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#Thread

Living with meltdowns.

A personal, very late diagnosed, autistic perspective.

#autism
#AllAutistics
#ActuallyAutistic

1/

Before my autism diagnosis I had occasional emotional outbursts. These generally happened at home after a sustained period of pressure at school or at work.

When I discovered I was autistic I realised that these were actually what people call meltdowns.

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Getting intensely upset was a bit of a family thing. Sudden shouting and throwing of things, with resumption of peace and calm afterwards, wasn't that unusual.

In fact we had a kind of mantra that it was much better to express our emotions than to keep them bottled up.

3/

It was hard to gauge my own emotions against other people's but by any measure I felt things incredibly intensely.

As a child the injustice of being told off for something that wasn't my fault burned into me. I sobbed until the tears stang my face and I could hardly breathe.

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But suppressing emotion was necessary for me to survive in the outside world. That's partly what led to uncontrolled outbursts of feelings at home.

I melted down because there was no justice and I'd been misunderstood. I wasn't using emotion as some kind of bargaining tool.

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A significant factor was the strain of behaving in socially acceptable ways. I was faced with constantly changing scenarios where different rules applied.

It was only at home that I felt truly relaxed, even there I risked getting into trouble. The answer was to be very good.

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My sensory world was rich and delightful. Burying my face in a rose or watching swirling petrol patterns on a puddle induced feelings of ecstasy.

On the flip side I was easily overwhelmed by my senses. The world was too noisy and smelly. Clothes itched and hair brushes hurt.

7/

Fork theory says that it's not just having enough spoons of energy that is important. We also have to consider all the sharp bits that are sticking into us.

Being teased, not having the right socks to wear, worrying about school exams, lack of sleep - these were all forks.

8/

As I got older life got more complicated. The problems that I had as a teenager couldn't be soothed away with a cuddle from my mum.

I often couldn't articulate what the problem was. And attempts to fit in with peers who were so different left me feeling even more isolated.

9/

Eventually things came to a head and I had a huge meltdown at home when I was 17.

I was in a kind of trance, banging a kitchen chair onto the wooden floorboards repeatedly. But the eruption of energy inside me needed more of an outlet. I felt the urge to break something.

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I picked up a large box of eggs and went out into the garden. I threw them at the back wall of the house where they smashed and dribbled down.

This became an apocryphal family story. Boyfriends were shown the marks on the brickwork as a jokey warning about my volatility.

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This episode scared my mother and frightened me. It was a significant enough event for my dad to be summoned home from work to speak to me.

We shared our home with a psychotherapist at the time. She saw the egg-throwing incident as a cathartic expression of teenage angst.

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A pattern emerged whereby I'd become extremely upset about certain events. In many people's eyes this might have been seen as overreacting.

My anxiety and sensitivity levels were so great that I very easily became overwhelmed. In public this was mostly tightly controlled.

13/

Because I didn't know I was autistic I had no way of explaining what was happening other than immaturity, lack of self control, and selfishness.

I felt like a bad person. I tried my best to suppress my emotions but they just made themselves known through physical symptoms.

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The most obvious manifestation of my distress were intense health concerns. Some of these were a bit unusual. A heightened sense of smell made me think something was wrong with my body. The GP found nothing wrong.

Even now, decades later, this might not flag up autism.

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There's no doubt that meltdowns had a very destructive effect on my personal relationships. It's not surprising that other people found it alarming if I suddenly got acutely distressed.

The lack of an autism diagnosis meant they had no frame of reference for this either.

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Once I left the protection of my birth family, where my differences were understood if not named, I felt very exposed.

I learned to manage my own mental health. I overdid things, then suffered the consequences, but most people were unaware of the extent of my difficulties.

17/

It feels shameful to be an adult and to behave in ways that most people regard as childish. It feels dangerous to want to be destructive and to feel the urge to flee.

But looking back I see these reactions as understandable and proportionate given what was happening to me.

18/

Emotional regulation isn't just to do with my internal thoughts and feelings, it's a lot to do with the outside world.

Trauma, meltdown and burnout are inextricably linked for me. Exposure to tragedy, unkindness and abuse caused cumulative harm. And eventually I broke down.

19/

Breaking down coincided with discovering I was autistic. Looking back at my life through this lens enabled me to make sense of things.

When I was threatened by abusers their actions triggered every similar episode that had ever happened to me. I was completely overwhelmed.

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Being overwhelmed could lead to shutdown too. Sometimes the whole world slowed and things felt unreal. I stood apart from the situation I was in.

Looking back at the most distressing episodes I can recall some things in minute detail. But in other places there are gaps.

21/

Something rather strange happened after my autism diagnosis, I actually started to have more regular meltdowns.

This was rather unexpected. I thought the sheer fact of knowing I was autistic would make a much bigger difference.

A number of things probably explain this.

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I was in burnout at the time I was diagnosed autistic. My energy levels and ability to regulate my emotions were extremely low.

Being assessed had opened up a confusing lifetime of experience that couldn't simply be packed away. I was going through things in my mind.

23/

I was reluctant to adopt the more cautious, less adventurous lifestyle the psychologist recommended.

Other autistic people warned me to expect an emotional roller coaster and take "baby steps".

Contrary to this advice I took on a full time job which involved commuting.

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Coming very close to having a full-blown meltdown in the office finally persuaded me to change direction.

I'll never know how my part-time greengrocery job would have worked out if we hadn't had a pandemic.

I'd probably be there now, bagging up potatoes and selling fruit.

25/

My next part-time job was wonderful. I got paid to line things up and do repetitive tasks.

It was a more controlled environment than the shop but my anxiety about Covid aerosol transmission slowly peaked.

Working is a double edged sword bringing both benefits and tensions.

26/

I hope to start an even more part time job soon, one I'm well-qualified for.

Now I'm openly autistic I have to prove my fitness in a way I didn't have to before.

But this isn't unreasonable as I have experienced stress at work. I need to be sure it's a good career move.

27/

I want to live a peaceful life, so I need to be sure that work won't disturb my home life by contributing to meltdowns.

And my relationship needs to be protected. Even in a challenging employment market, it would be far easier to find another job than to find love again.

28/

Strange things happen in meltdowns. Like not being able to speak, or becoming extra articulate.

Screaming and hitting my head are alarming, but it’s worse if I say hurtful things.

Eggs can be washed off walls, but the damage done by what’s said can’t always be repaired.

29/

When I worked in mental health units and prisons I met people like me.

I’ve had meltdowns without being sectioned, sedated or imprisoned.

Privilege protected me.

We mustn’t forget the many autistic people being detained in appalling conditions.

They need our help.

30/ end