Reflections on stress and autism

Stress is often described as one of the major barriers to a fulfilled life for autistic people. It affects people across the autism spectrum at all stages of their lives. Of course stress affects everyone, but there is growing awareness that autistic people may be particularly susceptible to high levels of unhealthy stress.

What is stress?

According to the NHS, stress is the feeling of being under too much mental or emotional pressure. Pressure turns into stress when you feel unable to cope. The NHS description helps us to distinguish between stress, usually a result of external forces and anxiety, which is more frequently found within the person and manifests in the form of worrying, and persistent thoughts. Too often the two are joined together and, although related, they are different and the approaches to manage them will need to reflect this.

Therefore, it is worth thinking whether the problem is related to inner or outer factors. Sometimes the source may be unclear, related to underlying insecurity, uncertainty, or to sensory processing problems that might not be apparent, even to the person concerned. They may manifest in tiredness, irritability or lack of concentration. Usually however, with some detective work the source becomes clear, although the person affected, their parents, teachers or work colleagues may need help in finding it.

Symptoms and effects of stress

Common signs of stress include:

- feeling anxious
- irritable
- having low self-esteem
- racing thoughts
- constant worry
- having to go over things again and again in your head.

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- losing your temper
- appearing unreasonable
- headaches
- muscle tension
- pain
- dizziness
- not finding enjoyment in things you have previously enjoyed.

Stress is also known to cause a surge of hormones called stress hormones, which are designed to react to stressful situations known as the "fight or flight" response. In most people, these usually return to normal levels once the stressful event has passed, but research has shown that in autism, these may remain in the body longer, causing a residual level of stress. This is important to address due to the harmful physical and psychological effects of too much stress over a prolonged period.

Stress may also cause other problems such as drinking too much alcohol or taking drugs to offset the effects. There is concern that in autism, there may be a tendency to self-medicate if the person is unable to access support or is not able to easily identify the sources of stress. This may be exacerbated by a poor diet, as the autistic person may lose their appetite. In turn, this may lead to additional problems at work or with sleeping. In some instances, stress has been dealt with by overuse of antipsychotic medication to subdue behaviour. Non-speaking autistic people, unable to communicate stress or distress, can be particularly vulnerable to this problem.

It is important therefore that we help people to identify the sources and mechanisms of stress and to develop coping strategies that I will call stress hygiene. This will include:

- regular exercise
- learning how to relax
- structured timetable to allow for time management and to build in ‘wind–down’ periods
- time spent in a relaxing hobby such as listening to music or painting or drawing.

A technique known as mindfulness is also thought to be helpful to some people.

**Sensory difficulties and stress**

There is a growing awareness that the sensory profile of autism may be related to how well a person copes with stress and is a factor in depression. Our research has shown that autistic boys with a sensory seeking profile (low registration) are much more prone to developing severe depression. This suggests that assessment of the sensory profile is important, as is the adoption of methods or activities to address these particular needs.

Some key areas to explore include the phenomena known as ‘meltdowns’, ‘shutdowns’ and ‘catatonia’, which may all be manifestations of stress and be related to feelings of
powerlessness or lack of control over stressor events – the build-up may go unnoticed until it is too late. These aspects are poorly understood, especially shutdown and catatonia, and a great deal of research is needed to better understand them.

**Stress in autistic women**

In our work with women across the EU, ‘masking’ of autism symptoms was described as a major source of stress, causing us to reflect on whether those interventions aimed at reducing those symptoms may be inherently stressful and bad for autistic people.

**Stress in families and professionals**

Stress is also an important factor for families of autistic people and front line professionals working with them. Reports in the literature of ‘burn out’ largely emphasise the difficulties and demands of living and working with autistic children and adults. The transactional nature of stress should therefore receive more attention. People forming the support network of the autistic person should be helped to understand their own stress and mind sets and how to manage these; in addition, the ‘problem’ narratives around people and settings should be modified.

**Conclusion**

It is clear that autistic individuals experience high levels of stress in everyday life. Chronic stress reduces ability to participate in academic, work, leisure, and social life and heightens the risk of ill health. Subjective experience of stress, coping ability and sensory profiles are all huge contributors and should be assessed in conjunction with the assessment of autism.

So what is to be done? We now know that it is stress and not autism that is a major barrier in life for most autistic people and this should receive the attention it merits from research, policy and practice. The solutions will be found through an alliance of autistic people, their families and the professional autism and research communities. This is the essence of the Research Autism initiative. Approaches that enable the person to control or moderate their stress would seem particularly important.

**Further reading**


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**NHD Choices – Stress anxiety and depression.**