

Appendix A: Clinic proforma used during focused epilepsy clinics

ASSESSMENT DETAILS		
ID NUMBER:		SERIAL NUMBER:
ASSESSMENT LOCATION:		ASSESSMENT DATE: DD / MM / YYYY
CHILD'S DETAILS		
NAME:	GENDER: <input type="checkbox"/> M <input type="checkbox"/> F	DOB: DD / MM / YYYY
HEAD CIRCUMFERENCE (cm):	WEIGHT (kg):	LENGTH/HEIGHT (cm):
FATHER'S DETAILS		
NAME:	DOB: DD / MM / YYYY	OCCUPATION:
EDUCATION		
<input type="checkbox"/> Illiterate <input type="checkbox"/> Primary <input type="checkbox"/> Secondary <input type="checkbox"/> Higher secondary <input type="checkbox"/> Graduation <input type="checkbox"/> Post-graduation <input type="checkbox"/> Diploma/other trade qualification		
MOTHER'S DETAILS		
NAME:	DOB: DD / MM / YYYY	OCCUPATION:
EDUCATION		
<input type="checkbox"/> Illiterate <input type="checkbox"/> Primary <input type="checkbox"/> Secondary <input type="checkbox"/> Higher secondary <input type="checkbox"/> Graduation <input type="checkbox"/> Post-graduation <input type="checkbox"/> Diploma/other trade qualification		
CONTACT DETAILS		
DISTRICT:		SUB-DISTRICT:
UNION:		VILLAGE:
POST CODE:		PHONE NO.:
TYPE OF CASE (select one): <input type="checkbox"/> New <input type="checkbox"/> Follow-Up		
SEIZURE CONTROL: <input type="checkbox"/> Same <input type="checkbox"/> Better <input type="checkbox"/> Worse		SEIZURE FREE ON TREATMENT: <input type="checkbox"/> Yes <input type="checkbox"/> No
COMPLIANT: <input type="checkbox"/> Yes <input type="checkbox"/> No	IF NO, REASON FOR NON-COMPLIANCE:	
REASON FOR POOR SEIZURE CONTROL:		
MAIN CONCERN:		
HISTORY AND EXAMINATION FINDINGS		
BIRTH HISTORY:		
SEIZURE		
FIRST:		LAST:
HISTORY OF PROLONGED SEIZURE (> 5 mins): <input type="checkbox"/> Yes <input type="checkbox"/> No		
CURRENT FREQUENCY: _____ times per <input type="checkbox"/> day <input type="checkbox"/> week <input type="checkbox"/> month <input type="checkbox"/> year		
TYPE:		
DURATION OF SEIZURE:		DESCRIPTION:
PREVIOUS MEDICATION & INVESTIGATION		

Appendix B: Guideline for drug choice at clinics**Table of Contents**

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MEDICATIONS FOR SEIZURE MANAGEMENT

PHENOBARBITONE

Dose range

- 1–6 mg/kg daily in 1 or 2 doses; start at the lower end of range and increase slowly if required.

Seizure types useful for

- For generalized seizures and focal seizures.
- Recurrent febrile seizures
- Neonatal seizures
- Less likely to help blank staring “absence” seizures

Adverse effects

- Allergic rash, rarely can cause extreme hypersensitivity reaction
- Hyperactivity
- Sedation

Comment

- Generally, a good medication to continue unless it is not working or the side effects are not tolerable
- Do not stop suddenly and wean over several weeks if patient has been on it for more than 3 months

SODIUM VALPROATE

Dose Range

- 20–40 mg/kg daily in 2 divided doses; start at 5–10 mg/kg/day and increase slowly to 20 mg/kg/day. Then increase further if required.

Seizure types useful for

- For all seizure types

Adverse effects

- Hyperactivity
- Liver dysfunction
- Caution with use in children with developmental delay less than two years or older who are likely to not have true CP. Valproate can cause fatal liver dysfunction in those with a history of mitochondrial disorders. This is suggested by a history of developmental regression eg. A child who was able to sit before can no longer do so.

Comment

- Valproate is likely to work for most seizure types and cause less sedation than phenobarbitone
- Valproate works synergistically with clobazam and lamotrigine.
- Lamotrigine should be introduced very cautiously if someone is already on valproate

CLOBAZAM**Dose Range**

- Start at 1-2 mg/dose once a day. Can increase as required to
 - 2.5-5 mg BD in children <2 years
 - 5-10 mg BD in children 2-10 years
 - 10 mg TDS in older children
 - maintenance 0.3-1 mg/kg/day in 2 divided doses
- The above doses are a guide and higher doses can be used in younger children if tolerated and if thought to be beneficial for seizure control

Seizure types useful for

- For all seizure types
- Also helpful for dystonia management in some cases

Adverse effects

- Sedation
- Hyperactivity
- Hallucinations
- Drooling

Comment

- Useful monotherapy or add on medication
- Start at small doses like 1 mg BD and grade up
- Can crush tablet and suspend in water to make up small doses if liquid not available
- If difficult for family to understand use quarter tablet / half tablet instead of dissolving
- Wean very slowly similar to phenobarbitone if patient has been taking Clobazam for more than 3 months
- Children can sometimes get used to benzodiazepines. If seizures break through after a few months of good control, then consider swapping over to another benzodiazepine like Nitrazepam.

NITRAZEPAM**Dose Range**

- Start at 1 month – 2 years: 0.25mg/kg twice daily, up to 0.5mg/kg twice daily
- The above doses are a guide and higher doses can be used in younger children if tolerated and if thought to be beneficial for seizure control

Seizure types useful for

- For all seizure types
- Infantile spasms

Adverse effects

- Sedation
- Drooling

Comment

- Useful monotherapy or add on medication
- Start at small doses like and grade up
- Wean very slowly similar to phenobarbitone if patient has been taking Nitrazepam for more than 3 months
- Children can sometimes get used to benzodiazepines. If seizures break through after a few months of good control, then consider swapping over to another benzodiazepine like Clobazam.

CARBAMAZEPINE**Dose Range**

- 10–20 mg/kg daily in 2-3 divided doses; start at 2.5-5 mg/kg/day and increase slowly to 10 mg/kg/day. Then increase further if required. Some patients can respond to low doses 5-10 mg/kg/day and can be maintained on these doses without further increasing unless required

Seizure types useful for

- Focal seizures only
- Avoid for generalized, absence and febrile seizures

Adverse effects

- Hyperactivity
- Liver dysfunction

Comment

- Useful drug for focal seizures, e.g. With hemiplegic CP

MEDICATIONS FOR DYSTONIA/SPASTICITY MANAGEMENT**TRIHENIPHENIDYL/BENZHEXOL****Dose Range**

- Start at 0.25 mg once a day and gradually increase to 0.25 mg tds.
- If tolerated, can trial up to 2 mg – 4 mg tds
- In older children, higher doses can be used if benefit is noted

Symptoms useful for

- Mainly for dystonia management. Can also help drooling due to its anticholinergic properties

Adverse effects

- Dry mouth, eyes
- Constipation
- Confusion
- Double vision

- Irritability

Comment

- About 25-50% efficacy for dystonia management if side effects are not a problem. Some children can benefit remarkably more
- Avoid other anticholinergic medications or if any of the adverse effects are already a clinical problem
- If not benefit after maximum doses for 3-4 weeks, then discontinue as delayed benefit is unlikely to occur.

BACLOFEN**Dose Range**

- **2-7 y** -10-40 mg/day divided in three to four doses/day. Start: 2.5-5 mg twice a day, may increase by 5-15 mg/day every 3-4 days, Max: 40 mg/day.
- **8-11 y** - Dose: 10-60 mg/day divided in three to four doses/day. Start: 2.5-5 mg twice a day, may increase by 5-15 mg/day every 3-4 days; Max: 60 mg/day.
- **12 y and older** - Dose: 20-80 mg/day PO divided in three to four doses/day. Start: 5 mg twice a day, may increase by 15 mg/day every 2-3 days; Max: 80 mg/day.

Start Symptoms useful for

- Mainly for spasticity management.

Adverse effects

- Hypotonia
- Drooling
- Sedation

Comment

- Baclofen is a good medication for high tone which is due to spasticity
- It is not so good when there is dominant or mixed dystonia
- Relatively high doses may be needed in some patients making side effects intolerable, these have to be balanced with dose
- Other sedative medications will add to sedative effects and drooling – benzodiazepines, phenobarbitone
- Taper and stop slowly over few weeks if patient has been taking Baclofen for more than 3 months.

LEVODOPA/CARBIDOPA**Dose Range**

- 1-4 mg/kg/day (levodopa component). Start slowly at 1 mg/kg/day divided in 2 doses and increase to target 4 mg/kg/day in 3 divided doses.
- Can increase further if focal but clear benefit.

Symptoms useful for

- Dystonia management
- Can be very helpful when dystonia shows a trend of worsening as the day progresses or is exercise induced

Adverse effects

- Nausea

Comment

- About 25% efficacy for dystonia management in cerebral palsy but a safe drug to try
- Very useful in genetic dopamine responsive dystonia which can mimic CP but is rare.
- Some preparations are available as Levodopa/Benserazide. Dose guide is same for levodopa component

MEDICATIONS FOR BEHAVIOUR MANAGEMENT**CLONIDINE****Dose Range**

- Start at 25 micrograms at night for sleep management
- Can increase to 25-100 microgram three times a day for behavior management

Start Symptoms useful for

- Management of hyperactive or aggressive behavior. e.g. biting, inattentive in school, disturbs other children, fidgety, can't sit still (these symptoms have to be sufficiently severe to be disruptive to daily home or school life to be considered for treatment)
- Also helpful for episodic management of severe dystonia in patients who get periodic worsening. Doses up to 100 micrograms 4-6 times per day can be helpful for short bursts of 3-4 days. Then wean back to baseline doses or stop

Adverse effects

- Sedation
- Sometimes postural dizziness due to postural hypotension – more likely at lower doses

Comment

- Wean slowly over a week if patient has been on clonidine for more than 3 months
- Average efficacy for ADHD, stimulants are better

RISPERIDONE**Dose Range**

- 0.25mg – 5 mg/day in children. Try to manage on least efficacious dose

Symptoms useful for

- Management of hyperactive or aggressive behaviour.

Adverse effects

- Increased appetite
- Weight gain
- Metabolic disturbance – hyperlipidemia after years of use
- Extrapyramidal effects like rigidity

Comment

- Try clonidine first
- Can be quite useful if behavioral issues are really disruptive for daily life.

MEDICATIONS FOR EMERGENCY MANAGEMENT**DIAZEPAM****Dose Range**

- 0.5 mg/kg <6 y/o; 0.3mg/kg 6-11 y/o; 0.2mg/kg >11y/o

Symptoms useful for

- Management of prolonged seizures >5 min at home.

Adverse effects

- Sedation
- Respiratory depression and arrest
- Local injury

Comment

- Only prescribe if family have received education on use and understand the administration process
- If a child is having a seizure in which he/she is convulsing or is unconscious, it is important to follow simple first aid measures ie. protection from injury, positioning on their side to assist breathing.
- Materials needed
 - a 25ml bottle of diazepam mixed with a stabilizing solution, containing 1mg of diazepam in each 1ml (or alternative concentration)
 - a reusable 10ml syringe
 - a reusable soft plastic tube to attach to the syringe for drawing up and injecting the diazepam
 - a sachet of lubricant jelly

REFERENCES

- Australian Medicines Handbook
- MIMS Australia
- Epocrates
- www.rch.org.au
- www.dhs.wisconsin.gov

Appendix C: Follow up questionnaire

Child's Name:				Gender:	<input type="checkbox"/> Male <input type="checkbox"/> Female
Weight in kg:		Phone No:		DOB:	DD/MM/YYYY
Mother's Name:			Father's Name:		
Assessment Location:				Assessment Date:	DD/MM/YYYY

Check before phone call/follow up clinic:

- Medications and doses the child is on Was there a change made in the last clinic

Phone Call: ☎

1. Is your child taking the prescribed medication regularly?

- No, is your child taking any other medication? Yes → Fill up table below No → Go to 3
 Yes, (Fill up table below) Has there been any improvements? Yes → Go to 2 No → Go to 2

Name of Medication	Formulation	Dose	Daily Dose Frequency
<input type="checkbox"/> Valproic acid [Valex/Epilim/Epilim/Valpro]	<input type="checkbox"/> Syrup <input type="checkbox"/> Tablet	<input type="checkbox"/> ___ ml/ ___ spoon <input type="checkbox"/> ___ mg, ___ tabs	<input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4
<input type="checkbox"/> Phenobarbitone [Barbit/Berdinal/Emer/Epinal/Pheno/Phenoba/Phenosaon]	<input type="checkbox"/> Syrup <input type="checkbox"/> Tablet	<input type="checkbox"/> ___ ml/ ___ spoon <input type="checkbox"/> ___ mg, ___ tabs	<input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4
<input type="checkbox"/> Epinephrine [Adrinor/Adrenaline/Adrin]	<input type="checkbox"/> Injection <input type="checkbox"/> IV	<input type="checkbox"/> ___ ml <input type="checkbox"/> ___ mg	<input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4
<input type="checkbox"/> Benzodiazepine [Clonazepam/Clobazam/Alsium/Clob/Clobam/Epson/Frisium /Epiclon/Epnil/Leptic/Myotril/Rivotril/Rivo]	<input type="checkbox"/> Syrup <input type="checkbox"/> Tablet	<input type="checkbox"/> ___ ml/ ___ spoon <input type="checkbox"/> ___ mg, ___ tabs	<input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4
<input type="checkbox"/> Clonidine [Catapres 0.1/Clonipres 0.1]	<input type="checkbox"/> Syrup <input type="checkbox"/> Tablet	<input type="checkbox"/> ___ ml/ ___ spoon <input type="checkbox"/> ___ mg, ___ tab	<input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4
<input type="checkbox"/> Piracetam [Neurolep/Neuratam/Piratam/Juvain/Piramax]	<input type="checkbox"/> Syrup <input type="checkbox"/> Tablet	<input type="checkbox"/> ___ ml/ ___ spoon <input type="checkbox"/> ___ mg, ___ tabs	<input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4
<input type="checkbox"/> Baclofen [Flexifen/Bacofen/Mylofen/Axant/Beclovan]	<input type="checkbox"/> Syrup <input type="checkbox"/> Tablet	<input type="checkbox"/> ___ ml/ ___ spoon <input type="checkbox"/> ___ mg, ___ tabs	<input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4
<input type="checkbox"/> Trihexyphenidyl [Hexinor/Trihexy]	<input type="checkbox"/> Syrup <input type="checkbox"/> Tablet	<input type="checkbox"/> ___ ml/ ___ spoon <input type="checkbox"/> ___ mg, ___ tabs	<input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4
<input type="checkbox"/> Other(write)	<input type="checkbox"/> Syrup <input type="checkbox"/> Tablet	<input type="checkbox"/> ___ ml/ ___ spoon <input type="checkbox"/> ___ mg, ___ tabs	<input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4

2. Is your child seizure free at current dose?

- Yes → End
 No, Frequency of seizure: _____ per day / week / month / year
Average duration of seizure _____ minutes/hours

For those **not taking any medicine now**:3. Has the medicine caused any problem? Yes → Fill up table below and end. No → Go to 4.

Problem	Immediate action on the phone
<input type="checkbox"/> Extensive rash developed on medication	Stop the medication and need to review urgently
<input type="checkbox"/> Child too drowsy to feed safely on medication	Reduce to older dose/previous medication
<input type="checkbox"/> Other Problem:	

4. Specify any other reason for not taking prescribed medication regularly:
