

Epilepsy Nursing Service Operational Policy

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Consultation Groups	
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Services	Applicable
Trustwide	
Mental Health and LD	
Community Health Services	Children's Community Epilepsy Nursing Service

Version Control Summary

Version	Date	Author	Status	Comment
1.0	03/05/2017	Lynn Willbourne	Draft	
1.1	26/10/2020	Louisa Griffith		<p>Reference to CCNS policy updated.</p> <p>Statement regarding Covid -19 Pandemic added.</p> <p>Service address and contact information updated.</p> <p>Video contact included as well as platforms currently used to facilitate this.</p> <p>Added: Out of hospital prescription of emergency medication where the family have not been trained how to administer this – URGENT</p> <p>Updated: In the interim medication changes can be reviewed by the Epilepsy Nurse Specialist who can request further changes from the named consultant using a written email request. The record of this change should be documented by the Consultant and a record of this uploaded to Rio and updated with the GP.” Fax requested was removed as well as appendix 2 as this is no longer used.</p> <p>Record of Buccal Midazolam administration teaching must be uploaded to Rio.</p> <p>Change to training program offered by the ENS.</p> <p>References Updated</p>

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1. AIM OF POLICY

This document provides children and young people, their parents/carers, service commissioners and referring agencies with a description of the operation of the Epilepsy Nursing Service for Children and Young People (ENS) as provided by East London Foundation Trust. This should be read in conjunction with the Community Children's Nursing service (CCNS) operational policy (ELFT 2020) which can be found on the trust Intranet.

It provides information on the aims and objectives of the service, who can use it, how it is accessed and who contributes to the service. Those aims and objectives are in line with The National Institute for Health and Care Excellence (NICE) Guidelines for Epilepsies: diagnosis and treatment (2012).

For information regarding Children's Community Nursing Service operational management during the Covid-19 pandemic please read the Community Children's Nursing service (CCNS) operational policy (ELFT 2020).

2. INTRODUCTION

The Epilepsy Nursing Service works in partnership with children and young people with epilepsy and their families to provide support that enables them to live a full and enjoyable life. NICE 2012 guidelines state that:

"epilepsy specialist nurses should be an integral part of the network of care of individuals with epilepsy. Their key roles are to support both epilepsy specialists and generalists, ensure access to community and multi-agency services, and provide information, training and support to the individual, families and carers."

3. SERVICE BASE

The ENS is part of The Children's Community Nursing Service which is based at:

Appleby Health Care Centre
63 Appleby Road,
Canning Town
E16 1LQ
Telephone: 020 3738 7063
Email: elt-tr.CCNSNewham@nhs.net

4. HOURS OF OPERATION and SERVICE PROVISION

The ENS operates Mondays to Fridays from 09:00 to 17:00 with no bank holiday cover. An answerphone service is available at all times; messages are checked daily during working hours. Professionals are able to contact the Epilepsy Nurse Specialist via mobile phone during working hours.

The ENS provides community based clinical assessment and monitoring of children and young people living or attending school within the borough of Newham, aged 0-16 years with a diagnosis of Epilepsy.

The service is mainly provided at patients own homes but also within a range of other settings including outpatient clinics, schools, children's centres and via telephone, video and email reviews.

Video platforms used:

Zoom
AccuRx

5. TEAM COMPOSITION

The current establishment of the ENS is:

1x Band 7 Epilepsy Nurse Specialist with administrative support.

Professional accountability for the Epilepsy Nurse Specialist is to the Lead Nurse for Children's Services.

6. GENERAL PRINCIPLES

The purpose of the ENS is to work in partnership with children and young people with epilepsy and their families/carers to provide support that enables them to live a full and enjoyable life.

NICE (2012) guidelines state that "epilepsy specialist nurses should be an integral part of the network of care of individuals with epilepsy. Their key roles are to support both epilepsy specialists and generalists, ensure access to community and multi-agency services, and provide information, training and support to the individual, families and carers". They go on to say "healthcare professionals should adopt a counselling style that enables the individual with epilepsy, their family and/or carers as appropriate, to participate as partners in all decisions about their healthcare, and take fully into account their race, culture and specific needs. In children, self management of epilepsy may be best achieved through active child-centered training models and interventions".

ENS service aims:

- To provide community based specialist nursing interventions; clinical assessment, monitoring, education and support to children and young people with epilepsy, their family and carers in order to improve their quality of life;
- To provide high quality training and education to a range of community practitioners to develop their professional practice to facilitate the social inclusion of children and young people with epilepsy in community settings;
- To provide patients with appropriate physical access/delivery in community settings;
- To work in partnership with parents within a relationship of mutual trust and respect
- Development of best practice guidance and service quality standards;
- To provide training/education to child/young person/parents/carers/other professionals to ensure that the care needs of each child/young person can be met in the home or other community setting;
- To reduce and prevent, where appropriate, re-attendance and/or re-admission to hospital;
- To facilitate 'Shared Care' for children requiring long term treatment, nursing care or support co-ordinated through specialist centres (e.g. child/young person receiving ongoing treatment);
- To co-ordinate individualised packaged of care in partnership with family, commissioning and other allied health professionals for children with complex care/needs;
- To ensure that patients are seen by the service in accordance with the agreed service lines and are subsequently referred back to specialist or general service providers as required;
- To ensure quality services are available to patients that cannot be accommodated by the existing community based provision;
- To provide a learning environment for student clinicians and nurses on appropriate and mutually agreed training secondments;

7. RERERRAL CRITERIA and SOURCES

7.1 Essential criteria:

1. The child or young person must have a diagnosis of epilepsy.

However, when a hospital medical practitioner has a strong suspicion of epilepsy, a referral for the specialist nurse to collate history or description of attacks will be accepted, but referral must come directly from the medical practitioner.

2. Children and young people must be aged 0-16 years

However, in some circumstances young people who are current or previous recipients of the epilepsy nursing service may remain so during their period of transition to adult services until they are 17 years old, but new referrals for a young person over the age of 16 will not be accepted.

3. The child or young person must be resident or attend school within the London Borough of Newham.

Children and young people that live outside of the London Borough of Newham but attend a school within the Borough are not seen in their own homes, they are invited for contacts at a Newham Health Centre location or their school.

7.2 Referral route

The service has an open referral policy. New referrals to the service will be considered by the nurse specialists as they are received against the above criteria and prioritised according to clinical information provided by the referrer as immediate (i.e. requiring telephone assessment within 24 hours) or routine (i.e. requiring an assessment within 6 weeks).

Prioritisation will be given to the children and families meeting the following criteria:

- Child Protection – URGENT
- Out of hospital prescription of emergency medication where the family have not been trained how to administer this – URGENT

Referral form: Appendix 1

7.3 Discharge criteria

Discharge from the service may occur in several cases, for example:

- Care complete (via stepping down of illness)
- Parent/carer self discharge
- Relocation of client to another borough
- Relocation of client to another NHS or non NHS provider
- Inappropriate referral so no care identified/given
- Transition to adult services

At discharge a summary letter is prepared and copies sent to involved professionals to confirm:

- The input provided from the service
- Discharge date/reason for discharge e.g. moved from borough
- Any services the child/young person has been referred to

8. CARE PATHWAY THROUGH ENS

The pathway of specialist nursing care begins with the diagnosis of epilepsy and a programme of care is provided for those 'New to Epilepsy'. Families are then discharged from the service to manage their lives independently with open re-referral back to the service if required, or are moved to the 'Complex Epilepsy' programme where an individually planned programme of care is implemented and evaluated again working towards discharge from the service.

A year following the point of discharge from the service an 'annual review of epilepsy' is carried out by the nurse specialist.

New to Epilepsy' care programme:

This programme consists of:

- The establishing of a partnership with the child and family; negotiation of boundaries for service provision, confidentiality, sharing of information, safeguarding responsibilities
- The co-ordination of clinical history and collection of data in relation to the diagnostic process
- The provision of education, explanation of procedures to reduce child/young person and family concerns and a critical appraisal of the diagnostic process is made
- The provision of general education about epilepsy; a package of information and specifically tailored information regarding the implications of the child/young person's seizure type, epilepsy syndrome, underlying aetiology and likely prognosis (where possible)
- The provision of age and development appropriate education about epilepsy for child/young person and their siblings
- The provision of education and planning for safe management of seizures with and without emergency rescue medication to promote independent family management of seizures to reduce acute service uptake
- The provision of education regarding the prescribed antiepileptic drug treatment plan, and lifestyle factors and assessment and interventions to promote concordance. This will include education for the family on monitoring the outcome of their treatment plans and when to seek an unscheduled review of condition. Failures in treatment plans are highlighted and discussed with paediatricians
- The provision of assessment and advice regarding safety with daily activities in the home and outdoors e.g. bathing, cooking, supervision
- The promotion of age appropriate inclusion into play, physical activities and other social activities through assessment and planning
- To explore and support the emotional impact of the diagnosis of epilepsy on the family system, considering issues such as coping, adjustment and stigma
- Baseline assessment of school functioning; academic performance, social relationships and behaviour
- To facilitate and support a discharge from the Epilepsy Nursing Service and the provision to families of new skills to self manage epilepsy and how and when to re-refer back to the service

'Annual review of epilepsy' care programme

NICE (2012) guidelines recommend children with epilepsy should have a regular structured review carried out by a specialist.

A year following the point of discharge from the service an 'annual review of epilepsy' is carried out by the nurse specialist and if required an appointment is scheduled. This contact is 60 minutes in duration and re-assesses the following domains:

- Progress with treatment plan, control of seizures, medication regimen, concordance.
- Child/young person understanding of their epilepsy taking into account their social, emotional and cognitive development, and that of the wider family.
- Emerging lifestyle and information issues in relation to living with epilepsy.
- Review seizure management plans, emergency medication, uptake of emergency services, injuries & safety concerns.
- Emotional well-being of child, young person and family.
- School functioning and behaviour.

At present there is no structured provision of transition to Adult Services within Newham, annual reviews will cover issues in relation to this. CYP are sometimes lost to follow up especially when discharged from tertiary centres or if they do not attend out patient appointments, annual reviews will pick up some of these CYP. Referrals to other professionals will be made as appropriate.

Complex epilepsy' care programme

This programme of care is less prescribed due to wide range of clinical problems encountered. Referral routes include:

- General Practitioners
- Schools (following changes in the nature of their seizures that are affecting attendance)
- Tertiary Centres (eg as part of discharge planning/support following epilepsy surgery)
- Children/young people transferring into the borough requiring assessment
- Children and young people who have complex epilepsy emerging towards the end of their 'New to Epilepsy' programme or who have ongoing support needs in dealing with their epilepsy will move to this programme automatically
- Liaison with other agencies to facilitate the provision of appropriate service
- Integrated working related to safeguarding systems such as MERLINS etc.

9. MEDICATION ARRANGEMENTS

Effective medication management is critical to the well being of the CYP. The ENS will support good medication management by offering practical suggestions around taking of medication, possible side effects and concerns around dosage. At all times the ENS aim to ensure that the CYP has the best possible control of their seizures as a priority.

Medication will be prescribed/reviewed at the point of discharge from hospital or in an outpatient clinic. In the interim, medication changes can be reviewed by the Epilepsy Nurse Specialist who can request further changes from the named consultant using a written email request. The record of this change should be documented by the Consultant, a record of this uploaded to RIO (operating system) and updated with the GP.

Training is provided to parents in the administration of emergency medication for use in the event of prolonged or clusters of seizures. When training has been completed the nurse specialist will return to the family home to assess the level of understanding reached. Both parties sign a checklist that training and understanding has taken place. This is to be uploaded to Rio.

Appendix 2 Midazolam checklist

10. TRAINING OF OTHER PROFESSIONALS

The ENS provides training packages to develop the skills of other professionals in the form of:

- a) An epilepsy awareness session for LBN School Nurses and Health Visitors. This session was developed by the Epilepsy Nurse Specialist with the Practice and Development Facilitator (PDF) from LBN. This session will be offered as part of their staff update programme as dictated by their service. Currently offered yearly. The ENS will provide supervision to the PDF to ensure this is reviewed and updated. The ENS will supervise one of these awareness sessions per year.
- b) 'Train the trainer' for school nurses and health visitors who are then able to provide an epilepsy awareness session for education staff. This is supported by supervision twice a year.
- c) 'Train the trainer' for health staff who are then able to provide training for non nursing staff, currently education staff, in the administration of emergency medication for prolonged seizures. This is supported by supervision three times a year.
- d) Training Non Nursing Staff In Admin of Emergency Medication for Prolonged Seizures in Epilepsy CHN – is available to view on the Intranet.
- e) Teaching sessions for student nurses on placements within the trust.

11. REFERENCES

Trust policies

1. Children's Community Nursing Service Operational Policy
2. Training Non Nursing Staff In Admin of Emergency Medication for Prolonged Seizures in Epilepsy

National Guidance

1. National Institute for Health and Care Excellence (2012) The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care. NICE, London.

www.nice.org.uk/CG020NICEguideline

2. Epilepsy Nurses Association (2019) 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. ESNA, Wolverhampton.

<https://ilaebritish.org.uk/content/uploads/2019/06/ESNA-Midazolam-Guidelines.pdf>

Appendix 1

Newham Children's Community Nursing Service – Referral Form

Which Service do you require?
(Please tick)

Children's Community Nursing Team

Epilepsy Nursing

Diana Palliative Care
Nursing

Continuing Care

(Nursing, Psychology and Play Specialist)

Section A: Details of child

Surname:	Date of birth:	Male/Female
Forenames:	Also known as:	NHS No. RiO No.
Address:		Post code:
Ethnicity:	Parent/Carer name:	Parent/Carer name:
Religion:	Relationship to child:	Relationship to child:
Language:	Telephone/Mobile:	Telephone/Mobile:
Interpreter Required YES/No Language:	Weight:	Alerts/Allergies:
Paediatric Consultant:	Base:	Hosp No.
GP:	Address:	GP Tel No.
School/Nursery:	School Nurse/Health Visitor:	Tel No:
Child Safeguarding issues? CIN / CP Plan / None (circle)	Social Worker Contact:	
Have you discussed referral with parents? Yes / No (circle)	Do they agree to referral? Yes / No (circle)	

Section B: Reason for referral

Diagnosis:	
Reason for referral (including previous medical history and details of equipment needed):	
Discharge letter/ other report attached Yes /	
No (circle)	
For hospital referrals: Date of hospital admission/attendance:	Planned date of discharge:
Discharge planning meeting date:	
CCNS Must have at least 48hr notice of DPM to attend and may require 24- 48 hours' notice to visit family at home for acute patients.	

IF REFERRAL IS FOR WOUND PLEASE COMPLETE BELOW SECTION, WOUND REFERRALS WILL BE SEEN IN OUR DRESSING CLINIC. WE WILL CONTACT FAMILY/CARERS WITH DETAILS. *IF NOT PLEASE CONTINUE TO SECTION C*

Last wound review:	Last Dressing Change:	Dressings supplied: Yes No (<i>circle</i>)
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Section C: Services involved

Please tick, to your knowledge of other services involved		Dietetics	Speech & Language
Child Development Service	Physiotherapy	Occupational Therapy	Wheelchair Services
CFCS/CAMHS	Social Services	Voluntary Sector / Other	PSHVT
Richard House	Tertiary Consultant Name & Hospital:		
Have Clinical Psychology services been offered to family already from outside the Diana Team? Yes / No (<i>circle</i>)			

Section D: Details of person making referral

Name:	Job Title:
Base:	Telephone Number:
Email:	Fax Number:
Referral Date:	Signed:

Section E: OUR OFFICE USE ONLY

Date referral received:	Team:	Triaged by:
Initial contact date/time:	Contact with:	Named Nurse:
Associate Nurse:	Planned date for visit:	Long Term Short Term (<i>circle</i>)
Priority		

ICES REF no

	provided by school nurse for staff.	
To understand possible problems of administration and what to do if this occurs	<ul style="list-style-type: none"> • Unable to give medication - could be for a variety of reasons e.g. cannot part lips, unable to draw up medication/open tube. Abandon procedure and call 999 • Child vomits during/ just after procedure - cannot give another dose as unsure of how much medication has been retained in the mouth. Family must abandon procedure and call 999. • Medication expired - cannot give medication. Abandon procedure and call 999. 	
To understand possible side effects of medication and what to do if this occurs	<ul style="list-style-type: none"> • Respiratory depression <input type="checkbox"/> once seizure has stopped colour/ breathing • Ongoing colour change <input type="checkbox"/> should return to normal. Prolonged colour Change/ breathing difficulty is emergency and family should call 999 • Sleep/ sedation - this is normal after a seizure but the child/ young person should be rousable even though they may sleep for hours. • Reduced memory of events - this is normal after midazolam medication • Reduced anxiety - this is normal after midazolam medication 	
Telephone number for Epilepsy Nursing Service	<ul style="list-style-type: none"> • 020 8475 8580 • 07956602340 	

Nurse Name : Sign/ Print Date:

Parent name: Sign/ Print: