

# Last but not least: Later life experiences of autistic people



Rose Matthews

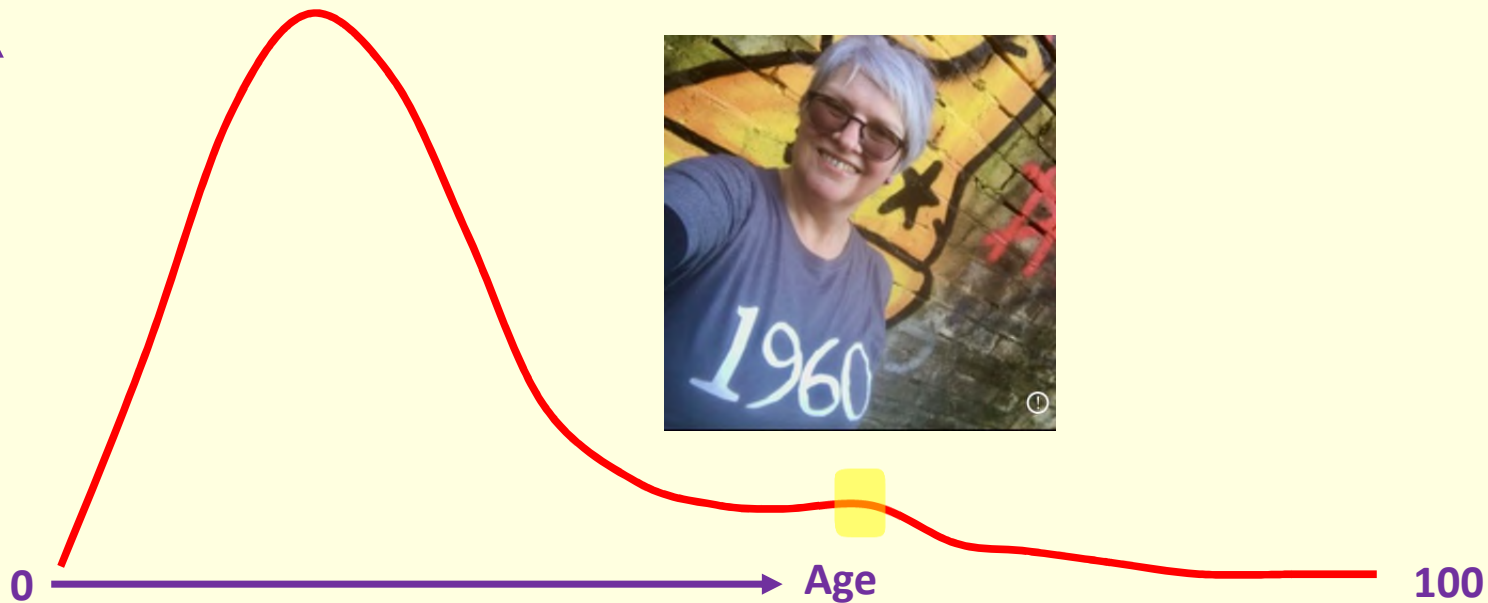
## Three key questions

- Why do we know so little about older autistic people?
- Why does it matter?
- What can we do about it?

# The thin edge of the wedge

- Most older autistic people are part of 'a lost generation'
- Few people aged 50+ are diagnosed (or self-identify) as autistic
- It's wrongly assumed that the crisis point hasn't been reached yet

Autism rate  
per 1000  
population



# When my life fell apart

- The cumulative effect of a series of catastrophes
- Being traumatised, but not understanding why
- Desperately trying to keep up appearances



“There was little professional curiosity about what kept on going wrong for me. With hindsight it was obvious that I was autistic. But no one really listened to my concerns or gave me the help I needed. In the end my life simply fell apart.”

Rose Matthews

# Perimenopause as crisis and catalyst

- Intense meltdowns mirrored puberty and post partum
- Out of character events, like being arrested, didn't get me any help
- I'd never have considered autism if an ex-colleague hadn't emailed me

“When I found research papers on autism and menopause I realised my experience was far from unique. It's difficult to describe how redeeming it felt to finally discover that I was not on my own.”

Rose Matthews

# Building a better life

‘It has been such a relief to learn everything was not, after all “all my fault”. I have learned new ways to “work around” the autism struggles I have to find new ways to build a better life with less frustration, struggle and discomfort. I have made a new network of friends, I have begun to live my “best life ever” since I finally found out about my autism.’

[oldladywithautism.blog](http://oldladywithautism.blog) January 2023

“I used to think I was in a minority of one, but there are probably 700,000+ of us”

Rose Matthews

# Biographical Illumination

- Transformed conceptualization of self
- Explanation for atypicality
- More valued self-concept

Catherine D Tan, 2018



“I finally feel able to fit in, just by being myself.” Rose Matthews

# Finally figuring it out

‘Many [women receiving an autism diagnosis in middle to late adulthood] were kinder to themselves, signifying a progression from self-criticism to self-compassion:

*“...to understand where those difficulties and stresses are coming from makes a difference in terms of how I think about myself.” (Mia)*

This extended to engaging in soothing, often practical and enjoyable self-care activities, such as art, communicating online, spa days, learning and gardening.’

Alexandra Leedham *et al* (2020)



# Relationships later in life

- Potential for repair, reconciliation or rift
- Decrease in social demands are welcomed by some BUT
- Increased risk of loneliness, social isolation, and exclusion
- Existing social/support networks (if any) tend to erode as we age
- People may need help to find new kinds of kinship and community

“I can make  
friendships, but I  
can’t sustain them”

Rose Matthews



“My closest friends  
have four legs rather  
than two”

Rose Matthews

# Autistic perspectives on death and dying

- Increased likelihood of early mortality
- Difficulty accessing and using healthcare services
- Need for research on autistic people's perspectives on the end of life

“I can't tell you what it is like to die as an autistic person but I can tell you why I fear it. During childbirth my reaction to intrusive medical procedures, sensory overload and uncontrolled pain was met with sarcasm and unkindness by healthcare staff. I don't want my life to end like that.”

Rose Matthews

# Whose expertise is it anyway?

‘Although knowledge is not yet power for many autistic people, identifying how autistic people think about autism is a first step toward developing research that is relevant to their interests and the needs of the community whom the research is intended to serve.’

Kristen Gillespie-Lynch *et al* 2017



# The needs of autistic people later in life

- Very late diagnosis or self-discovery doesn't mean we're any less autistic
- Mental health issues associated with autism appear to persist into old age
- We know very little about the circumstances in which older autistic people thrive
- Autism in later life is poorly understood by professionals, clinicians and researchers
- Self-acceptance may be impeded by biographical pain, stigma and internalised ableism
- Socioeconomic and structural disadvantage can limit our capacity for thriving and self-care

Anyway I'm not where I started...

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@NortherlyRose  
@SensoryJoy  
@Autism\_R\_And\_D

*Thank you*



...some days I feel I have wings!

# Padlet <https://padlet.com/rosematthewsresearch/lm82dpyrf9cij1hq>

Rose Matthews • 2d

**Autism and Ageing** ▾  
Resources to accompany 'Last but not least: Later life experiences of autistic people'

**The cognitive profile of middle-aged and older adults with high vs. low autistic traits**  
Gavin R Stewart et al / <https://onlinelibrary.wiley.com/doi/10.1002/aur.2866>

**Am I Autistic?** Birmingham Open Media guide.  
PDF Am-I-Autistic? We are living

**'I was exhausted trying to figure it out': The experiences of females receiving an autism diagnosis in middle to late adulthood**  
journals....  
Alexandra Leedham et al

**Journey to diagnosis for women with autism**  
Review paper Journey to diagnosis for women with autism  
PDF Journey-to-diagnosis-for-women-with-autism-

**Autism research is 'all about the blokes and the kids': Autistic women breaking the silence on menopause**  
bpspsyc...  
Rachel L Moseley, Tanya Druce, and Julie M Turner-Cobb

**'When my autism broke': A qualitative study spotlighting autistic voices on menopause.**  
PMC ncbi.nlm...  
'When my autism broke': A qualitative study spotlighting

# References and resources

## **Autism and ageing**

[Ageing and Autism: A BIG conversation – NDTi](#)

[Characteristics of Older Autistic Adults: a Systematic Review of Literature - Venus W S Tse et al](#)

[Old Lady With Autism blog – Late diagnosis , learning about autism and getting older at the same time](#)

[Quality of life for older autistic people: The impact of mental health difficulties - David Mason et al](#)



# References and resources

## **Autism and healthcare**

[Barriers to healthcare and self-reported adverse outcomes for autistic adults: a cross-sectional study – Mary Doherty et al](#)

## **Autism and menopause**

[Autism research is 'all about the blokes and the kids': Autistic women breaking the silence on menopause - Rachel Moseley, Tanya Druce, Julie Turner-Cobb 2021](#)

[‘When my autism broke’: A qualitative study spotlighting autistic voices on menopause - Rachel L Moseley, Tanya Druce, Julie M Turner-Cobb, 2020](#)

Bridging the Silos: Autistic Menopause Study (research in progress, building on the studies above:  
[www.autisticmenopause.com](http://www.autisticmenopause.com)



# References and resources

## **Autism and research**

[Older age autism research: A rapidly growing field but still a long way to go. David Mason et al.](#)

[Whose Expertise Is It? Evidence for Autistic Adults as Critical Autism Experts](#)

## **Autism and suicide**

[Self-harm and Suicidality Experiences of Middle-Age and Older Adults With vs. Without High Autistic Traits Gavin R Stewart et al](#)

## **Autism and trauma**

[Traumatic life experiences and post-traumatic stress symptoms in middle-aged and older adults with and without autistic traits - Gavin R Stewart et al](#)

[Autism, Adverse Events, and Trauma. Lobregt-van Buuren E, Hoekert M, Sizoo B.](#)

# References and resources

## **Death, dying and the end of life**

[The End: Death as Part of the Life Story](#)

**Autistic Perspectives on Death and Dying – Rose Matthews (JKP, forthcoming)**

## **Intersectionality**

[The Scholarly Neglect of Black Autistic Adults in Autism Research - Kayly M Malone et al](#)

["They Don't Know, Don't Show, or Don't Care": Autism's White Privilege Problem - Morenike Giwa Onaiwu](#)

# References and resources

## Late autism diagnosis or discovery

[A Pony in the Bedroom - Susan Dunne](#) (see also [Guardian blog](#) / [Guardian blog](#))

['A way to be me': Autobiographical reflections of autistic adults diagnosed in mid-to-late adulthood - Rozanna Lilley et al](#)

['I was exhausted trying to figure it out': The experiences of females receiving an autism diagnosis in middle to late adulthood - Alexandra Leedham, et al 2020](#)

['I was just so different': The experiences of women diagnosed with an autism spectrum disorder in adulthood in relation to gender and social relationships - Lucie Kanfischer et al](#)

[Living with autism without knowing: receiving a diagnosis in later life - Steven D Stagg & Hannah Belcher](#)

# References and resources

**Halleluah – Mary Oliver (poem)** [Wild & Precious Life](#)

## **Meltdown, shutdown and burnout**

["Having All of Your Internal Resources Exhausted Beyond Measure and Being Left with No Clean-Up Crew": Defining Autistic Burnout](#)

## **Relationships in later life**

[Understanding Autistic Relationships Across the Lifespan - Felicity Sedgewick & Sarah Douglas](#)

## **Thriving as an autistic person**

["I'm Proud to be a Little Bit Different": The Effects of Autistic Individuals' Perceptions of Autism and Autism Social Identity on Their Collective Self-esteem](#)