Good Practice Guidelines for Seizure Management in Paediatric Palliative Care

modified from Harris et al

1. Identify those at risk

Underlying condition predisposes to seizures

- Known epilepsy syndrome with previous episodes of status
- Structural CNS abnormality e.g. brain tumour
- Neurodegenerative conditions e.g. Battens, MLD, mucopolysaccharidoses etc.

Clinical condition compromises seizure control

- Vomiting or gut dysmotility prevents absorption of usual antiepileptic drugs.
- Intercurrent illness or metabolic derangement reduces seizure threshold
- Other drugs reduce seizure threshold

2. Be prepared

Discuss options for treatment

- Agree and write an advance care plan that includes the emergency management for seizures

Anticipatory prescribing

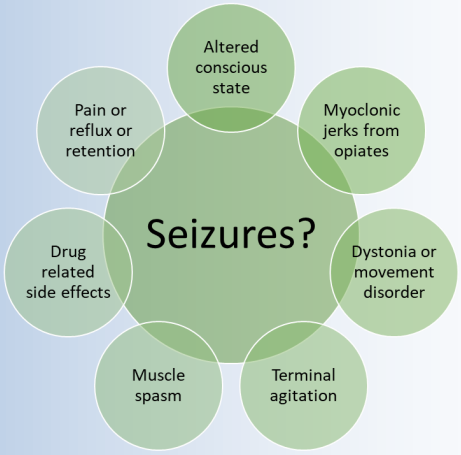
- Buccal or PR medications for first line users
- Subcutaneous infusion initial doses

Drugs and equipment

- Ensure medications will be available in all settings e.g. through a just-in-case box
- Adequate supplies of medications
- Syringe drivers or pumps, needles and connectors

3. Define seizure activity

Abnormal movements or events (eg a change in conscious level) can have a variety of causes. Find out about the usual types of seizure for this child, including tonic-clonic, complex partial seizures, or atypical seizures including apnoeic attacks. Keep an open mind — could abnormal movements be due to myoclonic jerks (as frequently occurs with large doses of opiates), muscle spasm, terminal agitation, or a movement disorder? Could this child be in pain, anxious, in retention, etc? If unsure, seek experienced medical advice, as the management of each of the above is different.



4. Pharmacology

For use in patients with advance care plans where intensive care options are not appropriate

Initial emergency treatment

If the child has a personalised seizure management plan, follow it. If not, proceed as below:

A) Buccal midazolam or rectal diazepam (age related doses as per APPM/BNF). If in the hospital setting and IV access is available, you may consider IV lorazepam.

Wait 10-15 minutes

B) Repeat buccal midazolam or rectal diazepam

Wait 10-15 minutes

C) Rectal paraldehyde as 50% solution with olive or arachis oil

Wait 15 minutes

Further doses of buccal/rectal meds are unlikely to be successful. If still fitting, move to the next step.

Do you have venous access?

Yes

Obtain IV/IO access. Give IV antiepileptic drugs as per APLS guidance. If seizures do not stop, proceed with midazolam infusion as below:

No

Start subcutaneous midazolam as per APPM. Give up to 60 minutes for effect. If continuing to seize, increase the dose as per the APPM formulary.

If midazolam is ineffective, add phenobarbitone or levetiracetam (see next).

If midazolam not suitable, consider starting phenobarbitone or levetiracetam (see next).

Has the fitting stopped?

No

Either

Start IV or SC phenobarbital infusion via separate syringe driver, with a loading dose if the child was not previously on phenobarbital. Note max dose 600mg/day.

Or

Start IV or SC levetiracetam infusion. Does not require separate syringe driver.

Doses of midazolam and phenobarbital higher than those listed have been used, but only under experienced medical supervision. Please seek advice from your local palliative care specialist team before proceeding.

Yes

Stabilise for at least 24 hours, then consider a slow wean off midazolam syringe driver (see step 6).

Other considerations

NICE guidelines

- NICE guideline NG 144: Cannabis based medicinal products
- NICE guideline NG 61: End of life care for infants, children and young people with life-limiting conditions: planning and management
- NICE guideline NG 217: Epilepsies in children, young people and adults.

Other drugs

- Consider the use of steroids in consultation with neurology teams and/or local specialist palliative care teams.

5. Supportive care

Monitoring in line with care goals

- Record seizure response, levels of reusability and resp rate.
- Inspect skin sites around infusions; resite needle as required

Symptom management

- Whilst seizure control is unstable, keep midazolam alone in single syringe driver to allow flexible dose titration.
- Once stable, combine midazolam with other compatible medications to simplify the syringe driver regime.

Keeping things calm and controlled

- Seizures may be a terminal event. Prepare family for this and ensure the child has adequate analgesia and sedation.
- Review plans regularly.

6. Review and Revise

Seizures continue

- Seek advice from specialist palliative care and neurology.
- Consider escalating doses of midazolam, phenobarbital or levetiracetam further; beware paradoxical agitation and excess sedation.

Seizures continue, EOL not imminent

- Ensure access to specialist neurology opinion is available to the child/family. Recognise that this might mean a change to the location of care.
- Consider other non-invasive options with neurologists e.g. ketogenic diet.

Seizures stop, EOL not imminent

- Once stable for at least 24 hours, aim to reduce by 10% per day as tolerated.
- Introduce antiepileptic drugs in partnership with a paediatric neurologist.