

Thalidomide: Liz Lash (2012)

Ruth Blue interviews Liz Lash for the *Thalidomide: An Oral History* project.

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Ruth Blue interviewing Liz Lash on the 10th January 2013, at her home in Polegate for Thalidomide: An Oral History. And this is our follow up interview.

To start with, Liz, did you get the transcript and have a chance to look through that.

Yes, thank you. I've read it in detail.

Okay. And was there anything in particular that came up from that that wasn't covered or you would have liked to say a bit more about?

Yes. I felt I hadn't given enough information, however you want to put it, about my friendships over the years because they formed a very important part of ... my adult life I'm talking about, particularly with regard to the fact that during the late '80s and '90s each year I went on holiday with a friend and I thought it was very important to mention that. She's called Denise and we're still very close friends now. We first met when she came ... she joined the secondary school I was at in the sixth form and actually it's quite interesting in itself because she had been involved with running a guide troupe at Chailey Heritage where there were a number of thalidomide children.

So quite early on, when she joined the choir, she asked me if I was thalidomide and, of course, I said, "No." And she was one of the close friends, when I started to investigate, I actually told. And she also was very close to my mother. So she was one of the people involved with when I should tell my mum and so I thought, how on earth I did not include how close ... it's a bond but it's a strong friendship. So we went on holiday each year and in a time when if you were disabled people tended to think you might go on holiday with a lot of other disabled people on a coach and that wasn't really my ... if you didn't go with your family ... I did go on holiday a few times with my mother when I was an adult but because she was that much older it started to get a bit difficult. I mean we did go to Canterbury a few times because we could visit animal places from there but it just wasn't appropriate.

In fact, the first time Denise and I went on holiday together, we went to the Isle of Wight and we also went to Jersey one year. I vividly remember the difficulties, because we flew, of getting on and off the aeroplane and being sat in a seat where the ... I got bruised from the sides of the street. I remember that as I did yesterday.

But we had a lot of laughs and a lot of ... we followed each other around the country when we were teaching. When I was teaching at Bexhill she then got a job down the road and when I was teaching in Rotherfield, she was teaching in Mark Cross, so it was really quite extraordinary.

So you had a long-term friendship with her.

Oh, very much so.

And are you still friends with her now?

Very much so. She was here on Monday actually. We're still very good friends and, in fact, she is very much involved with the religion side of things – I go to the church she is involved with.

Oh, okay. That's good to know because I hadn't picked up on your friendship with her.

And because she was like another daughter to my mother in many ways and when she had ... she's got issues with her family if you like, well she doesn't like, it's not a good word to use, but she used to go to my mother with problems because my mother was very good with other people with problems with other people, which is interesting. And always very good with young people.

I just ... I've got another very good friend from childhood, who I've known since I was five and I was very close to both her daughters. So I've got a lot of good friends and I didn't really mention that. It's like the Haven Players, the amateur dramatic group which I'm a member of. I've been a member of that since the late eighties and I've got some very good friends there and I thought I didn't mention that and it's such an important part of my life and friends and people ... I know it's a cliché but I am a people person. And I thought about it over Christmas ... I mean I know a lot of people say, "The dreaded round robin letter" but if it's the only contact ... I really value that, it's an important part of Christmas to me. And I discovered that when I went to the Paralympics last year, one of my college friends was actually there on the same day, which is an extraordinary coincidence.

That is a very strange coincidence, isn't it?

Isn't it? And one of my school friends and her family – they were at the Olympics on the same day, one of the same days that we were there. So I mean it's important.

Maybe sometimes you don't automatically talk about the things that you don't ... not that you take them for granted but that because they're there all the time ...

Also not disability related. We talked about relationships because, not that they are disability related but because there are connections with but with friendships it didn't come into it. I mean I have another very close friend who initially there was not a disability relationship at all. She was a year older than me in secondary school but we got to know each other a year later and she now has MS and I mean when she was first diagnosed ... I'm pleased to say it's the thought that is very slow, so it's not made a great deal of difference yet. But she's always felt that I'm someone that she can talk to about it because I understand the difficulties and the issues and when she was adjusting to it, and she's a very unemotional, doesn't like to share things ... now I have mentioned Rosemary with discussing the issues with my mother. She's someone else with disability issues and I'm very close to her. So it's a mixture of friendships and I thought, "I can't just talk about people I knew because of disability." I have a rich friendship life, if you like, and I thought that must go down. It's a very important part of me, just because it's not connected with disability it doesn't mean it's not important.

No. And they're probably people you would have become friends with regardless of ...

Well, who knows? You don't know where you would have been. But I mean, yes.

That's true, you don't know where you would have been. But they're people that you've got more in common with than the world of disability.

Yes, absolutely.

Well that's good that you brought that up. And also that we highlighted that a little bit later on we could talk about religion because we didn't talk about that before. I had a few things I wanted you to say a little bit more about if you don't mind.

Try and see.

Obviously one of the most poignant parts of your story is your mother and her keeping her use of thalidomide a secret from you. And you speculated about what the real reasons for her doing that might have been. But you only briefly touched on your conversation you had with her at the time, when she finally admitted to you that she had used thalidomide. And I thought because it is such an important moment and such an unusual story, I wondered if you could revisit that moment in a little bit more detail. How did it start?

I mean ... it's a funny word to use, but it was almost funny because I'd really braced myself for this conversation and I'd talked to Martin about how I might approach it. I'd talked to both Denise and to Rosemary. I'd talked to my aunt Diana about how I might start it. The advice, generally, was don't go on your own so I said to Dave, "Will you come with me?" And he said, "Yes, of course I will." And so we went on a Tuesday and I said to my mother, "I need to come and talk to you about something." And it was all quite ... I said to you, she wasn't well. Talking was not always easy for her because she had COPD.

And we sort of went there and we had to rearrange the seating slightly because her hearing was not ... she was the classic hard of hearing, "There's nothing wrong with my hearing, young people mumble" which always used to make me smile.

And when I started, I explained what I'd done and I said, "I need to know. I hoped I wouldn't have to ask you this question." I was totally honest with her and I explained what I'd done and I said I hadn't liked not telling her up to this point but I hadn't wanted to distress her unnecessarily. I think she was a little bit upset when I said that I'd talked to Diana but then I think she realised I'd taken the opportunity to do so because she'd been in this country. She did understand that. And she went very quiet and I could be back in that living room now with her sitting on that settee and I'm where I am now and Dave was sitting opposite.

And I said, "I need to ask you, do you actually know if you took thalidomide?" Because I had no idea at all what she was going to say, how she was going to react if she knew she'd taken it. I suspected that she didn't know she'd taken it. I thought she was going to deny it vehemently and I was anticipating a lot of emotion, a lot of anger. All I got was, "Yes, I took Distaval."

And it ... I mean it was funny because the only ... the cliché that comes to mind is wind out of your sails. I looked at Dave and he was sitting there trying not to laugh. I mean not at me. But it was, it was funny. You psyche yourself up for something and then ...

You get what you thought you weren't going to get.

Yes. It's like walking into a job interview and saying, "Well I don't think we'll have the interview, you can have the job. You can become the CEO or whatever." So I took a deep breath and I said, "Why are you so sure? Can I ask?" And she said, "Of course." And she told me about the fact that she'd been suffering from insomnia and this bizarre thing about it not being the morning sickness because I knew she'd had not morning sickness specifically but all day sickness. She'd told about the fact that she'd ... it was something we'd laughed about in the past about the fact that she'd sucked Spangles sweets and how months afterwards she'd found a pack in her pocket going all mouldy, well not mouldy, going all sticky because it had stopped and she's not the sort of person who had sucked sweets.

And she said, "I was suffering from insomnia. They'd given me some medication that the GP, Kitty ..." she was also a family friend in Seaford, I've forgotten her surname because we had a lot of trouble finding that out. She sent me to Brighton Hospital because, of course, she was living in Seaford so she must have been taken to Brighton Hospital. And she saw a doctor there and it was the doctor there who prescribed her with Distaval. And I said, "Can I ask a really silly question? Did it help?" Well, you know, again Dave smiled, I can see him smiling. And she said, "I wish I could answer that, I have no idea." And I said, "I'm not surprised but I just thought it was worth an ask."

And I said, "I'm really sorry ..." She said, "Right now, can I ask ... what can I do to help? What would happen?" And I said, "Well, if we can prove that you took it, my understanding is that I will get some compensation each year." And my mother was no fool. She said, "Right. What about all the back pay that you might get?" And by this point we already knew that wasn't going to happen because Dave had found this ... all the research he'd done online, he'd found the settlement that had been done in 2006, the legal agreement. I said, "No, let's settle for a yearly agreement. That'll do." And I could see ... let's not go down this guilt route because it's not going to help. I said, "No, no. You haven't done ... let's just settle on the practical." She said, "What do we need to do?" I said, "We need to look at your medical records." She said, "Right. What do I need to do?" I said, "You need to write to the practice manager." Knowing my mother, she would need to know what to do and everything was quite an effort for her and she went and sat at the table and said, "Right, if I write the letter, you can hand deliver it for me." So that's what she did. It sounds slightly as if I ... I didn't, that was what she said she wanted to do and I knew that if we got to the stage in her understanding ... bear in mind I had no idea what was going to happen, she would want to do the right thing.

So she wrote the letter and I said to her ... she said, "Now, I would like now to be on my own with this because I always thought this might happen." And I said, "Can I just ..." just for the tape, Ruth is pulling the faces that I felt ... the faces of non-comprehension that I felt at the time. I said, "Can I just ask why didn't you tell me?" And she said, "After all these years, I don't really know." And I thought, "What can I do?" And I said, "If we can get it sorted now that will be wonderful."

So we went out to the car and Dave said to me ... because he's terribly calm in times of crisis. Time and time again my mother had said this, "If you're going to have a crisis, Dave is the person you want around and it's true."

Unflappable.

Totally, even in a major crisis. He said, "Now then, I will drive. I'm sure you must want to cry, don't until we're away from the house." He reversed up the drive and said, "Now you're all right. Let go." He said, "Don't let her see you, she will be in the window, you know that as well as I do."

Now, what I would have liked now to be able to say to you is that I was able to talk to her at a later date. That wasn't going to happen because she just ... it's difficult to explain. She wasn't well enough

psychologically or physically and I had ... it's really difficult to explain. That was the August and we went, subsequently, she and I went and looked through her notes. She sat there and I looked through them and took photocopies of what I thought was relevant. Took them home and looked through and it was actually Dave who found the word 'Distaval' I didn't. I had said ... I would like to record that I did ask her if it was all right that Dave looked, I asked her permission and she said, "Yes, of course. Fine." And, for the rest of my life I will find his voice coming through, "Liz, I think I've found it. I think it says 'Distaval.'" And we looked at it, we enlarged it, and I said, "Yes, I think it does." And I then subsequently took it to a medically minded friend to check and I rang Martin, emailed Martin that day and said, "I think we've found it."

And then it took off. It was a waiting period until the Trustees met in December and then we had a really ... the only way I can put it is a really bizarre Christmas period when it was really good news and then I got ... and then Martin came to see me, he came down the following week before Christmas and it was like euphoria and underneath ... and relief ... perhaps euphoria's not quite the right word but it felt like that and relief. But at the same time, underneath all that as far as I was concerned, was this really strange feeling of, "What's happened? Why couldn't she tell me?" And there was Diana in Canada saying ... a bit like I was a horse, "Steady girl, it will be all right."

And then part of the next year, 2010, I was fifty in 2010 in the May and I had a big party in the May and I sort of was planning all that and whatever and my mother's birthday was two weeks after mine and I brought her over for a tea party after her birthday and it's funny I still remember her sitting where you are actually and I thought, "She really is so frail now. I don't think I'm going to be able to talk to her about it." Sadly that was true. So I never was able to revisit it. It wasn't ... the only way I can put it is that it wasn't kind. It was difficult enough for her to have faced that but at least she felt that at last she'd been able to do the right thing and she had known she'd made the difference.

Yes. It's just so odd that she waited for it to come from you. When you said the words that she'd said, 'I knew this would happen one day.'

I know. And when I found out that her brother had come over when he was dying and he'd come over from Canada and he'd actually said to her, "The reason I'm here is to persuade you to tell Liz." And when I found that out I thought, "Why didn't you? Why couldn't you?" It's not just ... okay, I'll be honest, the money is useful and it's made a massive difference to what I can now do in my life and that's ..." but it is more, for me, I'll be honest and say of course it is. But it is more about my identity and that's huge as far as I'm concerned.

Absolutely. Because there seems to be, with a lot of people I interview, you know, there's being born with a disability that's caused by thalidomide is a different ... produces a different way of thinking. I've not got to the bottom of what that different way of thinking is but I ask every person, "Do you think thalidomide-affected people are different to other disabled groups?" And they all say, "Oh yes, we're totally different." Some people have a reason why they think it is ...

I would say no, you see, to that.

Well, as an 'outsider' as it were, I can see lots of reasons why one would say no."

I guess if you've always known you might feel a bit ... maybe you feel angrier. I think getting on with life is more important than ... that doesn't stop me ... yes, I got involved with the campaign with the health grant but only on the edges. But I tried to do what I could and I would have been involved in other things and I may be again.

I suppose there is a difference ... the basic difference is that nobody knows the prognosis but then that applies to more than ... I suppose because I know professionally that we are not the only disability that's true of. I mean if you have a stroke you don't know what the prognosis is, for example. If you have a brain injury of any sort nobody knows the prognosis. So I suppose it's ... there is an issue around prognosis because we are the first, and please, the only generation ... nobody medically needs to learn from us in a sense and I think that there are issues around that. I mean certainly ... I don't know, there are differences. I said no very quickly because I was thinking of it from the point of view of dealing with life but maybe there are philosophical issues.

I think maybe it comes down to that more, the philosophical issues and possibly also the fact that there was a society set up by parents and there was a news story and people were all born within the same age bracket ...

Yes, yes, yes. And that draws you together.

... and it's mostly limb deficiency primarily.

I think the internal stuff is more difficult to cope with to be honest.

It is but it's not ... obviously well it's not visible ...

Hidden stuff is always more difficult to quantify.

It seems to generally have got diagnosed later on in people's lives as well.

Yes. I think it's an interesting one. That's given me something more to think about. That's interesting. Maybe something to talk about with Mikey.

It fascinates me too as to why thalidomiders do feel they're a different type of group. You talked about, and you've just mentioned it again now, going to the counselling to help you to come to terms with this. Can you say a little bit more about that and about what sort of feelings primarily you needed to resolve?

Yes. I mean I think firstly I was so fortunate in finding such a very good counsellor almost by luck. She'd be the first ... she'd know why I said that because it's remarkably difficult to find an accessible counsellor for a very simple reason, it's nothing to do with counsellors, the vast majority work from their own homes and the vast majority of houses are still not accessible.

Yes.

I didn't want to ... I mean, two things. I suspected it was going to be longer than a six week block of counselling I was going to need and also I thought well, I can afford to pay and because of the issue, the work I've done within the mental health world I know how many people are waiting for counselling and I thought, "Well, I can afford it" so I knew how I could access properly trained counsellors particularly as I'd done the first run of counselling and training myself. Sorry, I thought that was going [LL adjusts microphone]. It is after all a silk scarf, it's rather slippery.

It's very nice though. That's better. Just don't move, okay? [Laughs].

[Laughs]. I like that. It's like having a Victorian photograph taken.

Relax! Don't move! [Laughs].

Yes, don't move and relax. I like that. So I think ... that was the first thing I was lucky to ... because I rang two or three but they said, "I'm really sorry." But then somebody said you need somebody who works from a counselling centre. So I thought, right, okay. So there was somewhere in Hastings and it wasn't the most accessible in the world but I could manage and I was very fortunate in that ... because it does matter, you need to have an empathy with your counsellor; that is so important. And obviously I'm not going to name names but when I found out in the first session, are we going to get on or not, that I found out she had, this particular counsellor, has a daughter with Down's syndrome, I thought, "There's a link here somewhere." I also found out she's worked in education. I thought, "We're going to get on." And we soon found ... as well as I consider her to be a first class counsellor, we actually got on as well.

That's really important.

And she ... I think I was ... to start with I couldn't grieve for my mother, I just couldn't start the grieving process. The statutory lines you're meant to go down I just couldn't start because of the fact that I hadn't been able to talk to her before she died. And I'd gone through the practical stuff and I'd been so busy supporting her, because there had been so much to do, and I was so angry with her for dying before we'd managed to talk. And that's what I needed to talk through. I mean I knew that wasn't logical but knowing it's not logical doesn't mean you can deal with it yourself.

Absolutely, yes.

And I needed somebody to tell me, "Actually that's okay" before I could start grieving. And then, you know, it became more normal if you like. And that process ... and also I had to sort of ... there were lots of other bits in her life and my life ... understanding and talking through the way she'd behaved towards me. In some ways understanding her way of dealing with her guilt of not telling me, which I think it was, was the way she then channelled all her life into mine. And I needed, to some extent, to understand that. And it took just over a year of counselling to get through that.

One wonders how she must have felt carrying this secret around for all these years as well.

Well I've often wondered whether she did ... because I mean she had, as part of the treatment she had for clinical depression, she had counselling for quite some time. I now know that she was having psychodynamic counselling, I didn't know at the time that psychodynamic therapy ... I didn't know that at the time, I didn't understand enough, I do now. I do wonder whether she ever ... that ever came to light. I'd be fascinated to find out if she ever talked about that with the counsellor. I know one never would but it just would be interesting.

If only you could find that out.

It would just be interesting to find out whether she ever talked about it.

She must have talked about it.

One would think so.

Yes. Well, presumably she did talk about it with other members of your family like you've said ...

As far as I'm aware, she only talked about it with her sister and her brother. Whether she talked about it with members of my father's family, I will never know.

What happened when her brother came from Canada and persuaded her to tell you?

Well, he tried to and didn't succeed. I mean I don't know what she said to him. She just ... I think what she said to him was, "It's too late. I can't." And this is way before the days of the internet ... well, I'm not sure, I'm not entirely sure. And he'd done some research anyway from Canada, he was a very tenacious man, he quite liked to ring people up and find things out. And he had found out that I could apply for compensation, he'd done that and he actually said that to her. And she said, "No." She didn't believe him. Not that she thought I shouldn't have the compensation, it wasn't that. And so ... no, I just ... I don't understand but I've come to an acceptance, because I've got to, that I just won't understand because there is no-one left alive who can unlock that secret. That sounds a bit awful but it's the truth. There isn't anybody left. Unless there's someone in my father's family and I think it's very unlikely ... the generation that is now alive, still alive, there's no reason for any of them to know.

It's one of those mysteries that stays in your mind, isn't it?

It is, it is.

Well, following on from what we were saying about thalidomide in comparison to other disabled groups, would you say you feel like a thalidomider now?

I'd rather say I'm a thalidomide survivor, thalidomider I don't like. Yes, I'm a thalidomide survivor. If somebody asks me now ... that's really interesting that you should ask that ... if somebody asks me now what my disability is, depending on the context, I will say, thalidomide survivor. And then if it's appropriate I would say, "I've only know that since 2009."

What would you have said before 2009?

A congenital deformity because that's what I understood it was. I might have used that word beginning with ph ... thingamabob ...

Phocomelia.

That's the one but as you've just proved I've never been able to say it so ...

Something in you has been resisting saying it.

Yes, yes.

And you feel more happy now to meet up with other thalidomide survivors?

Yes. I mean I don't have a driving urge to do so but I don't have a problem with it either. I think if there's somebody who I felt ... I think as we were saying earlier, Mikey and I would probably get on. And it's interesting because Claudia from the television programme I was telling you about, I think she felt that ... not that we should, but that we would get on, there's a difference. And I felt that when Mikey and I had that wildly insane telephone conversation when she was trying to park her car when I was ringing her about the campaign last year. I think there was a click definitely.

Like you were saying earlier about friendships, I think you would have a lot in common outside of thalidomide.

Yes, exactly.

Okay. Moving onto a couple of different areas, you've talked about going for artificial limb fitting sessions at Roehampton and you mentioned meeting a couple of other children affected by thalidomide there and I wondered if you had any more memories there than came out in the transcript, or is it too hazy?

It's difficult because it is a very long time ago. I remember the children, I remember some of them quite well and I sadly know that one of them I knew well, because I talked to Martin, did pass away. I think in his late teens. I don't have that many memories. Instances rather than memories more than anything else. I'm trying to maybe recall a few more if I want to commit things to paper but there aren't many. I can see the room in the building, the layout of the unit as it was then. But it's not lodged strongly. It takes a big effort to ... I think it's because it's what children do. Memories that are not good they tend to push and also, as I said when we first met, I'm not good with memories and childhood. Some people have the most amazing recall. I don't.

Neither do I actually.

And that's not said defensively, it's quite genuine, I don't. I have some memories of when we went to Canada when I was five but much stronger memories of when we went to stay down in Cornwall when I was six. And if I could draw, I could draw the view from the window down to the estuary and the house.

One of the parts of the previous interview, you'd described how one little girl had said, "When the parents leave here they never come back" but that you had this absolute sense of security that your mum was coming back. I suppose that's what shows that very complicated combination of your mum being absolutely there for you but then not being there for you in one crucial way, which was telling you ...

Yes. I mean at that time it didn't matter because it was before ... that would have been about 1965 and so that would have been when it was first starting to be looked at because it didn't start breaking until '67 when the Sunday Times got hold of it. So it wouldn't ... at that stage it wouldn't have mattered. I mean why she chose not to tell me ... I assume then she chose not to tell me that she'd taken a drug which had caused me to be different which is quite simple really. I suppose you could say it didn't matter. So at that point it wasn't important. It became important later.

Perhaps because she had that very strong bond with you and you were very dependent on her, she thought she would lose something in your eyes.

I think she thought ... I'm not sure she'd thought it through quite as clearly as that but I think you've put your finger on something that's very important. Yes, I think that's true.

Fascinating. I've thought about it such a lot since I heard your story. Now, I did want to ask you about your love of animals as well. You mentioned that it started with Lawrence Durrell ...

Gerald Durrell, not Lawrence Durrell [laughs].

I wrote the right name and said the wrong name [laughs]. You talked about your love of animals starting then but for me it was a bit like you said you didn't really talk about friendships but you didn't really talk about that, what sort of role that's played in your life.

Oh gosh. Very, very important. Oh gosh, where do you go from there? I suppose it kind of ... although I read all that I could and watched all I could it didn't really become important until I got ... is that true? I was always going off to Drusillas and stuff, thinking about it, as soon as I could drive, and when I went away to Canterbury, where did we go? We went down to Howletts ...

What's Drusillas?

Drusillas is the local zoo to here, sorry. I beg your pardon. But it's a small zoo that caters particularly well for children – I don't mean that children are in the zoo, I hasten to add. [Laughs]. I just realised that it sounded slightly ... I mean it's not just ... I'm just interested in conservation and particularly Madagascar's always been my thing, if you like and I'm passionate for lemurs to such an extent that one of my friends gave me a toy sifaka for Christmas which is a bit sad really at my age, but there you go.

It's as close as you're going to get to a real one, isn't it?

Well, precisely. Although I was fairly close to a real one last week actually, being me. And then I sort of got very interested in ... yes, I suppose conservation animals. It's not just ... it's more domestic animals. I also have a strange passion for goats because loving cats, I think that they are ... there's something similar ... there's an anarchic behavioural thing about both cats and goats that appeals to me.

I'm trying to see the connection ...

Well because you never know what they're going to do. They do what they want to do and it's on their terms, not yours.

That does make cats a lot easier to live with I think than an animal that's ...

[LL makes panting sound]

I know.

I mean I like dogs. I like all animals but it always seems to me that dogs and horses have a sort of ... there's a relationship to me, they behave in a similar way because of their reliance on us although we've bred that into them because that's a very human thing to do. Whereas it doesn't really work with cats. It's like Scottish wildcat kittens, you cannot tame them, it's not actually possible which I love about them, you just can't. I mean it's still ... when we go away ... the interest in birds is more recent, it's in the last few years. You can blame Springwatch and Bill Oddie, that's what started me. It's entirely their fault and now I'm hooked on birds and a member of WWT and RSPB and I'm ... so birds and animals ... it's just wildlife and nature, making things as accessible as possible. So I can sort of go and watch ... I realise you can't do that everywhere but they're getting better and I would love to go and board and see things in the raw.

I think it's very important that we keep things, unfortunately we need breeding things to keep things going and we've got to the stage where it's got to be done unfortunately.

It's very sad, isn't it?

It is. But it's better than not having them in the future. We've got to that stage. It's funny, I remember when I was ... the book of poems I did for my ... I'm so ancient, O-level English included a book called *Poems of the Sixties* and in that there was a poem called 'The Rabbit' which I've never forgotten and it was basically about people taking their children to see the last ever rabbit. It was very clever and it stuck in your mind because it was poignant because rabbits are everywhere, but this day in the future this was the last rabbit. And it made you think that could be anything, even the last sifaka ...

There's something about rabbits as well.

Oh yes, sorry, with your daughter. But it just happened to be ... she must never see that poem, she would be ...

Even when you said, "The Last Rabbit" I could see her face looking at me.

Yes, yes. She'd understand what I meant. I mean look at me ... how many years ago is it that I read that? And it made a huge impression on me from a conservation point of view. I can't remember the author, unfortunately, but it really did. And animals are still ... it doesn't stop. As I said, last week we went away – Slimbridge two days and one day at the Cotswold Wildlife Park playing with the lemurs.

I think those animal stories are very ... they have a lot of impact when you're young. I interviewed somebody else who was talking about having read Tarka the Otter and how he cried for weeks afterwards.

Didn't we all? Not that I ... I didn't like that quite so much, I prefer people talking about animals rather than somebody anthropomorphising ... I mean I read it but it wasn't quite so ... it's like everyone talks about Richard Adams' book *Watership Down* whereas I would say if you really want to know how he writes, read *Plague Dogs* because that's ... and that's an anti animal experimental thing and it's just ... from the dog's perspective. And, again, just thinking about it I'm back at the beginning of that book.

I haven't read it but just what you've said then I'm kind of thinking I don't know quite when I'm going to make myself read that.

Well it's pretty amazing I tell you. And it's not the height of something really cruel because it's not necessary if that makes sense, you don't need to. But I think it's, you know, important.

Yes, okay well thank you for that. Now at the end of the last interview we were just about to move onto ... ooh, before that, I've just seen my little note, religion. I didn't ask you about religion at all. So ...

Well I was brought up as a church-going C of E. My father figure in my life was my uncle, my father's brother who was a bishop and he and I were very close although he never was a great one for impressing his religion on other people. He was a Franciscan friar and then became a bishop and then he was ... I was very, very close to him, he was a lovely man. And I know I mentioned I went Evangelical in my teens, I never ... my faith stayed with me and I went to the local church in Westham when I was living with my mother when I was teaching. But it's only recently that I started going back to church. I'm still very much a C of E person. At one point I pretty much tried everything, tried various denominations and at one point I did attend Quakers for a time and they were lovely because that was over in Bexhill that I went. I didn't go for very long but it must have been about a year later that I had the car accident in Bexhill and they saw it in the paper and a card arrived at the hospital for me, from the Quakers. And I thought that was so nice, lovely, I've never forgotten that.

But now I think it's a very important part of life for me.

What is it that it gives you?

I suppose, I suppose a reason why ... I know it's a cliché, a reason why we're all here, an understanding of the bigger picture. I'd like to think that, generally speaking, as I always say, there's more good than there is bad. Obviously it's not all good. Like most people I struggle when I hear terrible things, I mean like the children that were shot in America and I think, "Why?" Or what's going on Syria or what's going on in Northern Ireland in the name of religion at the moment. But, you know, it's ... and I suppose, like most people, we'd like to think there's an afterlife, wouldn't we? I don't think my reasons for religion are any different from anyone else. Even though I live with a very strong atheist.

So he doesn't go to church with you?

Oh no, definitely not. I think he might have come to the carol service to hear me read before Christmas but I didn't know until afterwards. Maybe he'll bend. I'm not sure.

The other thing, at the end of the last interview, we didn't have chance ... we didn't get on to bringing you up to the current day.

No.

With what sort of things you like to do with your time, how you like to spend your days. I know you said you were not working at the moment.

No, that's right, no. I mean basically I have been told medically that I should not ... full time employment of any sort is not a good idea because if I have a day when I'm ... it's not a good idea basically. And if the DWP decides that I should work again ... I mean I'm currently on ESA contributions based and if they decide that that's not right then the doctors are going to back me up so we'll see what happens. The last review was all right so we'll see what happens. Who knows in the great new world of benefit, who knows?

I mean I have been doing a lot of voluntary work for something called The Link which is to do with health and social care. That comes to an end nationally at the end of March and is going to be superseded by something called Health Watch. Now in East Sussex that is going to be run by something called East Sussex Community Voice and I have applied for and been offered a position as a non-executive director of that organisation.

Wow.

But I am not sure whether I'm going to take it because there are issues with patient and service user representation in the new organisation that I'm not too clear about so I'm not quite sure from April what I'll be doing. I remain an active trustee at the East Sussex Disability Association and that will continue. I'm also on the district committee for Pevensey and Westham East Sussex Disability Association where I am secretary and do some of the social secretary stuff as well. I'm also being doing some service user representation work for the wheelchair service in East Sussex which is new to me but I'm being drawn into that. I'm just a bit concerned that I'm going to end up doing all voluntary work for disability which isn't me and as Dave put it, it's a bit tunnel vision for you.

So I'm not sure, a bit of a time of change. In a way, Link coming to an end and me wanting to write a book may be the right ... but I need also the stimulation of being out with other people so it's a bit ... I've really enjoyed what I've done with The Link and I have a huge ... what I don't want to do is leave the mental health work behind because I don't want that to get lost and I'm not saying it's just me that can do it, I don't mean that, but I'm really concerned about whether Health Watch is going to pick that up because it's really important. Well, I happen to think it is.

Definitely. What about leisure time as well?

Well the Haven Players ... we're just about to do our pantomime run. That basically rules my life in January I tend to say. We kick off on ... well we've got technical and dress on Saturday.

What is ...

We are doing Red Riding Hood and the Not Very Bad Wolf because our wolf is vegetarian.

And you?

I'm prompting so I have to be there but it's not too arduous. Well I mean it's great fun but it can be a bit arduous if we're on the wrong page of the script and I don't know where we are. And we start on the afternoon when the Brownies and the Rainbows come and they're a great audience for a first audience, they're brilliant. It's often the best one to be at to be honest.

Where do you do it?

Local hall, Stonecross Memorial Hall and we're lucky because we rehearse where we do it and that's great. Because we do pantomime, two plays a year, to a musical evening in the summer and the Christmas evening as well it's busy. I enjoy it, I wouldn't want not to do that.

I'm also quite an active member of my local Women's Institute, including being publicity officer which is not desperately onerous, I enjoy that so that's quite ... and that crosses maybe this year because I'm also involved in quite a lot of quizzing. Sad but true and that may involve, possibly, it depends, either county or national WI quizzing.

And reading?

Yes, reading.

Fiction or non-fiction?

Both. It's funny, I've been ... I've just finished Jeannette Winterstone's autobiography.

I've never read that actually.

Well, I was ... a friend put me on it just before Christmas and it makes you angry, sad and you laugh. Absolutely brilliant book. Absolutely Brilliant.

I can imagine.

Why Be Happy When You Can Be Normal? Wonderful. I would put that ... brilliant book. I'm reading more autobiographies than I would at the moment because of what I want to do.

Because you want to get your story down.

Yes, I do. I have also got the new Ian Rankin for Christmas because that was a must because I'm a bit Ian Rankin fan.

And things like TV?

Yes. I mean I'm a mad keen Lewis fan so I'm very cross with him having split them. What else do I like? I like what I call the good quality crime dramas and nature programmes. Winter Watch is on next week. And some sport, athletics and stuff. But I'm not ... I don't ... I'm not a put the television on automatically and I'm just as likely to have stuck a CD of some old-fashioned music on than I am ... and I have to say cooking / kitchen, now I've got the kitchen right ... it's amazing how much time ... I've been in the house all day and actually what have I got to show for it?

A cake.

Yes, a cake. I like that [laughs].

Liz has provided an absolutely gorgeous cake.

And, of course, people. I haven't mentioned that. People are very important.

Yes, people, sociable things tpp.

I mean it's ... I swim once a week and I have hydrotherapy once a week so I like to try to keep a bit of exercise going. And I go to the theatre.

Of course.

Of course.

What are your feelings about thalidomide now? Have you been interested to learn about the origins of the drug or do you have any feelings about that published apology from Grünenthal?

I think Grünenthal are frightened. I think they can see, they're not stupid ... I think the apology was offensive in the same way as I think that piece of sculpture was offensive. I prefer that tree that was planted ... Sheffield I think, I might not be right.

Oh, Harrogate.

Harrogate. I beg your pardon. I knew it was Yorkshire, I apologise. I thought that was lovely and lovely that it was something that was growing. I think that's lovely because it's for future generations which I like. It might just be me. Because I thought they were children of people with thalidomide and therefore I thought that was important.

I think it's ... the history side of it, I have to be honest, I'm fascinated by and I've talked about it with Martin. And I look forward, with great interest, to the book that I hope he will get published. I think it's ... it fascinates me and I think sadly it may well ... it makes a dreadful sense to me that it was developed in the concentration camps. I get a little bit ... I get very angry with people who still want to harp on about the Germans / Japanese anti-war and all the rest of it because I think it can cause a lot of bad feeling still these days and I don't like that. But this is a historical thing, it's not the same thing. I'm not angry about the children of the people who developed it. I don't understand that. That doesn't ... but I think historically it's really interesting to trace it. But it doesn't make me angry now, I just think it's interesting. There's a

difference. And it does ... I suppose, because I've got Jewish blood it's bound to interest me what happened. As a disabled person it's going to interest me. I think most people would say that.

It's like I said to Martin, I found myself in a room with a Holocaust denier and that was quite interesting. I was incredibly polite.

I was going to say, how did you deal with that?

I took my Link badge off and then spoke to him, let's put it that way.

Yes.

And I got a round of applause from three other people in the room.

It's extraordinary that that can still happen.

It is very silly to say it in the company I was in but there you go.

Some people I've asked that question to have a lot of anger in terms of thinking how their life could have been different.

Oh I can't ... well, to be fair this may be because of coming late but I don't think I would have done it anyway because I can't say if sixty years ago somebody ... well, if my parents hadn't met I wouldn't be alive at all. I can't behave like that because I don't think there's any point because you can waste a lot of time being bitter. I'm not saying these people are, it's just a comment. To me, there's a lot of life that I can still live and I'd rather focus on that but that's just my opinion. But intellectually, I think it's really interesting. That's how I would put it.

Well, it's true what you're saying, who knows what different routes could have led people into different places.

I mean it's like ... I mean I've always thought that if I was a non-disabled member of society, there's a strong possibility that I would have gone down either the sporting or the acting route. But I have no idea, I might have done something totally different. I don't know.

You don't know because you don't know if those things appeal to you because they've always been a bit out of reach.

I mean I don't know so what's the point?

No.

I don't lose any sleep over that one.

No, that's good. Hopes and plans for the future?

Well, the obvious one is to say I would like to write the book. But it is about finding out how I found out why. It's not an autobiography. I mean I've got ... I do think it's got an interesting story and, in fact, when I ... I was a bit naughty. When I was on the phone to the guy from *The Independent* he said, "You write that book. If you write it, I want to know about it." And I thought, "That's useful if he's still there." I didn't realise until afterwards that he's quite an important person because I saw him subsequently on television and I thought, "That's who I was talking to."

And he's told me to write a book.

Yes exactly. And I had the same reaction from the woman who interviewed me on the BBC and I thought, "I don't know." I mean having the transcript is a tremendous help.

Oh good. I'm glad it is.

A tremendous help. It really is. The course that I went on last year, the same tutor is hoping to do a follow-up, well she's got it planned, bizarrely on my birthday which we both think is quite funny. She emailed the dates round because a lot of people would like her to do a follow-up. And I've got another oomph to do it because my aunt, I found out this morning, I had an email from her, she's coming over in June and probably won't be coming over again for a while so it would make sense to have got something done by then. So that's my immediate ... that is what I want to do.

That's good, that's good. And, in a way, it's quite handy that you haven't got an awful lot of the voluntary stuff going on at this moment.

I feel that it's kind of ... it's whether I take on that direction because I've got a lot of ... I've got to make my decision about that before tomorrow, by tomorrow, and it's not difficult. And the other thing is that we would like to go to Canada, we would like to ... I mean I don't mean to live, I don't think so. Not as far as I know. We were talking about doing that this year and that got put on the back burner last year because of the Olympics. Well, now we know my aunt's coming over this year, that works better because she's off on her travels again. My aunt's a great traveller. She's going off to South America. I think there might be some people in South America ... I haven't see her yet.

And that's your aunt, Diana?

Yes.

And so ... sorry, I feel as though I keep going like a magnet back to this thing with your mum ...

It's all right.

You were saying there was nobody living who you could ask about what your mum's reasoning was ...

Yes. She's the only person. We've talked ... we've talked and talked and I don't think there's anything left that she can tell me, because she would.

What does she think your mum's reasoning was?

She thinks that it's tied up with pretty much what I do about guilt, and she got to a certain stage where she couldn't say it any more. So I mean it's pretty much what I ... you know.

Yes. I think that must be where it comes from. And you can sort of see it. And maybe it's a bit like you were saying earlier even if you know something rationally you can't still make yourself do it.

Yes, that's right. That's right.

Perhaps that's what she was doing, "I know I need to but I can't."

No, I think that's right. You have understood, I think, and I don't mean to be patronising, I'm quite serious probably because of the other stories you've heard, you have understood a very complex story very quickly I think. And helped me understand as well.

And who knows how many times she might not have sat down with you and said to herself, "Today's the day I'm going to tell her."

I wondered that, oh yes. I've even pinpointed a couple of times when I thought maybe she was going to and something else happened.

Yes. Okay. Is there anything ... I'm done with all my questions now but is there anything further that you would like to add that you think we haven't covered?

I think the only thing I would like to say is it's not just ... it's a bit of a cliché but it's not just about the money. It's been so interesting, I think, to find out my identity and also the people that I have had contact with at the

Thalidomide Trust and also, I know it was only very briefly, the Thalidomide Society. I did almost think about going back to Vivien and saying, "It's okay now" because she was so ... it was such a lovely email she sent. That's been really ... again, I sound a bit American, but it has enriched what was becoming a really troubled part of my life. And I feel fortunate, blessed, whichever word you want to use, that I can now, you know, move on. Okay, it's very different and I do feel ... there is an odd loneliness to the fact that there's no-one left alive and the fact that I'm not ... one of the difficulties I'm facing now is maybe now I am facing ... more than in 2009, if I'm not going to work, I am alone much more and that ... that's probably a good thing, it's taken a longer ... and I think that that's ... but maybe knowing the people that ... maybe I'm going to meet other people and there are more connections to be made around being a thalidomide survivor.

That's got to be a positive thing so although there's been a lot of difficult emotions and negativity, the outcome ultimately, surely it's got to be positive. Okay, I'm going to be fifty three this year but surely there's got to be a few years left, hopefully, of good, positive whatever.

It's a new door that's opened, isn't it?

Yes. I mean I know I'm fond of saying, "Knowing my luck there's a set of steps the other side" but that's just my warped sense of humour [laughs].

[Laughs]. You are funny, you know.

Well, we try.

Yes. I think it will be a positive thing as well. And I hope you'll be able to come to the conference this year or consider it at least.

When is it again? You did tell me.

March the fifteenth and sixteenth I think. And it's sort of a weekend.

Sixteenth, I'm already committed on that ... seriously, I'm not just saying that. And if I uncommit to the people I've committed to on that night I'll be in big trouble.

Well, don't worry, some time.

That's the one in Coventry. So I was listening.

Forest of Arden. It's near Birmingham International airport.

Okay. I'll take your word for that. I've been to Birmingham twice in my life. If you were in Manchester I'd know where you were talking about but in Birmingham I don't know. I went for an interview for a job in Birmingham and got hopelessly lost. I remember it well.

Okay, well I think we're done here with this, aren't we? Thanks ever so much, your story's been ...

Well, thank you.

It's been an absolutely unique story.

Now, I've got to check page forty three, haven't I?

You've got to check page forty three. So thank you very much and I hope we get to meet again soon.

I hope so, Ruth. Thank you.

Thank you.

END OF RECORDING