

I've been involved with this university for a couple of years as a user / carer. I often get involved in talking to students of various nominations, i.e occupational therapy students but Alfie's now 10 and I quickly became a member if you like of this new world of disability. When Alfie was actually two years of age, because he used to see a certain paediatrician she asked me if I would like to go to the University of Durham, Queen's Campus to talk to first year students who were students to become our future doctors. So I did that for five years and it was five years consecutive, talking to the first year students but what was lovely was I came back each year, some of the students from the year before used to come along to see me and Alfie, and indeed his big sister Helen. So if we go back, what my story basically is, is around Alfie and the prenatal aspects, the birth and the couple of years following his birth.

Basically, right Sam was 17 months old when I fell pregnant with Alfie. With Sam everything was absolutely spot on, same as Helen, perfect pregnancy, breastfed, everything was absolutely fantastic. With Sam in fact I was home within four hours of giving birth which was great. Because of my age, I was 49, sorry 39, (I'm 49 now!) 39, me and my husband did want two children but time wasn't on my side so of course we went about it pretty quickly i.e the close age gap. So I fell pregnant, went to see a midwife who offered me the routine blood tests which has no effect on the baby, no effect on me, so I agreed to it. I thought 'well it's not like the amniocentesis where there is a risk of losing that baby' which I didn't want to take that risk of losing a healthy baby and having to go through all, you know, get pregnant again and all those awful three months where it's absolutely horrid, where you feel shattered and tired and yeah, it's quite hard those first three months of pregnancy. So anyway I went off to see my midwife and I said 'yes, I'll have the routine blood test'. 'Oh' I said, 'if there is a problem what will happen?' She said 'oh, I'll come knocking on your door'. So I thought 'oh nothing will happen, Sam is only 17 months old, he was a fine, I'm a healthy lady' anyway a couple of weeks later, after the blood test and time was getting on at this stage, I was probably getting on for half way through my pregnancy, just starting to feel pregnant, feeling well, getting that little bump, planned to go out shopping with my daughter and a friend, and the knock came on the door. And I looked and there was my midwife and I thought 'oh heck' - I remembered now she said 'if there's a problem, I'll come knocking on your door'. So, I answered the door and it was obvious that it was going to be sort of bad news, my daughter was upstairs with a friend, midwife came in, but basically I was left standing in my hallway and she said 'oh the results have come back, there's a 1 in 20 chance that you'll have a baby with Down's Syndrome. I'm really sorry, it always happens to the nicer people.' And straight away I felt 'oh heck, this is so negative; this is so serious' because I didn't have a clue about Down's Syndrome. Just I'd never grown up with anybody with any disability to be fair. Anyway as I say, I really had the wall holding me up and eventually we went through into the room, I sat down. She said 'well would you like to ring your husband blah di blah' which I did. BUT, in hindsight I didn't realise that Helen upstairs had heard everything - 'cos we were stood in the hallway and I wouldn't have wanted her to have heard that conversation because I did in fact keep that 1 in 20 result from most people including family, most friends, so I was quite upset later on that she'd overheard that conversation and even though she was 11, she did understand because they teach things about birth and what have you, you know sort of first year seniors.

So, anyhow she went, I phoned my husband but what she had said which did frighten me as well was 'oh but I booked you in for an amniocentesis tomorrow'. And I thought, I'm sure in an earlier conversation with her I said I don't want any sort of tests that might affect my unborn baby. Anyway, when Mark came home, my husband, he said, 'well we'll go down and then we'll know one way or another' but certainly with no intention of aborting the baby basically. So, I agreed with him. So I thought 'well, I'll go down' even though I really

didn't want to have this test, but then we'd know either way and we could prepare a bit better. Anyhow when we went down to the hospital, thankfully I spoke to a doctor, she was a female doctor and she sort of spoke to me and she made me think about both sides of the sort of coin really. Instead of it being all negative 'oh have the test, then you can get rid of this baby because it's got Down's Syndrome' which, at the time I thought must be the worst thing in the world. Anyhow so she, she didn't talk me out of it, but I said 'actually I don't want to have it, and we'll be happy, going through the pregnancy and seeing what's what'. So I left the hospital thinking 'YES, I haven't had that test, I'm not going to lose my baby', but then I thought 'hang on a minute, we're still not out of the woods, because we've still got the rest of the pregnancy to wait'. But I did try to put it to the back of my mind and people, like my husband would say 'well, if there's a 1 in 20 chance, why should you be that one person?' You know if there's 20 people in a room, if you work it out, it works out – is it 5% chance? So I thought, probably won't be me, well I hope it won't be me, to be honest.

But there was still those doubts so I went to the library, bearing in mind that Sam was just a little toddler still. While he was asleep in his buggy, I looked up a few sort of reference books in the library which were ancient, again really, really negative and I just sat in the library and just cried. And then I went home, I had a really, really lovely neighbour called Fay and she was like a mother figure really. So I told her, and again it was all negative 'Oh, Linda I couldn't bring up a baby with a disability. I work in a post office and there's people that come in with disabled children and they look haggard, their life is ruined.' And I thought 'oh heck' but I'd already, me and my husband had made our minds up that we were going to continue. And it was hard. The rest of the pregnancy was hard.

Anyway to sort of move forward to the birth, it was, wasn't a long labour, it was uncomfortable as labours are, went into the hospital. Soon as Alfie was born basically, we knew. Don't ask me how because I've never seen a newborn baby with Down's Syndrome, but the atmosphere just told us everything. I think, I don't know about everybody who's in labour but once I've had the baby, you go into a bit of a shock really. And all I noticed was no sounds, no smiles, my husband went over to a window and he was, well he was crying basically but while I was in labour I said 'Oh M will you tell me when the baby's born if everything's alright?' He said 'well how will I know?' 'Cos at the time you don't think you will, but in actual fact as soon as Alfie was born, the atmosphere just told us all. 'Cos I mean the midwife knows more than I do, and obviously he was much more floppy, he had those characteristics that, I don't know, I probably wouldn't have recognised because I'm not in that field. So the atmosphere was just awful and I went into I think a worse shock really, thinking 'oh God, how we going to tell people? How's the rest of our life going to be?' and sunk into a depression really. So we even had thoughts of moving to New Zealand to avoid people because we just thought it was that bad. I don't know, it's just all sorts goes through your mind. You just sort of think that you're one in a million, but you're not, when you learn more.

Anyhow, we brought Alfie home after about three days in hospital. And looking back, it's still hard, even ten years on, looking back because I had feelings, such awful feelings of what I'm going to tell you next.

Basically I'd breast fed two children very well, for six months, maybe a couple of months more; with Alfie because I didn't know a lot about Down's Syndrome, I thought he was feeding OK, breastfeeding and again not knowing much about Down's Syndrome, Alfie slept a lot so I did my best to feed him fairly regularly but he just seemed to want to sleep and people were saying 'oh God, you've got the ideal baby, you're so lucky, don't complain' and

a part of me thought 'this isn't right'. So in the middle of the night I was setting my alarm to wake him up to feed him and I honestly could have picked him and dropped him on the floor and he wouldn't have woken up. So I just thought 'oh that's Down's Syndrome.' So anyhow of course you have your daily visits from your midwife and I said to her 'well that pile of nappies there isn't going down. He hasn't had a poo' 'Oh don't worry it'll be low muscle tone and or it could be constipation, so don't worry.' So everyday I'd mention it again, 'he doesn't seem to be weeing much and he hasn't had a poo again' and me saying that didn't seem to acknowledge that there could be a problem there. Because looking back I think 'well, how stupid that I didn't put two and two together. If there's no wet nappies, obviously there's no fluid getting in him!' You know, my milk wasn't getting, he wasn't suckling like I thought he was.

Anyway, thankfully on day 11, the health visitor comes on the scene. And I knew this health visitor from when Helen was a baby because she was the same health visitor and she's a lovely person, obviously experienced in her work. And when I told her my tale, I think she could tell by looking at me anyway, because a woman who's breastfeeding, her boobs are absolutely full basically and she could probably tell that mine weren't. And she said 'Linda I want you to straight away start expressing milk' so I thought, 'right, I haven't got an expresser but I'll get one off my neighbour'. So I quickly, can you, 'I need to express the milk, have you got a machine I can use?'. She said 'yes' so I started but not a lot was coming through because this was day 11, I'd not really breastfeeding successfully and the milk wasn't, you know it's like a supply and demand effect. So she said 'start expressing every two hours' which, if you think I had two littlies, little Alfie there, fair enough he was sleeping a lot but I had Sam as well who was 17 months. So I did my best to get things rolling. I thought 'blooming heck, this is serious, something's not right' anyhow my health visitor rang me up later that day and she said 'Linda' oh 'cos she had said she would arrange for me to go to the doctor's. She said 'I've arranged for you and a hospital bed, I want you to go down there straight away.' So we went down, bearing in mind at this time Alfie as I say was sleeping a lot, there was a blue tinge round his mouth, which meant nothing to me, to be fair. His eyes were really wrinkly, like dehydrated it would have been, I didn't know at the time, I just thought 'oh it's just this thing called Down's Syndrome' but looking back it all started to fit into place that 'blooming heck, that wasn't a well child laid on my settee.' So we went down to the hospital, consequently we were in there for 12 days, basically feeding him up and getting him well. I don't know the exact what's in his notes, but I would believe that he wasn't well at all and I think if my health visitor hadn't come on the scene we could have lost him, I really do.

So in the hospital, were you and Alfie together all the time?

Yeah, yeah. We were together all the time. I had to go down into the intensive care baby unit to use their electronic machine to express milk. So for those 12 days in hospital, Alfie was being cared for, very well. I felt that my needs were sort of ignored, I was just a mum. And I started to get quite paranoid in hospital because I was in a little room on my own with Alfie. Every time I heard people laughing, I thought they were laughing at me. When I first went to express some milk there might have been an ounce there and I thought 'blimey that doctor's just tutted, how bad am I? What a bad mother I must be.' I felt totally inadequate basically. Anyway, and what was awful was the fact that nobody mentioned the word Down's Syndrome. I was Mum, Alfie was 'baby' and I thought 'do people know?' I really thought that people didn't know. And I don't know I just had awful, I was thinking 'oh people are laughing at me because of my age and oh they're laughing because 'she shouldn't

have been having a baby at her age anyway' and all these things, honestly were going through my mind and it was awful.

And after about a week a doctor came in and he asked me 'how do you feel about having a baby with Down's Syndrome?' And I thought, and it made it real then. And I said 'well, to be honest I'm a bit unsure about my future'. And he said 'well nobody really knows what's round the corner and life isn't easy for any of us'. And I thought 'well I know that because, you don't need to tell me that!' Anyhow he suggested writing things down. He said 'have you thought about writing things down?'. So I did, so I started to keep a little journal and I wrote a letter to a magazine. And I wrote to the Gazette about my experiences. And it was the health visitor who sort of, I think to take my mind off it a little bit, she said 'Linda why don't you think, there's nothing out there, why don't you think about setting up a support group?' So I wrote to the Gazette about my tale - that was publicised. And then suddenly I thought, I was on that sort of, not a roller coaster as such but like a treadmill of learning more about disability and accepting it.

And then with the breastfeeding I was absolutely heartbroken that I wasn't breastfeeding and then this other trainee doctor came in and he was lovely, he had a sense of humour, he made me feel quite normal and he said 'oh my wife had a problem breastfeeding'. So that made me feel 'oh there is other people have problems out there, whether they've got a child with Down's Syndrome or not'. And he said 'oh all she did was express milk into a bottle and then the baby, instead of getting formula was getting her milk.' And I thought, 'well why didn't I think about that or why didn't anybody sort of suggest it?' So simple. But when you're sort of in the thick of it and you are depressed or you are grieving or you are, you know, just going through that emotional, it was awful really. And just the simplest things, if they'd been suggested would have made such a difference. But I think sometimes people presume that because you've had two children already, that you know what you're doing. And that isn't the case, because having a baby with Down's Syndrome is a total different kettle of fish. i.e they do have low muscle tone, I know that now, and that includes the mouth! It's not just the limbs, you know it's everywhere, it could be the tongue, it could be anywhere.

Anyway, going back to the midwife who I was quite disappointed in, she would come and visit for those first 11 days and before I told her about the nappies she was saying 'oh hi Linda are you alright?' Well me being as I am, I would say 'oh yes, fine thank you'. But surely nobody would be alright if you'd just given birth to a child with a disability, you're not going to be alright, I don't think. But I pretended I was and I think with me saying that, she thought 'whoof, I'll just get on and talk about me own children, or talk about the weather instead of about little Alfie there being this model, perfect baby, just sleeping.'

And I must admit, what I wouldn't do, going back in time is have as many visitors. You know you feel dead popular and it's lovely people wanting to see your baby and, but it's so time consuming and it's tiring.

So do you mean professional visitors?

No, I mean friends

Friends as well?

Yeah, yeah. I would, you know because people do - whatever your child, whether it's born normally or with a disability or illness or whatever, you get that many visitors the first few days or weeks, then it all stops! So I would much prefer, if it was my own daughter for instance or anybody is - spread out your visitors, don't have them one after another, just in case there are any problems. There might not be but just in case, because that takes up your time and I remember one friend afterwards saying 'ehh Linda when you went upstairs, I actually went over and prodded Alfie because I wasn't sure whether he was alive.' So that's how still and quiet and different he was. (I'll just look at my notes)

Fine

So anyhow, moving on, when Alfie was about two, that's when I started doing my talks at the Durham University. And I think it is very useful to talk to professionals from my perspective 'cos I've been there, I've had the t-shirt, still wear the t-shirt. Anyway, as time went on, as I said Sam was diagnosed with Asperger's Syndrome. Alfie at the age of four or five was also diagnosed with Autism, so in effect I've got two. I've got Helen who's a young adult, I've got my two boys who are like kids from different planets. Absolutely, one at the able end of the spectrum and one obviously with severe learning difficulties and severe autism. So family dynamics are very, very difficult. And I wish sometimes that professionals, and not just social workers, but I wish they would understand more about what life is like. Not just the little half hour snapshot because Alfie is beautiful, he's endearing but he's hard work - because he has got a little bit of hyperactivity as well. He's ten, he doesn't speak, he's non-verbal, he's still in nappies day and night and very, very dependent and probably always will be - which, you know, we accept. But what would be lovely would be to have more support and more understanding from professionals. I can understand, being honest, why marriages split up and I can understand why, when I see in the newspapers and on the news, parents with the children, might go to a bridge and throw themselves off. And I'm only being honest but I can empathise with them because it isn't easy and people just do not understand. A lot of people are very presuming. For instance, I do live in a nice house, it's not a mansion and I've worked hard. We've got a nice house, I've got a lovely husband but that doesn't mean everything's OK inside them four walls. It really doesn't. And it doesn't mean because Mum might be like smiling, might be positive that things are alright because if you read between the lines or have the time for a conversation, people would realise that it just isn't, it's very hard. And there is support networks out there but what does support mean?

That's right yeah, it's one of the things I was going to ask you actually, is you mentioned when you went into the baby unit first with Alfie, like you said, you know there's mother and baby and there doesn't seem to me much meeting for the mother's needs

There isn't

Yeah, but what sort of needs do you recognise

What I passionately believe that parents should be offered such as ourselves at the time ten years ago, is some sort of listening service for the mum and dad, and siblings. It's optional, it's that you know it's there for when the right time is, because nobody knows when the right time is for advice and information support; but it's good to be aware of the way, somebody can signpost it when you're ready. For instance when children have a genetic condition I believe that they're automatically given the option of some sort of listening or counselling or whatever you want to call it, but with any other condition, there's nothing like

that offered. You're just left, you get the label, go away, get on with it. If you need any support, refer on to a social worker but there's no real support

M Support would be things like information?

F It would just be, I mean if I went to a support group and I'm on the committee of a support group and I'm really proud of it. But if there's a lot of you, you don't often want to talk in front of a lot of people about what your day's been like or ... I mean that happens more in a one to one. But in a support group, it's a group - so there's not often opportunity to have somebody there where you can just go in to another little room and say 'look, this is how I'm feeling; are these feelings normal?' Or it could be somebody in the group who knows where to signpost. Because I'm on this support group but I can't, I haven't got the qualifications to literally counsel somebody if you like, but I know that I can signpost them to somebody. But back then when Alfie was born there was nothing like that, there was Down's Syndrome Association in London and I think there was one in Newcastle but that was the

M It's quite limited really

F so quite limited. There's more now, thankfully. So yeah, I think other family members must be taken into consideration not just that, the person with the label. Because at the end of the day he was being looked after, he's none the wiser, he's a baby but everybody else, I mean poor Helen, she must have thought 'well hang on, me Mum's pregnant, why isn't she mentioning to me because I've overheard the story but Mum hasn't mentioned that my brother might have Down's Syndrome'. And when he was born, he was just a baby. And he was.

M I mean it was interesting what you said before about when the midwife came round and knocked on the door with the results and you said you didn't want to sort of like tell your family and friends. What was the decision behind that - was it because you thought 'oh I'll be able to soldier on or ...'

F Well I wanted to soldier on because I am quite a strong character and I just didn't want any sympathy

M Right

F And that's what I would have got off a lot of people. And I just wanted to go on and enjoy my pregnancy as best I could. I mean I did have my moments where I just wanted to cry and probably did cry. But again no one to talk to. Yeah that's what I've missed out really, quite an important point. We did have extra scans throughout the pregnancy and I'd said if there was anything there that was really serious, I might have to terminate the pregnancy. You know, say it was very serious, heart defect or... that's my thoughts at the time. Anyway but then I started having nightmares thinking 'blimey, after these scans we're having, if summat shows up, and I've over 20 weeks pregnant, will I have to give birth?' And it really did prey on my mind. So one day, Sam was asleep at home and I rang up the hospital, I said 'I need someone to talk to, I've been told there's a 1 in 20 chance, I've got no one to talk to and I'm worried sick that if one of these scans shows up something really serious and we decide to terminate, can you put me to sleep?' Basically, can you give me, you know what I mean, an epidural and all, not epidural even, a Caesarean?

M Caesarean right

F And they said no they couldn't do that because it's more risk to you because it's a serious operation, you'd have to give birth. So I was left to think 'oh my God if any of these scans show up anything serious and that's our decision, I have to give birth to a live baby?' Anyhow the lady on the end of the phone at the hospital was lovely. She said 'ah if you want to come down, come down'. I said 'well it's not as easy as that, I've got Sam here, he's asleep in bed but I just need my questions answered basically'. So it just shows that people do need someone at the end of the phone or ... But I'd lost trust in the midwife by that point 'cos of the way she broke the news; the way she made it all so negative.

M You know the health visitor, the person who came to visit you, was she not able to sort of answer your questions about those concerns?

F Well she was only around for so long

M Right, I see

F She probably could have, but once we'd been admitted to hospital, and we came home I can't remember that she was still on the scene. Because I think they're only there for so long, a certain chunk of that time. But she would have been the ideal person, yeah, but again your thoughts aren't clear at the time at all, so yes that was really hard that um, who could I talk to about my concerns, because there was nobody.

Anyway looking at Alfie, Alfie was born with Down's Syndrome but it was also found that he had a hole in his heart which is quite common in children with Down's Syndrome. So he had lots of tests and things to see whether they could do the surgery through his groin, you know it's quite complicated but rather than doing the open heart surgery, they were hoping they could do it that way but after going up to Newcastle the hole was bigger than what they thought here.

So anyway to cut a long story short, we knew that Alfie had a hole in the heart and it would actually need open heart surgery and they would prefer to do it before he went to school. So it wasn't urgent, the hole was there but all babies are born with a hole in their heart apparently, but it closes up itself. But Alfie's didn't, but I remember it was the 5th November which was bonfire night and we got a call from Newcastle, this was a Monday or a Tuesday, saying 'we've got a place on Friday for Alfie to have his operation'. And I thought 'can't do it, can't put him through major surgery because there's nothing wrong with him, he's a healthy boy, he's fine' because there was no obvious, there was no breathlessness, there was no, nothing, but it was something that had to be repaired. But what was great at Newcastle, they had sort of an in-between person, can't remember what her role was, well what the name of the role was but basically she was a go-between to ask any questions. And she said it's perfectly normal how you're feeling, if Alfie was like, if you felt he was really ill you wouldn't hesitate, 'cos his appearance and his you know, basically healthy child, it's much harder to make that decision to go for surgery and I said 'well I'm worried about Helen and how do we involve Helen in all this?' And she was so good, she was absolutely fantastic for advice and support and 'oh the surgeon you know is one of the best that you could wish for' and really made us feel at ease. So anyway we went off to Newcastle for surgery, had the surgery on the Friday. By the Sunday lunchtime he was up and running around as if nothing had happened. It was absolutely amazing. The only thing we had to be careful of is how we lifted him, because of the big scar on his chest. But it was amazing. 'Cos when they are sore, they appear poorly because they're all wired up and you know they're asleep and you think

'oh, is he ever going to be Alfie again?' anyhow he soon was, probably sooner than what we'd have hoped, 'cos he always has been quite a livewire. So that was quite traumatic to be fair. You know, any child going through surgery, but I think Sam had prepared us a little bit because he'd had a couple of minor operations so we'd got used to that sort of thing about going to the hospital, signing forms and having operations explained etc.

Other things that Alfie's had to endure - an eye squint, he's had surgery on an eye squint but again no problems, no qualms with any of the staff, all absolutely lovely. He's had grommets fitted in his ears. At one point we did think he was deaf and that came from a professional, told me that it seems he's profoundly deaf so that was another hurdle. I thought 'oh, bloomin' heck'

M So how old was Alfie when?

F Oh he was quite young, he was about three, BECAUSE that was the autism setting in. 'Cos he's so focused in his own little world, he would just ignore everything else no matter how loud or quiet, he would just focus on what he wanted to focus on and usually it would be something he wanted to twiddle or sort of a reflection in a mirror, or something quite, so yes so that's. And even now if you met Alfie you would think he was deaf because he doesn't reply to his name, doesn't wave, doesn't point. But he isn't. He can hear a sweet packet open like the best of children out there! So there's certainly no problem with his hearing.

He's had no chest infections which children can be quite prone to with Down's Syndrome because all the sort of airways and the make up of the face and ears, nose, everything is quite different to ours; but back end of last year bless him, he did develop pneumonia. And that's the first serious illness we've had with him so I feel quite fortunate about that. Yeah but it wasn't nice and I'd certainly know if he was going along that route to get pneumonia, what to look out for i.e the way he was breathing. Yeah, now that we've been through it I'd know what to look out for, the signs and get him to hospital sooner.

But ... but yeah, he's absolutely beautiful, all my kids are beautiful I have to say. Let's have a look through my notes, that's about his hearing.

Yeah with the autism, I'm going to blame the autism not the learning difficulty, he's got no sense of danger, absolutely none. And a sort of kick up the backside for me and dad, basically, was the day that he jumped out of his bedroom window, and survived thankfully – it was a miracle. It really was. Alfie has an obsession with water, absolute obsession, it could be a puddle, it could be taps, it could be a pond, it could be his own wee, ANY sort of flow of water or even stagnant water, and we didn't really realise how bad it was until this day. It was a day in June, 13th June and it was some famous footballer on the telly, can't think who it was now. Anyway, I'd put Alfie to bed and it was a really, really hot day, we'd been to South Gare for the day so I was red raw from the sun. Anyway I put Alfie to bed, went up to check on him, opened his bedroom door and I must have just slightly, he was probably just almost asleep, as I've opened the door I've woke him up, but didn't think I'd woke him up fully. Anyway I went downstairs, sat on the settee with my half a lager and bag of crisps, thinking 'oh I'll watch the second half of the football'. Mark was out because he was out every Sunday night (yeah football must have been a Sunday). Helen had left home at this point but she was there. All the windows were open because it was such a hot day. So I'd just sat down, the sprinkler was on outside, the garden sprinkler. Next thing I heard was an almighty thud. I jumped up, looked out the window and there was Alfie on the ground. So I

just screamed to Helen '999'. I just screamed and I ran outside and I just scooped him up off the floor and he was limp, he was unconscious then basically. I started going absolutely berserk. My neighbour came running round 'Linda, Linda what's happened' and I explained. She said 'Oh Linda you shouldn't have picked him up, with a fall or anything you have to leave them.' I said 'I can't, I couldn't have left him on the floor, he looked like he was dead'. So anyhow I picked him up 'cos I was like really, I'd gone hysterical. He came round. Anyhow the ambulance came so quick, so we rushed off to hospital, stayed there till the early hours of the morning. Mark came along and like I say it was a miracle, all he had was a black eye. BUT he hadn't fell out the window, he was on a mission, the water! And that's what really made us realise then, bloody hell, do you know what I mean? He has got NO understanding of danger whatsoever. 'Cos I didn't really know a lot about autism at the time, you know I've had quite a learning curve, quite a steep one. Yeah so it was, it was a miracle the fact that Helen was there, the fact that I'd sat down, 'cos normally kids are in bed you sort of potter round. I'd heard him fall. Where he fell was a miracle because it was wet with the sprinkler, he'd missed quite a wide part of the paving underneath the window, he'd missed the open window downstairs, which could have been fatal couldn't it, landing on that? He'd landed in my border which had cobbles, not little pebbles but cobbles and then there was a gap of nothing, just like mud if you like and then more cobbles and his head landed in that soft gap. It was amazing, absolutely amazing

M It's incredible that

F Yeah, so obviously since then we've had to put a lot of things in place at home and at school, respite, everywhere he goes to ensure his safety. Because he would run off and as he's got older he's got quicker, as he's got older he's got stronger. I mean he has got out of the window once since, and that's with his dad, it could have been me. That's why we hesitate who we leave him with. Because if things like that happen with us, it, you know it could happen even more so or maybe not, 'cos I guess if you leave somebody who you trust, leave somebody with somebody that you trust, they're probably, I'm not saying they'll take more care, but they'll probably shadow him more than a parent. I don't know, but we have to be so careful really that people understand Alfie's needs because even Helen, his big sister, 'cos she's left home she's become more like an auntie and even if she holds his hands when we're outside she doesn't understand still, if she doesn't hold his hand tight, he'll let go and he'll be on the road. So he's, he is hard work and what makes things harder at home is the fact that him and his big brother are so different. We acknowledge that. You can't force people to get on, you can't force people to play and over the Christmas holidays, it's been hard because one person said to me, 'Linda, what went wrong?' meaning 'What went wrong in the family', 'why do your two boys not get one, why don't they play?' and that was a family member. And I went to bed with those three words 'what went wrong?'; thinking 'is it me? Am I a bad parent? What have I' I don't know but it's not nice to hear. But again it's just people don't understand and it is hard. I mean they're all fantastic kids, but so different. But me and Mark are getting on with what we've been dealt. It isn't easy but we love the kids

M What are your hopes for the future?

F For the future, Helen is quite happy, she's single, she's working at the hospital, she enjoys that.

Sam has just started senior school. He's coping very well. I think if he's understood by everybody there'll be no problems. Because he's a little bit quirky. He is a little bit lacking

common sense sometimes but very intelligent in other areas. So I don't really worry too much about his future. I think he'll end up with a fantastic career, as long as people understand him that he's not sociable and just to be understood.

Alfie, to be at school till he's 19 and he's in an absolutely fantastic school at Redcar, a special school. Haven't given a lot of thought as to what will happen after that, but he won't be at home. You know I'm 50 this year, and it's only natural that children grow up and they leave home. So we have to sort of find a sort of lifestyle for him and there is options out there. Admittedly a lot of them are out of area, which is a bit of a shame, but no, I just hope Alfie continues to be so happy. And he's a pleasure. And I don't regret a thing. And anybody who's out there who's going to have a baby with Down's Syndrome, 'cos I understand Down's Syndrome, celebrate - go out and celebrate. Because I wish I had, I really do, because he's brought so much ... I've been to things like, for instance ice skating at Billingham with Alfie, except you can go on with him in his buggy or a wheelchair and I can go in with my flat shoes on and it's inclusive. It's something that you wouldn't think a child in a wheelchair would be able to do, but they can. I've been cycling with adapted bikes with Alfie which is fantastic. I've been to the Calvert Trust and that's an organisation that do sports and they challenge. They won't say no to anything. So Alfie, despite his obsession with water, has been canoeing, he's been sailing and I think he's lucky because he's got me now, I like to do all these things so .. he's been on this fantastic zip wire - I'm at the bottom, he's up there getting harnessed and 'wheeee'. 'Cos I know what he enjoys, do you know what I mean, and he is an active boy, but that's when he's at his best. Yeah, so we've and I've met some lovely people, I've helped a lot of people, so yeah, we'll see what the future might bring.

M If you were to give birth to Alfie now, and knowing what you do know now, do you think things will have changed? People's perceptions of children with Down's Syndrome, how they treat you and

F Alfie little bit

M Yeah? Alfie little bit

F A little bit. Yeah I mean to be fair, I think because Alfie is so endearing, he's so innocent and 'cos he doesn't talk and things, he seems younger than what he is. We've had very few adverse comments or tuts and things. You know, say 'cos I'll be like, see if he's thirsty, he'll just take a drink so it could be a family sat there you know having a few, you know Capri Suns or whatever and Alfie I'm thirsty, there's a drink, I'll have it. So there I am apologising profusely and most people when they see it's Alfie, they'll say 'it's fine, don't worry'. A couple of times I've had like people, 'cos he can be quite loud, vocally and so, and it's understandable, if I had somebody suddenly screech or go 'eeeeeee' behind me I would look. And I accept now that in the early days you'd think people are staring - but a lot of the times they're not, they're curious for whatever reason. 'Cos I will, if there was somebody over there with a child with Down's Syndrome I would be DYING to go over and say 'hello' but I'd be looking, thinking 'should I or shouldn't I?' and I'll be seeing what their child. And it's like with any child growing up you do, you don't intend to compare but you do, you sort of look and see what's similar or what is dissimilar. But I would hope things have changed. The main, I don't know I think the autism is the hardest part for people because it's a hidden disability. So I think that's the hardest part for people to understand, you know a child who's past that, SHOULD be past the age of tantrums, is still having them. And people think that's bad parenting and it isn't. It's just that child has got a lot of complex issues going on in

their brain, especially round sensory things. So I would hope for more awareness really about autism in the next ten years.

M Yeah. Do you feel that people THINK they're aware of autism, 'cos it does get quite a lot of publicity doesn't it?

F No, people think they know because they've seen Rain Man or, and that's ... it's a spectrum and they're all so unique, so different. It's fascinating, absolutely fascinating but complex, yeah you can't just say, you can't just think you've read a book or you've seen a film and understand it. You just can't, no it's quite, it's amazing. So yeah life is difficult but challenging, rewarding, interesting, keeps me going.

So yeah, I'll just check my notes so I haven't missed anything.

Yeah, one thing I'd like to say is once Alfie was born and I'd got over all that grieving, accepted my child with Down's Syndrome and looked forward to teaching him, I bought all these resources to help teach him, everything, colours to speak, matching pairs, everything like that. And then when he was diagnosed with autism, I had to go through all that grieving again, 'cos I'd lost that child with Down's Syndrome and a child with autism is a total different kettle of fish. So I did go through a little while of thinking 'I want a baby with Down's Syndrome only'. Because I'd really got my mind set on that, and I think my aspirations were a little bit high so I had a long way to fall. But yeah I did go through a period of grieving again once that diagnosis

M Did people understand that?

F Professionals did

M Yeah

F Some, like Alfie's psychiatrist did. The community nurse understood, but no lots of other people don't. And grief is a complex thing, you know 'cos men and women sort of deal with it quite differently so, but no

M You said your husband didn't quite understand at the time?

F Well, he did obviously he was there when we got the diagnosis of autism but I think to Mark, it was just Alfie, no matter what the label, which is a good way to look at it, where I was thinking more deep, thinking 'oh I've learned all of that about Down's Syndrome now I'll need to go and learn more about autism'. Where Mark just, I think, lives more day to day, just gets on with it. Yeah. I think some men sort of might, 'cos I know a lot of families, some men sort of put their head in the sand to ignore it, other families I've met, grandparents can be quite a challenge because they tend to ignore it, think it's going to go away. They'll say 'oh one day it will, you know he'll meet a lovely girl and get married.' But some children it's obvious, I mean Alfie probably won't to be fair. But I think sometimes grandparents want to make it better, they want to fix it. And that's quite hard for the mum or dad sometimes - 'cos deep down you know it can't be fixed

M Grandparents are sort of like trying to put on a very positive front

F Yeah some put on a positive front and some I've come across totally ignore it, ignore that child. And again it's probably their grief and no one to share that with; that 'hang on do you realise what you're missing out on, it's a child'. But sometimes whatever, it could be something that's happened in the past or.... So relationships can be affected in lots of ways. I think, I mean we've only got Mark's mum, grandma and she was quite tearful in the early days, sort of rushed us out 'cos the Salvation Army were playing in the street, 'come on, bring Alfie out' as if you know, something was going to cure him. But she's accepted him, yeah. So yeah, it's quite a journey but could have been better IF there was more positiveness at the beginning. It's too negative, this thing about disability just equals negative thoughts and actions.

M 'Cos you obviously recognise potential, you know in obviously all your children but because there are very special circumstances as well, there's got to be special considerations but you can still have that sort of vision of what these children can be like in the future as well, yeah?

F Yeah, yeah honestly children with Down's Syndrome are beautiful. And they are all so individual. I mean I've seen little girls of about say 11, and they're proper flirts. And they like to wear all the clothes like Girls Aloud, just like any other 11 year old. But they might not talk very clearly, might be a little bit slower, some on the what I would call Down's Syndrome spectrum, some of them are more, probably more able than some people without that label. Because you know some have gone to university, not many, some drive, some do get married. So you never know, you never know with that child that might be born with Down's Syndrome, what's ahead. Nobody does do they?

M No

F With any child? Nobody knows what's ahead. I'm at a funeral tomorrow, of a young lady who's just died, 16 and I'm, when people sort of complain about the children, not in a negative way but in whatever way, I think 'well, they're still here. The main thing is that they're here'. So make the most of every day. Yeah.

M Well I think that's a good positive message to end on because I know you've got to go, somewhere else you've got to be. So, thanks very much for sharing that experience with us

F You're welcome

M We really appreciate it.

F You're welcome