

Why do we disappear as we grow older?

Cos Michael

Projects I'm involved with

- Adult autism spectrum cohort. Newcastle
- Improving the Health of Older Autistic People. Newcastle
- Autistic adults and sleep. LiLas Lab. UCL
- Residential care for ageing autistic people. Edinburgh

Next year I will disappear

I will no longer be disabled

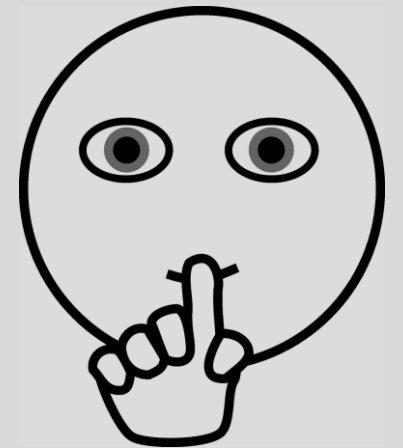
I will be old



How are we perceived, if we are noticed at all?

Terms used to marginalise us include:

Weird...unempathetic...reckless... outspoken... mad... odd...
difficult... aggressive...cold...unfeeling...unimaginative...
stubborn...disloyal... naïve... confused... thoughtless...
gullible...dreamer...unsavvy... and so many more...



Key findings from NAS reports



- 71% of over 45s have never had their needs assessed
 - Elderly parents continue to care for their ageing children without sufficient help or knowledge of where to find help.
 - 96% of parents are worried about their son/daughter's future
 - Discussing future support when parents age and die is a sensitive and complex area. Think about professional guidance
 - Many siblings are willing to help support their autistic brother or sister, but few are able to take over fully from their parents.
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- We exist too: valuing the contribution of siblings. NAS
 - The way we are. NAS

From the outset: trying to get a diagnosis

- There's a very long waiting list
- Why do you want a diagnosis at your age?
- There's no point after all this time
- You've managed so far
- Your original diagnosis of borderline personality disorder / bi-polar / schizophrenia / depression, was correct

Post very late diagnosis

- No information
- No emotional support
- No autism qualified adult counsellors
- No budget for autism support
- NICE guidelines routinely ignored
- No signposting to autistic networks – only the NAS

At the GP

- Blank looks – there's no treatment...
- Generic antidepressants, untested for autism
- Inappropriate support for sleep problems – opiates are OK, we're happy to get you addicted, but we can't prescribe melatonin
- No joining the dots between stress & stress related ailments

Age-related conditions (physical)

- Arthritis
- Cancer
- Dementia
- Dental problems
- Diabetes
- Eyesight loss
- Health problems related to medication
- Hearing loss
- Heart conditions
- Incontinence
- Menopause
- Mobility difficulties
- Parkinson's disease
- Stroke



Unanswered medical questions

- What are the physical implications of a lifetime of self medication?
- How can socially isolated older autistic people keep active?
- What are the long-term outcomes of autism interventions such as selective serotonin reuptake inhibitors (SSRIs) on depression, weight & physical health
- Is fibromyalgia more common in ageing autistic people? How can we be supported?
- How can ageing autistic people avoid gut problems?
- Why are obesity & diabetes rates so high?
- Why is the death rate from seizure so high
- How can we improve sleep for autistic people?

Ageing and autistic women

- Do hormonal changes of menopause affect severity of autism traits, anxiety or depression?
- Do processing speeds return to normal for post menopausal autistic women?
- Does years on anti-depressants affect severity of osteoporosis, post menopause?



Age-related conditions (psychological)

- Anxiety
- Dementia
- Depression
- Epilepsy
- Obsessive compulsive disorder
- Sensory processing
- Social phobias
- Stress-related disorders

Stress may link to conditions common to age

Some responses to stress

- Self-medication, by
 - Over eating
 - Alcohol
 - Smoking
- Poor sleep
- Isolation
- Anti- depressants

Be aware of cause and effect

Ageing related medical problems, common to everyone

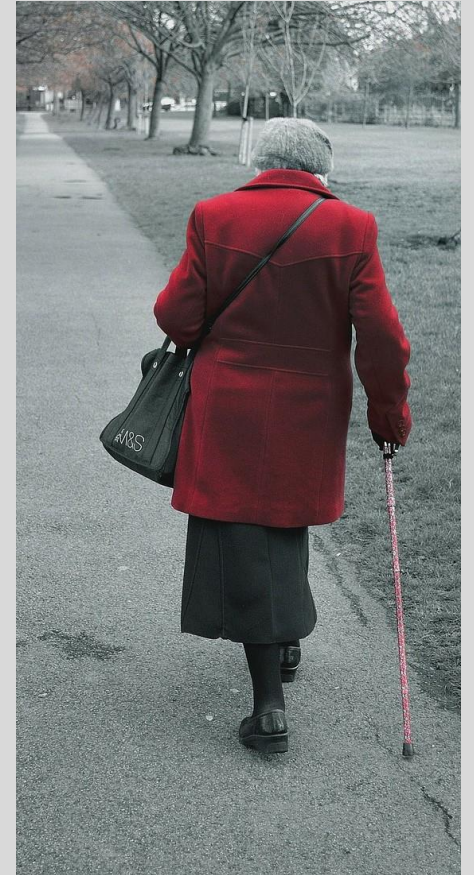
- Obesity
- High blood pressure
- Diabetes
- Heart attack
- Stroke
- Depression
- Arthritis
- Cancer
- Dementia

Unanswered psychological questions

- Is there such a thing as autistic burnout, where we need increasing recovery time & don't "bounce back" to full power, after tiring encounters?
- Any ageing people may get "scatter brained". As autistic people may already have executive function difficulties, how different is the trajectory?
- Does social interaction keep the brain more alert and protect against memory loss?
- If we get dementia, does it progress the same as in the general population?

Emotional wellbeing

- Autistic people go through the same life changes as anyone else.
- Physical changes, reduced mobility, bereavement, etc; all may affect emotional health
- Autistic people may suffer memory loss, dementia, etc, just as in the general population.



Unanswered questions about emotional wellbeing

- The value of autism aware advocacy, to reducing anxiety
- How integrated are ageing autistic adults within their families?
- How to help ageing autistic people maintain independence
- How to support autistic people at times of bereavement
- How to reduce social isolation among ageing autistic people
- Does support with day to day practical issues improve quality of life?

What do autistic older people want from residential care?



If this is the future, take me out and shoot me now

Unanswered questions about residential care

- Why don't Independent Mental Capacity Advocates (IMCAs) get useful training about older autistic people?
- Why aren't there enough residential care beds for older autistic people?
- If residential care home managers and staff are ignorant about ageing autistic people, how can they be expected to provide adequate and appropriate support?
- What do reasonable adjustments look like, for elderly autistic people in residential care homes?
- Are ageing autistic people in residential care settings getting regular health checks?

What to plan

- Where will you live as you grow older?
- Who will provide care, if and when needed?
- Financial planning, trusts, wills, etc
- How to access advocacy if required
- Maintaining domestic routines and tasks
- Social life and contacts
- Maintaining fitness, interests ,etc
- End of life plan
- Your will and funeral wishes
- Health file – document conditions, general family history, medications, doctors, therapists etc. Keep updated
- List of all contacts involved



Ageing can be a good thing too

- Getting older can bring experience and self knowledge
- Walking more slowly gives you time to think and look around
- Emotional health can improve with age
- Other people don't expect older people to rush at everything
- When you retire, you don't have to worry about employment

Autistic people can be



- Focused
- Talented
- Hard working & diligent
- Knowledgeable
- Truthful
- Loving
- Loyal
- Humorous
- Fun loving
- Unique

At any age

Where should we be visible?

- Health services?
- Home care?
- Supported living?
- Socially?
- Transport?
- By the law?
- Medical & social research?
- The autism industry?
- The media?

Thank You

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