highland NDhub

# Quick-Start Guide: Distressed Behaviour

Carrie Watts
Carrie.Watts@ThrivingFamilies.org.uk
Oct 2025

# Table of Contents

# General Information

Much too frequently, the wider population believes that neurodivergent behaviour and distressed behaviour are one and the same — that anyone who is neurodivergent is always distressed simply by the function of being neurodivergent.

That is not true.

**Distressed behaviour indicates that a person is experiencing distress**. And if we want to help them, we have to work with them to figure out what is leading to that distress and do what we can to change it.

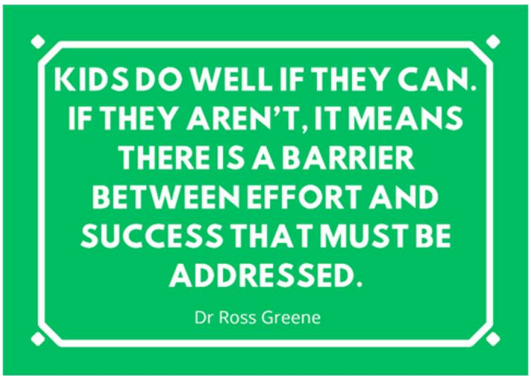
As a codicil to that: a common refrain in the support world is *"Behaviour is Communication."* While the intent behind it is good — to listen in all the ways we can to understand the needs of another — there are many ways in which it can be problematic.

For one, as it relates to non-speaking or situationally non-speaking ND people, those around them tend to assume what a specific behaviour is communicating and assumptions can be very wrong. For example, hand flapping is frequently assumed to represent distress by neuronormative standards. But very many autistic people flap in sheer joy — it isn't an expression of pain, but one of so much delight that it must take movement in the body.

Another reason the expression is problematic is because, as it relates to apraxic people (people who have difficulty directing purposeful movement), the 'behaviour' seen is not necessarily communicating the actual intent behind it. When the body doesn't do what the person is telling it to do, the observable behaviour others can witness is not a reliable indicator of need.

In both these cases, our responsibility is to check our own assumptions about what we are seeing and what it might mean that individual is experiencing. From there, our role isn't to correct or manipulate, but to support individuals in understanding their own needs and the methods available to them to get them met. The function of external parties is to provide safe and accessible opportunities for meaningful expression and supported emotional regulation, to empower neurodivergent people with agency and autonomy.

To do this as effectively as possible, it helps to understand what the body experiences when it is distressed, what the brain is capable of when in distress, and how long it takes to recover from periods of distress.



# Distress

## The Basics

The starting point in understanding distress is to recognise that the experience of it is individual — no two people will respond the same way in the same situation. People have differing sensitivities, needs, past experiences, and capacity, and so their experience of events are all different. This is why an event that is traumatic to one person can be only temporarily upsetting to someone else.

Understanding this individuality of experience is crucially important to supporting others through distress. Validating their experience demands that we not judge it by our own standard for what is and isn't distressing.

When we experience distress, our brain goes into survival mode. This is commonly referred to as the "fight, flight, freeze" response. If we are being very specific, there are actually 4 possible responses to distress: Fight, Flight, Freeze, and Fawn. All of them are trying to achieve the same thing — to make oneself safe.

The brain does something very specific when it perceives a threat to safety — it's like an "Emergency button" is hit. That button, the **amygdala**, then takes over, suppressing anything that isn't about immediate survival and enhancing all the things that will help. The amygdala overrides the Prefrontal Cortex, where reasoning and decision-making take place, and floods the system with adrenaline, cortisol, and other hormones to heighten strength and senses to aid in surviving threats. In addition to our biological make-up, our past experiences and trauma also influence how and when our bodies respond to perceived threats.

None of this happens by choice — these responses are deeply rooted in the nervous system.

This set up was perfect for keeping us alive back when the main threat we faced was getting eaten by something bigger and stronger. The problem now, though, is that our amygdala still initiates that same life-or-death response, even though the situations we experience are usually less mortal in nature. For most neurotypical people, today's distressing situations are few and far between. The "Emergency button" for them will get hit mostly in response to high-pressure situations like going to a new place, making a speech, taking exams, or scoring a goal when everyone is watching. Day-to-day life isn't a high-pressure situation because societal systems — the tasks that need to be completed, the rules that are enforced, and the public environments into which we must go — are all designed and set up to meet neuronormative expectations and experiences. So, the requirements of daily life (for example, going to school or work at certain times) aren't perceived as threatening to neurotypical brains.

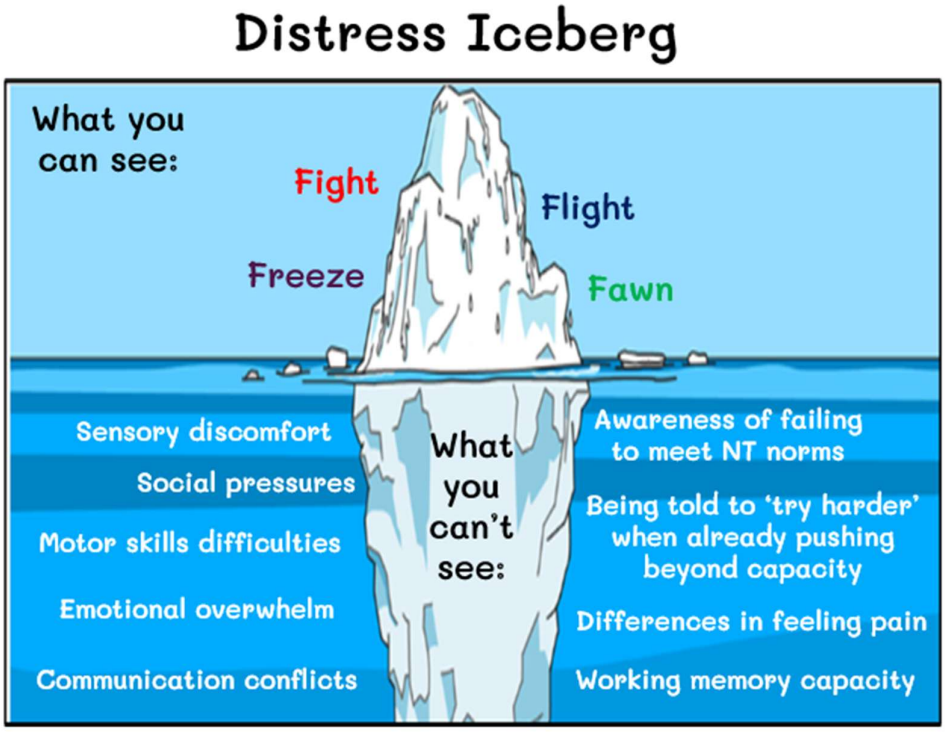
The same is not true for neurodivergent people.

Due to having hyper-connective brains, differing nervous system reception and processing, and alternate innate ways of communicating, socialising, and moving, the "Emergency button" is constantly getting hit, activating the life-or-death response. Even though our lives aren't technically in danger, our bodies have no other way to warn us to 'keep us safe' when it has perceived a threat — threats that come in every

shape, size, smell, sound, touch, emotion, and need that ND people have within a world that is specifically designed for the needs of neurotypical people.

This means that distressing situations for ND people are more frequent than they are for NT people — they are likely to occur on a daily basis, where internal needs and external pressures are in conflict with one another. Preventing this distress only happens by understanding where the conflict exists (i.e., within each area of development) and working to resolve it in an affirming way.

We can think about it like an iceberg: what someone can see — the survival response — is negligible compared to what is underneath that, driving it to happen.




The ND person's response is not the problem; the problem is whatever is causing the distress. When working to support a ND person who is exhibiting distressed behaviour, our role is not to stop the behaviour, it is to work to understand what is happening beneath the surface that is resulting in that behaviour.

Sometimes the distress behaviour can be physically harmful and/or dangerous. In that situation, whether the harm is to themselves or to others, the primary goal is to ensure safety. This can mean providing temporary alternative options for the ND person that are safer than the original behaviour but are maybe not the full end goal. For example, when people self-harm by cutting, the issues driving that are likely complex and will require concentrated and long-term work; it will not be fixed by saying "cutting is dangerous" and leaving it at that. In that case, we must assess the most immediate dangers to mitigate potential harm as we work towards the bigger end goal of being able to manage perceived threats to self without cutting. This could be ensuring there are always clean and sterilised razors available, as well as iodine and bandaging; responding to recent cutting without shaming or criticism; trying alternatives that don't actually cut but still provide a similar sensory experience; etc.

When distressed behaviour takes the form of posing a physical safety risk to others, such as younger siblings, parents, or peers, our immediate goal is again to mitigate risk while also working to understand the stressor that is resulting in that behaviour. Many families of ND young people experience dangerous and violent behaviour from their ND children, not because their children don't love them or because they wish to cause them harm, but because their 'Emergency button' is ALWAYS pushed and they are constantly in a state of hypervigilance, survival, and unyielding distress. There are organizations (such as Newbold Hope) that can help families to come together with others in a similar situation, to ensure they don't feel alone, and to help them learn to manage this behaviour in safer ways for everyone involved.

## In more detail...

Every human experiences situations that push them beyond their comfort level, that challenge them, and that create internal conflict. It is a normal part of learning and growing. But we don't expect every human to always be capable of learning and growing, do we? We all have periods of time, whether that's moments in a day or months in a year, where all of our energy has to go to something else. In those moments, we need the things around us to be as stable, predictable, and non-threatening as possible.

For example, say a person is getting married; would the morning of their wedding be a good time to start learning another language? Almost certainly not. Even though it is a 'happy' reason to be under stress, the situation would place so many demands on their cognitive functioning that there would be no extra capacity for taking in or remembering something new.


And when the situation challenging us is a perceived threat to our safety, the impact on cognitive function is even more significant. Remember: once the amygdala identifies a threat and that 'Emergency button' is pushed, our bodies are consumed with surviving and reasoning is suppressed. That doesn't just make it an ineffective time to try to learn, it makes it an impossible time to learn.

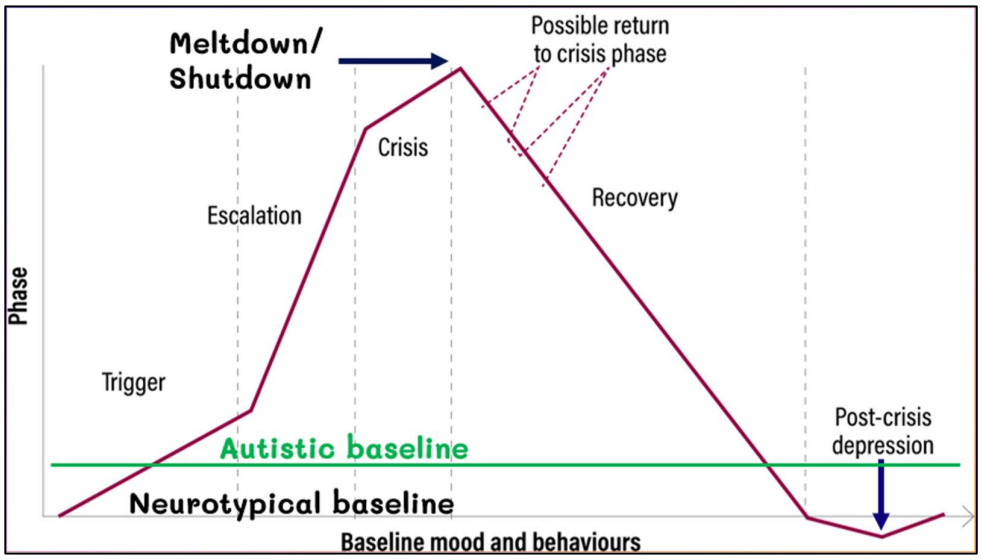
### The Assault Cycle

A useful model for understanding the stages of this process and its impact on the body is the Assault Cycle. It is a visual representation of the stages someone goes through that result in external distressed behaviour.

#### Baseline

This model (next page) shows that baseline moods and behaviours are not the same for NT and ND people; it specifies it as an Autistic baseline, but it could just as easily say 'neurodivergent baseline.' The important takeaway is that due to the differing internal and external needs of ND people, they are always having to cope with things that add stress to them. This means they start each day already part way up the Assault Cycle;

and, of course, this means that they are already part way to reaching crisis before anything else even happens.




### Trigger

A trigger is anything that further challenges a person's ability to cope with the demands already placed upon them. In a typical morning, for example, some possible triggers could be: the alarm clock doesn't go off; the hot water heater is broken when you wake; the milk has gone bad so you can't have tea; and so on. Anyone facing those challenges — especially if they all happened in one morning — would quickly find themselves heading towards Crisis.

### Escalation

For ND people, who are already starting hire up in the cycle, the trigger and escalation period can happen pretty quickly as one stressor compounds another. For example, waking too late could mean either foregoing the normal morning routine and thereby feeling unsettled all day or getting in trouble for being late because no one appreciates the importance of the morning routine. Foregoing it could then mean sensory discomfort, cognitive roadblocks, situational non-speaking, and so on. It snowballs fairly quickly. Each threat pushes that Emergency button again and pushes the person closer to full survival response.

It is only during Escalation that steps can be taken to prevent Crisis. This is the window where it is still possible to step in and help to De-escalate by removing some of the pressures and/or helping a ND person to mange these pressures in a way that doesn't feel so overwhelming. De-escalation depends upon:

- recognising the signals that they're moving up the Assault Cycle
- knowing what to do in response to the signals
- having the space, time, and understanding to enact the plan

### Crisis

Once Crisis is reached, there is no turning back — the full cycle will be gone through before someone returns to their Baseline. This is when Meltdown (Fight/Flight) or Shutdown (Freeze/Fawn) will occur. Meltdown is an external expression of the distress; Shutdown is an internal expression of it. Many people think meltdowns are worse, that because shutdowns are quiet, they're not as bad. But both are equally harmful to mental wellbeing.

During this phase, adrenaline and cortisol flood the body to create the physiological changes (increased heart rate, rapid breathing, muscle tension, sweating, possibly vomiting or incontinence) that were once useful in keeping humans alive. The prefrontal cortex and higher decision-making functions are suppressed. It becomes impossible to make a logical or reasonable choice.

This is the most important thing to remember — the behaviour witnessed from someone in meltdown/shutdown is **not a choice** being made. It is the work of the nervous system trying to keep the person alive, and they are just along for the ride.

### Recovery/Possible Return to Crisis

After a single stressful incident, adrenaline and cortisol take about 20-60 minutes to dissipate, keeping a body ready to respond to additional threats. This means that, even once a meltdown/shutdown has ended and Recovery has begun, the chance of being re-escalated into crisis is significantly high.

The changes that the stress hormones create (rapid breathing, increased heartrate, etc.) exhausts the body. After the meltdown/shutdown has passed the peak, ND people commonly feel incredibly sleepy, emotionally drained, and unable to think clearly. They also all begin to feel shame, embarrassment, and self-critical for having behaved in ways they never would have chosen to behave.

During this Recovery period, there is no value in discussing the trigger, the ensuing escalation into crisis, or the resulting behaviour in meltdown/shutdown because the amygdala is still in control. Any attempt at this point to 'talk through' what happened will only achieve re-escalation to another meltdown/shutdown.

### Post-crisis Depression

The Post-crisis Depression is a universal ND experience. It happens at the end of Recovery, when the adrenaline and cortisol are mostly gone and the reasoning brain is no longer suppressed and when realisation of what occurred hits the ND person. The shame, embarrassment, and emotional and physical exhaustion combine to result in self-loathing and self-chastisement, bringing a person's mood and self-esteem well below their normal baseline.

This is a time for external validation, comfort, and safety, a time for connection and compassion instead of correction, a time for re-establishing a sense of safety.

### Return to Baseline

Following the Depression, given that nothing has re-triggered a sense of threat, the person will slowly return to their normal baseline. This is the phase during which we can have discussions about what happened, what caused it, and how we can plan to manage things differently the next time. But these discussions must not be discipline-centric or shaming/blaming. Remember, none of the distressed behaviour that was witnessed was a choice, so none of it should be held against the person.

### Long-term Impact

Going through the Assault Cycle takes a significant toll on the body. The stress hormones have an impact on both physical and mental wellbeing, and it is not a minimal one. Those impacts are hard enough to manage when a person reaches peak distress

only occasionally; when someone is up and down the Assault Cycle several times a day, every day (as many ND people are), the entire body inevitably bears scars from it.

**Consider this**

**If this was your experience every day:**

**What would your behaviour look like to others?**

**When would you be able to learn and grow?**

**How would you know when you are truly safe?**

Prolonged and/or chronic exposure to stress events results in adrenaline and cortisol remaining in the system for hours – even months – meaning that the body and brain never really enter Recovery. If the physiological and mental toll after only one event is to be confused, sleepy, and harshly self-critical, just imagine the impact of days, weeks, months, spent in that high-vigilance and reactionary survival state. The heart constantly racing, the body constantly ready to fight or freeze or run away.

## Support During Distress

The support an individual will need when they are in distress is as unique as they are, but there are some relatively universal truths that can be applied.

**Overall, the approach taken should:**

- Be centred in meeting the person's needs, not enforcing compliance
- Encourage co-regulation
- Prioritise connection over correction
- Remove barriers to reaching Recovery
- Validate their internal experience



Certain specific regulation techniques can also be helpful. These include:

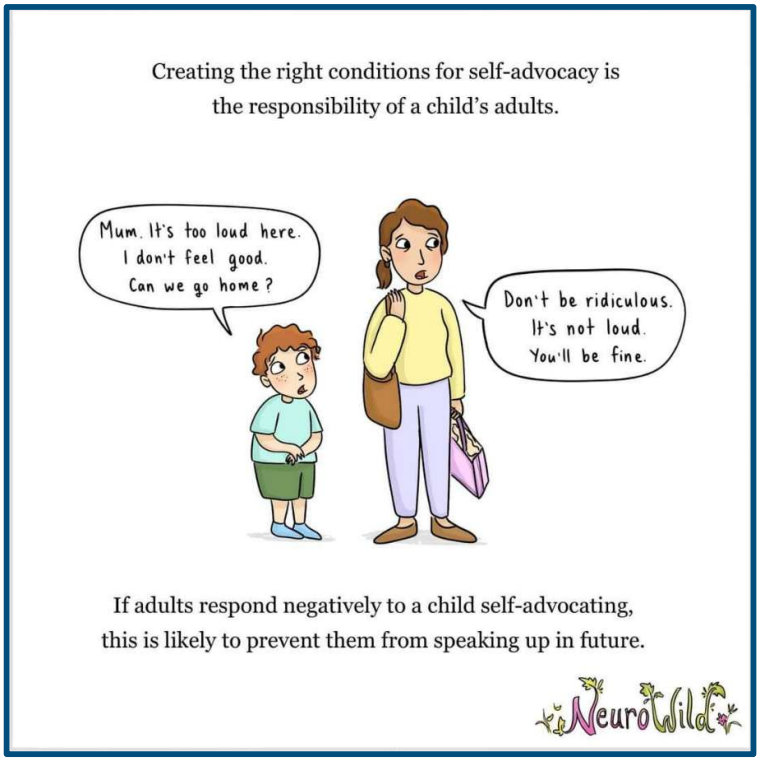
| Regulation Techniques – Sensory | | | |
|---|---|---|---|
| **Auditory** | NC headphones | Earplugs | Favourite song/sound |
| **Interoception** | Burrow & hide | Eat | Drink |
| | Deep interests | Soft blanket | Cool pack on forehead |
| **Movement** | Climbing | Running | Pacing |
| | Swinging | Stamping | Flapping |
| | Jumping | Rocking | Monkey bars |
| **Olfactory/** | Air freshener | Perfume | Lavendar spray |

| | | | |
|---|---|---|---|
| **Taste** | Favourite taste | Crunchy food | Nose plugs |
| **Proprioceptive** | Deep pressure | Squeezes | Weighted blanket |
| | Firm stroking | Punching pillows | Squeezing fingertips |
| | Blanket burritos | Stimming | Gentle scratching |
| **Vestibular** | Rocking | Swaying | Spinning |
| | Tipping upside down | Dancing | Swinging |
| **Visual** | Light projector | Put on sunglasses | Waterfall machine |
| | Book of happy pictures | Lava lamp | Favourite video on loop |

## Support After Distress

The immediate after care should be focused on providing opportunities for rest, hydration, validation, and acceptance. Once enough time has elapsed – which might not be for a couple of days – purposeful discussions can be broached about what happened, the impact it had, what was helpful during it, and what was less helpful. Those discussions should **not** be focused on blaming or shaming, or on telling an individual what they did 'wrong.' The focus should be on helping the individual get a better understanding of their internal experience (physical, emotional, and mental) leading up to, during, and after the distress. It is likely that those discussions will need to be had more than once, at different times and in different ways; building self-awareness is a lifelong event, not a one-time thing.

Modelling self-awareness through sharing your own experiences with distress and how you manage it is a key tool in validating their experience and confirming that distress happens to everyone. By helping ND people develop an understanding of themselves, to identify their triggers and the signs that they are starting to escalate towards crisis, we empower them to self-advocate for their needs and to value their innate way of being.



# Sources & Resources:


Greene, Dr. Ross. https://livesinthebalance.org/

Hallett, N 2018, 'Preventing and managing challenging behaviour', Nursing Standard, vol. 32, no. 26, pp. 51. https://pure-oai.bham.ac.uk/ws/files/47719890/Hallett_Preventing_and_managing_Nursing_Standard_2018.pdf

Harvard Health Publishing, https://www.health.harvard.edu/staying-healthy/understanding-the-stress-response

Leicestershire Partnership NHS Trust, https://www.leicspart.nhs.uk/autism-space/health-and-lifestyle/meltdowns-and-shutdowns/

NeuroWild, https://www.neurowild.com.au/

- Self-advocacy support, https://www.neurowild.com.au/product-page/self-advocacy-support
- I might need, https://www.neurowild.com.au/product-page/i-might-need-self-advocacy-poster-a4-a3

Newbold Hope, https://www.newboldhope.com/

Whelan, Barry. The 5 Stages of the Assault Cycle, https://behaviour101.com/2020/09/23/the-5-stages-of-the-assault-cycle/