

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.

EEG

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

Heterogeneous is an understatement y'all

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

Amiet C, Gourfinkel-An I, Bouzamondo A, et al. Epilepsy in autism is associated with intellectual disability and gender: evidence from a meta-analysis. *Biol Psychiatry* 2008; **64**: 577–82.

Strasser L, Downes M, Kung J, et al. Prevalence and risk factors for autism spectrum disorder in epilepsy: a systematic review and meta-analysis. *Dev Med Child Neurol*. 2017 Nov **60** 19-29

<https://www.autistica.org.uk/downloads/files/Epilepsy-autism-E-LEAFLET.pdf>

Michaelis R, Tang V, Reuber M et al. Cochrane systematic review and meta-analysis of the impact of psychological treatments for people with epilepsy on health-related quality of life. *Epilepsia* 2018 January 3.

Dubey D. et al. Neurological Autoantibody Prevalence in Epilepsy of Unknown Etiology. *JAMA Neurol*. 2017 Feb 6

References, cont'd

Thomas S. Hovinga ME, Rai D, et al. Brief Report: Prevalence of Co-occurring Epilepsy and Autism Spectrum Disorder: The U.S. National Survey of Children's Health 2011-2012. *J Autism Dev Disord*. 2017 Jan **47**(1):224-229

Sundelin H, Larsson H, Lichtenstein P, et al. Autism and epilepsy A population-based nationwide cohort study. *Neurology* 2016; 87 (2)

Cauffield, J. [INFOGRAPHIC] Medication use in Autism Spectrum Disorders: What's the evidence? *Formulary Journal* 2013 May.

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

<https://spectrumnews.org/features/deep-dive/weighing-autisms-obesity-crisis/>

<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

Cornwall Partnership 
NHS Foundation Trust

UNIVERSITY OF
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SCHOOL

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?

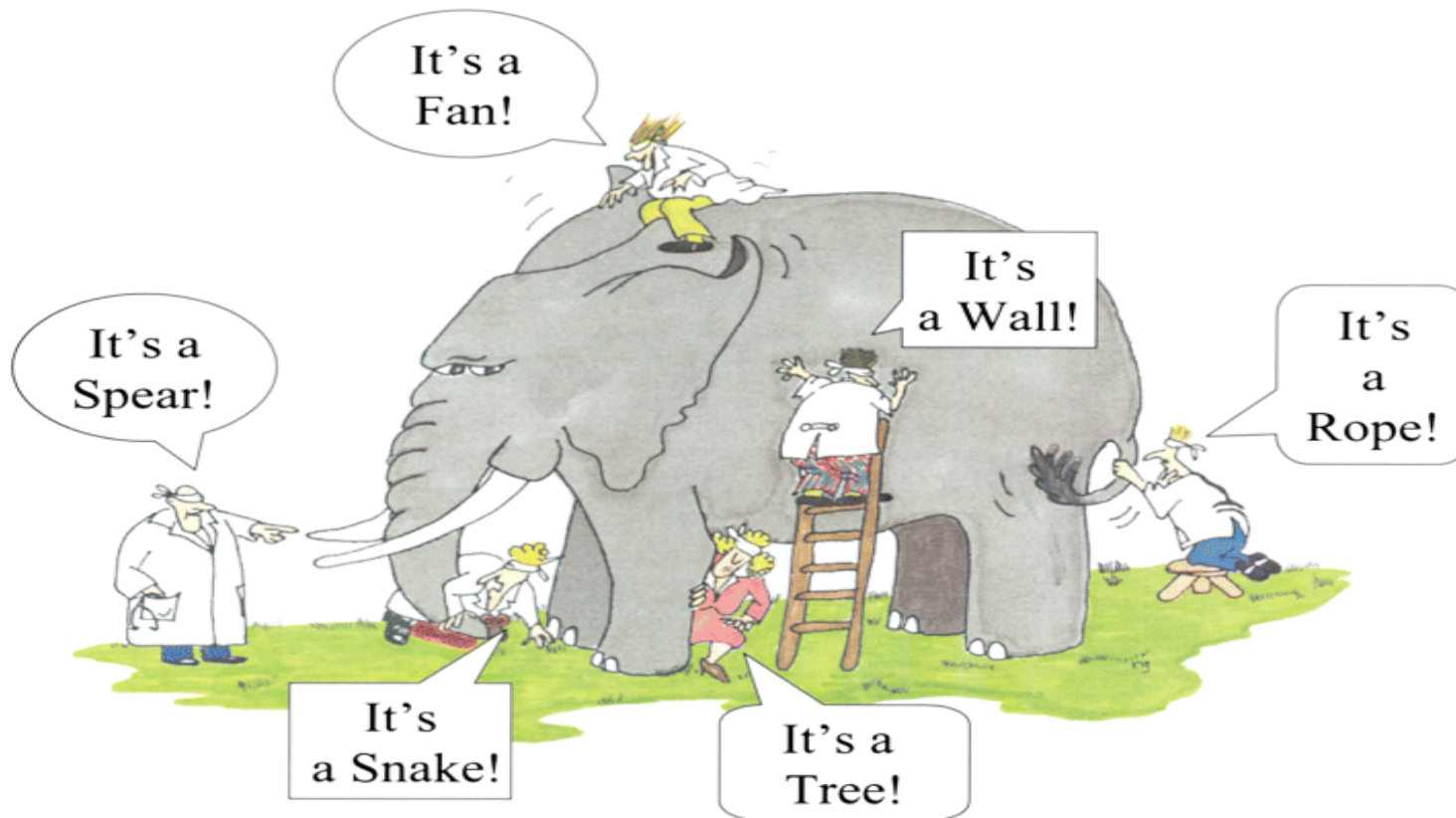
Learning from one's mistakes – case examples

Overview of association of Autism with Epilepsy

Current evidence base on prescribing

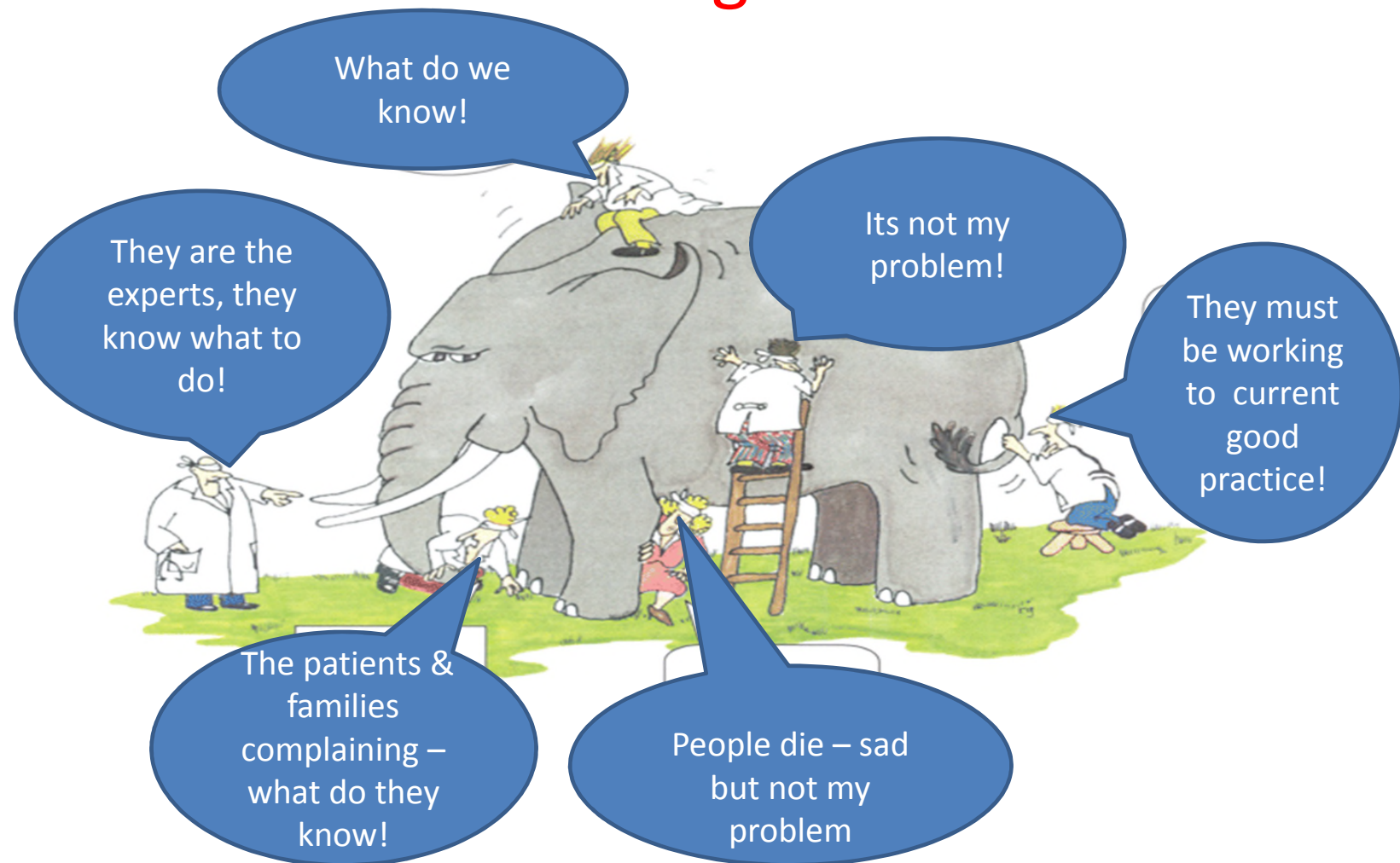
Ep-ID/PDD Research Register: concept, expectation & fallacies

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 lets substitute...Epilepsy care for people with Autism is fragmented...



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.

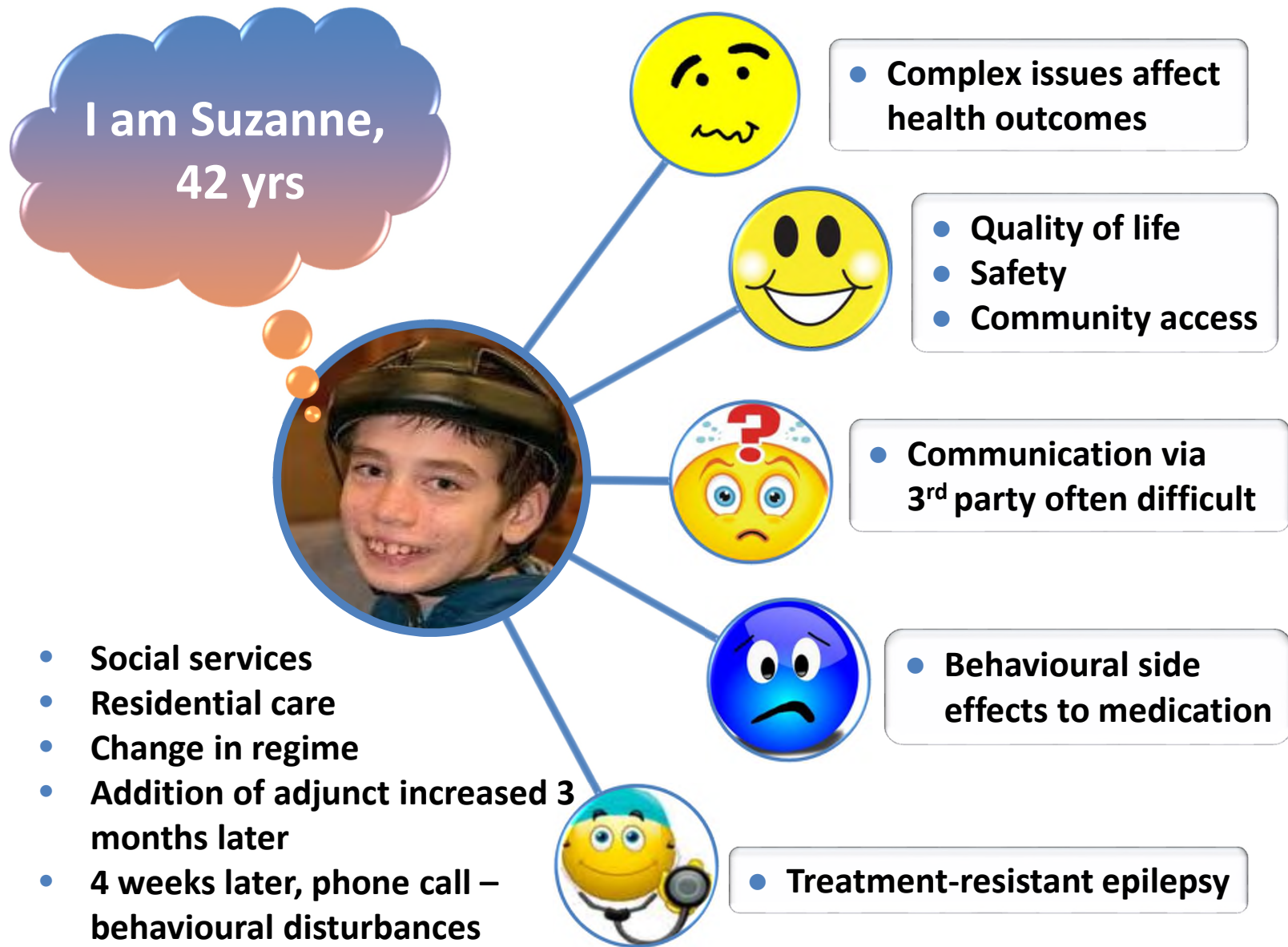
Suzanne 42 years

Relevant history

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

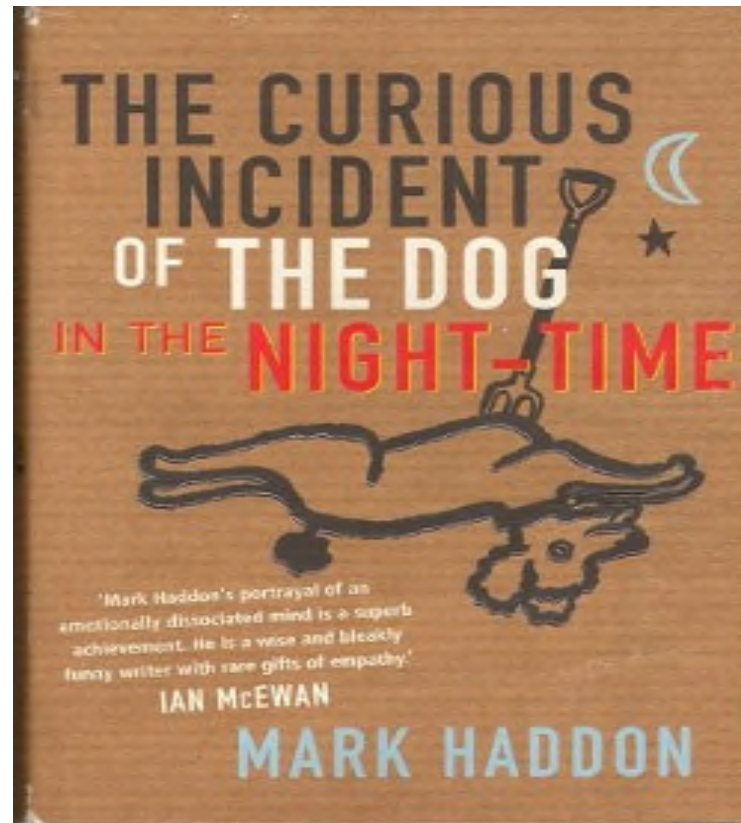
Seizure history

- 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



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

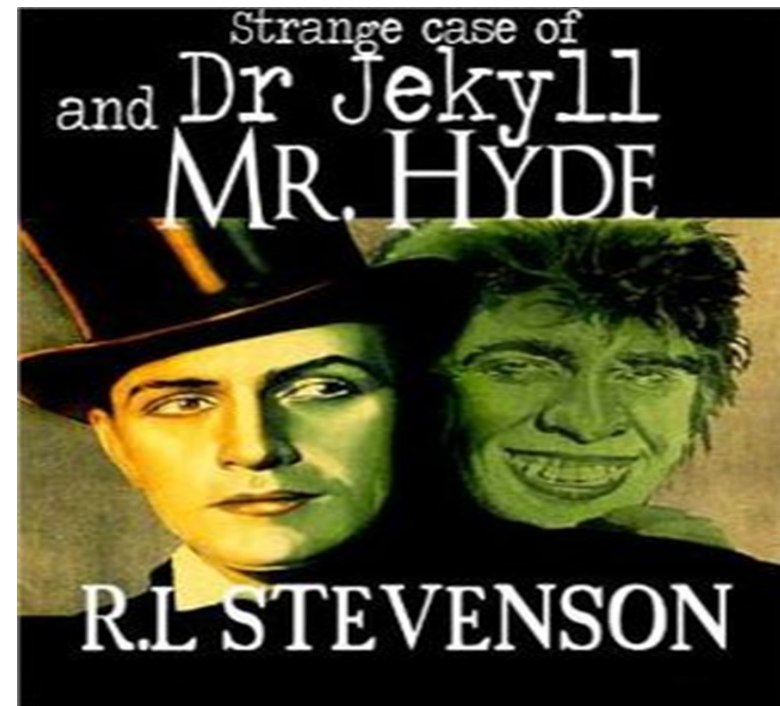


Sleep on it!

- 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!



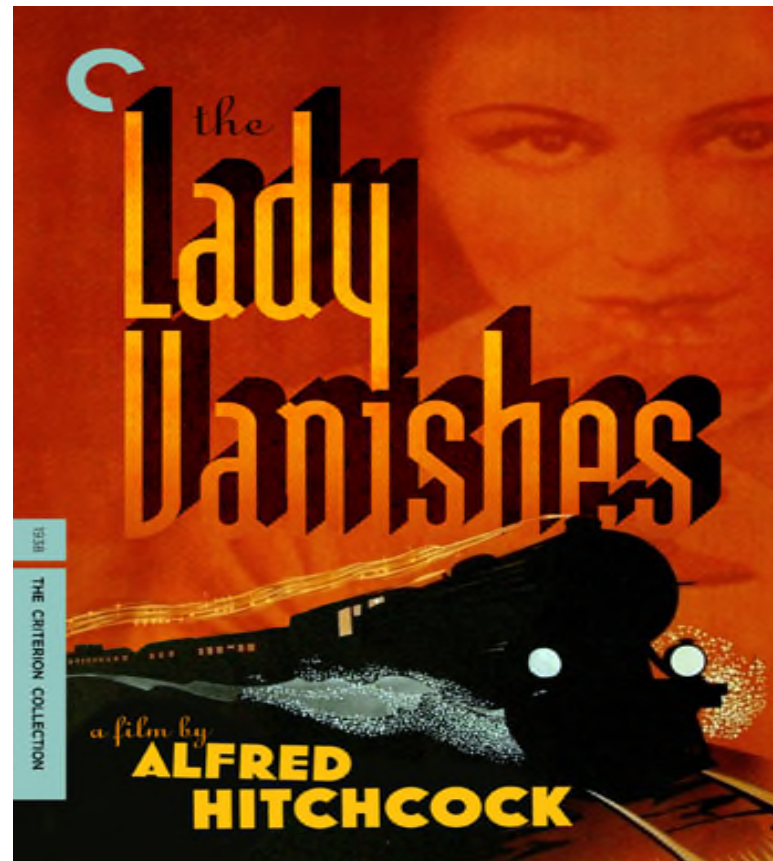
- Ben 22 years old
- Autism with stereotypies
- Sits in the corner and rocks
- Large farm house and joint family
- Non-convulsive status episodes
- Difficult to treat epilepsy
- Medication increased – c/o of behavioural disturbance
- Highly disruptive in family



“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.”

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



Number of deaths
rising yearly



All causes of deaths
before the age of 70



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

GP QOF indicator removed in 2012

Impact on the NHS

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

63% with no contact with health services



£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

RELATIVE SCALE OF RISK

600,000 people in UK with EPILEPSY

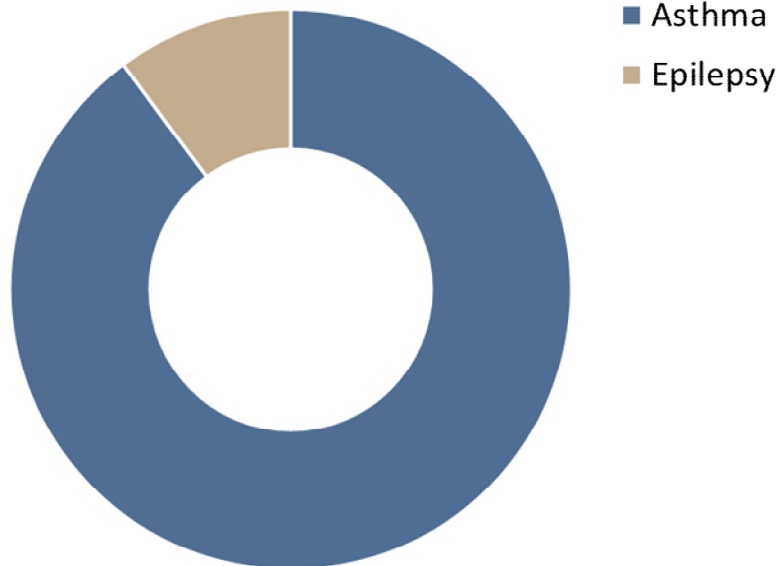
1,187 DEATHS

(2013)

5.3 million people in UK with Asthma

1,255 DEATHS (2013)

Epilepsy Vs Asthma Populations

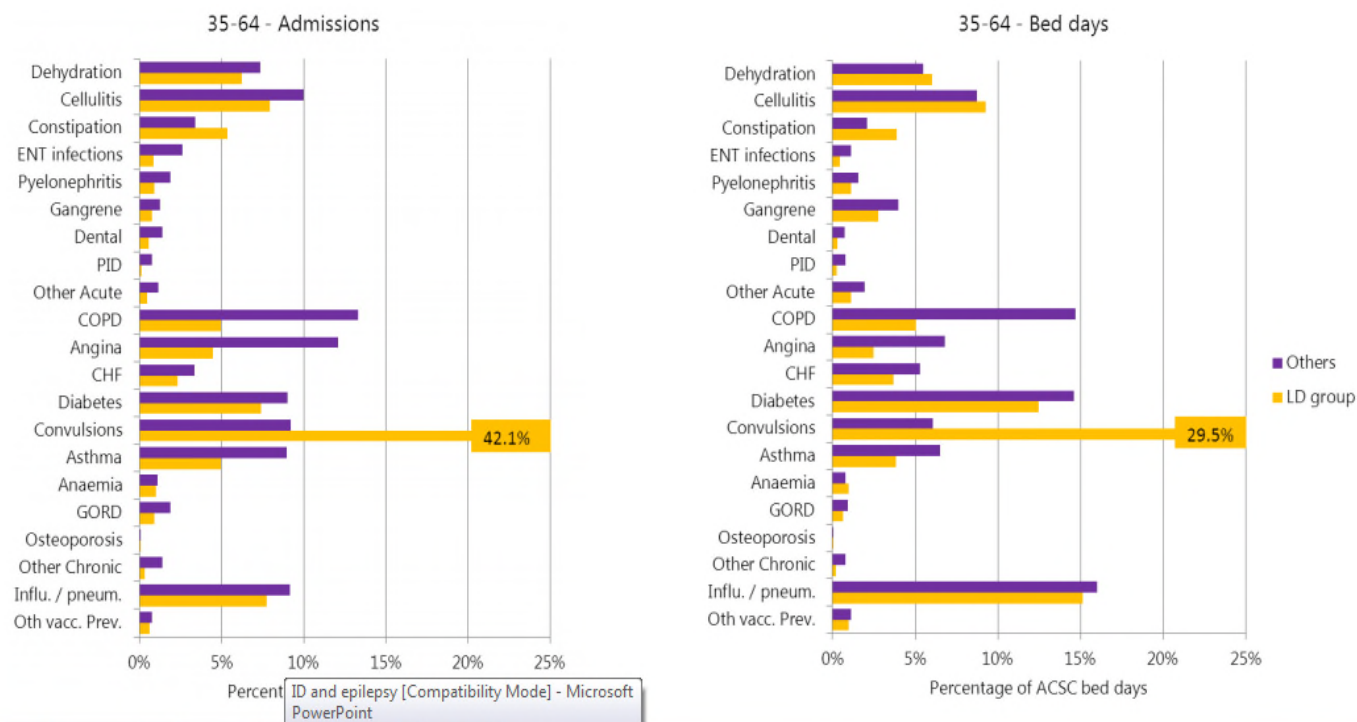


DEATHS



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 epilepsy¹
- Two peaks²
 - 0-5 years
 - 10 years +
- Seizures have low remission rate (16% in adulthood)³

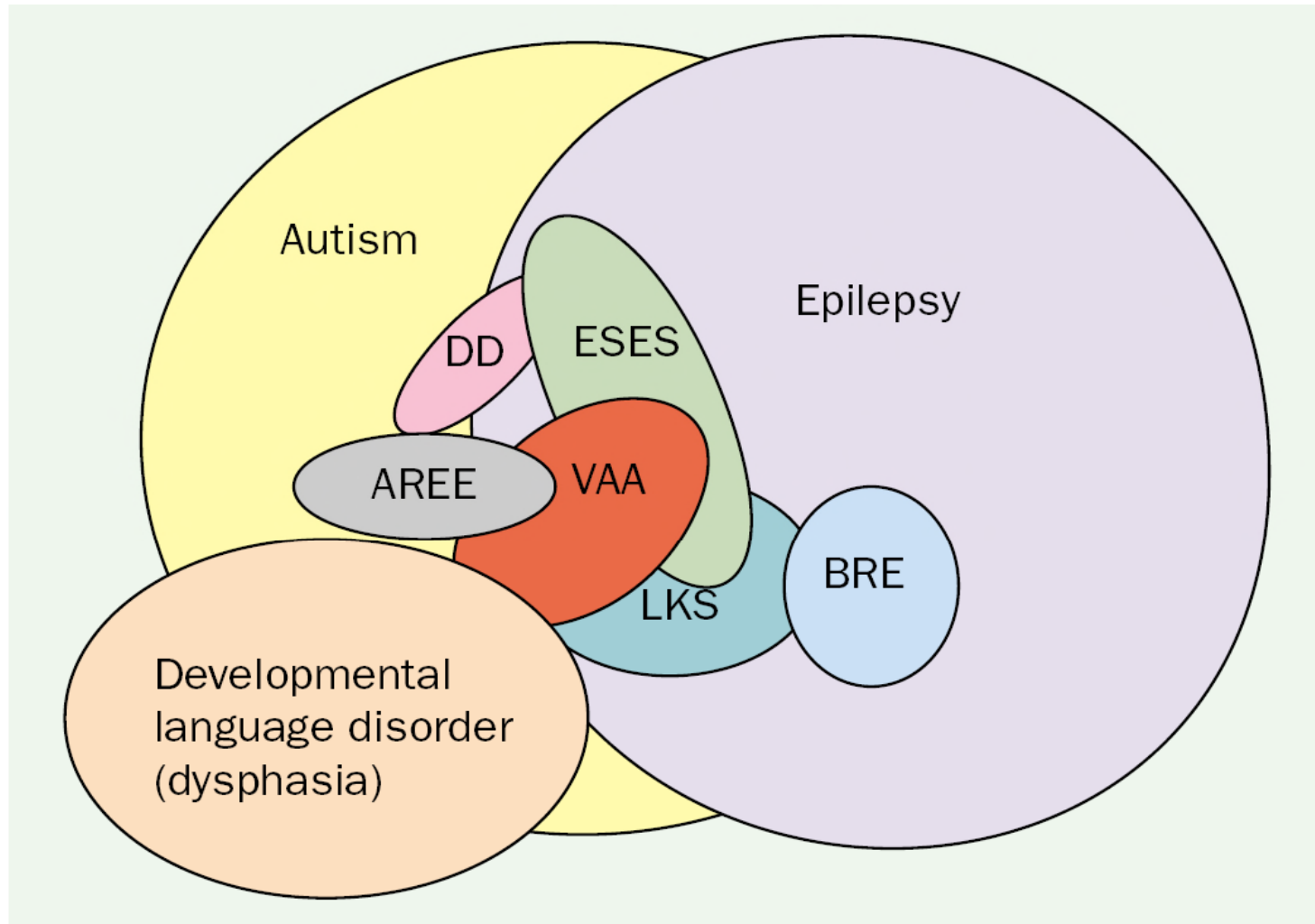
¹Rossi et al. Brain Develop 1995;17:169–74

²Volkmar & Nelson J Am Acad Child Adolesc Psychiatry 1990;29:127–9

³Danielsson et al. Epilepsia 2005;46:918–23

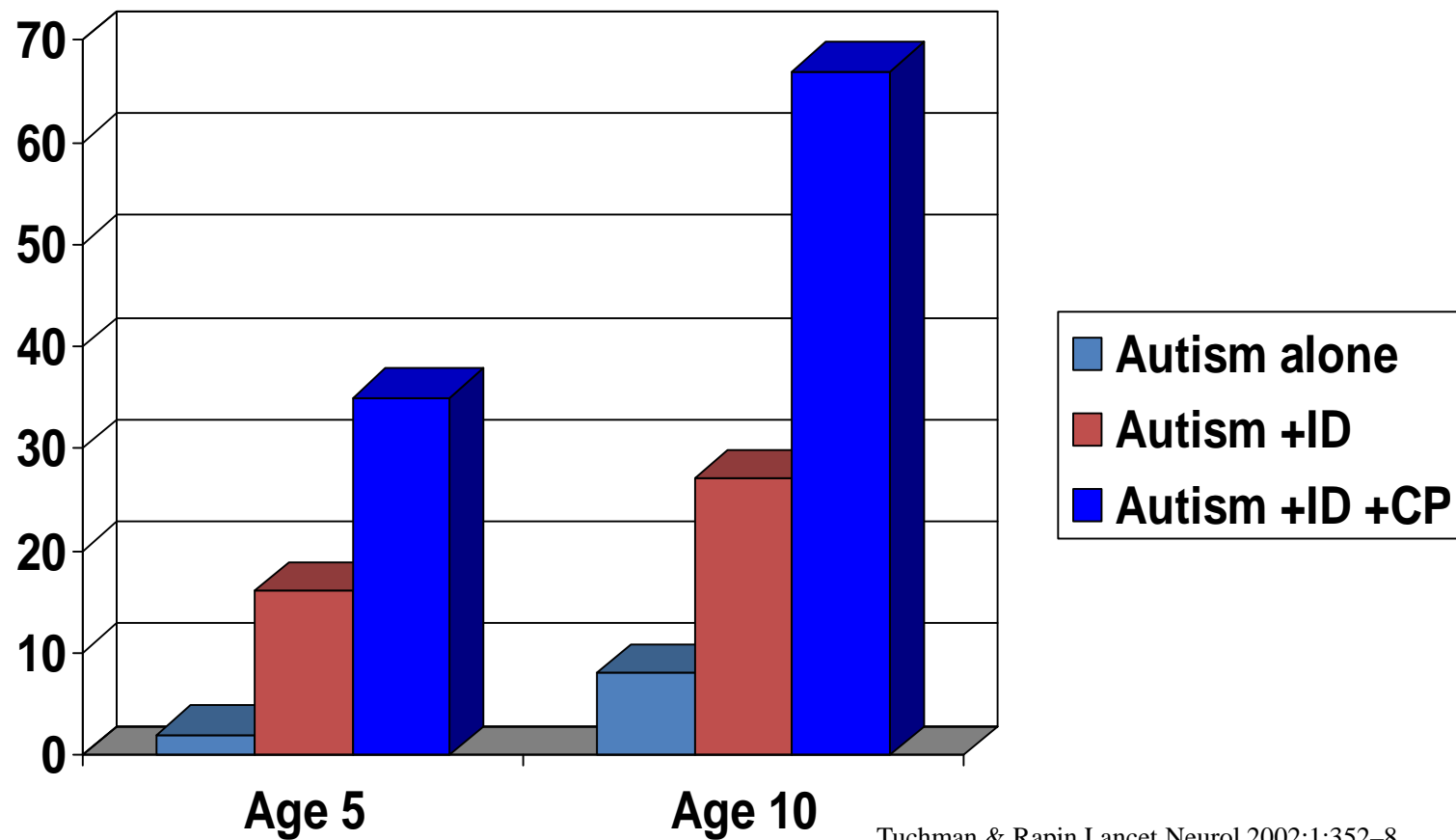
Autistic disorder and epilepsy: reasons for co-occurrence

- 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”



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 1
Characteristics of the individuals with or without epilepsy

	Epileptics (<i>n</i> = 33)	Non-epileptics (<i>n</i> = 97)
Gender (M/F)	25/8	81/16
Birth weight (g)	3227 ± 374	3172 ± 457
Head circumference (cm) ^a	33.5 ± 1.0	33.5 ± 1.7
Age when walking alone (months)	14.4 ± 7.0	13.7 ± 3.6
Diagnosis of DSM- IV		
Autistic disorder	26	75
Atypical autism	7	22
Speech loss in infancy (+/–)	7/26	17/80
Cognitive level ^{***}		
Normal–mildly retarded	1 (3.1%)	31
Moderately retarded	6 (20.0%)	24
Severely retarded	8 (22.2%)	28
Profoundly retarded	18 (56.3%)	14
Adaptive level (SQ) ^{b,**}	42.1 ± 16.8	59.4 ± 20.6
Psychotropic drugs (+/–) [*]	21/12	39/58

^a Six data points were not available.

^b Two data points were not available.

^{*} *p* = 0.026 (Fisher, both side).

^{**} *p* < 0.05.

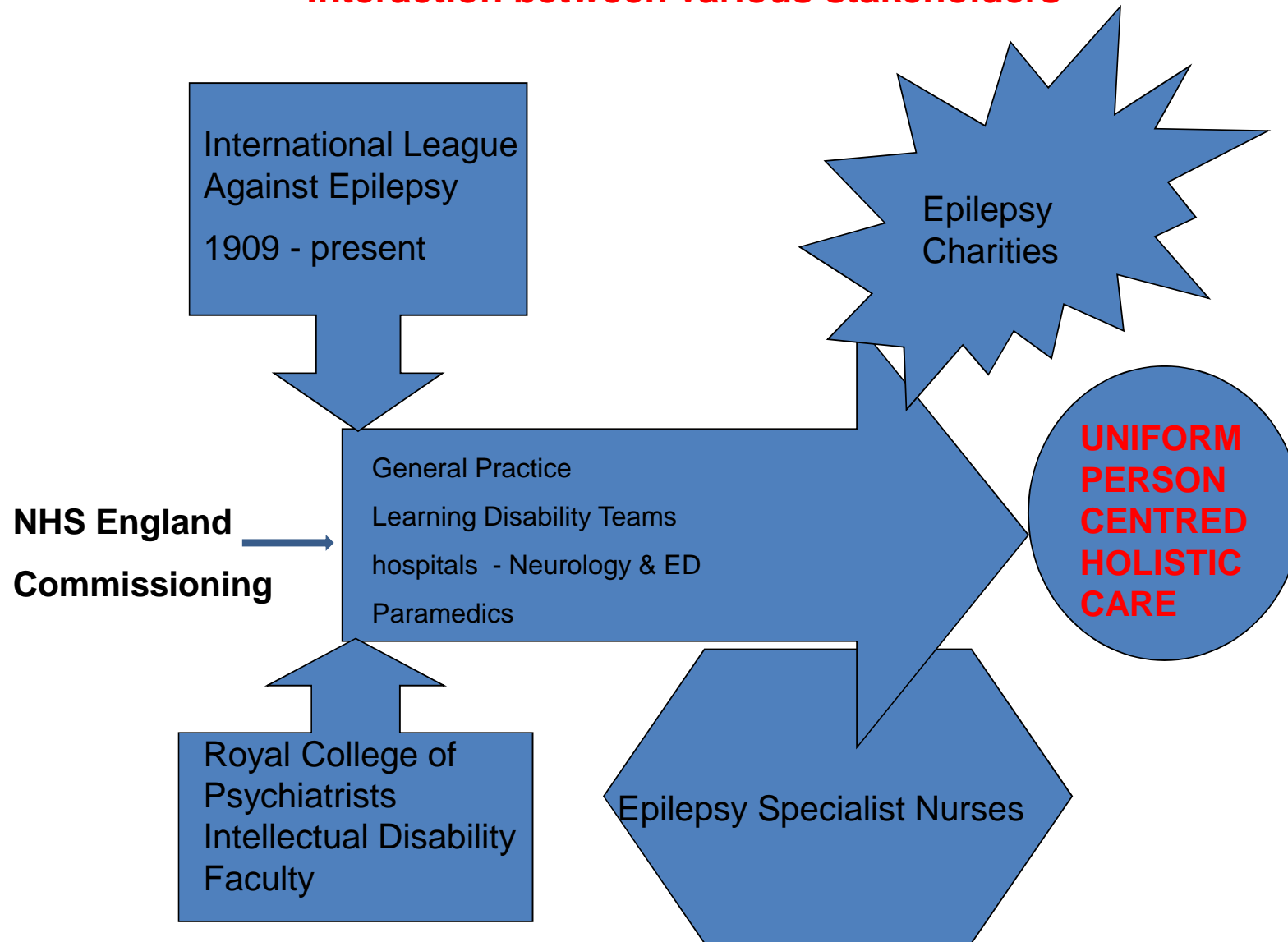
^{***} *p* < 0.001.

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



Current National Developments


GOOD PSYCHIATRIC PRACTICE CR203

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

COLLEGE REPORT


CR206

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

COLLEGE REPORT

ILAE UK INTELLECTUAL DISABILITY APRIL 2017

THE PROVISION OF CARE TO ADULTS WITH AN INTELLECTUAL DISABILITY IN THE
UK;

A SURVEY BY THE BRITISH CHAPTER OF THE ILAE

Authors

The British Branch of the International League Against Epilepsy (ILAE) Working Group on
services for adults with intellectual disability and epilepsy

Kerr, MP,¹ Watkins, LV,² Angus-Leppan, H,³ Corp, A,⁴ Goodwin, M,⁵ Hanson, C,⁶
Roy, A,⁷ Shankar, R.⁸

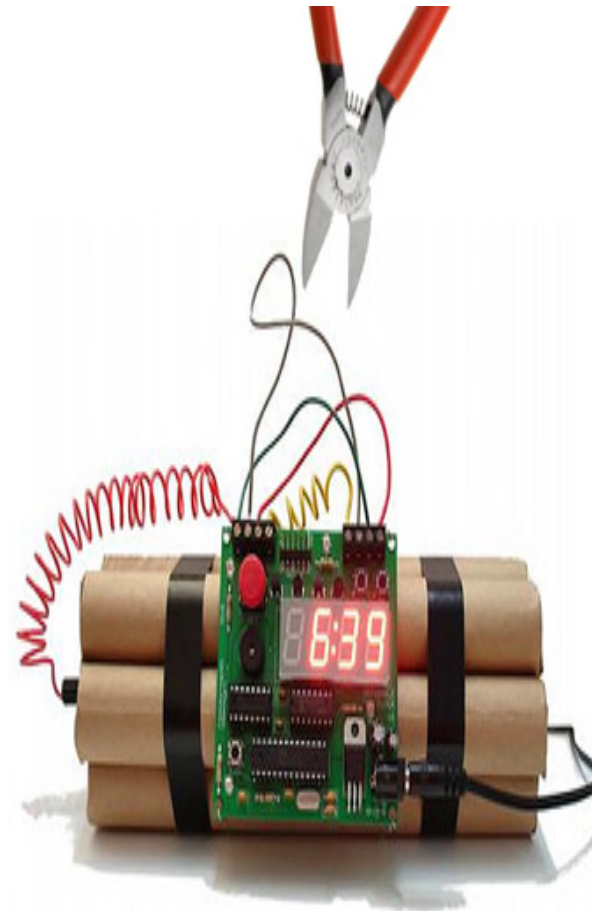
Professionalising the administration of Buccal Midazolam: Guidelines and testing for UK carers

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

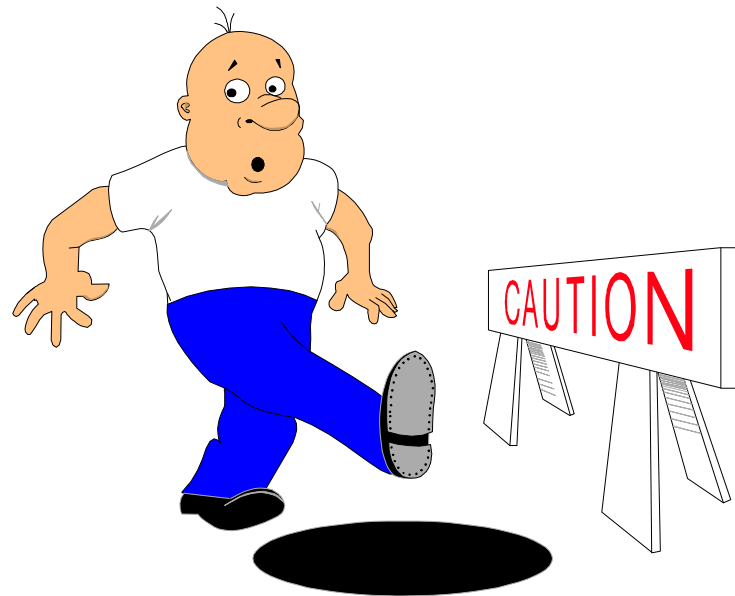
Current management practices



I know the way through the minefield,
step exactly where I do!



***Some assertions based on boring clinical
experience with some evidence based
justification...***



Grading of evidence

1a	Evidence from systematic reviews or meta-analysis of RCTs
1b	Evidence from at least one RCT
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

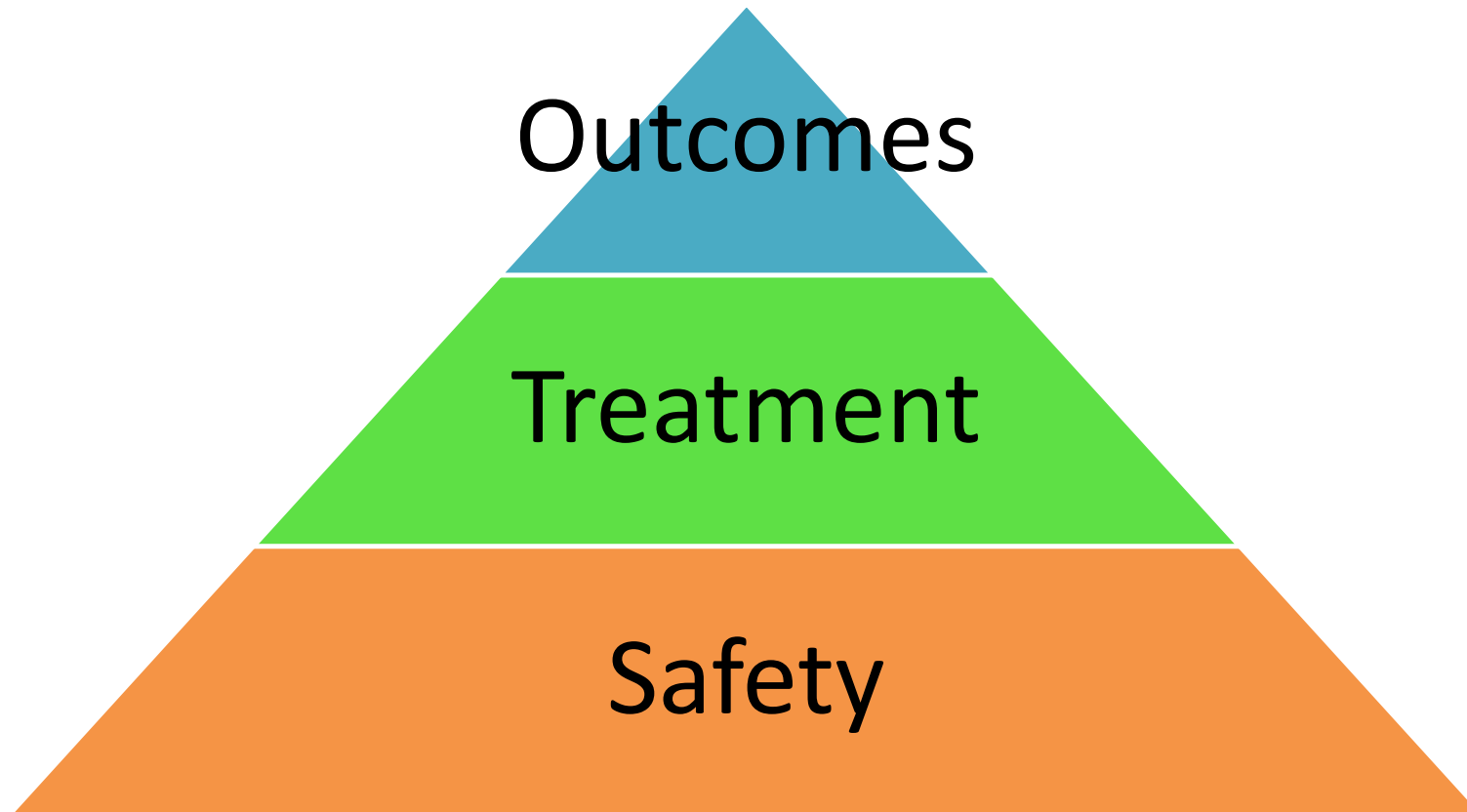
psychotropic drugs and AEDs

AED cognition and behavioural attributes

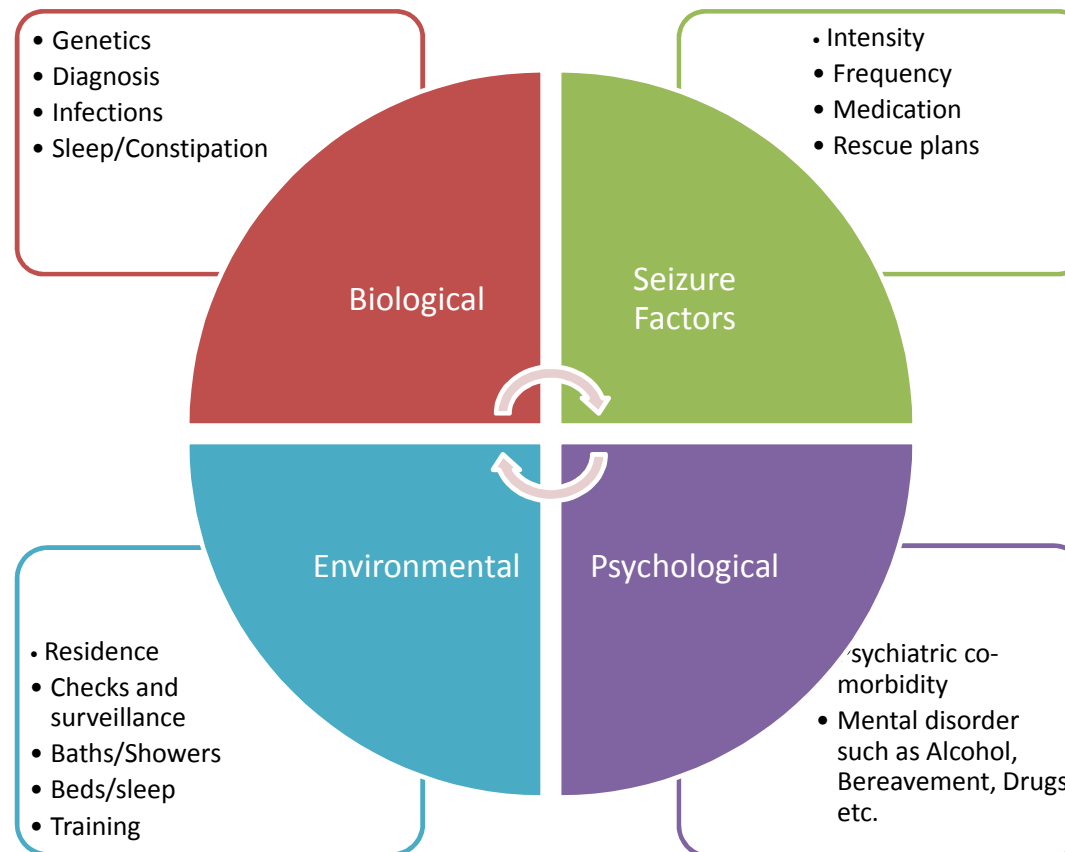
MHRA guidance

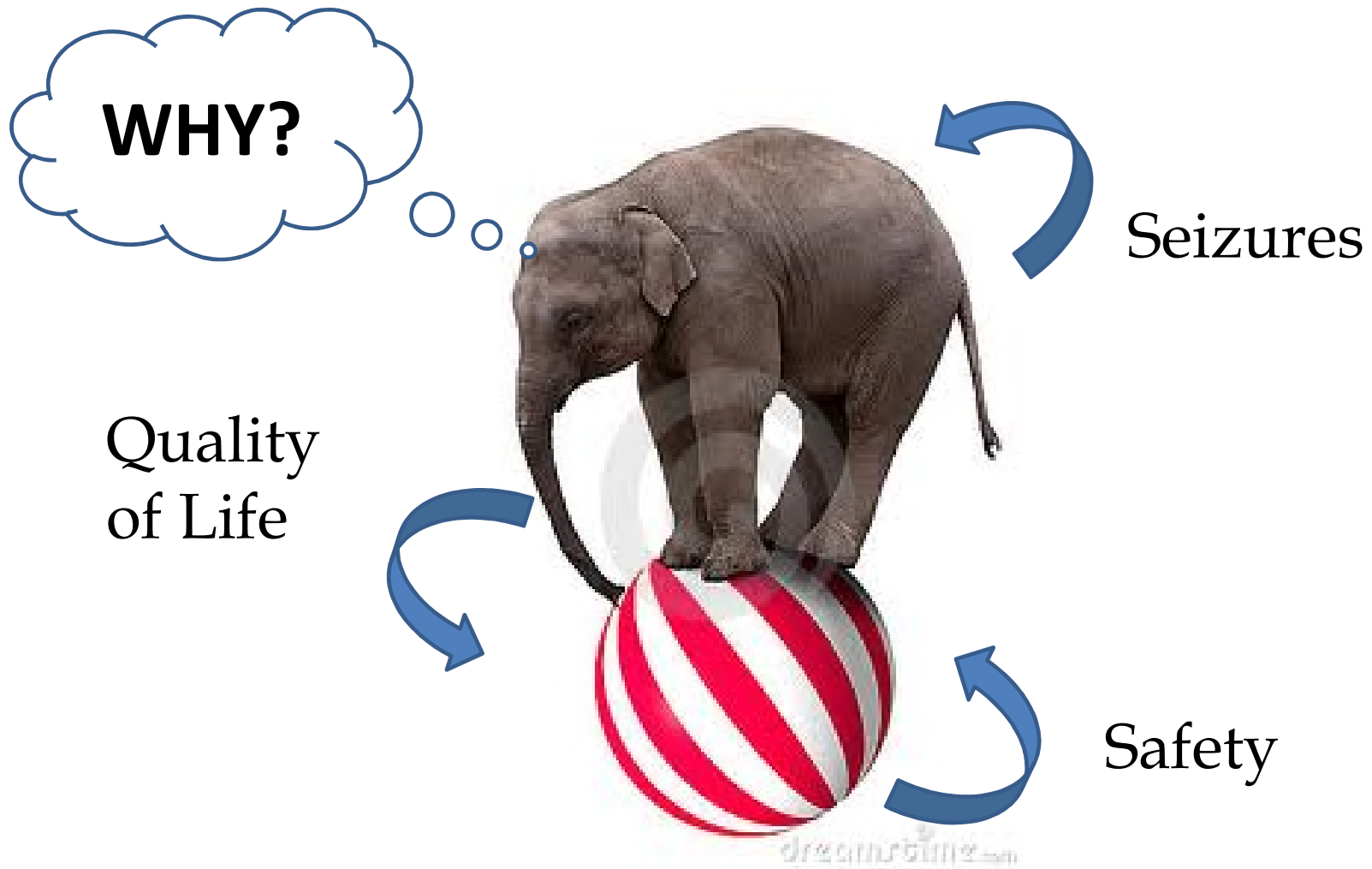


How should we approach Seizures?



Safety is everyone's business





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/cr203.aspx>

The Final Picture!

CALVIN AND HOBBS

