

Emergency Rescue Medication for Children with Epilepsy

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Key Amendments

Date	Amendment	Approved by
19 th Nov 2020	Document extended for 1 year	Paediatric QIM/Dr J West
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Introduction, Aim & Objective

Why do we administer buccolam [midazolam]?

The majority of children who have epilepsy usually recover within a short period of time after a seizure. However there are occasions when the child goes into a prolonged seizure and occasionally Status Epilepticus. A child who has experienced a prolonged seizure or Status Epilepticus may be prescribed BUCCOLAM [midazolam] by their doctor, in order to treat further prolonged seizures or serial seizures without recovery in between.

This guideline aims to establish a system for the prescription of BUCCOLAM [midazolam] to be administered within the home environment, and to provide parents and carers with the information and training in the management of acute seizures and the indication of when and how to administer BUCCOLAM [midazolam].

With the exclusion of neonates, the guideline covers all children from 1 month to 16 years of age.

The Aim

- To ensure that children and young people are prescribed BUCCOLAM [midazolam] where appropriate as per NICE guidelines 2012.
- To ensure that staff and/or parents are familiar with BUCCOLAM [midazolam] and its administration.
- To preserve the privacy and dignity of children when administering medication wherever possible.

The Objective

- To establish a system for the prescription of BUCCOLAM [midazolam] to be administered within the home environment. Using the **Emergency medication plan** [Appendix 1]
- To establish a system of documentation for the administration of BUCCOLAM [midazolam] **Record of administration** [Appendix 2]
- To provide parents and carers with the information and training in the management of acute seizures and the indication of when and how to administer BUCCOLAM [midazolam] **Parent information leaflet** [Appendix 3]

Midazolam

Midazolam is a medication from the group of drugs called benzodiazepines that affect the central nervous system. Midazolam is a muscle relaxant and has anti-convulsant properties. Midazolam is commonly used for sedation of children for medical procedures.

The licensed preparation that will be prescribed is **BUCCOLAM PRE- FILLED SYRINGES**. This guideline does **not** refer to other preparations of midazolam which are Hypnoval, midazolam syrup and Epistatus.

Side effects

All medication has the potential to cause side effects.

How your child will react to the medication is difficult to describe until the first time midazolam is given.

The side effects of midazolam may include:

- Nausea and vomiting is common.
- Flushing of the skin or a rash of pink spots can occur which disappear within 15 minutes, uncommon.
- Shallow breathing [respiratory depression] and hallucinations. [rare]
- Agitation, aggression, anger, dizziness, headaches, very rarely.
- Contraindications include severe chest infection or asthma attack
- In the community area **a second dose should not be given** by the carer within 2 hours of receiving Midazolam **unless** authorised by the Consultant looking after the child or related drug [Diazepam – rectally] because of risk of respiratory depression.

This rule does not apply to STATUS EPILEPTICUS when a second dose of rescue medication can be given after 10 mins by a paramedic who has the equipment to deal with respiratory depression, or medical personnel in hospital, as per protocol for STATUS EPILEPTICUS Paediatrics –Neurology Pathway.

The **Buccal route** of administration for midazolam means that a small amount of the medication is given into the side of the mouth, by the back teeth of the lower jaw, between the gum and cheek area. This is a more convenient and more dignified route of administration.

The midazolam is directly absorbed into the blood stream from this area and does not have to be swallowed.

As the indications when to administer medication and dosage will vary for each child, an individual **Emergency medication plan** is required. The child's Consultant will complete this and should be reviewed annually.

The **Emergency medication plan** [appendix 1] should clearly state:

- The preparation, strength, dosage, and amount of the medication to be given.
- When the Midazolam is to be given e.g. after 5 minutes.

Included on the Emergency medication plan should be an indication of when an ambulance should be summoned.

For simplicity, the following regime can also be followed.

AGE OF CHILD	DOSE OF BUCCAL MIDAZOLAM	LABEL COLOUR
Birth to <6 months	300 micrograms/kg	Yellow {please refer to status epilepticus guideline}
6 to <12 months	2.5mgs [0.5 ml]	Yellow
1 to <5 years	5mgs [1 ml]	Blue
5 to <10 years	7.5mgs [1.5 ml]	Purple
10 years and over	10mgs [2 ml]	Orange

Provision of Training to Parents

The medical staff will be responsible for teaching parents about the use of **BUCCOLAM** [midazolam] for their child and again the teaching will include:

- Ability to recognise and manage prolonged seizures including basic first aid.
- Familiarisation with the formulation of midazolam in pre-filled syringes.
- Familiarisation with the buccal route of administration.
- Knowledge of how to call a paramedic ambulance and the correct information to give when making an emergency call.
- Knowledge of how to record the administration of midazolam and the child's response.

Training

Members of staff out in the Community setting who volunteer to administer Buccolam [midazolam] must receive training for each individual child, from a qualified health care professional e.g. Epilepsy Nurse Specialist, school nurse, Nurse adviser.
Training must be updated annually

Appendix 1 - See Document Management System for printable version

Epilepsy Care Plan

Child's Name	
NHS Number	
Emergency contact details Parent/carer	
Emergency contact details- Parent/ carer	

Care settings where this plan is to be used

What do *(insert name)* seizures look like?

(Seizure one)

(Seizure two)

What happens before and after?

How long do they usually last?

Any triggers?

Usual recovery time and intervention?

When to call for an ambulance

- If it is the child's first seizure
- If the seizure goes on longer than 5 minutes and there is no emergency medication
- If the child has injured themselves
- If concerned

Do they have emergency medication? YES NO If yes please turn over

Parents signature	
Nurse's signature	
Date developed	Review date

Emergency Medication Care Plan- if not applicable please cross off

DOSE TO BE ADMINISTERED: ONE	PRE-FILLED ORAL SYRINGE of BUCCAL MIDAZOLAM
ROUTE: BUCCAL (between a cheek and gum)	
To be given if has generalised tonic clonic seizure lasting longer than: _____ minutes	
Other circumstances to give a dose of buccal midazolam _____	
_____ (e.g. other seizure types or cluster seizures) _____	

Has the child been prescribed a second dose? YES NO

Second dose for same seizure: ONLY if specified by the child's consultant. ALWAYS call an ambulance		
DOSE TO BE ADMINISTERED: ONE	<div style="border: 1px solid black; display: inline-block; padding: 2px 10px;">mg</div>	PRE-FILLED ORAL SYRINGE
Administer after _____ minutes from first dose if seizures show no signs of resolving		
Child is ONLY able to have 2 doses of buccal midazolam in 24 hours		

If child has only been prescribed ONE dose of buccal midazolam for a prolonged seizure and fully recovered, they can have a further dose within the 24 hour period for a SEPARATE seizure event at least 2 hours after the first dose
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When to call for an ambulance

- If it is the first time giving the rescue medication to this child in this particular setting
- OR
- If the seizure has not stopped after 5 minutes following administration of buccal midazolam
- OR
- If concerned

Please note the time that the medication has been given to pass on to emergency services or parents

Step	How to administer buccal midazolam
1	Take one plastic tube, break the seal and pull the cap off. Take the syringe out of the tube
2	Remove the syringe cap and dispose of it safely
3	Gently insert the syringe in the space between the inside of the cheek and the lower gum (buccal cavity)
4	Slowly press the syringe plunger to release the whole amount of the buccal midazolam into the side of the mouth
5	Remove the syringe from the child's mouth, keep the empty syringe to give to a doctor or paramedic so they know what dose has been given

Parents signature	
Nurse's signature	
Date developed	Annual review date

It is the parents responsibility to update the care providers with any changes in regards to epilepsy management in order for them to update the care plan

During a seizure what to be aware of

Try to-

- Time the seizure
- Record what happened before, during and after the seizure

What to record-

- Did anything happen before the seizure? (bump to the head, argument, sleepy etc)
- What happened during the seizure? (Stiff, floppy, jerking, eyes rolled, head turned, continence etc)
- What happened after? (how long they took to recover, sleepy, back to normal, do they remember it)

FIRST AID

DO

- Make the area safe- move any objects that may be in the way
- Cushion the head- a folded jumper will do
- Reassure the child
- Once the seizure is finished put in recovery position until fully recovered
- Respect the privacy and dignity of the child

DO NOT

- Move the child (unless in direct danger)
- Restrain the child
- Put anything in their mouth

School advice-

Epilepsy can have significant impact on a child's achievement. They can experience problems with:

- Visual/ verbal learning process
- Reading, writing, speech, language, numeracy etc
- Memory
- Psychosocial problems
- Concentration and attention

Ways to help

- Involve the child in all school activities
- Group work
- Written information/ instructions
- Make sure the student hasn't missed any information
- Encourage note taking
- Cue cards
- Highlighting
- Rhymes
- Repetition
- Revision

Risks and safety

- Having a regular sleep pattern can reduce seizure activity
- If going swimming, tell the life guard and encourage swimming along side of the pool
- Discourage any climbing above the child's head height
- If cycling, wear a helmet and try to avoid busy roads

Emergency protocol information- buccal midazolam

Midazolam is a benzodiazepine which is used to reduce the risk of a prolonged seizure developing into status epilepticus

There are other brand of midazolam available and your child may use a different emergency medication such as paraldehyde or diazepam- please familiarise yourself with the specific patient protocol

- Buccal midazolam can only be given by someone who has had up-to-date training.
- Updates need to be made annually.
- The training needs to be child specific

Please note: Buccolam has a short shelf life. Please contact parents for a new syringe if there is a month left from expiration

When is the optimum time to give buccal midazolam?

- 0-5 minutes – seizures are likely to stop spontaneously
- 5 minutes- the optimum time to treat
- 5-15 minutes- the child is less likely to come out of the seizure by themselves
- 30 minutes- status epilepticus

Extra considerations

Spat it out? Do NOT repeat the dose

Vomited? Do NOT repeat the dose

Extra salivation? Wipe the mouth over with a cloth and administer buccal midazolam

Seizure not stopped? Please call ambulance 5 minutes after administration

Potential side effects

- Breathing difficulties
- Drowsiness
- Agitation, aggression, anger, dizziness
- Headache
- Rash

If have not needed buccal midazolam for over a year, advise to call the ambulance if they have a generalised tonic clonic seizure last 5 minutes or more

Glossary of terms

Epilepsy- is recurrent seizures- caused by abnormal electrical activity in the brain	Tonic- Clonic- body will be stiff and all four limbs will shake	Myoclonic- Contraction of one or several muscles
Seizure- is episode where a person can lose consciousness and experience motor, sensory, psychic phenomena	Tonic- Body will stiffen	Absences- Fleeting moment of loss of consciousness
Status- epilepticus- prolonged seizure or clusters of seizures not resolving after 30 minutes	Clonic- Body will relax and jerk	Focal epilepsy- electrical activity is localized to one part of the brain
Clusters- seizures that occur one after another without fully recovering	Atonic- muscle tone is lost and body will collapse	Generalised epilepsy- electrical activity comes from the whole brain

Appendix 2 – See Document Management System for printable version

Record of Buccolam [midazolam] Administration at Home

Child's name:

Child's date of birth:

Date and time of fit:

Description of fit:

Date and time of giving BUCCOLAM [midazolam]:

Dose [ml] given:

Preparation used BUCCOLAM PRE-FILLED SYRINGES:

Paramedic Ambulance called? Yes No Time:

Did the fit stop after the BUCCOLAM [midazolam] was administered? Yes/No

If yes, how long after the BUCCOLAM [midazolam]?

Any comments, adverse reactions, hospital admission? [Please describe]

This form should be returned to:

**Cheryl Byrd Epilepsy Specialist Nurse Children's Outpatient Clinic Or
Dr M Hanlon Consultant Paediatrician
Worcestershire Royal Hospital,
Charles Hastings Way
WORCESTER WR5 1DD.**

Thank You

Appendix 3 - See Document Management System for printable version

Information for Parents about Buccolam Pre-Filled Syringes

What do I do if my child has a seizure?

- Stay calm
- Note the time and keep checking how long the seizure is lasting
- Loosen any tight clothing around the neck
- Protect your child from injury
- Cushion your child's head if he or she has fallen on to the floor.
- Once fit has stopped gently place your child in the recovery position
- Stay with your child until he or she is fully recovered
- DON'T try to restrain your child while having the fit
- DON'T force anything between the teeth
- DON'T try to move your child unless he or she is in danger
- DON'T give any drinks until he or she is fully recovered

If a seizure continues for more than five minutes, the Buccolam [midazolam] is given to stop the seizure before it leads to status epilepticus.

When Buccolam [midazolam] is being given for the first time ever, the paramedic ambulance should be called by dialling 999. If your child has had Buccolam [midazolam] before you do not need to call the ambulance. However, you will need to call the ambulance if the initial dose of Buccolam [midazolam] has not had any effect on stopping the seizure within 10 minutes, or there are difficulties in giving the medication.

When you dial 999, state that you need an ambulance for a child having a seizure and that you are giving Buccolam [midazolam]. Give your full address and postcode as the control centre may be in another part of the UK. Don't hang up the phone until ambulance control tells you to.

What is status epilepticus?

Status epilepticus is a seizure [convulsion or fit] or a series of seizures lasting for 30 minutes or more without complete recovery of consciousness. It is a medical emergency. Therefore seizures should be treated after 5 minutes to try and prevent the development of status epilepticus.

What is Buccolam?

Buccolam [midazolam] comes in a sealed tamper proof plastic tube containing one pre-filled ready to use oral syringe, which is **colour coded according to strength**. Each oral syringe contains **one** dose of Buccolam [midazolam] which is a colourless liquid.

Buccolam is a medication from the group of drugs called benzodiazepines that affect the central nervous system. Buccolam [midazolam] is a muscle relaxant and has anti-convulsant properties.

All medication has the potential to cause side effects.

What are the side effects?

- Nausea and vomiting is common.
- Flushing of the skin or a rash of pink spots can occur which disappear within 15 minutes, uncommon.
- Agitation, aggression, anger, dizziness, headaches, very rarely

- Drowsiness and sedation-----recovery is fast.
- Amnesia-short term memory loss is common. Your child may not remember having a seizure.
- Breathing difficulties-an effect on breathing is **very** unlikely to occur if midazolam is used in the dose prescribed .This is the reason for calling an ambulance when you give the very first dose.

What is the usual reaction to midazolam?

- With some sedation, ending of the seizure is expected within a few minutes.
- Flushing of the skin, or a rash of pink spots may appear but these should subside within 15 minutes.
- How your child will react to the medication is difficult to describe until the first time Buccolam is given.

Buccal

- The Buccal area is the space between the inside of the cheek and the gum of the lower jaw by the back teeth.
- Buccolam [midazolam] is absorbed directly into the bloodstream from this area. Midazolam should not be swallowed, but if swallowed accidentally will not cause any harm.

Instructions and procedure for administering Buccolam [midazolam]

- Check that the medication is within the expiry date.
- Give Buccolam [midazolam] when the seizure has been going on for minutes.
- Break the tamper-proof seal and remove the oral syringe from the protective plastic tube.
- Remove and throw away the oral syringe cap before use to avoid choking.
- Explain to the child what is going to happen
- Put on latex free gloves [this is optional]
- Place the tip of the oral syringe into the buccal area of the child's mouth, between the cheek and the gum of the lower jaw by the back teeth.
- Slowly drip the Buccolam [midazolam] solution into this area until the oral syringe is empty.
- If the child's teeth are clenched together they do not need to be parted.
- Remove the oral syringe from the child's mouth. Do not leave the child unattended until he/she has fully recovered. Ensure the child's privacy and dignity is maintained as much as possible at all times

If Buccolam [midazolam] does not control the seizure within five minutes, call an ambulance by dialling 999, if you have not done so already.

Disposal

After administering the Buccolam [midazolam] it is advisable to keep the used oral syringe until the child has **fully** recovered. Ambulance staff may wish to check which medication has been given. Once checked the used oral syringe can be disposed of in a closed waste bin.

Recording

After administering the Buccolam [midazolam],it is important to record that you have done so. The form you use should include:

- the medication you gave
- the dose/amount given
- the route of administration
- the date and time it was given

The incident should also be noted, including a description of the seizure and the length of duration and action taken. It should also include information about what happened to the child following the administration of the Buccolam [midazolam].

The Epilepsy Specialist Nurse will hold the information and it will be used to audit and monitor the use of Buccolam [midazolam]. The child's Consultant or ESN must be informed if there is a significant increase in the frequency or severity of the child's seizures.

Reporting

- The administration of the medication should be reported to the parents as soon as possible. [It may be that friends or relatives have given this medication]
- If an ambulance has been called the paramedics must be informed of the dose of Buccolam [midazolam] given and time of administration.

Important information you should know:

Storage

- Keep medicines in a safe place where children cannot reach them.
- Keep Buccolam [midazolam] at room temperature, away from bright light or direct sunlight and away from heat. **Do not store in a fridge.**
- If the doctor decides your child should stop taking Buccolam [midazolam], return any remaining medicine to your pharmacist.
- You may not be using Buccolam [midazolam] regularly, so please check the expiry date of the product periodically.

NB Your child may also have been prescribed rectal diazepam for epileptic fits lasting longer than five minutes. ***(It is important to remember that either Buccolam [midazolam] or rectal diazepam should be given, not both)***

Each person reacts differently to medicines and so your child will not necessarily suffer from any or all of the side effects mentioned. Please refer to medication leaflet. If you are concerned about any of the side effects or want more information about how to administer Buccolam [midazolam] by the Buccal route, or have any questions or concerns, please ask your consultant, nurse or pharmacist.

Appendix 4

CHECKLIST FOR COMPLETING EMERGENCY MEDICATION PLAN FOR BUCCOLAM

Consultant please complete all areas of plan

- ❖ Clearly complete the child's personal details {an address label can be used} Appendix 1
- ❖ Give a brief description of type of seizure that the child is experiencing which requires the Buccolam.
- ❖ **Clearly write** the amount of Buccolam required in MLs and Milligrams. This should also be done on the prescription for pharmacy and a request for **each tube of Buccolam to be individually labelled.**
Pharmacies are very particular on what should be on the prescription for Buccolam

Below is a **guide** of how it should be requested;

Buccolam Oromucosal Solution

Dose i.e 10mg/2ml to be given

Please supply four(4) x 10mg/2ml pre-filled syringes

Individually labelled

Sign across patient label affixed to script

- ❖ Consultant or Registrar should sign and date Emergency medication plan at time of completion.
- ❖ Discuss plan with parents.

The child's / young person's Consultant and / or Nurse /Epilepsy specialist nurse will:

- ❖ Discuss with parents/ carer's the benefits and risks of Buccolam, enabling them to make an informed choice.
- ❖ Provide them with written information. {Give appendices 2 & 3}
- ❖ Ensure the Emergency medication plan is completed correctly.
- ❖ Inform the Child's GP and request them to prescribe further supplies of Buccolam for home and school use.
- ❖ Liaise with the appropriate professionals to ensure that the Buccolam training is provided. Or **let Cheryl Byrd (Epilepsy Specialist Nurse) know and she will follow up to ensure this is done.**
- ❖ Document the above within the child's notes and forward a photocopy of the Emergency medication plan to the appropriate professionals.
- ❖ The original copy should be placed just behind the Outpatient divider please.
- ❖ Review at clinic the requirement for Buccolam on an annual basis, or more often as dictated by the child's clinical condition.
- ❖ **Completed Emergency medication plan must be photocopied once parents have received training and they have signed the form, it is the responsibility of the member of staff who has given this training to ensure this is processed.**

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