

Please Hear What I am ‘Saying’

In the following chart I have gathered—from research and from experience—a comprehensive list of the variables (environmental and personal) most likely to increase anxiety for people supported and therefore increase the risk of challenging behaviours. As you become familiar with this list and start to implement the recommendations, you will find that challenging behaviours arise much less frequently.

Conditions That Increase ‘My’ Anxiety and What You Can Do To Help ‘Me’

What you need to know and remember about my anxiety that can lead to challenging behaviours.		How best to help me self-regulate.
1.	I am a ten-second person living in a one-second world.	▪ Please slow down your communications and wait for my response.
2.	I hate not knowing my time limits. I really need to know timelines.	▪ Stay committed to established timelines, e.g. when we are going to the park and warn me when change is necessary. ▪ I really like a timer. Let me set the timer up and start it.
3.	I hate too many choices. Too many choices confuse me.	▪ Ask me “this or that” or “first this – then that.”
4.	I really need to think that I have a choice in what happens.	▪ Ask me, “Do you want to do it now or in five minutes?”
5.	An environment that gives me too much overload (social, sensory or cognitive) makes me anxious.	▪ Learn my sensory needs and support me accordingly.
6.	Some hours and some days will just not be good for me, and I don’t know why.	▪ Expect and plan for my “off times” with some of my preferred activities.
7.	When I start to get anxious, please stop making it worse by becoming more logical.	▪ I now need your empathy and validation. ▪ Help me with BB-ABC exercises.
8.	There is a 50% chance that I have PTSD syndrome.	▪ Please stop triggering me with a loud voice and shouting.

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9.	I hate changes – I fear the unknown.	- Stay on schedule as much as is possible and let me know when you have to change things. - When you tell me about the change, expect me to react with “but what if happens?” If I am non-verbal, I will still be thinking – but what if so keep telling me as much as is possible. - Think out loud as much as you want – the more the better.
10.	I am highly sensitive to your reactions and need to know and feel that I have not upset you.	Please work to stay emotionally self-regulated and tell me if something is bothering you.
11.	I have nine meanings for the word <i>no</i> .	- When I say <i>no</i>, remember it can mean any of the following: - I’m afraid of doing it wrong. - I don’t want to look bad. - I’m not ready yet. - I’m not sure what to do. - I want more information. - Ask me later/again/tomorrow. - I’m afraid to do what you ask. - Give me better reasons to do it. - I’m in pain; please help me.
12.	When I am physically uncomfortable because, for example of constipation, I get agitated and anxious.	Do everything you can to identify and treat my pain.
13.	Uncertainty scares me.	Be consistent and persistent.
14.	Sometimes I get so anxious that I hit, bite or kick.	- Please don’t think I really have a choice. It really does feel better than being really scared – also don’t take it personally. - Start BB-ABC calming as soon as possible.
15.	I have many reasons for not wanting to be around people. One big reason is that most people like to be spontaneous. I hate it!	As much as possible, let me do it my way if plans change. Also let me do a repetitive behaviour because it’s my way of calming when things go off schedule.

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16.	My sensory world is very different than yours.	▪ Learn what I need as a sensory diet – keep my list available for your reference. ▪ Even when you help me to process sensory input, remember I mostly can only process one sense at a time. This is especially true for hearing and seeing. Therefore, stop telling me to look at you when you are talking to me. ▪ My peripheral vision can be much better than yours, so let me use it when I want to. ▪ When you stare at me I feel anxious. ▪ Because of my linear processing abilities, don't expect me to listen to you while I am doing something else.
17.	Some of my defiant behaviour is me trying to keep my sensory processing on-line.	▪ Please stop confusing my sensory processing with non-compliance. For example, most often attention-seeking or not trying to do something is not only about a functional goal.
18.	When I am anxious, I sometimes freeze.	▪ Before and after I have a <i>fight</i> or <i>flee</i> blow-out I may look calm, but often I am really more frightened than ever, so I <i>freeze</i>. Continue to respond to me as if I am very afraid because often I am. Some BB-ABC Tools work well at this time.
19.	When I get scared my thinking brain (like yours) goes off-line.	▪ Please stop thinking that I am learning something from you once I get scared. Just like you, I say silly and often hurtful things when I get mad because my upper brain is off-line. If I am upset, I need your calming strategies not your logic. Many behavioural interventions at this time are annoying. I learn next to nothing from them because my learning brain has gone to sleep. ▪ Once I am calm, please revisit what happened and very slowly teach me what I need to know.
20.	More often than you, I lie and embellish the truth. I do this to stay-out of trouble and/or to impress you.	▪ Please stop vetting my words. At these times I am feeling “less than,” so please validate me and respectfully redirect my conversation. At these moments, I love to hear things like “you enjoyed doing that didn't you” or “I like the way you

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21.	I am a black or white, logical kind of person. I think everything has a reason. I sometimes get very anxious trying to figure things out. This makes me seem unfeeling at times because I am trying to figure things out.	▪ When you see me pondering something or fixated on something, give me time and cues to figure out what is happening. ▪ Even let me obsess a bit to figure it out. ▪ Asking me how or what I am feeling at this moment is unhelpful and annoying. ▪ Instead, give me help to find answers: “Okay Peter, that is a” ▪ I really need closed or alternate choice questions.
22.	I have many ways of stimming, such as rituals, pacing, hand flapping, rocking, finger flicking, vocalizing, tics, twitches, repeating words, etc. etc. Stimming generally (not always) means that I am not feeling comfortable/calm in myself and I need predictability and focus.	▪ Please help me calm with BB-ABC and my preferred activities, e.g. tactile, proprioception, balancing exercises. ▪ Please don’t think less of me when I stim. I don’t think less of you when you stim with your phone.
23.	Sometimes I unknowingly but intentionally annoy you, refuse to cooperate, keep asking questions that I know the answer to or pick a fight with you—even when you have done everything I wanted.	▪ Know that this often distracts my mind away from being scared, nervous or my pain. ▪ Stop responding to what I am saying or doing and respond to my real message. Please help me calm with BB-ABC and my preferred activities.
24.	Seemingly minor things that you as a supporter sometimes do make my life miserable and cause my anxiety.	▪ Please try not to: – rearrange furniture in my room or common areas; – stop my stimming unless it’s harmful; – get into power struggles with me; – change activities. ▪ If it is necessary to change schedules, please change things gradually with notice and with my input: – use inclusive language, like “Peter would you rather do this or this?” – a social story with pictures is helpful – when I am calm ; – be gentle and slow, but be persistent and consistent; – include BB-ABC exercises; – as appropriate tell me what might happen that would change our plan. “Peter, what might happen is this, and we will”

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25.	I will give you very clear cues that I am getting anxious and on the edge of a blow-out or blow-in.	Please develop your mindfulness skills so that you can learn to identify when I am becoming anxious and pleading to you for help with calming e.g. BB-ABC.
26.	I hate most transitions. I hate when good activities are over – especially abruptly.	- Please give me a heads-up with what will happen and when. - Please tell me what unforeseen event could happen and what we will do about it. - Please keep me in charge – Ask me – “Do you want to put your coat on before you” - I always need a three-minute notice.
27.	I dislike open ended questions – <i>what, how, when, why</i> .	- Use closed questions (that can be answered with yes or no) e.g. <i>would, could, should, is</i>. - Use alternate choice questions e.g. “Do you want this or this?”
28.	I don’t understand metaphors or similes. I take everything literally, even if it is not meant to be literal: e.g. <i>wait a minute</i> .	Be precise and concrete.
29.	I am most likely an introvert, so don’t expect me to live in your world if you are an extrovert.	- Learn my preferred social style. - Always give me choices if possible re: social outings.
30.	As with all neurotypical folks, feelings make up my mind around choices that are about me and you.	When possible, give me mostly feeling reasons to do things, not logical reasons: e.g. “Let’s do this now so that we can go and have fun swimming later.”
31.	I am often confused by requests to do things.	Always ask – “Would you please now?” This clarifies what you want and when you want it.
32.	I hate to hear <i>no</i> , because it means many things to me and confuses me.	Instead, say, “You can when but not right now. Now we need to do or What do you want to do?”
33.	I get increasingly anxious when I feel myself start to blow-out, and I need to know you will really help me.	- Make sure I am and others are safe, then as soon as possible reduce the environmental triggers that are in my Sensory Assessment and Plan: e.g. sensory issues, such as lighting, people or noise. - Start a sensory physical activity with me to help me calm. - Stay calm yourself: - fear begets fear; calm begets calm. - only by learning and practicing emotional self-regulation skills will you be able to stay calm. Most tactics that are done when you are upset (emotionally hijacked) are dangerous illusions of helping me.

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34.	When I do get upset, there are ways to help me calm down more quickly.	- Start by – - reducing your requirements of me and giving me some personal space. - direct me to BB-ABC strategies. - introduce some pleasant sensory focusing activities e.g. watching a falling feather, or balloons floating or popping.
35.	I need you to teach me literacy and numerical skills in concrete ways. Abstract ideas make me anxious.	Use the times when I am doing physical or sensory exercises or other concrete activities to teach me: for example, building structures with blocks or balancing objects. But keep it simple – only one sense door activated at one time.
36.	Concentrating wears me out, so I get bored easily and boredom makes me feel anxious.	Change my activities fairly quickly: every ten to fifteen minutes maximum.
37.	Incentives and reinforcers are good ways to get me to co-operate without making me feel anxious.	- Learn my preferred activities that you can use as incentives and let me do them as required for me to cooperate and learn. Don't use them to fill-in time, because I lose interest. - Don't give me food for incentives (especially simple carbohydrates and sugar): the more I get, the more I need.
38.	I feel less anxious when you let me watch you do something before I do it.	- Model what you want me to do and describe in words what you are doing: e.g. butterfly hugs or arms up and down with calming breathing. - Mirror neurons are alive and well in you and me (NLP research).
39.	Developing my medial lateral prefrontal cortex helps me to regulate my emotions—please help me.	- Two-Three times every hour, remind me to notice, pay attention – “blink if you notice “say or notice when - Let me use the rebounder.
40.	Some days I will not like something that I usually like.	Encourage me to try it, but know that there could be ten reasons why today it's not for me.

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41.	If I can see the things associated with my preferred activities all of the time, I will be unable not to focus on them and bug you to do them. We may then get into a power struggle.	Keep the tools and equipment for my preferred activities hidden from me, in a locked place if necessary.
42.	I'm not sure but it seems like for me and some of my friends' fluorescent lights, WiFi and microwaves and dirty electricity bother me.	- Please filter out these anxiety producing triggers, including keeping your cell-phone turned off around me. - Filter the outlets in my bedroom at least
43.	My number one sensory need is to stimulate my proprioceptive sense door.	Every hour for sure, give me proprioceptive activities.
44.	Your energy directs mine.	Please learn to stay calm, especially when I get anxious.
45.	When I get anxious, I often give you attitude and resistance. This often gets us involved in a power-struggle and I find fighting with you is an excellent diversion from my anxiety attacks.	Although your power-struggles with me are relatively better than my fears, they often get out of hand and just make things worse. Please learn to not get pulled into my behaviours. I need your calm, caring and conscious connecting to get me back on track.

Recommended Reading

Much of the above has been adapted from the following resources:

Bluestone, J. *The Fabric of Autism*.

Lipsky, D. *From Anxiety to Meltdown*.

Herbert, M. *The Autism Revolution*.