

# Copenhagen Q&A Session

# Research on Sleep Issues in Autism

Wintler et al (2020) *Jr. Neuroscience Res* 98 1137-1149

- 44-86% of autistic people have trouble sleeping
- Falling asleep, waking multiple times, less duration of sleep than the average for the person's age
- Insomnia is considered comorbid but could be **an integral part of autism**
- Problems falling asleep in the first year of life often **precedes an autism diagnosis**

# Sensory Sensitivity

- **Lighting:** level and type of illumination
- **Sounds:** Quiet – startle reaction, music
- **Digestion sounds:** Sounds and sensations, mealtime and choice of food
- **Temperature** – less than 23 centigrade (not too hot or cold)
- **Tactile:** Sleeping clothes (texture, seams) Weighted blanket, sheets
- **Pain** such as constipation: medical assessment

# Ways of Encouraging Sleep Onset

## Melatonin

- A natural sleep-promoting hormone
- **Defective metabolism** and secretion of melatonin associated with autism
- Dosage 1-10 mg, start at 2 mg.
- Needs to be pharmaceutical-grade melatonin
- Is a robust finding across 7 trials, e.g. Yan & Goldman (2020) *Canadian Family Physician*, 66(3), 183-185



# Bedtime Routine



- **Teenagers**
- Avoid using the bedroom for activities other than sleeping
- Avoid tea, coffee, energy drinks, cola and heavy exercise
- Computer games as a thought blocker or suppressant for anxiety and depression
- When switched off, the thoughts and emotions return inhibiting sleep
- Television, computers and social media switched off 30 minutes before bedtime
- Mindfulness, relaxation and Yoga

# Advice from Autistic Adolescents

Pavlopoulou (2020) *Frontiers in Psychology* 11 Article 583868

- 54 autistic adolescents
- **Evening/bedtime Factors**
- The right level of **sensory stimulation**
- Sensory comfort smell and tactile
- Clothing (labels)

# Advice from Autistic Adolescents

## Relaxation

- Relaxing music or **sounds/dialogue from familiar movies**
- Helps to ease worries and go into the sleep zone
- *Helps me push away the worries about the next day*
- *The sound of something familiar definitely helps me to sleep better*
- *I put an object on my belly and watch my belly as it goes up and down while the air goes in through my nose and out through my belly*

# Advice from Autistic Adolescents

- Calming by **drawing** and the **special interest**
- *Dr. Who helps me sleep. Looking at the Tardis helps me to relax and forget all other thoughts in my head, and then I can go to bed easier.*
- *Harry Potter, watching parts of a movie, the movement of heroes, the colours on a particular scene, it excites me and calms me at the same time*
- *Reaching a state of calm happiness that cannot be compared with any other activity*



# Advice from Autistic Adolescents

## **Parental company before bedtime**

- Reassuring conversation before bedtime *to wind down and feel safe*
- To **review the day** in a gentle, compassionate way and make a plan for the day ahead

## **Physical activity**

- *A short (15 minute) drumming session to release all energy*
- Enjoyable physical activity in the day
- *I sleep faster on days I had a swim*

# Advice from Autistic Adolescents

## Thoughts

- *Having fun during the day helps going to bed with less fear about the next day*

## School

- Sleeping better when they know that they will **enjoy the following school day**
- Positive school experiences and sufficient time for interests associated with good sleep patterns
- Being able to have more control and choice on how to spend time at school and home cultivate positive feelings that promote better sleep

# Autism and ADHD

## What do both look and feel like?

Can be a war inside:

- Making spontaneous plans (ADHD), but getting very upset if those plans are interrupted (autism)
- Struggling to organise the day/life (ADHD) but having a strong need for order (autism)



# What do both look and feel like?

- Struggling to be on time (ADHD) but upset when others are a few minutes late (autism)
- Hyper fixating on a wide variety of topics (ADHD), and also having long term special interests (autism), and time mgt difficulty (ADHD)



# Challenges when both

- Forgetting steps in plans (ADHD) but needing to execute plans perfectly (autism)
- Enticed by novel foods (ADHD) but being particular about food taste and texture (autism)
- Needing novel experiences (ADHD), and needing predictability and sameness (autism)



# Challenges When Both

- *One of the biggest challenges I face is that my brain often works in non-linear ways. I can see connections and patterns that others miss, and I have a natural ability to think creatively and come up with unique solutions to problems. But at the same time, I also struggle with organization, executive functioning, and other challenges that can make it difficult for me to bring my ideas to Fruition Noah*



# Research on ASD and Substance Use Disorder (SUD)

- *Rengit et al* JADD 46: 2514-2519
- Reviews the literature and suggests risk factors.
- **To alleviate anxiety and a coping strategy.**
- **Inclusion in a 'subculture'** which does not require extensive communication and provides social acceptance.
- Need to modify conventional SUD therapy for ASD, such as individual rather than group therapy.

# ASD and Substance Abuse

- Ressel et al (2020) Autism 24, 899-918
- Systematic review of research
- Recent studies suggest up to 36% of autistic individuals have co-occurring issue with substance abuse – but a general prevalence rate yet to be established
- Conventional risk factors such as familial substance use, adverse family events, early tobacco use and externalizing disorders such as ADHD relevant to ASD
- Additional ASD factors may be a sense of social belonging and breadth of social support, disengaging coping behaviours, and self-medication to alleviate psychological distress and negative cognitions



# Substance Use Problems

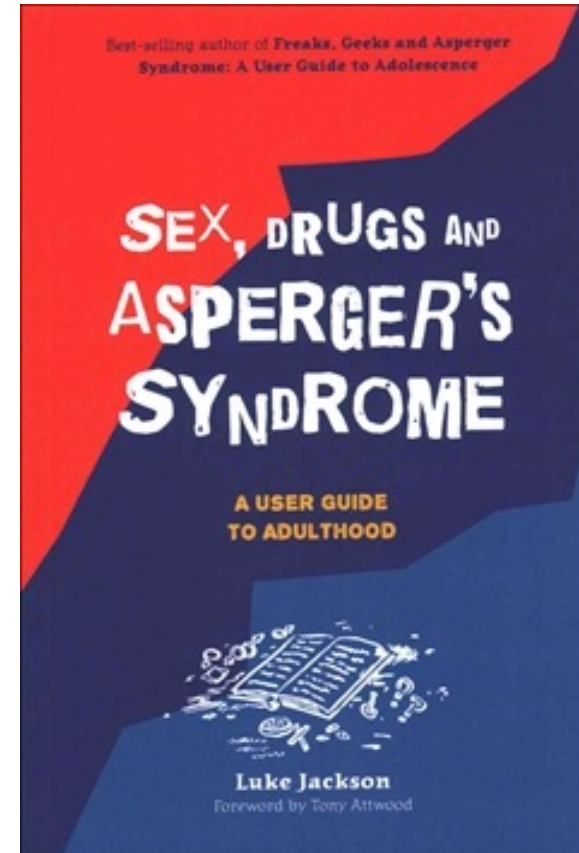


- Increased Risk for Substance Use-Related Problems in Autism Spectrum Disorders: A Population-Based Cohort Study.
- Butwicka, A et al. *JADD* Vol. 47, pp 80-89.
- Identified a **doubled risk** of substance use-related problems, the highest among individuals with **ASD and ADHD**.
- Substance use-related problems have been observed among **19% - 30%** patients with ASD, at least in **clinical settings**.



# ASD & Substance Abuse

- To **engage reality or escape reality.**
- Often starts with alcohol and marijuana to self-medicate anxiety.
- Can often be a social lubricant: **reduces social anxiety...**





# ASD & Substance Abuse

- Then become dependent on alcohol and marijuana to maintain lowered anxiety and to facilitate social engagement.
- **Membership of a group:** clear rules, dress, language and codes of conduct.
- Can become a special interest and peer **value for knowledge and advice.**





# ASD & Substance Abuse

- **Anaesthetized** from past trauma.
- **Emotional detachment**, a safe 'bubble'.
- **Purpose and structure** for the day.





# ASD & Substance Abuse

- *“It is relaxing and provides happiness”*
- *“My only friends are my dogs and alcohol”*
- Alcohol: *“A central solvent that my body chemistry had been missing. Alcohol is my cure for anxiety”*





# ASD & Substance Abuse

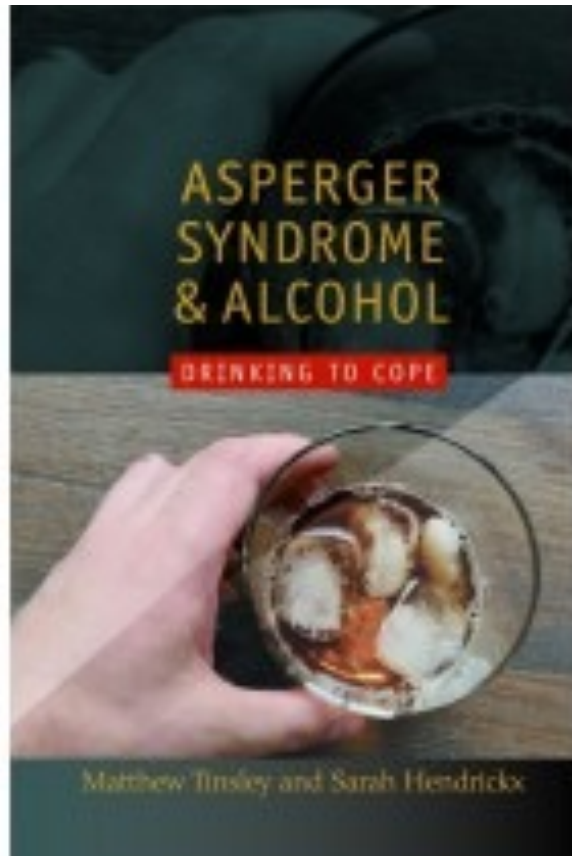
- Abuse of **prescription drugs**.
- Conflict with the law and entry into the **Criminal Justice system** (Will).
- ‘Switches off’ the frontal lobes and increases ASD characteristics.
- Contributes to **depression** and impairs decision making.



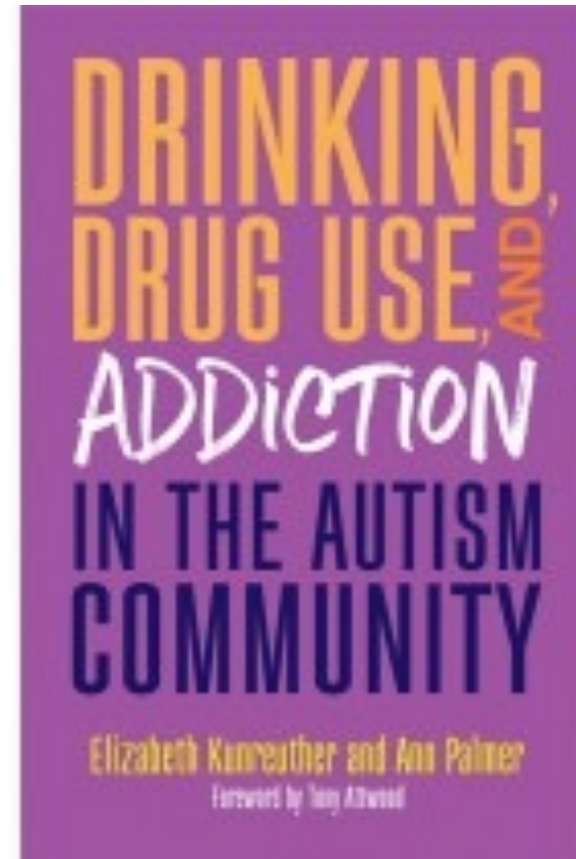


## Resources from [www.jkp.com](http://www.jkp.com)

Matthew Tinsley and Sarah  
Hendrickx



Elizabeth Kunreuther and Ann  
Palmer



# Treatment

- Address **anxiety, sense of self** and **fear of coping without** the interest
- Non-blaming, non-shaming supportive approach
- In the case of drugs, this may mean providing prescribed and carefully administered and supervised **medication** and **Yoga and meditation**
- **ASD-friendly adaptations to residential rehabilitation**



# Substance Abuse

- Treatment services to screen for ASD (25%)
- **Adapt therapy** to accommodate the experiences and ability profile associated with autism
- **Group activities** (require social abilities and competence with social dynamics)



# Adapting Substance Use Disorder Treatment to Accommodate the Characteristics of Autism

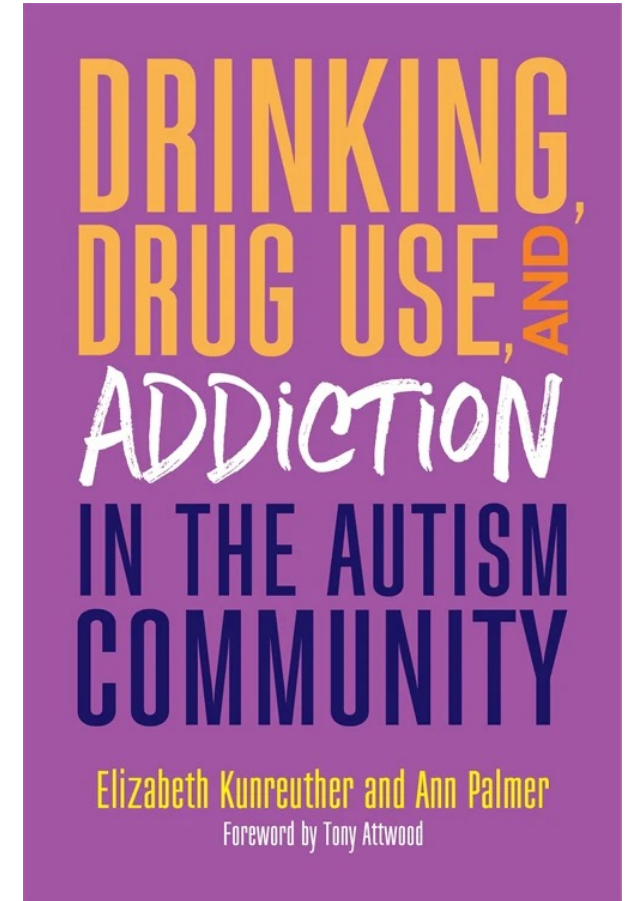
- Helverschou, Brunvold and Arnevik (2019) *Substance Abuse: Research and Treatment* 13, 1-10
- Norwegian study
- Typical interventions for SUD may be **particularly unsuitable for autistic adults**
- The study examined ways of improving SUD treatment for **4 ASD** adults in an ordinary outpatient clinic
- Three therapists given **monthly ASD education** and **group supervision**

# Adapting Substance Use Disorder Therapy to Accommodate the Characteristics of Autism

- Post treatment, **two participants ended their drug and alcohol abuse completely**, one reduced his abuse and one still had heavy abuse of alcohol
- Participants thought they were drug experts and reported they provided advice to others about doses and combinations of drugs
- **Both participants who ended their drug use completely did it their 'own way' and did not follow a recommended reduction plan**

# Adapting Substance Use Disorder Therapy to Accommodate the Characteristics of Autism

- Adaptations to CBT
- Minimum of 10 sessions, therapy 8-15 months
- Therapy more direct, **individualized, structured**, and extensive
- Included **psychoeducation on ASD, social training** and **life organization**
- Such as housing, employment, social contacts and leisure
- Guidance on the therapeutic relationship (therapist not a personal friend)
- Therapy reported by the therapists as more demanding than with other SUD patients



# Menopause and ASD

- Mosely, Druce and Turner-Cobb (2020) Autism 24 1423-1437
- Focus group of seven autistic women aged 49-64 years

**1 Lack of professional knowledge** and understanding of menopause and ASD

- Negative experience with professionals

**2 'Cracking the Mask' and adaptive functioning**

- Menopause:
- Amplifies the autistic presentation

# Menopause and ASD

- Masking more difficult and previous coping strategies failing
- Communication and relationship difficulties
- Sensory heightening and new sensitivity (especially heat and cold)
- Meltdowns in the context of sensory sensitivity
- *During menopause I was on 3 meltdowns per week*
- Executive functioning decline
- Negative emotions and stress reactivity

# Menopause and ASD

- Sleep and self-care
- Increase in anxiety and depression
- Midlife identity and life after menopause
- Finding support – scarcity contrasts with need
- Need for further research and resources

# Menopause

- Karavidas and de Visser (2022) *Jr. Autism and Developmental Disorders* 52, 1143-1155
- Interviews with 7 peri- or post-menopausal autistic people
- Menopause in autistic people associated with sensory sensitivity and daily functioning
- Three themes
- **Uncertainty about changes**
- Limited awareness and understanding of menopause combined with difficulties recognising internal states

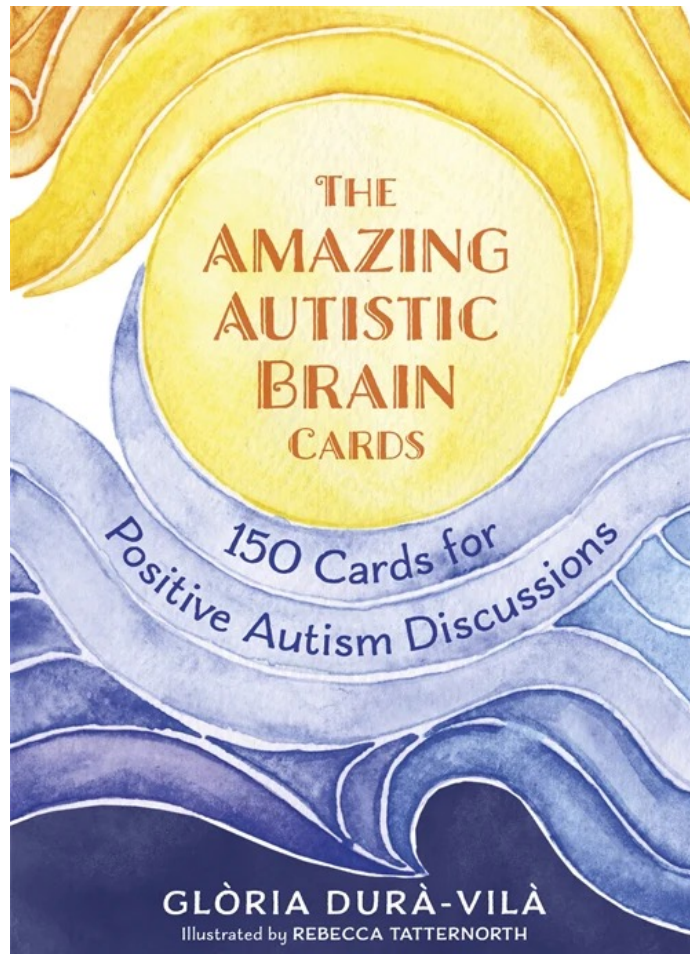
# Menopause

- Autistic traits come to the surface such as sensory sensitivity
- Confusion regarding temperature regulation changes
- **Growing self-awareness and self-care**
- Conscious efforts to resist negative societal constructions of both autism and menopause
- **Navigating support options**
- Interpersonal and systematic barriers when seeking support
- Peer support

# How to Explain the Diagnosis



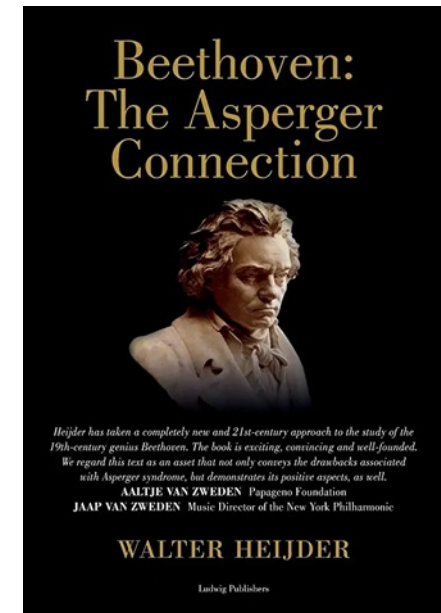
# The Amazing Autistic Brain



- Qualities and difficulties
- In diagnosis, we seek a pattern
- Congratulations
- **Discovery** rather than a diagnosis
- A different form of perception, learning, thinking and relating.
- Autistic achievers.

# Association With Famous Individuals in Science and Art

- Albert Einstein.
- Alan Turing.
- Thomas Jefferson.
- Howard Hughes.
- Hans Christian Andersen
- Jane Austen
- Marie Curie
- Greta Thornberg.
- Hannah Gadsby (comedian)
- Sophie Germain (mathematician)
- Bobby Fischer
- Temple Grandin
- Howard Hughes
- Carl Jung
- Gary Numan
- Tim Page
- B.F. Skinner
- Andy Warhol
- Thomas Edison



***“If the world was left to you socialites, we would still be in caves talking to each other”*** Temple Grandin



# Self-Identity in Autism

- Sense of self based on peer rejection and criticism rather than inclusion and compliments
- *I was afraid to be myself because I thought I wasn't good enough*
- *Teased unmercifully because other people just didn't understand my way of thinking*

# Self-identity

- **Alexipersona:** A lack of vocabulary to describe personality characteristics is an associated characteristic of ASD
- A list of **positive personality adjectives** as prompts to describe personality qualities



# Positive Personality Adjectives

Adventurous	Dependable	Imaginative	Reserved
Affectionate	Determined	Inventive	Serious
Ambitious	Easy-going	Kind	Shy
Articulate	Empathic	Loyal	Silly
Artistic	Energetic	Mischievous	Sincere
Careful	Enthusiastic	Neat	Studious
Cheerful	Fair	Persistent	Sympathetic
Compassionate	Forgiving	Polite	Thoughtful
Considerate	Friendly	Practical	Tolerant
Courageous	Funny	Proud	Tidy
Courteous	Generous	Quick-witted	Trusting
Creative	Gentle	Quiet	Wise
Curious	Helpful	Rational	
	Honest	Reliable	

# ***This is Who I Am Book:***

## **Qualities in Personality and Abilities**

### **Personality**

- Kind
- Caring
- A loyal friend
- Honest
- Forthright
- A perfectionist
- Determined
- Brave
- Humourous

### **Abilities**

- Drawing and art
- Acting and singing
- Creating model ships
- Exceptional long term memory
- Talented in mathematics
- Noticing details
- Expert on .....
- Problem solving

# Ring Binder or Computer Programme



- Each quality at the top of a page
- **Record examples** of the expression of that quality (a diary)
- Photographs, compliments from friends and family

# Ring Binder or Computer Programme



- Qualities of a **hero** in the family or character in a film or TV programme (e.g. Dr Who)
- Each admired quality of the hero has a page
- Add entries throughout and after the therapy
- Confirming progress towards a valued personality
- The book is an antidote to depression and builds a positive self-image

# Self-affirmation Pledge *Liane Holliday Willey*

- I am not defective
- I am different
- I will not sacrifice my self-worth for peer acceptance
- I am capable of getting along with society
- I will ask for help when I need it
- I will be patient with those who need time to understand me
- **I will accept myself for who I am**

# The Advantages of Autism

- The value of being different
- Autistic achievers in the sciences, arts and humanities
- Autism gives qualities as well as difficulties
- Be a first-rate Autie, not a second-rate neurotypical
- The authentic self

# Parkinson's Disease

- Geurts et al (2022) *Autism* 26, 217-229
- **USA**
- 209 adults aged 50-83 years, 100 males and 109 females
- **33% screened positive**
- General population expectation **2.6%**
- Data consistent with previous study PD assessment instrument – 16%-32%
- Common features:
- **Rigidity, stiffness and slowness**
- **Getting 'stuck', arm swing differences and tremors**