Thalidomide: Simone Baker (2012)

Ruth Blue interviews Simone Baker for the *Thalidomide: An Oral History* project.



This is Ruth Blue interviewing Simone Baker on the 6 July at her home in Reading for Thalidomide: An Oral History project.

Simone, this is the follow-up interview to our earlier longer interviews and I'd like to start by asking you if you've got anything you've thought of that you'd like to add to what we were discussing previously?

Just that I went to see my mum last week and I was talking to her about the fact that I was doing this interview and some of the things that you'd asked me about that I didn't know or I wasn't clear about and some of the things she remembered was that ... well, she wasn't clear about them particularly either. But she did think that she'd been given thalidomide for something else before she was pregnant with me. But she couldn't remember what she took them for. She seemed to think it was either not being able to sleep or being anxious. And she said that once she'd had me and she was questioning with the doctor who she said was really, really horrible and quite abrupt with her, telling her not to frighten the other parents, she'd sent my dad home to empty out the medicine cabinet and bring everything back that was in there that she possibly would have taken when she was pregnant because she wanted to have them analysed at the hospital. And I don't know whether she did have them analysed but definitely she would have known that she'd taken thalidomide at that point. And she said there weren't many tablets left in the bottle so I'm guessing she would have taken quite a few of them. Whether or not it was before she was pregnant with me or when she was pregnant with me. I don't know.

But it was just that really. I didn't ask her about any of the other things that I wasn't clear about.

Just following on from that, it just struck me that something I didn't ask you before is did you at any point go through an assessment process with the Thalidomide Trust to assess your level of disability?

Yes. I can remember that because I can remember not really understanding what was happening or why we were going but thinking of it as a bit like the Mary Marlborough Centre. That's how I kind of saw the place that we were. And I don't remember if it was a hospital or what sort of environment it was in. But I can remember being in a room with a desk and some men, one or two men, and I can remember that I was there with my mum and dad and my two sisters were allowed to go and play outside. And they had one of those great big Woman in the Shoe type Wendy house and I just wanted to be out there with my sisters playing. I just couldn't understand why I wasn't allowed to be and why I had to be in this room with my mum and my dad. And I can remember them asking me lots of questions and asking my mum and dad lots of questions about me and me sort of thinking, "I can't be bothered with all of this. I want to go and play. I want to be outside." It was a nice sunny day. So I don't remember any details about it, I can just remember, you know, it like that.

Do you think that shoe was ... I don't know if you saw the photograph in the conference exhibition, there was a sort of a shoe house with children playing around it. It would have been in the grounds of Chailey Heritage. Do you think that could have been the same shoe house?

Yes. Well, I mean Chailey isn't that far away and I'm guessing we all were taken somewhere to see people who knew about thalidomide and knew about the damages. I've got the transcript of that I know from the Trust, the interview that was held with my parents about their aspirations for me. And, you know, their analysis of my disabilities which was written quite matter of factly and it was quite interesting in that my parents' aspirations for me were really quite high. Like, you know, my dad and mum thought there was no reason why I shouldn't go to university and they didn't think there was any reason why I couldn't get a

job. And my dad was asked, "Well, what sort of job do you think she can do?" And he said, "Well, I think she could do something with computers" which, when you think that was 1969, computers were kind of not really known about at that time. And the doctors sort of ... it's written quite bluntly but basically, "Her mum and dad have got ridiculous aspirations for her and they don't seem to have any clue that she's not going to realise any of them. She's not likely to get married and she's not likely to have a family and she's not likely to go to university." And obviously that wasn't said to my parents but it was written in the report.

But someone has said to me that perhaps it was in the interest of me and my parents that the aspirations, you know ... to help with the compensation levels, we were made to look less able to get on in life than we actually turned out to be able to get on. But that meant ... we still didn't get enough money to live on so there you go.

I think, from what you were saying earlier about the fact that your parents transferred you from special school to mainstream school shows that they kept that level of aspiration for you going, didn't they?

Yes and the fact that my dad was looking at other places for me to go. I guess that if I hadn't been getting on at secondary school because they hadn't included me or I'd been struggling, then, you know, he was looking at alternatives for me, perhaps.

So we ended last time talking about the period of time when your daughter was small. Can you sum up a little bit about what happened in your life after that and your relationship since then?

Okay. Well, I just remember, you know, being probably at my happiest when Lois was little and just being a mum. When she was just totally reliant on me for everything really. It's just a nest-building thing, I suppose, when there's this little helpless baby and you are responsible for their every need, whether it be changing a nappy, making meals. I can remember sitting, making lots of little meals for her and freezing them in little ice trays and going and buying little nice pieces of fillet stake and pieces of fish and finding that really satisfying that I was doing all these things that were the best things I could do for her. I don't think she ever really suffered as a result of me being disabled in terms of me being able to do things with her. Obviously there were lots of things that I couldn't do with her that many people would do with their children and I talked about the sort of Tumble Tots incident.

But I tried to do the sort of things with her ... so, you know, she went to pre-school. Again, I had to do quite a lot of homework around making sure that the place I took her to was accessible to me because a lot of places have got handles that are high, out of children's reaches, but that also meant that I couldn't reach them either. And going to primary school for her, she actually got a place at the primary school I went to as a child which was lovely because I just felt like it was meant to be somehow because I had very happy memories of that school and when she went there, you know, I felt comfortable with the environment of the school. I'd gone to look at others because it wasn't her catchment area school and I didn't have high hopes of her getting a place there. A lot of the other schools were small Victorian schools which would have been very difficult for me to get her into and collect her from. And this school, when I went to look around, they said, "No, we've got a disabled parking space. We'll make sure it's left clear for you."

Changing times, hey?

Yes. And I can remember one of the places we'd gone to I think this head teacher had got a lollypop that he gave to her, or some sort of sweet, and at the primary school Whiteknights where she went, the head teacher had an apple on his desk, obviously for his lunch, and she was eyeing up this apple and I was thinking, "Oh my goodness, you know." I think she said, "I'm really hungry" and she was looking at this apple and expecting to be given this apple, you know, because that's what she associates going to schools with, getting some sort of a treat.

So really, you know, being a mum was quite a full time occupation. I'd given up full time work and I was working at home. She was going to the childminder a few mornings a week. I became aware that there wasn't a lot available for disabled people that were parents and I'd managed to find an organisation called Parent Ability that were part of the National Childbirth Trust, it was a small sub-committee, and I'd made contact with them and it just seemed like a couple of people who were very involved and doing all the work. And I was asked whether or not I'd like to join them as a committee member and I was ... this was at the sort of time where I was still quite flattered if somebody wanted me to be involved in things and I went up to a couple of their meetings and it was just around the time when they were talking about moving away from the NCT and doing something of their own because they were doing a lot of valuable work with disabled people who were parents. They weren't receiving a lot of acknowledgement for it. Because they were working under the auspices of the National Childbirth Trust they were having to ask permission to do certain things.

So they were talking about breaking away, they weren't getting as much funding because I think at that time the National Childbirth Trust were having their own funding problems. And they were kind of, you know, shall we or shan't we? They hadn't made any decisions and then I think not long after I became involved, they were told by the National Childbirth Trust that they would no longer be funded. So I think the decision was kind of, in effect, made for them. And I went off to a big meeting in Wales with a couple of other organisations, Parents Too, which is T double O with an exclamation mark. And another organisation called Parent Ability who were both charities, organisations working with disabled people who were parents but in different ways. And, through discussions that weekend and deciding what we wanted and where we wanted to go, we decided to amalgamate the existing organisations and create a new organisation. And I think we thought about names that weekend but we didn't come up with the final name but later on we did which was Disabled Parents Network.

So for the next ten years of my life, so from when Lois was about three I guess, until about 2010, I was very involved with this organisation. Basically it was creating the organisation and setting it up. I was a Trustee from the start.

Was that your main sort of full time work at that time when you say you were working from home?

Yes. No, I was working for the Thalidomide Society. The Thalidomide Society had just got a grant from the National Lottery's board to do ... I think it was three years funding to do, well, I don't know whether it had all come from the lotteries. But three years funding to do a bit questionnaire on ... asking thalidomide people about their quality of life. We got some funding from somewhere else to do a video about the lives of thalidomide people.

Is that Moving Forward?

Yes, Moving Forward. And so through the funding they were actually looking to take on a part time member of staff to assist with that. So I was a member of the Council of Management then but I applied

for the job because it was something I really wanted to do and I was interested in and it fitted in with being a mum and everything. And there was myself and another thalidomide person who applied for the job. But I kind of knew, out of the two of us, I was the more likely to get it because I was already involved with the Society. I'd had to resign as a Council of Management member to apply for the job. And I was successful in getting the job and so I was doing that from about 1996 because I can remember being pregnant when I was doing the interviews, to 2005.

So it was part time work and I was kind of working on a self employed basis so I was just being paid for the hours that I worked. And I really did enjoy that for a while, while there was some sort of meaty stuff that I could get my teeth into. But once the video project had come to an end then I felt I was just involved in general administration work which I didn't find as satisfying. I was still doing the Thalidomide Society newsletter, which was something that I did feel quite passionate about because it had kind of been me that had been the one behind having the idea that we should have a newsletter in the first place. And I'd created ... before I'd been a paid member of staff, I'd created this newsletter called The Independence which, when I was doing it a volunteer was one thing, but when I was doing it as volunteer it was one thing but doing it when I was paid was really nice because I could obviously give it a lot more time and effort and energy.

But around this time ... so Lois was, I'm trying to think, how old was she in 2002? In 2002 something happened which kind of really changed all of our lives really, the whole family's lives which was we'd gone on holiday to France for a week, we were going to drive over to France. We'd booked a caravan to stay in on a site in the West of France near La Rochelle. We got the ferry over there, we drove down. We found the caravan over there. It was a lovely caravan on a brand new little site with lots of children's activities and I think we got there on the Saturday or Sunday. And the following Tuesday ... so not even halfway into our holiday, we were coming back from the beach one day, we'd stopped to buy some eggs because we wanted some for breakfast the next morning and the shop we'd stopped at didn't have any eggs. So we talked about ... this is myself, my ex-husband and Lois in the back who was five then, we talked about going to another shop we knew, to try and find some eggs. We went back to this other shop and whilst John was inside the shop, buying these eggs, I'd turned the car around. So I'd basically done quite a few turns in the car in a very short space of time on this main road. And once he got back in the car we were sort of chatting away about the eggs ... they hadn't had any eggs, there was only one egg back at the caravan, "Oh don't worry. You can have the egg." Sort of general chit-chat.

Set off along this road and I can remember sort of seeing this car coming towards me and thinking, "Why is this car on my side of the road?" And suddenly the horrible realisation that I was on the wrong side of the road, the car wasn't on the wrong side of the road. I'd been driving on the left of the road and I should have been on the right of the road. So it was a fairly main road but it wasn't a busy road, thankfully and both of us ... the car coming towards us and myself, took avoiding action by going into the centre of the road. We both took the same path, so we were on a collision course, and we hit head on going probably ... I mean I think I braked, I don't really remember. But it was a massive impact. Airbag went off, dust everywhere. And I can just remember sitting there thinking, "Oh my God." And while I was sitting there trying to work out what had happened, and it was myself that was driving, what had happened, had I hurt myself. While all this was going through my mind, and it seemed like split seconds, but it probably wasn't, John jumped out of the car, his reactions were much more immediate. He jumped out of the car and said, "Get out of the car! Get out of the car! The car's going to catch on fire." And I can remember I just wasn't in a position to jump out of the car, I can just remember, you know, being flung forward and hitting the steering wheel. Not my face because I don't wear a seat belt which was really lucky but my chest ... either my chest had hit the steering wheel or more likely the airbag had hit my chest.

He jumped out the car, he ran around to the back of the car where Lois was sat behind me, opened her door, pulled her out and said to me, "Get out! Get out! The car's going to catch fire!" And just ran off down the road with Lois which I sort of laugh at now looking back, saying, "You just left me in the car." But

actually he did the right thing which was to get our daughter out of the car who was only five. And I don't think she was crying. I think she was probably in shock because she didn't know what was going on. And I was just left sitting in the car. And I knew that my ankle hurt, I knew that my leg hurt and with that a woman arrived at my door who'd obviously seen the accident. She pulled the door open and she said in French, "Come on lady, come on, get out of the car." And I said, "I can't. My leg, my leg!" I said it to her in French and she called these two men over, "Come and help this woman, come and help her, she's disabled!" But, you know, "She's hurt her leg." I don't know whether she thought I couldn't walk because I was disabled or whether she realised that I'd hurt my leg. And these two chaps arrived and sort of manhandled me out of the car which, because I haven't got long arms was very tricky because it was literally like for them to lift a bag of potatoes out of the car. A heavy bag of potatoes. I couldn't put my arms around their shoulders. So they each basically put an arm behind my back and took a leg each. So in the process of getting me out of the car I think I nearly had a few other injuries that I hadn't had to start off with.

They took me out of the car and I think they too were worried that the car could have caught on fire because there was a lot of sort of just dust from this airbag which we thought was smoke. They carried me off down the road and dumped me in this flowerbed, a bit unceremoniously but it was just basically by the side of the road and I looked at my ankle and I thought, "Oh ..." It didn't look broken. I didn't think my leg was broken, I just thought, "Oh, I've sprained my ankle." My ankle was swollen. I asked John to take my ankle bracelet off my ankle and I could see his hands were shaking and I was like, "Oh my God," you know, "What happened?" I was obviously in shock myself and I said to the woman, "My leg hurts. Can you get any ice?" I think I might have said that to her. And she went off and came back with these two lumps of ice in a paper serviette which obviously wasn't going to do very much.

Anyway, we all got out of it and the other driver got out of his car, his mouth was bleeding. And I can remember they called the Pompiers, the Fire Brigade. Basically this work's van turns up, that's what it looks like. And Lois and I were put into the back of that and I think John and the other driver went off in another vehicle. And Lois, she'd only got a swimming costume on. And I can remember as the ambulance doors were being closed, somebody came to the back of the doors and said, "Can we help you? We're staying at your campsite; we've just seen your car. Can we help in any way? What can we do?" And I was just kind of like, "Well, would you mind going to the campsite?" I think we were being treated in the back of the van, "Can you go to the campsite?" And I was talking very ... "If you go into the bedroom, the main bedroom, on the back of the door, you'll find sort of a pouch hanging up. It's got all of our passports in it and everything. Could you bring that here, please?" And I don't know why I thought I should have that. My E111 form, I was thinking we need to have that for when we get to the hospital. So I was thinking very logically. And I think they actually went back to the campsite and got back to us before the ambulance left with that document. Oh and I asked them to bring a jumper I think because none of us had clothes and it was getting sort of late evening, you know, and I'd just got a sleeveless top and a pair of shorts on and Lois was just in her swimming costume. And I didn't know what was in the car or whether it was safe to get it out of the car.

I had a long and bumpy ride to the hospital because I think they said they were going to take a short cut, which wasn't an ideal road but quicker. I got to the hospital where we were re-united with John. We were all together in one little room. It's not at all like health ... Accident and Emergency here. It was sort of a proper room rather than a room with a curtain. And the three of us were together in a room which was good because John didn't speak any French and I think also they recognised it was quite important that your child's with you etc. So we were all looked at, x-rayed, Lois had some quite sort of severe bruising to her shoulder and her hip where the seatbelt had, like, gone into her. John had ... where he'd put his arm out to brace himself for the impact ... and his leg; he'd injured his ankle. Sort of like twisted it. And his wrist. And I had a broken ankle which I was quite shocked about because it didn't look broken, you know. It just looked swollen. But they said, "No, you've got a broken leg."

And I had to have an operation on it and I was, like, "An operation? They don't do operations for broken legs and they just put, like, put it in plaster." So we all ended up in one room and it was quite late at night by now. And, as a result of ... I think I had to be transferred to another hospital for the operation on my leg because, you know, they tried to explain it to me that the doctor or the equipment they needed wasn't at this small hospital where we were. We'd have to go to another one.

And I spent the next week of my French holiday in hospital having to have an operation to fix a broken ankle. Lois and John were allowed to go home the following morning, or back to the caravan. But we were a ... they were a good distance away from the hospital and we had no transport, of course, because the car was written off. We didn't know it was written off then but we knew it was pretty badly damaged. So for the next week I was in hospital, basically, staying in touch with them on the phone because it was too far for them to get a taxi. It would have cost about ninety pounds return trip. And I said, "Don't worry. I'm fine where I am. Just try and let Lois enjoy the rest of the holiday. I'll use the money ... instead of you spending the money on taxis, I'm fine here. I don't need anything. Just stay there." And from a hospital bed I had to try and sort out getting us all home.

The caravan ... we'd only got until the end of the week but the holiday company were absolutely brilliant and just said, "Don't worry." I think the poor girl was an English girl who was in charge of sort of the holiday-makers was pretty traumatised as well knowing that one of the people she was supposed to be looking after was in a hospital as well. So she just basically found out what would happen. They said, "Don't worry, as long as you need the caravan for, you can stay there."

And did you have like a plaster cast?

Yes, I had the operation, I had a plaster cast. I was being well looked after in hospital but I didn't really ... I wasn't really taking any notice of my injuries. I was just busy working out how on earth we were going to get home with all our stuff. Because we had bicycles, we'd got a whole load of stuff that we'd taken with us – cool boxes, like you do, buckets and spades ...

And you'd had to give the car up?

The car was, you know, smashed up. John went and took some pictures of it and it was, you know ... I'm glad he took the pictures because I wouldn't have actually realised how severe the impact of the crash was if I hadn't seen those pictures. It was quite horrendous and, you know, people who have seen them since ... I've got a fireman friend who said, "You were lucky to get out of that, you know, not being funny but we quite often pull people out of accidents like that dead because the trauma of brain injury ..."

So I was having to negotiate with the insurance company. They were expecting John to pick up a hire car and drive home. There was no way he was going to do that. He'd never really driven in France, he hadn't been driving for many years, he'd been in quite a bad car accident. They were expecting him to take myself and my five year old daughter home to England and leave me there which he just mentally wouldn't have been able to do. So, after speaking to the insurance company, they asked whether he'd been injured and I said, "Well, he's hurt his ankle, he's hurt his wrist." They just said, "That's fine, that's all we need to know. He probably couldn't have a hire car anyway. He probably wouldn't be insured if they thought he was injured. We'll get you all home together" which was a huge relief. But then the next problem was we had to get the car home as well because although it was a write-off we couldn't leave it in France because we'd have to pay export duty on it or something.

So we had to ... anyway the insurance company were brilliant but lots of phone calls. It kept me very busy in hospital trying to work out how we were all going to get home. And then I started to think about myself, "Oh my God, how am I going to get home? How am I going to manage? I've got my leg in plaster. I won't be able to get up the stairs, I can't use crutches." I phoned my local GP I think ... yes, I phoned my GP and said, "This has happened. I don't know what you can do to help us but when we come home I'm going to need some help and I'm going to need a commode or something. I'm not going to be able to get upstairs to go to the toilet." And I got a phone call, while I was in my hospital bed, from social services saying, "Don't worry. We're going to get some care for you. We're going to get a commode. When are you coming home?"

Then the day arrived for me to come home and that was quite exciting because John and Lois turned up at the hospital and I'd not seen them for quite a few days. I'd been speaking French non-stop so I could hardly remember how to speak English. I'd learned lots of new French words like the word for bedpan and the word for x-ray and the word for injections and the word for pain and all sorts of words. And, interestingly enough, the word for ankle which ... I knew the word for every part of my body but I didn't know the word for ankle, which is chevilles I think now. And the day arrived and John and Lois were in the hospital room with me and the door opened and ... oh, they'd asked me what was our nearest airport. So I'd said, "Oh, Heathrow, I think." And they said, "Oh, is there one called Blackbushe near us?" And I went, "Oh, yes." It's a tiny little airfield near here but I thought they were just talking of regular planes, not small planes. But, of course, they were actually arranging for us to come home on a private plane. So the day arrived, they said, "Don't worry. There's going to be a medic with you. You're going to have your own medic who will fly all the way home with you." The door opened, this chap came in, "Hello, I'm David. I'm your medic." I'm doing another one of those voices. "I'm here to look after you, make sure everything is all right." I said, "You might find I speak French to you because I've been speaking French all week and I'm finding it really weird speaking English all of a sudden." He said, "Oh, don't worry about that. I can't speak a bloody word of the language."

And off we went in an ambulance to an airfield. And we were put in this little twin-engined plane with two pilots and I had to be lying down because I'd had this operation on my ankle. So whilst I felt quite well they were obviously worried about the risk of blood clots and things which is why they'd arranged for me to go on the private plane rather than try and take, you know, a regular passenger flight. They looked after us really, really well. When we were flying, they said, "Would you like lunch?" And I thought they were joking. We were on this little plane, where are they going to get lunch from? They got this little cool box; they pulled out sandwiches and drinks. We had a choice of sandwiches, really, really looked after well. We got back to Blackbushe airport and there was an ambulance on the tarmac waiting for me.

And then I suddenly thought, "Oh my goodness, we're going to turn up in an ambulance." And I'd phoned the neighbour we'd let know we were going to go away, to let them know we weren't going to be back when we said we would. And just as I'd been ringing them, John said, "Don't forget the lady next door has a heart condition, so don't frighten her." So I just said to her, "We've had an accident. Don't worry, we're all fine. The car's just a bit of a mess. We're going to be home a few days late." I thought, "They're going to see me being unloaded on a stretcher out of an ambulance, what will they think?

Anyway I got home and then I suppose everybody left, everybody went. The medics left, the ambulance driver went and there was just me and Lois and John on our own at home and I was like, "Oh my goodness," the reality just hit home then that I couldn't move around because I didn't have any crutches. My leg was in a plaster, I couldn't weight bear. We didn't have a toilet downstairs, how was I going to go to the toilet? The commode hadn't arrived. So I think ... I had to get John to get a bucked because I was pretty desperate to go to the loo at that point. And then about two or three hours later a commode was delivered from Social Services.

So the next few months and years were completely turned upside down because I was sleeping downstairs, Lois was still traumatised from the accident. She'd started to wet the bed at night; she obviously was still quite stressed by the whole thing. I couldn't take her to and from school; nobody offered any support with that. I think a few of the parents at school found out and offered to take her but that wasn't ... it was a very ad hoc thing and I recognised that she was going to need more than that because she was in shock herself and she was only five and it was a few weeks until the summer holiday so I just needed to sort a few things out for a few weeks. So I ended up ... I did have some agency care which wasn't ideal, it was half an hour in the morning and half an hour at lunchtime, just someone to make me a sandwich, get me washed, empty my commode. I just employed, privately, a carer to be here like nine hours a day who could take Lois to school, pick her up, wash me, give me breakfast and be here during the day.

How long was that for? How long did you have to have that set up for?

Well, it was months because probably my leg would have been in plaster for twelve or thirteen weeks. I couldn't drive and it was the school summer holidays and I didn't want to be here on my own with Lois because I couldn't get up and down the stairs. And if she got into trouble up the stairs I couldn't do anything about it. So basically we just carried on with the summer holidays and having this person here who could help me and who was quite young and Lois got on with her. And she had an open top car so I used to go to school with her to pick Lois up in this open top car, you know. It was quite ... it was making the most of the situation. A friend of mine let me borrow an electric wheelchair that could be taken to bits and so we had some way for me to get around. I carried on doing my work for the charity as best I could.

We had ... I think my leg healed up but even when I had the plaster off I was still in a lot of pain and I couldn't walk very well. They'd found me some old under the arm crutches that really looked like they'd come out of a skip. They looked like they were on their last legs but I didn't mind because it allowed me to get around a bit more safely. But I couldn't do anything. I was totally reliant on John to do a lot for me, I was still sleeping downstairs. The house just wasn't adapted at all. And I'm totally independent normally if I can get in a shower because I have a shower every day and wash myself. But without the ability to have a shower I actually can't reach to wash my body so I was totally reliant on someone to help me go to the toilet, to empty the commode, to wash me every morning, to make me food.

That must have felt quite difficult.

There wasn't a choice and it was difficult to start off with but you pretty soon get used to it. I mean it's very awful to have someone washing you, washing your private parts when that's something I've done ever since I was a child myself. Even worse when you've got to have a poo on a commode. It's horrible enough in hospital but at least you know it's a few days, you know. Having periods and things like this, it's really not nice. But you just learn to just ... you just can't be bothered about these things. There is no choice. There's no way that I could be without the help so there was no choice.

And do you think that had any long-term impacts on your family life, your husband and daughter?

Well, I think that, you know, John was completely in his element really. I think he quite enjoyed the fact that I was suddenly quite needy and he had a little role to play in running around and looking after me and looking after Lois. And definitely, you know, that's all you can concentrate on for however many months.

You're affected by it. It affects everything. My inability to drive, for example, put a lot of pressure on him, that he had to do all the running around and things ... I need to move my arm ... getting pins and needles. But also if it had been a straightforward broken leg then it would have been fine but it wasn't. It didn't recover. I had a lot of on-going pain; I had a lot of mobility issues. It became quite clear that I wasn't just going to be able to walk again.

I mean talking about my car ... my car was written off, the one that I'd had the accident in. So I didn't have a car, I needed to get a new car, that needed to be adapted. The house ... at the same time we had a leak in the middle of the kitchen floor that went on and on and on and on. So the whole ... I was sleeping in this room which was a dining room, with half a kitchen because we'd had to have a lot of furniture put into storage because half the house couldn't be used. So it was all going on and it seemed like when is this going to start to get better? It seemed to be getting worse and worse and worse. So that was in 2002.

By 2005, it became evident that I needed something sorted out with my ankle. And they were talking about fusing my ankle which I was ... they said it would stop the pain I was in. I'd already had another operation to take the metalwork out, to see whether that settled things down but it didn't. So they talked about fusing my ankle and I thought, "Are they just going to fuse it because they think I'm disabled and I don't need a good leg?" So I actually went up to Oxford to see a specialist and said, "Look, can you do anything else for my ankle? Can I have a joint replacement?" And he said, "No, one of your bones has moved out of position. There's not really enough space to get another ankle joint in. A fusion is your best option." So I reluctantly decided to go ahead with this option because they said, "Without it the pain is going to get worse and worse and you'll be in more and more pain."

So were you on very strong pain relief at that time to treat it?

No, because I can just deal with pain. But I mean it was fine as long as I wasn't walking on it but I wanted to be able to walk again and I didn't want to be walking and in pain. But it just basically was like a twisted ankle. It was very swollen and it was very painful to put any weight on. So in 2005, they took me into hospital and I had an ankle fusion which is actually worse than the original break because they basically have to go into your ankle, take all the cartilage out of your ankle joint and put a great load of screws through it to hold it into one position and so, you know, there's much more trauma to your ankle than with the original surgery. And, once again, I was off my feet, I was sleeping ... I don't think I'd ever ... yes, I must have gone back to sleeping upstairs but I had to come downstairs again, there still was no downstairs toilet. Back to using the commode again, back to needing carers to come and wash me again.

So that's a lot of years of this going on in the end.

Well, it's three years, yes.

Yes, but three years is quite a long time, especially in a child's life.

Yes, but my whole life really had changed. And I think that I'd realised that it wasn't going to go back to ever being exactly as it was. By that time I'd realised that a wheelchair was going to have to be a big part of my life. I'd had a hoist put into my new car so that I could ... it was just kind of like, "This is inconvenient but life has to go on." So I'd got this wheelchair and I'd got this hoist and I could still ... I could drive by then. I was independent again. Obviously then I had the reconstruction ... the fixation on my ankle. I

couldn't drive again. Just as we got it all sorted out, I think the leak in the house was sorted out by then. Everything had dried out. We'd got our furniture back so at least I had a room that wasn't shared with half the kitchen furniture.

And also in 2005, just after I'd had this ankle fusion, we'd made plans to have a downstairs bathroom put in so I was sharing the bathroom with all these builders. As I was recovering from all this surgery and dust and noise ... it was worth it just to get this downstairs toilet I realised. So as of that point, really, starting to have more formal care became inevitable because things just suddenly became a lot more difficult for me. The fusion of my ankle didn't actually resolve the pain problem, so I still was getting pain. They gave me a built up shoe and I kind of thought, "This is it now." I had the metal work taken out again in the hope that would resolve the pain, but I still was in pain. Not as much, certainly, as I'd been in before. I wasn't hobbling around but I couldn't walk great ... I couldn't walk very far.

And I wouldn't say it's as a result of the accident, but possibly what had happened is that, you know, we'd had a child, we'd ... I think couples just grow apart anyway during the process of having a family. And then we'd had this accident and whilst John ... whilst I'd had this accident ... that was something else that I suppose distracted us from our relationship as a couple. And certainly once things were back to normal, or as back to normal as they were going to be, things just weren't the same and things weren't right between us. John had always had sort of a bit of an anger issue. Not hitting me or anything like that but certainly losing his temper over nothing and shouting and being quite aggressive and moody which just isn't me. I don't like arguments and will just turn and walk away from them and just take myself off and away.

And certainly before the accident things had been happening. I'd had one day where he'd had a go at me and I just packed some stuff into a bag. He'd gone out somewhere and I packed some stuff into a bag and had taken Lois and I off to a hotel for two nights. And I didn't tell him where I was and I didn't answer my phone and I just thought, "Well, you know, I'll let you see what that kind of behaviour does." And I think my mum phoned me and she said, "John's just phoned me, is everything all right?" And I went, "Oh yes." She said, "He told me that you're not at home. And I said to him, well, you're not here. And I said to him, don't worry about her. Wherever she is, I'm sure she's fine." I think he told her that there had been an argument or something. And I just thought, "Well, I'm going to let him stew in it and I'm going to let him think about things." I mean I just really, you know, wanted to make him think about the result of his actions really. And I didn't have any plans about how long I wasn't going to come home for. I just thought, "Right, you know..." but I'd been quite ... the first hotel I stayed at I paid for in cash. I thought, "I don't want him to find out where I've gone. I might have to do this again."

And I don't think Lois really knew what was going on. She could have only been three at that time. So to her it was just an adventure, staying in a hotel. And he'd turned up at the pre-school, I had to go and do a stint at the pre-school. He turned up and I was washing up in the kitchen with one of the other mums and I saw this man walking towards me and his face looked really frightened and he said, "Where have you been? Where have you been?" And the other mum kind of realised something was afoot and made a quick exit and I just went ... he said, "Where have you been? When are you coming home?" And I said, "I'm coming later. Just go." And I think he just went. But the thing was he never really tried to address his anger. And each time I'd go, "You know, this can't go on." And he'd say, "I know." And I'd say, "What are you going to do about it?" And he'd say, "Well, I suppose I should get some help." But he never actually did go and get the help and I didn't like it, especially once there was a child on the scene. I don't like her to witness any anger or arguments.

Then much later on, it must have been about 2006, so the ankle fusion thing was done. I went off ... oh yes, that was it. I had a weekend away with some thalidomide friends and I was talking to one of them about how I wasn't happy and things weren't good. And she's one of these people who's very caring and she said, "Well, do you ever go out, just the two of you?" And I went, "No." And she said, "Maybe you

should. Maybe you should make an effort once a week to just go out just the two of you." And I said, "I don't want to. I don't want to go out with him." [Doorbell rings]. Can I ask you to answer the door?

Absolutely.

Just because you'll be quicker than me. It's a parcel probably.

All right. I know where I was. So I thought about it and I thought, "I really don't enjoy ... I wouldn't enjoy going out with him. We don't talk, what have we got to talk about? And I don't want to go out with him on my own. For a while ... we've got this child who's kind of, I suppose, come between us but maybe it was inevitable that if she hadn't arrived we would have just drifted apart anyway." So I said to him, "I think we ought to ... if you want this marriage to work, I think we need to get some help."

I mean something that had happened years before ... we'd only been married a year, was that he'd actually ... I mean it's another whole story actually. But we'd gone off to this international thalidomide gathering and been in the Netherlands and during the course of that holiday, we'd only been married a year and there was no child, he'd gone off with this other thalidomide woman. And I don't know the extent of what happened but I know something happened and it was really weird because whilst we were there something just ... it was like a message had been sent to me. It just suddenly hit me like, bam! And I thought, "Oh my God, this has been going on. I can't believe I didn't see it." I knew who the girl was and it was just like one night I said to him, "Right, are you going to come to bed now?" And he'd been sat at the bar talking to this girl who I'd been guite friendly with, she was a German girl." And I just thought, "Oh my God, something's happening between them." I don't know why - I'd not seen anything, nobody had said anything. It was like a message had been sent to me out of the blue and I went back and sat in the car outside the building where we were sleeping. It was like a big boarding school place. I sat in the car crying, thinking, "What am I going to do? What am I going to do?" I was trying to convince myself that I was over-reacting, that I hadn't seen anything and it was all in my imagination. Sat there in the dark and saw him walk past with her and he had his arm around her. And they were walking up to where I knew she was sleeping. And then I'd kind of thought; I've got to stop them. I went to the room where ... they were staying in a block where there were, like, lots of families with children and I just thought, "I'm just going to smash the fire alarm because they'll have to come out and they'll have to stop whatever they're doing." And then I thought, "I can't do that. There's children sleeping." So I drove back to the bar, found ...

It's quite a good idea though!

Yes, well as far as I was concerned I just had to stop it. I drove back to the bar, found a friend and said, "Look ..." I think he knew something was up. I said, "Quick, come with me." So there was him and another woman who both came with me. I drove ... it's quite a big campus we were on. I drove up to this place. They said to me, "You wait in the car, we're going in." So I just sat in the car and the next minute John turned up as white as a sheet with his top on back to front [laughs] and I just went ...

A bit of a give away ...

Yes. I just said something along the lines of, "You bastard." He was going, "Nothing happened, nothing happened." And we went back to our room where we'd been sleeping. We were in single beds, like it was boarding school. And I can remember him just falling asleep and lying there snoring and I was there

bawling my eyes out, thinking, "You bastard. How can you sleep? My life has just ended." And I just got up and I found another thalidomide friend, went and woke him up, and he went, "Oh my God, what on earth's wrong?" And he just went downstairs with me into the sitting room area, we drank lots of coffee, we talked, I did lots of crying. And I think the next day we were due to go home anyway and basically we just went home and on the way home I'd sort of decided ... I said, "Right, when we get home I'm going to phone up Lynne. I'm going to go and stay with her for a week. She's my best friend. You can stay at home. You can think about what you've done and I'm going to go and think about what I'm going to do. And I don't know what I'm going to do. I'm going to think about what I want to do."

And left him for a week and he kept phoning me up and saying, "How are you?" And I kept saying, "I'm fine," just not sharing anything really with him. I came home ...

Did he ever admit to what had happened or apologise?

No. And I didn't want to know. I didn't want to know the details because also, in my heart of hearts, I knew he was a liar. I knew he was a liar and I knew whatever he said I wouldn't really know whether or not he was telling me the truth. And I'd expect him to tell me the truth so I thought what's the point in asking? He lied about lots of little things, almost like childish lies. Lies that really didn't matter sometimes but I knew were lies. So when I got back home from my friends I said, "Right, I've decided what I'm going to do" and I hadn't given him any clues, he'd phoned me all the time while I was away. But I just thought, "No, you know, you just stew," which is what made me think about ... I came back and I said, "Right, I've decided." Well, actually, what I'd done was ... at my friend's was write a letter to this girl and say, "I thought you were my friend, you know, how dare you go off with my husband? How dare you? Just because you haven't got a man in your life doesn't mean to say you can take someone else's. You know, how dare you do that?" I poured out all my anger to her really. And I said, "I don't blame John at all for what happened. As far as I'm concerned, you were the one. He would never have ... he would have had to have some sign from you that you were interested."

Anyway, blow me down if I don't get a reply from this girl basically saying, "Well, actually your husband seems a very lonely man and, you know, I think he felt he could talk to me." And that made me even more angry, the fact that she was trying to defend what she'd done.

And say it was your fault somehow.

Yes. Almost saying that there was ... and yes, when I look back, she might have been quite right, you know ...

It's a bit of a "my wife doesn't understand me" scenario though, isn't it?

Maybe but lots of things I've found out since ... I don't think he was such a perfect person. For whatever reason, I don't think he could talk to me about his problems which caused problems between us because I've since learned that that's the most important thing really in a relationship. It doesn't matter how well you get on, you've got to talk and you've got to share things with each other.

So anyway I came back and I said to him, "I've decided what I'm going to do. If ..." I said, "You've had your chance," I said, "I'm going to give you one more chance and if I ever find out you've done anything

like this again, that's it. You've had your chance and you've got to live with the fact that I'm never going to forget about this. I'm never going to forget about it. And you've also got to think to yourself that I can do that now myself because he's done it." I said, "I won't. I don't plan to but you've got to live with that." So we just put it behind us and carried on. But we'd only been married a year. We had this fantastic wedding that, you know, was my dream wedding and I couldn't believe he'd done that to me after just a year of being married.

But, you know, now I look back I think it's easy to try and blame yourself but I really don't think ... I won't say I'm completely 100% innocent of not being the perfect ... you know, I wasn't the perfect wife. But also, you know, I would have tried to help him with any problems but he never told me if there was any problems in the relationship so how was I to know?

Well, you wouldn't, no.

So ... but there wasn't a lot of affection between us. But he was the first person I slept with; he was the first person I married. I didn't know what was, in effect, normal. I thought what we had was quite a normal relationship. It wasn't a particularly satisfying sexual relationship but it wasn't bad. He didn't hit me, he treated me well, he was kind, he was loving, he was a good dad to our child. And in my head I kept saying, "Well, he's ... what else do I want?" Because I didn't know anything different. I thought he was fine, you know. And he was good-looking, you know. That's why I was attracted to him in the first place, you know, at the age I was. He was a good-looking chap and he was hard-working, he had a job. His family liked me, he learned to drive ...

They're all perfectly valid reasons for being with somebody. But you talk about him now as your exhusband so what happened? How did the relationship end?

Well, we talked ... I had this conversation with my friend and she said, "If you think that's how bad it is, then really you need to get some sort of help, like go to Relate." And I went, "Yes, yes. I suppose you're right." And she said, "Yes. Go home today and phone them up and make an appointment." And I went, "Yes, yes. All right then." And she actually phoned me the next day and said, "Have you phoned Relate yet?" And I said, "No, not yet. I will." And I did do it; I thought she's caring about me.

So I phoned and made an appointment and they sent me a load of information and I read through all of that and it said ideally you should be seen as a couple. So I said to him, "I've arranged to go and see Relate and they said it's a good idea if you go with me too. You don't have to if you don't want to but I think if you want this relationship to last you have to think carefully about going with me." So he went, "I don't know when I'll go there. I'm really busy with work. I'm really busy with work." So I kept asking him and he kept saying, "Maybe we can go ..." they'd phone me up with an appointment and, "Oh yes, I'm really busy ..." and he kept putting it off and I had a holiday away with my mum and Lois. It was half term. I had this holiday away and all the way through I'm getting these calls from Relate with these appointments. And I was staying in an area where there wasn't mobile phone reception so I was picking up these messages and I couldn't phone them back because I was with my mum and she didn't know what was going on. I didn't tell her what was going on.

Got back home from this holiday and said, "Look John, I've had all these calls from Relate, what are we going to do because they keep offering me these appointments and I can't take any of them." And he said, "I've been thinking ... maybe it's better if I move out." And he just said it like that and I was like, "Oh, right, okay." And I wasn't upset. I was kind of like, "Wow, you've actually come forward with something concrete

that you want to do. You've actually admitted that something's not right." So part of me was quite relieved to hear that from him. And then I said, "Well, if that's what you want then, let's make that happen. Let's make it ... if you think that's what has to happen, then let's make it happen." And I'm never really quite sure whether or not he was saying that just to ... he said it lots of time before and he'd gone up and packed bags and the rest of it but he'd never gone. I was quite daring him to sometimes because I'd done it once but he never sort of ... "I'm going to go back home. I'm going to go back home to Liverpool." But he'd never gone.

So I said, "Well, let's do it then." And I actually realised that a huge weight was lifted from my mind and I thought, "Yes, this is what I want to happen." So within about two weeks I'd actually got estate agents round to value the house. I'd gone to see a solicitor and I think he actually was quite shocked at how quickly things started to happen. I'd said ... I think that was in October, in the October half term, and we'd got a holiday planned for December, away to Tenerife for two weeks, over Christmas and New Year. Was it that time? Well, it was over Christmas time. And I was ... I didn't want ... I decided that I wanted to tell Lois what was happening at Christmas time and until that time we would try and kind of pretend that we were getting on normally.

How old was Lois then?

She was nine. And I thought, "I want her to know when she's not got school the next day. When she's got a bit of time to digest things and she's with us both and we've got time to talk to her about it." So that's what happened and I think just before we went away on holiday I'd told ... I think I told my sisters and I told my mum. I didn't tell everybody. I had people working here so from their point of view, the people coming in to help me every other day, I wanted things to look normal because I didn't want to let on to Lois that things weren't normal.

So we went away on holiday and in the meantime I'd actually started already going online and looking at dating sites and chatting to people and thinking, you know, getting compliments and thinking, "I'm going to be okay. I'm quite looking forward to this." Not dreading it at all.

So off we went on our holiday and it was awful because we arrived at this place that was hot and sunny and wherever we looked there seemed to be couples in love and holding hands and little happy families and I just arrived and I realised I'd gone away from all my support networks. I just couldn't pick up the phone and chat to people. And, you know, we were in this perfect place, we'd got this lovely apartment and I was there with this bloke who I didn't love and my daughter whose life I was just about to rip apart. And he said, "When are we going to tell her?" And I said, "I don't know. We're not going to do it on this day or that day. We'll just do it when it feels right to do it."

And one morning she was just lying in bed and I said, "There's something I need to tell you, Lois." And she went, "What?" And I said, "Hang on a minute" and I called John. And I said, "Me and your dad are going to get divorced, we're going to split up." And she looked at me and said, "Oh, but you're joking, aren't you?" And I went, "No, Lois, we're not joking." And I saw her eyes fill up with water and it was like, "Oh, my God, this is awful." My daughter's life has just been ripped apart. And I didn't care at all about leaving John but I did care about spoiling her life. And it all seemed to be done in a place where we should be happy together and enjoying our holiday and I was absolutely hating being there. I didn't want to be there at all, I just wanted to be at home with my family, especially after I was doing this to her. And she started off just being angry and saying, "You're not thinking about me. You're just ruining my life." And I said, "No, actually we are thinking of you and that's why we're doing it. I don't want you to have to hear mummy and daddy shouting at each other and I just want you to be happy and I know you won't be happy whilst this is all happening but, you know, it's for the best."

And for the rest of that holiday, really, Lois and I were like a single family, a single parent family anyway. We got up, we had breakfast, we went to the beach, Lois and I. We left John at the apartment. He would come down and meet us at lunchtime, he'd have a sandwich with us on the beach and then he'd go off back to the apartment. So I don't know what he was doing there. But we were sort of kind of enjoying it. And then once we got home it was nice because it was kind of like, "Right, now we can actually come clean and let people know what's going on." So I told the people who were coming here to help me and John moved downstairs which was really nice to just get him out of the bedroom. And the way that the house is set up meant that Lois and I had the upstairs, a sort of girls' dormitory and John was downstairs and had his own bathroom. So the only time we sort of had to bump into one another was in the kitchen really.

And it was horrible because you're just like trying to avoid seeing one another and in the meantime I just went to the solicitor. I was like, "Right, what does John need?" I talked to the solicitor about the possibility of me keeping this house and how much I had to give John and how I would do that and I decided to basically re-mortgage the house to buy him out. And I worked out I could afford to do that and if it became a struggle. And basically I took on a nine hundred pound a month mortgage. It if became a struggle then there were ways I could get around it, I could take a lodger. But to move would have cost me more money and I'd have to start all over again trying to make a house suitable for me.

And, again, in the meantime I was going online and I was talking to people and that just made me feel ... it was quite nice talking to complete strangers about what I was going through and learning that other people were going through similar things. And one chap who I sort of really got on well with was a married bloke and I found that he could be quite objective. So I'd tell him about things that were going on in the house, on MSN Messenger or something. And I'd go, "I can't believe what he's done now. He's done this, he's done that." And he'd actually be quite defensive and say, "Well, look at the poor bloke. Look at what he's having to put up with." So sometimes he would kind of bring me to my senses quite a bit. But also he would be quite concerned if I was going through a bad time.

And I was chatting to all sorts of people and I realised that actually, all of a sudden, me being a disabled woman isn't a big issue any more, that actually people aren't bothered about me being a disabled woman when it comes to talking to me. So I'd be chatting to people and I'd say, "Oh, by the way, I need to tell you that I'm a disabled woman." They'd go, "What you telling me that for?" And I'd be, like, "Oh well, just because it's who I am, you know."

And I actually sort of met up with a few different people. I met up with somebody locally who was on one of these dating websites who said, "I'm actually ... I've met somebody on this website but if you want I'll meet you in town for a coffee." So I'm out with this chap and it was purely just coffee in town, you know, he was a nice chap to chat to and I thought, "It's all right, you know. People still think I'm an okay person." I kind of doubted it myself at that point, that I was ... you know, it wasn't all my fault and I was just awful. That's how I realised I'd been made to feel through the latter stages of the marriage. I was made to feel utterly unattractive, unwanted, worthless, fat, ugly, useless, all those things. And talking to people they'd say, "Oh, you seem really intelligent" or "You've got a lovely smile" or, "You've got really gorgeous eyes." And you're thinking, "Yes, yes, yes," you know, trying to flatter me. But after you've heard it from more than one person, the same kind of things, you start to believe it yourself – well actually, maybe they're telling me the truth.

And I can remember speaking to my best friend and saying, "It's really strange. Somebody said I was really intelligent. I'm not really intelligent." And she said, "Oh, you are. You're the most intelligent person I know." And I was, like, "I've known you for twenty years and you've never said that to me. How come you've never said that to me?" "I've always thought you were intelligent. Look at what you've done. You've done this, you've done that." And all of a sudden these compliments start flowing your way and people who were seeing me out and about were saying to me, "You look really well, have you lost weight?" And

I'd be going, "Oh, no, no, no." And they'd go, "What's going on in your life?" And I'd go, "I'm getting divorced." And they'd go, "Oh, you're getting divorced? Oh my God. How ... oh, I'm really sorry to hear that." I'd say, "Hang on a minute, you've just given me all these compliments and said how much better I'm looking and now you're, you know, you think it's a bad thing. I think it's a really good thing. I think it's what needs to happen."

So there was a very awful time when we had to live together under the same roof, which was basically between the December when we'd told everybody and the June, I think, when he eventually moved out. When we were living together, going through this divorce. He was buying things for this house that he hadn't even found. So the room was full of loads of stuff and it wasn't even cleaned because I wasn't getting anybody to clean it because it was his lair as far as I could see. We were bumping into each other and there were a couple of times when he ... the most awful thing he said was something along the lines of ... oh, that was it. Lois was on the stairs coming down and the thing is with John, and it always has been, is that he will say things and realise as soon as he's said them that he shouldn't have said them and you'll see that look on his face. And we were shouting about something and he put his face right in my face so that I could feel his breath on my face and he said, "I should never have married a cripple like you!" And I was just ... that in itself made me think, "I am so doing the right thing." And I just turned around and walked away from him. I thought, "I'm not answering that. I'm not answering that." There were so many things I could have said. I think I might have done, I think I might have said, "Well, at least my brain's all right, unlike yours" or something like that. But in front of Lois ...

Yes, yes. And to use the word cripple as well is ...

And the way it was done right in my face, it was very threatening. And, you know, as far as I'm concerned he never laid a finger on me but that kind of emotional and verbal abuse is equally as bad as thumping somebody.

I agree with you.

And I knew I'd done the right thing and I just couldn't wait for him to be gone out of the house. I really couldn't wait for it. It couldn't happen too quickly which is why when it came to sort of sorting out the finances, I just wanted to give him what he needed to be gone out of my life forever and for him never to have to come back and bother me again. So it was a very tough time but at the same time I was chatting to people online, I went out and met a few people, went on a few dates. I didn't even really ... I just was having to rebuild my self-confidence and make ... I mean, thankfully, I don't think it was too difficult to do that. I mean some people get to rock bottom and don't want to go out and I was sort of kind of like, "Wahay, well let the party begin. I'm going to get my life back. I want my life to be back as it was."

I mean I'd never given up my friends; I'd done a lot of things without him with Lois. I still stayed in touch with my friends. It was him that had lost touch with people.

And how many years did you do the sort of Internet dating thing? I know you've got a partner right now.

So it probably only went on ... like I said, I started chatting to people more or less as soon as I knew I was getting divorced. As soon as that decision was made, more or less the same day, it was, "Well, let's see what's going on out there in the world." I mean, you know, when I'd been single before there hadn't been

the Internet. Internet dating was like different and I suddenly realised that actually internet dating was fantastic because here people got to know you and it wasn't all based on your physical appearance and how you looked and I just seemed to have a way of making myself come across as being okay to people. People enjoyed talking to me. People enjoyed chatting to me.

I mean dating websites were a complete waste of time but I found this one called Flirtomatic which was basically a little online chat site and you could chat to one, two, three, ten people. And it wasn't a dating website and it wasn't anything else. It was just flirting with people. There were married people on there; there were single people of all ages on there. You could tell people as much or as little as you wanted to on there and through that I got chatting to different people who, I suppose, wanted different things. Some of them just wanted to talk dirty, some of them were obviously after more and ...

Did you come across any other disabled people on any of these sites that you were aware of?

Yes, there was somebody with achondroplasia. I didn't meet them. Another girl I was aware of who was disabled. And it started off as chatting and I can't kind of think where it moved into anything more of that. But with the married bloke I told you about, I did meet with him and that was my first ... I sort of got a bit infatuated just because he was giving me attention and was there for me and it suited me that he was kind of unavailable. But he was very intelligent and very articulate and that made me think, "Well, I must be okay because that's the sort of person that's talking to me." But I knew he was, basically, trying to cheat on his wife so I had no respect for him at all and that probably was quite good as well.

You weren't going to get attached.

No, exactly. But he was what I needed, he was my stepping stone into the big, wide world and he spoke sense to me, he made me be practical and sensible. I used to get quite cross with him if he disappeared off the face of the earth. And he used to say, "Hang on a minute, you know, excuse me, we're not an item or anything." But I think I just needed that emotional crutch and he was my emotional crutch at the time. And he would phone up and sort of ... we'd chat on the phone. We did meet but it was kind of ... it wasn't very great when we met. There was nothing attractive about him at all; he was a bald, middle aged, plumpish bloke. The only thing he had going for him was that he was quite funny to talk to. He was interested in me and he was intelligent. That was about it really and that he was unavailable to me. So with him it was just kind of kissing in the car kind of thing. But it still felt good; it was a good way to start, as it were, because it was like, for me, I haven't dated anyone for ages.

And it kind of went from there really, I got more and more into this whole Flirtomatic thing, meeting people, and I can't think how on earth it started really. It all just rollercoastered from there. But basically ... I'm not thinking of what not to say now. I'm trying to think of the order of things that happened. But quite quickly I just started meeting people for sex and the first time it happened I suppose it's a bit of a shock. I think it was a bloke off this Flirtomatic website who'd texted me one Sunday morning and said, "What are you doing today?" I think it was a bank holiday and I said, "Oh, nothing." And he said, "I'll come and see you. I'll be there in about an hour." And I was like, kind of ... I think because I'd just woken up and I didn't really have time to think about what I was doing and whether it was sensible or not, I just went, "Oh, okay then." And I think I ended up seeing him quite a few times. He drove up here from Portsmouth and we'd have sex and off he'd go again.

And there was something a bit addictive after a while with it. And there was somebody ... I don't know which website I met him on or how, was this twenty five year old who lived in Southampton. I was, like,

twenty five, that seems a bit young. But, you know ... and I think he came here to meet me and he lived with his mum down in Southampton. He'd been to university and he was working and he came here and stayed the night and I got on really well with him. And you don't think about age because he was very mature, very sensible, really kind of a nice caring person who actually, you know, washed up cups and things like this. And with him that sort of became a regular ... he became a regular visitor and we really, actually, enjoyed each other's company and the thing I think I discovered is if you see somebody more than once it's quite nice because you don't have to start all over again with all of that awkwardness.

One of the things he told me about was this girl that he'd been meeting off this other website which had a really awful name. I won't mention it. But the name of the website suggested it was something completely different to what it was. He said, "You should put a profile on there." I said, "Oh no, there's no way I'm going to put a profile on that, it's awful. How can you do that? How can you do that?" And he was, like, "Oh, go on. Put a profile on." And I think he put a profile on for me but no pictures or anything and he was going, "Oh, you've got all these people wanting to talk to you." And I was like, "Have I? Oh, oh!" And I suppose I was a bit intrigued by that, the fact that there was this sort of adult, no strings attached website which was very different to dating websites where there were all of these sad losers who really didn't have the personality to meet anybody and this was how they were having to do it. They write all these horrible things about them that you know is all a whole pack of lies and you've got to pay for it.

So on this website there was everything really. You create a little profile, so I created a little profile which I developed over time and I just started to meet people quite regularly and it did become a bit of a drug. And as to whether or not it made me feel better about myself I don't know but I just realised, with hindsight, it was what I needed to do. I'd missed out on this whole part of my adolescence of just meeting chaps and flirting and not having anything more to do with them, being able to do what I wanted to really and actually me being in control. That I wasn't having to feel that here was somebody who was being nice to me just because I was disabled. Okay, they might have just been interested in the sex but most of the people did seem to genuinely think I was an okay person. I'm sure they didn't all but I was always in control of who I saw and what I did with them and at no time did I ever feel that I was putting them in danger. Other people worried. I told my sisters about what I was doing and I told a few friends and they were really worried and said, "What are you doing?" You know. "Should you be doing this?"

Do you think any of the people you met during that period of time were actually particularly interested in you because you are a disabled woman or do you think it was more to do with personality?

I really hope not because I know that those people exist. But I think, from what I've heard and read, is that you'd be a bit more aware that they had a thing for disabled people because they'd be rubbing my bits that were missing or whatever. Most of them were just ... there was a whole mixture of people. They were young, they were older, they were married, they were single. Some of them were blokes who were asking me to set up a threesome with another bloke for them and they'd never had any sort of experience like that before but there were more than one of those. And actually I think I just kind of had my eyes open to ... I think I'd been quite naïve and quite normal and not really met any of the sort of ... I was just very sexually inexperienced and basically this just completely opened up my mind to something I'd missed out on. And because I was seeing a whole lot of people in a very short space of time my confidence grew and I wasn't, at all, kind of shocked or horrified or ... didn't have my mind closed to anything. I think I'd have said, "Yes, I'll try anything once, as long as it was what I wanted to do."

And how long did that stage go on for with the Internet dating?

Probably about a year and a half. And after a while I think it did become a bit of a, like let's keep a track of this. But just out of interest really, how many people I'm meeting, and it was just literally probably at its worst I think I met three people in one day.
Wow.
Yes.
I thought you were going to say in one week.
No, in one day. And I think over the course of a year, it was something like over seventy five people. After a while it did become a bit like, "Am I just doing this for figures? Am I just doing this to" But I think they were very I mean out of that seventy five, some of those were people I met more than once which also was nice because I thought, "Well, some of these people are" like the twenty five year old, he was just a lovely chap. And there was one time when he couldn't he shared a car with his mum and his mum had gone to see his sister and he said, "It's a shame. I'm all on my own here but I haven't got a car so I can't come and see you." And I said, "I'll come and see you if you want." And I went down to Southampton and I stayed at his house for the night and I was really terrified that his mum would come back. I mean she wouldn't have done but I was thinking, "Oh my God, she's probably the same age as me." And it just felt really weird; I was in, like, her son's bedroom in her house. But he cooked me a nice meal. I was quite impressed, he was good at cooking. Just sort of just actually you can tell when someone does care for you and they're looking after you rather than just using and abusing you. And I really don't think I met many of those, probably more of the people I met felt used and abused by me. I don't know. But, you

And what brought it to a close?

Meeting Andy. On this website that I'm talking about I'd kind of created this persona, if you like, this person that wasn't me but it was me. I was doing all these things but, you know, it was totally separate from my real life.

know, I never ever ... I mean some of the experiences were, "I can only be with you for an hour." "Okay, that's fine." And other people were like, "I'm passing through Reading on my way to so and so" and I'd say, "You're quite welcome to stay for something to eat and you can stay the night if you want to." Some of them were pre-planned and some of them were totally spur of the moment. I think some of the best ones were like totally spur of the moment things where I wasn't given time to plan and think about it, people just turned up and most of them I just chatted to afterwards. I mean very rarely did I go and meet anyone away from home and I just felt comfortable with what I was doing at home. Lois wasn't here,

What was the persona that you created?

obviously, during any of this. She was always with her dad.

Well, it was just like this bit of a flirty person who ... it was almost a bit like Ebay, you could leave feedback for people. So all these people had met me and said how lovely I was and, you know, things about what I'd done with them. And obviously if you've got a lot of feedback like that then on the site you start to become a bit like, "Oh so and so, I've heard about you." You know, and I'd get women emailing me and

saying, "So and so has said they want to come and meet me and I see you've met with them. Are they all right? What are they like?"

So it's a bit of a vetting system as well in a way.

Yes. For me, though, I was never ... there was a lot of people who seemed to do a lot of chat. They talked the talk but they didn't walk the walk. So a lot of people had these profiles and seemed to flirt and have a lot of interest but never met people and I was quite the opposite. I did it all and met them all and ... people would come from quite some distance away. Portsmouth isn't that close, it's not just round the corner, so I suppose meeting Andy is what brought it all to an end. I mean I'd chatted to him online and he'd said that he'd come and visit me and it was planned quite a way in advance and he was telling me that he wasn't online every day because he was visiting his parents. And we'd planned for him to come down and visit me and, to me; he was just like another one of the people I was meeting.

So he came down ... he was just going to stay for one night, I think, on the Friday to the Saturday and he was going to get the train and I was going to pick him up. So I went to pick him up from the station and it was just really like he was to start off with like the other people I'd met. I mean he was all right to get on with but so were most of the others. He was intelligent. We'd had a good chat beforehand and a good laugh. He stayed here one night and I said to him, "You can stay another night if you want." And he went, "Oh, are you sure?" And I said, "Yes." Because he'd travelled quite some way and as we talked I found out that he wasn't working and that he'd paid all this money to get a train to come down to see me and I felt a bit guilty. I thought, "Oh my God, he's come all this way and I'm just sending him back on the train."

And we actually just got on quite well. We chatted a lot, talked a lot. I think we spent the whole of one day in bed but just talking really about this, that and the other. I took him out for a drive and showed him bits of Reading and I took him to the pub and we had a drink and I liked him, you know, he was interesting and he was interested in me. And at the end of it, off he went back home and I just carried on meeting other people and I mean I was quite open with what I was doing and the people I was seeing and I carried on to be the same with him. And I think I might have phoned him up and I said, "What's wrong?" And he said, "I don't want to hear about this." And I went, "Oh." I was talking about some other date I'd had or something and he said, "I've actually taken my profile off the website." And I said, "Oh, why?" And he said, "I realised it's not what I want." And I said, "Well, what do you mean?" And he said, "Meeting you it's made me realise that I don't just want to meet people for sex. It's not really what I want. I thought I did but I don't."

So not long after that I invited him to come down for a week because it was April half term holiday and Lois was away with the Scouts for a trip and I just thought, "Do you want to come down for a week?" And he said, "Yes, all right." And he came down for the week and we had a really ... it was like a week's holiday really. We planned different things and went to different places and at the end of that he went home and I kept chatting to him and suddenly sort of realised that he was actually quite keen on me which was flattering and I'd spent a lot of time with him and so I supposed I'd got to know him quite well in that time but part of him was like ... he was more or less asking me to give up doing what I was doing and I felt a bit annoyed really because I thought, "Well, I'm enjoying it. And who are you to tell me that I should be giving this up? This is what I'm doing and I'm enjoying what I'm doing and I'm not ready to give it up yet."

But I suppose a part of me was, like, "How long can this go on for and am I really enjoying it? Am I really enjoying it?" But it's also like a secret life. My mum just thought I was sitting at home moping on my own and I didn't let onto her that actually I was having a whale of a time. So I kind of said, "You're asking me to stop doing this." And he said, "Yes I am." And I said, "Well, is it all right if I keep my profile and talk to people because I've made a lot of friends." And he said, "Yes, that's fine."

I mean one of the things that I had to talk to him about was the fact that I'd often not been ... I'd had a lot of unprotected sex and he'd ... one of the first times he'd met with me, we'd had unprotected sex and afterwards I said to him, "I think you should know that ..." it wasn't a discussion, that was his choice, if you like, to have unprotected sex with me. And I suppose ... this is the thing, suddenly when you're becoming involved with someone ... and I think it suddenly hit me, "Oh my God, what have I ..." He was really cross and then I was really cross because I thought, "Hang on a minute it wasn't discussed with me no discussion happened with me about whether you should have worn a condom or not."

And you had as much risk from him being unprotected as he did from you.

Exactly. So basically we decided ... I said, "I suppose I ought to go and get checked out." And he said, "Well, I suppose I should too." So we actually went together down to the sexual health clinic and got tested at the same time and thankfully I was all right. But when you're being tested for AIDS, the reality of how stupid you've been suddenly hits home. But, interestingly enough, out of all the people I met, the sensible ones seemed to be the very young ones. The young ones were the ones that said, "Sorry, I'm not going to go near you because you've told me this" and people just didn't discuss it. People didn't ask, they didn't question and neither did I, I suppose. If people wanted to use some protection I went on with that and if they didn't, I didn't. And I know, again, with hindsight ... very silly, running a great risk. You know, luckily I got away with it.

Well, perhaps you needed a moment of recklessness.

I think I did. And I don't regret it. I mean obviously if the results of any tests had been different I might have regretted it deeply. But I'm always somebody who believes in living with the consequences of my actions and I'd have had to do that. So I think in the summer holidays Lois and I went off to Euro Disney together and we'd planned that and during the time we were in Euro Disney I was ringing Andy up and she knew I was ringing this person up. And I suppose that was it really, we were in a relationship and I carried on chatting with people and I had a conversation with somebody, one of these people who basically said, "I'm surprised he let's you talk to all of these people." And I said, "I've asked him and he said he's happy." And he said, "Well, if my girlfriend asked me I'd say that but I'd know that I wouldn't really be happy. So I think had a conversation with Andy, "Do you really not mind me talking to these people or are you just saying it?" And he admitted he was just saying it and I said, "Well, okay. In that case I'll delete my profile." I think he actually found out ... he went on the computer and he'd seen I'd been talking to people and he said, "It looks to me like you've joined another website." And I realised it was a bit like a drug. I was having to withdraw. So I said, "Right, I'm going to delete my profile." And I deleted my profile and it was weird, it felt really odd doing it. It was like I was killing off part of me. But it was short-lived.

That was the next stage of my life and I was putting that part of my life behind me and the good thing is that I don't really stay in touch with anybody. There's no need to because I wasn't having a relationship with any of them. I suppose there are, like, two people that I talk to and Andy knows that they were both people from my past but they both know that I'm with Andy and it's gone from there.

Very interesting. And you and Andy have been together for how long now?

Well, it would be about four years about now really, about this time of year.

And so, as we're nearing the end I don't know how you are for time, Simone, it's gone on longer the you meant to.	ıan
That's all right.	
Are you okay until about one?	
Yes.	

So let's just bring your other details up to the present day ... as you're getting older, have you found that things like your level of pain or any difficulties you have have got worse or changed?

Yes. Definitely. Whether or not some of that is to do with the car accident ... I'm less mobile. Obviously there's pain from that but having the problem with my ankle has altered the whole way that I walk and has given me ... whether as a result of that or whether I'd have had that anyway. Back problems, shoulder and neck problems, I'm probably doing a lot less physically than I used to because I'm doing a lot less in the house because I used to kill myself trying to make the bed. But also, you know, part of that is keeping yourself physically moving and active and that's guite important too. So it's difficult because I've got to find some sort of medium between the two ... moving to keep myself fit and mobile but not running the risk of damaging my body further. But at the moment I found that the way I ... I mean I'm lucky, I don't take painkillers every day and I really don't like taking painkillers. But I go once a fortnight to have a massage on whichever bit of me hurts the most. So it's usually my shoulders and neck.

And that is just ... it's not just ... it's a proper deep tissue massage from a sports injury clinic and that kind of keeps me moving and mobile and I feel the benefits of having that. And they've also got a team of physios so if I have any problems that doesn't seem to be resolved with a massage session. I refer over to one of the physios who says, "Oh yes, your pelvis seems to be a bit tilted, we'll sort that out" but the problem I've got at the moment is an inflamed bursa on my left hip. So, again, it's then identifying what's causing the pain because a doctor will just say, "I'll give you some painkillers." But yes, I don't want to be taking painkillers day in and day out so I've been introduced to acupuncture as a result of going to that clinic and I would have been really sceptical beforehand about the benefits of acupuncture but actually even for my ankle which, in my eyes, is beyond help has been helped by some acupuncture treatments.

But I would say if I thought about it I've always got some pain in some parts of my body day and night. Worse at some times than others, certain things aggravate it. If I do a lot of physical stuff like I was doing a lot of tidying and weeding and plant moving one weekend and really ended up having over-used my muscles too much. And suffering a few days afterwards as a result of that.

And are you working now? Are you still continuing to work?

No, I don't do any work. I do some voluntary committee type work for the local council. I chair the Physical Disability and Sensory Needs Partnership Board which is a bit committee and it's quite a responsibility but basically all I have to do is turn up and chair the meetings which is probably about thirty people and is quite daunting and doesn't bother me at all. And all the hard work of organising the meetings, putting the agendas together, having people come and speak to us, is done by a paid member of the council. I might go ... like we organise different events and workshops and I'll turn up at those and I'll have a speech given to me that I just read out. I can change it if I want to. But that really doesn't bother me, standing up and talking to a group of people and I do find the idea of the Physical Disability and Sensory Needs Partnership Board is to bring people together service users, council employees, other voluntary organisations, charities, people providing services for people's sensory needs in this area. And by coming together we actually learn what's on offer, we learn from each other, it's a really huge awareness-raising thing that goes on and it's really valuable I think and it works ... I do feel that we have a voice that is listened to in the council which is good, it's not just like we're paying lip service. I do feel we make a difference and we do have an effect on ensuring that disabled people's voices are heard in what goes on.

In terms of thinking about hopes and wishes for the future, is that an area you'd like to continue working in or do more in?

One thing I think ... one thing I've been trying to do for about the last three years is to do something around counselling and I've ... when I first hit upon the idea I thought, "Yes, I'm going to do a degree in counselling" and the local university here in Reading had stopped doing that particular course, they were bringing it to an end. So I thought, "Oh, right, okay." Did I really want to do a full time course? Probably not. So I found another course that was one day a week in Wokingham. So I went along, signed up for the course, paid an enrolment fee to get a call saying there weren't enough people who signed up to the course so they couldn't run the course. So I thought, "Right okay." So I found a New Directions course running locally one evening a week. Went along, met the woman who was in charge of making sure all my access needs were met, paid my fee, got a letter saying that they hadn't had enough people signing up to the course so they were having to cancel it. So I thought, "Right, I seem to be getting a message here that this isn't the time I'm supposed to be doing this." And that was around the time that Lois wasn't very well and had a lot of time off school so possibly there was some sort of reason why I wasn't supposed to do that then. But it's something that ... I just had something through now that the university are doing: Introduction to Counselling Skills, ten week course, starting ... I think there's one that starts in October of this year, one that starts in April of next year and I think I'd probably like to do the one that starts in April just because it's an evening class and it will be lighter and the weather will be better. I don't like going out in the evenings in winter, I just like to shut the curtains and put the telly on and, you know ... be a hermit.

And what kind of counselling do you want to do? Have you got an idea of what sort of area you'd like to do counselling in?

Yes. I think I'm particularly interested in Cognitive Behavioural Therapy from what I've read. But the whole idea of doing Introduction to Counselling would be to learn about ... I mean I don't know much about any others. That's just what I know about it and I'm interested in it because I just think it makes sense that you're giving people the skills that they need to counsel themselves and to work through their own problems so you're not just giving them therapy, you're actually putting them in charge of their own thoughts and feelings and teaching them how to ... I suppose deal with the situation in a way that they're not used to doing, to see what the effects would be. And I suppose when I ... I only know as much as I've read which is the Dummies Guide to Cognitive Behavioural Therapy. And reading that book I just thought that makes complete sense to me, what I'm reading. And this is how I do deal with things myself.

Yes, it's about changing patterns of thinking, isn't it?

I'm just astonished that there are people who don't think like me and people always say, "You're so strong and you're so emotionally balanced and this, that and the other and you seem to be able to deal with any situation." And I think, well, maybe that's just something I'm born with. And it's a shock to realise that people aren't just born with it and other people are born thinking in a completely different way about things. I'm very trusting and very open with people and other people aren't for whatever reason and learning why do they think like that and what do they think is going to happen. Are they going to change or is that something that happens ... you don't change out of it? It is something I'd like to do because I think ... sometimes just talking to people I realise ... why do they do that to themselves? Why do they ... why are they beating themselves up? Why do some people think that they're worthless and useless and unattractive? Why are they doing that to themselves? And I've actually met people and they can't say out loud, "I am a nice person." They can't say those words. And I think that's so sad.

So I suppose a bit like my work with Disabled Parents Network, I'd like any job where it gives me the opportunity to make a difference to an individual's life. I don't want to change the world; I just think I'd be really happy to know that if once a year I managed to impact upon some peoples' lives and make them make change happen for themselves and that it was positive change. I would feel good about that and I would enjoy it.

I can see you doing something like that, something that's quite motivational for other people. I can see you in that role.

I mean I am quite a motivated person myself and if I want something badly enough I'll get it, whatever extreme I have to go to to do it. And I'd like [Simone sneezes]. Simone sneezes [laughs]. I really don't have days where I wake up and I think, "I can't face the world today." And I can't believe that ... speaking to people it seems that's really rare and I'm thinking, "Why is it? Why is it so rare?" Because if somebody looked at my life they could say, "Hang on a moment, you've got all this pain and you can't do this, that and the other for yourself, you're not working, you know, you don't have a great social life. What have you got to be grateful for?" But I can always think of lots to be grateful for in my life, I can always do it without a problem.

I could sit here and reel off a lot of things and if you said to me, "Well, what do you want to change in your life?" I would actually struggle to think of things that I really was totally unhappy with. We'd all like more money, we'd all like more in our lives, we'd like more physical things but actually that doesn't bring happiness and I get really cross when people moan about their lot in life and do absolutely nothing to change it. Those people frustrate me so much. Especially when you bump into them a year later and you find they're still moaning about the same things. And I just want to punch them in the face and say, you know ... or slap them in the face and say, "What's wrong with you? Wake up to what you're doing to yourself. Wake up to how you're wasting your life away." We're only on this planet for probably eighty years and over half of it, in my case, is gone and I've got lots more things I want to do and try and experience.

And, you know, success for me isn't about having a well-paid job and having lots of public praise and being popular. It's much more subtle than that. If you said to me, "What is happiness?" It's about ... happiness is completely from within and it's being satisfied with what you've got at the moment at the time, not, well, "It's okay but if I could have this and I could have that and if that hadn't happened to me in the past ..." people are amazed that I just had my accident and got on with life. I say, "Well, it's a bit like when you have a baby." You have a baby ... you want a baby and the minute you have a baby you think, "Oh my God, what have I done? My life is ruined. I can't go out and get drunk any more. I've got this little thing that's totally reliant upon me." And then within the blink of an eye that's gone because you're in the here

and now and you look back and think, "How could I be an irresponsible reckless person always going out and getting drunk? It's so much more satisfying being a mum."

I'm not saying it's more satisfying being in the pain I'm in but my life has changed, there's no point in thinking back to what life was like before my car accident. It happened, this is my life now, it's a different life and I've just had to learn to adapt and get on with life as it is now.

I think that's a very good point to stop actually because I think everything you've told me is ... you know, throughout your life you've adapted to whatever has been there and you've done very well with pretty much everything that you've done. Is there anything at all that you think we haven't covered or that you would have liked to say anything more about?

I suppose really it's just a bit like when you asked me this question before and I was looking at it and, you know. I just feel very fortunate that I was born into the family I was born into with the sisters that I had, the mum and the dad that I had. That is what has made my life what it is. And it might have been very different if I'd been born into any other family. But I wouldn't say we're a hugely close family, we don't live in one another's pockets. But we do care what happens to each other, we do watch out for one another and we do keep in touch enough to know what's going on in one another's lives and we do miss each other. If any one of us ever goes off on holiday ... if my mum goes on holiday, if one of my sisters goes on holiday, we feel that distance between us and we do miss one another.

I mean, if they were around ... if I didn't speak to them for two weeks I wouldn't notice. But if they're not there to speak to, all of a sudden you want to speak to them and you want to see them. So it's ... I think, you know, I'm really glad that I've got ... my mum's still alive but my sisters both live near enough for me to see them when I want to or for them to be a part of Lois's life and for me to be a part of my nephew's life is really important to me. I could never move to another country, whatever the draw was, whatever the appeal was, I would really want to be near to my family. Not because I need them in a physical sense but we're a family and that's important.

Well, I think hearing your story ... I think your ... the way your parents raised you as part of the family is u 's V

quite inspirational for that period of time. The fact they wanted to support you in doing whatever yo wanted to do and made efforts to speak to the school to make things happen, I'm sure some of that rubbed off on you in terms of your attitude towards adapting and getting things done. So I can see wh you're saying family was, and is, very important.
I hope a bit of it's rubbed off on Lois.
I'm sure it will.
Yes.
You've got to get past the teenage bit and then it will all start to
Reap its rewards I'm hoping.

Not so many pages this time. You've still managed quite a few! Probably about two and a half hours there. Wow. Thank you very much.	I'll send you a copy of the transcript as soon as it's done.
Wow.	Not so many pages this time.
	You've still managed quite a few! Probably about two and a half hours there.
Thank you very much.	Wow.
	Thank you very much.

END OF RECORDING