

# Menopautism

**Jane Renton is a journalist and filmmaker with Aspergers, who is approaching menopause - and certainly mid perimenopause.**

**In the course of researching her own symptoms, she feels she has seen that there is a wall around the idea of autistic women experiencing menopausal symptoms.**

**Her Menopause Matters Blog shares her thoughts...**



Menopause, like puberty, is the great leveller for all women. No matter how attractive or successful you are, educated or athletic; the menarche has an inescapable appointment with its antonymous twin. As sure as eggs are no longer, eggs.

Autistic women are no different. But while we all experience menopause – and the more protracted perimenopause – that is where this egalitarian Age of Aquarius ends. Physically, we are sisters – neurologically, we're closer to second cousins.

## **Autism**

People are diagnosed with autism because they experience difficulties within a clear triad of impairments – social communication, integration and imagination. It is described as: “a lifelong developmental disability that affects how people perceive the world and interact with others.”

The key is in the word “lifelong.” Through every developmental stage, an individual with autism will experience it refracted through the prism of autism. And it really doesn't matter how far along the spectrum you are – from HFA (High Functioning Autism) to severe autism it will still be qualitatively different to a neurotypical brain.

The problem for women with autism is that there is less – much less – open and available information during every stage of their childhood and adult lives. And it's really no surprise, as it has only been relatively recently that women and girls have been widely acknowledged as being capable of even having autism.

A label that has stuck is that autism is the state of having an extreme 'male brain.' Hans Asperger did not initially believe that girls could have the syndrome, while Leo Kanner's 1943 study found that there were four times as many boys to girls with autistic traits.

In reality however, it is now believed that women – particularly women with high functioning autism – are better at hiding their difficulties. Or 'masking.' Partly due to a wider social and cultural conditioning for women to just-get-on-with-it, and partly because the social-communication areas of the female brain are generally better developed, they therefore pass under the diagnostic radar.

In younger women this leads to a disproportionate amount of undiagnosed women with autism develop-

ing disproportionately female-dominated problems like eating disorders, or languishing under the broader banner of compromised mental health.

A survey conducted in 2016 by the National Centre of Social Research, found 31 per cent of women in the UK suffer from mental health problems. It is tempting to wonder how many diagnoses of Borderline Personality and Bipolar Disorder, anxiety and depression are actually victims of a missed diagnosis of ASD. The restricted interests that are so easily odd or unusual in men or boys with autism are not so easily identifiable in women and girls. At the lighter end, girls might become fixated on horses or the next X-Factor star – at the darker end, they will obsess over food, or the lack of it. What we do know is that these female obsessions are trivialised.

### **Freud has a lot to answer for**

The nineteenth century obsession with women's complaints being bracketed under the diagnosis of hysteria was given updated relevance again with his use of psychoanalysis to examine the volatile (read often hormonal) nature of his female patients mood swings. The concept of the 'wandering womb' as a mysterious, even dangerous catalyst to odd behaviour had been in circulation since Egyptian times. It is tempting to speculate that the clash of hormones with differently wired brains may have played a part in creating this awkwardly limbed golem that meandered throughout our bodies.

When Freud famously posed the question: "*What does woman want?*" perhaps someone should have replied that women are not simply the product of their reproductive system. So if a woman is neurologically different, won't her relationship with her body be slightly different too?

It stands to sense that if the menopause is an under-researched for women in general, menopausal women with autism in particular are going to be critically under-researched. Local authorities are now chronically underfunded – particularly in the areas of social care and mental health. These are the areas that autistic people generally connect with.

However, as people age, their needs change, and more often than not there is not even a meaningful way of calculating how many autistic adults live in an area. Critically within this, any data that is collected rarely differentiates between autistic men and women. This differs hugely to the non-autistic world where people are evaluated by gender as well as age.

### **Making provision**

So how can we make provision for older autistic women going through the menopause when we're not entirely sure how many of them there are – and that's if they've been lucky enough to be diagnosed in the first place? It seems to be a classic case of there being no need to respond to because statistically there is no need.

Clearly the evidence – or lack of it – suggests that there is more than enough reason why a large-scale research study should be instigated into the lives of older autistic women. But there is little appetite for investing money in an area that carries slender opportunity for a good return – either financially, or to gain distinction in a disproportionately male dominated research prize field. This is a disgrace.

Where we can start today however is by carrying on the work that people like India Knight, Gillian Anderson, Miranda Sawyers and other successful public figures have done in raising the profile of neurotypical women going through the menopause. Coming out from behind the mask of embarrassment and misunderstanding that surrounds the consequences of ageing is hugely significant. By initially demystifying the process and acknowledging it's effect on our physical and mental health, we hold open the door to women who may not have the immediate capacity to understand that what is happening to them is a natural, manageable process.

There is an old saying that cocks crow but hens deliver. If anyone is going to deliver change in the area of adequate and achievable support for autistic women going through the menopause, it is other women. And with the statistics of newly diagnosed autistic women going through the roof, we might just find that sisters are actually doing it for themselves.

### **So bearing in mind there are little or no existing resources available for older autistic women, what can we do now?**

Clearly, setting up research studies takes time and our hormonal seasons will carry on regardless of the time it takes to publicise collected data. We really do need to steal a march while advocating for greater awareness.

#### **Here's how:**

- Firstly, all women – but particularly women with high functioning autism should look back at their own medical and pharmaceutical history. If we have taken hormonal contraceptives, how has this affected us? Did it make us worse or improve symptoms?
- In my own experience, hormonal contraceptives were unbearable, pitching me into intense mood swings. This clearly has implications for my choices on whether to opt for HRT, although hormones used in HRT are different types, different doses and used in different circumstances compared to hormones in contraceptive pills.
- Similarly, many autistic women will have taken SSRI's to control anxiety and depression, and to deal with premenstrual symptoms. Long-term use of SSRI's and some other anti-depressants is known to increase the risk of developing osteoporosis. Would we need to offset the possibly unpleasant hormonal effect of taking HRT with the therapeutic benefit of the drug protecting bone density?

If more people start asking more questions from more doctors – and discussing issues more widely on platforms like these, the profile is raised. And if the profile is raised, then things start to happen. Just a few high-profile women discussing the menopause has had a hugely positive trickle down effect. How much more urgent is that in the case of women who may lack the capacity to advocate for their own reproductive and mental health?

With diagnosis rates of women increasing, there is no time like the present. Talk to your doctors, discuss it on forums – do please get in touch with me with your stories and personal accounts. As women we know, if you want something doing – do it yourself. Let's do this.

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*Jane has written for the Guardian and Independent, as well as other local publications. She is currently working on her documentary Girl Versus World, with 104 Films – the UK's leading production company focussing on disability.*

*Jane was diagnosed with Aspergers in 2011.*

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