

Twitter Thread by NortherlyRose ■



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A #thread about #autistic #meltdown. One of the reasons I can suddenly and unexpectedly become overwhelmed is the difficulty I have monitoring how distressed I am. The tipping point when things kilter out of control is as much a surprise to me as it is to other people.

#autism

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Emotional regulation is difficult when I'm not fully aware of how emotions are making me feel, until overwhelmed. And for me the 'why' is always important. My mind wrestles with possible explanations for feelings that are strong but confusing.

#AllAutistics

#ActuallyAutistic

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Like many #autistic people I find that past #trauma often intrudes on the present. Analysis and recognition of patterns is how I best understand human behaviour. Something happening now that maps onto ways in which I was bullied previously can be utterly terrifying.

#bullying

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The way I process things as an autistic person means that there's often a lag in making sense of what's going on. The thing that completes the picture and tips me into #meltdown can be so slight as to seem ridiculous. The proverbial straw that breaks the camel's back.

#autism

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For me #autistic meltdown is a huge release of energy. A catharsis so intense it sometimes feels unsurvivable. The aftermath is the complete opposite. Total physical and mental exhaustion. Since my #autism diagnosis I've become far more analytical about why I was overwhelmed.

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When I got my #autism diagnosis I was given a diagram of a wall made of blocks. Each block represents something stressful. There's a maximum height the wall can reach before everything comes crashing down. Meltdown avoidance has a

lot to do with emotional regulation.

#autistic

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The annoying thing about being #autistic is that good stuff counts as stressful too. Something that excites me, and gives me sensory pleasure, adds to the height of the wall. I don't like routine, but if I deviate from it too much, additional stress makes the wall higher too.

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It's difficult to write about #meltdowns because of the feelings of shame they induce. A loss of control is a deeply traumatic experience. We're often acutely aware of the effect on other people. People we love and trust often witness a reaction to things happening elsewhere.

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A child at school may hold things together all day with extreme difficulty. All the tensions and stresses accumulate without release. In the safety of home things can suddenly explode without apparent justification. The trigger for #meltdown often seems totally insignificant.

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It's the same for autistic adults at work. We get better at controlling our reactions and suppressing emotional responses but that doesn't make the tensions go away. We are still affected by sensory and social sensitivities. We learn to feel overwhelmed without showing it.

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Another diagram I was given when I got my #autism diagnosis was the 'emotional arousal curve'. Basically, once you've tipped over the edge and gone into #meltdown it takes time to calm down. If something happens during the calming down phase it can tip you back over the edge.

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I often underestimate how long it takes me to calm down after having a meltdown. I also overestimate how well-equipped I am to deal with a challenging situation. I can research, plan and research what I should do, but sticking to the plan is impossible if I get overwhelmed.

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Autistic people are often fiercely independent, probably due to the fear of being misunderstood. Asking for help can feel dangerous. How can we explain what's going on when we don't understand it ourselves? But if we struggle on without assistance things may simply get worse.

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Autistic people often feel like we should be able to cope without assistance, that it's a question of trying harder, being less sensitive, a change in mindset. But we're living in a predominantly neurotypical world; it seems obvious we'll need some kind of help to survive.

14/

Help and support can come from other #autistic people (family, friends, therapists, strangers we connect with on Twitter). It can also come from #allies; allistic people who see #autism not as a defect that needs to be cured, but as a different way of experiencing the world.

15/

Recently, when I finally told my partner I needed his help, I spoke quietly and he was facing away so didn't hear me. It took me another three days to ask for his help again. It might have taken me three years. It's even harder to ask for help from people we know less well.

16/

Attempts to get help in the past may have gone badly making it difficult to trust people enough to communicate our difficulties. We're aware that crises may seem hard to comprehend from a neurotypical perspective. We may be seen as emotionless or as far too emotional.

#autism

17/

When I analyse meltdowns several days afterwards I can see there was a build up of tension that needed to be defused before it got out of control. I wish I had some kind of gauge to look at, an indication of how difficult things are getting, an early warning signal.

#autism

18/

Sensory sensitivities sometimes provide this early warning. If things sound too loud and smell too strong and feel too itchy it's a sure sign I'm feeling stressed. But I need to consciously process this disturbance of my equilibrium and take some action to rebalance things.

19/

In the same way that I don't realise I'm thirsty until I consciously think about it, I need to check in with myself regularly to review stress and distress levels. I'd no idea how tough things were for me at the moment until I looked at this chart■

#ActuallyAutistic

#autism

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Adapted from: Watson, P., Gist, R., Taylor, V. Evlander, E., Leto, F., Martin, R., Vaught, D., Nash, W.P., Westphal, R., & Litz, B. (2013). Stress First Aid for Firefighters and Emergency Services Personnel. National Fallen Firefighters Foundation.

There are things I can do to recover quicker from an autistic #meltdown, but shame and guilt make self care seem like an undeserved indulgence. And messages from the past can be hard to let go of. We may be left feeling selfish, spineless and childish, as if we are to blame.

21/

Being autistic in non-autistic places can be challenging and exhausting. It's almost inevitable that things will get too much for us at times. The fact that our struggles are largely invisible makes things more difficult. It's very hard to explain what being autistic is like.

22/

At the root of many difficulties #autistic people face is low #SelfEsteem. It's hardly surprising when you think how #autism is portrayed, but it's more than that. For 58 years no one knew I was autistic, including me. But I still felt slightly out of tune and out of place.

23/

One reason so many autistic people end up traumatised is we get a constant stream of feedback that the way we think, feel and act is slightly odd, slightly wrong. Sometimes this is unconscious. People don't know they're doing it to us. At other times it's deliberate bullying.

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One antidote to being bullied is good self esteem. If we respect ourselves we're less likely to be targeted. Another is assertiveness; refusal to accept abusive behaviour. Programmes that train autistic people to be compliant are dangerous given the risk of us being abused.

25/

Meltdowns help us monitor what's happening and recognise when we need help. This is a painful issue for many autistic people who reach out to find help isn't there. Services that should assist us may reject us or minimise our difficulties because they don't understand autism.

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To me regular meltdowns mean something in my life is out of step and needs to be fixed. I don't believe this is an inevitable part of being autistic. The exhaustion that follows can be totally debilitating. Repeated meltdowns, or trying to suppress them, can lead to #burnout.

27/

The wider context for everyone currently involves #COVID19. There are additional pressures relating to risk, rules and new ways of doing things. Some of us may experience relief because there are fewer social invitations. Working from home can be both a blessing and a curse.

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I can lower my anxiety about the risk of COVID infection at work by wearing a mask, but sensory issues (heat, breathlessness, texture) create a different kind of stress. Clear boundaries between work and home life can be a protective factor, but sometimes these get blurred.

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#Autistic #meltdowns are often caused by a multitude of factors including past #trauma. They're preventable but not easy to predict without hindsight. Checking in with ourselves can alert us to impending #crises, but we may need trustworthy help to resolve things properly

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