

Scottish autism

WHERE AUTISTIC PEOPLE
ARE VALUED

Autism Advice Live
Peter Vermeulen, Autism in Context
4 June at 7pm

Question

As a parent of two children with autism I find myself drained bored exhausted and irritated with the situation. My youngest is really interested in technology and goes on and on about his latest discovery that he's really enjoying. I find it really hard to stay interested and listening and supportive that I feel like I'm being unkind about it sometimes and we've all done this as parents and sometimes I hide in the toilet and just to disappear from it for a little while. It's the same with my oldest I'm alone with them most of the time and I feel really kind of empty. How do I coach myself to become a better mother? I'm feeling disappointed.

Answer

Let me start with saying you're not a bad mum. Right now especially if you're a single parent you have to live with your two children all the time and in non covid times they can talk about their special interest to different people; for instance at school they can talk about it to their peers to the teacher to support workers and now everything comes down to you as a mum. That means that you have to take in what normally maybe three, four, five, or even ten people take in a day and I think rather than being empty, maybe you're too full of what your kids are saying. You're not a bad mum if you're tired of certain behaviours of your child whether that child is autistic or not. It's perfectly normal at a given moment to say I'm full can't take it in anymore because we all have our limits. So you're not becoming a better mum by forcing yourself to take in even more that you can.

The first thing to do is to accept your limits and again it's perfectly normal that you can say at a given moment I've had enough of this discovery, how nice it is but this I don't want to listen to the discovery anymore. The only thing is that if you do that at the moment that you think I should go to the bathroom again and cover my ears then it will become too sudden to your children. Your children, if they are autistic, they need a lot of predictability so I would advise you to make the amount of talking about the tech object about the special interest about the discovery to make more predictable and there are several ways of doing that. For instance you could use a

green card and a red card and the green card says mommy is ready to listen to your talk about your discovery and you hang it up on the fridge or on a place in the house where your kids can see them and the moment you feel oh okay I'm getting to the to the edge of what I can take in you change it to the red card. Red card means no talking about the discovery no talking about and that way and please do this before you'll need to run through the bathroom because if you need to run to the bathroom that means you won't be clear in your communication anymore because you will be tired or empty the feeling that you use.

You could also do something else why don't you plan the talking about the special interest and planning could be that there are certain times in the day that you say every time after we had a snack or a meal then you can talk about special interests. You could again visualize that with that's discovery a picture of that and if it's visible you can talk about it if not. You can relate it to certain place in the house and saying look when we're sitting at the table then you can talk about your special interests. When we're sitting on the couch and mommy is kind of relaxing and reading a book on the couch no talking. So try to make it more predictable and you know you're not going to be a bad mum if you do that, on the contrary, what you're doing is teaching your children that it is okay to talk about your own interests but sometimes people want to talk about their interest as well so actually you're preparing your kids for the future where not everybody will always be willing or even able to listen to their stories about their special interests.

So it sounds like hard if you limit the talking about the special interest but actually you're doing them a big favour because if they know when they can talk about it and when not it gives predictability and predictability means less stress you know talking about the special interest is often one of the things that kids do to get rid of their stress they go back to the part of the world that they know and that they are very competent at.

So you're actually doing them a big favour if you would say mummy now can no mummy's empty now come in anymore it's okay to do that and you're certainly not a bad mum because I admire parents, especially single parents, who now have to take all these different roles they have to be teacher they have to be mum they have to still do that the chores at house. They have to be the friends and replace the peers and the friends of the children you know that's a lot of different tasks and roles so my last advice is if you indeed want to become a better mum please take some me time because you can only be good mum if you feel well yourself.

Question

What methods are advisable in trying to chat with somebody in a social environment?

Answer

There's many things that can be done, there's a lot of social skills training but to me when autistic people say I want to have friends, I want to have a relationship, I want to get in touch with other people, and the very beginning is to start chatting with other people. To use a metaphor: when autistic people want to get connected to non-

autistic people it is like if you're going into a completely different culture because autistic and non-autistic brains have a different approach to the world. Now imagine that you go to a different country with a complete different culture that you don't know what would you do? Well what I would do is I would ask for a coach or a guide that explains to me about that different culture. You can take with you a book with very common phrases in the other language for instance if you go to Italy you can learn with a book to say hello good afternoon but I can guarantee you sooner or later there will be misunderstandings because you don't know the culture and the other people don't know your culture so what helps is someone who's kind of an interpreter. Now this is the metaphor that I use because we're not talking about going to a different country here we're talking about you wanting to get involved in conversations with other people. Well I would advise you to get yourself a coach, that could be a counsellor or a psychologist, who translates what the non-autistic people like in conversations but also who can help you to translate your behaviour to them because the tricky thing about relationships is there are no fixed rules so therefore I cannot give you a set of rules and say do this, then do that, then do that and then you will be successful in chatting with other people because if I would give you the rules I would only make you fail and then you would feel bad about yourself because then you would think you're not doing good.

The thing about conversations and chatting with other people is there are no rules. Temple Grandin, who is a well-known lady on the spectrum, she once wrote a book together with another autistic person Sean Barron to coach her autistic peers in navigating the social world. It was about relationships and she put in there the rules for relating to other people and rule number one in that book is there are no rules. They are content, context, and people dependent so therefore there is no specific rule I can give you.

What I would say is don't focus too much on chatting because then you immediately look for the most difficult part in getting connected to other people. An easier way to get connected to other people is not having conversations and talking but doing things together. So maybe a good advice would be look at your own interest and then try to find a club or a place where other people come together doing the same interest. That interest could be sport activity that could be a hobby club that could be an art club that could be a quiz club you know and doing things is actually easier because then you have to don't have to talk then there's less misunderstandings that's more concrete the moment and it will be easier to start a conversation because then you don't have to figure out what the other people want to hear what is polite in this case for the socially appropriate because you can just talk about the things you see and the things you're doing that might be a little bit easier but please my advice is go and find the coach that can be the interpreter between you and the non-autistic world.

Question

What is the most important thing to focus on right now to start becoming your own life coach but also manage any anxieties and uncertainties that autistic people may be facing at this time?

Answer

As I said in my presentation there's four areas where you can coach yourself you know the physical exercise your body the pampering yourself the doing the flow activities and then managing your thoughts. Now this is especially about the last part - the anxiety.

The first thing to do is again as I said with the control chart don't try to fight your anxieties and your worries. That's you know maybe you can win a battle and that means one day it will work but you will lose the war so if you're anxious if you worried that's ok but don't let the worries take over. So I ended my presentation with saying maybe the most important thing to start with in becoming your own coach is take an agenda or make one and start filling in what you will do. Planning your behaviours, not just saying okay I should be less worried I'm going to try to think positively. Now write down when you will think positive things but when it comes to anxieties and worries you know it's one way to control them and it's not to find them but to be in control of your own anxiety and worry. You know that the further you push them away the harder it will be. Imagine that your worries it's kind of something that weighs on your shoulders and it's a weight you carry now if you had to walk with the worries holding like that you would feel pain in your arms after maybe 10 meters 15 meters so the thing is to cherish to take it closer you will be able to walk further with heavy weight if you take it closer and that means, accept your worries and anxieties but then go and plan them as well.

I'm a big favour of so-called worry time plan it in your day and say okay today I'm going to worry from let's say eleven to eleven fifteen or and plan it may be several times a day if you are a person that that constantly worries plan it several times a day and connect it to a specific place as well. For instance don't worry chair pick out one chair in your house put it in a certain location and that's your worry chair and plan it and go and sit there and say now I'm going to worry and be anxious and the remarkable thing that you will notice is it will be pretty hard to worry because you're sitting there and you give yourself the instruction to worry and at that time your brain will say wait a minute that's not the way that I'm used to worry normally things pop up spontaneously so it's kind of a paradox I know that but plan some worry time that will not mean that from time to time during a day your anxiety or worries will not pop up. The moment they pop up say oh wait a minute I have a chair for that I'm go and sit on the chair. Obviously this is more difficult if you go outside of the home but then plan when you return home to sit on your worry chair again at the time you come back home and allow yourself to worry there but set the limits and say okay I'm allowed to worry here for and then it depends five minutes 10 minutes you decide it's up to you and this is all again about control remember that I started the presentation with Martin Seligman stories with the dogs and the control, you cannot get rid of your anxieties in the world she shouldn't but you can up to a certain point again I'm realistic here up to a certain point you can control your anxiety.

Question

My son has Asperger's and his coping strategy is to cope outside of the home and he uses lots of his coping strategies to deal with the outside world but when he comes home he gets very frustrated and takes it out on myself and my wife. He's 19 years old and understandably is becoming a lot more independent but as a result has effectively ceased his engagement with his family they were terribly worried about him how can we help him?

Answer

The fact that he wants to cope outside and you know to show that he's coping that he's strong is actually good you know that that says that he has a lot of motivation to make it out there in the world. The only thing is that probably he a little bit underestimates the limits of that or overestimates his coping strategies and that's where you could help he could and the first thing to say is it's okay that you do that again it's okay to try to act as normal as possible and to be strong and to show that you can cope but you know all of us have our limits, whether you're autistic or not and what we see is when you come home that probably you went a little bit into the red zone if you did a little bit too much and then it's again it's very understandable and it's very human that if you have gone into the red zone that you need to do things that make you again feel better.

As a parent even when your son is an adult you're allowed to say there are certain behaviours that we accept as relaxation as de-stressing as coping strategies the certain behaviours that we don't accept because we're living here together so there are some rules but we see the need there for you so I think as parents sit together with your son be clear about saying look this is hard for us as well because maybe he even doesn't know that he has this effect on you.

Be honest and be open about it but address the need and say we understand that when you come home you may be so full in your head or you're so chaotic you're so you know over the edge that you need to do things and then try to sit together and say okay let's find out together what things you could do when you come home to get rid of all the stress and the frustrations you had out there but that are not you know having a negative effect on the harmony in our family and on the relationship we have and again maybe he will not know about strategies that you can propose and not saying you should do this or you cannot do this not say let's make a plan but the most important thing about it is that when he comes back home from getting outside that there is again this kind of transition time where you create the opportunity for him together with him to say look the first 15 or 20 minutes we won't ask you for instance about how was it out there how was the shopping how was the meeting because if head is full you come home and you went into the red zone and people start asking questions with good intentions because you want to know how he did that's too much and then I can understand that a head explodes.

So give him the time to make the transition from a very stressful and demanding world outside to the safe environment at home because if he feels the home as a safe environment that will also help him to engage in other coping strategies to de-stress at home when he gets home.

So instead of a worry chair here you could say look this you know like a zone and we leave you alone for 15 minutes and when you're ready we can ask you how your day was maybe also look together with him what kind of activity that you can do think about the flow activities that I mentioned last time or the pampering yourself what can he do to pamper himself a favourite drink for instance and sitting there and doing nothing and he doesn't have to talk he doesn't have to help in the household you don't expect anything at that moment except that he know he pampers himself. You could also ask how can we help you but I can understand that adults will we prefer we not want you to those things because that puts them again in the position I'm not a child anymore you know I can do this myself well say yes you can but let's find out together but be clear about the behaviours that are stressful for you because maybe he doesn't even know that.
