

## Interview with Peter about his son, Billy

**Interviewer:** Tell me who you live with who's in you family.

**Peter:** With myself and my wife Sally, we have got four children. The oldest is a girl called Kemi, she's twelve and she's at secondary school. I have three boys, Colm who is at the top of junior school, about to move into secondary school and then Dominic who has just started at the junior school and Billy who is in his first year, the reception year at the infant school. It is Billy who has Downs Syndrome..

**Interviewer:** How old is Billy and what does he like doing, what are his capabilities and limitations?

**Peter:** Okay, he is 5 ½ years old. The thing he likes most is video. He has quite a variety of videos that he likes now. It used to be just one which was a Dave Benson Macton video but he has now gone through 'Fun Song Factory' and 'Shrek', 'Jungle Book', and his favourite at the moment is 'Sesame Street'. He likes cars. He has a particular lorry that he likes that he can't find at the moment so he keeps coming around saying 'lorry, lorry, lorry', but we can't find it. He likes football, playing football, certainly when the other kids are playing and particularly in the house he likes playing football. He likes music, he likes the computer which he is quite good at, he is getting more confident using the mouse to sort of find his way around different games and software. But his limitations – he does have quite severe limitations. We are quite clear about that really, we know that he does, even in terms of other children with Downs Syndrome I would think at his age there are others who would be quite far ahead of him in terms of the more academic skills or language skills. He is quite good at 'Macaton' he has quite a lot of Macaton signs and he has quite a bit of spoken language now as well but a lot of it tends to be single word use or single sign and he is starting to put two signs together or more often now two words together, sometimes three as well but a lot of it isn't clear to other people who don't know him well or are not used to his language formation. But that is coming, he's making progress with that. That's fine, he's at that level. The other thing he does which is sort of something he likes but is also a bit of a limitation in other ways is he gets a bit locked in to his own, not necessarily his own world but his own little game which is not very interactive with others. He is really into dogs as well at the moment. We had friends stay for a week or so and they had a dog with them so he became a dog and he has not really got out of it since, so he goes round finding sticks and holds them like he is wagging a tail, so he is really into that but that sorts of locks him into that. It is very hard to get him to play anything else or to join in with his game. He will occasionally do that with other things as well. Sticks he will use as drum sticks but he will wander around the house with sticks in his hand and play and sing to himself, you can lose him for a little while in that sort of world. It's to such an extent that I think we have both queried or wondered whether he might have autistic features as well, but we are not really quite sure of that.

**Interviewer:** How is he physically?

**Peter:** Physically he is very good. I think he walked at a reasonably early age, I think about 18 months he started to walk. He was slow to begin with walking out. As we were walking to Nursery a year ago he would want to be carried on the way home and stuff like that but now he walks quite happily down to school which is only quarter of a mile away. He will do that without problem. But also as a family we go out for walks in woods and by the sea and he does really quite well and occasionally he will want to be carried and a piggyback sort of thing but depending on his mood and depending on the games we are playing along the way and if there are stones to throw in a river he can walk quite far. But it is slow. As a family walk there is a big gap between those at the front and those at the back. But otherwise physically I think he enjoys playing football, he enjoys more and more running about and jumping up and down, playing on the trampoline. A little bit he will play in the park going down slides but sometimes he will go down once and that's it, he's done it. Other times he will go again and again. His fine motor physical skills are quite limited and that's something that I think has hampered his learning and development in terms of he doesn't really enjoy drawing or even colouring or holding a paint brush to, a little bit with the paint brush, actually, he has had a go at. But things like holding a pencil I think he finds difficult so he just doesn't do it. He will avoid things that he is aware that he cannot do so he just doesn't do them.

**Interviewer:** When did you know that Billy was a Downs baby?

**Peter:** It was more or less as soon as he was born. Sally in fact I think it was that spotted. I think I heard she said since she felt that he just didn't quite look the same as any of the others not that the others are all identical but she just felt that there was something in his look and then she looked at his palm and the single crease across his palm she queried and thought from there that he had Downs Syndrome and asked me and I thought well, yes, possibly, so that must have been within the first hour of him being born, so were alone together in the maternity room after his birth.

**Interviewer:** *What was your reaction?*

**Peter:** I think just curious, really, to find out. I think for both of us, because my professional work is with adults with learning disabilities and Sally as a physio has always worked with children with physical disabilities mainly but also with learning disabilities I think we were both fairly well steeped in the world of special needs or disability and it's something that with each of our children I think that we had always in pregnancy considered that well that would be a possibility so I think for us it wasn't such a shock that we couldn't, you know maybe for other parents they would never have expected anything but a perfect child, but we had that thought in our minds, maybe not to the fore front but in the backs of our minds that that was a possibility. So I don't think it was the bolt out of the blue that maybe other people experience. It was a surprise but not a dreadful shock. I think we were just quite accepting of that fact really from the word go. I don't think it's, there are other difficulties

which maybe we will cover but the fact of him having Downs Syndrome in itself wasn't, we didn't feel was a huge disaster or anything.

**Interviewer:** What were other people's reactions, your family and so on.

**Peter:** I think they were a little bit more taken aback. Grandparents probably. I think partly because we have got four children and in this day and age that is a big number of children, everybody says 'oh you have four, how do you do it, how do you manage?' And I think you know a fourth child who has special needs with learning difficulties there are greater demands and having three others as well there is quite a lot of juggling and organising so I think that other people's reactions were that on the one hand, yes, I think people thought, and I suppose it is a bit flattering in a way, that it couldn't happen to two better people, knowing friends and people who obviously were aware of the work that we do 'well that's right up your street' sort of thing. So I think they felt that that wasn't really a problem to us and therefore why should they see it as a problem. So I think reasonably positive and accepting. People have said that they have been really quite inspired by some of the way they have seen us work or deal with Billy or bring him up or just accept him into whatever we are doing really.

**Interviewer:** Are there any particularly difficult care demands?

**Peter:** Very ordinary every day things like he will take ages to eat his breakfast some days and on a school day obviously you think 'come on and get on with it' but he will just sit there and he won't because he's maybe not quite woken up or something yet, but little things like that really I think, -when he doesn't want to do something that you are trying to get him to do like get dressed, He is not physically skilled / able to get himself dressed and sometimes he just doesn't cooperate and doesn't help and will actively do the opposite of what you are trying to do.

But he sleeps well which isn't necessarily the case for a lot of children with Downs Syndrome, so I think we are quite lucky there. He is a good eater in the sense that although he might be slow to start his breakfast he does eat a good variety of foods, he is not particularly picky, certainly not any more than any of the others, in fact he is probably better than the others at some things so he is quite good for stuff like that. Sometimes communication can be a barrier for him and for us. There are times when we just don't know what he wants and he can get quite upset and you go on and on trying to get the message across and maybe end up with him being distressed and crying and we don't quite know what he wants so that's a difficulty, so the communication is quite a problem.

**Interviewer:** What about impact on family life, finances and the impact on his brothers and sisters?

**Peter:** Finances – whether it has made an impact on us financially I don't know. We do get benefits from disability living allowance. We wouldn't know if there's been an impact financially, I don't know if it does particularly. I mean

there are things which the allowance covers for and things like when you are looking into getting switches or access or other stuff for the computer or games or new books if you like we can do that because we have got a disability allowance coming in which covers extra things which we wouldn't necessarily otherwise buy. But yes, impact on us as a family – he definitely does have an impact and some of that is positive. I want to say that first he definitely is positive in terms of relationships with his brothers and sister and theirs with him, but other things that, say, we are out for a family walk we have to be aware that he will be slower or he will need carrying or we can't go very far, but also some of the times that he does need somebody with him quite a bit of the time to do a lot of the stuff that he might want to do unless he is sitting watching video which obviously you can't do all the time. So he has a lot of social needs really in terms of needing one or other of his parents to be around so that limits how much we can do with the others and that kind of thing. So I think that he has an impact in that way and probably, again, part of that is just because we have four children so we do find it tiring. It's difficult to share ourselves between all four of them when they have individual needs or homework or after school things and you've got to be in different places at different times. That's hard anyway but some of the time it's just that little bit harder because of Billy I think.

**Interviewer:** So what about his brothers and sisters, how do they get on with him?

**Peter:** Very well. Some of them better than others in terms of the way they interact. Some of them, like the older ones have more homework or more schoolwork. Dominic being that little bit younger and maybe closer to him in age I would say is particularly good, he does have a wonderful way with him in terms of not just play but in terms of knowing how to get the best out of Billy. The others do too, but they maybe have less time or less frequently do so because they are busy with a lot of other things just being that little bit older. But being older, I mean again Kemi is more recently now starting to help get him ready for bed if we are busy or out or something like that, so she is at an age where because she is older she can take more of a role with that at times. But that is not very often, but she can do that.

**Interviewer:** So they're probably becoming very caring.

**Peter:** Yes, I think they are pretty caring people anyway so whether that is Billy or not I don't know really. I think that by and large they pretty much accept him and a lot of the time don't pay him any more attention than they would do to any other younger brother, so sometimes I think they don't actually see his needs or they don't see them any more than the fact that in a way that he's a younger brother, and maybe he can't do this or can't do that in a way that the oldest might not see the needs of a younger brother.

**Interviewer:** So they just look at him as a younger brother.

**Peter:** Yes, they just look at him as a younger brother and they may be aware that his development is slower and there are certain things he can't do

but some of the things they are not aware of simply because they see him as a younger brother and sometimes younger brothers can't do as much as older brothers or sisters.

**Interviewer:** What is your experience with Education?

**Peter:** I think we are aware that in South Tyneside we don't feel that in terms of special education needs they are very forward thinking as an Authority, so we were fairly sure that we would have difficulty and battles along the way in terms of going for inclusion in Education. So we started early with actually requesting a statement when he was very young, probably 18 months / 2 years old, requesting a statement which came but it took a long time and at least that got something established and got him known to the Authority I think. I think it was when he started approaching nursery age that we revisited and reviewed it and that was our first battle in terms of really acknowledging his needs and getting the amount of support to be at nursery that he would really need and I think that we had quite a struggle with that over his statement at that stage. We had a statement which was fine at an early age but as it came to looking at school the number of hours support that they were offering was purely based on what they could afford and not on his needs and that was why we were keen to have him statemented early on so that we could say 'well that's what he needs', which was more or less full time support at that stage in nursery. He ended up getting double what they first offered. They offered 5 hours a week and we ended up getting 10 hours a week. That took a lot of stress, a lot of letters, a lot of meetings, a lot of looking into the issue, getting a lot of support from the Downs Syndrome Association, or Downs Ed, people there were very good and other things like IPSIA, I was going to these people and saying 'you know this is what they're coming back to us' and they were saying 'well you can't have that' and they were very supportive in saying 'well actually no they're wrong to just try and brush you off and hope you go away'. We didn't go away and in the end they did relent and give the 10 hours support that he needed. It did get to the stage where we had said, 'well fine you put that in a statement and we will just take it to appeal and we will go that process' and then it was at that stage they finally said 'well we'll give you 10 hours then'. I just feel that they needed pushing to the brink before they would actually turn around and acknowledge the needs that were written in the statement. Since that time actually it has been a lot better, I don't know, partly they might say it is because of improvements they are making in the Authority but I think it is probably because they have acknowledged that we are not going to be brushed off with less than Billy needs so when it came to transferring from infant school and looking at the amount of support he would need there we had a lot less trouble and he is quite happy with the eight sessions per week more or less four days per week that they offered and he now receives. But it was that battle I think that we had initially that was definitely very stressful.

**Peter:** Social Services we actually haven't had a lot of contact with so I couldn't say a great deal about what their support systems are like.

**Interviewer:** Did he have to have heart surgery? When and what was the experience like?

**Peter:** He did, yes. That was quite traumatic. I think, obviously, we recognised early that he had Downs Syndrome so when we went back to hospital after a couple days and they checked his heart and at first they found that they couldn't hear anything but we were sent from South Tyneside Hospital up to the Freeman Hospital for further checks with cardiologists there and they found a murmur and a hole in the heart which was a ventricular septal defect and so we discussed the need for an operation. So he was booked in for an operation when he was three months old and that was really, really traumatic. That was a nightmare. Apart from anything else we have had that was the worst. They were absolutely excellent in the Freeman from top to bottom. Since the stories in the press and the media that there have been about people or children with Downs Syndrome not getting heart surgery because they had learning difficulties or whatever, we had no experience of that whatsoever. They were absolutely brilliant. It was still traumatic. The whole process went, the operation went very well but after that it took a long time to get him off the ventilator and he had RSV, Respiratory something Virus and he had bronchialitis so he had various problems that they struggled to get him off the ventilator and instead of the whole thing taking a week, you know in, operation, recovery, out, I think it was 3 or 4 weeks before we finally got home so he was in intensive care unit there for probably three weeks and we were frassled. I think basically the one thing that would be there at the back of our minds was that we were going to lose him and that was really really scary because he was on this thing all the time and they tried to get him off but they had to put him back on again. So it was very upsetting and I think that we might have at one stage had this conversation with one of the anaesthetists because we weren't quite sure whether it was in the back of our minds because of the fear that he could die or whether that was a real possibility, so I think we had that conversation and I think he reassured us 99% that, no, he wasn't going to die, it was just going to take time. But still you can't guarantee these things, so yes, that was a nightmare really. Chiefly because of that fear and what he went through for such a long time but again practically it was a nightmare having three children at home and him in hospital and us coming and going. Fortunately we are both lucky with our employers in that we were able to be off sick and take time off for that whole time. But yes that was difficult really. We took him out and he was on oxygen still, he still had trouble breathing so for months afterwards his pushchair had an oxygen tank at the bottom, but it was fine, he only needed a little bit but he needed a little bit of oxygen to begin with through the day and during the night and then it got to just night time and I think it went on for so long we went camping in the summer holiday, we go camping, so we went camping and we had to take the oxygen bottle with us, so in the tent there was the tent pole and we had the oxygen bottle strapped to it. So he recovered fine and eventually came off the oxygen so, but I think it was obviously something worth doing and it made a big difference to him. I think the first three months because he had it early at three months of age he was quite a sleepy baby and I think more or less as soon as he had had his operation that changed, he was sort of more awake, more alert, or awake for longer periods. So I think

we saw a real difference in him and obviously in the long term it's good for him.

**Interviewer:** What about Billy's quality of life? It sounds quite good doesn't it?

**Peter:** I would say so, yes. You mean in terms of health or just generally?

**Interviewer:** Generally.

**Peter:** Yes. He loved nursery. When he moved across the infants school he found that very difficult with it being a new situation. A lot of the children were new although he had been at nursery with some of them there were many that were new and new teachers and new support / care assistants so he struggled, he was quite stressed, he was wetting himself quite frequently at school and reluctant to go down there to begin with. That gradually improved in the first half term and then once the holiday came he must have thought that was all over and going back was even worse because he did not want to go back. So that was again a struggle but again towards the end of the Christmas term he gradually got used to it and was getting better and was improved and we thought now with two weeks' holiday he is really going to think he's not going back, but for some reason or other when he went back in January he was fine, he has enjoyed it since. He has had other problems since in terms of his behaviour, in terms of he has got into something more recently of kicking out at either teachers or other children. Some of that we really don't know why it is happening. Some of it there is maybe other causes that we are trying to deal with. And the school have been very positive through all the first term and the difficulties they had there and through the difficulties with his behaviour now they have been great.

The thing is now that he enjoys it and he enjoys going down to school. He is gradually getting more sociable with the other children because he is actually quite a shy person, he is quite a timid little boy really in some ways so socially it has taken him a while to get his confidence with other children, but he knows all their names now and he's got photographs on the wall here with them all and he sees them and says their names. So he does enjoy school and he's learning there. As I say, it's slow and maybe slower than we expect, probably slower than School expects because although they have no experience of it I think they probably looked around at other schools with children with Downs Syndrome and maybe saw children who were reading very well or doing this and doing that and Billy is not doing that. I think they have not been quite aware of how wide the range of learning difficulty is compared to the children they are used to anyway. Ourselves, I think we are still finding out what his level is really and he is beginning to read and recognise words and be able to say words and beginning to put little sentences together, but it's slow and he's not, he loves books but he doesn't necessarily like reading them himself. He will repeat words after you but he doesn't want to necessarily do it himself, initiate the reading himself. He will listen first really.

**Interviewer:** He's quite a happy little boy generally?

**Peter:** Yes. I would say generally he is. You know at times, that is, as long as he gets his video but at other times it's just because he is generally happy and he will watch his video and come and chatter away and live out and act out the songs and actions he has seen on there or the counting things that he has seen on Sesame Street. He will sort of re-live them.

**Interviewer:** I know that Billy is only 5 ½ yet but what do you see in the future? How do you think he'll integrate and do you think he'll have relationships?

**Peter:** It's difficult really. Partly I think it's difficult because we actually don't know very well for any of our children what sort of future they'll have. We kind of imagine we know, but I think we are beginning to find out more and more that we don't really. They all get on well at school academically, but at times we have worried – are they spending enough time with their friends or are they spending too much time with books and you know I think socially you worry about them as much as you might about Billy. But, yes, we probably worry more about Billy or be aware more that it's not easy for him to make relationships partly because he is quite shy and timid but also partly because of good communication difficulties that he has, - and also partly because his learning difficulty will mean that he will be at different levels or interested in different things to other children. As they grow the educational gap gets bigger. At the moment the other children in the school are great with him, they are positive towards him, they enjoy having him there. They are very keen on his Macaton signing so they do that in their little group at the moment. Actually they do have a lunchtime club for learning new signs. So they have been very positive to him. He gets regularly invited to birthday parties and all that kind of thing so he has got a lot of contacts which he is beginning to be able to cope with better himself and develop that so that is all very positive. One day there will be a blip in that because we are actually going to keep him in the reception class for another year so all his co-ward now will move on and he will have new sort of relationships to develop this time next year, so that may be a slight pause but I think he will still have the children that have moved on and are still just a year above him – they will be around in the school. For the future I think it is very hard to know. We do want him to stay in main stream school and carry on. I mean he is staying back this year, but beyond that he will then move on up the school and we want to maintain that through mainstream school. The future is unknown and I think we slightly differ, I think that Sally is probably more worried about it than me and I think the future is unknown but I think that that is probably because it is the future and we don't actually know. We just imagine we do and we think that as long as we're doing what we can now, and looking at the school he needs to get through, and maintain relationships that he is starting now, then the future won't exactly take care of itself but we'll have to deal with that when it's time for that. But I think partly the fact that he is at his local school, he is well known by lots of kids not just in his class but in his year and probably the whole school, walking home from school they're all sort of saying 'oh, there's Billy'. So he's quite well known and the fact that he has been able to be in the

mainstream school has maintained his presence in the community and being the place East Boldon is, that is quite an important thing really because he will be known and staying around here in the future.

**Interviewer:** Do you think about when he's an adult?

**Peter:** Yes, I mean we have talked about that as well. We haven't really gone into detail of what we want for him or what he might want for himself at that stage really. I mean I work with adults with learning disabilities and am forever saying that you've got to listen to what they want, not to what their parents want. So that's something we're going to have to deal with in the future - that really he is going to make his own decisions about where he wants to live or who he wants to live with and I would guess he will need support in the future. He won't really be able to lead a fully independent life but that's a guess and it may not be so, but the kind of support - his living circumstances - whether he lives with other people with learning disabilities or whether he lives on his own. I don't know, that may be his choice in the future and hopefully by then will be. You know that services will develop in ways that people do have choice about which they don't necessarily have at the moment. So, yes, other relationships he has, it's really hard to say whether he has a girlfriend and gets married or if he's gay and doesn't get married or whether gay people can get married by then, I don't know. Ten years is a long time really and I think certainly in the field of learning disabilities things can and have and I think will change a lot really. It's not that long ago that people, everybody, would just go off to a big institutional hospital and that was that. It's not that long ago that people started to move out really and not go into those hospitals, so in terms of the history of things, things have moved on quite quickly. But, yes, there is still a long way to go but I think things are moving so it really is hard to predict what his future will be and what the support services will be at the time really.

**Interviewer:** Can you say briefly what would you say is the most rewarding thing about having Billy?

**Peter:** One thing which is the most rewarding - I think it's - how can I capture one thing that is the most rewarding? It is actually probably not a lot to do with the fact that he's got Down's Syndrome and that makes him somebody special. I think we have 4 children because we like children although they are very tiring and sometimes I think we forget that, but that he does just the very ordinary bits like he does funny things like other children do - funny things and you can enjoy those funny moments and there are little moments of pleasure in his life when he gives you a kiss or a cuddle or he does something funny and he laughs himself silly and that would be the same whether it's him because he's got Down's Syndrome or one of his brothers or sisters really. You're just enjoying the moments of pure pleasure, of being a parent really. So, yes, I would say that's it.

**Interviewer:** What about the most difficult thing?

**Peter:** Is it getting him to eat his breakfast in the morning? I don't think so. I think it was certainly his heart surgery – that was the most difficult thing to cope with. I think the other thing that is more related to Downs Syndrome itself rather than the fact that he had a hole in the heart was probably the stress we went through for the educational support that we felt he needed. But on a more day to day basis now I think that it is probably bits where we do sometimes feel a bit down because he has had a bad day at school and that is maybe to do with his behaviour and stuff like that. Or at times where we feel we're failing him because we're not giving him the support, or the time that he needs at home to just have the fun that he needs, or the play that he needs or the time that he needs as much as any of the other children. He maybe needs that a bit more. That's quite hard, so emotionally I think sometimes we feel we are failing him and sometimes that feels that if we fail then he's going to fail and maybe that isn't so but sometimes it feels like that. It's that we don't do things right. If we don't support him and with his reading, support him with his learning that he's not going to learn those things. I think that's probably just us seeing things on too short term a basis and not really giving him the credit to feel he will learn them but it will just take him longer and that sort of thing.

**Interviewer:** How has it affected your life personally?

**Peter:** It has probably meant that in the same way as it has affected family life, things that again partly just having a fourth child means that the older ones can't necessarily do all the things that they would want to or would be able to by now because we still have got a younger one in tow as it were and that's probably going to go on for longer. So probably for myself it's probably the same really, the amount of energy you put in to a three or a two or a four or a five year old we're maybe still going to be putting in when he's six and seven and eight, or it's still going to be there for us to put in, if we've got the energy left by then, I don't know. So it's that stage of life moves on more slowly I think, so that we're parents of the younger child for longer than we otherwise would have been. So I think that, energy is something that we probably need, but we are probably at that stage of life anyway. We are both past 40 and we would be feeling it whatever.

**Interviewer:** So what would you say to prospective parents that were going to have or have just had a Downs Syndrome baby?

**Peter:** I would say if they had no experience of children with Downs Syndrome or people with learning disabilities or anybody else with a disability I would say it would be good for them to see and meet lots of other people. I think it is sometimes a bit dangerous if somebody has got no experience and then they meet one other person because then it's two of you and you compare. 'Oh my God, my child's going to be worse than that' or 'oh dear is my child going to be that bad', and people can sometimes get a bit of a shock, but I think that people need, the whole world needs to wake up to the fact that people with other needs, special needs or learning disabilities or any disability are around and are a part of life really. If people just wake up to that by finding out and meeting people, then they will see their own situation in much

more of a more reasonable context rather than feeling, which possibly people do, that suddenly something terrible has happened to them and they don't know how to cope with it because they have got no experience.