

Our purpose

Working together to achieve the healthiest life possible for everyone in Ayrshire and Arran



Managing epilepsy treatment and rescue medication for people with learning disability in a community setting

Our values

Caring Safe Respectful

Aims

- ▶ Place the epilepsy needs of individuals with learning disability into context
- ▶ Discuss prevalence of epilepsy for people with learning disability
- ▶ Recognise how co-morbid health needs impact on seizure management
- ▶ Discuss current seizure rescue treatment options and access to treatment
- ▶ Highlight who is involved in the care/treatment of a person with learning disability with epilepsy/what barriers exist and good practice examples

Health Needs of People with Learning Disability



People with learning disability should have the same access to the same range of investigations and treatment as the rest of the population (Health Needs Assessment Report, 2004, Keys to Life, 2013)

Health Inequality

People with learning disability have poorer health than their non-disabled peers, differences in health status that are, to an extent, avoidable. As such, these differences represent health *inequalities*.

Health Inequalities & People with Learning Disabilities in the UK: Improving Health and Lives: Learning Disabilities Observatory (2011)

Health inequality

- ▶ Social determinants (reasons) of poorer health such as poverty, poor housing, unemployment and isolation
- ▶ Physical and mental health problems associated with specific genetic and biological conditions in learning disability
- ▶ Communication difficulties and reduced health literacy
- ▶ Personal health behaviour and lifestyle risks such as poor diet, lack of exercise and lack of awareness around specific health issues
- ▶ Deficiencies in access to and the quality of healthcare and other service provision

Improving health and lives - IHAL (2013)

Epilepsy & Learning Disability

- About 30% of people with mild learning disability will have epilepsy
- In people with severe/profound learning disability this figure will increase to 50%
- Currently 52% of the total population with epilepsy are seizure-free (Joint Epilepsy Council, 2011)
- Only 25% seizure freedom is reported for people with learning disability in some studies
- People with learning disability and epilepsy are more likely to have more than one seizure type and more frequent seizures which then may be more difficult to treat
- The more seizure types and medication used, the less likely it will be that the person will be seizure-free, possibly with greater occurrence of side-effects from medication

Health needs with high prevalence for people with learning disability:

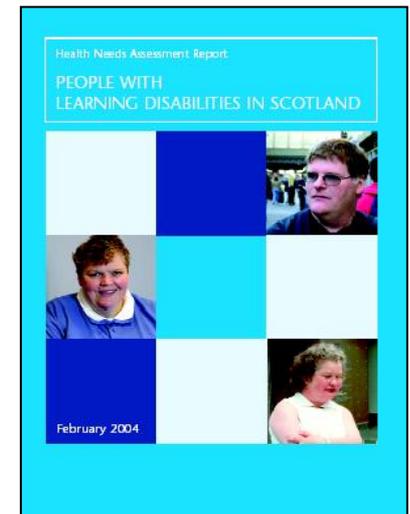
Epilepsy, vision and hearing , Mental ill- health and behaviour perceived as challenging, G.O.R.D, Constipation, Osteoporosis, Oral health, Sleep problems, Nutrition, Mobility and foot care, Polypharmacy (use of multiple medications)

Diagnostic overshadowing –

Health needs incorrectly

ascribed to the person's learning disability.

Difficulty in assessing what may be epilepsy and what is not.



Learning Disability

- ▶ Prolonged / serial and cluster seizures and non convulsive status are common in this group
- ▶ Co-morbidities (aetiology, mental health, challenging/ stereotyped behaviour, autism. Concomitant Health conditions)
- ▶ Complex care
- ▶ Complex epilepsy care and treatment pathways
- ▶ Impact on seizure management

Risks from Seizures

Prolonged (>5minutes) / serial (without recovery) and clusters (escalation freq, premonitory to SE) of seizures are implicated in :-

- ▶ Morbidity from seizure
- ▶ Status Epilepticus
- ▶ Mortality
- ▶ Significant post-ictal effects: anorexia, chest infection, sleep, mood, social

Important to stop prolonged serial and cluster seizures

- ▶ Earlier intervention is more successful at reducing morbidity
- ▶ Options are either call ambulance or treat on site with seizure rescue medication
- ▶ Epilepsy/seizures –accounted for 40% of avoidable admissions
Glover and Evison (2013)



Hospital Admission

- ▶ Evidence has shown that experiences of hospital admission for people with learning disability are often poor
- ▶ Communication, extreme dependence behaviours, autism.... in a busy receiving ward?

Status Epilepticus

ALWAYS TREATED AS A MEDICAL EMERGENCY

Convulsive Status epilepticus

“Emergency treatment should be sought or given once a seizure has persisted, or there are serial seizures, for 5 minutes or more.” SIGN 143 2015

Midazolam

- ▶ Usage now widespread and recommended as first-line for people in the community
- ▶ Fast onset of action
- ▶ Convenient and portable
- ▶ Evidence shows that it is most effective at stopping seizures in a community setting
- ▶ Short duration of action so less prolonged effects - improved recovery
- ▶ Side-effects



Buccal Midazolam

- Patients with recurrent prolonged or serial seizures in the community should be given Midazolam 10mg buccally or intranasally

- All carers of patients with epilepsy who may require Buccal Midazolam or rectal diazepam should receive recognised training in its administration

- Where a care plan is required, it should be drawn up in consultation with the GP and/or specialist service, used by everyone working with the individual patient, and reviewed at regular intervals

SIGN 2015



Protocol

Protocols for rescue medication should be reviewed regularly may be withdrawn or amended where such plans have not been enacted after a prolonged period
SIGN, 2015.

Name	CHI number
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Treatment Protocol for the Administration of Midazolam buccal/nasal liquid
For the treatment of Prolonged and Serial Epileptic Seizures – to be completed by the named nurse and signed by the Consultant or GP.

Before giving always check when Midazolam was last administered.

When should Midazolam buccal liquid be administered?

How much should be given initially?

Method of Administration – Buccal (side of mouth)

1. Push down and twist lid off bottle. Insert syringe to top of bottle and turn upside down.
2. Pull back the plunger of syringe until prescribed amount reached.
3. Withdraw syringe from bottle and insert it gently into side of mouth, between teeth and cheek, tilt down and slowly push syringe plunger until empty.
4. Check time, place on side if possible and observe.

Nasal administration

1. Follow steps 1 & 2 as above.
2. Place the person on their back if possible, so that head tilts slightly back.
3. Place syringe at entrance of first nostril.
4. Slowly push in plunger, dripping Midazolam liquid into each nostril in turn.
5. Check time, place on side if possible and observe.

After how long can a second dose of Midazolam be given? What is the second dose?

When should further action be taken and what action should be taken?

Do not give more than mg of Midazolam in hours, or mg in 24 hours unless directed by the doctor.

This protocol is agreed by (prescribing GP):

Signed:	Practice stamp:
Dated:	

This plan should be reviewed annually.
Check expiry date before use. Store in a secure environment and at room temperature.

This documentation has been produced by the West of Scotland & Tayside Epilepsy MCN (Dec '08) Page
Guidance on completion & copies of all care planning documentation are available at www.epilepsytoolbox.scot.nhs.uk

Record

- ▶ Time, date, who gave the medication, type, length, duration, number of seizures and treatment outcome/ observations

RECORD OF USE OF BUCCAL MIDAZOLAM FOR:		CHI:		
DATE				
GIVEN BY				
TYPE OF SEIZURE				
LENGTH AND NUMBER OF SEIZURES				
DOSE GIVEN AND TIME				
OUTCOME/ EFFECT OF MIDAZOLAM				
OBSERVATIONS				

Please complete when Midazolam used and forward to: Gareth Davison, Epilepsy Nurse Specialist, Room 70, Admin Building, Ayrshire Central Hospital, Kilmanning road, Irvine KA12 8SSTel – 01294-323362

Other seizure rescue medication - Clobazam

- ▶ Recognised as especially useful as intermittent seizure rescue medication
- ▶ Often to manage cluster seizures
- ▶ Also considered appropriate for 2nd line therapy for all major seizure types

Others – Lorazepam, Clonazepam

Who is involved?

- ▶ Multiple individuals/agencies involved

Royal College of Psychiatrists (2017) highlight fragmented care, poorly defined care pathways across UK and talk of a 'bystander effect' if 'no-one has clear responsibility, each clinician involved thinks someone else is going to take charge of the situation and make the changes that are required'

Barriers

- ▶ Patient/person led barriers – cognitive awareness, understanding, stepping into a GP surgery. Individual doesn't realise there is a problem
- ▶ Clinician led barriers – Not recognising that this group of people require extra support, extra nurturing, comfort, communication, structure and that some are more individual than others
- ▶ Institution led barriers –commissioning- one size fits all- top down approaches – missing the most vulnerable – the exception should prove the rule

Reasonable adjustments

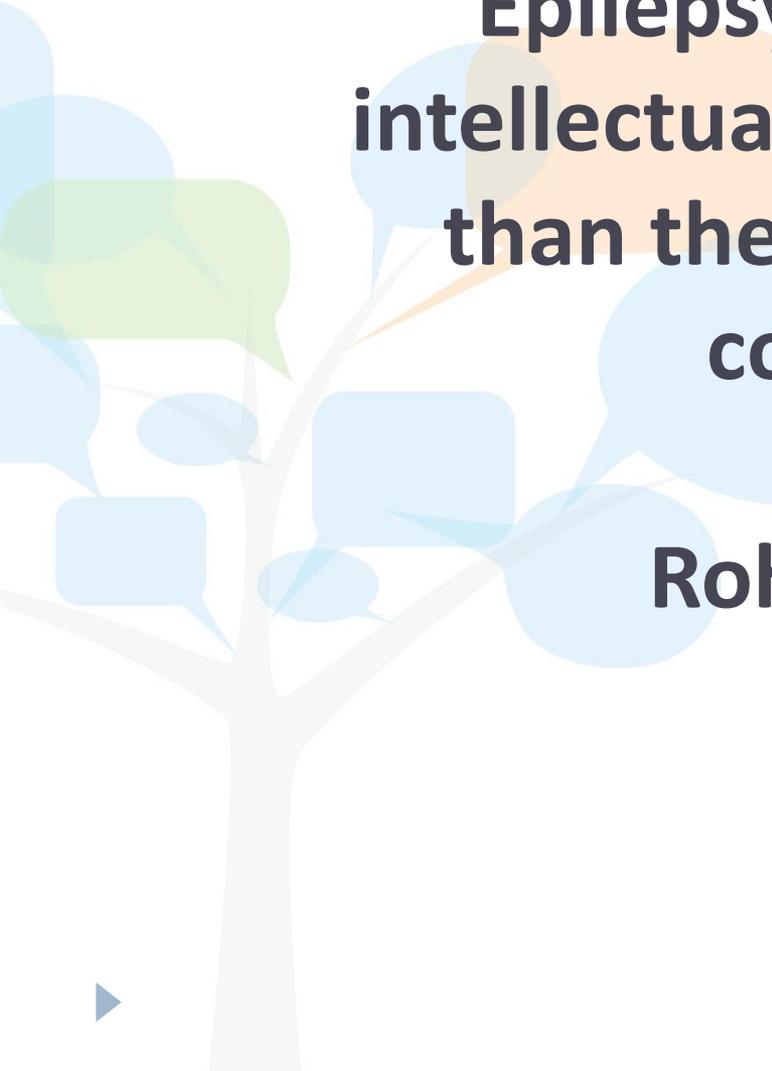
- ▶ Equalities Act 2010 – to ensure that services are accessible to disabled people as well as everybody else

Public Health England (2014), via UK LD Network advocates:

- ▶ Regular, structured reviews (also recommended by NICE, 2012)
- ▶ Sufficient time
- ▶ Epilepsy specialist within multidisciplinary LD team (also recommended in Keys to Life)
- ▶ Epilepsy Action (2013) identified almost half of acute and foundation trusts surveyed did not offer access to LD Epilepsy Specialist Nurses

Good practice – UK LD network

- ▶ Individual accounts of working collaboratively across disciplines to reduce admissions/admission times/access to investigations and assessments
- ▶ People taking their own drugs to hospital to avoid formulation changes
- ▶ Educational courses for people with learning disability – (the My Epilepsy project, Berkshire)
- ▶ Accessible clinics within day services
- ▶ Designated tele-clinic services for people too far away, too unwell to attend out-patient appts
- ▶ Home visits - new referrals routinely in the person's home to assess environmental risks
- ▶ Easy-read appointment letters
- ▶ Pre-appointment questionnaires sent to service-users in advance to enable full information to be gathered



**‘Epilepsy in people with
intellectual disability is more
than the sum of the two
conditions’**

Rohit Shankar



References

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- ▶ Glover and Evison (2013) *Hospital Admissions that should not happen: Admissions for ambulatory care sensitive conditions for people with learning disabilities in England*. Stockton-on-Tees. LD Public health observatory
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- ▶ Public Health England (2014) *Making reasonable adjustments to epilepsy services for people with learning disabilities*
- ▶ NHS Health Scotland (2004) *Health Needs Assessment Report*. Glasgow.
- ▶ Royal College of Psychiatrists (2017) *Management of epilepsy in adults with intellectual disability CR 203*.
- ▶ Scottish Government (2013) *The Keys to Life. Improving quality of life for people with learning disabilities*. Edinburgh
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