

ADULT AUTISM IN DAILY LIFE · 9.10

Autism and Identity: Who You Were, Who You Are, Who You Get to Be

A late autism diagnosis is, for many adults, the most significant identity event of their adult life. It reframes the past, opens up the present, and changes what the future looks like. The reorganisation takes time and follows a recognisable shape.

FOR

Late-diagnosed autistic adults

AUDIENCE AGE

18+

REVIEWED

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PART OF

The NeuroFX resource library

IN SUMMARY

Autism and Identity: Who You Were, Who You Are, Who You Get to Be

What the literature describes

- **A recognisable arc, not unusual.** Qualitative studies (Leedham 2020 on women diagnosed in middle to late adulthood, Hickey 2018 on older autistic adults, Stagg and Belcher 2019 on practical reorganisation) describe the same shape across cohorts: recognition, relief, reorganisation of the past, grief, identity reconstruction, practical changes, often a new community.
- **The four common phases.** Reframing (first weeks to months): a flood of memories viewed through the new lens. Grief: often substantial, for the missed support and the years of masking. Reorganisation (months to years): practical changes to work, relationships, routines. Integration (longer-term): the diagnosis becomes one part of who you are rather than the lens through which everything is filtered.
- **Grief is normal, not pathological.** Common shapes: grief for missed support, grief for the years spent masking, grief for relationships lost or never built, grief for the version of life that might have been. A reasonable response to learning that significant difficulty had a name for decades and you carried it without it.

What helps

- **Read autistic adults, not just clinical texts.** Clinical literature explains the diagnostic frame. Writing by autistic adults explains what the identity work actually feels like. The mix of both is more useful than either alone.
- **Find other late-diagnosed autistic adults.** Online communities, local groups, peer support. The single most-mentioned helpful thing in the qualitative studies. Mutual recognition is regulating; you have not been alone in the experience.
- **Be cautious about over-disclosure in the first six months.** The reframing phase is intense and the temptation to disclose to everyone is strong. Some disclosures land well; others do not. The decision is irreversible. Take stock before making it permanent in every context.
- **Make changes slowly and deliberately.** Large changes to work, relationships and routines made fast in the first months are sometimes regretted. Smaller deliberate changes layered over time tend to hold up better. The reorganisation phase rewards patience.
- **Distinguish autism from related but separate things.** Anxiety, depression, burnout and co-occurring ADHD often surface around late diagnosis. These are their own clinical questions and respond to their own treatments. Autism is the frame; the other things still need addressing.

Where the integration lands

- **The diagnosis is information, not a personality transplant.** The person you were before the diagnosis is the same person you are after. The diagnosis adds a frame for what was already true; it does not replace your sense of self.
- **The honest position is between two extremes.** Neither 'this changes nothing' nor 'this changes everything'. Most late-diagnosed autistic adults find a landing somewhere between, where the diagnosis informs decisions without dominating them.
- **Where to get support.** A therapist with experience of autistic adults can help with the identity and grief work. The National Autistic Society publishes post-diagnostic guidance. Where autism has not yet been formally assessed, NeuroFX offers private adult autism assessment as a parallel route to the NHS pathway.

WHEN TO SPEAK TO A PROFESSIONAL

Speak to your GP if mental health is significantly affected by the post-diagnostic period. A therapist with experience of autistic adults is often the right professional for the identity and grief work specifically. Private adult autism assessment with a CQC-registered provider is a legitimate parallel route where the NHS wait is the gap. Seek urgent help via 111, 999 or A&E for any acute mental health crisis; the Samaritans helpline is 116 123 (free, 24 hours).

SOURCES

Lancet Commission on Autism (Lord et al. 2022); Leedham et al. 2020 (Autism); Hickey et al. 2018 (Autism); Stagg and Belcher 2019; Hull et al. 2017; National Autistic Society

NEXT STEPS

Speak to NeuroFX

Private ADHD and autism assessment for adults and children aged 6 and upwards.
CQC-registered. Bedford Consulting Rooms, 4 Goldington Road, Bedford MK40 3NF.

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