Taking Stock – APDUK Chair’s report 2013

© Alyson Mountjoy

It’s been a few years since the last APDUK newsletter, but things have progressed in the UK and APDUK has been working in the background all this time. Steps have been made in the right direction and we are achieving all our mission statement aims:

- Accurate multi-discipline diagnosis of APD at Great Ormond Street Hospital and Southampton University;
- More on-going research into APD, both in the UK and worldwide;
- More Local Authorities are aware of APD and more Statements of Educational Need have been achieved for children with APD;
- More adults with APD are claiming Disability Living Allowance and Carer’s Allowance;
- Greater publicity of APD on online forums/social media;
- The APDUK helpline is up and running and we even get referrals from NHS Direct.

But what comes next?  
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Taking Stock (continued) ©Alyson Mountjoy

The Way Forward

In order to make further progress we need help. APDUK intends to hold our next Annual General Meeting (AGM) at the start of 2014. This will be held online and will start by appointing a new executive committee. Volunteers are very welcome, but in order for the committee to be effective, all members have to be able to commit to providing a little time each week to support the work of APD. Although this need not be long (anything from an hour a week) it is essential that this commitment is there, as appointment to the committee is for a minimum of a year. Committee members will also be expected to assist with the APD helpline, but this will not cost you anything and training will be provided.

APDUK has been functioning on a ‘skeleton staff’ for the past few years and it has taken its toll. Although we feel that we have still made steady progress, as a result we have not been able to progress as fast or as far as we had hoped. We do appreciate that you all have families and other important commitments, as do the existing committee members, but if you have an interest and any skills to share, particularly in the areas of finance/treasurers, administration, committee management, fundraising, marketing and publicity, grant funding, or helpline please email me at adpduknews@aol.com. We welcome applications from parents and adults with APD or suspected APD. Unfortunately we cannot accept professionals in the field of APD as this is and always will be a parent-led organisation and the current members also happen to also be adults with APD.

Next steps

I have already started putting together a national database of APD testing centres and I hope to add to this a list of APD aware/APD compliant Local education Authorities to recommend to parents. If you can help with this please send me details of where in the UK you received APD testing for your child or yourself. The details I would ideally like, if you have them, are where you received your diagnosis of APD – name and address (if you have it) of the institution and specialist, whether they are an audiologist or what type of specialist they are, what tests they used (if you know) and whether you were given a report or any suggestions on APD management. Also if your LEA is aware of APD and/or if they provide adequate accommodations for APD for your child, please could you let me know the details. Please email me at adpduknews@aol.com.

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FM systems

I have received many requests for information on FM systems, often suggested to parents on diagnosis of APD as being helpful to some children. Questions that I have received are usually concerning whether APDUK can provide them, or where parents can get funding for them. The simple answer is firstly that APDUK do not have the funding to do so at this time. Secondly, you can request that your local education authority provides one as one of the conditions of your child’s Statement of Educational Needs. I have even known of schools providing them without a statement, if they have the resources. Should you have an FM system or if anyone you know of has one that they no longer need and wish to donate it, rent it or sell it, please email me at apduknews@aol.com and I will set up an APDUK database for the UK.

Website

The APDUK website http://www.apduk.org.uk will be undergoing an update and this will take place in early 2014.

Adults with APD Research

The world’s first adults with APD research project, run by APDUK in conjunction with Dr Damien Howard, will recommence in early 2014, via our online international chats for adults. These chats have provided the basis for the research in the past, also articles in this and other APDUK newsletters, as well as vital adult support. We hope that many of the adults with APD from our online forums will again be part of this vital research project.

APD Presentation

A while ago I put together an APDUK presentation on APD. If anyone would like a copy to take to their school or to present anywhere, please email me.

Local APD Support

APDUK wants to set up maybe 5 or 6 regional groups for APD support in the UK, managed by members of the Executive Committee. Hopefully this will lead to establishing local groups in each region so that everyone in the UK will be in reasonable distance of other parents to share support, meet up for coffee mornings, fundraisers etc. This will take time, but we want to make sure that everyone in the UK ultimately has access to support - not just online, but in-person support for parents and their children and for adults with APD. Thank you to you all for supporting APDUK so far and I look forward to meeting some of you in the near future and working with you as new members of the Executive Committee!

Aly Chair APDUK  apduknews@aol.com  http://www.apduk.org.uk

“It is better to light a candle than curse the darkness” - Eleanor Roosevelt
People take various routes to finding out that their child has APD. Admittedly there is a lot of overlap of symptoms in invisible disabilities. For that reason, I would always recommend testing for APD first - APD is diagnosed via scientific tests ideally administered by audiologists, trained medical professionals, and therefore easier to rule out. The wrong diagnosis leads to the wrong sort of help and the APD, which can exist with other conditions, never gets properly addressed. Each and every condition affecting a child needs separate attention and accommodation. APD is present for life and does not just affect education – this and other conditions can also inhibit communication and social interaction, often in different ways. We need to get it right from the start, to give our children the best possible chance of success.

There are 2 centres where multi-discipline assessment for APD is carried out in the UK.

First and foremost is the APD Testing Centre at Great Ormond Street Hospital (GOSH) in London, run by Dr Tony Sirimanna. The current criteria for accepting referrals are on the right of this page but I have been informed by Dr Sirimanna that these might change and I will update you as soon as I am informed of any changes. This is free but there is a long waiting list. There is also a private clinic. See here for further information.

http://www.gosh.nhs.uk/medical-conditions/search-for-medical-conditions/auditory-processing-disorder/auditory-processing-disorder-information

To clarify a point that has been raised with me by some parents, I have been informed that at GOSH, if it is found that a child does not fit into the diagnostic criteria for APD yet has some abnormalities on testing, rather than saying they do not have APD, a diagnosis of “auditory processing difficulties” is given. In other words, for anyone who has abnormalities that fall within the criteria for diagnosis of APD (at GOSH) they always use the term Auditory Processing Disorder. If you have any queries, please email apduknews@aol.com ©Alyson Mountjoy

Auditory Processing Disorder (APD) Clinic at Great Ormond Street Hospital - Referral Criteria 2013

Consultants:
Dr Doris Bamiou (Monday AM)
Dr Tony Sirimanna (Tuesday AM & PM, 3rd, 4th & 5th Thursday PM)

Who is suitable to be referred?
Age: minimum developmental age 6 yrs, maximum age: 16 yrs at the time of the appointment (older patients: Contact Dr Doris Bamiou at the National Hospital for Neurology and Neurosurgery).

There should be suspicion of APD by Educational & Healthcare professionals such as teachers, speech and language therapists, educational or clinical psychologists, psychiatrists, ENT surgeons, Paediatricians or audiologists.

The child should have normal hearing thresholds in both ears with normal middle ear functions

Who can refer: GPS: GPs can refer if they attach a copy of the report suggesting an APD assessment by an audiologist, ENT surgeon, psychologist or speech & language therapist with evidence of normal hearing.

Hospital or Community Consultants: We also accept tertiary referrals as long as there is a suspicion of APD and there is evidence of normal hearing and normal peripheral auditory system. If there are language, phonological, cognitive or other developmental problems these must be assessed first and relevant reports must be attached to the referral.

It is expected that these children have reached a developmental age, language abilities and maturity adequate to complete the complex audiological test battery e.g. repeating different numbers heard in both ears simultaneously, repeating words presented in background noise, repeating the sounds patterns heard, detecting varying gaps in sounds. It would be difficult to test children who are severely autistic, who have severe speech & language disorder, and untreated severe ADHD or ADD.

If there are questions please e-mail Dr Tony Sirimanna at sirimt@gosh.nhs.uk

Information on APD testing at Southampton University can be found here. http://ais.southampton.ac.uk/auditory-processing-disorder The BSA Auditory Processing Disorder Special Interest Group can be found here. http://www.thebsa.org.uk/index.php?option=com_content&view=category&layout=blog&id=21&Itemid=29
CLOSED MINDS

by Veejayah ©

Why don't they try
Try to understand
Hearing is fine
Listening is tough
Processing those sounds
Making sense of what's heard
Too many people talking
Unfamiliar accents
Traffic going by
Pencils tapping
Fridges humming
Fans buzzing

He was told
It was explained
He's had a good day
What did he tell you
He didn't tell us
He's playing us off
If he doesn't tell us
We can't help him
He must tell staff
They won't know
How he's feeling
Feeling he's wrong

He tells staff he's fine
He smiles, he's happy
He's had a good day
Inside he's confused
Feeling stupid
They don't understand
His need to control
Conversation
To talk and talk
Process later
Talk it through
Understand.

APD ALERT CARDS

As a result of requests from parents, APDUK have developed an APD alert card for children to take to school/show their friends. It explains what APD is how it affects them and ways to help. There are 3 designs to choose from. These can be found at the end of the newsletter, after the hand-outs section.

Similar cards for adults with APD are also provided there.

Ały apduknews@aol.com

APDUK Helpline
- 07815 995491

Parent stories

If you would like share your journey with APD for our next newsletter, please email apduknews@aol.com

SUPPORT FOR PARENTS

The APDUK website is here with a wealth of information for parents. http://www.apduk.org.uk

There are several online groups for parents of children with APD. This one is managed and moderated by APDUK members. https://www.facebook.com/groups/122185968465/ Please join us!

APDUK also have a Facebook page here. https://www.facebook.com/pages/Auditory-Processing-Disorder-in-the-UK-APDUK/133487318301

SUPPORT FOR ADULTS

Often parents will find that they also have APD when they get a diagnosis of APD for a child. There are two online groups for adults with APD if you would like to join. There is one at Yahoo groups here: http://groups.yahoo.com/neo/groups/OldAPDs

Also we are on Facebook here. https://www.facebook.com/groups/APDadults/
Look at people when they speak to you; this also helps with lip-reading.
Explain to people that you have trouble understanding them; a good friend will understand and help you.
Try to talk to people where it’s quiet, or in small groups and ask them not to all talk at once so it is easier to understand.
Work out what makes things easier for you – maybe you prefer people to repeat things, or say things a different way.
Ask people politely not to interrupt you till you get to the end of what you want to say, in case you forget.
You may find it easier to have things explained to you using pictures rather than words, so tell people if this helps you.
If you have trouble following lists of spoken instructions or remembering things in the right order, you could ask people to write them down for you.

REMEMBER – it’s not your fault! © APDUK

A BOOK ABOUT A BOY WITH APD

‘I Get It! I Get It! How John Figures It Out’

Yvonne Capitelli & Loraine Alderman

Autumn Word Search

Find the 10 autumn words in the word search below!

If you print this page out, you can circle or highlight them.
squirrels, halloween, pumpkins, colours, harvest, bonfire, autumn, leaves, acorns, rain

Please send us a painting, a drawing or a story for our next newsletter, apduknews@aol.com
Auditory Processing Disorder means...

Trying to listen to people and having their speech just not sound right. Missing the majority of emotional non-verbal information because it's not possible to take in all of the body language and facial expression and still process what they're saying. Not really learning how to express emotion non-verbally because that information never made much sense.

Seeming controlling because where we sit and who sits where is important to being able to hear anybody. Seeming anti-social when it didn't matter that the maitre'd moved us twice, because afterwards someone seated a loud party of six right near our table. Going to a loud environment and needing a day to have silence afterward.

Trying to converse, read, write, paint, or think in a loud environment and feeling unable to do it. Just not going places because they are too loud and chaotic, even if not trying to have a conversation. Finding out that those places don't seem loud to other people.

Feeling a physical constriction of the ear canal when uncomfortable noises happen. Not enjoying 80s music because MIDI sounds are painful. Knowing what a sine wave sounds like because it hurts. Feeling "old" at 19 because loud bass coming from the next floor of the dorm is a Sensory nightmare that brings on nausea and JUST MAKE IT STOP.

Tolerating simultaneously the noises of the hard drives, air conditioners, drying, fluorescent lights, squeaky chairs, squeaky shoes, nails on denim, loud breathing, music through someone's headphones, brakes on a car a block away, sirens, piped in music, plates clanking, keyboards clacking, paper rustling, other conversations, birds outside, tinnitus inside, noises of cars, church bells, telephones ringing too loudly, -- and then people wondering why one direct tiny thing creates an overly sensitive reaction.

Showing up early to get a seat in the front because not sitting in the front means it is impossible to filter out people talking who shouldn't be. Realizing that five minutes before the event starts no one else is in the front row anyway because no one sits in the front. Being perceived as the teacher's pet because paying attention requires all the focus, and sitting in the front is too keen for the cool kids. Getting older and realizing that being the teacher’s pet wasn't a bad thing, except it has resulted in fear and self-consciousness every time because of all the teasing. Not even understanding how much teasing happened because it was not possible to hear most of it.

Continued on the page 8
Writing everything down because reading the text is easier than hearing it, but then having writer’s cramp AND brain cramp by the end because it was so much effort.

Figuring out just the right amount of effort to apply to be able to hear and process, but not so much that focusing to the end is impossible.

Feeling emotionally broken because upset and excited and angry voices scramble.

Thinking to the point that nothing makes sense.

Feeling cut off from everyone because nothing makes sense.

Asking for an assistive device every time at the movies, and only going to certain movie theaters because other theaters don't have the desired movie in captioning that day which means watching a movie but not understanding it.

People not understanding why a captioning device would be needed for someone who seems to hear just fine.

Videos online with no captioning and the music is too loud so turning up the volume makes it worse.

Automatic captioning on youtube that doesn't work (which is worse than no captioning) turning on some music in order to relax and then getting stuck trying to do the task that was at hand.

Trying to listen to a person while doing a task and missing parts of what they're saying.

Having to ask a person to repeat themselves.

Having to ask a person to repeat themselves.

Having to, sorry, ask a person to repeat themselves.

Feeling embarrassed when it still doesn't make sense.

Feeling like people expect an answer faster than it’s possible to process a question and then formulate an answer/

Stumbling through a group conversation because it's not possible to process five other people at once.

Feeling fake because making eye contact while conversing makes listening hard but looking away makes people think they aren't being paid attention to.

Feeling fake after discovering it's possible to trick people by looking at their foreheads or their lips.

Feeling not smart with a far above average IQ.

Feeling slow because it takes longer to respond.

Feeling powerless because some voices are too hard to hear.

There is a support group for teenagers with APD on Facebook. It can be found here.

https://www.facebook.com/groups/apdteen
Q & A
With Logan • Aged 18 • UK

Q. What coping strategies do you use, if any?
A. I don’t know - they’re subconscious.

Q. Do you tell people about your APD?
A. No, because I surround myself with people who don’t judge people on who you are, what you do, what you’ve done or how you live.

Q. Did you use any programs to help with your APD?
A. No.

Q. Do you wish that you didn’t have APD?
A. Not really.

Q. Are there stressful situations that you would avoid because of your APD?
A. Yes – noisy crowded places/ using the phone.

Q. Do you have any advice for other teenagers with APD?
A. Don’t worry about it and just live your life!

TOP TWELVE TEEN TIPS © APDUK

APD accommodations - for school or college

Preferential seating- where you can see the teacher or tutor and whiteboard/OHP clearly, not necessarily at the front.

Printed hand-outs of any information to be copied down, to save you making notes so you can just focus in listening.

Information provided by hand-out or email beforehand on the topic of the lesson/lecture (pre-teaching) so that the topic isn’t totally new to you and you can prepare.

A note-taker or a tape recorder to help you with making notes.

Instructions presented in small easy steps with time to process them in between and the teacher/tutor to ensure you have understood - you can repeat back to them what you think they said to make sure you have it right before you start.

Extra time to complete tasks to allow for delayed processing.

All group work to be undertaken in small groups (3-4 max) in a quiet area with one person speaking at once and one member of the group taking notes to send to all participants afterwards (in case you missed anything).

A home-school/college diary - completed by your teachers/tutors daily to make sure you don’t miss deadlines/have understood assignments accurately/remember meetings and events.

Extra time in tests and exams to allow for delayed processing.

Use of an FM system if this helps you.

Use of more visual/hands-on teaching methods to compensate for APD deficits.

Support in explaining your APD to your peers - if that’s what you want.

Recommended Books for Young Adults

‘Chaos Walking’ – A Trilogy by Patrick Ness

1. ‘The Knife of Never Letting Go’
2. ‘The Ask and the Answer’
3. ‘Monsters of Men’

Only for older teens/young adults due to mature content

An award winning science fiction trilogy that will leave you on the edge of your seat. Not for the faint-hearted, but well worth the read! Hard to put down, with heart-stopping action and more than a few surprises and tears along the way. For male and female readers alike – something for everyone!”

Please send your hints/tips, articles or poems suitable for teenagers and young adults with APD to Aly at apduknews@aol.com
One day, I went to a pizza parlor with a friend. The noises from the various machinery that is needed to keep a pizza parlor functional were very loud. It felt as if the loud humming noises were bouncing around my head like a ping pong ball in an empty room. I tried to appear to be a Normal Human Being by pointing to a slice of pizza in a display case and asking the person behind the counter, “What flavor is that slice?”

“Screechy steak,” said the person behind the counter. “Screechy steak?” I repeated. The person behind the counter looked at me as if I had three heads.

My friend had me look right at her face as she said in a loud and clear voice that overpowered the loud humming noises, “Three-cheese steak.”

“Screechy steak,” I said. “I’ll have the screechy steak.” My friend laughed. And I laughed, too, thinking of the strange things that I believe that I hear because I cannot block out extraneous background noise. All sound comes through to me at the same loud level.

Another day, I was busy with the laundry. I had one load in the washing machine, and another in the dryer, which were located in the basement of the house that I was living in at the time. I went upstairs to read a book. All of a sudden, I heard an ear-splitting sound. I raced downstairs, trying to figure out the source of the noise. It sounded as if it were coming from the dryer.

“Oh no! The dryer is overheating and will soon explode,” I thought in my usual dramatic style. I turned off the dryer. The noise did not cease. I unplugged the dryer. The noise stopped. My ears, however, did not stop throbbing. I went upstairs, trying to ignore the pain in my ears.

The laundry, unfortunately, was still wet in the dryer. “Maybe there isn’t anything wrong with the dryer,” I thought optimistically. I went downstairs, re-plugged the dryer and turned it on again. I had equipped myself with earplugs, just in case that horrible high-pitched sound resumed. No noise. I returned upstairs to read my book. After about half an hour of blissful silence, the terrible wail began again. I raced downstairs to turn off and unplug the dryer. Then I called the business that had sold me the dryer. I told the man that the dryer seemed to be malfunctioning and that it was making a terrible noise. The man spoke but I didn’t understand a word that he said because of the loud, shrill sound that was bounding around painfully in my ears.

At that moment, my landlord, who lived in the ground floor apartment, returned home. He heard the terrible noise and descended the stairs to the basement. I was still trying unsuccessfully to understand the man on the telephone over the never ending racket. “Oh, the smoke detector is going off,” the landlord said nonchalantly, as he removed the battery from the smoke detector. At that, the noise ended quite abruptly.

**ADULTS WITH APD**

*Screechy Steak and other APD tales*

*By Alice Gerard ©*

Always face the person you are speaking to (to aid lip-reading).

Hold conversations somewhere quiet whenever possible.

Explain to people whether you prefer repetition of what is said or rewording it, or maybe if you cannot process well at that time, ask them to write it down.

If phones are a problem, use other forms of communication such as email, texting or other written means; calls should be taken in a quiet environment, especially at work.

Avoid noisy crowded places and social gatherings; also crowded shops and those that play music.

Processing can be worse when tired, stressed or unwell, so make allowances for this.

Request instructions on paper, or one at a time, ensuring understanding.

**AND REMEMBER TO BE KIND TO YOURSELF!**

**TOP TIPS FOR ADULTS**

© APDUK

**ADULTS WITH APD GROUPS**

Please join us at Yahoo groups here:

http://groups.yahoo.com/neo/groups/OldAPDs

Also we are on Facebook here.

https://www.facebook.com/groups/APDadults/

**COMING UP NEXT**

- ‘Screechy Steak’ (continued)
- ‘Narrator in my Head’
- Adult with APD blog

“It’s not always necessary to be strong, but to feel strong.”

Jon Krakauer - ‘Into the Wild’
“I am sorry to bother you,” I said on the telephone. “It seems that there is nothing wrong with the dryer. The noise was caused by the smoke detector.”

“That’s all right,” the man said, as we ended the conversation or the attempt at conversation.

I walked away, feeling a little bit stupid. But difficulty in locating the source of sounds is another one of my APD issues. I was, however, grateful that the dryer did not explode and that I was free to continue the adventures of life with APD.

I told these stories to illustrate what daily life is like for a person with APD. Here are a few suggestions for improving communication with a person who has similar difficulties as I do.

- Look at me directly, especially when there is background noise, when you are speaking. Speak clearly and not too fast. It would help if you steered me away from the source of the noise.
- If you are in a different room and you call out to me and I ask you where you are, it’s not too helpful if you just say, “here” or “in the other room.” I will not be able to figure out where you are because of my difficulty in locating the source of sounds. It’s much more helpful if you tell me, in a clear voice, exactly where you are located so that I can find you.
- If I seem not to understand what you are saying, please don’t shout. I’m not deaf. Generally, I will request that you speak slower or more clearly. Simply raising the volume while continuing to speak unclearly is generally not helpful.
- And please... be patient. APD does not have an off switch. It doesn’t go away because it is inconvenient for the family and friends of the person with APD.

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AN ADULT WITH APD BLOG

© Author

Thank you to this anonymous reader, who sent me their blog to share with you.

“One resource for broadly sharing information about APD in adults is a collection of descriptions and links to places like the ADPUK and Old APDS Yahoo group, gathered at About Auditory Processing Disorder (APD).

http://wp.me/p30k25-2 Created by a member of the Old APDS Yahoo group, the information is intended to fill a gap in the information that can be found on the Internet about adults with APD in order to raise awareness and understanding."
The Horrors of Small Talk

By Nina Robertson ©

Oh the Horror! Yes, this seems a bit exaggerated at first thought, but in all honesty, many of us with APD find small talk so exhausting that we will do crazy things to avoid having to go through this social nicety. Yours truly, for example, ducked through the back door of the produce section of our neighborhood market to hide amongst the wilted lettuce to avoid talking to her dear acquaintance that she had not seen in ages. Why would she do such a thing, when the dear lady gliding her cart up the cereal aisle is one of her favorite people? Why would something as simple as a casual exchange of words cause angst and mental fatigue in someone with APD?

First of all, much of small talk involves asking questions and actively listening to the answers and responding appropriately to the exchange, and for a person with APD, questions can be confusing. Even if we decode the question easily, we still have to access the information in our brains that will provide the answer to the question. Once we access the information, then we have to process the information and formulate a response. The problem is that this often takes a few seconds longer for us and often by the time we are able to articulate the appropriate response, the other person is on to another question. This is confusing and exhausting, especially when the other person is not really interested in the answer, but is just making conversation. In other words, Small Talk.

When describing this experience to a friend, I was told that “I read too much into it.” Perhaps I do, but if there is a signal that indicates that what type of response will be expected from this exchange, I totally miss it. I do not know if the incoming questions are important enough to expend energy on until I have already spent the energy decoding and processing the questions and then my response. I don’t know that it is an unimportant verbal exchange until I have processed the question and formulated the answer. Then the articulation of the answer is sometimes garbled because I am not sure if I understood what was asked, or if the other person is asking for a specific reason or if the question is random. For many people, small talk is as automatic as breathing. For most people with APD, small talk is a manual process that takes concentration and energy to navigate effectively.

Small Talk Example ©Author

A friend started asked me questions about my family right as we were finishing our visit. I think it is because she felt that she was the one doing all the talking. I did not mind listening, as long as a response was not required. But I was mentally fatigued by then and her questions could not be answered without going into a long-winded story. My terse answers only resulted in additional questions, for example:

My friend asks, “How is your brother?”

Me Processing: I process the word “brother” and have to figure out which of my two brothers she is referring to and then realize that she has only met the one. When I finally process her question, I am also wondering why she wants this information. I do not realize yet that I am in the initial stages of small talk. So, I think about how he is doing but I have not seen him in a while, so I formulate a response and say something noncommittal, while I am trying to figure out why she is asking and if I understood her question correctly.

Me answering: “He is fine, as far as I know.”

My friend: “Oh when was the last time you saw him?”

Me processing: Process the question, when? I don’t remember the last time I saw him because I have trouble processing time, especially quantifying timeframes for events that happened in the past. Why is she asking me these questions?

Me answering: “I don’t remember.”

Friend: “Are you still mad at him?”

Me processing: Am I still mad? Was I mad at him? Oh yeah, when he crossed a personal boundary a few months ago, I had to call him on it, but I was not really angry with him. Is that what she is asking about? Why does she keep asking me these questions?

Me answering: “I cannot remember.”

All during this Q&A small talk session, I was simply trying to give her enough information to satisfy her questions without prompting more questions. I was so mentally fatigued by those questions, but it is not because I don’t want to provide her with the information. I don’t mind if she knows those things. I know that she was just showing interest in my life in a way that is socially normal. I know she meant well, but when I explained how questions like that cause me distress, she did not understand. I understand that she cannot understand. I would not understand either if I did not experience this type of exchange and subsequent exhaustion every day of my life.
Speaking, Listening and Self-compassion by Dr Damien Howard ©

It is common for people with listening problems to feel ‘dumb’ when there is regular communication failure. People can become habitually very hard on themselves. Cultivating self-compassion can be a helpful antidote to the self-criticism that is a consequence of frustrations because of listening problems. There is a self-compassion activity at the end of this article. The main part of this article though is about the skills needed by speakers to create easy listening for those with listening problems.

Good communications outcomes for those with listening problems depend not only on what hear and see and how they process that information.

People with listening problems need access to the best quality auditory information possible to overcome their listening difficulties. Those with listening problems often have a strongly visual communication style and benefit by others incorporating visually rich content in their communication. People with listening problems usually rely more on fitting what is communicated into frameworks of existing knowledge (thinking/listening strategies). Their existing knowledge helps fill in the gaps, i.e. what they have not heard.

The extent to which those trying to communicate consider these communication needs greatly influences the communication outcomes for those with listening difficulties. This article describes some of the ways that speakers can make understanding easier for those with listening problems.

Maximising access to what is said

- Speak slowly and loud enough to be easily heard
- Avoid speaking if there is background noise.
- Use words and concepts that are familiar to the listener.

If someone speaks too quietly, too quickly, or uses unfamiliar words, it diminishes the capacity of those with listening problems to use available auditory information.

- Try and ensure others keep silent when people are trying to listen to you.

People with listening problems have many more problems when there is background noise when they are trying to listen. Other voices are particularly difficult to tune out. Those without listening problems are better able to cope with cross conversations; they can easily tune out competing conversations to focus on the speaker they want to listen to. Those without listening problems assume others can do the same as them. They are not aware that those with listening problems can’t do this as easily and that their cross conversation can greatly impact on others’ ability to listen.

Using visual communication

Speakers using gesture and animated faces when speaking helps listeners clarify what is said by watching facial expression and reading lips. Also, it is important to face the person when speaking. If someone turns away while speaking, or speaks when they can’t be seen, it limits the number of visual cues available to enhance understanding of the verbal message.

- Another aspect of visual communications skills is using pictures and diagrams to help explain things. Drawing while telling, or pointing to prepared diagrams creates an easier-to-understand message.
- Effective communicators also use the opportunities in the surrounding context to help ‘illustrate’ their words. For example, going through the actual activity to demonstrate what is expected when explaining something.

‘Learn from yesterday, live for today, hope for tomorrow. The important thing is not to stop questioning.’

Albert Einstein.
Speaking, Listening and Self-compassion (CONTINUED)

Thinking/listening skills
As mentioned earlier, placing things in a familiar context for listeners helps communication. So it is important to introduce the topic being spoken about in a way that enables the person with listening problems to accurately place the topic within the wider context of their existing knowledge. This enables the use of past experience or other knowledge about what is discussed to help understand what is being talked about.

Indicating when there is a change in topic is also really important. If there are many rapid, ‘unflagged’ topic changes, then the listener will not be able to ‘shift thinking frameworks’ and to place what is said within its correct context. When this happens, the person’s reliance on ‘thinking/listening’ is counterproductive. People are liable to misunderstand what is said because they are trying to place what is being talked about within the wrong context. They believe they are discussing one topic when in fact the topic has changed without their knowing it.

- **Keep to a single topic.** When people fill their conversation with verbal asides or ‘entertaining’ elaborations that are irrelevant to the topic being discussed, it is confusing to those with listening problems. While such asides may be entertaining for those who like to play with words, they create challenges for those with listening problems. Those with listening problems don’t know if the aside is an important new topic or something that can be ignored. Such asides make it very difficult to follow the conversation and to extract the important information in what is being said.

- **Speak clearly for a short time.** If people speak for too long, they create the danger of ‘listening fatigue or listening overload’. It is cognitively demanding using ‘thinking/listening skills’ and people can only keep up that level of concentration for a short time. Watching for indications of ‘listening overload’ is a critical visual communication skill for when talking to those with listening problems. When indications of listening overload or confusion about what has been said is observed, it is important to stop talking and give people an opportunity to ask for clarification, or just have a break from listening.

As mentioned above it is common for people with listening problems to feel ‘dumb’ when there is communication failure. In an earlier APDUK newsletter article ‘Smart Lids dumb classrooms’ I described how this happens in classrooms with kids. But the same things often happen with adults. In fact the repeated communication failures in the past may create acute sensitivities and fears about being in situations similar to those where they have experienced communication difficulties in the past. Participation in formal training, going for job interviews, meeting new people in unfamiliar places - which may be noisy and/or dark - may provoke intense fear and anxiety. People may experience distress when communication is not successful and feel demoralised for a time after those kinds of experiences. It is important to realise that these are normal and to-be-expected reactions because of the repeated listening challenges and frustrations experienced in the past. It is especially important to be kind to yourself about these frustrations. A good self-soothing strategy is to practice self-compassion as an antidote to the self-criticism or blaming of others that can result from the regular frustrations experienced in listening.

**Self-compassion activity**

Sit is a quiet place where you won’t be disturbed.

Think about a safe place. Somewhere where you feel completely relaxed and at ease. Imagine how that place looks. Think about the shapes and colours you would see, the sounds you would hear, the textures you would feel.

Now think about someone you care about deeply and in your imagination send caring compassion to that person for a minute or two. Think about all the difficulties that person is facing in life and feel the compassion for them in the challenges that they face.

Now, put one or both hands around your neck and upper chest and imagine sending that same compassion to yourself for a few minutes. Try and do this regularly, daily if you can.

**Dr Damien Howard** is an Australian psychologist who has specialised in the psycho-social outcomes of listening problems (hearing loss and auditory processing problems). He is available for internet based consultations and can be contacted here: [damien@phoenixconsulting.com.au](mailto:damien@phoenixconsulting.com.au)

**Adults with APD Research**

The Adults with APD Research project with Dr Damien Howard, on which many groundbreaking articles for our newsletters have been based, will recommence in 2014 via online chats for adults. Details will be posted on our adult forums. Please take part! Email Aly at [apduknews@aol.com](mailto:apduknews@aol.com) for information.
**ADULTS WITH APD**

The following was suggested by an adult with APD (who wishes to remain anonymous). It is a format for a description of APD and your particular difficulties, to hand to employment agencies/employers etc. This description applies to the author but your difficulties and how they might affect you at work can be listed in place of sections 2 and 3.

### APD, ADULTS AND EMPLOYMENT

1. **What is APD**
   Auditory Processing Disorder is a listening disability, problems processing all sounds that the ears hear. Issues can include problems processing the gaps between sounds, having processing problems with low levels of background noise, poor auditory memory, poor sequencing skills and abilities, working memory issues especially stress related, word recall problems, problems following conversations, following multiple verbal instructions, problems repeating unfamiliar words/names, problems with reading aloud.

2. **How APD affects me**
   I have all of the problems listed above in varying degrees and severities, and on a good day when my working memory allows I can work around many of these problems using the alternative compensating skills and abilities I have developed. Alternative compensating skills and abilities are run in the working memory, and working memory use is prioritised subconsciously, which means coping strategies cannot be switched on and off when needed - I can only hope I can access them when I may need them. Which means a voluntary work trial is the best initial option to let both sides find out how things can work out.

3. **How my APD affects the work I can do**
   I can only work my way, or the way in which my working memory allows me to cope with any task at any given time. I have developed a holistic approach to living which means I do not cope well in a “need to know” environment, I need to understand the complete picture, including details of every task I may be expected to perform, to work out if I am able to carry out each task, or if I may need to develop new coping strategies, or if the task is beyond my limitations. I have problems with low levels of background noise, problems using a telephone as a means of communication, and problems providing instant verbal and written communications.

---

### ANOTHER OPTION IS LISTED BELOW. ADD ANY DIFFICULTIES AND REASONABLE ACCOMMODATIONS THAT APPLY TO YOU AS WELL AS CO-EXISTING CONDITIONS AND EFFECTS.

(NAME) has the following difficulties due to APD (and other conditions) and will need the following reasonable accommodations to allow him/her to access paid work/voluntary work/succeed in training and in the workplace.

<table>
<thead>
<tr>
<th>DIFFICULTY</th>
<th>HOW TO HELP</th>
</tr>
</thead>
<tbody>
<tr>
<td>Poor auditory processing means that information given orally may not be understood or retained;</td>
<td>Group sessions are to be avoided;</td>
</tr>
<tr>
<td>At times, part of the information might be processed, but not all of it and sequencing may be wrong, so this leads to incomplete understanding of information and instructions;</td>
<td>Speak clearly, facing the person with APD so that they can lip-read;</td>
</tr>
<tr>
<td>Difficulty with processing speech if people speak too fast, quietly or unclearly.</td>
<td>Give instructions one at a time, allowing time to process them;</td>
</tr>
<tr>
<td>Difficulty with distinguishing speech in background noise, especially in group settings and open-plan offices;</td>
<td>Always provide written instructions as backup;</td>
</tr>
<tr>
<td>Sound sensitivity, inability to concentrate in noisy surroundings and difficulty with word retrieval leads to confusion, problems in answering questions and making quick decisions.</td>
<td>Allow extra time to process information and directions/to complete tasks;</td>
</tr>
<tr>
<td></td>
<td>Allow extra time to respond to questions/make decisions and also list them on paper/via email;</td>
</tr>
<tr>
<td></td>
<td>Provide training in a quiet one-to-one setting to decrease background noise;</td>
</tr>
<tr>
<td></td>
<td>Provide a quiet workstation.</td>
</tr>
</tbody>
</table>
APDUK runs two online groups for adults with APD. These can be found in Yahoo groups at [http://groups.yahoo.com/neo/groups/OldAPDs](http://groups.yahoo.com/neo/groups/OldAPDs) and on Facebook here. [https://www.facebook.com/groups/APDadults/](https://www.facebook.com/groups/APDadults/)

Over the past few months we have undertaken some surveys and polls of adults with APD on our online forums and the following are the results of this research. Thank you to those members who participated!

**Adults with APD Q&A** - We asked our members 3 questions and here are the replies:

<table>
<thead>
<tr>
<th>Question</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. &quot;What is the one thing that you hate most about having APD?&quot;</strong></td>
<td>Many people with APD also suffer from Hyperacusis – noise intolerance, sound sensitivity/hyperacute hearing. This is not part of APD but is one of those conditions that can make coping with APD more difficult, even in a mild form. It can be very debilitating if severe, even causing physical pain. It can be separately diagnosed by an audiologist.</td>
</tr>
<tr>
<td>• <em>My noise intolerance.</em></td>
<td></td>
</tr>
<tr>
<td>• I don't hate having APD, it's part of me, it's just not knowing I suffered with it for so long.</td>
<td></td>
</tr>
<tr>
<td>• That it's invisible and seems to cause resentment or avoidance.</td>
<td></td>
</tr>
<tr>
<td>• I really hate not being able to have good communication and listening skills with people.</td>
<td></td>
</tr>
<tr>
<td>• The worse thing about having APD is how so many &quot;normal&quot; people perceive it and how they treat me as a result. Most think I am either faking it, trying to get attention (which is ironic, as I am an introvert), or they decide that I have selective hearing, or they judge me to be a hypochondriac.</td>
<td></td>
</tr>
<tr>
<td><strong>2. &quot;What one tip would you give to other adults on how to cope with APD?&quot;</strong></td>
<td><strong>'Hearing aids' here refers to the type of aids that improve the quality of speech and reduce ambient noise, not ones that simply amplify all sound. Some people with APD find this beneficial in aiding processing of speech. FM systems also use hearing aids or headphones to amplify the speech of a person wearing a specialised microphone linked to them – often used in classrooms or colleges and worn by the teacher or lecturer. These can be requested as an accommodation. They are very helpful to some people with APD while others do not find any benefit and some people have become reliant on them in certain situations, finding they are less able to cope when not wearing them.</strong></td>
</tr>
<tr>
<td>• <strong>Wear hearing aids.</strong></td>
<td><strong>Wear hearing aids.</strong></td>
</tr>
<tr>
<td>• Concentrate and avoid noisy situations where possible.</td>
<td><strong>Wear hearing aids.</strong></td>
</tr>
<tr>
<td>• Be assured you don't have a character defect.</td>
<td><strong>Wear hearing aids.</strong></td>
</tr>
<tr>
<td>• A tip is to just love yourself and accept it.</td>
<td><strong>Wear hearing aids.</strong></td>
</tr>
<tr>
<td>• The one tip I would give other adults with APD is to give yourself a break, literally. I have found that if I take regular breaks without being around noise or other people, I am able to function better. Even five minutes alone can make a difference with sensory overload.</td>
<td><strong>Wear hearing aids.</strong></td>
</tr>
</tbody>
</table>
As you see we received a wide variety of responses there and some very good advice! This shows that people with APD have to find their own unique way of coping with it as individuals, because APD affects everyone differently, everyone has different strengths and coping mechanisms estratégicas. Also it has to be remembered that everyone with APD may have other difficulties to deal with too, because APD rarely exists in isolation and the interacting difficulties have an influence on how hard it is for people to cope.
OLDAPDS FORUM RESEARCH

An APDUK poll for adults with APD was posted on the OldAPDs forum at http://groups.yahoo.com/neo/groups/OldAPDs/. This is an international forum and the impact of APD is the same worldwide. The questions asked were about aspects of adult life that the participants considered to be affected most by APD. These are the results.

### Poll 1 Questions

<table>
<thead>
<tr>
<th>Question</th>
<th>% of responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Communication difficulties at social events due to APD</td>
<td>13.19%</td>
</tr>
<tr>
<td>Feeling isolated by APD</td>
<td>10.99%</td>
</tr>
<tr>
<td>Problems in explaining your APD and how it affects you</td>
<td>9.89%</td>
</tr>
<tr>
<td>Difficulty in making friends due to APD</td>
<td>9.89%</td>
</tr>
<tr>
<td>People you meet not understanding APD</td>
<td>7.69%</td>
</tr>
<tr>
<td>Limited career choices due to APD</td>
<td>6.59%</td>
</tr>
<tr>
<td>Wishing you did not have APD</td>
<td>6.59%</td>
</tr>
<tr>
<td>Strained family relationships because of your APD</td>
<td>5.49%</td>
</tr>
<tr>
<td>Barriers to finding work due to APD</td>
<td>5.49%</td>
</tr>
<tr>
<td>Lack of family support for your APD</td>
<td>5.49%</td>
</tr>
<tr>
<td>Lack of workplace support for your APD</td>
<td>5.49%</td>
</tr>
<tr>
<td>Financial difficulties caused by your APD</td>
<td>4.40%</td>
</tr>
<tr>
<td>APD causing barriers to adult education</td>
<td>4.40%</td>
</tr>
<tr>
<td>Lack of educational support for your APD</td>
<td>2.20%</td>
</tr>
<tr>
<td>Inability to cope due to APD</td>
<td>2.20%</td>
</tr>
</tbody>
</table>

### POLL 1 RESULTS

From these results we can see that the areas most affected were problems with coping with APD at social events, isolation, self-advocacy, difficulty in friendships and people not understanding about APD. Career/ work problems followed close behind as did family problems with lack of support at home and at work. There were financial and educational impacts for some people and some felt unable to cope because of APD. These are all significant daily difficulties that adults with APD have to cope with. Many of the adults with APD were not diagnosed until late in life, until in fact they were adults. If there had been earlier diagnosis, acceptance and support, many of these difficulties that they now experience might have been avoided, or at least have had a lesser impact. The one thing most adults with APD wish is that they had been diagnosed earlier. We owe it to them and to our children to try to make sure that this happens so that the impact is lessened for adults who have APD and do not know it and for future generations of adults with APD.
POLL 2 RESULTS

After the publication of the poll, consultation with the adults in the group resulted in an additional poll of adults with APD. This covered additional difficulties that had been encountered and that were not included in the first poll. The second poll produced the following results.

<table>
<thead>
<tr>
<th>Poll 2 Questions</th>
<th>% of the responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you feel that having APD has added to stress in your life?</td>
<td>11.69%</td>
</tr>
<tr>
<td>Do you feel that having APD has caused you to have low self-esteem?</td>
<td>10.39%</td>
</tr>
<tr>
<td>Do you feel that having APD has caused you to have poor self-confidence?</td>
<td>10.39%</td>
</tr>
<tr>
<td>Have you suffered from discrimination socially because of your APD?</td>
<td>10.39%</td>
</tr>
<tr>
<td>Do you feel that having APD has caused you added anxiety in your life?</td>
<td>10.39%</td>
</tr>
<tr>
<td>Do you prefer not to tell people about your APD?</td>
<td>9.09%</td>
</tr>
<tr>
<td>Do you feel that having APD has caused you to develop depression?</td>
<td>7.79%</td>
</tr>
<tr>
<td>Have you suffered discrimination in your everyday life because of your APD?</td>
<td>6.49%</td>
</tr>
<tr>
<td>Do you tell people about your APD?</td>
<td>6.49%</td>
</tr>
<tr>
<td>Have you suffered from discrimination at work because of your APD?</td>
<td>5.19%</td>
</tr>
<tr>
<td>Have you suffered from discrimination in adult education because of your APD?</td>
<td>5.19%</td>
</tr>
<tr>
<td>Has telling people about your APD made things worse for you?</td>
<td>3.90%</td>
</tr>
<tr>
<td>Has telling people about your APD improved things for you?</td>
<td>2.60%</td>
</tr>
</tbody>
</table>

CONCLUSION

Everyone who responded had experience of one or more of these difficulties. These results highlight the emotional impact of APD on adults with this condition. Stress, low self-esteem, poor self-confidence, social isolation and anxiety are the highest scoring areas – depression is also very common, higher I expect than reflected by our poll. These are ALL lifelong issues, not just seen in adults. More people voted that they prefer not to tell people about their APD than those that do – is it any wonder when discrimination in every area of life is evident for people with APD? In short, APD affects every aspect of an adult’s life – at home, at work, at social events, out shopping, in education and training with family, friends and partners. It is only when the following are in place that APD will be adequately addressed in society – the ‘5 As’ approach:

1. **Acknowledgement** that APD exists – a definitive definition of APD and how it affects people and how to manage it effectively – a consensus agreed by everyone, worldwide;
2. **Acceptance** of APD by yourself and your peers, family and friend, employers etc;
3. **Advice** on APD to be freely available to all and free support provided for those that need it – by professionals worldwide, not just by APDUK;
4. **Advocacy** for people with APD in all areas of life - so it is publicised and understood by all – to stop the discrimination that takes place (also the freedom of self-advocacy without ridicule).
5. **Accommodations** to be provided for people with APD at work and in the community - quiet seating areas in restaurants and bars and no music playing there or in shops etc.

So please help - circulate the APD hand-outs from our website [http://www.apduk.org.uk](http://www.apduk.org.uk) (and the poster and alert cards at the end of this newsletter); talk to your family and friends; discuss it with your GP and ask them to put up a poster and keep leaflets in their surgeries; approach local councils and education authorities, talk to your children’s schools and colleges (even if your child doesn’t have APD other children there may well do), job centres and employment agencies and ask what they are all doing to support people with APD in the community. Send this newsletter to anyone and everyone you can think of. Then we will all be a step closer to where we need to be.

Aly Chair APDUK ©
‘Same Journey Different Paths, Stories of Auditory Processing Disorder’ – by Various Authors

An update provided by the authors. ©Authors

Once we were all mothers and children from around the world dealing with auditory processing disorder on our own; we felt all alone on our journeys, not knowing anyone else with this disability. There was not a lot of information available to us about how to deal with this disorder and we were looking for advice, help, and just someone who understood what we were going through.

Then one day, in our own times and ways, we found each other via the internet and more specifically Facebook. We used this well-known social networking site to establish and/or join support groups for people with auditory processing disorder. Through these groups, we started talking to one another, sharing advice, telling our stories, and developing a relationship with each other. These support groups became our lifeline where we knew we could turn to others who would be there for us.

In time, we who live far away from one another (Australia, USA, Canada) grew to care for one another and each of our families. We laugh, we cry, we share our successes and help find answers to help each other. We became each other’s resources and cheerleaders.

We soon realized that as a collective, we had a lot of knowledge and experience that we all wish we would have had when our child or ourselves were first diagnosed with auditory processing disorder. We wanted to share what we have found with each other with the world.

So with the nudging of our fearless team-leaders Nancy Pittman Outten, Beverly Prince-Sayward, and Bonnie Landau Weed, we came together to write our book Same Journey Different Paths; Stories of Auditory Processing Disorder in the hope it would help others and no one would have to feel alone again on this journey.

When we finished writing our book, we realized that not only did we have a resource for people dealing with auditory processing disorder in their lives, but we also had created a wonderful snapshot of what auditory processing disorder can look like in different children and situations. We have found that our book is proving to be just as useful to teachers, therapists, psychologists and all professionals who work with people with auditory processing disorder.

To our extreme happiness, the reception of our book has been amazing! We are receiving a lot of positive feedback about all of our stories and how they are helping others in wonderful ways. Our book has been at conventions, in libraries, in the hands of celebrities and government officials, and even on national news. We are so glad we have been able to help bring awareness of auditory processing disorder to so many people.
I have Auditory Processing Disorder (APD). My hearing is fine, but sometimes I can’t understand everything I hear. It isn’t my fault.

Auditory Processing Disorder in the United Kingdom (APDUK)
<table>
<thead>
<tr>
<th><strong>APD - HOW TO HELP</strong></th>
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</tr>
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<tbody>
<tr>
<td>Get my attention before you talk and face me when you speak. Talk to me somewhere quiet. Speak clearly. Please repeat things if I don’t understand, or say them in another way. Please give me time to answer; be patient. Please don’t interrupt me when I speak or I might forget what I want to say. Write all instructions down.</td>
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</tr>
<tr>
<td><strong>THANK YOU!</strong></td>
<td><strong>THANK YOU!</strong></td>
<td><strong>THANK YOU!</strong></td>
<td><strong>THANK YOU!</strong></td>
<td><strong>THANK YOU!</strong></td>
</tr>
</tbody>
</table>
### Auditory Processing Disorder/APD?

*Do you have problems understanding what you hear, even if you have been told that your hearing is good?*
*Do background noise and/or crowds make this worse?*
*Do people think you don't listen to them?*
*Do you have problems following spoken instructions?*
*Do you have reading/spelling problems?*

If so, you might have **Auditory Processing Disorder/APD**. (These difficulties might not all be present).

### WHAT IS APD?

Auditory Processing Disorder (APD) is not a problem with hearing, but with the way sound is processed by the brain. This can be diagnosed by trained specialists but will not show up on normal hearing tests. Those with APD can appear unable to hear but may have perfect hearing, although it can also co-exist with hearing loss. APD can exist alone or with any other learning difficulties or disabilities. It is a major cause of dyslexia. APD is for life but coping strategies can help, as can support at school, at home and at work.

### CONTACTS

Website: [http://www.apduk.org.uk/](http://www.apduk.org.uk/)

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Helpline: 07815 995491

Vice Chair: Graeme Wadlow [dolfrog@dolfrog.com](mailto:dolfrog@dolfrog.com)
Have you heard about
Auditory Processing Disorder/APD?

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