

PDA-related suggestions for healthcare passports



The National Autistic Society has created a health passport template that you can download and complete for yourself, your child or someone you care for: <https://www.autism.org.uk/advice-and-guidance/topics/physical-health/my-health-passport>

There is also helpful guidance on the National Autistic Society's website about how to fill in the template.

These are some suggestions that may be helpful to include in relation to a PDA profile of autism.

They are designed to be used in addition to, and should be read in conjunction with, the National Autistic Society's guidance.

You can pick and choose from the suggestions to **just include the points that are relevant for you.**

It's best to keep the information as brief as possible so that busy healthcare workers can take it on board more quickly. One way to do this might be to colour code the points (if you're filling the template in by hand, you could use different coloured pens or highlight the most important points):

- **red** for things that healthcare settings and staff **must** know
- **yellow** for things that are important **for** you (things you need for wellbeing)
- **green** for things that are important **to** you (your likes/dislikes)

My medication and my medical history

Medication

As well as listing the medication you take, include any medication which doesn't agree with you or which you have been advised against.

Medical history

I fit the PDA (Pathological Demand Avoidance) profile of autism. This means, in addition to my autistic traits, I ...

- experience extreme levels of anxiety
- have a need for control
- am driven to avoid demands and requests
- can find everyday tasks like appointments very difficult
- may hide my distress, react unpredictably, lose control or become disruptive very rapidly

PDA is a hidden disability, and my autistic traits may not always be immediately evident.

NB. Conventional support approaches – including those often recommended for autism spectrum conditions – are often ineffective and counter-productive with PDA.

Please see the PDA Society website for further information: www.pdasociety.org.uk

Communication (just include the points that are relevant for you ...)

Whilst I may appear to be able to communicate fluently, I have processing difficulties – please **take and allow extra time** when giving me information and instructions.

Word requests **indirectly** and offer me **choices** (see below for more on this).

Please communicate with me via phone/email/text/WhatsApp/Skype/other (as applicable)

Or if this works for you ... you may like to say:

I may prefer it if you talk to my parent/carer/partner/advocate and they will talk to me

Pain (just include the points that are relevant for you ...)

I have a heightened/lowered (as applicable) sense of pain.

I may try to ignore pain or pretend it doesn't exist, and may not be able to describe my experience of pain accurately.

Causes and avoidance of distress (just include the points that are relevant for you ...)

I often find I can't do things that are asked of me – you can help by:

- Ensuring **all staff are aware** of PDA & how best to support me
- **Following the lead** of my parent/carer/partner/advocate if they are accompanying me, and not questioning the approach they may be taking in supporting me
- I may need my parent/carer/partner/advocate to stay with me on a **1:1 basis 24/7** in order to keep me and everyone else safe – please try to facilitate this
- **Picking your battles & prioritising** the demands you make of me, as I have a limited capacity for demands (for example, I may be able to take my medication but not then have a shower as well)
- Treating me as an **equal** – build up my **trust** & maintain a **friendly** tone
- Being **flexible & collaborative** in your approach
- Changing your **phraseology** so that it's more indirect (for instance, saying 'patients wait here' rather than '**you** should wait here', or providing a commentary on what you're doing rather than telling me what to do)
- Showing rather than telling me what to do or letting me do parts of a task myself – do things **with** me rather than **to** me
- Helping me to **feel in control** by allowing for some **choices** and **negotiation** – e.g. being flexible with appointment times and communication methods, or allowing me to choose the order things are done in where possible
- Keeping me informed of **what** is happening & **why**
- **Reducing the need to wait** wherever possible & allowing me a quiet space to wait in if necessary
- Providing me with **access to quiet space** in order to self-regulate
- Gentle **humour** or **distraction** can help, but please remember I may take things quite literally at times

Other things you should know about me (just include relevant points for you ...)

I have **difficulties knowing whether I'm hungry/thirsty** so my intake needs to be monitored. If I'm not drinking, for instance, please just simply say 'here's a drink' rather than reminding me that I should drink.

Please **warn me** if you need to touch me or put something over my face.

I experience **senses** differently - include details about whether you are

- under/over responsive to sight, smell, taste, touch, hearing
- or whether you have
- vestibular (balance)
- proprioception (position/movement)
- or other interoception (feeling & understanding what's going on in your body) needs.

Think about ways in which these sensory experiences may be relevant in a hospital setting – there are some examples in the National Autistic Society's guidance notes. For instance, are you able to swallow tablets or do you need medication in liquid form? If someone needs to touch you, do you prefer firm pressure or a soft touch?

You can recognise if I'm becoming increasingly **anxious** and when my tolerance for demands is low because I (fill in how this shows in you/your child/the person you're caring for – for example maybe you ask lots of questions or start to talk a lot or withdraw into fantasy ...). You can help **de-escalate** by (fill in what works for you – for example, using humour, distracting me or enabling me to have some time and space).

Do you need to include any information in relation to **sleep** – for example, anything you need to help you sleep (levels of light, aromatherapy pillows, your own bedding ...) or anything healthcare teams may need to know about your sleep patterns?

PDA can lead me to have difficulties with **regulating my emotions** and I can switch between calm and upset in quick succession.

- **Meltdowns** can occur quickly – I may not always know the trigger, or be able to communicate whilst in crisis, or remember what I've done/said. Please consider this as a **panic attack**. At this time, I'm unable to process what you're saying or doing, so please only provide gentle reassurance. If I hit out, struggle, swear or shout during this time please understand that this is an involuntary **anxiety** response and I'm not being deliberately aggressive. Wherever possible, please try to move other people away from me to protect them, and allow me time and space to calm afterwards.
- Another involuntary response to stress and anxiety is **shutdown**. This is a protective mechanism but can sometimes present like a mental health difficulty – please check before assuming (this article may be helpful: <https://network.autism.org.uk/good-practice/evidence-base/catatonia-and-catatonia-type-breakdown-autism>).
- Sometimes I may **mask** (hide) my anxiety at the time, but may melt/shutdown at a later point when I feel safer or when I feel overloaded by an accumulation of demands.