



VERY LATE DIAGNOSIS OF  
ASPERGER SYNDROME  
(AUTISM SPECTRUM DISORDER)

*How Seeking a Diagnosis in Adulthood  
Can Change Your Life*

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## *Chapter 6*

# THE ‘COMING OUT’ PROCESS

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The ‘coming out’ process is part of the healing process, which occurs during, or even after, our identity-alignment process. Remember that identity alignment begins with the tipping point – when self-identification is irreversible – and ends when we accept our new identity.

There are several variables inherent in the coming-out process: timing, manner of communication and the person(s) in whom we confide. There is no right or wrong way of coming out, although each choice carries its own risk. Most individuals who have Asperger syndrome are likely to come out in one of the following ways:

- during a meltdown, after the ‘tipping point’ of self-identification
- during the exploration and information-gathering stage, prior to diagnosis
- after a positive diagnosis or pre-diagnostic assessment
- after we have chosen a suitable lifestyle or plan for the remainder of our life
- when we have completely accepted our condition and revised self-image.

Of these manifestations, probably the most inappropriate time to come out is during a meltdown, shortly after self-identification, because a meltdown is usually driven by anger and confusion, so we may regret some of the things that we say later. A safer time to come out is after we have effectively researched our new identity, when we feel comfortable with our condition.

Be aware that, even with a formal diagnosis from the most respected psychiatrist, there will still be people who doubt your claim. As Michael John Carley says, many parents and relatives may not feel comfortable discussing the origin of our neurological condition (interview, 16 November 2012).

### **Misinformation on the Internet**

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When I confided in one of my friends about my newly identified condition, I received the following response:

‘This is just a lot of [impolite word] bull. Believe it or not, I have never heard about anybody who suddenly *got* Asperger syndrome (ASD) – it’s a mental disease you are either born with or not. I had to use Google [a lot] to find this out.’ This response reveals two major avenues of misinformation. First, most people do not realise that there are millions of undiagnosed autistic adults who have lived with ASD all their lives. An undiagnosed adult with ASD may become aware of their condition during their lifetime, but many go to their grave without this knowledge.

Second, the response shows that my friend believes that Asperger syndrome (ASD) is a mental disease, which confirms that the Internet is rife with false information. As mentioned earlier, mental illness is a secondary psychiatric condition caused by adverse environmental issues and lack of appropriate support.

My neurotypical ‘friend’ who searched the Web for (mis) information about ASD has above-average intelligence and two tertiary degrees, so he is neither stupid nor uneducated. I wonder what less intelligent and less educated people would make of ASD after a 30-minute Internet session!

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Of course, the safest and possibly most sensible time to come out is when we have completely accepted our new self-image;

however, this is 'easier said than done' because the crisis period usually involves many intense and painful feelings. Also, one of the prominent characteristics of ASD is saying whatever is on our mind without any effective filter to protect us (and others). This means that it is difficult for us to keep secrets, and once we realise our real identity, it would seem like a massive breach of integrity to hide our inner truth.

The method of communication we use when we come out also influences the responses we receive. The main advice is to communicate as clearly, logically and smoothly as possible. One major pitfall to avoid is communicating such emotive issues while under the influence of anger or alcohol (or any other mood-altering substance). Also, remember that conflict is often easier to deal with via email rather than by telephone or face to face.

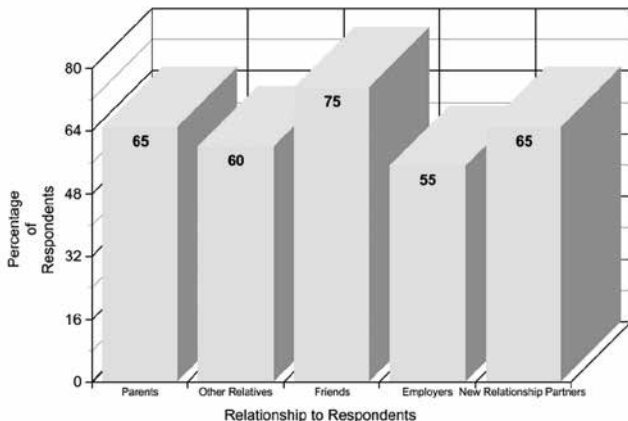
The key groups of people that we might want to 'come out' with are:

- parents and relatives (if they are still alive)
- potential employers
- friends and acquaintances
- current or potential relationship partners.

Figure 6.1 is from our survey (Wylie and Heath 2013, p.23) and shows who our respondents told about their late diagnosis.

Our survey revealed that approximately 66 per cent of the respondents told their parents, relatives, friends, employers and potential relationship partners about their ASD condition (Wylie and Heath 2013, p.23). But bear in mind that many of us are in contact with very few people.

A possible explanation for the high prevalence of coming out to all parties is that many adults with ASD only have contact with other autistic individuals, perhaps at a local support group. The respondents' friends who have ASD would not use the information against them, as some neurotypical people might do, even inadvertently.



**Figure 6.1 Coming out as having ASD**

## Key groups of people in whom we might choose to confide

### *Parents and relatives*

Older autistic adults do not usually receive an empathetic response from parents and relatives because of their ingrained beliefs, ‘stiff upper lip’ and inflexibility. Most parents and relatives of late-diagnosed adults do not want to be associated with any form of autism, even though they may know that ASD is primarily inherited genetically. Unfortunately, the medical model for autism (which is consistent with behavioural therapy) encourages people to deny their condition and pretend to be neurotypical.

The medical model for autism is based upon the premise that if an autistic person acts like a neurotypical person, they have been cured; however, this model does not take account of the resulting damage to the individual’s mental health and self-esteem. The medical model may work for successful autistic adults who have a sound support network with adequate resources.

In ideal circumstances, every disabled child has parents who are able to explain to them about their developmental disability and provide the necessary support; however, if adults with ASD have been left to discover their differences on their own, in most cases

their parents are probably too old, conservative and inflexible in their thinking to accept the truth when it is revealed. In such cases, coming out with parents is humiliating and frustrating, causing further estrangement.

### **Jen Birch's disclosure to her mother**

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Jen Birch waited an entire year before she told her mum about her diagnosis because she didn't want to upset her. Jen states:

As it happened, it did not upset her, but only confirmed her feeling – which had started as soon as I was born – she told me that something was different about me. Mum has been extremely supportive towards me; all the more since hearing my diagnosis. (Birch 2003, p.243)

Jen admits that she feels lucky that her mum reacted in such a positive way.

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A vitally important aspect of the healing process is the information collected about the psychiatric disorders in the family. A thorough investigation of the psychological profiles of all first-, second- and third-degree family members should be mandatory. It is essential that we understand how we inherited our condition to explain the communication problems within our family. My mother commented on many occasions about the constant fighting between her husband and his father, and between her husband and son. Only after my late diagnosis and considerable research into the family did I begin to understand the reasons for these problematic relationships.

One way of identifying psychiatric conditions is to observe each person's best friends and personal heroes, because like minds attract one another. For example, narcissistic people tend to respect fellow narcissists. Likewise, people who have ASD are typically attracted to those who have autism. However, neurodiversity is complex, and in some cases, there can be an overlap between ASD and Narcissistic Personality Disorder (NPD).

If you are a late-diagnosed individual and your parents are alive, it can be very helpful to identify the genetic path of autism in your family, and therefore it is necessary to ask some awkward questions.

## *Employers*

In general, our chances of getting an employment contract are much slimmer if we express ourselves transparently. Sadly, due to the prevailing ignorance about ASD across society, it still pays to tell white lies about our neurotype. Tony Attwood says, 'Men with Asperger syndrome can also be admired for speaking their minds, having a sense of social justice and strong moral convictions' (Attwood 2006, Chapter 13). So it is much more difficult for people who are on the autism spectrum to tell lies, even white lies. Inevitably, we 'shoot ourselves in the foot' by being overly transparent and consequently lose potential opportunities.

Unfortunately, the negative stigma attached to the autism label is everywhere. Rod Morris, who has ASD and is studying for an MA in Autism at Sheffield Hallam University, states:

There is a stigma. I have educated many local authorities and organisations and have found that people have difficulty seeing someone with autism as being a professional. The majority of autism charities just want to use people like me for free information, while the remunerative contracts are reserved for neurotypical professionals. (Rod Morris, interview, 27 February 2013)

Another matter of concern is that in many social enterprises, charities and autism support organisations, autistic people are under-represented among their staff. Surely, autism charities would benefit by employing people who have first-hand experience of ASD. Employers benefit massively by treating autistic people as healthy human beings and adjusting the work environment to enable us to be fully productive.

Employers that promote themselves as equal opportunity, mindful or inclusive employers are not necessarily to be trusted as such because these organisational 'badges' are essentially purchased

through an accreditation process so that they can portray themselves positively to customers and other stakeholders. (In a similar vein, many companies have pretended to be environmentally friendly to gain favour with environmentally friendly customers.) Remember that the actual decision makers in the recruitment process may not be quite as empathetic towards autistic people as their corporate employer portrays itself to be.

Regardless of whether you tell your potential employer about your ASD condition, it is beneficial to explain to recruiters your key strengths. Typical positive traits of autistic people are the ability to focus on a single task for a long time, above-average intelligence, adept systemisation skills, goal orientation, ability to see 'the wood for the trees', abstract thinking ability and integrity.

Autism expert Dennis Debbaudt recommends 'soft disclosure', which may be considered as the middle way (2002). Soft disclosure is the communication of our key strengths and weaknesses without mentioning specific diagnostic labels (such as ASD). This method of coming out is practical because the individual who discloses his or her condition softly is being transparent and ethical but not scaring people by using psychiatric labels that most people associate with madness. If you decide to tell your potential employer about your ASD condition, it may be a good idea to wait until the final stage of the recruitment process. Coming out at the outset of the job application process would probably limit our chances of being invited for an interview, unless the employer is specifically looking for an autistic employee.

Sometimes being honest about our neurological condition with employers can be beneficial, particularly if they support accommodations at work for people who have disabilities. An increasing number of employers, particularly computer software companies, are actively seeking autistic employees who are hard-working and focused.

Jen Birch says she told potential employers about her ASD condition at the interview stage, and eventually she was offered a suitable job. Of course, Jen's approach increases the risk of



rejection, but naturally she felt better about herself by being open and truthful about her condition (Birch 2003).

Try to perceive the situation from the employer's viewpoint. Employers want hard-working, reliable, productive employees who add value to their shareholders' investment. We know that autistic people can be hard-working, productive and focused. Most of us are goal-oriented, honest (to a fault) and good at keeping appointments and meeting deadlines; however, we are sometimes difficult to work with because we misunderstand people (and vice versa), and we usually need to work in our own unique way. We may be direct in our communications and impatient to 'get to the point'. Also, our quirky or 'freaky' ways intimidate some people.

### ***Friends and acquaintances***

It probably pays to be discerning about the friends and acquaintances we 'come out' to because many people are influenced by the negative press about people who are autistic. Many people only want to associate with other healthy and successful people, which is understandable as a survival strategy. Remember, there is a massive amount of misinformation about Asperger syndrome, and most people confuse ASD with mental illness, and few people want to have friends who are mentally ill. Even doctors and psychiatrists believe that ASD is a disorder or disease, so what chance does the lay public have of understanding this potentially hidden condition?

Some friends and acquaintances would disbelieve us anyway if we told them about our condition. It's understandable because ASD is a hidden intellectual disability and some of us may appear to be completely normal, albeit slightly eccentric. Our friends may incorrectly assume that such psychiatric conditions are always identified during childhood. Therefore, it may be a challenge to explain why we have been unaware of our condition for several decades; an excellent article to show these sceptics is that by Simon Baron-Cohen and colleagues (Baron-Cohen *et al.* 2007).

We must also remember that gossip and inaccurate rumours can ruin a person's social life, so it is important to consider the

consequences of telling any friend. As mentioned earlier, a single 'coming out' blunder can cost us our entire social life.

If possible, it is best to come out to friends and acquaintances on a highly discerning basis, and preferably *after* we have accepted our condition fully; however, this advice is not necessarily easy to apply, especially during meltdowns or crises, when it's nigh on impossible to control ourselves.

Also, many autistic people have enough trouble knowing who our true friends are anyway, due to lack of cognitive empathy, so we can easily confide in the wrong people (those who misunderstand ASD). Moreover, as mentioned previously, we find it difficult to keep secrets, preferring to be open and fully transparent about who we are. Several respondents in our survey said they would tell everyone about their condition because they are not ashamed of it. For example, John Carlisle says, 'I've nothing to hide; I am what I am' (Wylie and Heath 2013, p.23).

Overall, it's the individual's choice, but if we share our revelations with friends, we must ensure that they are properly informed about ASD; therefore, if possible, we should wait to tell selected friends after we understand ourselves better and are in a position to explain our situation to them clearly.

### ***Current or potential relationship partners***

The majority of autistic adults who are diagnosed late in life tend to live alone without a relationship partner or carer; however, many autistic adults identify their condition via their relationship partner. If you are in a relationship, make sure you and your partner read *Alone Together: Making an Asperger Marriage Work* by Katrin Bentley (2007). This book explains the challenges faced by both the person with ASD and the neurotypical person in a 'mixed' relationship. Of course, it is necessary to discuss any psychiatric issues with a current partner at the earliest possible opportunity; otherwise, misunderstandings and issues will grow and get out of control.

In the case of a potential relationship partner, it's an individual's decision about when to disclose their ASD condition, although the

majority of older autistic men may well have given up on romantic relationships by the time they figure themselves out. Remember, also, that there is a tendency for people who have neurological conditions, such as ASD, to attract others with similar conditions. For example, I attracted relationship partners who had bipolar disorder, narcissistic personality disorder and attachment disorder, as well as ASD. On a positive note, such couples should have lots to talk about, assuming both parties are willing to 'come out'. If either partner wants to have children, obviously it's very important to discuss the potential genetic issues. It is noteworthy that autistic children can be happy if they are properly cared for, and some of the happiest adults with ASD have children.

## Conclusion

How we come out, and with whom, is the individual's choice, so there is no single clear-cut solution. At one end of the coming-out spectrum is Jen Birch, who says, 'For me, it is a case of that saying of Jesus: "The truth will set you free". Getting rid of that one big secret certainly makes me feel liberated' (Birch 2003); however, Liane Holliday Willey's mother holds the view that: 'The truth may set you free, but it doesn't necessarily set everyone else free' (Murray 2006). At the other end of the coming-out spectrum are autistic people in senior positions – typically doctors, researchers, lecturers, scientists and engineers – who choose to tell nobody for fear of being a victim of the prevailing stigmas and possibly losing their career status.

After experiencing some of the feelings (not all negative) and consequences as a result of receiving a late diagnosis, how can we live with our condition and look to a brighter future? Chapter 7 explores some tried and tested coping strategies that can open the door to a more fulfilling future.