



## Exploring psychology

### *Exploring Psychology: Living with Memory Impairment 3*

**Researcher:** Miranda developed memory problems in her 30s, when she had meningitis followed by encephalitis.

**Miranda:** My sister brought a diary into the hospital for me. Just a blank notebook, and advised me to write notes of the thoughts and feelings that I was experiencing. And my fears and concerns, that I was having at the time. And I kept this diary for some months actually, after I was ill. And in the early stages, it's really quite terrifying to read the confusion that I was experiencing. I wasn't sure where I lived. I wasn't sure if my husband and I had split up. I wasn't sure what had happened to my family. Where my family lived. The extent to which the most basic parts of our lives that we know, had gone. And needed to be put back into place, on a regularly basis. By visitors. And so visitors would write in the book, what was happening. And who they were, and what connection they'd got to my life. And what was going to be happening next. and so that there were no shocks for me.

This entry is written I think about six days after I was in hospital. And it's dated Tuesday 18<sup>th</sup> June. I woke up Ward D5. I can't remember how on earth I got here. How long have I been with James? What I would most like is to see James. I can't remember anything. What year is it? Do I have a partner now? Who? Is it James? This is two or three days later. I write in my diary, can someone bring me in some family photo albums to jog my memory. I can't believe how much of my life I have totally forgotten. It would be lovely to have a timeline. Jogged by photo's. Because I forget what everything looks like. It sounds like I have some wonderful friends, looking at my book. That's my diary. But I can't remember what they look like. I asked them to apologise to people if I have been strange.

**Researcher:** That's about five years ago now isn't it?

**Miranda:** Yes.

**Researcher:** And I know things have moved on a lot for you, in your life. I wonder if you could say a bit about how things have changed over time?

**Miranda:** Well early on. I didn't tell people. I was very frightened all the time. In case I was going to be found out. And it's very hard to explain how frightened you feel, when you've lost your memory. Frightened by everything. You're frightened when you leave the house, in case you turn the wrong way, and you can't get home again. Frightened that people are going to think you're foolish. And frightened when you go to the shop in case you don't know your way out of the shop. Everything is frightening. Going to a meeting about your children, that you don't know what to say because you don't know what they said last time. And as the time has gone on, the way of dealing with that is to choose your moment. And to say that you have a problem. And that way people can be more sympathetic. But you have to be selective about it. I wouldn't say it ordinarily. Unless I felt people needed to know.

But you have a very two dimensional world you know. Because everybody else has a very rounded world. They've got a present, a future and a past. I've only got the present and the future. And a lot of past has gone. So it's terribly two dimensional. And that's really a strange feeling to have. Everybody else has this rounded world, and you don't.

**Researcher:** How do you think that affects your sense of yourself as a person?

**Miranda:** I lost an enormous amount of confidence. I doubted everything. Everything that anybody said to me. I didn't want to contribute. I felt I couldn't contribute in any kind of intellectual discussion. I couldn't participate socially. Because my life was the here and now.

We always have a point of reference don't we. Well I didn't. And that's tremendously frightening, and very very lonely. And you just lose an enormous amount of confidence. You need somebody to say 'It's okay, you're doing alright'. Part of the angry feelings that I had when I was first ill, and in the year subsequently. Was because I was mourning a life that I'd had. That I couldn't get back. It really is like losing somebody. And I've had a lot of help. But I think counselling for that loss, would be very very helpful. Would have been very very helpful. And also counselling for the family. Because my husband lost part of his wife. And he's felt very very angry about that too. But he's not been able to express it. Or had the support network there to help that, help him overcome that. Yes. It's like someone's died in the family.

**Researcher:** And is anger still a feature of life for you? Or have things changed in that way?

**Miranda:** It can be. There is.. my husband used to employ this strategy of trying to make me work for every memory. By never telling me the answer. Never being straight with me. By always setting cues so that he could draw the memory out. And the thing is, I've moved on from that. I don't need that anymore. But I did then. But he still does it. And it really annoys me. And I get really angry about that now. So yes, I guess that's a feature.

**Researcher:** Is there any other things that strike you that have been particularly unhelpful to making the kind of progress that you want to?

**Miranda:** I think trying to do things too quickly. Immediately after I was ill, we'd got this plan to go climbing in the Alps. And I was ill in the early part of the summer and we were due to go climbing in the Alps at the end of the summer. And for some reason I just decided that I had to go. Because it was going to.. I wasn't going to let it get to me. And I jumped too quickly. I should not have gone. I wasn't ready to go. So I guess very early on, I had to learn that I can't do things too quickly. I've got to be very realistic. And sometimes I don't like being that realistic. I am much more ambitious than that.

**Researcher:** So it's about finding the right goals and sometimes accepting that you might have to take several steps, before you get to them.

**Miranda:** Yes. I have limitations. I am worried now. Well worried is not the wrong word. I am thinking about doing another teaching qualification. And in the back of my mind. I am much more realistic about my difficulties now. But in the back of my mind I am thinking its exam based. How realistic is for me to take an exam, where I do have to remember. I have always taken the approach that I've got to be really positive about my problem. And I won't let it stop me doing anything. And so I've set myself goals and targets to achieve, over the last five years. And I complete one, I think of what I can do next. And so my life has moved on based around those targets. So I suppose it started with being able to cook properly. And it moved on to being able to climb again, in the mountains. And so every step of the way I've had something from the mundane to the more serious. And I retrained two years ago, to teach English as a foreign language. And that's been an enormous achievement for me. And I have found something that I really enjoy doing.

**Researcher:** Yes. I remember that when you went to work in the shop, you were having to start to grapple with a computerised system there. And that was a challenge.

**Miranda:** Oh it was a nightmare. Yes. It was terrible. I had no. My memory wasn't as good then as it is now. Once I lost the fear of using a new tool, I suddenly realised that it could actually offer me an awful lot. But it's another goal, that I set myself that I was going to learn to use the computer. Because it was going to help me enormously, with whatever I was going to do in the future. No computer, very difficult to move into the world of work today. I find Email has been very very beneficial to me. Because I am obviously bad at remembering to turn up to things. And if somebody Emails me, I am much more likely to remember.

**Researcher:** What do you think is the biggest impact if you like, the biggest area of your life that's affected the biggest difficulty?

**Miranda:** Being able to move on. And it's like going through that mourning process, and suddenly like waking up one day and thinking 'I'm okay. I'm here. I'm fine. I can move on now.' But that's quite hard to do. Because it's taken me a number of years to come round to that in a way. To put it all behind me. And to sort out the practical side, and the emotional side of losing your memory. They have done a lot of testing, to see where they thought the damage was. And then the scan proved that the damage was in the place they thought it was. And I have to say that was enormously reassuring. Because I just realised that it wasn't me. That what I said I'd found difficult, really I did find difficult. Like a weight off your mind really. To realise that yes. I really feel I've put a lot of my problems behind me. I'm certainly not angry about it anymore. I don't think I am. I can be. Because I now know that there's a reason behind it. And it's like a security in a way. Every so often I think to myself 'Gosh I couldn't have done this last year.' Or I couldn't have done this six months ago. In fact I'm still improving to be honest. I found myself teaching certain things at school, and thinking 'my god, a year ago I couldn't have done that.' And that's incredible. That's a big step.