen. You never know how you're going to end up when you live alone. Um you don't, if I'd have lived to be a hundred how would I have, what would have happened? I haven't got that, that uncertainty now. I know I'm not going to. So I don't have to worry about that.

**Interviewer: Is that quite a relief?**

Yes absolutely, completely relief.

It's the quality of life that's important, not the length of time you live. Obviously we all want to live a wonderful long life with full of quality for a long time, but if you're, if that's taken away from you, if the length of time is taken away you've absolutely got to make sure you've got the quality every day.

Coping mechanism - learning to adapt

Well I've had the wheelchair probably about nine months, but it was horrible at the, at the beginning because I couldn't face the thought of being in a wheelchair. I was just petrified of, of the whole thing. Do you know my attitude towards my wheelchair has changed completely because it's become my friend rather than my enemy. So it's the same life with just a different mode, just a different mode [laughing] of transport.

### **Aloneness**

I've been alone now for seven years. So I suppose I've got used to it.

I miss not having my husband here. We had each other to, to discuss problems, and so you're on your own. You've got nobody to talk to about things. And I, you've got to make the decisions yourself, and that uh I find hard

The hardest thing is pfft, I don't know whether I can say this on film. Uh the hardest thing is going to the toilet. It's a physical thing and I am absolutely fine in this wheelchair as you've seen me and people see me getting about and looking fine, looking fine, but out, out of this wheelchair I am a wreck. I can't walk, I can't hardly stand up and I can't do anything with my arms.

And whenever I'm out I always have to think, is there going to be a disabled toilet? If there is am I going to be able to get off it? All these sort of things. And that's something I don't like.

### **Independence**

I could of course have gone and lived with my son. My younger son offered me to go and live with him as soon as he knew the situation,

but I don't want to do that. I don't, I'm, I'm just too independent. I can't go and live their life. I have to live my own life here, and when I can't do that any more then I've had enough. That's, that'll do.

Cos the thing is I live on my own here in a small one bedroom flat, and I, I shall need increasing care as time goes on. At the moment I have a carer that comes in and she comes for an hour in the morning and she comes back in the evening, to get me dressed and undressed, and get my food etc. Um so as I get worse I will need more time and then eventually I will need twenty-four hour care.

And I also don't have the money to pay for that care. So I'm looking at, they're going to say to me you'll have to go into a nursing home. Now that to me is an absolute horror. But if I had a lot of money and I could have, and I had a big house and I could have a private annex for a twenty-four hour carer of course that would be wonderful, hah, uh but I haven't.

But I am worried about becoming what I would call a blob in a bed, completely useless and but still with my active brain, and being totally dependent on other people. Now that is going to be a living hell for me and I don't want it.

## **Death and dying**

I'm dying without any regrets, except that it's a little bit earlier than I expected. That's the only regret I've got. I'm facing the end of the summer now and the winter is coming and although I've got a lovely warm flat it means that I'll be stuck in here simply because I can't put a coat on to go outside.

I'm not worried about dying at all. That doesn't bother me. I've, we, we've all got to go. What I want to know is that I'm going to die with

some sort of dignity and I would preferably like to choose when and how I die.

I've decided that I don't want to see this disease through to the end, because it's particularly horrible. In my opinion it's worse than cancer because my brain will remain as it is while my body completely um gives up in every way and I will just be a blob in a bed and I don't want to be that.

Unfortunately um... I cannot take any easy way out in this country because it is against the law at present. So I am forced to look at other options.

**Interviewer: What have you decided then?**

I've decided that when the time comes I will go to Switzerland. I don't want to go and I will have to go too early because I need to be fit enough to travel, but I haven't got a, I don't see any other option. I really don't see any other option, but I'm not happy about it.

**Interviewer: You're not a rich woman are you so how do you manage [A: No] to afford it?**

It's – hah, it's taking every last penny. It will take every last penny I've got.

My children are grown up. They've got families of their own. They've got lives of their own. They don't need me, and I, I live on my own and I've got not even any pets. So I feel sort of free to go. And I think those people that don't go, don't go because of the other person or the oth-, or the children or whatever keeps them there. There's nothing to keep me here now.

So I don't want my children to be upset. I want them to remember me as a person who enjoyed life, had a good time and lived every minute of it, and then they'll have happy memories hopefully, I hope they will. [Laughter]

**Interviewer: Do you feel brave?**

No, not really. I've never felt brave. I just, no. It's not har-, uh it's not a hard thing I'm going to do. In fact, it's harder for the people, for other people than it is for me. I've got the easy part.

**Interviewer: Why do you think it's easy?**

All I've got to do is go on another trip, another airplane ride, drink a drink, off I go. Wonderful. That is how we all want to go isn't it?