Lesson 4: Worry, stress

You can read the content of the lesson 4 videos here.

About stress

When we face pressure and expectations that we struggle to manage, we experience stress. Some things stress out almost everyone; other things are more individual. What makes something stressful is always determined by the individual's experience and reaction.

How we react to stress can also vary from one person to the next. Stress reactions are impacted by several factors. Major or sudden life events, like an accident or changing classes, or something more positive, like moving or starting a new job could all be stressful.

Learning difficulties are an innate sensitivity that will have an impact, as will struggling with emotional regulation or finding it hard to communicate your needs. It also matters if the stress is caused by something temporary or if it is long-term.

Recognising signs of stress and understanding its causes are among the most important tools for being able to keep it from having a negative impact.

Causes of stress

Stress can lead to several different kinds of symptoms, such as worry, anxiety and problems with sleep. There may also be behavioural problems, such as avoiding certain situations, maybe staying home from school, for example. If you are having a hard time understanding these symptoms and can't find an explanation, you might consider whether it is indeed stress.

Stress often has multiple causes. It doesn't have to be that way; there might just be one cause. But it is common for several different causes to be behind stress. Some things that might impact stress include innate sensitivity, as we discussed in earlier lessons. What are your basic conditions? And how do you regulate your emotions? What are your previous experiences of stressful situations or life events? How did you handle them and what is your environment like? Is the environment caring or conflict-filled?

Other factors that could impact stress include sudden life events, such as parents separating, high-conflict family situations, being bullied at school, or a sudden death.

The duration of stress also matters. Short-term stress is often harmless; it can even be helpful. It's when stress becomes a long-term or recurring issue that it is problematic, and at that point, we need to seek help. It isn't just that stress is

problematic; it can also lead to poor mental health. So it's essential that we learn to recognise the signs and causes of stress. That is our most important tool for combating it. When it comes to people with autism, this is especially important and also particularly challenging.

Autism and stress

Because stressors and how we react to them are highly individual, it is important to not only consider our own perspective when interpreting a child's reactions. To understand what your child is reacting to, we need to take a step back and observe the situation as objectively as possible.

Once the acute stress has subsided, you can invite the child to participate in trying to understand exactly what brought on the stress and how to prevent it next time. How children with autism express stress can differ quite a lot from how it might usually look in someone without autism.

For example, the child might start laughing or swearing when frightened. As a result, they might be misunderstood, which in turn leads to more stress. Remember that your child's reaction is often an attempt at a solution – either a way to regain control or to avoid the stressor entirely. These reactions might be intentional or unintentional. They are using the strategies available to them, and that have worked in the past. The child's solution could also be perceived as a problem by the people around them, such as acting out, self-harm, isolating, refusing, and not responding.

Stress reactions

If the adults in the room can recognise the child's reaction to stress early and try to remedy the cause, this could prevent it from developing into mental illness.

To explore what it looks like in your child, here is a list of common stress reactions in children with autism:

- Their special interest might increase in an unusual way; they might completely immerse themselves in it. For example, if they like to play video games, then they just sit in their room and play video games Or if they like sorting things, then doing this a lot.
- Repetitive behaviours and stereotypic behaviours may also emerge. They might sit and rock to soothe themselves. Doing this more could indicate a stress reaction.
- Becoming overly excited.
- Becoming extra sensitive to sound, light and touch, for example.
- Increased worry, anxiety, compulsions, acting out and self-harm behaviours.

These are the kinds of changes to pay attention to in your child, as well as what we talked about earlier regarding chaos: it doesn't have to be acting out and shouting and fighting; it can also be withdrawing and isolating.

That can be just as much of a chaos reaction as acting out. And the important thing then is to be attentive, because the signals can be very subtle and the changes are often quite small. As a parent, you know your child best. Try to maintain good communication with the school, for example. If you're noticing a stress reaction, check to see if they're noticing it at school, too. If so, can anything be changed?

The last point on the list – increased worry, anxiety and compulsions, as well as acting out and self-harm behaviours – these things could transition into mental illness which could require help, and you may need to take additional action to reduce stress.

What we said about perception – that it's better to lower the volume than to change someone's ears – also applies here: instead of trying to change a child's stress reactions and behaviours, try to change the stressor in the environment.

And if you're struggling to get help in the school, or if they aren't making enough changes and these symptoms are increasing, it is important that you contact us at the BUP clinic for more help.

Stressful situations

Here is a summary of things often perceived as stressful by people with autism.

Sudden and unpredictable events: these can be stressful for everyone, of course. But for people with autism, who have cognition differences, many events are sudden and above all unpredictable. It is hard for them to imagine how things will be. And because it is hard for them to imagine how other people think and feel, situations in which they have to try to interpret or read others can be stressful.

Changing activities can also be difficult. If they're doing something fun, then switching gears to something else will be hard. They often need a lot of preparation.

Busy environments are also stressful, for example at school, when a lot of people are running or talking all at once. There might be sounds and lights, or changes to sounds and lights. A lot of different things happening can be stressful. Even something like what we've talked about before: going to have coffee with friends. You get to a café and you have to decide what you're going to order and keep up with various conversations. Maybe other people are coming in and that draws your attention.

Changes are also related to cognition differences. They have a reduced capacity for flexible thinking. Once you've decided something – that a thing should be a certain way – it is very difficult to accept that it won't be. Such changes can be stressful.

There may also be physical discomfort, for example something chafing: tags on clothing might chafe or itch. They may be wearing new clothes, for example, or something might be squeezing. Things like this can be stressful and people with autism might have a hard time explaining exactly what it is that is uncomfortable, causing their reactions to seem unjustifiably strong for the circumstances.

And keep in mind that they have difficulty communicating their needs.

Stress as a teenager

Now we will talk a little more about stressors that are particularly evident for teenagers.

Being a teenager is a challenge in and of itself. They're filled with questions about who they are, their identity, their body, their sexuality and more. And often, teenagers turn to their friends rather than their parents to talk about these things.

For some teens with autism, these kinds of questions will come early and for others they will come later. As a parent, it can be good to be aware that questions like this are coming up for your child. For example, relationships with friends may be sensitive because social interactions are difficult. They might not have many friends and they may wonder why. They might wonder what it will be like to be in a relationship, for example. Physical changes that arrive with puberty and sexuality and all of the questions that can arise in the child can also be stressful.

Maybe they feel like they aren't keeping up with their friends of the same age when it comes to development, maybe they feel behind. They may feel like they don't really fit in when it comes to these things.

Teens in general have lots of choices to make about the future, and so do teenagers with autism. They might be wondering: what kind of studies can I manage? What kind of job will I be able to manage?

Given all of these questions and concerns, it is important that as a parent, you are there to talk to your teen and provide support. If your child or teenager feels like you're being pushy – which all teens feel from time to time – then you can see if there are other adults who your child trusts and who they could talk to about these things.

And how does your social network look otherwise?

Stressors and protective factors

Now we've been in the red 'understand' field again (thought model).

We've talked about stressors and stress reactions in general, and specifically when it comes to autism. We will take a closer look at understanding when it comes to stress. But we will also delve deeper into the blue box and talk about what we can

change. And like before, we can then move to the green box, for example if you've worked with a specific problem and the situation functions better now for the child. If so, great. If not, then we go back to the red box to see if we need to improve our understanding, and maybe also look at the blue and purple boxes in the model. Is there anything I can change and anything we can clarify?

Once you're stressed out, it can be hard to do anything about it. So it's best to take a preventive approach. That means we want to reduce the risk factors and increase the protective factors. What might the risk factors and protective factors be for a child with autism? Risk factors that we might need to change involve different factors in the individual as well as in the surroundings. We have mostly talked about the risk factors of the individual. We've looked at innate sensitivity and basic conditions, as well as any negative experiences of stress in the past, and the day's mood.

- What is it like?
- Are we well rested?
- Do we have energy?
- Have we eaten?
- Have we slept?

Risk factors in the surroundings with which parents might need to help a child with autism could include being exposed to excessive demands. That might be at school, but it could also be at home or during free time. Can we adapt the environment? For example, if the child is in a messy setting, can we clarify?

Unpredictability – we could work with more preparations. And changes, which are also often a struggle for children with autism. That means both large and small changes. There, too, we can try to clarify and work with preparations.

Let's look at the other component: protective factors.

- We may need to help a child with everyday skills when they're younger, but they'll need to learn more of these skills when they're older. Solid everyday skills and being able to handle everyday situations are protective factors.
- Self-confidence, which we discussed earlier, can be built up during free time by doing something educational and stimulating.
- Good experiences handling stressful situations in the past. And the ability to receive help, which can be hard, but is a skill that can be strengthened.
- If we look at factors related more to the surroundings, we see that structure and preparation are also protective factors, which we've discussed a bit already.
- Another protective factor is to adapt demands based on the individual's abilities, giving the individual a chance to meet the demands.
- Having good relationships that work is a protective factor.
- A low arousal approach from others is also a protective factor for children with autism.

The stress cup and chaos curve

Remember the stress cup? It shows what can happen when multiple challenges or stressors together cause the cup to overflow. You lose control.

If you know what stresses your child out, then you can have some foresight and maybe offer help to keep it from becoming too much. Of course, you won't always succeed.

In the picture, we see the different levels of the stress cup on an affect curve (*see video*). There are numerous variations of curves like this; the first one was made in 1983 by two researchers, Kaplan and Wheeler, to illustrate an outburst.

The green field is where you have control. You are doing things that you're used to and comfortable with, and with which you feel confident. There won't usually be any signs of stress here. But it can actually also be a little boring.

The yellow field has some challenges. It can be irritating and hard. This might also involve learning new things or solving problems. In the yellow field, you have access to strategies. You have margins and you can use trial and error. You can receive help and take in new information that you need to handle the situation. You might be a little tired afterwards because it can be tough, but you will usually be able to work things out.

But if it becomes too much or if there are too many irritating factors... Or if you've tried all your strategies and exhausted your options and you just can't do it anymore. Or if you were tired from the start and you don't have the energy to try. That's when you find yourself in chaos, in the red. At that point, you might panic or get so angry that you have an outburst. Or you shut down completely and want to isolate, and you don't want to participate. And up there, you don't have... You aren't thinking very clearly, you don't have the energy to try and you just get irritated if someone tries to help you.

When the stressor disappears or when you're no longer in the situation, the stress eases off and you return to the yellow. You might feel a little tired and fragile. You might also feel a little ashamed, especially if you had an outburst, which can be a bit embarrassing. That really isn't exactly the time to start talking about it. Give some time and back off; that's usually the best approach. And that way, they can feel grounded again and regain control of themselves.

Here are the three levels: green, yellow and red. Infants essentially only have green and red. Life is either great and everything is fine; it's all nice and cosy – or everything is screaming and panic. They are hungry or want comfort, or feel alone, or just feel uncomfortable.

But whatever it might be, the reaction is equally strong. Fairly soon, however, even babies can wait for a little while. They can give slightly milder signals, because they trust that someone will come and help fix the issue. It usually goes well; it's usually fine. That is when you develop the orange area, where you haven't lost control completely yet. And that continues to develop throughout life, including from

experiences and from handling things, and from being supported by others to handle things.

As an adult, the red area is usually very small. It's rare to lose control completely, but of course it can still happen. For people with autism, it may happen a little more often. This is both because different things are stressors for you than for other people, and because it's often harder to interpret and regulate your emotions. It can also take longer to get a sense of what you are feeling.

Let's check out how it can look:

We often know our kids fairly well, so we can tell when something is up. But sometimes, it feels like an outburst can come out of nowhere. Take Anna, who is 12 years old. She went to school, just like usual. She came home and seemed a little bit grumpy. You send a quick text to the teacher and find out they had a pop quiz at school. You know she doesn't usually like that. So you suspect that she might be somewhere up here. When she comes home, her little brother is there and he has a friend over. They're playing and it's fairly loud. Anna quickly goes into her room and shuts the door. You know she thinks it's way too loud, so she needs to be left alone. She's probably a bit more bothered by it.

Today is her brother's day to decide what to have for dinner. She doesn't love that, but it's already in the works. When she comes out for dinner, it's something she doesn't like. But her brother is chatting away, cheerful and satisfied, and she gets even grumpier because it isn't something she likes.

Then she stands up and leaves the table. Her brother says, "Are you going now?" Then she loses it completely and slams the door to her room. She puts on loud music and you can hear that this isn't good. Now she's in chaos, and you've seen this before, so you know it will take a long time. You hope she doesn't do anything dumb in there.

Today is total chaos for Anna. And once you've reached the point of chaos, like today for her, there isn't much you can do. Take it easy; give her as much space as you can. Show that you are there. Knock gently
and say that you understand. Because it usually makes things worse and causes the curve to last longer if you nag, try to fix it, or try to cheer her up. That can also be tough.

Chaos doesn't always look the same. Anna mostly shuts herself in. Someone else having an outburst might throw things and shout awful things at others. They may be different, but both are expressions of chaos. So leave her alone and let it be.

When she opens the door and comes out, she has calmed down a bit. You still shouldn't go up and ask, "How are you? What happened?" You risk stirring it all back up again if you approach her with too much talking. There will often be 'warnings' of that. Leave her alone, let her be, and she will settle back down. Maybe offer something a little distracting, something extra yummy, or watch a good movie and things will calm down a little more. This is how you help her come back down. And eventually, she will be calm again. But up here,

the things from the last picture are important. Back off; be relaxed. Too many feelings, and ‘sweet’ feelings, can make the situation worse and harder. The crying never ends.

This is called low arousal – to back off from a chaos state. On another day, you might be able to avoid the chaos. Because maybe...
In this situation, maybe you... If her brother would stay calm, then maybe you could have knocked on the door and said, “Hey, I know you’re supposed to help with dinner today, but I can do it.” And then leave them alone. If the brother backs off in time, if you tell him to take it a little easy, or not be around, then you might be able to turn the situation around already then. Or if you find something fun that both she and her brother enjoy. Humour often helps. If you know what would be fun, you might be able to turn things around beforehand. So: be aware of the stressors; don’t trigger too many things; don’t start asking questions. Try to come up with something else, slip away, and you might be able to turn the curve.

So when should you address these problems? As I’ve said, it’s usually never time to address them on the day it happened. Let a day or so go by, and wait for a calm moment. Preferably when you know it’s going to happen again, but not today, not right now.

Then you can discuss: what should we do when it’s time? Or if it happens again. What can we do then? What is the best way for us to help you? What should we keep in mind?

That way you may have better success. These are actually the things that minimise space for chaos, because you’re handling more and more situations.