

## **Getting a diagnosis: Visiting your GP**

As a girl, woman, transgender or non-binary person, or a person of colour, getting an autism diagnosis is difficult in the UK and globally. Often we have spent our lives masking to some degree or another, camouflaging so that we appear to be 'normal' and fit in. On top of that stereotypes of what constitute autistic traits still abound, even amongst the medical professionals.

If you are considering a trip to the GP to ask for a referral for an autism diagnosis, it is worth reading some of the following.

When girls or women go to see the GP to say that we think we are autistic, the GP will often see the persona that we present rather than our unmasked self. Since we often only feel safe at home, or in another safe place we have created, that is the place that we are usually the most ourselves. Unfortunately not all GPs realise that this is the case and that observing us for ten minutes in a surgery should not form part of a diagnosis. Women have reported that GPs have said that they *don't look autistic, are too successful* (they have a job and/or children), *can give eye contact, can have a conversation* and therefore couldn't possibly be autistic. There is still a widely held belief amongst the medical profession that the autism profile is a white male with special interests (trains, planes, science, gaming) who is socially awkward.

In an ideal world GPs (or gatekeepers to diagnosis) would listen to what we are saying, what we are reporting about how we feel and the struggles we have in life.

However, this is regularly not the case. If you are considering approaching your GP there are some things to consider before you go:

- Read or listen to a book like Ellie Middleton's *Unmasked*.
- Write down some of the reasons you think that you are autistic. Include any childhood behaviours. Keep this to an A4 typed sheet. (No-one has the time to read more than this). Take it with you to the GP. I have included a copy of what I took to the GP in Resources as an example.

- When you go for your appointment, if possible, take someone who knows you well and is able to recognise some of your autistic traits. Depending on your age, this might be a parent. It could be your partner or a friend, or even an ex-teacher. For some reason corroboration is often seen as an important piece of evidence for GPs and psychologists.
- Please note that research indicates that Black women are even more likely to encounter opposition and difficulties. This is unacceptable and changing GP attitudes and prejudices will be a long-haul involving education. Realistically, taking someone with you for support could be really important. If you know a woman who already has a diagnosis, then community support at an appointment is also an option.
- Before the appointment, think about how prepared you are to unmask. This can be really scary. You might decide to show only certain behaviours that are the real you. You might decide to start the conversation by saying that you will be masking because you spend your life on autopilot and therefore the GP will probably not see the real you.
- Focus on the difficulties in your life that happen because you are an autistic being in a neurotypical world: sensory issues (noises, bright lights, textures, tastes, smells), the fatigue of masking, particularly in the workplace, how hyperfocus might cause problems including executive functioning issues around planning, eating, sleeping, self-care.
- Research shows that females are more likely to have sensory issues, but, often due to societal expectations, appear more able to engage in social activities. Of course, it needs to be pointed out that this too can be exhausting. Our special interests might not be so obvious. For example we might be really into reading, or fashion and make-up, or horses, things that might be expected of a girl or woman. This can often be in a seemingly obsessive fashion though!
- Regarding soothing behaviours or stims, girls and women might play with their hair or jewellery, or massage their hands, or move their foot under the table, all of which can get overlooked. Some GPs and diagnosticians are still looking for rocking or hand flapping.
- According to research women have to show a greater level of autistic traits than men to get a diagnosis. We are also disadvantaged regarding diagnosis

if we are of average or above average intelligence. (Girls and women with additional learning needs are more likely to get a diagnosis). However, the intelligent Sheldon-like geek in men is more recognisable and more likely to get support. It may be necessary to point some of this out to a resistant GP.

Of course your GP may be clued into how autistic women present and may be a good listener. It is important though to realise that anyone who is not a cis white male may find it harder to get a referral and a subsequent diagnosis, due to diagnostician bias, diagnostic criteria and screening tool bias and the numbers that falsely indicate that autism is more prevalent in males.

Going to visit the GP armed with information and a support person will give you a greater chance of being referred. Once you are referred, it is highly likely that you will have to deal with a long wait for an appointment. This can be from months to years, depending upon where you live.

Please remember that self-diagnosis is acceptable in the autistic community. However, if you feel a diagnosis would be helpful in order for you to receive reasonable adjustments at work, or to validate your experiences of the neurotypical world, then I can tell you from my own experience that getting a diagnosis was one of the best things I ever did. It has been life-changing.