

Below: Living with autism 'adds that little bit of chaos' to family life, says Geordie Mills, far right, with his sister Amelia, mum Elizabeth, and dad Robert. Left: Geordie recently passed an Australian Air Force Cadets leadership course with a credit.



Living with

AUTISM

by LISA MCINTOSH

Like many 16-year-old boys, Geordie Mills loves playing video games – especially sci-fi ones. In Year 11 at Golden Grove High School in Adelaide's north-eastern suburbs, he really enjoys drama lessons – especially the chance to act and 'make fun of himself' on stage.

Another favourite is IT classes. 'It's fascinating for me learning how big things are', says Geordie, who with his family is a member at Golden Grove Lutheran Church. 'For instance, we were learning about the internet one day and it was so interesting to learn how the internet actually works and how vast it is.'

He hopes to join the Royal Australian Air Force as a Communications and Information Systems Controller when he leaves school. For now, he is a member of Australian Air Force Cadets and recently passed a leadership course with flying colours.

'Cadets is probably the most favourite of all things I do outside of school', Geordie, whose mum Elizabeth Mills works in administration for the Air Force, says. 'I like the military side, like when you're out bush and you're sneaking around behind people. That's the fun part about cadets, all the chaos. I ended up having to dolphin dive over somebody. It's heaps of fun.'

Readily admitting that he has regular arguments with his younger sister, Amelia, who's 9, Geordie seems typical of high-achieving, active teens.

But, along with what for most people is the toughest part of high school, and dealing with all the usual pressures of being 16, he has the added challenge of living with Asperger's Syndrome. Asperger's falls within the autism spectrum as a subtype and is a condition that affects the way people communicate and relate to others.

Currently, there is no single known cause of autism or Asperger's. It is estimated that there are 52 million people on the autism spectrum worldwide.

For Geordie, one of the most difficult things about living with autism is struggling to ensure other people understand him – and for him to understand others as well.

'It does make me frustrated', he says. 'I am definitely frustrated especially when I have "complicated" days. But I just keep pushing on, to be honest.'

When he has a 'complicated day', Geordie says playing video games is probably the best way to feel better. 'I just shut myself off from the rest of the world', he says.



Geordie enjoys helping out at Home of Praise day care centre in Bangkok while on church mission trip to Thailand with his family in 2016.



'I know I'm born with it and I have it for a certain REASON. I don't know what that is just yet, but I reckon I will find out.'

'Getting older it's easier to recognise when I'm having a complicated day. But when I'm around my sister (who is also on the autism spectrum), I can't back down from an argument or when things do get complicated. But I know when to avoid my friends, when they're in a mood where they reckon they're joking but I don't want to be around them.'

Living with autism also can make being involved in the things he loves doing stressful for Geordie.

'I'm constantly stressing out about cadets but I still enjoy it', he says. 'Actually it's the fear of being wrong and getting in trouble.' Geordie also thinks it would help for those he encounters at cadets to have a greater awareness about autism to go with the medical condition identification tag he wears.

And while he enjoys having a mum in the defence forces, he hasn't thrived on the associated moves that can go along with the job – from Wagga Wagga in the New South Wales Riverina, to Newcastle in the same state's Hunter region, then to Adelaide.

'Having an insight into the military is definitely helpful', he says. 'I plan to get into the military and mum's just loaded with information that I can ask. But I don't like moving because then I have to make new friends and I'm not very good at making new friends.'

Geordie was diagnosed with Asperger's at around seven years of age. He has recognised in the years since that he has been treated differently from other people at times. And, naturally, that's pretty hard to take.

'People don't really want to approach me', he says. 'I get looked at funny. To be honest, it makes me feel depressed. Those moments when you have awkward conversations, I hate it. It feels like I can't talk to anyone about my problems.'

What would he most like people who don't live with autism to understand about it? 'To be understanding', he says, 'to try to understand what I'm trying to say. That's the worst thing, when I'm trying to explain something to someone and it's difficult, I have no words to explain it.'

He knows having a loving family around him is a help. 'Yeah, it is, I mean sometimes. Well it depends on what mood my sister's in, if she's looking to annoy me', he says of Amelia, who has Attention Deficit Hyperactivity Disorder (ADHD), which likely heightens the trigger points between the siblings.

He knows that living with autism affects his whole family. 'It just adds that little bit of chaos. With Amelia and me, we're constantly arguing with each other and we'll keep going because she won't stop and I don't know when to stop.'

Elizabeth and Robert Mills have made sure the family home has two separate living areas so Geordie and Amelia can

keep some space between them when they need to.

Despite facing their own challenges, the Mills family are keen to help others – and Geordie is no exception. They took part in a mission trip to Thailand in 2016 organised through LifeWay Lutheran Church, Epping in suburban Sydney, and LCA International Mission, while the family were members at LifeWay Newcastle in New South Wales. This included painting at a kindergarten attached to a Lutheran church and time at Home of Praise day care centre in the slums of Bangkok.

And since a move to South Australia in 2017 and joining Golden Grove church, Geordie has become involved with the youth group there and has put his hand up to be a junior youth leader. He also likes to operate the data projector in church as often as possible and helps his mum out with catering when that is required.

'We help out as much as we can', he says.

So does having Asperger's impact on his faith? 'Kind of', he says. 'I know I'm born with it and I have it for a certain reason. I don't know what that is just yet, but I reckon I will find out.'

Dwelling in God's word:

A STUDY ON

PASTORAL CARE FOR PEOPLE WITH DISABILITIES

by PASTOR TIM EBBS



For a person with Autism Spectrum Disorder (ASD), everyday experiences, sights and sounds can present heightened challenges and cause anxiety.

How might God's word guide us in practical, pastoral care for those with autism and their families?

See John 9:1-3. What was the question surrounding the man born blind? What does Jesus say?

Disability, frailty and illness are not God's judgement on particular people.

See Romans 8:21-22. How does Paul describe the devastating consequences of Adam and Eve's desire to place themselves above God?

In Romans 7, Paul explains how he is personally affected. See verses 15-25. What are your reflections on Paul's struggle?

I see a parallel in our home. Our son, who has high-functioning autism, knows what he should do but can't carry it out. That's because ASD is also a physical disability. There is a breakdown in how the brain sends and receives signals. Empathising with the complexities of ASD helps us understand socially inappropriate behaviours, but doesn't excuse them, so it's necessary to teach gently what is appropriate.

This has also taught me to reflect on my part in a broken creation, my self-centredness, my inability to do the good that I want, and my need for God's grace and compassion.

**How is this true for the Pharisees in John 9?
How is it true for us?**

The child who doesn't verbally respond or give eye contact, or who runs around screaming, or hits

other children, could be acting out of overwhelming anxiety. In church, these behaviours may cause us discomfort, but that child is likely highly uncomfortable themselves. The Pharisees ostracised the man formerly blind, assuming he was unable to provide any wisdom (John 9:34).

**What might this man be able to teach them? Was his worth as a person dependent on what he could do?
See Isaiah 43:4; Matthew 10:30-31; 1 Peter 1:18-21.**

God has a plan for his people, including those with disabilities. See Jeremiah 29:10-14.

We should highlight gifts and look for opportunities for people with ASD to grow in a way meaningful to them, as well as the congregation. What do they enjoy? What special role could they have to give them a sense of belonging?

How do the scriptures call us to help the families of people with disabilities? What can we do in a worship space, where parents of children with autism feel most self-conscious?

Listening, praying for, and accepting people with ASD is crucial. See James 1:19, Matthew 7:1-5, Philippians 4:5 and Colossians 3:12-14.

**Who strengthens us to do this, and how?
See Philippians 4:5 again and Colossians 3:16.**

We all need God's unconditional love because we are powerless to earn it. He loves people with disabilities more than we ever can. Parents and carers of those with ASD, he loves you, too. Christ took upon himself all the sin of the world, human frailty, brokenness and vulnerability, to redeem us.

No matter what each day brings, God is with us, bringing the hope of divine steadfast love and faithfulness.

BIGGEST CHALLENGE our greatest joy

Asher Lewis wants to be a movie producer when he grows up.



Parenting a child with Autism Spectrum Disorder (ASD) is a challenge that can push people to breaking point. But, along with the hard years, Kirra and her husband Rowan have experienced wonder and delight in having 11-year-old Asher in their family, along with Elijah, 13, and Aliya, 9.

by KIRRA LEWIS

We suspected early on that Asher's development was progressing differently to that of his brother and peers. After months of questioning our parenting, we sought a diagnosis. What was then called 'Asperger's Syndrome' (now diagnostically referred to as 'autism') was confirmed when he was three.

In the early years, Asher struggled with anxiety, meltdowns, misunderstandings, sleep disturbance and disruption to routines. Life was complicated and perplexing. In his world, shoes made his feet scream, tags on clothing were like mosquitoes biting and bright lights hurt his eyes. Raised eyebrows were confusing.

These days, Asher's feet still scream but he has learned to manage the sensation. At school, he does very well in the classroom with its clear rules and routines. But the playground is a jungle of unpredictability, filled with loud noises, strong facial expressions and bizarre social rituals. What we find easy, even fun, for Asher can be torturous and exhausting.

The early years were tough. But as we've all grown and matured, Asher too has grown to become absolute colour and life to our family. He has wisdom. He has insight. He's funny. He knows who he is and how he is wired. He looks at us 'neurotypicals' and thinks we're weird in the way we think – and maybe he's right! There is such beauty in autism. It reminds you that there is more than one way to approach things. Order, routine and predictability have their place. So, while parenting can be a hard slog, there is so much to learn and gain through the process.

As soon as Asher was diagnosed, we were galvanised into action. As limiting and destructive as labels can be, this label provided much-needed answers. We figured out which therapists and support services we needed and got to work.

It has really helped him to see a psychologist, working on emotional awareness and regulation – getting Asher's 'engine' to run not-too-fast and not-too-slow. Occupational therapy helped with everyday skills, like putting shoes on

Kirra, Aliya, Asher, Rowan and Elijah Lewis took part in the ALWS Walk My Way fundraiser last year.



Kirra Lewis (centre) says her faith has been shaped for the better by 'parenting amidst autism'.



those screaming feet, gripping a pen or getting into a swimming pool. And there was speech therapy, social skills groups, sensory programs, and the list goes on.

Of course, this has an impact on family time with our other children and as a couple, and really stretched our capacity to cope. There were times I parented out of frustration and exhaustion, as opposed to being the Pinterest mum I really wanted to be! Those times taught us about forgiveness, as I needed to seek my children's absolution as well.

Having autism in the family also affects siblings. Elijah just wanted a traditional brother who would kick the footy with him and run barefoot in the backyard. As the eldest, he often carried the burden of being the one to compromise to help Asher navigate his world. Our youngest, Aliya, naturally fell into the role of nurturer and social worker. From a very young age, she would alter her play expectations and needs to accommodate Asher.

We also learnt that therapists and counsellors weren't just for Asher. Each of our children have benefitted from processing their experiences with a professional, as have Rowan, and I. Having a child with additional needs can add pressure to a marriage. In the harder years, with a pre-schooler, a baby and Asher in-between, nothing was ever easy or uncomplicated. If someone had told me everything would be okay, I wouldn't have believed them!

Today I am astounded by Asher's maturity, creativity, and his capacity to cope and understand the world. He has many interests. He loves reading fantasy – the Harry Potter series, *The Hobbit*, *The Lord of the Rings* and Emily Rodda books were all devoured before he'd finished Grade 5. *Minecraft* and similar video games provide him with the release of being in a predictable world where he can be in control.

He's also a writer and has a trilogy of books written in his head. He'll type drafts of chapters, then delete them because, as he says, 'it's in his head now'. One day I'm sure he'll just sit and blurt the whole thing out. With his trilogy, he's also figured out how the movie adaptation is going to work, camera angles of certain scenes and has designed Lego sets to go with each book.

Asher identifies with the work that's been put in and the benefit it has been. He knows it's been hard. Without the tools he's been equipped with, he'd be a very different child. He's at a new school this year and the fact he can meet new people, build relationships and settle in to a whole new routine is amazing. He is proud that his neurons aren't typical, but to the kids of his new school, he is just another kid. Asher speaks of wanting to be a movie producer like his hero Peter Jackson. And

given all the challenges he has already risen to, what's stopping him?

Many other people go through the struggles and joys of parenting amidst autism. To those starting this journey, I would say that it's okay to cry. It's okay to ask for help. It's okay to seek professional support – in fact, it's important. Some days I have literally fallen to my knees, saying, 'God, how can I get through this day?' Sometimes these are prayers of protest and accusation. Other times they seek wisdom, grace, forgiveness, peace and endurance. The whole experience has shaped my faith for the better. I no longer consider Asher's autism to be a fallen or broken part of God's creation. Instead I see it as an expression of diversity. We need the genius, colour and flare autism can bring, and our humanity is enriched as we learn to live together.

I no longer consider Asher's autism to be a fallen or BROKEN part of God's creation. Instead I see it as an expression of DIVERSITY.

I have learnt that beautiful things emerge out of the cracked and the broken moments of life. Out of those ashes and the depths of the miry clay, beauty rises up. Yes, we have put in a lot of hard work, individually, with Asher, in our marriage, and as a family. But where would we be if we didn't see our circumstance in terms of God's grand design, or if we shut ourselves off from his promises to sustain us, or been isolated from his church's support?

I'm quite certain our present circumstance is nothing more or less than unwarranted grace. And because of this grace we are now able to look back on it reflectively with thankful eyes.

And we give all glory to God for all that has happened.

A 'product' of Lutheran congregations in Melbourne's east, Kirra Lewis is Community Education Officer for Australian Lutheran World Service.

SUPPORTING FAMILIES ...

what can we do as church?

Statistics show there are many families living with autism, but what can congregations do to support them? At one Lutheran church in suburban Adelaide, members have developed programs, groups and facilities with the aim of making life and worship more welcoming and less overwhelming for people with sensory issues.

by LYN ROEHRS AND LYN BENDER

What can we do as church to support families living with Autism Spectrum Disorder (ASD)?

Every day, every hour, ASD families are trying to find ways to provide an environment in which their children can function and flourish. Now let's think about one of these families planning to come to church and look at some of the issues they may be facing:

- This is not the regular school/kindy routine and the whole family needs to get ready
- They have to wear different clothes and it's a different time of day
- There may be battles over breakfast and over what they can take with them to church. 'No, not your 50 cars or a tub of Lego.'
- When finally in the car ... is the seatbelt on? Do they feel squashed in? Are they squabbling with their siblings in the back seat?

When they arrive at church, what does the child who has sensory issues face?

- Unfamiliar surroundings
- Being greeted by an unfamiliar person
- Lots of strangers crowded around
- Handshakes or hugs – ugh!
- Strong smells from perfume, hairspray or flowers
- Loud music and bright lights

The child may well think, 'And you expect me to sit still and be quiet in church? But I need to wiggle/make loud noises/fidget/move about ... and I can't cope with that music, those lights and people so close to me. Help! Get me out of here!'

A meltdown is on the way as the child is overloaded with sensory stimulation. How does the congregation react? Do members criticise parents for their 'lack of discipline', ignore or even exclude the family?

The family makes a hasty retreat. The parents and siblings miss worshipping with their church family, the social contacts, support and understanding, just when they need it most. Will that family return to church – or is it just too difficult? At The Ark at Salisbury Lutheran Church, we pondered this problem and came up with ways to make our church more inviting for our families and visitors with children with sensory issues.

We applied for and received a mission stimulus grant from the LCA to fund projects to support families living with ASD. These included upgrading the church welcome area, creating a sensory area, providing some education for members, including hosting a workshop, and staging a 'Purple Picnic' for families in support of autism awareness.

We refurbished the foyer with two areas, as some of the children prefer isolated play. We also provided comfortable seating for the families, including lounges, beanbags, cushions and a swivel egg chair. We purchased squishy fiddle toys and placed them in drawstring bags, and bought some weighted stuffed animals and wiggle cushions from online

suppliers. We also purchased several headsets that were very helpful in filtering out noise.

On Pinterest we discovered a variety of easy-to-make ideas for sensory toys, such as gel pads, sensory/calm-down bottles, mazes and weighted cushions. We also bought cheap waterwheel toys and church members made some puzzle cubes. Even a bundle of colourful pipe-cleaners can be twisted, curled and joined to keep young hands busy.

We were careful not to purchase any items with small parts that could become a choking hazard. The toys are regularly disinfected or washed, and checked for safety. The items are placed in one area of the foyer but are

How does the congregation react?
Do members
CRITICISE parents
for their 'lack of
discipline', ignore or
even EXCLUDE
the family?



Salisbury Lutheran Church in SA has a number of initiatives to support families living with autism, including (clockwise from top left) welcoming play and quiet spaces; sensory items such as weighted lap cushions, squishy balls and black 'ear defenders'; and a monthly coffee and chat time group for parents and carers.

available for all families to use. Many families are taking them into the church with their children rather than staying in the foyer, which is wonderful.

We also put posters around to help other members of the congregation understand why we have those things in the sensory area. And one of the children got up in front of the church to explain why he chose the items he did and what they did for him.

We also have a library of books available for our congregation, as part of the ASD education and awareness process. Members have become aware of the challenges that these children have, what the sensory issues are, and what is in place to help them.

We also have two groups that meet regularly, offering an outlet for families with children on the spectrum.

A couple of families from our church had said it would be good to talk to others in the same situation, so we started a monthly coffee and chat time group on Monday mornings in 2015. People from the wider community are also welcome and we provide a crèche. It is a safe place where parents or carers of children on the spectrum can just be themselves and can share the realities of life – because they do it tough.

The other thing we offer on a Thursday afternoon came out of a request for something for the whole family. The Salvation Army-run organisation Communities for Children has government funding in this area and they came to us and asked if we could partner with them. So in 2016

we started a fortnightly group with activities for families, which is run by Communities for Children support workers. We also have dads coming when they finish work and meeting the family here and it's great for the siblings who seem to miss out otherwise. We also serve those families a meal. This group is attended by people from the wider community, though members are welcome, too – so it's a wonderful outreach.

Volunteers are an integral part of the programs and groups we run to support families – from creative input for the sensory area, to staffing the crèche, providing meals and helping in the kitchen – we couldn't do without them.

We're all learning as we go along. We just want to continue to see where God leads us. Because he's led us big time in this.

Lyn Roehrs is a member at The Ark at Salisbury Lutheran Church. She has been a part of planning and introducing its programs, groups and facilities aimed at making the church more inviting for families living with Autism Spectrum Disorder and other sensory issues.

Lyn Benger is Care and Connections Coordinator at The Ark.

HELPFUL LINKS

Autism Awareness Australia – www.autismawareness.com.au

Autism NZ – www.autismnz.org.nz

Australian Autism Alliance – www.australianautismalliance.org.au

Health Direct – www.healthdirect.gov.au/autism

Ministry of Health NZ – www.health.govt.nz and search for ASD

Autism Spectrum Australia – www.autismspectrum.org.au