THE NEST APPROACH

Support autistic young people with meltdowns

Important:

It is impossible to follow the NEST Approach when you are highly stressed yourself! Self-care is an essential foundation to supporting young people in distress.

This guide is heavily influenced by the work of Studio 3, the CPS model and the PDA Society.

Written by autistic adults, in equal partnership with autistic young people
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HOW/ WHY WAS THIS DOCUMENT CREATED?

This document was created by the Spectrum Gaming community, as a result of autistic young people sharing the negative impacts of support that has been offered while they are experiencing meltdowns.

We worked together with them to create this guidance around meltdowns, using the insight of the community, plus the best practice work of Studio 3, Ross Greene and the PDA Society.

The important key thing to remember here is that people do well "if they can". No one wants to experience meltdowns, and meltdowns in themselves are horrible to experience.

What do meltdowns feel like?

- "They feel like an uncontrollable explosion of emotions. No coping strategy or convincing could be used or work. It makes everything harder and I can't do anything, nothing makes real sense and there is so much anger, confusion and sadness."
- "I feel like my world is crumbling before me and feel as if I've lost control."
- "It's like the raging monster in you lets itself loose."
- "I feel like I'm floating in the void, I cannot control my actions and every object around me feels like it needs to be destroyed. I feel like I could die."
- "When inside my brain is exploding and I can't talk and everything everyone does makes me scream and cry and shout."

How do you feel after a meltdown?

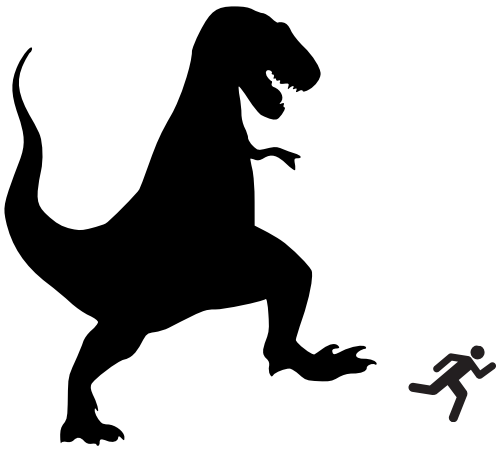
- "Guilty and reflective, and regretful that I would have just stopped it if I could."
- "Really embarrassed, but I don't usually get over what I was thinking until 1-2+ days when I think "wow, I really did that? I feel so bad."
- "I feel like a different person and really negative about everything."
- "Tired and my head hurts from tensing it and under my eyes hurt from crying. Even when I've stopped crying I will then go into shut down and just "go live in another world" for a while."
- "I feel guilty, upset and shameful."
- "I feel like I've let my family and myself down, I have bad thoughts."

One thing that will have a huge positive impact on the long term wellbeing of autistic young people is supporting them with meltdowns in the right way.

There are also three things that are incredibly important to consider when supporting young people:

1. What do we do after a meltdown to repair any harm that was caused?
2. How do we reduce the chance of a meltdown happening again?
3. How do we stop the meltdown from contributing to a young person's trauma?

The NEST approach is a four step approach that covers all of the above.



What can meltdowns look like?

When survival mode is activated, our brain prioritises keeping us safe in one of six ways:



Fight

The body attacks and is aggressive to fight off danger

- Blaming, deflecting responsibility
- Demanding, controlling
- Irritable, aggressive
- Yelling, screaming, using mean words
- Hitting, kicking, biting

Flight

The body wants to flee the scene to get to safety

- Wanting to escape/ run away
- Unfocused, hard to pay attention, restless
- Preoccupied, busy with everything else
- Demand avoidant
- Ignores the situation



Freeze

Your body freezes - you are unable to fight or flee



- Shutting down, mind goes blank
- Isolates themselves
- Unable to speak, or says "I don't know" a lot
- Difficulty with completing tasks
- Zoning out/ daydreaming
- Unable to move, feeling stuck

Flood

- Crying, overwhelm
- Girls are likely to do this as told you are not allowed to 'act out' due to societal expectations

Fawn

Your body aims to avoid conflict through people pleasing behaviour

- People pleasing
- Struggling with boundaries
- Feeling overwhelmed
- Difficulty saying no
- Prioritising other's needs
- Masking
- Submissive



Flop

- Feeling weak
- Feeling sleepy
- Exhaustion

When you have a survival response (a meltdown), you are no longer properly in control.

NURTURE

The very first thing we need to remember is to help a young person feel safe - remember that experiencing a meltdown is incredibly scary. If someone is upset/ stressed/ having a meltdown, focusing on helping them to feel calm is important as people cannot think logically at this time. Until they feel safe, there is no next productive step.

If a young person is not currently highly stressed or experiencing a meltdown, the Nurture step may not be applicable and you can start problem solving with young people from step 2: Empathise. The Nurture step shares a variety of strategies that can be used to help someone become relaxed in the short term, avoiding crisis.

Be calm

If you aren't relaxed, this can make a young person more stressed due to the emotional contagion effect. Take the time to calm yourself, don't pretend, most autistic people sense the difference and it can make things worse. If you are calm, they will feel that calmness and feel reassured due to emotional mirroring. This will allow them to use you to coregulate. Remember that even if things are heated right now, they will be ok eventually, and in the heat of the moment a young person may not be able to recognise that, so showing you recognise this by being calm is really helpful.

This includes:

- Using a relaxed, comforting posture rather than appearing stiff/ rigid.
- Using a calming, caring tone. Speak slowly and softly.
- Keep your language simple and clear
- Try not to show stress on your face.
- Speak in the affirmative rather than the negative (saying "don't do that" doesn't give an alternative option of what to do).
- A stressed person is usually trying to communicate something, so show active listening and acknowledge what you think they are trying to communicate.
- Make sure to not be 'too' relaxed by joking/ not paying attention as this could make it look like you don't care about their distress. The aim is to look confident that things will be ok.

Use Distractions

Distractions are not a 'reward for negative behaviour' as they are sometimes viewed. Distraction should be seen as a positive support tool to help avoid a crisis.

Distractions are also not always effective - offering a distraction can make it feel you aren't taking their distress seriously, but it can also be used to break focus of any stressors, and help a young person to get back on track, so you need to time this right and be creative in how you do it in order to be helpful.

Invite a young person to watch a video, listen to a song or play a game together. Many autistic young people have special interests, so talking about or doing an activity around these can also help give them something meaningful to focus on.

Physical activity can also be really helpful, as people in crisis often really benefit from a 'physical release' of their emotions.

Activities that create a sense of 'flow', where you can focus on it without worrying about other things in life are really helpful. Every young person has different things that can get them into this 'flow state'. It could be computer games, art, a DVD, going on a trampoline, music or just going for a drink.

Know that things you do to try and help may appear as a threat

Be wary of physical touch

When you are in survival mode, your brain is looking for danger and is more likely to perceive things as a threat. Calming touch like a firm hand on someone's shoulder could feel like an attack. A soothing hug could feel like you are being trapped by someone. When you are in meltdown, you are not as rational as you usually are so any things that are normally safe or calming can be perceived as dangerous.

Touch can be a sign of affection, warmth and security but it also can be a sign of threat and hostility

When a young person is distressed, it is helpful to avoid stress wherever possible, unless the young person communicates that they would like physical touch in order to feel more supported (this happens the minority of the time)

Slow your movement down

Fast movements can be perceived as threatening, but they can also be overloading as your brain is trying to work out their intentions, but is currently unable to. This can activate more fear/ threat. Slow down and be as predictable as possible to show a sense of calmness. When moving, try not to move towards the young person without warning, as they may interpret this as a threat. People often do this in an attempt to calm or reassure a young person, but it often has the opposite effect.

If you feel approaching a young person is really important, let the person know in advance and approach them in a calm and slow manner.

Keep your distance

Everyone has a 'comfort zone' of how close they are comfortable with people being to them. This changes depending on the person and the environment. A young person may be ok with a parent sitting right next to them but may struggle to sit next to a stranger on a bus and feel comfortable.

When a person is distressed, the range of their personal safety zone can change massively. As a result, being too close to them can feel threatening, and so they will require more interpersonal space. Try and stay at least 2m away if someone is struggling, unless that person requests/ shows they need physical touch/ comfort from you. Sometimes if someone cannot tolerate you being in the same room, waiting outside and calmly reminding them that you are there could help them feel safer.

If someone is in 'flight mode' and you get too close, this may put them into 'fight mode' which is not safe for you.

If someone is in 'fight mode', it is also helpful to keep your distance so you can keep yourself safe.

Gestures can be misinterpreted

Laughing can feel like someone is laughing at you. A friendly wave can feel like a taunt.

Gestures are a natural part of human communication that enhance what we are expressing. But be mindful that people may not perceive gestures in the way you expect them to while they are highly stressed. Using just gestures, or just speech rather than both at the same time can be helpful.

Avoid gathering staff

When someone is distressed, there should only be one person speaking/ supporting them at a time as they will find it difficult to process communicating with multiple people at the same time. If the supporter is struggling, then they should swap with someone else, rather than someone interjecting while you are already supporting.

Too many supporters can heighten stress much more. Supporters might feel safer, but this isn't always impactful as it makes the person you are supporting feel more unsafe.

This also increases the 'audience effect' (Strauss, 2016), in which being watched by others whilst in a stressful situation feels like a form of coercive control - this should be minimised as much as possible.

It is helpful to have a second staff member nearby in case they are needed, but they should be out of the line of sight and should only assist if requested by the lead supporter..

Avoid direct eye contact

Eye contact can be really overwhelming - a lot of autistic people can find eye contact difficult, and this can be amplified when they are highly stressed. Eyes are incredibly emotional, so having to make eye contact with people when you are struggling emotionally can make you feel much worse.

Intense direct eye contact is also used as a way of asserting power and control, so this can lead to a power imbalance. When a young person feels unsafe, one of the best ways to give them a sense of safety is to make them feel they are in control of what is happening.

When you are supporting someone who is highly stressed, try to avoid staring at them and do not force any eye contact. Intermittent eye contact may be ok.

Remove other people

The audience effect makes even the right support feel threatening at times. People 'feeling' you are doing the wrong thing and interjecting also means that there may be too much input for the stressed person to process, making the situation worse. It is much easier to remove other people than to remove the distressed person - so try and remove them so you can focus on helping the distressed person become calm/ relaxed.

Trying to remove the stressed person is likely to escalate the situation and is often what leads to physical restraint.

Sometimes, someone in crisis may focus on one person, and that person moving out of the environment and being 'followed' by the person in crisis can also remove the audience effect. But making a stressed person move out of the environment often has a negative impact.

Tactially withdraw from the person

Sometimes withdrawing from a situation can lead to a decrease in stress. We can often get into arguments, disputes of 'stand-offs' with young people.

When this happens, somebody needs to back down, and more often than not this will need to be us. When a young person's brain is telling them they are unsafe, they may not be able to back down, even if they desperately want to.

If you stand down, try not to view this as 'giving in' - it is really important for avoiding distress/ crisis. Reflection, support and learning will be far more achievable when everyone is in a calm and relaxed state.

"When someone is drowning, that is not the best time to teach them how to swim"
- David Pitonyak

Reduce demands

In a crisis situation, verbal demands, requests and boundaries are often triggers to distressed behaviours.

Research shows that nearly two thirds of behaviours of concern were preceded by staff demands/requests (McDonnell, 2010).

If someone is unable to meet our demands, can we remove the demand completely, or at least reduce it for now?

How you word things is also important in whether it is perceived as a demand. Autistic young people in general can struggle with being told “what to do”, and instead thrive when given a reason “why” something needs to be done. This allows them to come to their own conclusion, and so reduces external demands

Remove environmental triggers

People who are highly stressed become more sensitive to their environment.

It is really helpful to remove any potential triggers in the environment:

- Turning down lights or turning them off completely.
- Reducing sounds
- Removing ourselves from sight/ the room

Make sure to consider all of the senses.

Having a safe/ quiet space to go to is often incredibly helpful - though it is easier to access this if a safe space is agreed in advance, before a young person reaches a state of distress. This also works better as a proactive tool, where young people can go there freely and use it to pre-emptively avoid stress, rather than using it only as a place to be sent to when they are no longer in control.

Be flexible with the rules

Learning happens when people are calm. Swearing may not normally be considered socially acceptable in many environments, but commenting or focusing on someone's swearing whilst they do not feel in control you may unintentionally make them feel more stressed and overwhelmed. It is helpful to be more flexible with rules now (as long as they aren’t putting themselves or others at risk), so you can focus on helping them to become calm as quickly as possible with minimum damage/ impact.

Note: While the Nurture step is for when someone is visibly struggling, assume young people who do not show they are struggling may need input too. If someone has an issue then stops interacting with others or avoids the community, the NEST approach is still important ('flight'/ 'freeze' responses are less visible than a 'fight' response but still need support).

If you would like to learn more about supporting young people when they are stressed, visit Studio 3 Low Arousal website.

They also have a range of free webinars around the 'Low Arousal Approach'. Our favourite is from Professor Andy McDonnell on 2nd June 2020.

When should you move on from the nurture step?

The young person is now calmer/ more relaxed, what next?

Straight after the incident, it is likely that all the young person can think about is addressing threat - threat of punishment, exclusion or judgement. Threats like this are common when you're autistic.

The very first communication with a young person after an incident is therefore important to ensure they feel safe and not under scrutiny. You should reassure the young person (and any parents/carers if involved) that they are not in trouble. Following on from this, you should clearly explain that your first focus is their well-being, as well as theirs and others' safety.

You may need to keep repeating this throughout the NEST steps as this supportive approach may be something the young person is unfamiliar with. They may need time to recognise that this will be the approach of supporters moving forward.

When a young person is out of crisis, they may be feeling shame, guilt and embarrassment, but may also have feelings of anger/ resentment about the situation and what happened. Although they were unable to control their emotions during the incident, some of their actions whilst in meltdown may have been dangerous, frightening to others, or had a negative impact on themselves and others. Therefore, it is very important to work with the young person to fully understand the situation, and to identify actions that can be taken to reduce the chance of this happening again. This is a three step process that is outlined below.

It is important to not work on understanding the situation too soon. It takes at least 45 minutes from crisis for a young person to reach a calm/ relaxed state, but it is often much longer. It is usually ok to wait until the next day to start this process with a young person. As the experience was difficult for the young person, they also may not be able to talk through this all at once. This debrief may be done over a long period of time, and it is really helpful to not push discussion with a young person around this. Use your judgement to consider when they may feel ready to talk about it, or they may let you know when they are ready.

EMPATHISE

If someone is struggling or has reached crisis point, it is important to assume there is a good reason why and to try to understand their perspective, plus any reasoning for their current struggle.

Why is this important?
One of the main reasons autistic young people say they are failed by services is that they don't feel listened to. Young people have also said that feeling listened to and valued is much more important than all of their needs being met. We will never be able to solve everything (though we do aim to solve as much as we can), but we can always listen, work together and try our best. These are the things that matter the most to young people.

If we just focus on what we want and what we deem to be acceptable behaviour without looking at a young person's perspective/ needs, we are never going to be able to truly meet their needs. Everyone is different and needs different things in order to thrive, so taking the time to understand an individual person's needs is incredibly important.
This is a two step process:

Initial enquiry

No matter what the person has done and how you may perceive this, the first step is showing you care about them and would like to understand their thoughts and feelings at the moment. In order for a young person to feel listened to, it is really important here that you don't offer solutions or judgements at this moment in time.
The first step is for a young person to be heard, and to make sure you fully understand their perspective. Here are some examples of ways to start the conversation:

- "I saw... is there anything I can help with?"
- "I saw that you are struggling with... at the moment"
- "You looked quite upset in... earlier, can I ask if everything is ok?"
- "It looks like... is difficult at the moment, would you like to talk about it"
- "It must have been difficult to be so distressed earlier today... is it ok to ask what made you feel this way?"

Understand more

Once a young person has shared their perspective, it can be helpful to do some reflective listening and ask clarifying questions. Focus on understanding the who, what, where and when of the problem. It may be useful now to ask them what they were thinking or feeling during that time, bearing in mind this can be tricky if they struggle to express or identify their emotions.
Showing you are listening in an empathetic way takes practice. There are 3 ways you should try and do this:

- Try to understand their perspective, and show you are trying by asking questions that show you have processed what they have said and would like to understand more.
- Stay impartial and show no signs of judgement. Even if you feel they are in the wrong, act neutral.
- Recognise and communicate their emotions.

There are two YouTube videos that we love which give a strong picture of what empathy is, and how people can get it wrong when they try to be empathetic:
Brené Brown on Empathy - RSA
Being A Good Listener - The School of Life

SHARING CONTEXT

Why do we want to problem solve with the young person? We need to show that how the young person feels is important to us, but also share the perspectives of other people so they can fully understand the situation if the situation is a result of miscommunication.

Why is this important?

We don't believe in punishments or telling people off, as they do not do anything to help meet underlying needs. This part of the process aims to help young people to reflect on the situation and see the impact it has had. This may help them to see that the 'Teamwork' step is important if they agree that something might need to change as a result of the discussion. Sharing context also means you can share perspectives they may not have thought of, enabling deeper insight into the issue. Please note, sometimes sharing the perspectives of others is not appropriate as they may be feeling too guilty/ upset to be able to tolerate this, but this step is still important to show you care about the young person.

Example starting phrases:

- "I am worried about..."
- "I am wondering if..."

When talking about concerns, they are normally in one of two categories:

- **How the problem is affecting them**: It ALWAYS affects them in some way, so make sure to always include the problem they have to show you care about them. They could have been through distress that you would not like them to go through again. But also, others seeing them in distress could affect their relationship with them, and it may be important for you that the young person feels connected with others, in case they want to have a relationship with them.
- **How the problem is affecting others**: This may involve speaking to others to understand their perspective. Speaking with everyone involved then impartially sharing people's perspectives with each other can really help to improve mutual understanding. But make sure they know in advance that when you share another person's perspectives, you aren't taking sides but are trying to enable reflection.
    - Sometimes when it comes to supporting an autistic young person, they may become upset as a result of miscommunication, so sharing other people's perspectives, when done in the right way, can be really helpful.

Check they understand your concern and that you have been clear. Do not start talking about solutions yet or judge/ lecture them. We want to let young people know we are here for them and want to work together. By judging them or making them feel you are not on their side you are reducing the likelihood of being able to problem solve together. **Now you have fully explored the issue, you can get to problem solving!**

TEAMWORK

Why is this important?
Most services and settings focus on a system of rewards and punishments for changing behaviour. We understand that when young people are struggling we need to address the root cause. The best way to do this is by working together.

Initial Enquiry

Raise the concerns that were identified in steps 1 and 2 e.g. "I wonder if there is a way...". Let the young person have the first opportunity to propose a solution, but remember this is a team effort so you should work it out together (sometimes just having a break is enough if they are struggling due to a short term situation rather than a need).

When you are problem solving

Don't just put the onus on the young person
It is likely it isn't just them who may need to make changes, but also others involved in an issue and you too! If feedback means you may need to make changes to how your service runs, it can be helpful to share this with the team and look at this together in more detail. It may be beneficial to explain to the young person that you plan to make these changes, and how their input has helped to improve the service for themselves and others.

Work out the probability of the solution being successful
If you think it is improbable, say this and see if you can work out something else.

Remember you should focus on solutions that focus on meeting needs/ fixing underlying reasons
Adding punishments or telling people off are not long term solutions so should be avoided. Young people may feel shame at their actions and may feel they deserve a punishment. But we know that doing this does nothing to fix the root cause of the issue, and doesn't help the young person to process their actions/behaviours in a healthy and productive way.

You don't have to come up with solutions straight away
If you need more time or want advice from your team, that is ok. Let them know you need more time and will come back with ideas when you are ready.

Important key factors

Make sure the proposed solutions are possible from both sides, and address everyone's concerns.

The teamwork step always ends with agreeing to start this process from the beginning if your proposed solution does not stand the test of time.

The teamwork step may involve contacting and working together with other caregivers, depending on the situation. It is about doing what you can to come up with a meaningful solution that meets both your needs and the needs of the young person.

Thank you for reading

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