

Siren Film and Video

Answer Project

Interview with Jack Wood's Parents (spina bifida – 2 years)

Interviewer: How old is Jack and who else is in the family?

Mother: Jack's nearly 2. He'll be two in February, and our James is 8.

Interviewer: So what are Jack's disabilities?

Mother: At the moment he still can't walk, but he is taking a few steps now. Other than that he's champion. Really good in himself. He's more advanced than a lot of children his age.

Father: He's got bowel and bladder problems which we think is going to take some time to sort out. Like I say we're not sure, but the main thing at the minute is his walking. He should be up on his feet now and he's not.

Mother: Though he did have a lot of operations.

Interviewer: Can you describe exactly where he's paralysed?

Mother: He's not paralysed. He's spina bifida but just really at the base of his spine, so we thought he was going to be paralysed but he's not paralysed. But when he was born his feet were actually stuck on his legs and they said this might not have been due to his spina bifida but it might have just happened anyway. But that's the main concern – his feet other than anything else.

Father: He had an open spina bifida at the base of his spine and his feet is congenital vertical talus and more of his right foot really was stuck. His toes were just about touching his shin and he had very little muscle in his calves and Mrs Quinby, his consultant, did a couple of operations on each foot and now his feet are lovely and flat and he's just started taking a couple of steps. So it's pretty good that his feet are absolutely marvellous now like to what they were. They're brilliant.

Interviewer: So when did you find out that there was a problem?

Mother: When he was born. About ten seconds after he was born. It was a caesarian and we knew there was something wrong as soon as he came out. I mean he cried and everything when he came out and there was a look on the surgeon and the nurse's faces and everything which just said it all. Andrea never saw anything – she was just laid flat on her back. I was

sat there and it was just a heart wrench. Everybody knew. Everybody in the room knew something apart from us and then about 10 / 15 seconds later the nurse came over, pulled me to one side, showed me –
Moringeseal they called it. She said Jack's got a moningeseal on his spine. I didn't have a clue what it was. Not a clue.

Mother: Nobody mentioned spina bifida did they?

Father: No, not at first. They took our Jack away. They took Andrea to recovery. They took me to have a little chat with the doctors, with a paediatrician at Hartlepool and that's when I asked if it could be spina bifida. He said 'that's exactly what it is, spina bifida.' It was just, oh, horrendous.

Interviewer: What did you feel like?

Father: I didn't know what to feel. I just felt sick, felt disappointed, felt, I don't know really, just frightened of everything.

Mother: Because when you've never heard of spina bifida you don't know what to expect do you? And the main thing that was in my head was our James. That's the main thing that I was thinking. What about our James? What's he going to think? He expected to come in and take his baby home and then when we told him and he came in ... he didn't really understand, did he, at first? But we never hid anything from him. We made sure he knew everything that was going on. It really affected him.
But it was all the tests and everything wasn't it? Every day they were doing different tests on him, like his head to make sure his head hadn't grown any bigger because he was on the 99th percentile when he was born, his head circumference, which is large for when he's first born. Then they were measuring it all the time because they thought they were going to have to put a shunt in which luckily he did get away with without having a shunt fitted. Like everything was just one thing after another wasn't it? Like one worry after another. It was like we were just getting over one and another hurdle would come. But I think it really affected our James didn't it?

Father: Oh, you could see he was worried all the time. The night that Jack was born, I came back from hospital, took our James home, he had a photo of him and that, and he was just like well why can't he come home? We were trying to explain to him that he had a poorly back, and he says 'well it doesn't matter, we'll just bring him home, it'll be alright.' And obviously it's like us, we didn't understand it, so we couldn't really expect our James to understand it either. He wasn't that upset at first but as soon as he went up to the hospital up to the RVI and he

knew he had to have operations, that's when our James started getting upset and just one thing led to another, from the closing the back to the operating on the feet. It was just horrendous. Ann Walton came up (*from ASBAH*)- it was the day after he was took to the RVI, like the third day, and she left Andrea with a load of leaflets and you just can't look at them, you just don't want to know about them. And just reading all those leaflets is so frightening, at the time it was anyway.

Interviewer: So how long did that go on for?

Father: He was in the RVI just getting his back closed and measuring his head for about 8 days I think it was. He was up there for about 8 days and then he came home and we had to take him back in the next day because his wound had swelled up on his back where it was closed. He was in for another couple of days and again luckily he never saw Mrs Lawson who operated, she didn't think a shunt was necessary. We're thankful now, like, she just kept putting off and putting off which I think is probably the best., But hospitals - we know he's had at least 150 hospital visits, at least, since he was born.

Mother: But it's just every week you're either at the doctor's or the hospital, or ... but it's dwindled down now hasn't it? When he was first born he was there nearly every day to a different hospital. But it's hard when we were under one hospital but then you go to another hospital and then you're having to explain again and you go to another hospital and you have to explain again. So we asked the RVI if we could just stop with them, so we didn't have to explain to everybody and they weren't poking and prodding him all the time. So now we just really stop with the RVI, we don't really go to any other hospitals do we? Bar the Freeman for his feet, but other than that it's just the RVI.

Interviewer: Why were they moving you round all those hospitals?

Mother: Because with us living here, we were under our local hospital, with him being born at Hartlepool, so they still wanted to see him and see what he was doing and what he wasn't doing. So, we were going down there and explaining everything again, they were prodding and poking him again and I just thought, they shouldn't be doing it should they? It was quite upsetting for myself to keep on explaining about our Jack as I still hadn't come to terms with having a disabled baby.

Father: The three main hospitals was our local hospital, the RVI and the Freeman. Now everything the Freeman wanted to do, the local one had a different view, if you understand what I mean,

like the doctors down there were trying to put him on one set of treatment, then the RVI was wanting to put him on another set of treatment so we said, hang on ...

Mother: We just didn't know where we were did we?

Father: The RVI and the Freeman were more clued up and they'd got a lot more experience, so we just stuck with them. And like I say, they've been absolutely fantastic to be honest. They've really been good.

Interviewer: Can you describe his development now?

Mother: He's really bright isn't he? Really bright. Compared to other bairns his age, he's so bright and inquisitive. He's just in to everything. And it's just mainly to get him up on to his feet. I mean he will take steps, but he knows now it's quicker to get there on his knees, so we've got to learn him to get off his knees and get on his feet, but if he's not walking properly by January they're going to give him an aid, like a little walker or little crutches or something like that, but hopefully he might do it, I think he will. He's got so much determination, hasn't he? He's very determined.

Father: His mind, he's inquisitive all the time, he really is bright as a button. He can do his shapes, build blocks, you know what I mean. He'll sit and talk to you. He'll tell you that he wants a drink.

Mother: He's too independent isn't he? Sometimes he's too independent himself. He'll not let you touch him to feed him, or put him up in a high chair, he has to sit in a proper chair, he'll not let anybody touch him. He likes doing everything himself. He'll not let anybody interfere with him will he?

Father: I mean he's a joy, and he gets on great with our James. Our James absolutely loves him. They're inseparable. They just sit and play together or fight with each other, you know just like two brothers should do. They really, really are close. He gets excited when he goes to pick our James up from school, you know what I mean, it's just great.

Mother: One thing we haven't done, I've never ever mollycoddled him, have we? We've never wrapped him up in cotton wool. We've brought him home and he's a baby that's going to be treated normally. I mean our James has pulled him by his feet all over hasn't he? And the nanas will say 'oh, don't do that', 'oh don't yell at him, don't do that'. We say 'oh, he's all right, just let him get on with it'. Our Jack loves it, doesn't he, he just

loves it, I mean he bashes him all over and he's just totally round the twist isn't he?

Father: They're both a joy to have.

Interviewer: Do you think they're closer because Jack's got a problem?

Father: No. I don't think so. I don't think so anyway. I think they'd have been close anyway. You see our James adores him. He always has done. He's never, ever said 'oh it's always Jack, or this, that and the other ...

Mother: Because we were frightened, weren't we, thinking, are we going to end up pushing him out because we had to do everything for our Jack. Our James always had to wait didn't he, when we brought our Jack home, it was always 'you'll have to wait a bit', which we thought this isn't right this, we shouldn't be telling him to wait because he's going to be thinking, 'huh, he gets everything and I'm getting left out', but he's never really mentioned it, has he? It never bothered him, one bit, our James is a big help in his own little way.

Interviewer: Have there been specifically difficult care demands.

Father: At first there was. Yes, he would probably have been about a month old, and he had splints on his legs. And for Andrea, it was harder for Andrea obviously because Andrea was like the main carer looking after him. His splints had to be taken on and off and he had to be bandaged up every nappy change, because as I say the Velcro just kept coming off so he had to be bandaged up all the time. Then after that they put him in casts, and he was in them for six months, roughly about six months altogether. And obviously that was hard because we couldn't bath him, it was just a like a fibreglass cast, so we couldn't get him wet, so we had to lie him down in the bath and keep his legs stuck up in the air, put carry bags and that around, and then after that he was operated on. He was in casts again for another four months which again we couldn't obviously get them wet, and he's had them off since, he's had them off more than a year now has he? No ...about seven months.

Father: Spina bifida babies are prone to infections of the bowel and bladder. He's on an antibiotic every day, what we thought was going to be for the rest of his life, but it's just in the last couple of weeks he's become immune to it so we've had to put him on another antibiotic and we think that we're going to keep him on that one as long as he can, until he becomes immune to this one. So, it's always going to be ongoing that.

Mother: He's always on antibiotics isn't he? He's always poorly isn't he? He's always a poorly little boy.

Father: Like with infections. Infections sort of like flues and sniffles and stuff.

Mother: But the doctor said that can be anybody, but we're never away from the doctor. I mean the doctors are brilliant, aren't they? They get us in straight away for him to see the doctors. They get us in straight away. No bother. But he's always going on antibiotics, isn't he?

Father: Yes.

Mother: All the time. We went on holiday to Majorca and he was rushed to hospital there, because he started fitting didn't he?

Father: Aye, he got a throat infection and temperature. You think is it linked to spina bifida or is it not. He's always getting like little bits of sniffles, temperatures, like urine infection and stuff. He gets taken off one set of antibiotics and put on another But whether it's just because he's a normal little lad or whether it's linked to the spina bifida or not I don't know. We'll just have to grin and bear it.

Mother: It's unbelievable how many nappies you go through. I didn't think any baby could go through that many nappies. But nobody understands do they? Even our own mothers don't understand. Every time it's 'oh, he's dirtied his nappy again!', but that's his condition and we kept saying, 'well I've just changed his nappy', 'yes but it's dirty', and you think, well, what do you want us to do? We could go through 100 nappies a day. If we changed him everytime someone said 'oh, he's dirtied his nappy'. He just constantly is doing it all the time.

Father: You can't leave a nappy off him. Like you say, you change his nappy, you take it and by the time you've wiped his bum and that, and put a bit of talc on there's another one on the way out. Like you say, his bowels are opening that much all the time. It's just constant. And you can put a nappy on him, drive to his grandma's which is 5 minutes in the car, you get there, 'oh he stinks, he must have dirtied his nappy', and you just think, 'we know that'

Mother: We tell them don't we?

Father: You tell everybody, it just doesn't sink in. Unless you live with it all the time it doesn't sink in.

- Mother:** I mean I take him to toddlers and sometimes I feel embarrassed because I think 'oh I bet they're thinking she never ever changes that baby's nappy'. Sometimes I feel like that, you'll say 'oh no, they're not, they're not' but I bet they do think that way, because I mean many times he stinks all the time. You know, getting him out of the bath and putting his pyjamas on ...
- Father:** If I get in the bath with him and there's like little floaters all over the bath. Obviously he's only little at the minute and obviously it'll get embarrassing for him, like.
- Mother:** Like a lot of people will say, 'oh, he stinks'. 'If people are going to say that he's going to start getting a complex – like oh, I stink', because a lot of people do don't they? They say, 'oh he stinks, change his nappy he stinks'. And I think well if they're doing that when he's starting to understand what 'stink' means he's going to start thinking 'oh right, I stink, then I must be smelly', but hopefully that'll get sorted out, won't it?
- Interviewer:** Have you had much help from Social Services?
- Mother:** Well, we've had to fight haven't we? I mean Anne's been a godsend. Anne Walton. She works for ASBAH. She said, some people don't like me because I'm straight which I would rather somebody be straight with us, instead of giving us false hope.
- Mother:** Well without her we just wouldn't have known anything. I mean, it was frightening, the leaflets that she gave us. When she did leave the ward I kept on looking at them and putting them back down and thinking 'I just don't want to know'. I just didn't want to know, but I was more inquisitive and I kept picking them up and putting them back down. But without her we didn't know we could claim anything for our Jack. We were just oblivious because we've never claimed nothing, so we didn't know what was what, I mean nobody comes to your door saying, look you know you can claim this and that and Anne said, 'look, you need to get the forms for disability living allowance', she said you need to get them in, So we were refused, so she said 'I think we've got a fight on our hands'. So we put in again and we were refused again. So we went to a Tribunal, and we had to take our Jack with us. And they just turned round and said, 'he's a normal baby', and Anne said, 'I was disgusted, I couldn't believe what they said'. We were sitting there. I mean, fair enough he does look normal doesn't he, but they don't realise what is actually going on, what extra care he is actually getting.

Father: But like we said earlier on, without the likes of Anne Walton, we would have been stuck. I mean she got us a portage worker straight away, she ... with her and Mrs Quinby they got physios out straight away. Who else comes? There's a physio, there's a portage worker, health visitor ... You see Anne's been a rock. She's retiring this year, at the beginning of next year and they're not going to replace her. They haven't got the funding for another ASBAH representative over here and like you say families are going to suffer like we wouldn't have had a clue, not a clue.

Interviewer: What does ASBAH stand for?

Mother: Association of Spina Bifida And Hydrocephalus. But people who are going to have babies in the future now from this area will be lost, I'm just so pleased that our Jack was born when he was, because we just wouldn't have known anything. I mean, she would come out and she would notice if his eyes were dipped which we just took for granted, but when he had hydrocephalus his eyes would dip into his cheeks so he had no pupils and she would say 'oh his eyes are looking a bit funny today, keep an eye on it', and where we just thought it was normal because we were seeing him every day, but when she came she would make sure his head was alright and look at this and look at that, where we were just used to him being him.

Interviewer: How has it affected your family life?

Mother: Well, I went back to work part time. There was no way I could have gone back full time. No way at all.

Father: No way.

Mother: Because he would have missed all his hospital appointments and everything really. But the hospital work the appointments round us now. I mean, I take him to hospital a lot, but you take your days off don't you, you take your holidays to go into the hospital with me, so really we don't have many holidays together because we use them all up by going into the hospitals.

Father: That's right, yes. Like you say, I get 20 days holiday per year and probably I would say I try to keep my two weeks for holidays and the rest of that, well ten days, at least half of them will go towards hospital appointments in half days here or half days there. But work's been pretty good as well. They've been brilliant. But it shouldn't really happen that way, you know what I mean. You shouldn't, I know it's hard to say like,

but you shouldn't have to take your holidays to look after your kids.

Interviewer: Has it affected you very much financially?

Mother: It has, because I was originally planning to go back full-time. I mean, I don't know what's going to happen because they do think he's going to need catheterising. Every 2 ½ hours we'll have to put a catheter in to relieve his bladder. But I'm not so sure whether my mum would be able to do that because I mean she's hard to see anyway isn't she, she can't really see good, so I don't know what will happen with my job then, because I can't work night shift and keep getting up every 2 ½ hours to go to my mum's to catheterise him, so I'm not really sure what will happen then.

Interviewer: So did you end up getting the disability living allowance for him?

Father: Yes, beginning of the year.

Mother: We just started getting it. Which did help because we go through sort of tons and tons of nappies.

I also think kids get victimised. We went on holiday and we got extra travel insurance for Jack. It cost us a higher premium and unfortunately he got the throat infection. Now the premium said, the policy actually said it will be £50 excess if it wasn't linked to spina bifida. Now the doctors diagnosed him as having laryngitis. Now the insurance company automatically linked that with spina bifida. We had to fight. We've been back from holiday two months and we've only just got our excess back which was £200. We had to pay a £200 excess because it was linked to spina bifida. They said it was actually linked to spina bifida. Now we've had to go through the Insurance Ombudsman, the insurance company itself to get our excess back because it wasn't linked to spina bifida, just little things like that, you know what I mean. You don't realise, but it's always going to be there, you know what I mean. Everything's going to be a struggle for him.

Interviewer: What's the best thing about having Jack?

Father: The best bit is just Jack the way he is, now, he's a funny little kid. You know what I mean.

Interviewer: And what would you say are the worst things for you personally?

Father: The worst things were when he was first born, and to be honest it brought us ... well it did affect me quite a bit, you know I wasn't I would say depressed or whatever but it dragged Andrea right down. She had a caesarean. The bairn was taken away from her, the same night that he was born to the RVI, which was no fault of anybody's - that had to be done. I had to call the Health Visitor because Andrea was just absolutely wounded and like not talking to her, so I mean, thre she was ratty, you know what I mean, you would break down into tears every five minutes, so, I got in touch with the health visitor. The health visitor came out and she ended up on, well you still are aren't you, on anti depressants.

Mother: Yes.

Father: It might purely be one tablet a day, but the difference it made, like, within the space of a couple of weeks was tremendous, like. And she was getting support off everybody at the time.

Mother: It's just one worry after another. As soon as he's poorly you're just constantly worried aren't you 'should we take him to hospital', I find it hard because not a lot of people know what spina bifida is. Like even physios who come out and different people like that. I think they link spina bifida with downs syndrome and things like that where spina bifida has got nothing to do with the brain or nothing. Everything there is working brilliant, all it is is he was born with a hole in his back what needed closing up and things like that, but even certain things with health visitors. Health visitors say like 'take him to a light room' where you don't need a light room. Light rooms are for children who are really disabled where Spina Bifida children aren't classed as really severely disabled are they?

Father: No, not in our Jack's case.

Mother: But that's the bit that I find hard, because nobody understands what spina bifida really is until it hits them. Because we wouldn't have would we. We would have been none the wiser.

Father: The school which our James goes to doesn't want to take him. Well they haven't actually said they don't want to take him, don't want to take him, but as Andrea went to put his name down and it's 'oh this school will be better for him', or 'this school up the road's got this', but at the end of the day, his brain's all there, and there's nothing wrong with him and the schools have to provide ...

Mother: A nurse.

- Father:** They have to provide support for kids who actually go to that school, so even getting him into the school we want him to go to, just like to follow like continuity on where our James went our Jack should go, I think that's even going to be a fight, just even getting him into the school we want to.
- Interviewer:** What would your advice be to parents who think they are going to have a spina bifida baby?
- Father:** Think hard. Very hard.
We consider our Jack and us being pretty lucky the way Jack was born. I mean we didn't know about it. To be honest, if we'd been given any of the information that Anne had given us ...
- Mother:** Our Jack wouldn't have been here.
- Father:** I don't think he would have been here. Now it might seem hard for you, I mean some people might not agree with it, but I honestly don't think he would have been here today. Whether we could have brought up a severely disabled kid, I don't know. I mean the way he is, we've been pretty, I wouldn't say, well if we were going to have any disabled kid we were lucky to have Jack the way he is.
- Mother:** We don't know what's to come, though, do we? We don't know what's round the corner?
- Father:** Just think hard, get all the information, take your time and think hard, like, because it is, it is a big, big push.
- Mother:** I think it's hard when you've got another one, because when he was born, I mean if we knew before hand with our James being here, because we, our whole life was our James wasn't it. Well, if we'd been told before-hand, I think we'd have thought well we can't do this with our James, but life itself can be so cruel towards people with disabilities, but nobody will understand this until it actually hits them. Then, they would understand what we mean.