

NEW WRITING

Being an older brother

Josh in conversation with Nicola Dean



Josh is 15 years old and lives in East Yorkshire with Aaron (AJ) and his parents Sally and Noel. Josh was interviewed by Nicola in March 2009. Nicola works for Sibs* as a Sibling Group Development Officer.

* www.sibs.org.uk

Nicola Dean: *Who's who in your family?*

Josh: Well, there's my mum called Sally, I'm not going to say how old she is, I'll probably say she is about 70 and she'll hear me! [laughs] She gets really stressed, we've just had two months of Aaron constantly screaming so she's a bit stressed. But hopefully she's back to karate in the next few weeks so that'll do her good.

ND: *So there's your mum...*

J: Got my dad, 44, grey and hairy! He's an e-bay addict, he goes to auctions and he's a postman. And then we've got Aaron, he's my adorable brother [laughs]. He's 9 now I think, yeah 9, he might be 10 actually! He's disabled, got ATR-X** which I'll say more about later.

ND: *And who lives near you? Because I think you live near your family, don't you?*

J: Yeah, we've got my grandparents next door, we're actually in their back garden, that's where our house has been built, just got like a fence separating us. So this is in theory the back garden. They're both coming up to 80 and they have a dog called Shadow and each Sunday I go round there to watch 'Wild at Heart' which I can't do now because it's finished.

ND: *Do you like Wild at Heart?*

J: I love it!

ND: *And do you have other members of your family nearby?*

J: Not in this town, I have an aunty and uncle in a nearby village. So they're not far away and they used to breed Alsatians, that's where we got Digger from. They've got about 4 dogs now, two of them just passed away. Which is quite sad really. They've stopped breeding them, so they're just going to stick with those 4 dogs; they've got Jake, Max, Tyler and Jess. They're all Alsatians; I could talk for ages about them!

ND: *Do they have any kids? Do you have cousins?*

J: No, just the animals!

ND: *Do you have friends who live near?*

J: Yeah, quite a few, all mostly from school. But they are scattered about, in the villages.

ND: *Do friends come round?*

J: Oh no, I don't bring them round here, I just have a quiet life really. I see them at school and that's alright.

ND: *Do you go to see them at their houses?*

J: Not really. I'm not a highly sociable person.

ND: *But what is your hobby?*

J: My hobby? KARATE!

ND: *And that's sociable, isn't it?*

J: Yes, I've got loads of friends at karate. My mate Harry lives in a village on the coast where I work. So sometimes I go round to his house. He does sometimes come over here, about twice now. But I'm working two days a week and we've got karate twice a week so the petrol costs are high.

ND: *So what's your job?*

J: At a garden centre, I just do anything and everything. Taking baskets, moving plants, re-potting them, it'll get my muscles up! So all better for the girls! And my fitness levels will go up for when I go to the Himalayas.

ND: *And what are you going to do in the Himalayas?*

J: It's kind of a world challenge, it's 25 of us out of Year 11 and we're doing like community work in India, then we're off to do 2 weeks trekking in the Himalayas, but we've got to be really fit for it and raise £3000, ourselves, for each person. And I've done my maths (which I'm not very good at) but if I work every weekend until September then I'll get about £2000.

ND: *Wow, a good amount!*

J: Then I've got 600 in the bank so that will leave me 400 to get from car boots and stuff.

ND: *I think you'll do it.*

J: I hope I do. But I feel a bit guilty because half the people in my group are like 'Oh, I can't get a job here'. There's nowhere to get jobs – which is a problem if they want to raise that £3000.

ND: *So how do you travel to your work?*

J: Saturdays my granddad takes me, Sundays because my dad's off work he'll take me and bring me back but it is a loooong day. And by the Monday when I get up for school I'm like 'Oh, give me 10 minutes more in bed!' – 'cos I'm really stiff but it's 'cos I'm not used to it, I'll admit it I'm lazy! Just sit watching the telly!

ND: *What made you want to do that?*

J: I'm really good friends with the people who own the garden centre. And it will get me out the house, get some fresh air and I'll feel better in myself and get fit. Save going for 20-mile walks! I walk about 20 miles when I'm there, walking around, up and down, up and down.

ND: *Did you watch Comic Relief?*

J: Yeah, up Kilimanjaro. Yeah, it's probably the same height as that so altitude sickness is on my mind, but that doesn't affect everyone. There was this lad who went up 1500 metres when he went skiing and he got altitude sickness then – and we're going three times as high.

ND: *So what do you like doing at school?*

J: Well I'm doing GCSEs at the moment. We've just done mocks and generally I've got good results. Spanish. I've taken Spanish, and French which was a big mistake. I'm better at Spanish than French, I really regret taking French now, I can only say 'hello', 'goodbye', 'thank you very much', that's about it!

ND: *So how about your karate?*

J: [laughs] Long story, last November it turns out my instructor was a complete fraud, cheated everyone out of money, all my certificates were false – so I'm not really second degree black belt. I'm just a black belt.

ND: *How did you get into karate in the first place?*

J: Being bullied at school, just for something simple, my left ear stuck out. So I had an operation on that and it looks normal, it just feels different. Umm, I thought 'Nah, I'm not taking any more of this' and went to a local class.

For two years – and I got to my purple belt and started teaching the youngsters which I didn't want, I wanted to go up in the grades so I went to another club. Now all this has gone on and I'm with the new club and we're moving. And it's the only purpose-built gym for karate in the area. My new instructor has bought all the mats and pillows from where we used to train.

ND: *So karate is your main hobby still?*

J: Yes.

ND: *So what about your brother, can you describe his condition?*

J: Oh, he's adorable [laughs]. He's got ATR-X, can't remember the exact proper name for it, that's just the abbreviation. There's only about 100 people in the world that have got it. It's really rare. It means he'll never be able to talk, he can make some sounds and noises, and mum is teaching him some swear words at the moment so when he gets mad he can just say them! We're going to try to get him to say a few words. He'll never be able to walk.

ND: *How does he get about?*

J: He has got several chairs, ones for different activities, he's got a standing frame which is really good, he goes in that for two hours at a time.

ND: *Quite a bit of equipment?*

J: Lots! But we haven't had to fund it all ourselves.

ND: *Do you do things together?*

J: Yeah, I had a wrestle on the bed with him the other day, he likes that, he poohed himself! He's got his Pooh Bear phone that he's addicted to, I like to play with him with that, we sit in front of the telly and watch telly together, CBBC which gets on my nerves, a lot! And sometimes we go out for walks if he's feeling ok. Not a long walk.

ND: *Can you take him out by yourself?*

J: I could try, but if something happened to him, like he started to cry, I couldn't manage him. Mum knows him better, what he needs kind of thing, better than I do. It's getting to the point now, with Aaron that mum and dad are struggling to handle him. And struggling to cope. We've put him on some medicine for his

behaviour, I mean, we never wanted to do that but it's the only thing we can do.

ND: *So what's he been doing?*

J: Just wild. Absolutely wild. Screaming and shouting, and we don't know if it's pain or what, that's the thing with Aaron, we don't know if it is pain, or if it is just hyper [difficult behaviour]

ND: *So that's why you would like him to have words to express himself?*

J: Yes, we're doing like flash cards with him like drink so he'll point it, we've got Tigger and Pooh Bear toys and we say 'Which is Tigger?' and he'll go like that [makes a hand movement], he's got all different toys and he can tell which is which. So if we have pictures for 'food', 'drink', 'toilet', and 'bed' – he can tap which one he wants. He is really clever but he's...

We've got this herbalist person and she's brilliant, she gives us tablets for him, like soluble ones, and they sort him out just like that [clicks fingers] She's a brilliant person.

ND: *What difference has it made to you, your brother's behaviour getting better?*

J: We can do more things when he's better, like go out in the car, like go to the beach maybe when he's a bit better. When he's not, I just go in my room and watch a bit of telly. 'Cos at night, I can't get to sleep if he's shouting.

ND: *Does that happen regularly, not getting to sleep?*

J: Well, I can get to sleep, I just have my headphones in. If I'm through there [in bedroom] mum will bring Aaron in here [lounge] and it will take me an hour to get to sleep which is normal for me now.

ND: *Do you get woken up through the night?*

J: That's the thing, no, I never get woken up. Because once, as my dad was driving his lorry, we were up quite high. My dad was awake all night and I was just on top bunk, snoring! There was this storm shaking the lorry all over, rain, hail, thunder, and I never woke up!

ND: *So once you've got to sleep...*

J: I never wake up!

ND: *So you use the headphones to get to sleep?*

J: Yes. If AJ has an early night, everyone has an early night, except dad who's on e-bay, he's got a business, you can't blame him, well you can if he's up till one o'clock in the morning!

ND: *So your brother's behaviour and sleeping affects everyone?*

J: Yes, everyone, even the dog! Digger picks up on the atmosphere, he just lays there on the mat, I'm turning into Cesar Milan, the Dog Whisperer! 'Cos I'm just trying to get what is right for Digger, 'cos all his life he has been in this house with Aaron screaming and I'm sure Digger gets bored, he takes all the grass up. I can't take him out on my own for a walk, dad's too busy to take him for a walk.

ND: *Is he too strong for you to walk?*

J: When he gets barking, I just need to learn how to control him, if it was down to me, twice a day, I'd take him before school and after.

ND: *I remember your brother has had a lot of time in hospital in the past.*

J: Yes, but he's had a gastrostomy [tube] fitted in his tummy so we can get medicines into him, all sorts into him. Like if he's not eating, we can feed him through his tummy. So it's just perfect.

ND: *So what was it like before?*

J: Before, he was in hospital every year, maybe twice, three times some years. There was one time when he got so thin he slipped through the bars, none of the doctors were in there, mum had gone out to get some chips I think it was, and the doctors weren't in there looking in on him. And he was so thin he slipped through the bars and his bottom half was literally sticking out the bottom of the bed. He was only held in by his top half.

ND: *I remember that it used to take hours of feeding at that time. So the gastrostomy made a difference?*

J: Yes, we can put Gavescon in, and all sorts of medicine, sleeping medicine, if he's..., if we really need a break, if we really need an early night, he'll just go to sleep in an hour's time, if he has his medicine.

ND: *Sounds like you don't like to do that though?*

J: No, we don't like drugging him up and making him tired or anything but if we have to, then if there's no other choices, then we have to. But he's getting respite at the moment. In a short breaks unit!

ND: *Oh, brilliant!*

J: But we've not been allowed, we had been having mid-week, Wednesdays sometimes, but some people from the council there said 'No, you can't have that' – because he's not from that area.

ND: *He's from the East Riding?*

J: Yes. There's nowhere in this town or anywhere he can go. And we've pulled him out of school ages ago.

ND: *So he doesn't go to school anymore?*

J: They didn't want him, couldn't handle him, couldn't handle him. They just sat him out in the corridor when he was being noisy.

ND: *So what does he do during the day?*

J: Playing, he just likes to play.

ND: *He's at home with your mum?*

J: Yeah, but sometimes he gets weekends at the short breaks unit. But we're gonna... there's this other place not far away, we're gonna... I can't remember what it's called now, it's like this big school, so we're gonna try and get him in there.

ND: *Go to school during the day and just be at home at the weekends? Do you think that will make a difference?*

J: It will for us, but I think Aaron will learn more, it will give us a break, it will be good for all of us.

ND: *Yes, it will give you a real break.*

J: Yes, and Aaron can get rid of his energy, he must have so much energy not being able to run around or anything, and if he's sat in a chair playing with toys, or rolling around in bed it's still not burning off all that energy. His standing frame, he get's knackered out in that! That's good in his standing frame.

ND: *He needs to go to school, doesn't he?*

J: Yes, not every day, maybe twice a week, that'll do, I mean two days a week is probably what we

all need to catch up on our sleep. And it will be good for Aaron to have a change of scenery, because he's just sitting here looking at all this [points around the room] and he sees it every day.

ND: *He's 10 and that's what you do, go to school and see your friends.*

J: Yes, one of his friends just passed away, I'm not sure exactly what was wrong with him, and every time I saw him I thought 'That hair, that hair is like Aaron'. I mean, he was lovely, I only saw him twice.

ND: *Do you worry about that for your brother?*

J: I just worry all the time, because if... you don't know what is going to happen, if they are disabled, if they've got something wrong with them... You just don't know what is going to happen. But I think [friend] was much worse than AJ, I think Aaron will be fine.

ND: *Now that he has the gastrostomy?*

J: Yes.

ND: *So what happened when your brother went into hospital, what did you do?*

J: It really put me off my school work, I couldn't concentrate, mum and dad took turns staying with him overnight, mum would come home on the train, have a bit of sleep, dad would come home, have a bit of sleep, and I would just stay here. I'd go with them every time they went to swap over, but I mean, seeing him all hooked up to machines and stuff, that upset me did that, and just seeing him on machines, over and over in my head, at school, I mean it really put me off.

ND: *So that's quite recently if you were doing French and Spanish?*

J: Yes, I've been doing them about three years. But he's had his gastrostomy quite a while now. So if I do think about him at school I think 'Oh, he's sat or laid in his bed with his toys laughing', so it's a much different picture to what I had before.

ND: *Did you have anybody around you to talk to at that difficult time?*

J: Yes, I had a brilliant form teacher at school, Mr B---- he was called, he's left, and my Spanish teacher, she was brilliant. Not only does she

support Real Madrid but she's brilliant, like talking to me if I needed it, talking about Aaron. She was really interested in him kind of thing, what's up with him.

ND: *How did they know about Aaron?*

J: 'Cos I think with my Spanish teacher it started when I took some photos in from when we went to France, 'cos she teaches French as well. So I showed her some pictures and she said 'Ah, I didn't know you had a brother.' So we got talking about that. And my form tutor, 'cos we had some issues at school with people saying stuff about Aaron so I just, I mean I knew I could say something to my form tutor, so I got talking to him about it.

ND: *Oh, that's really good.*

J: I mean, we were always taught in karate, self-control, and that's really good, self-control when you feel like doing that [punches his palm].

ND: *Did you feel like doing that?*

J: I did, yeah, sometimes, yeah. But that's all stopped now, for the past couple of years now. I think it's since about Year 8.

ND: *That's good. So if you had to describe your brother to your friends, what would you say?*

J: I'd say that he's adorable [laughs] but if he wasn't there nothing would be the same, I mean if he wasn't there it would just be empty, I know he's a handful sometimes and some days we get really stressed but we do love him really.

ND: *Do you have any funny stories about being with Aaron?*

J: Aaron? No, but he can stand up against the window and look out, he likes tickle time, he likes that and he does fill his pants! It's not a bad thing because sometimes we complain about him not being able to go to the toilet, so tickling and fighting with him, he usually gets me right in the face with his fist, he's a good fighter! He's really cheeky, really cheeky! Especially around women, he's just eyeing them up all the time, and at the short breaks unit, when he first went there, big grin on his face!

ND: *If you had to think about the future, what do you think is going to happen?*

J: Well he might, when mum and dad get older he might have to go into care but that's like 20 years down the line. When I leave home mum and dad want to get a place in the country, I mean this place was designed round Aaron, designed around his needs but maybe, they've always wanted to live in Wiltshire, since we went to Longley, lovely place. Just out in the countryside. But there's a downside to that, if Aaron needed to go into hospital, there probably wouldn't be any hospitals around. They'd get out of this town mum and dad, go somewhere nicer but...

ND: *And what about you? What would you like to do?*

J: One day I want to do this, the next day I want to do something else. Animals, I love animals. I wouldn't mind doing something with animals. If not that, I am good with computers.

ND: *Are you going to go to university?*

J: I'm not thinking that far ahead. I'm thinking 6th form, and then take it from there. I'm the kind of person that likes to do it one step at a time, which in a way can be bad.

ND: *One step at a time?*

J: Well, I'm going to take biology next year, if you want to do something with animals you've got to have biology. I'm going to take the subjects next year that I think I'm going to do something with in the future but I'm not too sure about the future. Karate, I'm never gonna stop! This 75-year-old came down the other day and he could kill somebody! With his little finger!

ND: *You'll have to get you grandma and granddad down there then!*

J: Oh yes!

ND: *You went to a sibling group with Barnardo's. What did you do with them?*

J: That was really good, it brought the confidence out in me. And on the last day we did a talent show and I went in my karate stuff. And did a bit of karate, they all liked that.

We did team activities, I think that's helped me do more team things, like. I do work better on things on my own 'cos I don't have other people bugging me kind of thing. But in groups I think I

can work better now, 'cos in the Himalayas I'm going to have to work in a group then.

ND: *So it gave you confidence in a team. How many people were in the sibs group?*

J: Quite a few, the same people were there week in week out which was good, as we got to know them, what they liked and stuff, and got to know more about their siblings and stuff, it was good to see how other people cope with it and what they do if they are stressed. We did all activities like that which I thought was really helpful, it was good that. It was mainly girls actually. NO! They were all girls! They were all girls, how about that!!!!

ND: *Do you keep in touch with anybody?*

J: I've got all their email addresses but I haven't actually spoken to anybody since. I might, I think I will because I've got their email addresses. I just keep forgetting.

ND: *You're busy.*

J: School and karate!

ND: *So the group finished, is there any support you would like now?*

J: I've got my karate and I think it is the best thing I am ever going to do, I'm out of the house more now than what I was before the siblings group. I think it is because it brought out the confidence in me so now I am doing more things and meeting more people.

ND: *Ideally, if you could have chosen when you would come to the sibling group, what age would you have come?*

J: I think I went at the right time, because when I was really young I was a kid and I wasn't getting stressed, I wasn't getting as stressed as I was a couple of years back when I went to siblings.

ND: *So it came at the right time?*

J: It came at the right time, because now I'm older and I hope, I like to think I'm more mature, sometimes! I'm more sensitive now; I get more stressed now than say when I was 10. So I think it was the perfect time.

ND: *And some people may worry about running a group for teenagers.*

J: I think it is the right time to do one, for teenagers, I think it really is a good time because I think, they say when you are a teenager your emotions are all over the place. I think that helps with that.

ND: *What's helped you over the years?*

J: I think being able to talk to people about it, being confident enough to talk to people about it. Like get my feelings out kind of thing, that's helped a lot. And doing sport to take my mind off it, karate. When I'm there I'm in a totally different zone. I'm in killer zone! Not quite [laughs]. It's something to take my mind off it, I mean school does a bit, but every now and then I'm thinking 'How is he, is he ok?' Yeah.

ND: *So you'd recommend doing a sport?*

J: Definitely, doing something you love to do and that you're passionate about, it can take your mind off things, it does you the power of good it does.

ND: *And what would you say to professionals who have contact with disabled children and their families?*

J: Anyone who has contact with disabled children, I just think they are amazing! Because you have to have a special thing to... dad says you've got to be a special person to work with disabled children. I think I'd be able to work with them; I'd be able to do that kind of work, yeah.

ND: *And what about anyone who comes into contact with siblings like you? What would you say to them about being a sibling?*

J: It's not easy at times. But in a way it's brilliant, they are a special part of your life. Especially Aaron, he's a really special part of my life and like I said before, if he wasn't there, I mean, I'd never be able to know, I'm waffling on now, never be able to know what it feels like.

ND: *Have you always felt like this or has it changed over time from since he was born? You've grown up and he's grown up.*

J: Mmmm, I think, when he was born, the day I found out he was disabled, I was like in tears, but erm, I've grown to live with it. And since then, since AJ's got older, it's got much more difficult. And he's got much more of a handful. But we are coping. But it will get to a point when none

of us can cope. I mean, if I leave home and mum and dad can't cope I would happily come back and help them, I would give up what I'm doing and come back, because that's how much Aaron does mean to me. He's like the world to the moon and round the solar system!

ND: *So what sort of help would help you and your mum and dad to cope?*

J: Breaks, breaks. I mean just having a break from him. We've got people coming in to him, what is it, Direct Payments? People come in to sit with him; we can go out for say an hour but we can't leave Aaron for more than an hour with somebody that doesn't know him as well as mum and dad do. But if we send him to school... Like the short breaks unit, they are amazing with him and we know when he goes there he'll be fine and they know what to do and there's a hospital just across the road. And we can go out for weekends. We went to Longleat and Cheddar Gorge, cor that didn't half hurt my feet, walking up there! And just some B&Bs we stayed at in the New Forest. And it was a really brilliant time, absolutely brilliant. And I think more weekends away to do stuff, just me, mum and dad.

I mean, when we take Aaron out, it's like people staring at him, I just wanna say 'What you staring at?' To see what they say.

Yes, I think the best thing for us would be a break.

ND: *Do you ever get a week away together?*

J: Not a full week, no. We went to France, I think that's the only time everyone in the family went together, Aaron, me, mum and dad. He was fine then. Shame the weather wasn't a bit nicer, we could have got out a bit more. We were stuck in this little gite thing, whatever you call them, by the lake, rain pouring down, fishing.

ND: *You can't book the weather, can you?*

J: No! Before it was boiling, the hottest it's been in that area, that year. Week after, boiling! The week we were there, chucking it down! Freezing! We couldn't go outside 'cos we'd freeze our toes off!

So we haven't had a full week away since, just the odd weekend. But it is going to be difficult to get Aaron on a plane 'cos one, he'll be too

noisy, two, he'll pooh and stink the whole plane out.

ND: *It's quite stressful?*

J: Yes. Like going on holiday with Aaron, if he's not behaving it'll like not be worth it. So going to the short breaks unit for the weekend for Aaron is his holiday 'cos he loves it.

ND: *He gets looked after properly by people who like him and want to see him. But has that finished?*

J: The mid-week one but we can still have the odd weekend every couple of months, which really isn't enough. I mean me, I'm ok, I go to school every day, that's my break, and karate. But mum and dad, they're stuck in here every single day.

ND: *Was he going every week?*

J: Nearly every week.

ND: *And it really made a difference?*

J: Yeah. I mean, Mrs G---- the herbalist she ran a test for Aaron and she picked up that he doesn't like the change of scenery and when he's at the short breaks unit he misses his mum especially, and dad. So I think once he's settled in he'll be ok.

ND: *Well, he will miss you because you're his family.*

J: I know it sounds a bit odd, 'cos we want a break but we're still worrying about him, it's natural to worry about him but we still miss him even when we're relaxing.

ND: *Yes, it must be a bit strange not to have him here?*

J: Yes, it's much quieter. We notice a change in Digger as well, he's just better behaved. When Aaron's here and Digger's stressed he goes up and steals the plants for no reason at all [points to dried flower arrangement] and takes them onto his mat, and firewood and he just doesn't want them, he takes them there out of badness. I'm amazed at how it does affect Digger as well.

ND: *You said he picks up on the atmosphere?*

J: He must do, yeah?

ND: *How do your mum and dad calm down? De-stress? You've got your karate.*

J: I don't think they ever de-stress. I do, but I think mum and dad are just... they do need a break. If mum's off back to karate then that'll be brilliant 'cos she loves it and really missed it since everything happened. Punching those punch bags is a de-stress kind of thing.

ND: *Would you recommend it to other parents?*

J: Oh yes, take up some form of karate. I mean, it doesn't have to be intense kind of karate but it is something very good to de-stress.

ND: *It's physical, isn't it? What does your dad do? Does your dad go fishing?*

J: He hasn't been for a while. Because he's a postman at the moment, that's like only half a day though, and he gets back and he's on e-bay, he's trying to make money for like when Aaron is in respite for us to go out for weekends, so that's like his second income, e-bay, but it's turning out to be his first income he's on it that much! It's a proper business he's doing, that good. He's taken over the garage, he's taken over the shed, he'll be taking over my bedroom in a minute! I'll be sleeping outside!

ND: *So that's his hobby more than the fishing?*

J: Yes, he hasn't been fishing for ages. You'd expect fishing to be a break but when he comes back saying he hasn't caught anything in a match then he's kind of stressed!

ND: *Fishing's like that!*

J: Yes. I used to like fishing too but I haven't been for about a year. Now Aaron's got bigger we don't have the time.

Time I think, time and breaks is probably the main thing at the moment that we need. That would be the best thing that we could have at the moment, just a break.

ND: *Is anyone looking at it – to get you more breaks? If he goes to that new school do you think it would make a difference?*

J: I think so, they're booking an appointment to go see the headmaster and have a look round. We've looked on the internet and it looks brilliant, a brilliant place. So if we get him in there, even if it is just two days a week, that's

two days for us. Maybe we could go see a film and go out and have a KFC, that'd be nice, I like a KFC!

ND: *Is there one around here?*

J: There's one not too far away, the closest fast food place is McDonalds on the coast.

Even just one day out, that would be brilliant.

ND: *Sounds like he needs somewhere purpose-built to go if he can only be left at home for an hour or so?*

J: Yes. Grandma, she's going on 80, she comes round every morning offering to help and sit with him, but she's getting on a bit and she won't be able to hold Aaron when he's wild. And if Aaron gets any bigger, and grandma gets any smaller it's not really going to work out! [laughs]

ND: *Yes, she's getting older. To manage someone with difficult behaviours can't be easy?*

J: She's doing really well for an 80-year-old. I don't think we'd be able to cope with Aaron so well, because she's been doing it since Aaron was born, helping out with him. She knows what he needs as well, almost as well as mum does.

ND: *I guess as she gets older your mum may need help from other people?*

J: Yes, we've got someone called Sue in, she comes round every two weeks or so, to sit with him for a couple of hours. But that only allows mum time to do her housework and clean up but she's still in the same house, the same area as Aaron and if Aaron's shouting she isn't going to get de-stressed really. It needs to be out of the house, we need a longer period of time. I know it sounds awful wanting time away from your little brother but it is just something we have to do if we want to lead a life, kind of thing. Without, well you can't lead a life without stress but without so much stress. It probably doesn't make sense!

ND: *It totally makes sense; it's what the government has been hearing from families from a long time. Everything you've just said you could be quoting what the government is saying about short breaks.*

J: I could be Gordon Brown I could!

ND: *Anything you would like to tell readers of the journal? That they should know?*

J: Nothing about Aaron, but something funny!

My grandma, t'other month, had a row with granddad about cooking. Granddad said, 'Right, your food's not good enough, I don't like it and I'm not having that for tea.' It only took him 50 years to tell her! My grandma wasn't very happy, she storms off and we didn't see her for the next 5, 6 hours and we thought 'She's gone missing, she's gone into town'. And it was the middle of winter, absolutely freezing cold, she hasn't got a coat on, she'll be huddled up on some bench somewhere.

So we went out in car, took dogs out, we got my aunty down to call her dogs out looking for her. Turns out, granddad wanted me to stay in the house in case she came back, turns out I was just randomly shouting 'Grandma, now if you're in one of these rooms, then I'm going to have an absolute fit if you're in one of these rooms, and I went looking in the rooms. And there she was. Sat in the chair in the corner. And granddad says 'I've checked all the rooms'. She'd only shut herself in the dining room! In the pitch black. She was there for 6 hours, sleeping!!! I went in whoaaaaa, nearly had a heart attack! She was their snoring away, sat with her coat on. So I had to ring everyone up and say 'Right, she's here'.

ND: *Missing grandparent!*

J: Missing grandparent! She was sitting in the chair all the time!

ND: *Was she intending to walk out?*

J: She said she wasn't. When I went in I said 'Grandma! What you doing here?' and she says 'Oh, hello. Have you come for some flapjack?' And I said 'No, we thought you'd gone out, we thought you'd gone missing' and she goes 'No, I've just been having a sleep in here.' She didn't have a clue that the whole family was looking for her!

**** ATR-X - Alpha Thalassaemia (Alpha Thalassaemia - US)**

ATR-X syndrome is an inheritable condition which affects boys. World-wide, over one hundred and fifty affected families have been

identified with this condition. The underlying gene was identified in 1995. Affected boys have severe learning difficulties and milestones are delayed. Speech is usually not achieved. Affected boys tend to suffer frequent colds and recurring chest infections. Most of the boys have genital abnormalities, most frequently undescended testes. Feeding problems and regurgitation are commonly present. Sleep disturbance and mouthing may occur in some children.

(Source - Contact a Family Directory 2009

www.cafamily.org.uk)