My mum wrote this but based it on my thoughts and feelings. We did a similar one together when I was trying to stay at school. I’ve read this, changed bits of it and agree with it all now. I don’t think there is anything missing

I.A.K. Russell

I have Pathological Demand Syndrome. It means my brain is wired differently from most people’s. I have some things that I can do better than most people as a result and I find other things very difficult. I get very anxious much of the time and am quite good at covering it up sometimes but it makes life very difficult for me.

I also have hypermobility syndrome which means I get tired, have muscle pains and it also affects my gut, so I feel sick quite a lot.

I hope this sheet will help you to know what will help me.

|  |  |  |
| --- | --- | --- |
| **PDA Trait** | **What it means for me** | **What would help** |
| Demand avoidance:  I struggle when I **WANT** to do something for myself – I often find I can’t | I get anxious when I start to do everyday things like thinking about showering, and even going to do something nice eg trip to cinema, is hard | If people encourage me it makes it worse, but with time and space and others around me doing the same things, I think it will get easier.  (At the moment I need Mum to do most things for me – I hope to be able to do more for myself again) |
| Demand avoidance:  If asked to do something directly, I can almost never do it | I usually get anxious, panic or freeze when I am asked to do something, especially when asked by an adult (and especially mum or dad) | I know that the way people say things to me makes a big difference - it’s the way my brain responds to requests, and not a behavioural problem.  If I am asked in an indirect way I am more likely to be able to do something (eg ‘dinner is ready’ might work, whereas ‘please can you come for dinner’ will not.)  Changing approaches regularly helps too – you could try texting one day?! |
| Mood lability (extreme mood swings) | I find I can be really enthusiastic and excited one minute and really quiet and down just a few minutes later.  I feel tired and sick quite a lot and don’t seem to feel better by thinking about the good times | After doing something exciting and fun, I need to wind down and rest. When I’m feeling down or sick I need people to acknowledge how I feel. |
| Plans and lack of routines | I find I like to know plans in advance, but also I hate ‘routines’  I find variety, flexibility, and being able to control things are important to me | When things are de-personalised it is much easier, so timetables which everyone is following together might be ok for me. Making things fun is helpful too - I sometimes use apps which help me develop good habits.  I need people to listen carefully to me. |
| Overload and Choices | At the moment I don’t like to be given choices, as I find it hard to take decisions. I’m quite easily overloaded. | I visibly get more anxious when I feel overloaded, so hope that people will understand and give me a bit of time when that happens. I very rarely have meltdowns these days, but if I lose it, I’m most likely to cry and curl up. |
| Affirmation but not praise | I need very regular affirmation, and I appreciate indirect praise.  Direct praise for achieving something can make me feel bad though. | I like it when people, including adults, show an interest in what I am doing, or to listen to me talking. I like it when we agree about things. I can find it difficult when people have a different point of view – I don’t like debates these days. |
| Impulsivity | I get an idea that I want to do something, often related to my special interests (eg watch something, or buy something) and I get a bit distressed if I cant do it pretty immediately | I don’t know how to manage these feelings but I know I need to be able to learn to manage money better in the future. |
| Sensory difficulties | I’ve become more restricted in my food and drink tolerances in recent years. I don’t have much sense of thirst.  I don’t like very soft fleecy fabrics. I cant touch wet-wipes, soap or use toothpaste. I have trouble brushing my teeth.  I sometimes find sounds too loud | I only drink (diet) coke and other fizzy drinks and only drink through a straw. I tend to eat very plain food, such as pasta and sometimes rice and I like soft fruits.  I worry that I can’t eat enough, but just do what I can when I can. Having mum help me has been important. I’m most worried about this when moving, but I think that a more structured approach should work better as long as there is food I can eat.  My sensory difficulties just make it harder to do some of the things I need to do. I can use a flannel, bubble bath, shampoo and deodorant. |
| Difficulty conveying some thoughts | I think it depends on my mood, but sometimes I find it difficult to express myself. | I hope people will have patience with me |
| Easily distracted / tuning out | I can find it very hard to concentrate on things that are not my special interests. | I often use my ipad as a stim toy. Sometimes I can concentrate better if I am using it, so don’t assume that because I’m doing something I’m not listening. |
| Tendency to get absorbed in own ‘special interests’ | When not concentrating it’s often because I find it hard to think of anything except my special interests. Sometimes I have no choice – it’s my ‘safe place’ | My interests are specific films, TV shows, and musicals. They are often series that have a fantasy or psychology aspect to them. |
| Difficulty stopping talking | When younger I was often chatty (eg in class) | I hope I don’t do this *too* much… but I appreciate it when people talk with me. |
| Unable to understand what people are thinking or feeling | I’ve had difficulty understanding my neuro-typical friends which makes me more anxious | I think that I will have fewer problems if spending time with other autistic people – I have autistic friends that I understand well. |
| Have very high levels of anxiety | I find it hard to get to sleep (so often wake late). I get more tired because I don’t eat well, I don’t like to go out to places very often (but I like to be driven around) | I cope by listening to music or fiddling with my ipad or watching things. I hope this will decrease over time as I get used to doing more. |
| Hypermobility  (hypermobility syndrome / ehlers danlos syndrome) | In the past 2 years the pains in my muscles have become regular and quite severe and I get very tired.  My hand-writing is very poor and I write slowly. | When I go out I sometimes use a cane and I walk quite slowly. I know this can be helped by doing some exercises and gradually building up my strength. I feel stuck at the moment, but as I move more this should improve.  I hope people will believe me when I feel too tired or in too much pain though. |
| Tummy problems | Because of my restricted diet, lack of drink and hypermobility affecting my gut, I have constipation and feel sick a lot. | I would be really, really happy to have my own bathroom as sometimes I find I can stay there for quite a long time, and I would worry if other people were waiting to come in.  I take ducolax each evening to help me. |
| **I am also good at these things….** | | |
| Unique ideas and logic | I have a creative mind. I am good at problem solving. I’m logical and can ask questions that give a different perspective.  In debates I’m good at seeing all the arguments but know which one is ‘right’. (It can be frustrating that others are not so logical!) |  |
| Skilled in certain subjects / topics | When I’m enthusiastic and able to focus I am very keen to know more and engage. | I often used to put my hand up in lessons when I was engaged and it made a big difference to me to be allowed to contribute in class and for my effort to be recognised by teachers |
| Strong sense of equality and justice | I’m very passionate about some topics |  |
| An interest in grammar | I like to make sure my grammar is good and enjoy the use of interesting words | Language is important to me, and I can get upset if people use some terms (eg ‘high-‘ and ‘low-functioning’) – but I can explain why so this shouldn’t be a problem. |
| Memory of special interests | I have an amazing memory, remembering all the details of my interests and I have a talent for researching and learning new things associated with them. |  |
| I care about others | I try to be kind, and while I can’t always put other people first, I care about them. |  |

**Summary**

I would like support to:

* Find ways to be able to do things for myself, so one day I can live independently and hopefully be able to work as well.
* Improve my strength (and health) and ability to concentrate on new things
* Learn to find ways of dealing my extremes e.g. so I can manage money
* Be encouraged in my enthusiasms
* I think these will make a difference

Being ‘at home’ is my problem as I can’t do things when asked by mum or dad and can’t take responsibility for myself either. I need to be with other autistic young people, and I think that if there are a lot of people around, it will mean there will be more structure and I have more chance of making friends – I don’t want to go from one ‘family home’ to another.

I need to have people who will care for me and not tell me what to do all the time – professional people who understand PDA and will work with me.

I would like to have opportunity to build up my strength by doing some fun activities without lots of travelling, but I would like to be able to visit the cinema, theatre or go to a cafe sometimes.