

Adults with APD - Coping with Stress

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During a recent Adults with APD research chat, on the effects that APD can have on finding and maintaining employment, other themes emerged - those of coping with stress, the ability to relax, related sleep problems, using coping strategies to deal with stress and the effects that the need for these coping strategies can have on family members. This was a large group of topics in its own right, APD-related problems that are not just caused by employment issues alone, and does not just affect employment.

Recognising stress

One of the biggest issues for people with APD and other invisible disabilities is stress, which in some people can lead to a range of physical and emotional symptoms including anxiety, or depression – which are also invisible disabilities in their own right. Dealing with APD is stressful enough on its own. Add to that problems at work, difficulty with seeking work; lack of appropriate support and not being able to find a job, (thus leading to added money worries and difficulty negotiating the benefits system) and this increases the impact of stress on people with APD. Also stressful are other people's poor awareness of APD at work and elsewhere and lack of knowledge about APD and the lack of acceptance of a person's APD by their family and friends – one of the biggest issues they face. Stress often makes it harder for people to cope with their APD and symptoms can become worse as a result of failure of these coping strategies, due to the brain's diverted focus on the causes of stress. Also lack of sleep due to worry is another factor that can cause the coping strategies to falter, creating a vicious circle of worry, stress and anxiety, which is not at all helpful to those seeking and maintaining a job, running a family or just living day to day - even without the added factor of coping with APD. People with APD need to find their own individual ways of dealing with stress and what follows are the ones that were shared at the research chat.



Sleep problems

Lack of sleep is a common problem in people with APD, and this can include the inability to fall asleep. It can make daily living very difficult. Stress is one of the factors responsible for this, and lack of sleep can also cause stress itself. There are various methods used by people with APD to relax and get to sleep. Some people have a need to 'offload' what happened in their day by talking to others so that they can sleep. One participant's adult son has done it since childhood and another lady said, **"I do agree telling my day to my husband helps."** It is not a natural coping strategy in everyone however, as one person stated that, **"I don't know that I ever learned how to do that; insomnia often results as I try to process on my own."** But it is a skill you can learn and one which may be very useful. The act of going over everything in your mind after the event is known as post-processing.

Some people with APD also have Hyperacusis (hypersensitive/hyperacute hearing - not caused by APD but it seems to accompany it in a lot of APD sufferers) and this can make it hard to relax. One person said, **"I hear everything; I hear my own body processes. I hear all the havoc, I have tinnitus, I can't shut out or filter stuff, startle response never goes away."** Tinnitus is another issue that can accompany APD in some people, which like Hyperacusis, can be diagnosed by any audiologist and they can recommend desensitising treatments. Someone described this post-processing as, **"trying to deal with the backlog of what's already happened"** – and one person said, **"I can go over a conversation for hours - wishing I'd said something different."** Finding just the right reply in conversation can be caused by APD- related word retrieval difficulties. Also you may not have processed the question correctly and don't even realise it until hours later - as described here, **"I feel that a lot, like wishing I'd said something different, or wondering how I'd missed what I missed."** Rehearsing conversations e.g. possible question responses for a future conversation can help – **"sometimes my husband has to remind me to pre-rehearse before I make a phone call."** This can take time and effort, as one participant explained, **"It can take me months to pre-rehearse a conversation or presentation."** Analysis and self-criticism can follow when you realise you got something wrong. People with APD doubt what they hear and what they have said, all the time - it isn't a negative response, but more a way of life. But it all adds to the effects of stress, which can also affect self-esteem and self-confidence, and keep you awake at night.



Some useful sleep-related strategies

Working out how APD and the resulting stress affect you is the best way to find strategies that help you to cope. Other people employ different strategies to get things out of their head, and for different reasons. Such as the act of forward - remembering, which some people also have problems with, **“I write notes or I can't sleep - things I need to remember for the next day.”** For others who cannot even put it into words, or don't need to - **“I think in pictures”** - a quick sketch or doodle, just jotting down some relevant symbols etc. might allow that sort of visual thinker to fall asleep. Also if you wake in the night and your mind is racing about your problems and you cannot get back to sleep, this is not a restful sleep and it can be as harmful as no sleep. As well as being mentally exhausting, struggling to cope can cause people to also experience physical distress. **“Probably the biggest way I'm taxed by auditory stuff is in my body. It's a visceral disability not just a cognitive one... physically exhausting, but not just in the way we often think of physical. It is a general feeling or malaise, being needing to always be alert and mindful of what people say and what you reply, which can be very stressful on the body as well as the mind,”** – as one chat member put it, **“like brain strain, muscle strain, Eustachian tube strain, eye strain, and more all rolled into one.”** This is because, **“we have to rely on other sensory processing systems to help us cope and that can tax them,”** like needing visual clues. This is why people with APD can tire more easily and NEED time to relax and de-stress each day. One participant said, **“I need my coping strategies most of the day, and it is only when I can do things my way that I can relax.”** Another pointed out that **“all strategies work otherwise we wouldn't have developed them, they are worth respecting.”** Unfortunately some people's coping strategies are not easy to use, or reliable and this adds to stress - **“I cannot switch my coping strategies on and off when I need them... I also need to switch coping strategies between tasks as I may need different coping strategies for different tasks.”** One chat member stated, **“Winding down is not easy. I now realise, for me, I should go into a quiet space and use relaxation techniques.”** Although everyone is affected differently and has different coping strategies, they all agreed that they need to find peace and quiet in order to recover, because **“quiet time is healing time.”**



Why the brain needs rest

Rest is vital to the health of both the mind and body. The brain needs to recover from the strains of the day, to 'delay-press' speech from the day and store long-term memories. It cannot do this when it is overloaded - so if sensory overload, tiredness and stress prevent this from happening, the cycle of stressful circumstances continues.



This cycle needs to be broken and relaxation methods can help with this process. People cope with stress and relax in different ways. Strategies such as meditation and art can be helpful in post-processing and relaxation. One adult commented, **“When the whole system breaks down ... I feel so overloaded that ... I stop being able to be verbal.”** This comment sums it up - **“non-verbal mode is when all the thoughts go away, when I don't live in a world of words but just a world of colours/shapes/lines/textures.”** One attendee told us, **“I do art, not as often as I would like, and that often helps integrate things... when I do art I find I feel much better. I think it channels a lot of attention towards a visual thing, which puts a great deal of my brain into non-verbal mode. Then while I'm in that non-verbal mode I think I can process a lot of things - even the verbal stuff - better than if I'm trying to think about it. So much of listening and processing isn't verbal, but I think I often mis-focus on the words - the content of what's said.”** So by going into 'non-verbal mode' she allows the brain time to process, without the need to focus on speech.

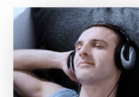
Relaxation methods

Other methods of relaxation that the adults with APD listed were yoga, meditation, bike riding, and hiking. As one person said, **“art or yoga is just a state of (being) really happy being less verbal, living on a plane where language fades away.”** It seems that, **“being in a quiet or non-verbal state either alone or with very trusted others”** is beneficial. Non-verbal activities give the brain a chance to wind down, a rest from struggling with speech. Yoga focuses on the body,



breathing and relaxing, not thinking. Mindfulness can help, living 'for the moment' and taking one day at a time are all most people can cope with - letting go of what happens today and taking each new day as a fresh start. Reading was also found to be helpful as a way to relax and it can help people fall asleep - **“I find that as I read (even if I have to re-read a paragraph), I immerse myself in the book and it is like I am watching a movie,”** and another said, **“it takes me away from the present.”** Watching films is another

method of escapism from the stresses and strains of living with APD, with regard to employment or any stressful situation. Others find a different type of noise like music can also ease the stress. The type of music all depends on personal choice, it can be relaxing or energising. One adult said **“I relax with headphones on listening to classic prog rock, loud!”** This loud music has the effect of blocking out all other unwanted sound. For some people, especially those with sensitive hearing/Hyperacusis, even listening to music can be stressful. However some people find that bland noise – like white, pink or brown noise - can help.



Daytime issues

Having an early morning routine is also a vital strategy in coping with APD. One attendee said that her husband hardly speaks for the first hour he is awake in the morning - it takes time for him to wake up properly and be ready to process speech- and her son is the same. She also said that she also finds processing speech difficult first thing in the mornings, and that **“waking up with no noise is great.”** It is her time to get herself sorted, answer emails and do tasks that need peace and quiet, before the family gets up. Unfortunately as she gets up first, she also finds that when she is ready for a conversation, others may not be because they have only just got up and she has to be mindful of their need for quiet. People also need a period of quiet time alone during the rest of the day, in order to relax and refresh their brain. This can be difficult to find when at work. For some people this could be a lunchtime walk to a local park or library, or even hiding in the toilets if you can't find a quiet room in which to unwind! Work cafeterias can be very noisy because of many people speaking and reverberated sound in large spaces. Cafes and shops are also noisy, as is the noise in the street from traffic and people. Teachers (and children) with APD often find this at school too. Things like coffee, chocolate and soft drinks containing caffeine are often used to help relieve stress or to keep people going through the day, but they can make people more agitated. Some people don't get a chance to have this 'quiet time' or any chance to relax until they get home, and this lack of a quiet refuge, the inability to escape from noise, can add to stress. Even the journey to work can be noisy and stressful and can cause a bad start to the day.

Impact on family from needing APD coping strategies



There can be an impact on partners and family members from these very necessary coping strategies, or from the effects of the APD itself. They may not understand why people with APD need them and they may feel left out, even rejected by the adult with APD's need to be alone, to be incommunicative. This can take its toll on relationships and cause stress in relationships. One lady said, **“My husband really doesn't like the silence I need. Or the time I can take to process the things he says to me.”** Another lady stated, **“I won't answer the phone; my kids or husband answer, then once I know who it is, I will answer.”** Some people with APD are unable to use the phone because of the degraded speech/sound signal and inability to use coping strategies to aid processing - like lip-reading and reading visual cues and body language.

Explaining your need for these coping strategies can help. Over time, partners and families can come to terms with this need. One person told us, **“My husband gets annoyed because sometimes it can take a couple of minutes for me to realize what he has said to me; he gets frustrated. But now that we know it is APD he is more understanding. Still doesn't fix things, but he understands a bit better.”** In this relationship,



her diagnosis of APD was the turning point that aided understanding – the validation that there was a reason behind the miscommunication and the need for coping strategies and 'quiet time'. Another lady said, **“My husband really didn't understand things before, I think he understands better now.”** But APD can cause stress in relationships even where there is a common understanding. A third contributor spoke about the effect of coping strategies on her family, **“If they don't need them it can be hard to understand the need for them I expect - my husband and I both have APD so we understand, but are still short with each other occasionally, impatient.”** So even with this knowledge and mutual understanding, APD can still cause stress, and even if it is infrequently, it can cause problems in a relationship. Another person explained that when you both have APD, it can sometimes help a relationship **“My wife and I both have APD and it was only after 20 years of marriage when we were diagnosed as having APD that we realised why we understood each other so well!”**

Adults with APD must find their own way to explain to their family, friends and partners the strategies that they need to use daily to cope with APD – and the ways they deal with the stress it can cause. Intuitive, empathic people with APD often expect other people to 'just know' what they need, but often the other people don't pick up on it because they

don't have the same level of empathy. In some relationships such activities can be shared; in others they need to explain why they need their own space. The key is ironically communication, which can be so hard for people with APD.

How to cope with stress

Stress can affect anyone at any time. But the daily pressures on people with APD are huge, at home and at work, and often there is little or no escape from it. It is essential to try to set aside a little time each day to relax to let your mind and body recover. For some people, this time is only when they are asleep - if they can get to sleep. APD can leave a person exhausted, and lack of sleep only adds to their distress. You can try to do more to help yourself relax by adopting some of the strategies mentioned. Here are additional everyday causes and effects of stress (not everyone will have all of them) and some coping strategies that might help.

Stress causes and triggers	Possible emotional symptoms of stress	Possible physical symptoms of stress	Some ways to help reduce stress
Noise pollution Auditory overload Education pressures Employment pressures Unemployment/financial pressures Relationship pressures Social pressures/isolation issues Expectations of others and yourself Pressures placed upon you by yourself Depression and anxiety	Mood swings or changes in your mood Irritability or having a short temper Inability to relax Feeling overwhelmed. A sense of loneliness Depression Anxiety Low self-esteem Poor self-confidence Trouble getting to sleep and staying asleep	Low energy Headaches Upset stomach, including diarrhoea, constipation and nausea Aches, pains, and tense muscles Chest pain and rapid heartbeat Frequent colds and infections Reduced sex drive	Relaxation Plenty of sleep A healthy balanced diet Hobbies - art, reading, walking, sport etc. Yoga and meditation Mindfulness Music and nature sounds – sea, whale music etc. White/pink/brown noise Breathing exercises Counselling

Conclusion

There are ways that you can combat stress and win.

- Be aware of the physical toll and the effects on your mental wellbeing. Learn how stress affects you.
- Never be afraid to ask for help. Everyone needs help sometimes.
- Seek medical help first to evaluate the cause of your physical and emotional symptoms, in case there is an underlying medical condition that may be causing them or be making them worse.
- Speak to a counsellor if you need extra help with the emotional effects of stress.
- Talk to your family and friends about what you need to help you cope with your APD and make your life less stressful. This will help them understand you better and it will benefit them too. The support and understanding of partners, friends and family is vital in helping people with APD.
- Set aside a small time each day to take a vital 'time-out' away from noise - time just for you, even if it is just a few minutes to clear your mind.
- Adopt strategies to cope with your APD.
- Try the strategies employed by the people in our chat and find ones that suit you – it can be anything that can help you relax, unwind and be refreshed for the next day, or at the start of the day.



But most importantly don't let stress get the better of you – you can fight it. Below are some sources of mental health support in the UK:

Mind - <http://www.mind.org.uk/> - There are branches all over the UK. They can be found here: <http://www.mind.org.uk/information-support/local-minds/>

Samaritans - <http://www.samaritans.org/> - See below for confidential helpline and other contact details: <http://www.samaritans.org/how-we-can-help-you/contact-us>

Mental Health Foundation - <http://www.mentalhealth.org.uk/> - Support for people with mental health issues and learning disabilities.

