

## Answer Project

### Interview with Alison Melia (39 yrs - spina bifida)

**Interviewer:** Can you describe who you live with and who's in your family?

**Alison:** Right, I've been married for 15 years to Michael and I have a nine year old son, Joseph.

**Interviewer:** And can you describe what your physical difficulties are?

**Alison:** Well, with spina bifida, probably the biggest problem for me on a day to day basis is mobility. I use a wheelchair for work and outside. I can walk a little bit but I find that what tends to happen is that my feet tend to degenerate. I get ulcers and they're an ongoing problem. They have been since my late teens. So using a wheelchair means that I can keep off them for a certain amount during the day and make the most of being able to walk when that's opportune. For example, if I go out to a restaurant or something I might choose to get a taxi there and not take the wheelchair because it's only just a short walking distance at the time. Besides that, I have problems with incontinence. I had many, many years of trying to deal with bladder problems and that was actually resolved about three years ago, followed a colpo-suspension and self-catheterisation. The operation had been done in my early twenties, but wasn't as successful as the one that I had re-done about three or four years ago following pregnancy and that's been absolutely wonderful. I'm drier than I ever have been for the first time in 30 years. I was 36 years I suppose at the time. A slight problem was that following that I had other technical problems with prolapse of the bowel and the vaginal wall and that sort of thing. They were put right last year and since then I have had extreme problems with my bowel just seizing up and it doesn't want to do anything, so I might just see what happens as a result of that. I've got appointments for that over the next couple of weeks.

**Interviewer:** So do you have faecal incontinence as well?

**Alison:** The exact opposite. I'm finding I have to take massive amounts of laxatives, the bowel is just sort of, there's no activity, it just really, really has just sort of reached a point where over a space of 10 / 14 days I'll just bloat up and bloat up and bloat up until a massive amount of laxatives and manual evacuation will eventually start to get things moving again. So it's kind of ruining my life at the moment. It was never a problem before. I always stuck to a high fibre diet for most of my life. It seems to have been since following the surgery last summer that at some point, whether or not there has been a bit of interference with nerves or something - I had a uterosacralpexy so they've gone right through to the back of the spine to support all the internal bits and pieces and whether or not something's happened there or whether it's adhesions or what I don't know. I've been having various diagnostic investigations for that. That is my biggest problem at the moment. Hopefully it is going to be resolved. I've had a lot of scans and tests over the last couple

of months and I'm going to see a surgeon on Thursday so I'll wait to see what he's got to say about it. If that's resolved, then I would say there aren't any problems and life just goes on. But at the moment that's being a bit of a problem in that if I want to go away for a few days I'm having to make sure I take a day off work, take laxatives the day before and spend the day in the house and then go out. You know, if I want to have a couple of days away and not being ruled by it. The other side is of course that after about four to five days if there is no movement you start to get severe headaches, I can break out in spots, I get very bloated, irritable and by seven or eight days I actually just take to my bed for a day or two. I find I can't actually move around much because I just haven't got the energy and it must be a build up of toxins and that sort of thing. I don't know the technical side of it. It's not pleasant at all and it's only been this last 12 months and I am desperate to get that resolved. Other than that, all the other things like the mobility and the bladder problems, they just tick over fine and everything's sort of wonderful.

**Interviewer:** Can you describe where the paralysis is?

**Alison:** It's quite uneven actually. There's one or two people tried to identify it medically over the years. The lesion probably covers about three of the lumbar vertebrae. I have no sensation in the buttocks and the outside of my legs at all. I have no sensation from the knee down on the left hand side, but I do have sensation up the inside of the left thigh, but I have some sensation on the instep of my right foot, up over the right knee and then right up the inside of my right thigh, which is why I can feel if my bladder or bowels are full. I just don't have the ability to actually do anything about it.

Muscles tend to work in pairs and that's fine, but one lot of mine are working and the other lot aren't. You know, it's sort of one set with responses and one set without. It causes problems in terms of I've done daft things like burning my bum, leaning against a radiator. I've had severe burns to my feet from putting them on a hot water-bottle because they've been very, very cold with the circulatory problems they do get cold and that stops ulcers healing up and I've done daft things like using those beanbag heater things and then it could take six months for a burn to heal because of the slow response of the skin. I'm getting better at that sort of thing. You learn.

**Interviewer:** Do you use callipers or other aids?

**Alison:** I don't use callipers, I've never had callipers. I use one stick, although I really need sort of support on two sides, I tend to use one stick and whatever's available to hold onto. More than a few yards is a problem, simply because my back twists and as I say my feet start to sheer, so I can walk in bare feet without too much difficulty, obviously that's just not an option outside the house so rather than lose the mobility I do tend to walk round the house most of the time, but I always need support with furniture, or a stick or something, otherwise I just literally fall over. I don't have the tripod effect, you always need three points in contact with the ground. All the weight's on my heels, so I've only ever really got two points in contact with the ground at any point, so it's just there isn't the stability.

**Interviewer:** How independent are you?

**Alison:** I would say I'm probably very independent. I've travelled abroad on my own. I regularly fly down to London for business meetings or travel by train. I work for the civil service. I'm a middle manager. So it's a fairly responsible job with a half a million pound budget, and 40 staff and I manage fraud and security. So it's quite a responsible job, but it does take me out and about quite a bit and it's a question really of you get on with it and you just get on, I treat work as important, because it's the means to all my other things that I do, in my off time, and I do tend to be out and about. I have a lot of different sort of hobbies and activities and I work with a few different charities and do various things, so the independence is important to me. Firstly, from the work point of view, in earning a living, and secondly from the point of view of being able to go out and do the things I enjoy doing.

**Interviewer:** So what about bringing up a child?

**Alison:** That's been fun from the start. Pregnancy I knew was an option but I also knew that because of the internal problems I'd had - I'd already had to have the uterus supported because the pelvic floor was very weak and everything was causing problems with my bladder in my early twenties. I knew that a) I was going to have a caesarean section - I also have spinal curvature which means that the pelvis was slightly out of tilt so it was going to be an elective caesarean and I knew that there was a chance that the pregnancy might undo the surgery I'd had, which it did, so it was probably going to be a one off option, so it was fairly well planned in as much as that I didn't get pregnant until I was of twenty nine, timed it according to what I wanted to do, made sure I'd been out and travelled a bit and knew that there were a lot of risks around it. I had been told that there were some possibilities of the spina bifida being passed on, but we weren't sure about that. I had a wonderful, wonderful consultant who took a very practical approach to things and said, "well, you know, right, this is what we've got to do, but other than that, this is a normal pregnancy. You will be treated normally. The only thing I don't want you to do is ever go in to labour. Just make sure that if there's any twinge of it that you're on the phone straight away and arrive at the hospital before labour starts." Other than that, he was wonderful. I did have the usual pregnancy things, like anaemia and slipped a couple of discs, which was probably inevitable. With regard to passing it on, I said I wanted the AFP test to find out whether or not I had and he said, "well my dear you've already told me that you wouldn't terminate the pregnancy." Yes, I wouldn't, but I would also like to know about the practicalities. I'm not going to start potty training if my child may be born paraplegic, you know, there are other things I will do and have a different approach to it. They came back saying that it was negative for spina bifida but very high risk of Downs Syndrome, which was probably more due to my age really wasn't it.

I got the results around the same time that I had had a show and possible miscarriage, which started at work one day. But we had just come back from a week's holiday and we'd had the roof taken off the house because we were in the middle of renovating the cottage. It was all a little bit fraught and it was

probably more to do with just the general stress of day to day living as well. I think pregnancy went fairly smoothly. They found the baby was lying diagonally for about the last couple of months, in as much as with the spinal curvature there wasn't a lot of room there and by the time they delivered him it really was time to deliver. As for the practicalities, the biggest thing for me was how was I going to lift him in and out of a cot when he was born and this really worried me through pregnancy, I kept thinking I can't see how I'm going to carry this, physically, once he's actually delivered. I had support from my GP on this sort of thing as well. She was wonderful and we managed really well when it actually happened. I found a cot with a completely drop down side, where the side dropped down and swung away under the bed, which made it easy for me if I'm sitting in the wheelchair, to lift the baby on to my knee. I improvised a device I found in a catalogue for high chairs which was a sort of a strap seat and found I could actually fit it onto my knee and a friend has since actually managed to get that manufactured as a baby carrying device for a wheelchair user. I had a little old fashioned polystyrene type car seat, they used to call them nest eggs, with a strap, and I used to put him in that and just drag him round the house, and instead of a baby bath, we had a bidet installed which meant I could actually fill it as a small bath and sit him in that and I used that until he was about two and would no longer fit in it, so I didn't have to lift a baby bath and empty a baby bath. I could just fill the bidet and bath him in that, and it was at the right height for me, without having to lean over an adult size bath which I physically couldn't have done. It was really about adapting and just generally getting to grips with it. Unfortunately, he was a horrendous baby in terms of sleeping, he just didn't, but that's normal I think for some of them. In terms of the actual practicalities, he very quickly learnt that mum didn't carry him. Physically once he got to the crawling round and toddling stage, if I was in the wheelchair he would ask to sit on my knee, but if I wasn't in the wheelchair he didn't. He just would toddle along beside me or he would sit in his buggy and ask to be pushed, and because I could walk a little bit I found that pushing a buggy wasn't too bad because it steadied me and I could use it a bit like a zimmer frame. I made a point of getting a very old, heavy, silver cross pushchair which was sturdy enough for me to actually lean on without it tipping and that worked really really well as well. It meant I could take him out and go a couple of hundred yards up the street and back again with him until he fell asleep and that sort of thing. Round the house, once he got too heavy to drag around in the nest egg, I bought an old MacLaren Baby Buggy, one of the little lightweight ones and I would literally put him in that, wrapped in a towel and then push him through to the bedroom, put him in to his cot, or on to the changing mat, put him back into the MacLaren Buggy and push him through to another room. So it was about improvisation and that sort of thing. He very quickly learnt my limitations. I remember he was about three years old and I fell in the kitchen and had hurt myself quite badly and he appeared beside me with an empty tea cup, saying "mum having a cup of tea and you'll be fine." And then he'd realised I'd cut my arm. I was still lying on the floor because I had hit my back - where the nerves are just below the skin it can actually leave me quite unsteady for up to an hour. It can just leave me totally paralysed from the waist down for about half an hour to an hour and I just have to sit there until it eases off and he came back with a first aid kit saying, "you're bleeding".And

similarly when he was about five I actually fell very badly in the kitchen and had knocked myself out a bit, and he tried but he couldn't reach the telephone, so he went out in the dark and knocked on the neighbour's door and came back. And then when she came down I was sitting up and he looked at her, she's a doctor, and he said "should I get mum's wheelchair? should I get a blanket because she's shivering?" and, so, he's taken a practical sort of approach to things. Now he leaves me to my own devices. He's nine. He's independent in his own right.

**Interviewer:** So what was it like for you growing up as a child?

**Alison:** I think I probably knew that I had differences. We lived out in quite a rural area out in Sussex at the time. I didn't go to school until I was about 7., My parents arranged home tuition. I know they had quite a fight, because at the time there was a tendency to, if it was a severe disability the child should go into some sort of institutional care, and my parents refused that. They had run ins with medical people I know over things like the decision that used to be taken just to automatically do an ileostomy and my father was very, very reluctant to have any major sort of surgery done because he kept saying that things are changing – there are other advances coming that may be better, and so he was reluctant to have some surgery done, other than what had to be done. I think a big problem I know for my parents was they were actually members of the Spina Bifida Association because a friend's child had it and yet my mother didn't know until I was three that Spina Bifida was my diagnosis. When she said to a health visitor, 'I can't understand why I'm not managing to potty train her' and the health visitor said, 'what do you expect with a child with spina bifida', and my mother said, 'what are you talking about?'. They hadn't actually told her. I'd had the myelomeningocele removed, or partially removed but they had never actually given them a diagnosis and told them what it was, so they didn't know how to deal with it and I think that information would have made a big difference to their approach to things perhaps at an earlier age if more information had been available.

As a child myself, I was bullied. Mostly the fact that I was still in incontinence pads and things weren't quite as refined as they are now. And that was probably the case up until I was 9 or 10 and started expressing my bladder myself on a timed basis and learned to cope with things and then I actually went to school. I think I went to school when I was 7 ½, but it was still a question of my mum coming along to school to deal with me three or four times a day. We moved up to the north east when I was 9 and that was the first time I went into a mainstream primary school and by then I was managing things myself, and I found it quite different actually. There was maybe a different sort of attitude to it. I went to a standard comprehensive, did my O-Levels and my A-Levels and went to work for Lloyds Bank. So I would say through the first part, I mean I had odd bits of surgery on my feet and on my bladder until about the age of nine and then I had quite a gap and at 14 I needed more surgery on my feet, but just minor, but it was when I actually reached 17 / 18 and started getting severe ulcers. A lot of it was because I had started work and was initially on my feet all day. It hadn't occurred to me

that it would damage my feet and I didn't realise that what I needed to do about it was actually keep off them and that took quite a bit before I actually got the balance right. It probably took me four or five years. I was always inclined to just lead a normal life. I mean even when I started work I used to cycle to work every day, it didn't occur to me to have driving lessons at first. I just got on a pushbike and cycled to work, but I was actually probably being too active and not getting the balance right. I started work two weeks after I left school and have been in work ever since. It's only in the last three years again when I have actually needed major spells off work for surgery. It's quite nice to get this far, I've got to 37 / 38 before I had major problems and we know that the major problems are really following the pregnancy, but I wouldn't change that, I'd still go through it.

**Interviewer:** Did you suffer any discrimination?

**Alison:** I did have discrimination in my first job. When I started saying - "look I'm having problems being on my feet and it's starting to cause ulcers and I'm going to need time off work" or "I'm going to need to use a wheelchair", - they gave me more of a backroom job but then didn't let me advance up through the grades for the training because they said 'oh well we'd better not put you on the counter and front facing', and there was a little bit of a reluctance to let me serve staff and be in the public eye, which is a total difference to what I have now where I've dealt with everything from ministers through to the customers on any level and nobody queries it in my current job. But I did find when I worked in the bank that there was a bit of a reluctance to have me in front line customer service. My reaction to that was that I worked for them for four years and then started looking for alternative jobs. I made a point of going out and getting my driving licence and seeing what else I could do. I had done some evening classes and some extra A-Levels and qualifications and decided that a life change was probably appropriate, so I went to work at the Civil Service in the Overseas Division, because I had a few languages and I still work in that unit, but within a different capacity. There is absolutely no discrimination in the job I have now whatsoever, and it's almost at the point now that I find it quite amusing if I'm on the second floor and everybody's going out and most people use the stairs, they hold the door to the stairs open for me and I say, 'well excuse me if you don't mind I'll take the lift', and they don't see the wheelchair, and that is a big difference. You know when they booked the Christmas Party and it's up three flights of stairs that they've forgotten that you're in a wheelchair, that's when you feel like you've actually you've cracked it.

**Interviewer:** So you don't have a problem with people staring at you?

**Alison:** I have very odd problems with people when I'm out. If I walk I get stared at. I have actually had stones thrown at me walking down the street when I was younger, and I have been followed by youths with knives. Fortunately I rang my father and said 'can you meet me off this train'. I don't get that when I'm in a wheelchair. I get a different attitude entirely in the wheelchair. I do find perhaps because I'm young and I'm usually in a suit or whatever, I can pull into a disabled bay and have abuse hurled at me for

parking in the disabled bay. And you have to look at them and say 'excuse me are you going to give me a hand to get this wheelchair out?' and then they'll sort of 'ah', - there's a second take on it. And yet you can get a totally different attitude, - go out on the motorbike and I have my wheelchair in the side car and there's a sort of stunned silence, a) that I'm a female, b) that I've got a wheelchair and I'm riding a 1200 cc motorbike and that's a different attitude entirely, you know, There's a sort of stunned disbelief that you're doing this sort of thing. And that's quite pleasant, because people just look and say, well I didn't know that those sort of things existed and that you could do that. I have had comments around the fact that people like that shouldn't be allowed to wear make up. I have had certainly comments 'people like that shouldn't be allowed to get pregnant', But it's different people's attitudes and you can face it down. I've had the odd instance going back to the disabled bit where I've just burst into tears, but it's been an off day and I've just thought I really don't need to put up with this. It's their problem, it's other people's problem, the discrimination. It's not my problem and I just have to say that to myself and say, right that's their attitude to life. I find certainly with having a child that I get a really good attitude from the kids that he interfaces with. I've had children come in here, wander round the bungalow and say, where are your stairs? My son said 'I don't think we could afford any, we don't have them'. But then he went to a friend's house and they were getting an extension built. This child had said to his parents, "that's excellent now that we're going to have a downstairs toilet because when Joe's mum comes she'll be able to use it." And he was seeing it from a different aspect from his parents. His parents were building a utility room, he said, "yes but Joe's mum can use it now." It's different things. Certainly the same with younger children. Children will say to me, 'why do you walk like that?', or 'why are you in that chair?'. A child yesterday - I was up a flight of steps, my husband had carried the wheelchair up and I had climbed up and sat in it and a child came down, just looked at me and said, 'how did you get up here?' I just looked at him 'I haven't learnt to fly yet'. That sort of thing is fine, I can deal with that. I find it difficult when it's adults because I tend to think, "yes, but for the grace of God you could walk out in front of a bus tomorrow and be in a wheelchair yourself." But most people don't see that.

**Interviewer:** What would you say to prospective parents who'd been screened and were trying to make a decision about whether to go ahead with a spina bifida pregnancy?

**Alison:** I would say I know if the lesion is higher there can be more problems. I haven't had any problem with hydrocephalus, I've been lucky like that. I would say go ahead with it. I've had one heck of a life, you know, I mean I fly aircraft, I ski, I've skied in many countries. I've skied the World Cup run in Italy in a sit-ski. I've got a wonderful son who skis with me and does most of the other activities with me. I get out on a motorbike, I hold down a full time job in a responsible position. I've got an excellent husband who's athletic and he's sort of sports mad, you would think we're a total contrast, well we are, but that's the way couples are. I would just say you've really got to give a child a chance because there is absolutely nothing that you can't do. It's about making the adaptations and about just changing your perspective of how

things will be achieved and the rate at which things will be achieved, things might happen a little more slowly. But go for it, it's not a disaster to have a child with spina bifida.