



Autism Guernsey
First Floor (East), Island House
La Grande Rue
St. Martin's
Guernsey
GY4 6RU

Tel: 232879

Email: office@autismguernsey.org.gg

Website: www.autismguernsey.org.gg

Our Patron is Lady Kathryn Corder
Registered Charity No: CH 419

Designed and written by Sandra J Robilliard

May 2019



Asperger's Syndrome in Adults

Diagnosed and undiagnosed



Ensuring a positive future for autism

This leaflet has been written by Sandra Robilliard,
who was diagnosed with Asperger's Syndrome
at the age of 52

The hidden condition

No-one knows how many adults there are with undiagnosed Asperger's Syndrome (an Autistic Spectrum Condition or ASC)

Many of us grew up and were educated at a time when little was known about the condition. We may have experienced difficulties at school and into adulthood, but these have gone unnoticed or been attributed to something else (e.g. an emotional health difficulty, or maybe even just us being 'a bit odd').

How does it feel to live with undiagnosed Asperger's Syndrome?

- It may seem there is no reason for some of your difficulties
- You perhaps find it hard to cope at work, but are not able to understand why (you are good at your job, but can't make sense of the social elements of the work environment)
- You may have difficulties making friends or maintaining relationships (perhaps you would like to spend time with others, but friends tend to avoid you and relationships repeatedly break down; and you don't know why)
- Maybe you feel you are 'different', but are not able to say what that different actually is
- It might seem as if you just 'don't fit in'
- You may find some situations exhausting, but not know why (after all, everyone else seems to cope perfectly well, so why can't you?)

Post diagnosis

The journey doesn't end with diagnosis, and in many respects the journey is now just beginning. At this point you may be experiencing a range of different and confusing emotions, and questions, including: -

- Relief - finally things are starting to make sense and you have an explanation for your difficulties
- The diagnosis may bring a sense of belonging and self-understanding
- Anger – why didn't someone spot this earlier?
- Grieving – for the person you believed you were before your diagnosis and the sense that everything that happened prior to this no longer makes any sense or no longer matters (remember though, that you are still the same person and nothing has changed in that respect)
- You may even question whether perhaps the diagnostician made a mistake, and you are not autistic after all
- Do I tell other people, my family, friends, employer? (The decision to disclose your ASC diagnosis is a very personal one, and it is entirely up to you whether you choose to do so.
- What does this mean for my future, my employment prospects, etc; and how do I move forwards in my life now?

Local autism charities, health professionals, family and friends can be great sources of support during this period of adjustment. You may also begin to form new friendships with other adults on the spectrum, and benefit from a shared understanding.

.....as for the **doubts** - they will happen to most of us. It can be quite a shock to learn you may be autistic, and you may have all kinds of confused feelings and thoughts about it. That's okay. Take as much time as you need. Read information about the subject or speak to others when or if you feel able to do so. You do not need to make any decision immediately, or indeed ever if you choose not to.

It is worth remembering that Autism Guernsey and NAS Guernsey are happy to provide support to individuals who feel they may have autism as well as those with a formal diagnosis.

The decision to undergo assessment

By now you may have read several books, spoken to professionals or other individuals on the spectrum, and have started making connections. Perhaps for the first time in your life things are starting to make sense. You can relate to the accounts you are reading and hearing about. For me this was a positive experience, but for some it might feel scary or daunting.

The decision to undergo an assessment is a very personal one. You may have reached the conclusion you probably do have Asperger's, but you feel no need to formally confirm that – which is just fine.

Assessment and Diagnosis

Currently the process of reaching assessment stage is not easy for adults in Guernsey. However, it can be done.

Receiving a diagnosis later in life often comes as a huge relief. For most it will also require a period of adjustment and reflection.

- Maybe you are very disorganised (despite your best efforts to manage your diary and day-to-day activities)
- Perhaps you have started to blame yourself for your difficulties (maybe even assuming there is something wrong with you, you are incapable, or inadequate)

Have you ever considered you might have Asperger's Syndrome?

Then one day the possibility of Asperger's Syndrome is raised. Perhaps you saw a TV programme or read something about the condition and thought: "That sounds like me." Or maybe someone else suggested to you that perhaps you have Asperger's.

A person's initial response to this possibility will vary greatly, and might include: -

- No, that's impossible!
- Surely I would have known if I had Asperger's
- If you are a female, you may well respond the way I did: "I can't have that – it's a boy's thing!"
- You may be offended or upset by the idea, or even angry that someone has suggested this.

And so on.....

People around you may be surprised (or not) if you tell them you think you may have Asperger's.

Their responses may include: -

- Actually, that seems to make a lot of sense
- I have wondered about that, but didn't know how to raise the subject
- No way! You don't look as if you have Asperger's (I have yet to find out what the 'Asperger's look' is!)
- But that can't be right. You are so intelligent, good at your job, really clever and smart. (Having Asperger's does not mean someone can't also be highly intelligent and skilled).
- Why would you want to label yourself in that way?
- I am your friend/partner/parent/doctor, etc, and I would know if you had a condition like that. (Not necessarily. Even health professionals often do not pick up on adult Asperger's traits, which is another reason why so many of us remain undiagnosed or are not diagnosed until much later in life).

You may decide not to pursue this any further or perhaps revisit it at some point in the future, and that's totally fine.

Alternatively, you may decide to explore the idea, even though you still think it is highly unlikely (for all kinds of reasons).

Assuming you have made the decision to find out more.....

What next?

How do you find out more information?

Who do you talk to?

.....and what about all those doubts you have?

Well, it can take a while to adjust to the idea that maybe you have Asperger's. You might wish to give yourself time to get used to the possibility, or you may be eager to seek out information and perhaps speak to someone about it.

Local Organisations – **Autism Guernsey**, **NAS Guernsey**, and the **Guernsey Autism Partnership (GAP)** can offer advice and information, and a place where you can go to speak to someone in confidence. *Please see the back of this leaflet for contact details.*

GP or other Health Professional – you may wish to discuss things with your GP or another health professional involved in your care.

Information – there is lots of information online, also many books and leaflets. Please visit the GAP website: gap.org.gg

Adults with Asperger's – some adults are very happy to talk about their condition and GAP can facilitate that if you want to meet with someone for an informal chat

Self-assessment Questionnaire – some people may choose this as a way to allow them to find out whether Asperger's is a possibility. The **Autism Spectrum Quotient (AQ)** can be found here: <https://psychology-tools.com/autism-spectrum-quotient/>
(Note: a high score may indicate a strong possibility of Asperger's, but is not a diagnosis in itself. Formal diagnosis requires a full assessment by an appropriately qualified professional)