Self-help, coping strategies and therapies for adult PDAers

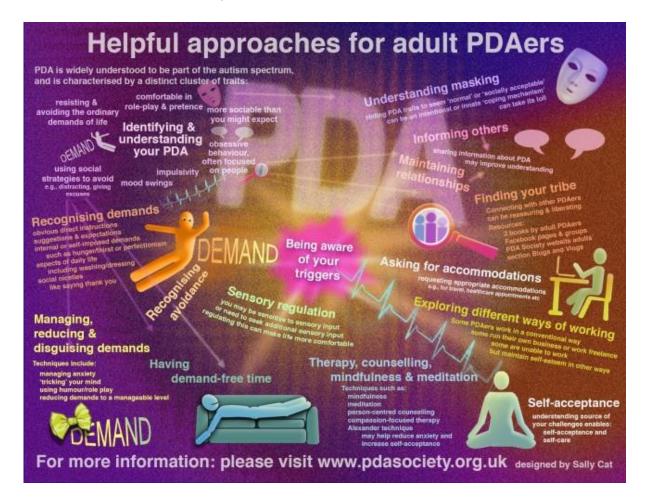


These suggestions for self-help, coping strategies and therapies were assembled from a variety of first-hand accounts shared by adults, diagnosed or self-identifying as having a PDA profile (PDAers being their preferred term of reference), in books, blogs and on social media and from the other information for adults on the PDA Society website.

The suggestions are grouped under the following headings:

- Recognising demands
- Recognising avoidance
- Identifying & understanding your PDA
- Self-acceptance
- Understanding masking
- Finding your tribe
- Managing, reducing & disguising demands
- Being aware of your triggers
- Sensory regulation
- Having demand-free time
- Exploring different ways of working
- Informing others & asking for accommodations
- Maintaining relationships
- Therapy, counselling, mindfulness & meditation

The information has also been captured in this infographic, kindly created by Sally Cat (a higher resolution version is available here)



Recognising demands

The first step may be recognising what constitutes 'a demand'. Demands take many forms – from the more obvious direct instructions to suggestions and expectations, internal or self-imposed demands such as hunger/thirst or perfectionism, aspects of daily life including washing/dressing, social niceties like saying thank you ... the list goes on.

Some who are new to PDA are shocked to find out that things they've always struggled with are actually demands, like returning books to the library or saying "thank you" to people – Riko

Recognising avoidance

Avoidance processes are also many and varied – distraction, excusing yourself, incapacitating yourself, role play and fantasy, procrastination, negotiation, controlling, masking ... demand avoidance is about much more than just saying 'no'. The PDA Society video Demand Avoidance of the PDA kind gives some examples from children, young people and adults.

Identifying and understanding your PDA

Recognising that some of the challenges you face (as well as some of your strengths) may be explained by PDA is an important starting point ...

For me self-awareness is the key. If you don't have self-awareness how can you modify or avoid things that cause anxiety? – Julia

Learn as much as possible about PDA and other conditions. Read, listen and be open to new information – Riko

Self-acceptance

Once you understand the possible source of some of your challenges, self-acceptance and self-care can follow ...

If I could say one thing to my younger self it would be: "your struggles are real and you are worth loads. You are a squiggle-shaped peg that is unique and amazing. Learn to love yourself and you can soar to great heights – Sally

And you can adjust your expectations of yourself a little ...

Every single thing I do involves battling demand avoidance and I can only do so much ... awareness of my limitations has given me the wisdom and confidence to set personal goals that I can keep – Sally

Understanding masking

Masking or social 'mimicry' – hiding PDA traits and trying to act in ways that seem more 'normal' or 'socially acceptable' – can be an intentional or innate 'coping mechanism' for many PDAers, though this can take its toll ...

I suppose masking is the way many of us survive socially, especially as many of us were brought up in families who had little or no knowledge of autism, much less PDA, so we had to find ways to cope – Riko (PDA by PDAers pg 84)

I mask, didn't know I was masking. Just knew I couldn't be myself. Myself was way too much for people, too strange, too intense, too bubbly, too deep, too all over the place, just too much. I am learning to be myself now, at 33 – Laura (PDA by PDAers pg 78)

Masking was a way of flying under the radar, avoiding unwanted scrutiny or attention. I found early on that I was extremely good at interpreting what people thought of me and at playing exactly to that expectation. Since I have been diagnosed I have to a great degree stopped masking ... Trying to mask for the world all the time is a quick track to burning out and being miserable for me – Tony (PDA by PDAers pg 76-77)

Finding your tribe

Connecting with others who understand can be reassuring and liberating ...

I set up an adult support group on Facebook ... after several weeks a few people joined, and now several years later we have 1473 members. It was great to be able to say 'does anyone else do this?' and discover that I wasn't alone – Julia

There are several books written by adult PDAers: PDA by PDAers compiled by Sally Cat, Pathological Demand Avoidance Explained and Calendar Girl: The memoirs of a PDA child in a dysfunctional family by Sally Cat and Being Julia by Julia Daunt & Ruth Fidler. There's also many Facebook groups, pages and blogs and vlogs; the adult life section and adult case studies on the PDA Society website.

Managing, reducing and disguising demands

As demands are many, varied and pervasive, finding ways to manage demands and make them feel less 'demandy' is essential ...

I try to do small demands over a longer time period with plenty of planned downtime in between. I generally only aim to do two things every day, aside from the usual dressing and eating, but if I don't do them then that's fine, if I do more then that's great – Riko

I cook in large batches and portion it out so that on days where I can't face the demand of cooking, there is food for my girlfriend to take for lunch or for me to put in the microwave – Tony

I keep daily demands and expectations as low as possible so as to keep my anxiety low enough that I can function and enjoy life. I do this by reducing/removing unnecessary demands and routines, by changing tack often, taking naps when I begin to feel overwhelmed and by planning my weeks carefully ... so that events/demands are spread meaning I'm able to have prep and downtime too ... I meltdown if I'm not able to do this – Julia (PDA by PDAers pg 292-293)

I can sometimes get something done by starting it with no end expectations – Alice (PDA by PDAers pg 293)

I can sometimes 'burst' demand avoidance by focusing on it. The more I coax myself to think about my demand avoidance, the less power it has ... sometimes I can squeeze past it by finding something exciting or otherwise appealing about the thing I'm avoiding – Sally Cat (PDA by PDAers pg 299)

Excuses ... useful for when demands are sprung on me ... by delaying them I can wait until I am better equipped to do the demand – Riko, PDA by PDAers pg 302

When anxiety is lower it may be possible to cope with more ...

It's impossible to remove every demand but removing or reducing the most demanding of demands is helpful. We need to learn how to cope with the anxiety of demands. There's no reason to jump in at the deep end. We can build up demands slowly and master techniques to help as we go. A bit like learning to drive or walk. Then hopefully, one day we'll be able to manage most everyday demands without having a panic attack – Riko

In some cases, 'tricking' your mind can be a useful technique ...

I've found that by giving myself an 'out' then it is much easier to meet demands, because I know I can change my mind whenever I want – Riko, PDA by PDAers pg 301

I find that if I am able to distract my thoughts from the task I am better able to actually get the job done. This works best for getting out of bed. It used to take me hours to get up ... I found that by not thinking of getting up at all my body would automatically move of its own accord – Riko, PDA by PDAers pg 302

I will make a list of things I need to do that day and then avoid them all, thus competing a whole different list of demands that also needed doing but were deliberately being ignored – Riko, PDA by PDAers pg302-303

Sometimes I'll decide not to go to a social event. This can mean that the anxiety is removed and minutes before the time for leaving I may change my mind and go anyway – Riko, PDA by PDAers pg 303

I have found introducing something new or mixing it up a little can actually help, there's less anxiety sometimes around something new ... When I feel myself avoiding daily activities I will do something to change the activity, I may buy new bath products, try new foods or eat out, buy new clothes or try a different style ... even moving the demand to a different time of day can help. Showering before bed ... or having cereal for dinner – Riko, PDA by PDAers pg 303-304

Or using humour/role play can also be helpful ...

It's easier to get things done if we can laugh about it and generally mess about, so if we can make things into a game then we do. There's an ongoing thing with our friends that I'm a super smart bear in a great human costume. 'I'm a bear, bears can't do x' is seen as a legitimate excuse or reason for needing help. If I can distract myself with debates, music and made-up songs/rhyming games I'm able to do a job on autopilot – Becca B (PDA by PDAers pg 295-296)

I find chores easier when pretending I am being filmed for TV. I adopt a character (say, a cleaner) and pretend I am doing a job for TV. I'll imagine cameras following me everywhere, watching what I'm doing and that people are asking me questions or commenting on my actions – Riko (PDA by PDAers, pg 300)

Being aware of your triggers

PDA is 'dimensional' in that it manifests in different ways for different people in different environments and at different times. What triggers you may be different to what triggers someone else. Being aware of your triggers and how this feels may mean that you can begin to reduce anxiety and stress before your 'bucket' overflows ...

The more anxious I get the more cognitively impaired I feel, I get muddled and forget what I'm saying. The gap between trigger and meltdown when I was a child was very small. As an adult it's longer, which I put down to a mixture of maturity and self-awareness, having greater control over my own life and knowing what strategies help – Julia

Sensory regulation

Processing sensory information can be challenging: you may find that you're particularly sensitive to sensory input or that you need to seek additional sensory input – finding a way to regulate this can help make life more comfortable ...

I get overloaded easily; many different things can cause it. Sensory overload is where I become too hot or too hungry or too itchy and my brain starts to shut down so I can't handle any more input from external sources. I have to remove myself from the sensory issue or try to reduce the sensory attack in order to function again. If not then it all becomes too much and I lash out verbally or physically, shouting or throwing/hitting objects – Riko (PDA by PDAers pg 146)

I find sensory and emotional overload connected, i.e. if I am emotionally heightened the sensory stuff is more of an issue, and vice versa – Vanessa (PDA by PDAers pg 149)

I like to try and keep on top of it. Taking short breaks, having a nap, changing task or just looking out a window are all helpful to me throughout the day – Julia (PDA by PDAers pg 148)

Having demand-free time

Allowing yourself demand-free or low demand time helps in reducing anxiety and can enable your system to reset. Spoon theory can be a helpful way of thinking about managing demands based on your capacity ...

PDA brains overload easily (this might be because it is very tiring having to fight demand avoidance all the time). We are better able to fight demand avoidance if we have had enough rest – Sally Cat

In order for me to be an adult for a full day (like when I attend a conference) I have to do nothing (literally) for a week beforehand. I don't dress or wash or cook, I have no social interactions, I don't do any of my hobbies. I sit on the sofa and watch TV. That way my anxiety is nice and low. I need another week's recovery time afterwards – Julia

I find things like logic puzzles and tactics-based Facebook games very calming, so if I play a bit before I have to do something it gets me in a much calmer frame of mind. Having a little quiet time before also helps get my head in gear – Elizabeth, PDA by PDAers pg 294

Exploring different ways of working

Some PDAers are able to work in a conventional way, some run their own business or work freelance, some find working life tricky and others may find that they aren't able to work but can maintain self-esteem in other ways ... (please also see Workplace Adjustments for PDA)

Being a PDA advocate, helping others and learning about myself as I go along, fills a gap and gives me a purpose. And because it's not an everyday, 9 to 5 thing it's a 'when I can handle it' role, it works for me – Julia

It's important to choose a role that a PDAer can do, that they like and that has plenty of room for accommodating the PDA aspects of the individual. Basically, work to your strengths – Riko

Wages are not a motivator for me. In fact, being paid a wage turns activities into demands that I'm compelled to avoid. My ideal career future lies in having an agent so I can produce creative works unhindered by admin demands. In the meantime, I am now on disability benefits and not in poverty for pretty much the first time in my life, which is really great – Sally

With work, flexi-time was really helpful to me and time off in lieu ... it allowed me space when I needed it. I did better the more latitude I had to make decisions about what I did when, and the more it felt like deadlines and expectations were reasonable. In one job I got to arrange my side of the office to suit me and re-orientated my desk which helped. I prefer teamwork to hierarchy. The unknown makes me anxious. 'Can you pop in to speak to me at 10ish about x' is better than 'I need to you in my office at 10.00 precisely – TC (PDA by PDAers pg 311)

Informing others and asking for accommodations

Deciding whether to tell other people about PDA is a very personal choice, and it may depend on how 'disabling' an effect you find demand avoidance has in your life. Some PDAers find that sharing information about PDA with others helps to improve mutual understanding (also please see section below on maintaining relationships) ...

I now only have friends, or cleaners or beauticians, who are PDA- friendly. I've found this to be quite a vital strategy and I'm much happier now I don't have to mask – Julia

Requesting appropriate accommodations can help make some situations (travelling, healthcare appointments etc.) easier. The PDA Society PDA Alert card may be useful for this too ...

We are highly prone to overloading in crowds; suffer great anxiety and intolerance of uncertainty; and being forced to wait and be penned in triggers Demand Avoidance. So schemes that enable us to be fast-tracked in queues, given priority seating or being able to choose appointment times make a big difference. One strategy I've implemented is to press for institutions to communicate with me via email, not phone or even face to face. This works better for me. I am more in control of my own world in that I can choose when to deal with emails and take my time considering my responses – Sally Cat, PDA by PDAers pg 310

Maintaining relationships

PDA can be difficult to explain to family, friends, colleagues or professionals and maintaining relationships can be tricky for all parties ...

We need flexibility in nearly everything. Rewording things so it feels less demandy. Giving options in how we do things. Explaining rules that are important and why we need to do some things, and doing away with anything that isn't essential. Allowing us space when we are struggling and giving us time to do tasks and time to recover afterwards...Don't take things we say and do personally, especially during meltdowns/panic attacks – Riko (PDA by PDAers pg 306-307)

Please keep me in the loop. I need to know what's going on. Keeping me informed is necessary if I am to avoid intense anxiety. Please consult me about appointment times and allow me plenty of notice. Further, if I miss an appointment, be lenient with this – Sally Cat (PDA by PDAers pg 309)

I need enough time to process, without listening to more words. The ability to get things in writing, and go through them in relative solitude, before responding – Barry (PDA by PDAers pg 309)

When I'm not coping I hate to be crowded or babied. Just leave me to it. Don't ask me when I'm melting down stupid questions like 'are you okay' – of course I'm not okay! I'm in meltdown! Also, no, you can't help and, no, I can't just stop. Just leave me to rant and get it out of my system. Don't baby me after too. I'm not made of glass and I don't need mothering. I'm often emotionally exhausted and embarrassed after a meltdown so just having you act normally will make the world of difference – Julia (PDA by PDAers pg 292-293)

I have my partner Julia to thank for this – a demand shared is a demand halved. She will involve me in cooking, washing, cleaning ... which I know this makes it more manageable for her. So, share the demand and then it becomes less – Paul

Therapy, counselling, mindfulness and meditation

For some, understanding PDA and putting coping strategies in place enables their emotional wellbeing; others have been prescribed medication for anxiety, depression, OCD etc.; for many it is a combination of both that helps them stay well. Therapy and counselling can be quite a demand in itself, and practitioners may need to adapt approaches to take account of this. Here are some ideas that others have found helpful ...

I started Alexander Technique lessons in my teens for foot and back pain. I've been a teacher myself for over 20 years and I now realise this was the best thing I could have done. It gives me a level of physical control and comfort that mostly can overcome the negative symptoms of PDA – Jenny Penny, PDA by PDAers pg 299

I've succeeded in reducing the amount of anxiety I feel through years of counselling and, perhaps most effectively, one-on-one Compassion Focused Therapy and a small group mindfulness course. These two techniques have both been proven via brain scans to rewire the brain to have fewer 'threat' responses (Fight/Flight/Freeze). I still feel a lot of anxiety, but less so ... I continue to perform mindful meditation every day (but only very briefly because it feels like a demand!) – Sally Cat (PDA by PDAers, pg 298)

The person-centered counsellor training I've done has been a coping strategy for me ... [it] has empowered me to trust mySELF. To believe that I might be OK as a functioning, interacting member of society. This training also, I feel, has empowered me to express myself to create my graphic memes about my experience of living with PDA and, perhaps most importantly, to feel that I'm OK inside – Sally Cat (PDA by PDAers pg 300)

Resources and further information

- Demand Avoidance of the PDA kind video
- Books
 - PDA by PDAers
 - Pathological Demand Avoidance Explained
 - o Calendar Girl: The memoirs of a PDA child in a dysfunctional family
 - Being Julia
- Facebook groups
- Blogs and vlogs
- Adult life
- Adult case studies
- Workplace Adjustments for PDA
- PDA Society PDA Alert card

In addition, we'd like to draw your attention to these additional sources of information, topics or fields of study which we feel are helpful in furthering understanding about PDA.