

NEURODIVERSITY > AUTISM > FATHER AND GRANDMOTHER'S JOURNEY

Father and Grandmother's Journey

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1. A Father and Grandmother's Journey - start of the journey

Hi, I'm Helen Wagstaff, Autism Coordinator. Thank you so much for coming along to talk to me today. As you know we're doing videos for families to hopefully answer some of their questions of what it was like for you guys going through that diagnostic process and so hopefully it will answer some questions for them. So I'd like to welcome you, if you'd like to introduce yourselves, thank you for coming. Thanks Helen, so my name is Susan and I have an autistic grandson. Awesome, thank you for coming. Hello Helen, my name is James and I have an autistic son. Thanks for coming. So I guess the first question that I want to ask you is what was the journey like for you guys?

If I'll ask you first Sue. it was um because I wasn't hands-on parenting Keith day-to-day like James was, it was a little bit mystical.

I personally did not know a little bit about lot about autism at all I knew that from very early on from when Keith was probably one month that he was different parenting James's parenting had to be different because of his behavior and his language and a lot of things and I didn't know what was happening and I know that you James you were very hands on with him and it was you day to day had sought diagnosis sought help from GPs and so I was very much an observer on the sidelines and so James how was it for you going through the diagnosis with your son I would say that it's probably one of the most frustrating things any parent that's got an autistic child will go through um you start off with you for status there is no way of knowing when you're holding them at six months uh one year you're still not you're still not unsure you've started noticing some mannerisms and behavior um then for me for us the biggest one was my son

went from learning the mum and dad yeah to he just refused to use it so stop talking stop talking and um he would um drag you by the finger places he'd lead you places to get things um or he just do it himself um and you and it led to of course you try to correct them because they're going to do something dangerous they don't like that the outbursts are massive you don't know really what's going on um eventually you will um happen you will take the take your child to the GP um and they will pretty much notice from typically my son was having a quite a bad breakdown in the in the foyer of the medical center um and the my my GP his GP came out and went straight away just brought us in and said look um I think we need to send them in to be assessed um up until then you're not sure you think you're doing stuff wrong it's um self-deprecating you need you never blame anyone else or never blame something like the autism you blame it on you and also I remember two Jones they were at the time the um doctors and specialists and they were throwing around things like um tongue tied at one point didn't they yeah restless syndrome um there was lots but the last one that was that really came to it was he could be on the road

2. A Father and Grandmother's Journey - accepting the autism label

How do you feel about the autistic label? Did it help? Did it not help? Do you not like it? How do you feel about having a label? The label of autism autistic, it doesn't bother me at all, but in the same vein, I find it quite confusing because if you have an autistic child in your family, you have met one autistic child and it's not the same. It's not like saying, I have brown hair and I get labelled as a brown haired person. It's so different because of the spectrum that it's almost not a label as I see it. It's a diagnosis rather than a label and that's how I see it. I don't actually see it as a label.

Okay. Well, that's interesting. James? I believe it's probably going to end up, if you accept it for what it is, it is the most important tool that you'll be given. So you're seeing it more as a tool as opposed to a label. The way that I, with my son, the practice of it is he's 10 and he's old enough to know. He's asked questions. He knows what it is. He knows that it affects him. He knows how it affects him. The thing that I teach him the most is that, first off, don't use it as a defensive mechanism. It's not an excuse. It's not an excuse. Don't turn around and go, I have autism, leave me alone.

Turn around and try your hardest. And if people aren't figuring out or can't understand why you're having an issue with it, then maybe turn around and go, look, I'm sorry. If you're in an environment you don't like and you need to excuse yourself and it's the kind of thing where you don't really, you can't excuse yourself. You can excuse yourself. That is your right. But it is not, not something to use, I don't feel like doing this. Exactly. And so it's a very hard, it's a toll. It is a toll. It is a reason, not an excuse. That's right. It's a reason why I might struggle to listen to Dad saying, please do the dishes.

And I've got to process what I've got to do, what I've got to do now, when I'm going to do it, I don't want to, as opposed to being an excuse like, well, I just, I'm autistic. That's exactly right. That's right. I mean, Keith has turned around and he has said it to people. He has gone up and introduced himself in his funny ways. And he's gone, hello, you know, asked him a few interesting probing questions to a stranger he hasn't really met before, and then finished it by going, hi, my name is, and I have blah, blah, blah. I'm sorry. Thank you. Bye. So he uses it as his justification to why he's just introduced himself in that manner.

So he's, he gets it. He, he knows that it's limiting, but he knows that it's also, it shouldn't be the reason he stops doing things. Yeah. It should just be the reason that if he doesn't do them exactly how he, he wants to, you know, um, if he's not doing it to somebody else's standard, they don't know, they're not going to understand why he's not. And I guess I would say that it's not limiting as such, but it opens up a whole lot of doors. That's right. Exactly. Right. You know, there are so many people in this world who are autistic and lots of money are very creative, are very intelligent and it doesn't hold them back.

Yeah. Yeah. I, I saw it, as I said, it, I don't notice, but there's a pathway to understanding and more so than a label. And I, and I think you're right in the same. Cool.

3. A Father and Grandmother's Journey - accepting the diagnosis

So James, when your GP came and said to you, I think he might be on Spectrum, how did you feel? Had you heard of autism before? Was it something that surprised you? How did you feel about it? You've heard these terms, you know, I had a job where I was part of doing disabled transport, so I'm no stranger to the terms. The problem was, in all honesty, yes it was offensive. It comes across as offensive. When someone labels your child, you're not prepared for it, you're not expecting it and you certainly didn't want it. That's not to say you don't deal with it, but it's not something you would wish, you know, and so when someone says that to you, you do get offended.

It's hard to accept. You accept it because the only way forward for your child is going to be to accept it and move on. The quicker you can do that, I would give any of that advice, the quicker you can do that, the better. That's cool. It will help you in terms of immediately stop thinking it's your fault. But at the time, it's really confronting. At the time, it's confronting. You blame yourself, as any parent would.

And for me, when I hear that from families, I'm always saying it's never your fault. It's nothing that you've done, despite the fact that that's the way you might feel. It's just how it happens.

Yes, that's 100% right. So for you Sue, how was it when you first heard the term and thought this might be autism? How did you feel? Felt, and this may sound weird, but it was the way I felt. I felt relieved because finally I knew that my grandson had a diagnosis. And to me, that then opened up a pathway for me to move forward. It was very difficult to form, as a grandparent, a close bond with my grandson up until that point because he didn't like cuddles, he didn't like being touched, he didn't talk. I'd ask him questions, I'd get no response. At age four, he wasn't even calling me Nana.

So it was very difficult to establish bonds. But once we knew he was on the spectrum, I then became an internet warrior to look at ways of engaging with Keith even, like I didn't even know until I searched, there were particular toys that are well suited for autistic children. And I wasn't even looking at those toys when I was buying him gifts and presents. So it just, it made, to me, it made things better. And isn't it funny that you felt one way, but you felt the other way. Do you feel now, James, that you... Have turned that corner and you now feel that this has been helpful? Well, yes. The more information you can get, the more people, the more services, as soon as the diagnosis hits, from that point onwards, you're on a path to get the services you require, the assistance that you need, as well as your child.

It's not just about the child, it's about yourself. Mental health for both parties is important. If your child's having a bad day, you're having a bad day. If your child's having a bad day, you're having a bad day. If you are, so is the child. It's as simple as that. And I think, yeah, that's why I say the first thing is acceptance. It's the hardest part. It's a lot like anything in life, but the moment you accept it, it's not fixable. It's something that, and even more stranger is, it's not like accepting it's a rainy day. There's rules for a rainy day. The moment someone says your child is on the spectrum, your rules are your rules for your situation.

You can't even look at the next situation next to you and apply the same rules. You have to overcome. You can't even adapt at a level that not many people will ever see. And you're so right. If you know one autistic child, you know one autistic child. Everyone is so, so different. That's right. I'm fortunate that Keith, or sorry, my son, he is high functioning. He's verbal. He is very intelligent. I'm grateful for that because I've met a lot of other autistic children, and some families are not that lucky. Yeah. So I would say that I have. I have difficulties on different levels where some children aren't verbal.

I have a son who is, and that leads to very vast array of wants and demands and knowledge and everything else that he wants, and he will seek it out. If you won't give it to him in a controlled environment, he will find it himself. That is just the way they work.

4. A Father and Grandmother's Journey - when to get a diagnosis

What I want to ask you now is, how old was he? We're talking about different times. How old was he when he actually got his diagnosis? Three. Three. Okay. Awesome. Do you think it would have made it any better or any different had it been earlier? I don't think you're going to get the level of behavioural presentation where they can make an assessment and say, yes, he has, until they get a wee bit older. I know girls are entirely different, so I only speak from the context of a male. But my son, it was the going backwards with the speaking. That happened in between two and three. And that was the first sort of noticeable thing.

And when you brought it up with other people, people would try and downplay it. That's not a medical profession. As soon as I mentioned it to my GP, they were like, well, no, you should have said something. And you're so lucky with your GP. Some GPs will say, actually, let's leave it until they're a bit older, until they've gone to school. But I guess what I want families to do... What I want families to realise is, if you feel there is something wrong, that, yes, go ahead. Ask for that opinion. Ask another opinion. You don't have to wait. The youngest child that's been referred to me is probably 18 months.

That's really little. But mostly it's around about two. Is there something you would have done differently to the way it played out? No, there isn't, actually. I think from the moment we were told, that Keith may be on the speech room, and we had our first appointment at the hospital, from that point onwards, it's just been, it is a time, it is a waiting game. It's the only thing. There is nothing that you can do to make it happen earlier. If you're waiting three months for an appointment to be assessed, that's three months. There's a massive waiting list. You can't give people patience, but that'd be the one thing I wish that I could do differently, is just have more, you know, and more just deep breaths and sighs, and that's just the way it is.

Move on. That's what I say about acceptance. There's a lot that people will be confronted with, and it's going to be, it all comes down to acceptance. If you're waiting nine months, trust me, what you get after that meeting will be the launch pad. So, trust me, nine months is a short time to wait, you know, for the, when you consider the help you're going to get. So, yes, I just, the biggest one is patience, and just, yeah, for you and for your little one, it's just patience. Cool. You too. Was there anything? You would like to have seen that happen differently? I know you've seen that following the diagnosis, you did a lot of Googling.

Yeah. I would suggest to families that Googling isn't always the best thing. No. Because Google is not, doesn't, it comes up with lots of exciting and different things. Yeah. So, what would you have seen or like to have seen to be done differently, or is there not? Yeah, I think the process played out well. Mm-hmm. In terms of time, but I agree with James with patience, and whether it's a factor of me, I think I was probably a bit of a niggly nanner at one point saying, when's Keith's appointment, what's going to happen, what happens after that, and wasn't I always saying, when does this happen, who's he seeing, why is he, why is that happening?

So, you were the one that didn't have a lot of patience. Yeah, and I think that was me, and also with regard to patience, a bit of advice for nannies and granddads with ASD grandchildren is that things just go with the flow, because a lot of things have to change. You might have plans for a family dinner, or a picnic or barbecue, or an outing, or a trip to the beach, or Mother's Day. Yeah. Or Christmas, or all those family get-togethers, and I know that before Keith started school, we would, the number of times our outings got cancelled, or our trips got, plans got changed, or things didn't happen, that was, you know, there was countless.

So, for you, it was more around having a bit more of an understanding. Yes. As well as the patience. Yeah. And an understanding of, would it be the process, or the autism? The autism, I think. Because obviously we didn't quite know by then, did you? Yeah. So. Yeah. But another thing that related to that was when my grandson was almost six, he got a sister. Right. And that's when, as a grandparent, I really felt the ability to step up. Because things, you would plan a family trip to, around a park, or the movies, or a barbecue. And the little girl was all excited and ready to go, and all of a sudden things don't happen.

Yeah. Because her brother's having a meltdown. That's where a grandparent can step up, and you can take the other ones out, while parents stay home. Yeah. Or you can take your autistic grandchild, and have them one-on-one. Yeah. Well. Yeah. That's how the family goes out. Perfect. Yeah. And that's, I think, the biggest support that a grandparent can give. So it's not just the patience, but it's the understanding. Yeah. And then on top of that, it's the supporting. Yeah. Of your family. Yep. Your child's. Yep. Children. Awesome. Thank you.

5. A Father and Grandmother's Journey - working with the GP

You were really lucky, James, with your GP and the fact that your GP says, hey, I think potentially your son's on the spectrum and that we need to look at this. If you had not got that at that appointment when you turned up and he was having his little meltdown in the waiting room, what would you have done? Would you have challenged your GP? Do you think that it's okay to challenge your GP and ask, oh, hang on a minute, this is how I feel? What do you think? Well, I think the thing with your GP is the GP is looking at it as a diagnostician. Professional? Yeah, professional. He's trying to tick boxes to get him to the category of where we might be.

So I think the important part is communication. If you communicate with your GP on the stuff that you have noticed, he will be able to go, okay, well, they should be here, here, and here, and here. If the GP goes, no, and just fobs you off, and you don't feel you've been listened to, then by all means, seek another opinion. That's good to know because a lot of people, a lot of families will hear the GP say, no, can't make a diagnosis until he's six, wait until he grows up, and they accept that. But you wouldn't do that? You would recommend not doing that? I mean, accepting medical advice and turning away from it is a hard thing to do.

It's a gut instinct. It always will be a gut instinct. Other people? Other people, particularly your ECE, your Early Childhood Centre, they are the ones that will notice because they're the ones that you will typically leave your child with, and they're the ones that have seen more children than you will have hot breakfast. And so if they're saying stuff as well, they should be more than happy to get on board if you go to your GP and say, look, this is what the ECE you've noticed. This is not something that we can just fob off and put under the rug. The child is X age. We've missed some milestones.

We've got this going on. He's short. And if you then still don't feel that way, unfortunately, then it's still a gut instinct. Go to someone else. Okay. And that's good. And I think you've just brought up, you've touched on a subject that's really good. Your Early Childhood Centre, they are really important. Finger on the pulse. But it's important when you go to your GP to also have that information. Yeah, definitely. So getting a referral into paediatrics, we need that information. We need to know what's happening from a school perspective. We need to know what's happening from a hospital perspective.

We need to know what's happening from a hospital perspective. We need to know what's happening from a home perspective. Because making that diagnosis of autism is about all or different contexts. So different places. Home, school, community. Yeah. And even in the clinic. So if we only get your point of view, what's happening at school? Or preschool? What's happening out in the community? So if you do get fobbed off by your GP, or you're going and you're really certain that this is what you want, having that information from there. And if you go to the education centre, be it primary or be it preschool, then it's really good to take that information with you.

And I think from a grandparent's perspective too, we come from a different generation. We are probably more likely to listen to what the doctor says and follow what they say. And we almost think that to challenge someone who's a professional is rude. Yeah. It's absolutely

not. And it's okay if your child takes your grandchild to the doctor and says, oh, doesn't agree with what they say, and they're going to a new GP. It's to support them with their process. Yeah. Because you know. You guys are their advocate. Yeah. They don't have that voice. That's right. That you need to advocate for. Yeah. Perfect.

Cool. I was just going to say, I think the important part is challenging medical advice. Versus questioning medical advice. If it's viewed as a challenge to the doctor, it will get standoffish because it's his profession. If it's questioning, you communicate the general way. You can do all this without offending anybody and still going, hey, I need to see someone else. Yeah. That's. Yeah. Yeah.

6. A Father and Grandmother's Journey - support - courses

For you guys, what I'd like to know now is following the diagnosis, how much support did you get and who supported you? What would you recommend for other families? Who would they seek out that support from? For example your GP, the education system, any other community resources? Who provided you with support? I would say that the first one, the first biggest one was Autism New Zealand, which will give you the resources for varying courses, which both me and my mother have done. There was Exploring through Autism, Exploring Autism, which is a multi-week course. It is a big course, but by the time you're done, you realise how, and I hate to say it in this way, but how bad it can be, and makes you see just how mild it can be and see how far apart they are, and then you can kind of see where you stand on it.

So that's great. It'll give you a lot of tools as well, a lot of resources. Did you meet other families? Yes, and of course it's always good to hear there are other people doing the same things that you are. Going through the same thing. You don't feel alone, and everybody that attends those courses are all there for the same reasons. We're all there trying to figure this out and trying to get our head around it. Did you find it good? Oh, I found it fantastic. I'd recommend any grandparent with a child on the spectrum, grandchild, on the spectrum, to go through at least one course. I know there's some shorter ones.

I think there's a half-day or a couple of day ones, but I did the same six-week one that James did. I'd recommend all grandparents do it because it does open your eyes, and it gives you context, and it lets you know that things are okay. And I guess the other thing it does is it lets you know that your son, your child, is actually doing a good job at parenting. Oh, absolutely. Because sometimes you would potentially think, maybe I wouldn't quite do it that way. But once you've met the other people on the course, then that gives you some... Oh, it absolutely does. And it was the best thing that I actually did to help support Keith, I think, because I just learned so much from it.

Mm-hmm. I mean, I wasn't going to do it. I heard about it because I babysat my grandson whilst James went to the course. And he would come back and tell me about all the things he'd learned, and so I enrolled in it as well. And my background's in education, so I thought this is something I can learn and develop. And it was the very best resource that I could absolutely name, better than anything else. And just for you, viewers at home, we'll put links to all these courses and all these resources for you as well. Cool. Awesome. Thank you.

7. A Father and Grandmother's Journey - support - Lifelinks

is there anything else that you found invaluable um yes definitely lifelinks lifelinks is a respite respite care or respite agency that will provide um financial assistance for respite and that comes in many forms and i think it can come in the form of being able to provide a a weighted blanket for your autistic little person or come in the form of giving you a giving you a carer for a couple of days but they are they're important they're not they're they are for your little person in multiple areas they're for your little person so that you have a break away from them so you don't end up both you know tearing each other's hair out over each other yeah refilling that tank of yours yeah and i'm giving you some time out for because this is not only do normal parents get time out you have a special little person and he and they are going to yep they're basically at times two for how stressed they can make your time up and i think that's where grandparents can really step up yep and and help with the the family dynamics and um they the the grandparent you can be the respite you can have your autistic grandchild stay overnight with you one-on-one and just it helps you develop a special relationship with your grandchild but it also helps the the rest of the family and that's what i you know when james um had another child well when that child was a newborn and they're developing that bond and trying to get into routines plus they've got um an autistic autistic five and six-year-old who's who's tearing around just being him it can get really stressful for the family unit and that's where grandparents particularly can step up and it's enjoyable it's really fun because it allowed james to get that bond with their newborn to start to get routines in place and you know i'd have keith quite often i'd have him like two or three weekends a month wouldn't i so i'd just pick him up on a friday and drop him back on a on a sunday and in that meantime you'd have one-on-one with your daughter yeah to get to know her and and spend time with her because that can often um you can often find as a family with an autistic child that all of a sudden the family dynamics and everything starts to center around the autistic child and you work around that and yeah so it's good it's good it's good for our family to have a break yeah it does it is and just remember to look up for those um youtube clips about lifelinks and explore we've um got them on listening to families as well okay um so other people that have helped with um with keith keith uh

with his extreme needs he did require assistance from occupational therapy that's not for everybody but for him he did require it i will say that there is there's going to be a lot of acronyms that come your way that you will end up you know will and be invaluable they will be invaluable for you um they're going to pop up they're going to do their piece and they're going to move on your problem you might never see them again once it's done but once it once they've they've done their little bit all of a sudden you will notice it in the follow-on effect of what they do and i guess the thing for me when i come to visit you is making sure that you're hopped into all of these services and that you've got um the things that you need um and i'm i'm there for you for two years following your diagnosis um so yeah

8. A Father and Grandmother's Journey - support - Hapai Foundation

Was there anyone else that was particularly important? Just the Hapai Foundation, which my mother works for. So can you explain Hapai to us? Okay, so a Hapai access card is a card for children with disabilities, because it helps with their access needs. I've been working there now for two and a half years. I started working there because of Keith, because I had a grandson with ASD, which is classified as a disability. And I wanted the chance to, this was working with children and adults with disability and their access needs. It's completely unique. We're not just a discount card, we're not an ID card.

We help with access needs using icons for barriers. Typically, a child I've got some cards here. Yeah. A child with autism will have four key needs when they're out in the community, which helps them to engage fully. So a child with autism will have difficulty standing in a queue. So if you go to the swimming pool at holidays, there'll be queues out the door to get into the pool. Children with autism either don't understand the concept of queuing, or they may have a bit of crowd anxiety. This helps them with that. They'll also often have difficulty processing that signal that says, I need to go to the loo.

And usually it happens, I need to go to the loo right now with very little wait time. They also need a one-on-one carer. And that's over and above what all children need to be supervised. But this is more. This is where a parent may be able to take three children to the beach and the summer time and have a picnic and go home. You can't do that if one of those children is on the spectrum, you need another adult to look after that child while the other parent looks after the rest. It just doesn't work that way. And then also we signal that that child has a TID in disability, something you can't see when you look at that child.

I hate to use this term, but it gets bandied around where we are. They don't look disabled, and they don't, So when that child has needs like all of a sudden they're in a supermarket or a movie theatre and they start to feel overwhelmed and they're not processing that well, that results in what we call the meltdown. That child is not naughty. That child is not having a temper tantrum. And this signals that that child, there's something else going on that you can maybe help with. And so that's what the Half-Life Access Card does. Cool. Fantastic. I know lots of families who want it and lots of families I support in getting that by supplying medical certificate.

Thank you. Yeah, that's great. We have these lanyards, which a lot of our ASD parents have. They're a safety lanyard, so they don't get caught up in gym equipment. They break away. And they say that their child, they call them their VOP card. And when you see a child with this, you know that that child may have needs over and above what other children have. And having the lanyard is really good as well because otherwise you'd have the card in your pocket. And you don't, you can't be identified. Exactly, exactly. When you're out and about and your child's got this, people know that they may need to help with their child in some way.

9. A Father and Grandmother's Journey - special needs school

How did you find your support from school, from the education system, following the diagnosis? It was fantastic. Everybody, okay, even going to when Keith first left ECE, his early childhood education, by that stage we had a diagnosis and we were transitioning to mainstream school. And he did attend a mainstream school and they did try. They did try, but unfortunately Keith was an escape artist. He caused a couple of quite large events where he went missing. He did have a one-on-one, but it didn't stop him. He would be into a bush and the one-on-one couldn't follow him and he'd be gone. So eventually he became aware that he did require more safer surroundings.

That's where he was assessed to be able to transition to a special services school, special needs school. He's attended a couple. Can I just stop you there? Yes. In terms of getting into that special school, did he need, what did he need? Did he need anything to be able to go to one of those special schools? He did require an assessment. The assessment was to see where Keith was standing in terms of behaviour, attention span, could he learn? Was he a danger to him or people around him or teachers? That did become the case. And he got some funding, didn't he? To enable him to do that? Yes. Called AUS funded, is that right?

Yes, AUS funded. So he's AUS funded. Yes. Sorry, carry on. He's currently attending quite a nice special services school out in our area. And that has been a world of difference. Dedicated facilities, dedicated teachers who understand his condition, who know what his triggers are, who work with other children, who have been a part of other schools, with other children that are similar. They have

their own network to be able to talk to other schools to see if they've got children that have similar disabilities or similar sort of mannerisms. And they will apply, will try to apply what they've done at other schools just to see if it works.

And so it gives them this massive, massive array of very bespoke teaching for kids. This then means the meltdowns of this. It means the learnings more. It means the routine is then set. He's learning how to cook. He's learning how to 3D print. He's learning how to do programming of Lego robots and everything else. And if you go back even just a year where he didn't really have that support, he was very much like it was, I would say that it was breakable. It would break me. I would have days where I just didn't know what to do. And that is so cool. It's so cool to hear because I did come and meet you about a year ago.

And it was such a difference. Yes. And I guess the important thing for other families to know is that not every child with autism will get AUS funding. It is really difficult to get, but you get it if you need it. And then that does offer you the opportunity to go to a special school. It does mean that you can stay within mainstream. You don't have to go to a special need school with. AUS funding. And I'd like to point out, too, that just with the doctors and being able to question them and make sure that you are seeing the right doctor and GP for your child, same goes for the school. Because Keith has been, he's actually been to three.

Yes. The first one was in a different town and moved. But that was, we watched his progress there. And whilst his behaviour was okay, apparently, at school, it was not good at home. And his educational progress in terms of learning to read and write was abysmal, quite honestly. He then moved locations and attended at another school where his behaviour at school was disastrous, wasn't it, James, to be honest? Yes, entirely. It was not. And it was. It had nothing to do with the, it was just the environment and Keith. Yeah. I think the school is great. They had great teachers, a great campus. And it was a special services school.

It was a special school. But it just, that was not where Keith, he didn't feel that he fitted there. And you're right. It is important to get the right school for your child. Yes. Do not try and fit them into a school that's closest to you or that you think might be the best. Yeah, exactly. And then finally, we're at his current school and he is just blossoming. Right. That's fantastic. One thing that Keith is, we're all lucky that this works for Keith. But even if they're eligible for a specialist school, you can choose the school within reason. They do let you do that. So if you find a school that does, that you take your child to and your child likes the school, but it is quite far out of your way, Keith is eligible for SESTA.

So he can tolerate. SESTA. He can tolerate getting on a bus or on a van, just a high-ace van. He gets his own row of seats. Yeah. One child per row. So that way, you know, they don't feel like crammed in and everything. And he goes to a school which is 15 minutes away from my house, just one way. So, you know, so, and when I've got children all finishing at different schools at the same time, you know, it is, it's sort of what, instead of picking the closest one to fit your timeline, maybe look at further afield and using SESTA. Because if it works for your child, everyone will understand. That's fantastic.

So, yeah. Thank you.

10. A Father and Grandmother's Journey - single parenting

so James for me when I've come to visit you I've only really met with you and obviously with you Sue at one point so for me what I want to know and I want you to let other people know what is it like from a parent's point of view when you're parenting as a single parent but you're co-parenting as well obviously because with keep her going because it is not I think the most important part is no matter what is to from the time you have your child you immediately that's you that's your situation you need to separate it that is your your will yeah so you need to make it fun you need to show them that from the time they're in the car even if it's for a trip around you know trip across town picking the child up that's your fun time make it your time make it your environment make an environment for them to feel safe and even if it's in a car even if it's you know um even if you're waiting you know to drop them off don't let them dwell on this angst of um the swap over because there will be ants because they're transitioning from one environment to the next environment the important part is to make your environment consistent yeah consistent for them so when they know they're with you they know exactly where they stand and what to expect so that way um they and so that way they when it happens they're not going to be anxious worrying well where am i going to what's going to you know how's this going to you need and it will be rough the first couple of times for any parent going through it um the routine of it will they will adopt the routine even if everything else in their life is blown out nothing is in a routine if you are the routine they will acknowledge it and when they come to you they know what your routine is they'll go to mum they know what mum's routine that's exactly right they feel comfortable with you don't jellyfish parent and just try and mold to the best things the most fun things they want consistency wake up breakfast you know shower go to bed you know these consistent things that is what they're seeking they're actually seeking that because it's the set rules that they're looking for and you're right because children like boundaries yes they push them yep damn right they push them yeah but they're pushing them to make sure that those boundaries are there as opposed to pushing them to make necessary make you move like don't think that it's very different for autistic little people i think they all will do that yeah and once again routine on uh the way that you do things routine on the way that you treat them routine on the way that you do bedtimes breakfast that is the important part of co-parenting it's just routine and i think if you are

in the lucky position and you can communication between parents is always good but it doesn't always happen that way so yeah and you so have you have you found it um i've obviously it was i found it yeah yeah i i found it um difficult from a a grandparent's perspective when the i don't know if i'm allowed to say this but you can edit it out if you want but it was when the children were residing primarily with their mother and they would visit their dad i found it difficult because um because their time with dad was limited and so it meant that my time as a nana was very very limited and i had been used to um seeing my grandchildren three four five times a week i would just pop in on the way home from work or whatever to say hi and that disappeared and then the times that we did get to see them we had them for a weekend one weekend a month and so it was very difficult and i think that we need to be aware of the fact that for a lot of families they either are going to live majority with mum yeah and visit dad occasionally yeah or vice versa so whatever it is for you as a family you need to make it work and you need to keep like you said james keep those routines keep it so that when they are with you and it works and but we know that with um having a an asd grandson for him consistency in so that he knows what to expect and i know a funny little story my mother his great grandmother whenever she comes to visit she always brings fruit for the children as a little treat and so that was the thing was he knew he'd come to visit dad and then nina and gran would come and visit and bring fruit and that was his thing.

It's just consistency and routine and just being regular that way they know exactly what to expect that way like they may learn to love it they may learn to dislike it but the point is is that at least they know exactly what they're in for and for them that they're not they don't understand what they're in for ninety percent of the time with the way the world goes. No half the time nor do we. Exactly so giving them something that's rock-solid is always going to be their good foundation for the way they are and how calm and how good they are you know in terms of like on their level they can be blown out by seeing something that's upsetting outside the window or on TV or something that we take for granted yeah and so you've really yeah because i just can't stress that enough consistency and patience okay

11. A Father and Grandmother's Journey - Googling for information

So it's been really great having Sue and James here. I know Sue mentioned earlier that she spent a lot of time on Google. I would like you guys to be really careful about Googling. Sometimes Google comes up with some very interesting opinions and ideas. What we're going to do at the end of these videos is have some links for you about websites and things that you can access. Some of them may have some QR codes. We've got links for all sorts of things, all about autism, so do check it out. Thank you very much.

12. A Father and Grandmother's Journey - key messages

So I guess what I'd like to do now is just say thank you very much to both of you for coming along. It's been great listening to your stories and to finding out a little bit more about a grandma's perspective and a father's perspective. What I'd like you both to do now, just very briefly, is tell me, is the one thing that you would like dads, or you would like grandparents, because you're representing grandparent, not just grandma, that you would like them to take away or to think about for or with their autistic child or grandchild? Yeah. James? I think I'd like to turn around and say that, yeah, you are going to have bad days and it's okay.

Most parents are going to have bad days and they're going to, they'll raise their voice or they will snap because they can't handle it anymore. It is okay. It's, you know, yeah, acknowledge it. You know? Put it to the side yourself and realise, yep, you let it slip. But don't turn around and ruin yourself over it. Don't think you're a terrible parent. There is not one person on this planet that couldn't turn around and do the job that you're doing right now probably any better than you are. You are doing your best and that's all you're asked of. Don't stop doing it. That's it. And I guess for me, I would just say to you, if you've felt in that, find someone to reach out for.

Most definitely. But, yeah. Thank you. And so, as a grandparent. As a grandparent, I think you have to trust in your children's parenting. They learned how to parent from you because they saw you as a parent and they're copying your behaviour. So, they are being great parents. And also, parenting styles change over time. You know, it's okay if the children have devices, which you probably didn't give your children devices, for instance, because they weren't there. You know, things change and society changes. But trust in their parenting. They are doing their best and don't be critical. You can have your opinions, but I've found opinions are best kept to yourself because they are doing a great job with your grandchild.

They really are. Thank you so much. Thank you both for coming. Thank you. Thank you. Thank you for having us. That's all right. Yeah, Peter.