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## **Autistic burnout**

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The Research Team are unable to ensure that the information listed below provides an accurate & up-to-date snapshot of these matters

#### **Research questions:**

What are the symptoms of autistic burnout? How long do symptoms typically last and how are symptoms managed? What does recovery look like after autistic burnout?

What are the usual causes or triggers of autistic burnout?

How does autistic burnout differ from occupational burnout, stress, depression or anxiety in autistic or non-autistic people?

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# Research paper

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### 2. Summary

Autistic burnout is the experience of exhaustion brought on participating in activities or being in environments that are not accessible for autistic people. It has long been recognised by the autistic community as a feature of autistic people's experience. However, the earliest formal study sourced that focusses on autistic burnout was published in 2020.

Since then, a handful of preliminary studies have focussed mainly on defining the concept, differentiating it from similar constructs, understanding how autistic burnout is experienced by people with autism and establishing reliable outcome measures.

Symptoms described in the literature include fatigue, cognitive difficulties, loss of skills and sensory intolerance. Triggers described in the literature include the effort of suppressing or covering up autistic traits or behaviours, adopting neurotypical traits or behaviours, frequent social interaction and sensory overstimulation. The duration of autistic burnout is unclear. Episodes reported in the literature may be as short as a few hours or as long as a few years.

The relations between autistic burnout and other constructs are unclear. Autistic burnout shares similarities with depression, anxiety, chronic stress and occupational burnout. Researchers have observed that autistic burnout is described by those who experience it as having features uniquely related to their autism, which often differentiates autistic burnout from other more general conditions. More research is required to clarify the differences between these concepts.

The only published study focussed on treatment or management approach is a single case report describing successful use of stimulant medication to resolve symptoms of burnout in a young adult with autism. Some management strategies are reported by people with lived



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experience of autistic burnout. These include withdrawing from social activities or inaccessible environments, focussing on special interests and requesting reasonable accommodations to make environments more accessible.

### 3. Current state of research

The earliest formal study sourced that focusses on autistic burnout was published in 2020 (Raymaker et al, 2020). Most research to date is qualitative, focussing on the burnout experiences of autistic people or attempting to understand or define the concept of autistic burnout. Current research examines symptoms, triggers and management strategies mostly through survey or interview-based studies (Arnold et al, 2023a-b; Øverland et al, 2022; Mantzalas et al, 2022a-b; Higgins et al, 2021; Raymaker et al, 2020). One quantitative observational study examines the relationship between autistic burnout and escapist behaviour (Pyszkowska et al, 2023).

At present, there are no validated measures of autistic burnout (Arnold et al, 2023b). Some research exists describing occupational or professional burnout experiences for people with autism, though this is intended to be a construct distinct from autistic burnout (Watanabe & Akechi, 2023; Tomczak & Kulikowski, 2023; Cage & McManemy, 2022).

Only one study was found that proposes an underlying mechanism responsible for autistic burnout (Mahony & Ryan, 2022). In this review paper, the authors suggest susceptibility to autistic burnout may be a result of early life stress or chronic adolescent stress.

More research exists focussing on phenomena overlapping or contributing to autistic burnout, such as depression, fatigue, masking, accessibility of social and occupational spaces. For example, Zhuang et al (2023) review 58 studies linking camouflaging or masking by autistic people with stress, depression, anxiety, and burnout. The literature on autistic burnout takes masking or camouflaging as central to the definition of autistic burnout (Arnold et al 2023a; Higgins et al, 2021; Raymaker et al, 2020).

### 4. What is autistic burnout?

The idea of autistic burnout originated from within the autistic community. It describes a complex experience of exhaustion brought on by the effort of suppressing or covering up autistic traits or behaviours, adopting neurotypical traits or behaviours, or frequenting inaccessible places or places not designed for autistic people (Deweert, 2020). The concept is intended to be distinct from, but analogous to, occupational burnout (Tomczak & Kulikowski, 2023; Cage & McManemy, 2022; for more on the relationship with occupational burnout, refer to 4.4 Autistic burnout and other conditions).

#### 4.1 Definition

There are two definitions of autistic burnout that are used in the research literature:





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**Raymaker et al:** Autistic burnout is a syndrome conceptualized as resulting from chronic life stress and a mismatch of expectations and abilities without adequate supports. It is characterized by pervasive, long-term (typically 3+ months) exhaustion, loss of function, and reduced tolerance to stimulus (2020, p.133).

**Higgins et al:** Autistic Burnout is a severely debilitating condition with onset preceded by fatigue from camouflaging or masking autistic traits, interpersonal interactions, an overload of cognitive input\*, a sensory environment unaccommodating to autistic sensitivities and / or other additional stressors or changes. Onset and episodes of autistic burnout may interact with co-occurring physical and / or mental health conditions. The following criteria must be met:

- Significant mental and physical exhaustion
- Interpersonal withdrawal.

With one or more of the following:

- Significant reduction in social, occupational, educational, academic, behavioural, or other important areas of functioning.
- Confusion, difficulties with executive function\*\*, and/or dissociative states.
- Increased intensity of autistic traits and/or reduced capacity to camouflage/mask e.g. increased sensory sensitivity, repetitive or stimming behaviour, difficulty engaging or communication with others."

The condition is not better explained by a psychiatric illness such as depression, psychosis, personality disorder, trauma- and stressor-related disorders.

Extended or chronic episodes of autistic burnout may be preceded by brief or intermittent episodes (2021, p.26).

Raymaker et al (2020) based their definition on 19 interviews with people who have experienced autistic burnout as well as thematic analysis of 19 online sources, including blogs and social media posts. Higgins et al (2021) base their definition on a Delphi consensus process including 23 participants with lived expertise of autistic burnout.

There is overlap between these definitions and they may be compatible with one another. Raymaker et al (2020) refer to "chronic life stress and a mismatch of expectations and abilities", whereas Higgins et al (2021) expand on this by specifying stressors or inaccessible situations (masking, social situations, sensory or cognitive overload). The most significant difference in definition relates to the timeframe. Raymaker et al (2020) reserve the diagnosis for symptoms lasting longer than three months. In contrast, Higgins et al (2021) found people who have experienced autistic burnout reported widely varied duration, from hours or days to months or years. Arnold et al (2023b) argue that there is not currently sufficient information to determine the typical duration of autistic burnout.



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Available research has not formed a consensus on the best definition. Mantzalas et al (2022b) endorse the definition from Raymaker et al, though without considering the definition from Higgins et al. An Australian study of 141 people who had experienced autistic burnout found that most participants strongly endorsed the definition from Higgins et al (Arnold et al, 2023a). Of note, the studies reported in Higgins et al (2021) and Arnold et al (2023a) were conducted by the same team of researchers.

### 4.2 Symptoms

Studies agree on some core symptoms of autistic burnout including exhaustion, reduced cognitive function, social withdrawal, and increase in autistic traits (Arnold et al, 2023b; Mantzalas et al, 2022b; Higgins et al, 2021; Raymaker et al, 2020). Symptoms identified as features of autistic burnout also include:

**Physical symptoms:** fatigue, exhaustion, sleep problems (Arnold et al, 2023a; Mantzalas et al, 2022a; Higgins et al, 2021; Raymaker et al, 2020; Deweert, 2020)

**Cognitive symptoms:** confusion, dissociation, loss of executive function (Mantzalas et al, 2022a; Higgins et al, 2021; Raymaker et al, 2020)

**Emotional symptoms:** difficulties with emotional regulation, short temper, depression, anxiety, emotional numbness, suspicion or loss of trust in others (Mantzalas et al, 2022a; Higgins et al, 2021; Raymaker et al, 2020)

**Other psychological symptoms:** dissociation, suicidality, lower tolerance for sensory stimulus (Mantzalas et al, 2022a; Higgins et al, 2021; Raymaker et al, 2020)

**Behavioural symptoms:** increased intensity or frequency of self-stimulating behaviour, increased repetitive behaviours, avoiding social situations, escapist behaviour (Pyszkowska et al, 2023; Mantzalas et al, 2022a; Higgins et al, 2021; Raymaker et al, 2020; Deweert, 2020)

**Functional symptoms:** loss of social skills, reduced capacity or desire for social interaction, inability or reduced ability to speak or communicate, loss of daily living or self-care skills, increased difficulty of work or school; reduced quality of life (Vinayagam et al, 2023; Arnold et al, 2023a; Mantzalas et al, 2022a; Øverland et al, 2022; Higgins et al, 2021; Raymaker et al, 2020)

There is some disagreement about whether certain symptoms are features of autistic burnout or of co-occurring depression. For example, Raymaker et al (2020) note that sleep problems and emotional numbness or inability to feel pleasure are features of depression that are outliers in autistic burnout. In contrast, Higgins et al (2021) cites sleep problems and emotional numbness as characteristic features of autistic burnout.

There is also some ambiguity around the behavioural symptoms associated with autistic burnout. What are described as symptoms may also be coping mechanisms or management strategies. Pyszkowska et al (2023) find that autistic burnout is associated with self-



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suppressing escapist behaviour in the form of time spent playing videogames. However, the authors note that this observation is in line with some autistic people's preferences for time outside of social situations, special interests or hyperfocus. Researchers also note that increase in self-stimulating behaviour and social withdrawal may be appropriate management strategies to address the symptoms of autistic burnout (Mantzalas et al, 2022b; Higgins et al, 2021; Raymaker et al, 2020; for more detail refer to <u>5. Management</u>).

#### 4.3 Triggers

Researchers suggest that autistic burnout is a result of the accumulation of life stressors and exacerbated by a lack of supports or reasonable accommodations. The stressors identified in the literature generally relate to the added effort of actively engaging in inaccessible environments. This is characterised as a lack of fit between the needs and preferences of an autistic person and the environments that form the backdrop of everyday social and occupational activities (Arnold et al, 2023a-b; Mantzalas et al, 2022a-b; Øverland et al, 2022; Higgins et al, 2021; Raymaker et al, 2020; Deweert, 2020). Stressors that may precipitate an episode of autistic burnout include:

**Masking:** suppressing autistic behaviours in order to function more easily in non-autistic environments

**Sensory overload:** acting in environments that are not aligned to the autistic person's sensory needs

**Interpersonal engagement:** participating in activities that demand a high level of social interaction

**Task design:** performing tasks at school, work or in social activities that are inaccessible or not aligned with the autistic person's cognitive or physical needs or preferences.

#### 4.4 Autistic burnout and other conditions

Researchers observe that characteristics of autistic burnout overlap with occupational burnout, stress and depression. However, most researchers argue that autistic burnout is a distinct construct with core features that differentiate it from these other conditions (Tomczak & Kulikowski, 2023; Mantzalas et al, 2022a-b; Cage & McManemy, 2022; Mahony & Ryan, 2022; Higgins et al, 2021; Raymaker et al, 2020). Autistic burnout has also been compared to other experiences described by autistic people including autistic inertia, meltdowns and shutdowns.

#### Burnout, inertia, meltdown, shutdown

Phung et al (2021) proposes a distinction between four autistic experiences:

**Burnout (feeling exhausted):** extreme exhaustion after masking in inaccessible environments

Inertia (feeling stuck): inability to initiate tasks, even personally desirable tasks

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**Meltdown (feeling out of control):** significant overwhelm accompanied by externalising behaviours

**Shutdown (feeling frozen):** significant overwhelm accompanied by internalising behaviours.

Phung et al found substantial overlap between inertia, meltdown and shutdown and Raymaker et al's definition of autistic burnout. The authors note that these experiences can occur consecutively, with meltdowns preceding burnouts or happening at the start of burnouts.

Higgins et al (2021) suggest that meltdown can be distinguished from burnout as the latter is more likely to involve emotional numbness, whereas the former is more likely to involve inability to control emotions. As noted above (<u>4.1 Definition</u>), the presence of emotional numbness in autistic burnout is a point of disagreement between Higgins et al and Raymaker et al.

More empirical work is required to differentiate between these categories (Arnold et al, 2023a; Phung et al, 2021). Arnold et al (2023b) suggest a possible autistic exhaustion syndrome that could encompass burnout, inertia and shutdown, though more research would be required to substantiate this posit.

#### **Occupational burnout**

Occupational burnout is a response to chronic work stress that involves physical or emotional exhaustion, cynicism or indifference to people associated with the job or to work related tasks and reduced personal achievement at work (Edú-Valsania et al, 2022). The concept of burnout was originally applied to care workers, then generalised for other workplace and professional contexts. It has been expanded to include responses to non-professional contexts such as education, and to systemic problems such as racism and sexism (Wolbring & Lillywhite, 2023; Watanabe & Akechi, 2023).

Burnout is not included in the DSM-5 and is counted in the ICD-11 as an occupational phenomenon, but not a distinct health condition (Higgins et al, 2021). There is a lack of consensus in the literature on burnout regarding its definition, subtypes, causes, symptoms, prevalence, and appropriate measurement tools (Tomczak & Kulikowski, 2023; Wolbring & Lillywhite, 2023; Edú-Valsania et al, 2022; Higgins et al, 2021). Some studies suggest that the difference between occupational burnout and depression is artificial (Higgins et al, 2021).

Autistic burnout was named by analogy with occupational burnout, though the constructs are intended to be different (Tomczak & Kulikowski, 2023; Higgins et al, 2021; Raymaker et al, 2020). While acknowledging the similarities, Higgins et al (2021) differentiate autistic and non-autistic burnout according to differences in triggers and symptoms. They note non-autistic burnout is almost always employment related, whereas autistic burnout is generally precipitated by masking, social interaction and inaccessible environments. Whereas non-autistic burnout is characterised by cynicism towards the workplace or task, autistic burnout may be characterised by indifference or antipathy to non-autistic people, social groups or

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environments. Autistic burnout may include more severe cognitive symptoms and skills loss compared with non-autistic burnout.

Considering the lack of consensus in burnout research, it is not clear if the differences described in Higgins et al are sufficient to differentiate two conditions, rather than broaden the existing category of burnout. Cage & McManemy (2022) note that autistic traits, even in non-autistic people, are correlated with increased risk of occupational burnout. They suggest that autistic and occupational burnout may be two manifestations of a more general construct.

#### **Stress**

Stress is a core feature of all conceptions of autistic burnout. Researchers argue that autistic burnout is a response to chronic stress, with unique triggers and symptoms. Mahony & Ryan (2022) note the similarities between descriptions of autistic burnout and early life stress (ELS) or chronic adolescent stress (CAS). Based on these similarities, they suggest that autistic burnout is a specific type of CAS. However, further work is required to substantiate these ideas.

#### **Depression**

There are apparent similarities between depression and autistic burnout, such as fatigue, lack of emotional control, and social withdrawal. Risk of depression is increased for autistic people even in the absence of burnout. Depression is also a commonly reported feature of autistic burnout (Higgins et al, 2021; Raymaker et al, 2020). According to Mahony & Ryan (2022, p.4):

Both [Major Depressive Disorder (MDD)] and autistic burnout are associated with chronic fatigue, cognitive incapacitation, and suicidal ideation; however, the anhedonia and existential hopelessness that characterizes MDD is not always a defining feature of autistic burnout. While depression is described as a lack of motivation to participate in life, autistic burnout is experienced as a lack of capacity to do so. Nevertheless, autistic burnout can lead to the subsequent development of MDD and vice versa.

A further reason for differentiation relates to appropriate treatment methods. What works for depression may not work for autistic burnout. For example, whereas physical activity and community or social participation are appropriate management strategies for depression, they may exacerbate the underlying problems that lead to autistic burnout. In contrast, social withdrawal and focus on individual special interests is a commonly recommended management strategy.

### 5. Management

One treatment study was found, a conference abstract included in a supplement to the journal *Neurology*, that investigates the management of autistic burnout (Hale & Sanders, 2023). The authors present the case of a 24-year-old autistic student who presented with symptoms of autistic burnout. They were prescribed dextroamphetamine, associated with treatment of attention-deficit hyperactivity disorder, and reported positive outcomes.

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Several qualitative studies note strategies that those who experience autistic burnout have used to recover. Examples include:

- Social support from the right people (which could include other autistic people)
- 'Unmasking', reducing masking behaviours or avoiding situations where they are necessary
- Taking time to understand one's own needs and preferences
- Taking time to focus on a special interest
- Request reasonable accommodations and appropriate supports from work or school
- Reduced activity, rest, regular breaks (Gabrielsen et al, 2023; Mantzalas et al, 2022a; Higgins et al, 2021; Raymaker et al, 2020).

### 6. References

- Arnold, S. R., Higgins, J. M., Weise, J., Desai, A., Pellicano, E., & Trollor, J. N. (2023a). Confirming the nature of autistic burnout. *Autism: the international journal of research and practice*, *27*(7), 1906–1918. https://doi.org/10.1177/13623613221147410
- Arnold, S. R., Higgins, J. M., Weise, J., Desai, A., Pellicano, E., & Trollor, J. N. (2023b). Towards the measurement of autistic burnout. *Autism: the international journal of research and practice*, *27*(7), 1933–1948. <a href="https://doi.org/10.1177/13623613221147401">https://doi.org/10.1177/13623613221147401</a>
- Brouwers, E. P. M., Bergijk, M., van Weeghel, J., Detaille, S., & Dewinter, J. (2023). What is the Meaning of Paid Employment for Well-Being? A Focus Group Study on Differences and Similarities Between Autistic Adults With and Without Employment. *Journal of occupational rehabilitation*. Advance online publication. <a href="https://doi.org/10.1007/s10926-023-10136-0">https://doi.org/10.1007/s10926-023-10136-0</a>
- Cage, E., & McManemy, E. (2022). Burnt Out and Dropping Out: A Comparison of the Experiences of Autistic and Non-autistic Students During the COVID-19 Pandemic. Frontiers in psychology, 12, 792945. https://doi.org/10.3389/fpsyg.2021.792945
- Edú-Valsania, S., Laguía, A., & Moriano, J. A. (2022). Burnout: A Review of Theory and Measurement. *International journal of environmental research and public health*, *19*(3), 1780. <a href="https://doi.org/10.3390/ijerph19031780">https://doi.org/10.3390/ijerph19031780</a>
- Gabrielsen, T.P., Begay, K.K., Campbell, K., Hahn, K., Harrington, L.T. (2023). Autism Diagnosis in Adult Females: Post-secondary Education, Careers, and Autistic Burnout. In: Assessment of Autism in Females and Nuanced Presentations. Springer, Cham. https://doi.org/10.1007/978-3-031-33969-1 11
- Hale, E., & Sanders, J. S. (2023). Autistic Burnout: A Report of Treatment Success [Abstract only]. *Neurology*, 100(17S) https://doi.org/10.1212/WNL.0000000000202510





### **OFFICIAL** For Internal Use Only

- Higgins, J. M., Arnold, S. R., Weise, J., Pellicano, E., & Trollor, J. N. (2021). Defining autistic burnout through experts by lived experience: Grounded Delphi method investigating #AutisticBurnout. *Autism: the international journal of research and practice*, *25*(8), 2356–2369. https://doi.org/10.1177/13623613211019858
- Mahony, C., & O'Ryan, C. (2022). A molecular framework for autistic experiences:

  Mitochondrial allostatic load as a mediator between autism and psychopathology.

  Frontiers in psychiatry, 13, 985713. <a href="https://doi.org/10.3389/fpsyt.2022.985713">https://doi.org/10.3389/fpsyt.2022.985713</a>
- Mantzalas, J., Richdale, A. L., & Dissanayake, C. (2023). Examining subjective understandings of autistic burnout using Q methodology: A study protocol. *PloS one*, 18(5), e0285578. https://doi.org/10.1371/journal.pone.0285578
- Mantzalas, J., Richdale, A. L., & Dissanayake, C. (2022a). A conceptual model of risk and protective factors for autistic burnout. *Autism research: official journal of the International Society for Autism Research*, *15*(6), 976–987. https://doi.org/10.1002/aur.2722
- Mantzalas, J., Richdale, A. L., Adikari, A., Lowe, J., & Dissanayake, C. (2022b). What Is Autistic Burnout? A Thematic Analysis of Posts on Two Online Platforms. *Autism in adulthood: challenges and management*, *4*(1), 52–65. https://doi.org/10.1089/aut.2021.0021
- Øverland, E., Hauge, Å. L., Orm, S., Pellicano, E., Øie, M. G., Skogli, E. W., & Andersen, P. N. (2022). Exploring life with autism: Quality of Life, daily functioning and compensatory strategies from childhood to emerging adulthood: A qualitative study protocol. *Frontiers in psychiatry*, 13, 1058601. <a href="https://doi.org/10.3389/fpsyt.2022.1058601">https://doi.org/10.3389/fpsyt.2022.1058601</a>
- Phung, J., Penner, M., Pirlot, C., & Welch, C. (2021). What I Wish You Knew: Insights on Burnout, Inertia, Meltdown, and Shutdown From Autistic Youth. *Frontiers in psychology*, 12, 741421. https://doi.org/10.3389/fpsyg.2021.741421
- Pyszkowska, A., Gąsior, T., Stefanek, F., & Więzik, B. (2023). Determinants of escapism in adult video gamers with autism spectrum conditions: The role of affect, autistic burnout, and gaming motivation. *Computers in Human Behavior*, 141, 107618. https://doi.org/10.1016/j.chb.2022.107618
- Raymaker, D. M., Teo, A. R., Steckler, N. A., Lentz, B., Scharer, M., Delos Santos, A., Kapp, S. K., Hunter, M., Joyce, A., & Nicolaidis, C. (2020). "Having All of Your Internal Resources Exhausted Beyond Measure and Being Left with No Clean-Up Crew": Defining Autistic Burnout. *Autism in adulthood: challenges and management*, 2(2), 132–143. https://doi.org/10.1089/aut.2019.0079
- Tomczak, M. T., & Kulikowski, K. (2023). Toward an understanding of occupational burnout among employees with autism the Job Demands-Resources theory perspective. *Current psychology* (New Brunswick, N.J.), 1–13. Advance online publication. <a href="https://doi.org/10.1007/s12144-023-04428-0">https://doi.org/10.1007/s12144-023-04428-0</a>

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- Vinayagam, R., Tanner, C., Harley, D., Karatella, S., & Brooker, K. (2023). "My Autism is Linked with Everything": at the Crossroads of Autism and Diabetes. Journal of autism and developmental disorders. Advance online publication. https://doi.org/10.1007/s10803-023-06033-3
- Watanabe, T., & Akechi, T. (2023). The mediating role of psychological flexibility in the association of autistic-like traits with burnout and depression in medical students during clinical clerkships in Japan: a university-based cross-sectional study. BMC psychiatry, 23(1), 302. https://doi.org/10.1186/s12888-023-04811-y
- Wolbring, G., & Lillywhite, A. (2023). Burnout through the Lenses of Equity/Equality, Diversity and Inclusion and Disabled People: A Scoping Review. Societies, 13(5), 131. https://doi.org/10.3390/soc13050131
- Zhuang, S., Tan, D. W., Reddrop, S., Dean, L., Maybery, M., & Magiati, I. (2023). Psychosocial factors associated with camouflaging in autistic people and its relationship with mental health and well-being: A mixed methods systematic review. Clinical psychology review, 105, 102335. https://doi.org/10.1016/j.cpr.2023.102335