A Call For Action
A plea from the heart and mind of a person with Autism and Epilepsy

Jen Leavesley
Independent Supporter for SEND
Introduction

I’m Jen

American, sorry about the accent
Dx Autistic on the NHS in 2014
Husband and 2 daughters have ASD (and ADHD, Tourettes, ARFID, migraines, dyslexia, etc)
And I have epilepsy
I’d always been a quiet, shy, very serious, and quite anxious perfectionist.

One of my favourite hobbies ->
A Tale of Two Diagnoses

Two epilepsy diagnoses
  • One was 20 years ago in the US
  • One was 4 years ago in the UK

Different circumstances

Neither was delivered particularly well
First Go

1997, USA, age 20
Tonic clonic, ambulance ride
Big, physical seizure that everyone noticed.
After the second big physical seizure, diagnosis was given quickly.
Message was left on my answerphone.
Just ‘Epilepsy.’
Things we didn’t know

They didn’t ask me about feelings that came before the seizures:

• The rising wave that started in the middle of me and went upwards
• The feeling that something was suddenly wrong
• The familiarity without cause
• The buzzing in the top of my head

And I didn’t know to tell them. In fact, when those feelings happened on their own, I just assumed I just got lucky a seizure didn’t happen. I didn’t understand what they were.
Lifestyle changes

They said stop driving.
No baths unless supervised.
No swimming unless supervised.
Careful with sports.
No heavy machinery. Job restrictions, etc.
These changes can be hard to accept, especially loss of driving licence.
The feeling of being a burden can be difficult to deal with
Relocation, relocation...

Moved to the UK in 2000, still on meds.
Didn’t bring much in the way of paperwork with me. Didn’t know I needed to.
Naively assumed my diagnosis would just be accepted as truth by the NHS, as it was my truth, my life.
New Beginnings

That happened --->
Quit my meds not long after.
New life, new beginning.
No one here was taking my epilepsy seriously and I couldn’t see the point in pursuing it so I didn’t.
Thus begins the second tale

- Not long after quitting the meds, start having the rising feeling and the familiar, the fear etc, on it’s own, with no tonic clonic.
- Made no connection to epilepsy. Why would i?

- Told my NHS GP about the symptoms
- What does a newly wed young woman get diagnosed with?
- ANXIETY.
- Spend the next 12 years wrongly dx and wrongly medicated for 20 second “panic attacks”
Life goes on

I had no reason to doubt my GP. Array of “panic” and “anxiety” meds that didn’t really help.
Meanwhile we had children, in 2003, 2008

Eldest got an HFA dx in 2007.
Husband got HFA dx in 2007.
Youngest got ASD dx in 2010.
At last!

I finally convinced GP to let me go to neurology in 2013. Attended whilst still on 2 failed panic meds. I had absolutely **no vocabulary** to describe the rising wave or the fear, it was too peculiar and too abstract.

The hospital was a horrible place, the clinic just off a busy corridor, very sick people on trolleys, crutches, strokes, parkinsons, etc. The registrar only humoured me but blamed my kids for causing stress.
I was up all night as requested. It was too hot, too bright. They said it wouldn’t hurt but every one of those bits of metal stuck to my head felt like a thumb being ground into my skull.
EEG cont’d

• I could not fall asleep despite being asked to
• I could not relax, I’d been up all night on strength of will alone
• Hyperventilate for 3 minutes
• Look at these awful flashing lights that made me feel a bit sick
• I came away with a thumping headache
• They patronisingly said it wouldn’t hurt, but they missed the part where it actually did and argued when I tried to tell them.
MRI

- Ear defenders pinched below my ears
- Arms more or less pinned down in a tube
- In the tube up to my sternum - for a claustrophobe could have been terrifying
- Hold perfectly still for 20 minutes
- Deafeningly loud
- Disturbing pattern of clicking that you can feel in your chest, vibrating like a rock concert that you can’t enjoy
The verdict... number 2

Review with the consultant
Asked NEAD specific questions eg biting the tip of my tongue
Internally i was irritated

Didn’t they pay attention the first time? Why wasn’t my American dx good enough? Why was I having to do all of this again?

Read my witness account from a friend
Diagnosed complex partial seizures
Prescribed meds
Several years later...

Several meds later
Lots of lifestyle changes later
Many races later
Here I am, stood in front of you.

It got better when I took control and stopped being passive.
Broader Representation

Epilepsy is a clinical diagnosis made on history. EEG and MRI add weight to the diagnosis but do not disprove it.

Autism/epilepsy overlap up to 30%. Average 8.6% - Thomas et al

“When divided by type, the risks of ASD for general epilepsy, infantile spasms, focal seizures, and Dravet syndrome was 4.7%, 19.9%, 41.9% and 47.4% respectively.” - Strasser, et al.

Wakeford, 2013 found incr signs of ASD in TLE. - Univ of Bath
Autism is very heterogeneous. Epilepsies are plural.

Many genetic syndromes eg Landau-Kleffner, Dravet, tuberous sclerosis, SHANK3, etc lead to both seizures and autism.

ID is the biggest risk factor for developing epilepsy in autism.

(sic) Those with autism tend to develop epilepsy later, it may have a different pattern, and be harder to treat. -Autistica epilepsy leaflet
Mysteries

We may not know we’ve had a seizure. I went how long thinking it was “panic”? It may be assumed we are panicking or “behaving challengingly” for those with ID/LD

Seizures can affect the memory. Nighttime disturbances and/or buccal injuries may be the only sign

Bitten tongues, bouts of sudden irritability or sleepiness may be clues
Interoception

We may genuinely not have the vocabulary to describe what we are feeling.
We may not know what we are feeling other than it is “wrong”.
We may associate the wrong word with the wrong meaning.
We may have a different contextualised meaning for a word than the one you’d expect.

   Eg “anxiety” describing that awful fearful feeling and rising wave, but it being assumed I meant “panic attack” by professionals.
Do:

- Set aside all preconceived notions
- Make reasonable adjustments eg email
- Make clinic ASD friendly, as it is generally hideous
- Train registrars in autism presentations incl female
- Odds are that even without a formal ASD dx, mother of ASD kids is likely autistic herself
- Give time to find a med that works, not “2 meds failed = you have NEAD”
Don’t:

• Don’t assume anything
• Don’t rush me please - rapid fire questions are not helpful.
• Don’t carry on legacy meds or dx because the registrar before suggested them
• Don’t mistake seizures for “behaviours” in those with ID/LD
• Don’t assume verbal = able to express all symptoms or feelings
• Don’t ignore other expert reports in making dx eg psychiatrist
• Don’t forget you’re working as a team with the person!
Other:

Exercise. Yeah yeah, I know (this smug skinny gal used to be 15 stone)
Cardio burns off adrenaline/cortisol
Running is the **best thing** I ever did for myself
Obesity can be a function of inflammation, which can contribute to seizures
Obesity is a well known comorbidity in autism
Address depression, it contributes to seizures - Michaelis, et al
(The verve lyrics here...)

- Medications - side fx / QoL balance
- If it makes you feel worse, you ain’t gonna take it.
- Most AEDs have sleepiness, balance, working / short term memory, word retrieval issues, weight gain, etc
- Find one that you can live with.
- And a neurologist who has patience while you do (!).
- Statistics about how many become seizure-free after the 1st drug, 2nd drug, etc. Just statistics. Doesn’t always pan out in real life
Autistic considerations

• Autistic people seem to be more sensitive to the side effects of medications – Whiteley, et al
• Autistics may need less of medication to achieve an effect
• Or they may need far more / paradoxical effects
• Other meds, eg antipsychotics eg clozapine, TCAs eg amitriptyline, painkillers eg tramadol, may lower seizure threshold
• Valproate in females, ultimate last resort if she could get pregnant because transgenerational teratogen - EMA guidance
References


References, cont’d


Whiteley P, Shattock, P. The use of medication for people with Autism Spectrum Disorders, Durham Conference, 2004. [https://t.co/M5JfT1U1vm](https://t.co/M5JfT1U1vm)


[https://www.bath.ac.uk/news/2013/05/16/wakeford/](https://www.bath.ac.uk/news/2013/05/16/wakeford/)
Thank you.
Epilepsy & Autism
Simplicity is complex!

Dr Rohit Shankar  MBE, FRCPsych
Consultant Neuropsychiatrist & Hon. Associate Clinical Professor
DISCLOSURES

Dr ROHIT SHANKAR –
Has received institutional/research support, lecture and consultation fees from:

UCB, Eisai, Bial, Special Products, LivaNova and Desitin outside the presented work in the last 2 years
What this presentation is **NOT**....

- Talking of new neurobiological theories, concepts and genetics to ‘solve’ epilepsy for people with Autism

- A critical research presentation on the merits and demerits of certain drugs, therapies or interventions for people with Autism

- Look to provide new research insights to Epilepsy and Autism

- Possibly interesting with lot of new jargon
What this presentation is about.... applying science

• How while we worry for ‘new solutions’ we have not applied current evidence base

• “Simple fixes” which can help improve lives for many

• Common sense and stating the obvious!

• Making complex simple

• Defining the lowest common denominator
Should we treat PWE & Autism differently?

Learning from one’s mistakes – case examples

Overview of association of Autism with Epilepsy

Current evidence base on prescribing

Ep-ID/PDD Research Register: concept, expectation & fallacies
You all know this story.....

The blind men and the elephant. Poem by John Godfrey Saxe (Cartoon originally copyrighted by the authors; G. Renee Guzlas, artist).
Now let's substitute...Epilepsy care for people with Autism is fragmented...

What do we know!

They are the experts, they know what to do!

It's not my problem!

They must be working to current good practice!

The patients & families complaining – what do they know!

People die – sad but not my problem
The Importance of Being Suzanne,
A Trivial Comedy for Serious People

I am sick to death of cleverness. Everybody is clever now-a-days. You can't go anywhere without meeting clever people. The thing has become an absolute public nuisance. I wish to goodness we had a few fools left.
Suzanne 42 years

Relevant history

- Autism & moderate ID, poor communication and social skills
- No genetic syndrome
- Father – dementia

Seizure history

- Childhood onset
- Generalised seizures
- Tried all medication, from phenobarbitone to zonisamide
- Regular 1st line medication – lamotrigine
- Was having 1 seizure/week – difficult to administer midazolam
- Airlifted to Derriford
- Not suitable for VNS/surgery

ID, intellectual disability; VNS, vagus nerve stimulation
I am Suzanne, 42 yrs

• Social services
• Residential care
• Change in regime
• Addition of adjunct increased 3 months later
• 4 weeks later, phone call – behavioural disturbances

• Complex issues affect health outcomes
• Quality of life
• Safety
• Community access

• Communication via 3rd party often difficult
• Behavioural side effects to medication
• Treatment-resistant epilepsy
The Curious Incident of the Dog in the Night-Time

- Christopher 20 years
- Moderate ID + Autism
- Communication difficulties
- Behaviour change and increased seizures
A bitter pill to swallow

- Childhood seizures treated with Phenytoin
- Autism & in an institution
- Seizure remission @ 11 years continued on Phenytoin
- Gingival hyperplasia leading to Dental problems
- Behavioural disturbance
- Died of aspiration during a dental procedure under GA at age 22
Sleep on it!

- Justin moderate ID, autism and no verbal communication
- Midazolam 1/month
- Increased to 3/week
- Home visit to residential home
- Back to baseline
- Environment matters!
• Ben 22 years old
• Autism with stereotypies
• Sits in the corner and rocks
• Large farm house and joint family
• Non-convulsive status episodes
• Difficult to treat epilepsy
• Medication increased – c/o of behavioural disturbance
• Highly disruptive in family

“I’m not the same everyday. There are times where I’m loud and chatty, and there are times when I’m really quiet. I don’t think I can define myself.”

Strange case of and Dr Jekyll Mr. Hyde

R.L Stevenson
The GP vanishes

• Gareth - Autism and communication issues

• Consistent self harm behaviour

• Regular complaints of increase of self harm behaviour with each medication change or dose increase

• Best Interest meeting with GP and IMCA
The problem: There is no UK wide NHS Plan to reduce the epilepsy burden

All causes of deaths before the age of 70

GP QOF indicator removed in 2012

60% of deaths in epilepsy can potentially be prevented Asthma 25%

Number of deaths rising yearly
Impact on the NHS

73% of first-seizure patients are not given seizure management advice

£1.5 Billion
(Yearly cost of Epilepsy)

60,000 additional emergency attendances

40,000 epilepsy-related hospital admissions

National Audit of Seizure management in Hospitals (NASH) – 2012 & 2015

63% with no contact with health services
RELATIVE SCALE OF RISK

600,000 people in UK with EPILEPSY
1,187 DEATHS
(2013)

5.3 million people in UK with Asthma
1,255 DEATHS (2013)
Hospital Admissions which should not happen: for Seizures

Figure 2 Comparison of the causes of emergency admissions for ACSCs admissions for people with and without LD or associated conditions (cont).
Autism & it’s spectrum

• Up to 38% may develop epilepsy\textsuperscript{1}

• Two peaks\textsuperscript{2}
  – 0-5 years
  – 10 years +

• Seizures have low remission rate (16% in adulthood)\textsuperscript{3}

\textsuperscript{1}Rossi et al. Brain Develop 1995;17:169–74
\textsuperscript{3}Danielsson et al. Epilepsia 2005;46:918–23
Autistic disorder and epilepsy: reasons for co-occurrence

• Both conditions are totally independent
• The same brain pathology causes the autistic phenotype and the epilepsy (e.g., Fragile X-syndrome)
• An epileptic process interferes with the developing function of specific brain networks involved in communication and social behaviour
• A focal (multifocal) brain pathology (e.g. tuberous sclerosis) can cause an autistic phenotype as well as trigger epilepsy that aggravates the autistic symptoms
• An epileptic process causes a specific sensory or cognitive dysfunction with “autistic withdrawal”

Deonna, Epilepsia 2006; 47 Suppl 2:79-82
Overlaps between autism with or without epilepsy and other disorders of young children with or without language regression.

Risk of epilepsy in autism and ID

Tuchman & Rapin Lancet Neurol 2002;1:352–8
ASD subtypes & epilepsy
(Tuchman & Rapin 2002)

• Core autism (autistic disorder, AD)
  – About 30% show AR
  – About 30% develop a clinical epilepsy by adolescence
• Asperger syndrome
  – ~5-10% develop epilepsy in early childhood
• Pervasive Developmental Disorder NOS
  – Increased risk of epilepsy linked to severity of brain dysfunction
• Disintegrative Disorder
  – up to 70% develop epilepsy
• Rett syndrome
  – >90% develop epilepsy
<table>
<thead>
<tr>
<th>Characteristics of the individuals with or without epilepsy</th>
<th>Epileptics ((n = 33))</th>
<th>Non-epileptics ((n = 97))</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender (M/F)</td>
<td>25/8</td>
<td>81/16</td>
</tr>
<tr>
<td>Birth weight (g)</td>
<td>(3227 \pm 374)</td>
<td>(3172 \pm 457)</td>
</tr>
<tr>
<td>Head circumference (cm)&lt;sup&gt;a&lt;/sup&gt;</td>
<td>(33.5 \pm 1.0)</td>
<td>(33.5 \pm 1.7)</td>
</tr>
<tr>
<td>Age when walking alone (months)</td>
<td>(14.4 \pm 7.0)</td>
<td>(13.7 \pm 3.6)</td>
</tr>
<tr>
<td>Diagnosis of DSM-IV</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Autistic disorder</td>
<td>26</td>
<td>75</td>
</tr>
<tr>
<td>Atypical autism</td>
<td>7</td>
<td>22</td>
</tr>
<tr>
<td>Speech loss in infancy (+/-)</td>
<td>7/26</td>
<td>17/80</td>
</tr>
<tr>
<td>Cognitive level***</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Normal–mildly retarded</td>
<td>1 (3.1%)</td>
<td>31</td>
</tr>
<tr>
<td>Moderately retarded</td>
<td>6 (20.0%)</td>
<td>24</td>
</tr>
<tr>
<td>Severely retarded</td>
<td>8 (22.2%)</td>
<td>28</td>
</tr>
<tr>
<td>Profoundly retarded</td>
<td>18 (56.3%)</td>
<td>14</td>
</tr>
<tr>
<td>Adaptive level (SQ)&lt;sup&gt;b, **&lt;/sup&gt;</td>
<td>(42.1 \pm 16.8)</td>
<td>(59.4 \pm 20.6)</td>
</tr>
<tr>
<td>Psychotropic drugs (+/-)&lt;sup&gt;*&lt;/sup&gt;</td>
<td>21/12</td>
<td>39/58</td>
</tr>
</tbody>
</table>

<sup>a</sup> Six data points were not available.

<sup>b</sup> Two data points were not available.

<sup>*</sup> \(p = 0.026\) (Fisher, both side).

<sup>**</sup> \(p < 0.05\).

<sup>***</sup> \(p < 0.001\).
What we want
Help the individual and not the condition

• Better outcomes to general population

• Recognition of the unique characteristics & challenges

• Consistency of care

• Person centred care

• Inclusion in research
Interaction between various stakeholders

International League Against Epilepsy
1909 - present

General Practice
Learning Disability Teams
hospitals - Neurology & ED
Paramedics

NHS England
Commissioning

Royal College of Psychiatrists
Intellectual Disability Faculty

Epilepsy Specialist Nurses

Epilepsy Charities

UNIFORM PERSON CENTRED HOLISTIC CARE
Current National Developments

**Management of epilepsy in adults with intellectual disability**

**Prescribing anti-epileptic drugs for people with epilepsy and intellectual disability**

**Professionalising the administration of Buccal Midazolam: Guidelines and testing for UK carers**

Authors

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Phil Tittensor, Royal Wolverhampton NHS Trust, Rohit Shankar, Cornwall Partnership NHS Foundation Trust, Mathew Walker, University College London Hospitals NHS Foundation Trust, Manny Bagary, Birmingham and Solihull Mental Health NHS Foundation Trust, Sarah Tittensor, Choices Housing Association, Erica Chisanga, Cambridge University Hospitals NHS Foundation Trust, Caryn Jory, Cornwall Partnership NHS Foundation Trust
Current management practices
Some assertions based on boring clinical experience with some evidence based justification...
### Grading of evidence

<table>
<thead>
<tr>
<th>Grade</th>
<th>Level</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1a</td>
<td>Evidence from systematic reviews or meta-analysis of RCTs</td>
<td></td>
</tr>
<tr>
<td>1b</td>
<td>Evidence from at least one RCT</td>
<td></td>
</tr>
</tbody>
</table>
| 2a    | Evidence from at least one controlled study without randomisation  
       | Evidence from at least one other type of quasi experimental study |
| 3     | Evidence from non-experimental descriptive studies, such as comparative studies, correlation studies and case–control studies |
| 4     | Evidence of post study analysis of a section of ID population following large study sample studies |
| 5     | Evidence from expert committee reports or opinions and/or clinical experience of respected authorities |
Traffic light system for prescribing

The traffic light system couples both clinical experience, evidence of efficacy and side effects to provide a recommendation.

Only use in exceptional circumstances

Considered if benefits outweigh risks or 2nd line

Needs to be considered as first line treatment
Always told what is dangerous and what we cannot do...poor highlighting of what we can do!
Sometimes you have to make a plan....

Common AED drug interactions

How to prescribe and monitor

psychotropic drugs and AEDs

AED cognition and behavioural attributes

MHRA guidance
How should we approach Seizures?

- Outcomes
- Treatment
- Safety
Safety is everyone’s business

- Genetics
- Diagnosis
- Infections
- Sleep/Constipation

- Intensity
- Frequency
- Medication
- Rescue plans

- Residence
- Checks and surveillance
- Baths/Showers
- Beds/sleep
- Training

- Psychological co-morbidity
- Mental disorder such as Alcohol, Bereavement, Drugs etc.
Epilepsy management is about balance.
College Report 203 & 206

- [http://www.rcpsych.ac.uk/usefulresources/publications/college-reports/cr/cr206.aspx](http://www.rcpsych.ac.uk/usefulresources/publications/college-reports/cr/cr206.aspx)

- [http://www.rcpsych.ac.uk/usefulresources/publications/college-reports/cr/cr203.aspx](http://www.rcpsych.ac.uk/usefulresources/publications/college-reports/cr/cr203.aspx)
The more you know, the harder it is to take decisive action.

Once you become informed, you start seeing complexities and shades of gray.

You realize that nothing is as clear and simple as it first appears. Ultimately, knowledge is paralyzing.

Being a man of action, I can't afford to take that risk.

You're ignorant but at least you act on it.