



The challenges of
applying high quality care
in epilepsy & ID
the UK perspective

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DISCLOSURES

Rohit has received institutional / research support in the last 2 years from various pharma: UCB, Eisai, Bial, GW pharma, LivaNova, Averelle and Desitin

Rohit is the chief investigator or co-Investigator in various grants from – NIHR, NHS England, SBRI, ESPRC, ESRC

UCB/Eisai/Bial/Jazz Pharma – have unconditionally via IIS funded the Ep-ID register

Rohit is a stakeholder of the not for profit 'SUDEP and Seizure Safety Checklist' and the mobile app based on the checklist – EpSMon



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**WHISTLE
STOP**

Physical health & Epilepsy the last decade

Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD)

Final report



NEWS

Home | Coronavirus | Climate | UK | World | Business | Politics | Tech | Science | Health | Family & Education

England | Local News | Regions | Oxford

Connor Sparrowhawk death: Doctor suspended for a year

© 21 February 2018

A doctor responsible for fallings before a teenager's NHS care unit death has been suspended for a year.

The Learning Disabilities Mortality Review (LaDeR) Programme

University of Bristol North Fry Centre for Disability Studies

Mortality in adults with learning disabilities with and without a health check: a cohort study

Natasha Kennedy • Prof Sinead Brophy • Jonathan Kennedy, PhD • Prof Michael Kerr, MD

Published: November, 2019 • DOI: [https://doi.org/10.1016/S0140-6736\(19\)32824-7](https://doi.org/10.1016/S0140-6736(19)32824-7)

Health A-Z | Live Well | Mental health | Ca

Home > Health A to Z > Learning disabilities

Annual health checks

Learning disabilities

B News > Bristol News > Courts

The full story of how Bristol boy Oliver McGowan died in Southmead Hospital

His life-support machine was switched off in 2018

News > Health

'I knew he was dying': NHS report reveals decade of failings in care of vulnerable man

Exclusive: 'I cannot describe the feeling of knowing that he was dying but nobody cared', says Elaine the sister of Clive Treacey

Rebecca Thomas Health Correspondent • Thursday 09 December 2021 18:02 • Comments



Challenges



- Physical & mental health comorbidity



- Polypharmacy



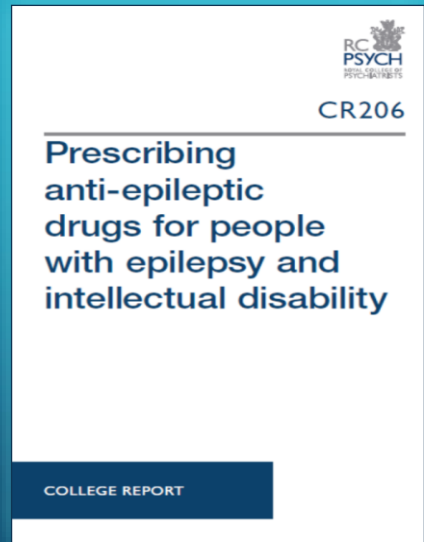
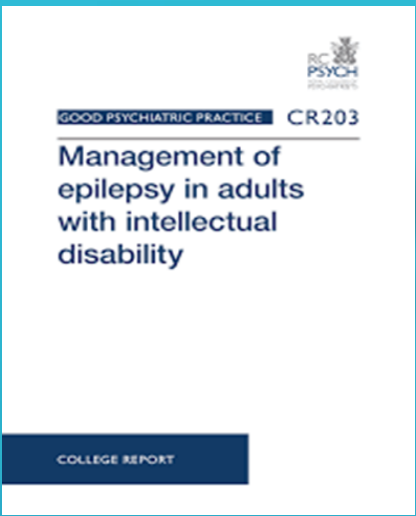
- Communication
- Cognition
- Choice



- Behavioural side effects
- Cognitive side effects

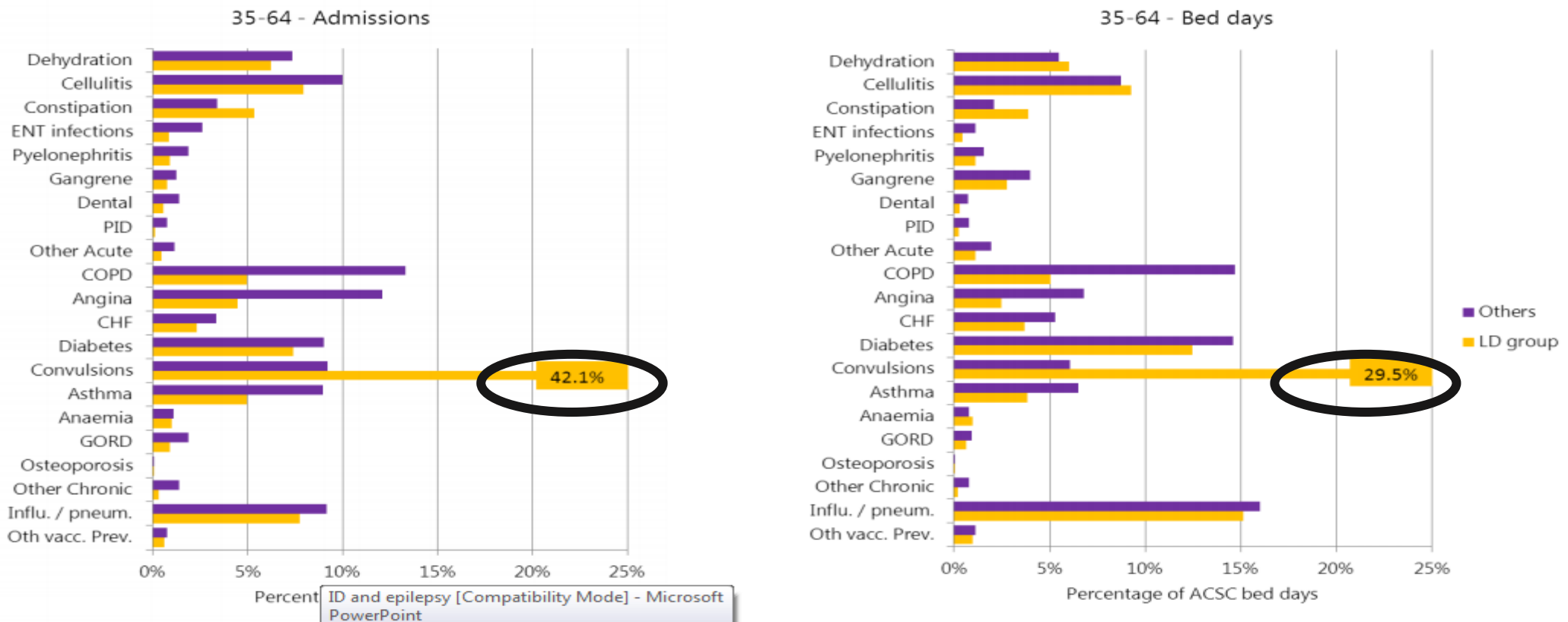


- Treatment-resistant epilepsy
- Diagnosis – challenging
- **Premature mortality**



HOSPITAL ADMISSIONS WHICH SHOULD NOT HAPPEN

Figure 2 Comparison of the causes of emergency admissions for ACSCs admissions for people with and without LD or associated conditions (cont).



SUDEP VARIES WITH THE EPILEPSY POPULATION

Seizure 25 (2015) 112–116

Contents lists available at ScienceDirect

Seizure

journal homepage: www.elsevier.com/locate/yseiz

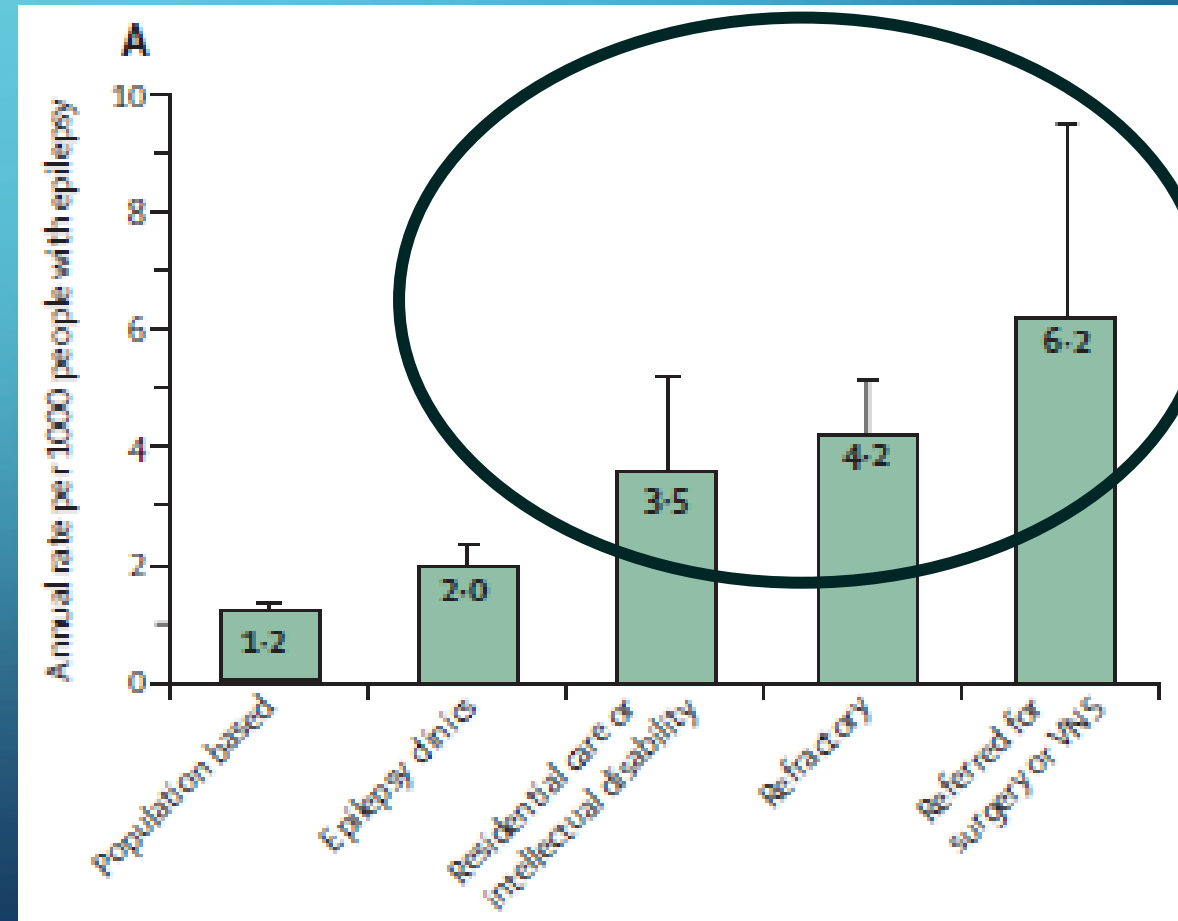
ELSEVIER

Does intellectual disability increase sudden unexpected death in epilepsy (SUDEP) risk?

Charlotte Young^a, Rohit Shankar^{a,b,*}, Joanne Palmer^c, John Craig^d, Claire Hargreaves^a, Brendan McLean^c, David Cox^a, Richard Hillier^a


CrossMark

In patients with ID and epilepsy the risk of sudden death was found to be >3 times higher compared to PWE without ID



Original Communication | [Published: 24 January 2022](#)

Epilepsy related multimorbidity, polypharmacy and risks in adults with intellectual disabilities: a national study

[James J. Sun](#), [Bhathika Perera](#), [William Henley](#), [Heather Angus-Leppan](#), [Indermeet Sawhney](#), [Lance Watkins](#), [Kiran N. Purandare](#), [Mogbeyiteren Eyeoyibo](#), [Mark Scheepers](#), [Geraldine Lines](#), [Robert Winterhalder](#), [Samantha Ashby](#), [Ravi De Silva](#), [Jonjo Miller](#), [David E. Philpott](#), [Chris Ashwin](#), [Joshua Howkins](#), [Harriet Slater](#), [David Medhurst](#) & [Rohit Shankar](#) 

Journal of Neurology (2022) | [Cite this article](#)

128 Accesses | 14 Altmetric | [Metrics](#)

England & Wales

10 NHS Trusts

Prevalence study

Largest global sample

Look at co-morbidities,
treatment &
management

	Mild ID (n=320)	M/P ID (n=584)	Both (n=904)	p
Gender Male	190 (59%)	352 (60%)	542 (60%)	0.86
Age (10 year intervals 18 -60+)				0.78
Genetic disorder	51 (16%)	143 (24%)	194 (21%)	0.003
Diagnosis of ASD	101 (32%)	236 (40%)	337 (37%)	0.01
Diagnosis of ADHD	31 (10%)	28 (5%)	59 (7%)	0.007
Any psychiatric diagnosis	140 (44%)	165 (28%)	305 (34%)	<0.001
Psychotic disorder	34 (11%)	27 (5%)	61 (7%)	<0.001
Depression	24 (8%)	38 (7%)	62 (7%)	0.58
Anxiety disorder	22 (7%)	61 (10%)	83 (9%)	0.09
OCD	7 (2%)	13 (2%)	20 (2%)	1.00
Bipolar disorder	11 (3%)	23 (4%)	34 (4%)	0.86
Hypertension/IHD	20 (6%)	11 (2%)	31 (3%)	0.001
Diabetes	22 (7%)	16 (3%)	38 (4%)	0.005
Obesity	22 (7%)	14 (2%)	36 (4%)	0.002
Osteoporosis	17 (5%)	21 (4%)	38 (4%)	0.23
Hearing/visual impairment	24 (8%)	48 (8%)	72 (8%)	0.80
Mobility problems	26 (8%)	81 (14%)	107 (12%)	0.01
Other	154 (48%)	278 (48%)	432 (48%)	0.89



	Mild ID (n=320)	Moderate-profound ID (n=584)	Both (n=904)
Total medications: median (IQR)	4 (3)	5 (4)	5 (4)
AED medications: n (%)	287 (92%)	554 (97%)	841 (95%)
AED meds: median (IQR)	2 (2)	2 (2)	2 (2)
AED type: n (%)			
generation 1	27 (8%)	34 (6%)	61 (7%)
generation 2	240 (75%)	467 (80%)	707 (78%)
generation 3	143 (45%)	265 (45%)	408 (45%)
generation 4	24 (8%)	51 (9%)	75 (8%)
Anti-psychotics: n (%) median (IQR)	71 (23%) 0 (0)	165 (29%) 0 (1)	236 (27%) 0 (1)



SERVICE DELIVERY & SUDEP RISK

N= 904 (MILD 320 & M/P 584)

Mild n= 320	M/P = 584
Compliance issues more likely	More likely <16 years age
Alcohol dependence more likely	> 15 years of seizures more likely
Lack of documented SUDEP risk	Nocturnal seizures more likely
Lack of epilepsy care plan	GTCS in last 12 months more likely

- 72% had been diagnosed <16 years
- 76% epilepsy > 15 years
- 13% status epilepticus in last 5 years
- 21% ED/Paramedic callout in last 5 years
- 31% nocturnal seizures
- 23% of those with nocturnal seizures had no surveillance
- 25% no epilepsy care plans
- 61% documented evidence of SUDEP communication
- 10/13 SUDEP and seizure safety risk factors significant $p < 0.05$ Mild vs. M/P



NO COUNTRY FOR OLDER PEOPLE WITH ID?

- Health profiles of PwID ≥ 40 years are comparable to general population ≥ 65 years
- Compared older PwID (n=405) & epilepsy with their younger peers (n=499)- first time
- Older PwID had significantly higher co-morbidity, polypharmacy & epilepsy risks
- **Significantly lesser levels of review**



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seizure
European Journal of Epilepsy

The Official Journal of **epilepsy action**

Submit Log in Regist

FULL LENGTH ARTICLE | [ARTICLES IN PRESS](#)

PDF [874 KE

Tackling increased risks in older adults with intellectual disability and epilepsy: data from a national multicentre cohort study

LV Watkins • W Henley • JJ Sun • ... G Lines • R Winterhalder • R. Shankar • [Show all authors](#)

[Open Access](#) • Published: May 30, 2022 • DOI: <https://doi.org/10.1016/j.seizure.2022.05.022>

STEP TOGETHER CO-CREATION

Expert Advisory Group n = 6

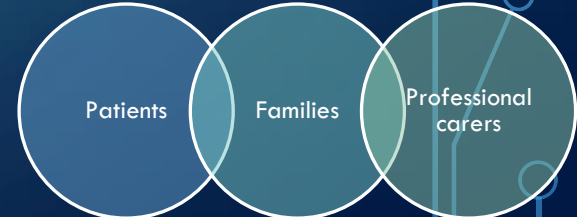
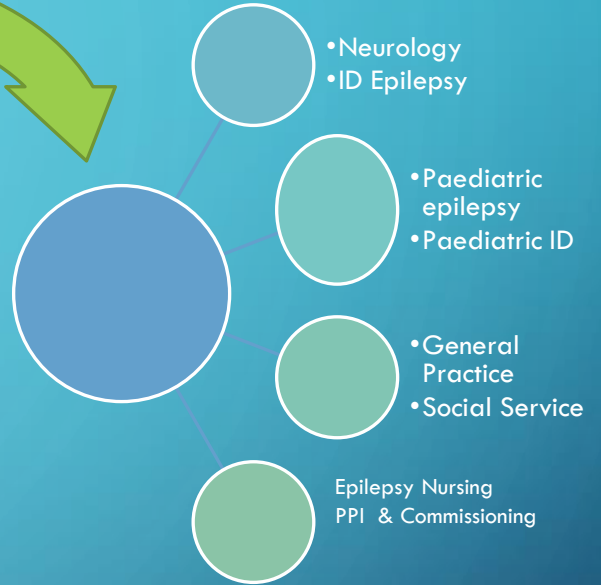


- Patient Facing Organizations – NHS Trusts etc.
- Professional clinical stake holder organizations e.g. RCPsych, ILAE etc.
- Non-clinical stakeholder organizations – schools, Charities etc.

MAKE Co-production with expert working committee

DISCUSS professional consultation day to co-design
N = 36

LISTEN 3 Full days co-design workshops
N = 84



Quality of Life

Psychological

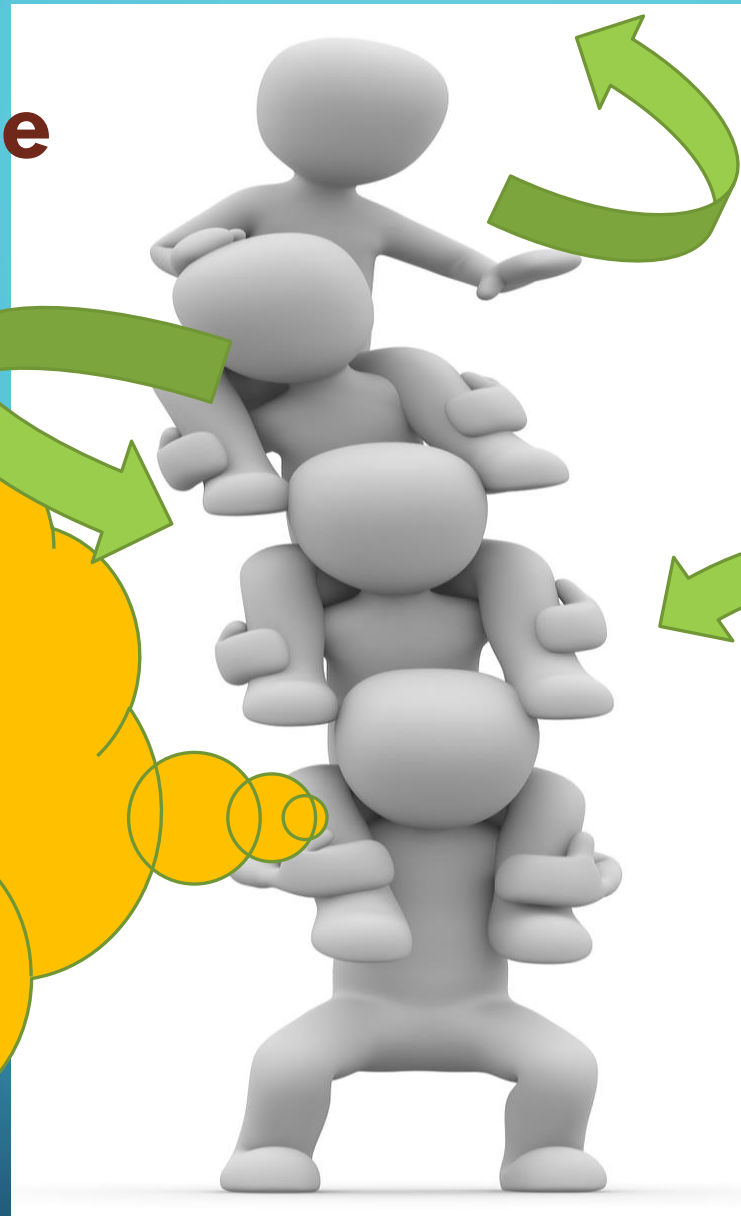
Social

Biological
factors

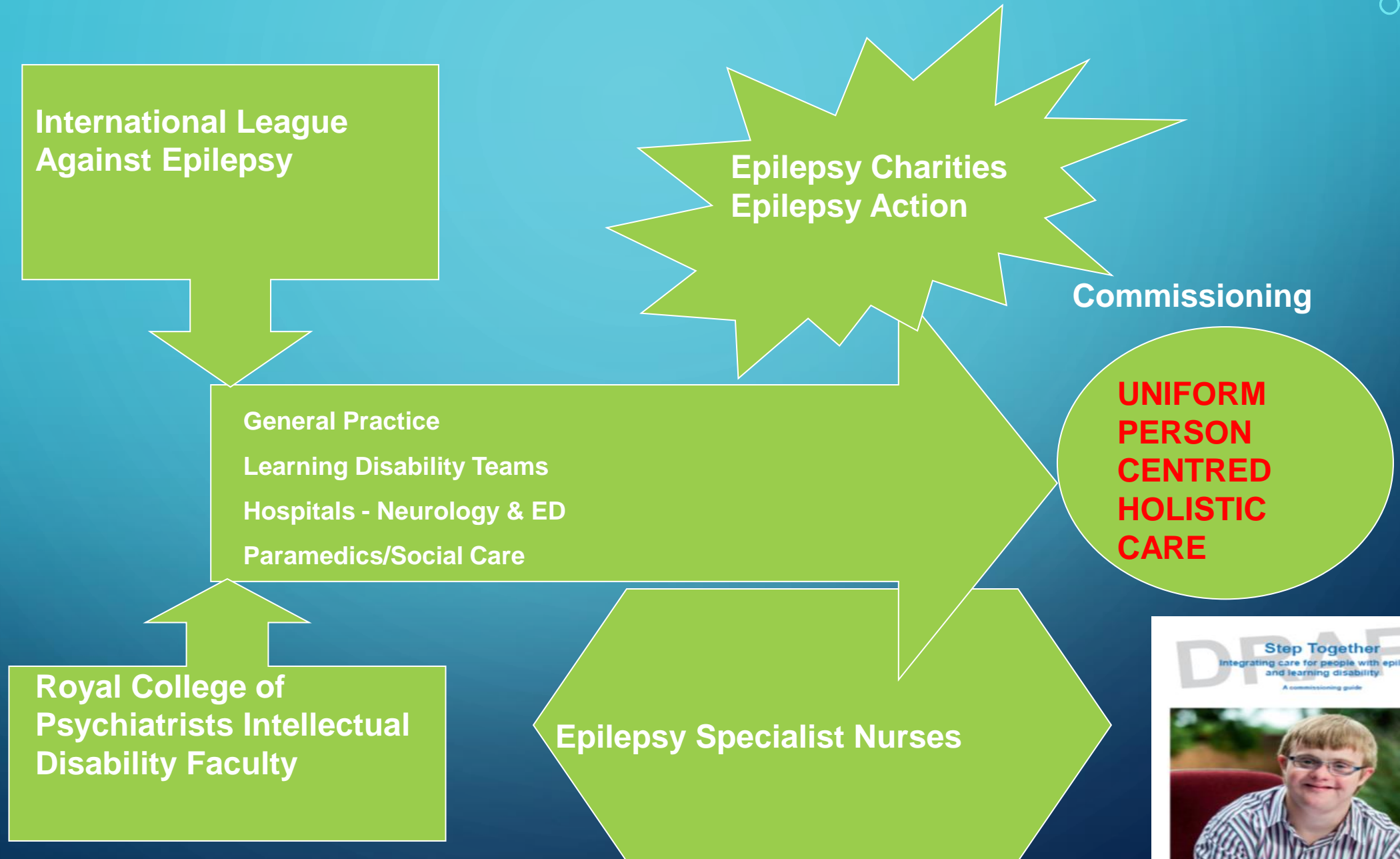
Seizures

**WHAT WE
UNDERSTOOD -
EPILEPSY
MANAGEMENT NEEDS
TO BE BALANCED**

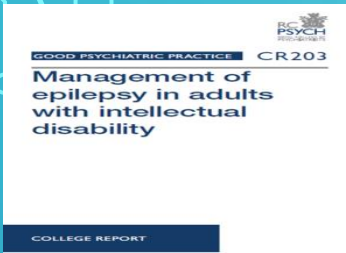
**What
patients/families &
carers want**



Interaction between various stakeholders

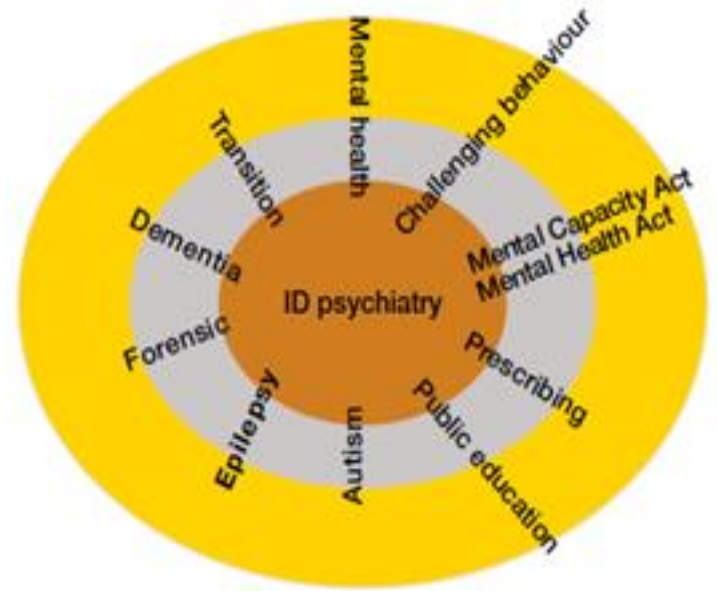


PSYCHIATRIC COMPETENCIES



Patient with ID and epilepsy, seen in psychiatric context

Psychiatrist has no input into epilepsy management Psychiatrist has epilepsy management role



Bronze ★

- Identify and manage epilepsy needs
- Assess impact of disease and treatment on mental disorder
- Able to treat NEAD
- Support use of rescue medication

Silver ★

Additional skills in:

- drug change
- seizure classification
- understanding EEG/ MRI
- rescue plans
- side-effect assessment
- SUDEP risk

Gold ★

Additional skills in:

- diagnosis
- new AEDs
- VNS
- surgical assessment

LEARNING DISABILITY EPILEPSY SPECIALIST NURSE COMPETENCY FRAMEWORK

EXAMPLE COMPETENCY: Diagnosis of epilepsy

Novice Nurse (Bronze)	Competent Nurse (Silver)	Expert Specialist Nurse (Gold)
<ul style="list-style-type: none">To identify routine investigations that may be completed during diagnosis	<ul style="list-style-type: none">To identify and understand the relevance of each investigation and possible outcomes	<ul style="list-style-type: none">To identify and request appropriate investigations, interpret each investigation and its outcome, and identify the need for referral to an appropriate specialist. Is actively involved in the diagnostic decision-making within the MDT.



NEUROLOGIST WHO SEES PEOPLE WITH A LEARNING DISABILITY

- Awareness of recent relevant legislation such as Mental Capacity Act 2005, Equality Act 2010, Social Care Act 2012, Accessible Information Standards
- Professional Developmental Plan identified CPD in learning disability and epilepsy appropriate to the work in learning disability being undertaken
- Knowledge of major psychiatric co-morbidities such as depression, psychosis, anxiety and interactions between commonly prescribed psychotropic and antiepileptic medication
- Knowledge and awareness of local pathways to refer for learning disability specific issues
- Links with learning disability experts e.g. learning disability liaison nurse
- Able to make reasonable adjustments as required by the person with a learning disability. Adjustments may be required for effective communication by providing easy read material in particular when planning for appointments



TABLE SHOWING STAR RATINGS OF COMBINED NEUROLOGY, LD & EPILEPSY NURSES

Neurology Service	Learning Disability Service	Specialist Epilepsy Nurses	Star Rating
E	1	1	1*
E	1	2/3	2*
E	2/3	1	2*
D	1	1	2*
D	1	2/3	3*
D	2/3	1	3*
E	2/3	2/3	4*
E	2/3	2/3	4*
D	2/3	2/3	5*

Key

Neurology

E = Essential Requirements in learning disability

D = Desirable Requirements in learning disability

Learning Disability Service and Epilepsy

1 = Bronze

2 = Silver

3 = Gold

Specialist Epilepsy Nurses

1 = Novice

2 = Competent

3 = Expert/specialist



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

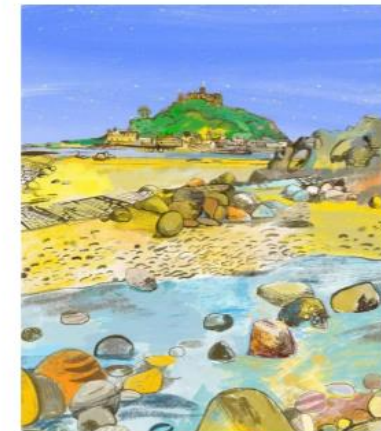
Best practice guidelines for training professional carers in the administration of Buccal (Oromucosal) Midazolam for the treatment of prolonged and / or clusters of epileptic seizures in the community

Safe & Effective | Kind & Caring | Exceeding Expectation

Step Together

Integrating Care for People with Epilepsy and a Learning Disability



RightCare: Epilepsy Toolkit Optimising a system for people living with epilepsy

In England, people living with epilepsy and the systems supporting them are experiencing challenges including high misdiagnosis rates; inaccurate epilepsy population estimates; increasing mortality attributed to epilepsy and a lack of optimal management strategies that could reduce unnecessary emergency care for people living with epilepsy.

This toolkit provides a focus for improving local health systems, tailored to the needs of the epilepsy population with expert practical advice and guidance on how to address these epilepsy-related challenges.

Home > NICE Guidance > Conditions and diseases > Neurological conditions > Epilepsy

Epilepsies in children, young people and adults

In development [GID-NG10112] Expected publication date: 27 April 2022 [Register as a stakeholder](#)



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Introduction

The Workforce

Local Planning

Key Service Provision

Diversity of Provision

Care Planning

Transition

Sharing information

Service User & Carer Participation

Results

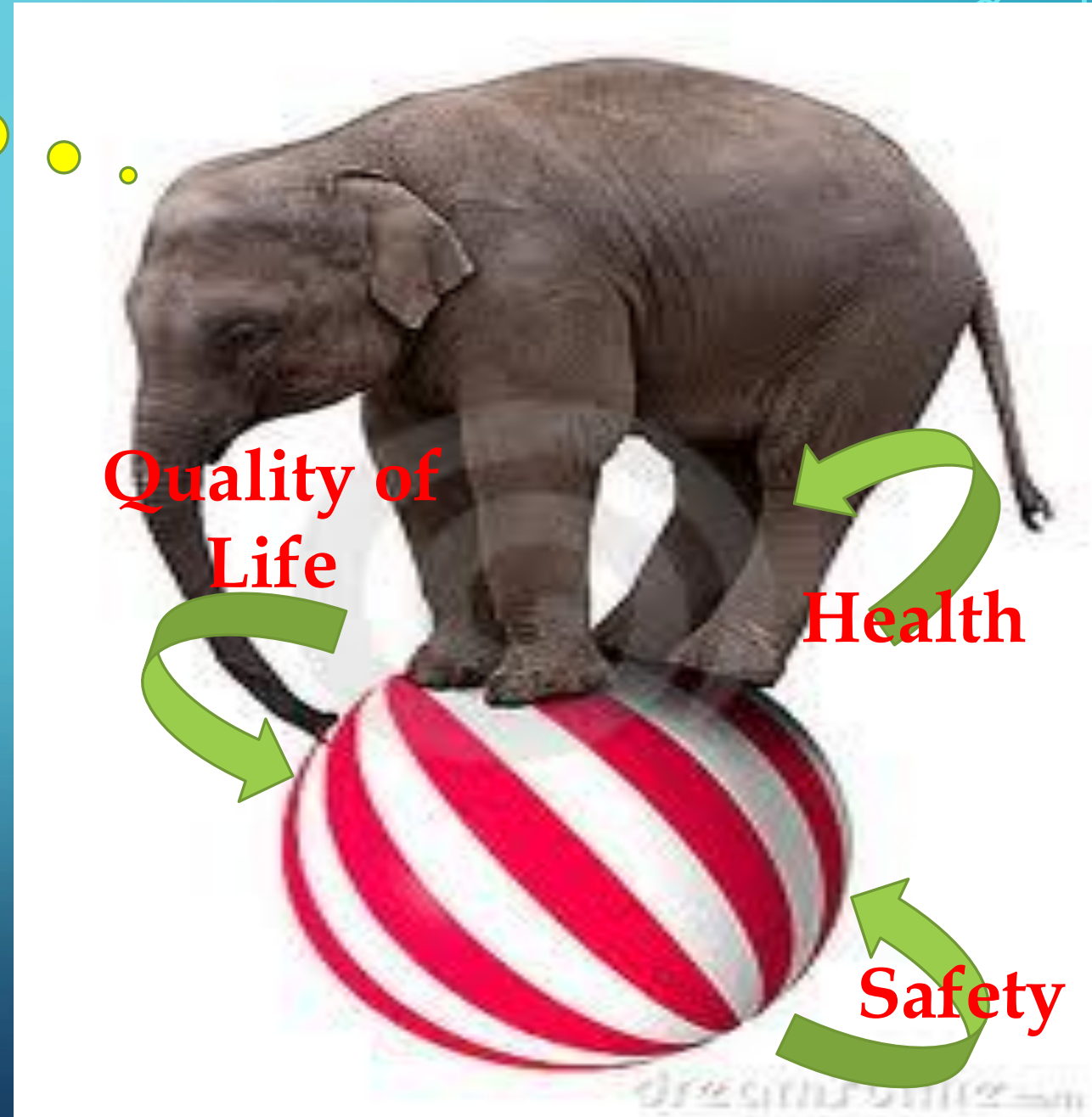
Download Results

Learning Disabilities and Epilepsy Benchmarking Tool

WHY?

“Life for people with major disabilities supported by good services will often look quite ordinary. But this ordinariness is the product of a great deal of careful planning and management”

Mansell 2007





The Cornwall Intellectual Disability and Epilepsy Research Centre



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Cornwall Partnership
NHS Foundation Trust

CIDER – Cornwall Intellectual Disability Equitable Research

Enhancing the care of people with intellectual disability through research and service development



<https://www.plymouth.ac.uk/research/cider-cornwall-intellectual-disability-equitable-research>

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