



Royal College
of Nursing

Specialist nursing of children and young people with epilepsy

RCN guidance for service planning and career development





Acknowledgements

This publication builds on the RCN's *Competency framework and guidance for developing paediatric epilepsy nurse specialist services* published in 2005. The RCN would like to acknowledge contributors to that work and thank those who supported the development of this new publication, including:

Christine Bennett, Epilepsy specialist nurse, Hull

Diane flowers, Epilepsy specialist nurse, Bristol

Margaret Wilson, Epilepsy specialist nurse, Glasgow

Brian Chappell, Director, NeuroEducation; Consultant Lecturer, Leeds Metropolitan University

British Paediatric Neurology Association (BPNA)

Epilepsy Action

Epilepsy Nurses Association (ESNA)

Epilepsy Society

RCN Children's and Young People's Professional Issues Forum

Roald Dahl Foundation

Royal College of Paediatrics and Child Health

Strategic Paediatric Educationalists & Nurses in Scotland (SPENS)

Young Epilepsy

Bernie Concannon, Epilepsy specialist nurse, Birmingham Children's Hospital

Berni Waldron, Senior lecturer, DeMontfort University and epilepsy specialist nurse

This publication is due for review in December 2015. To provide feedback on its contents or on your experience of using the publication, please email publications.feedback@rcn.org.uk

RCN Legal Disclaimer

This publication contains information, advice and guidance to help members of the RCN. It is intended for use within the UK but readers are advised that practices may vary in each country and outside the UK.

The information in this publication has been compiled from professional sources, but its accuracy is not guaranteed. Whilst every effort has been made to ensure the RCN provides accurate and expert information and guidance, it is impossible to predict all the circumstances in which it may be used. Accordingly, to the extent permitted by law, the RCN shall not be liable to any person or entity with respect to any loss or damage caused or alleged to be caused directly or indirectly by what is contained in or left out of this information and guidance.

Published by the Royal College of Nursing, 20 Cavendish Square, London W1G 0RN

© 2013 Royal College of Nursing. All rights reserved. Other than as permitted by law no part of this publication may be reproduced, stored in a retrieval system, or transmitted in any form or by any means electronic, mechanical, photocopying, recording or otherwise, without prior permission of the Publishers or a licence permitting restricted copying issued by the Copyright Licensing Agency, Saffron House, 6-10 Kirby Street, London EC1N 8TS. This publication may not be lent, resold, hired out or otherwise disposed of by ways of trade in any form of binding or cover other than that in which it is published, without the prior consent of the Publishers.

Specialist nursing of children and young people with epilepsy

RCN guidance for service planning and career development

Contents

| | |
|---|----|
| Key messages | 4 |
| Introduction | 4 |
| Purpose of this guidance | 5 |
| A vision for CYP epilepsy nursing services | 6 |
| Workforce planning | 7 |
| CYP epilepsy specialist nurse career pathway | 8 |
| Competences for CYP epilepsy specialist nursing | 10 |
| Implementation and evaluation | 13 |
| Appendix 1 Example job descriptions | 14 |
| Grade 6 | 14 |
| Grade 7 | 16 |
| Grade 8 | 18 |
| Appendix 2 References and further reading | 22 |

Key messages

- Every paediatric epilepsy service must ensure that children and young people (CYP) are seen by an epilepsy specialist nurse who they can contact between scheduled reviews.
- Funders/commissioners of services must ensure that there are sufficient, appropriately qualified CYP epilepsy specialist nurses to provide good standards of care for children/young people and their families.
- Funders/commissioners of education must ensure that there is adequate education and training to support specialist CYP nursing services across the UK.
- Managers and educators should encourage and support career development for nurses according to the framework in this publication to ensure ongoing continued leadership and high quality services in the specialty.

Introduction

Epilepsies are common neurological disorders of childhood characterised by recurrent seizures and having a significant morbidity and mortality. The prevalence of children and young people aged 17 years or younger with a diagnosis of epilepsy and receiving anti-epileptic drugs is 3 per 1,000 (NICE, 2013a). For many children and young people, seizures can be controlled with an anti-epileptic drug or other interventions. Optimal management improves health outcomes and can help to minimise any detrimental impact on social, educational and employment activity (NICE, 2013b). A number of children could benefit from surgery; in 2012, a new Children's Epilepsy Surgery Service (CESS) was set up to provide brain surgery for children with epilepsy in England (Epilepsy Action and NHS England, 2013).

Recommendations for the management of childhood epilepsies were published by the National Institute for Health and Clinical Excellence (NICE) in 2004 (updated in 2012) and by the Scottish Intercollegiate Guidelines Network (SIGN) in 2005. These guidelines recognise the complexity of paediatric epilepsies and the need for specific knowledge and skills for effective management and support. However, the first UK-wide audit of epilepsy care for children and young people (Epilepsy12) reported that there is little evidence of sufficient implementation of these guidelines and that service provision is variable across all four UK countries (RCPCH, 2012). Additional concerns have been raised by Epilepsy Action related to changes in the NHS in England: 'Not enough is being done to plan for better services once changes to the NHS, planned for April, have taken place' (Epilepsy Action, 2013).

A major gap in current services is the lack of access for children, young people and their families to epilepsy nurse specialists. NICE (2012) and SIGN (2005) guidelines both specify the requirement for paediatric epilepsy nurse specialists 'as an integral part of the network of care'. One of the nine NICE quality standards for children and young people with epilepsy published in February 2013 requires that: 'Children and young people with epilepsy are seen by an epilepsy specialist nurse who they can contact between scheduled reviews' (NICE, 2013b). As recent reports indicate, urgent action is needed to achieve this standard. Epilepsy12 found that 47 per cent of units audited had no

epilepsy nurse specialist and across the UK the majority of children had not received any input from a specialist nurse within the first 12 months of assessment (RCPCH, 2012). Similar figures were reported by Epilepsy Action:

- Over half of trusts that provide a paediatric epilepsy service do not offer their patients access to a paediatric epilepsy specialist nurse.
- 42 per cent of children who are still having seizures reported never having seen an epilepsy specialist nurse. (Epilepsy Action, 2013)

‘In some places the basic elements of an epilepsy service, such as an epilepsy specialist nurse, are missing.’
Epilepsy Action survey finding 2012

‘Forty seven per cent of units audited had no epilepsy specialist nurse.’
Epilepsy12 audit finding 2012

Epilepsy12 recommendation

Epilepsy specialist nurses are an essential component of paediatric services and all children diagnosed with epilepsy should have specialist nurse input offered as per NICE and SIGN guidelines. Epilepsy specialist nurse provision includes care planning, facilitating appropriate participation, risk assessment, school and respite care liaison, rescue medication training and telephone advice.

All services without an epilepsy specialist nurse should create new posts to ensure adequate care. Units where many children with epilepsy are not having input from an epilepsy specialist nurse should improve their care pathways and epilepsy specialist nurse provision. (RCPCH, 2012, p.15)

Purpose of this guidance

This RCN guidance document is intended to support professionals, commissioners and service planners to comply with these recommendations on specialist nursing. However, meeting the NICE and SIGN standard requires more than simply employing specialist nurses – there needs to be a sustainable and comprehensive approach to recruitment, education and career pathways. This will ensure that there are sufficient numbers of appropriately qualified and supported specialist nurses to deliver quality care to children and young people with epilepsy and their families.

Many of these children and young people have a range of complex needs in addition to their epilepsy. A key role of specialist nurses is to provide expert advice and support for other professionals. They work with community children’s nurses, learning disability nurses, school nurses and others who may have the role of lead professional for the child/young person and who also require competence in epilepsy management. Many of these nurses develop specialist epilepsy competencies as part of their wider role, as is reflected in the senior practitioner level of [Table 1 \(p.9\)](#) and grade 6 competencies in [Tables 2-4 \(pp.11-12\)](#). Some of these nurses may develop their epilepsy specialist knowledge and skills further without taking on an epilepsy specialist nurse role. This guidance may be helpful for their continuing development, but the main focus is that of the specialist role – in support of the recommendations cited above.

To address the recommendations, a vision for specialist epilepsy nursing services is presented, recognising that nurses function within a range of service models but increasingly within clinical networks supporting effective care at all stages of the care pathway, including home and school. A career pathway and competence summary are provided to guide nurses, managers and educators in developing an appropriately skilled specialist workforce. Sample role descriptions are included in [Appendix 1](#) as a practical support for employers and for nurses seeking to influence the quality of epilepsy specialist services. Additional resources supporting the development of specialist knowledge and skills are listed in [Appendix 2](#).

The purpose of this document is therefore to:

- inform planning and commissioning of epilepsy specialist services for children and young people (and their families)
- underpin the development and review of specialist nursing services, including measurement of outcomes and service quality
- support managers in workforce planning and preparing role requirements/job descriptions for specific posts
- inform planning and commissioning of educational programmes to prepare nurses for these specialist roles
- support nurses in career planning and personal development, informing the planning and delivery of learning opportunities and more detailed competence frameworks for competence assessment.

A vision for CYP epilepsy nursing services

Services should be commissioned from and coordinated across all relevant agencies encompassing the whole epilepsy care pathway. An integrated approach to the provision of services is fundamental to the delivery of high-quality care to children and young people with epilepsy, and the quality standard should be delivered by multidisciplinary teams through a local epilepsy clinical network (NICE, 2013b).

Local epilepsy clinical networks include professionals from all disciplines, forming an integrated team that includes the child/young person and their family. Within this network approach, children's epilepsy specialist nurses have a key role across the entire pathway, helping to ensure continuity between settings and being a main source of epilepsy expertise for the child/young person and their family. They work with and support a range of other staff including community children's nurses, school nurses, teachers, learning disability nurses and medical colleagues. Specialist epilepsy knowledge and skills are particularly required as the young person transfers to adult services because specialist nurses have been instrumental in setting up clinics for young people with epilepsy and establishing transitional referral pathways to adult services.

Team building, collaboration and communication are an integral part of this role. These skills are required for local network meetings and regional and national networks where nurses contribute heavily to promoting the delivery of high quality care and equitable services to children and young people with epilepsy (see the Scottish Paediatric Epilepsy Network www.spen.scot.nhs.uk). Role descriptions and contracts for epilepsy nurses working across local networks need to reflect this broad role.

In summary, the CYP epilepsy specialist nurse:

- promotes good practice in the assessment, diagnosis, treatment and care of children and young people with epilepsy
- supports and advocates high quality epilepsy services for the child/young person and their family
- is the main contact point for GPs and other professionals on epilepsy related matters, liaising between agencies and visiting at home and school when necessary to ensure continuity of care
- supports the ongoing care of the child/young person and family providing specialist information, emotional support, teaching, and referring to other professionals when necessary, such as for counselling
- provides training, education, awareness raising and advice to other professionals in schools, primary and community teams, social services, learning disability teams, and so on
- works as a key member of the multi-disciplinary team, helping to develop responsive, evidence-based, accessible and appropriate services (including nurse led clinics) and engaging children/young people and families in service reviews and developments.

Modern health services require a nursing workforce that continues to evolve, creating opportunities for innovation and developing new roles to meet changing health needs. The need for flexibility and the development of career pathways was highlighted in *Modernising nursing careers: setting the direction* (Department of Health, 2006). The range of epilepsy nurse specialist roles required to ensure quality of care delivery, to support service development and achieve good standards of education, management and research is presented in [Table 1 \(p.9\)](#). This proposed career pathway encompasses clinical, management and leadership, and education and research roles. Further detail of the CYP epilepsy nurse specialist role is reflected in the competence summary in [Tables 2-4 \(pp.11-12\)](#) and in the example role descriptions in [Appendix 2](#).

Workforce planning

An appropriate skill mix for specialist nursing services varies widely as it is dependent on the number of children and young people and their needs, the local and regional service organisation, and the composition of multidisciplinary teams. In some areas, epilepsy specialist nurses work as part of a wider community or learning disability team but would also be expected to link to their relevant epilepsy clinical network/specialist service. Paediatric epilepsy services should work with the nursing lead for the epilepsy clinical network to review the epilepsy specialist nursing workforce, and plan for meeting local needs and supporting career development across the network and more widely.

The RCN's guidance on *Defining staffing levels for children and young people's services* (RCN, 2013) covers all types of services and provision, providing minimum essential requirements for all providers of services for babies, children and young people. This guidance should be referred to for guidance on staffing and skill mix, caseload, and evidence-based approaches to workforce planning.

CYP epilepsy specialist nurse career pathway

Anyone undertaking a specialist nursing role caring for children and young people would be expected to have a minimum of five year's experience achieving expertise in general children's nursing. This includes competence related to:

- legal, ethical and rights-based care of children and young people
- safeguarding children and young people
- health promotion and growth and development needs including those of the CYP with disabilities or learning disabilities
- communicating with children of different ages/cognitive abilities and their families
- physiological, physical, social and emotional responses of children and young people to health conditions and their treatment
- child and adolescent mental health
- family responses and adaptation to long-term conditions or disabilities.

The additional epilepsy-related knowledge and skills and the level of competence required depend on the type of service, the number and skill mix of nursing staff in the team/network and the needs of the children, young people and families. Currently, there are many different job descriptions for epilepsy specialist nurse roles and not all of the competences in the career pathway and competence summary in [Table 1 \(p.9\)](#) will be relevant to each practitioner. However, to deliver safe and effective care, all nurses must function at an optimal level for their role. Evaluating and demonstrating competence is essential in ensuring quality of care and maintaining the confidence of children and their families in epilepsy nursing provision. Using the career pathway and competence summary in [Tables 2-4 \(pp.11-12\)](#) will help to ensure a more consistent and standardised approach at all levels.

Different roles require varying levels of competence, depending on the nature of the work and level of responsibility. This pathway considers roles spanning grade 6-8 of the Agenda for Change pay bands (NHS Employers, 2011). In order to progress both academically and professionally, nurses working in the specialty must be supported to identify a relevant study path for their level of experience and qualification. For example, progression from senior practitioner to advanced practitioner requires the attainment of specific clinical knowledge and skills as well as appropriate academic enhancement, as illustrated in the CYP epilepsy specialist nursing career pathway in [Table 1 \(p.9\)](#).

| Table 1: CYP epilepsy specialist nursing career pathway | | | | | |
|--|--------------|---|--|--|---|
| | Grade | Career pathway | Related knowledge and skills | Professional qualifications | Academic pathway |
| Consultant practitioner | | | | | |
| Staff working at a very high level of clinical expertise and/or responsible for planning services. | 8 | Lead nurse, lead educator, nurse consultant, advanced nurse practitioner. | Masters level skills in (eg) education; assessment and diagnosis; nurse prescribing; leadership; negotiating and influencing; strategic awareness of population of children and young people with epilepsy; and the clinical, social and psychological challenges they may face. | RN Child, independent supplementary prescribing. NMC requirements for advanced practice. | Masters PhD |
| Advanced practitioner – expert in specialty | | | | | |
| Experienced clinical professionals who have developed their theoretical knowledge to a very high standard. They are empowered to make high level clinical decisions and have their own caseload. | 7 | Advanced nurse practitioner, clinical nurse specialist, matron, educator, ward sister. | Good knowledge of treatments and medication management; potential psychosocial implications of a diagnosis of epilepsy; high level of interest and awareness in public health; ability to identify long term needs of population; and case management, multi-professional/ agency working. | RN Child, independent prescriber. Working towards Masters level education/advanced practice. | Postgraduate certificate/diploma Masters |
| Senior practitioner – competent in specialty | | | | | |
| Staff would have a higher degree of autonomy and responsibility than practitioners in an inpatient environment, or managing one or more service areas. | 6 | Senior staff nurse, community children's nurse, school nurse, learning disability nurse. | Equipped with a variety of clinical skills related to effective management of children and young people with epilepsy, including care co-ordination skills. | RN Child, working towards honours degree and mentorship qualification. CPD accredited qualifications usually related to children's epilepsy/neurology. | BCs (Hons) Postgraduate certificate |
| Practitioner – novice in specialty | | | | | |
| Registered practitioners in their first or second post. | 5 | Staff nurse, ward nurse, community children's nurse, school nurse, learning disability nurse. | Consolidating learning from registration and putting a range of skills into practice. Developing a portfolio of competencies related to epilepsy. | RN Child (Degree or Diploma). Undertaking CPD modules related to children's epilepsy/neurology. | Continuing professional development modules |

Competences for CYP epilepsy specialist nursing

The NHS Knowledge and Skills Framework (KSF) comprises of six core and 24 specific dimensions of knowledge and skills that apply to different roles in health care (NHS Employers, 2010). The RCN's 2009 publication *Integrated core career and competence framework for registered nurses* (RCN, 2009) brings together core and specific dimensions of the KSF that are relevant to nursing and provides the basis for the development of other specialist competences. The six core dimensions are: communication; personal and people development; health, safety and security; service improvement; quality; and equality and diversity. In 2012, the RCN published the below detail of KSF Health and Wellbeing (HWB) dimensions at different levels that are relevant to nurses caring for children and young people (Royal College of Nursing, 2012).

- HWB1: Promotion of health and wellbeing and prevention of adverse effects on the health and wellbeing of children and young people.
- HWB2: Assessment and care planning to meet the health and wellbeing needs of children and young people.
- HWB3: Safeguarding the health and wellbeing of children and young people.
- HWB4: Enablement to address health and wellbeing needs of children and young people.
- HWB 5: Provision of care to meet the health and wellbeing needs of children and young people.

For CYP epilepsy specialist nurses, the following KSF Information and knowledge (IK) and General (G) dimensions are also considered important.

- IK1: Information processing.
- IK2: Information collection and analysis.
- IK3: Knowledge and information resources.
- G1: Learning and development.
- G2: Development and innovation.

[Tables 2-4 \(pp.11-12\)](#) build on these core dimensions, listing the specialist knowledge and skills required for clinical management of children and young people with epilepsy and their families and for clinical leadership in children's epilepsy services. Note that all competences apply to the consultant practitioner/Grade 8.

| Clinical management | | Grade |
|----------------------------|---|--------------|
| 1. | Uses knowledge and understanding of epilepsy syndromes and seizure classification to explain epilepsy and its management to CYP and their family. | 5-7 |
| 2. | Using epilepsy specific expertise, assesses seizures and treatment options and develops a plan of care in collaboration with the CYP and their family. | 7 |
| 3. | Encourages the child/young person and family to discuss issues related to quality of life, prognosis, and sudden unexplained death in epilepsy. | 6-7 |
| 4. | Discuss triggers for seizures and provides seizure management advice, including rescue medication (eg buccal midazolam) advice/education. | 5-7 |
| 5. | Identifies subtle changes in the CYP through understanding the pathology and presentation of epilepsy. | 7 |
| 6. | Explains investigations and results: electroencephalogram (EEG), magnetic resonance imaging (MRI), positron emission tomography (PET), single photon emission tomography (SPECT), video-telemetry, genetic tests. | 7 |
| 7. | Recognises side effects of medication and the effects of polypharmacy including behavioural changes and cognitive decline. | 7 |
| 8. | Discusses alternative treatments for epilepsy, eg ketogenic diet, epilepsy surgery, VNS. | 7 |
| 9. | Manages CYP with vagal nerve stimulation (VNS)/on ketogenic diet. | 7 |
| 10. | Supports CYP and their family with neurodegenerative condition and epilepsy plus. | 6-7 |
| 11. | Takes into account differing needs of adolescents with epilepsy and the information they will need over time. | 6-7 |
| 12. | Addresses adolescent issues at appropriate time, discussing lifestyle issues, SUDEP, contraception and pregnancy. | 6-7 |
| 13. | Works in partnership with CYP to encourage adherence to medication and seizure control. | 6-7 |
| 14. | Uses advanced communication skills to optimise family coping. | 7 |
| 15. | Documents assessments, plans care and outcomes, manages data including data collection for audit. | 6-7 |
| 16. | Conducts audits to monitor and improve nursing care quality and outcomes. | 6-7 |
| 17. | Makes autonomous clinical decisions ensuring that care reflects latest evidence/research developments. | 7 |
| 18. | Case manages children ensuring continuity and quality of care. | 7 |
| 19. | Liaises with school staff about the implications of epilepsy on children in school and liaises with school nurse. | 6-7 |
| 20. | Discusses with teaching staff how seizures can impair a child's learning and describes referral pathways for multidisciplinary team involvement. | 7 |
| 21. | Liaises with all the agencies that may be involved with the more complex child, eg social services, community health, respite care. | 5-7 |
| 22. | Works across boundaries (mainly education and social care) giving expert advice. | 7 |

| Clinical leadership | | Grade |
|----------------------------|--|--------------|
| 1. | Understands all roles across the children's epilepsy network. | 5-7 |
| 2. | Acts as a resource for nursing, medical staff and allied health professionals across the network, role modelling advanced generalist as well as specialist clinical skills, knowledge of practice and problem-solving abilities. | 7 |
| 3. | Leads inter-professional working to ensure co-ordination of transition to adult services across the network. | 6-7 |
| 4. | Participates in research and multidisciplinary audit within the epilepsy speciality. | 6-7 |
| 5. | Develops and drives policy, protocol and pathway development for improved case management. | 7 |
| 6. | Influences and supports educational provision and learning opportunities for nursing and multidisciplinary colleagues. | 6-7 |

| Specialist knowledge | | Grade |
|-----------------------------|--|--------------|
| 1. | Demonstrates in depth knowledge of anatomy and physiology of the central nervous system associated with epilepsy. | 6--7 |
| 2. | Identifies the causes of epilepsy and its relationship to symptoms in epilepsy. | 7 |
| 3. | Understands differential diagnosis and co-morbidities. Has the skills to recognise non-epileptic attack disorder (NEAD). | 6-7 |
| 4. | Explains the many epilepsy syndromes: juvenile myoclonic epilepsy (JME), juvenile absence epilepsy (JAE), childhood absence epilepsy (CAE), benign epilepsy with centro temporal spikes (BECTS), Dravet's, Lennox Gastaut, West syndrome etc. Defines refractory epilepsy. | 7 |
| 5. | Understands which medications are used for different seizure types/epilepsy syndromes and mode of action. | 7 |
| 6. | Describes medicine interactions and undertakes accurate drug dosage calculations. Knows potential side effects of anti-epileptic medications. | 6-7 |
| 7. | Recognises the range of emotional responses to a diagnosis and knows when to refer onto psychology / relevant MDT members. | 6-7 |
| 8. | Knows when to refer CYP to psychology/neuropsychology services for educational or behavioural assessment. | 6-7 |
| 9. | Is aware of other syndromic diagnosis that may present with subtle changes in cognition. | 7 |

Implementation and evaluation

This guidance complements clinical and service guidance, addressing the specific requirement to have a sufficient number of nurses with the right knowledge and skills to provide quality care for children and young people with epilepsy, and their families. The impact of implementing this RCN guidance should be measured as part of service evaluation and audit with specific measures focused on:

- a) the child or young person and their family's reports of access to and experience of specialist nursing services (and other indicators of quality care)
- b) percentage of CYP epilepsy services that include appropriate nursing skill mix as reported by CYP epilepsy network nursing leaders
- c) numbers of CYP epilepsy specialist nurses at each level across networks compared with agreed requirement for each network
- d) nurses' reports of access to courses, learning opportunities and other support for career progression in the specialty.

Appendix 1 Example job descriptions

With thanks to:

- Alder Hey Children's NHS Foundation Trust
- Central Manchester University Hospitals NHS Foundation Trust
- Birmingham Children's Hospital NHS Trust

Grade 6

| | |
|-----------------------|---|
| JOB TITLE | Epilepsy specialist nurse (ENS) |
| PAY BAND | Band 6 |
| DIRECTORATE | Community services business unit |
| ACCOUNTABLE TO | Epilepsy lead nurse |

Job summary

To provide the specialist practitioner function in the delivery of specialist care to the child or young person and carers who have a confirmed diagnosis of epilepsy. The postholder will be involved in developing and delivering patient-centred care within the business group and trust objectives.

To work across primary and secondary care, and in partnership with the person with epilepsy, their families and health and social care professionals to offer specialist clinical support, and provide relevant information and education.

To work to best support continuity of care within an integrated care organisation following the patient across the acute and community care pathways.

Key duties/responsibilities

Clinical

- Participates in the review of epilepsy documentation used.
- Facilitates good communication links between the child or young person with epilepsy and carers/others involved in the management of the condition.
- Deals with calls/queries and following discussion and consultation with the ENS communicate any plans to the person with epilepsy, their carer or other professionals as appropriate.
- Provides education and information to the person with epilepsy, their family and/or carers around epilepsy related issues eg management of epilepsy, lifestyle and recreation, safety, schools etc.
- Works autonomously to manage his/her own caseload of patients whilst working as part of a multidisciplinary team.
- Enables the child or young person and carers choice and involvement in decisions about care and initiates appropriate action.
- Co-ordinates patient care pathway and liaises across organisational boundaries.
- Plans specialised programmes of care and provides specialised age-appropriate advice to the child or young person, relatives and carers.
- Ensures each child or young person is placed in the correct treatment pathway at the appropriate time and necessary investigations and treatments are organised.

- Provides clinical advice and support to health care professionals within and across organisational boundaries.
- Provides clinical advice in accordance with current evidence-based practice.
- Participates in nurse/consultant-led clinics and multidisciplinary team meetings.
- Participates in case conferences in relation to future management or discharge arrangements.
- Ensures the child or young person and their families are given appropriate verbal and written information regarding planned care.
- Maintains accurate patient records and ensures all relevant information is documented in the patients' medical and nursing records.

Education

- Participates in training and education of the child or young person, their carer and health and social care professionals involved in the management of the condition/seizures.
- Supports in the teaching and development of health care professionals, the child or young person and carers.
- Provides clinical supervision and mentorship to junior or new clinical nurse specialists/practitioners/nurses/therapists and medical staff as required.
- Identifies, assists and meets the educational needs of the child or young person and their family.
- Maintains own professional development, skills and competencies through participation in training and development activities.
- Maintains and updates evidence-based knowledge and skills.
- Fulfils all mandatory training requirements for the trust and assists others within the department to do so.
- Undertakes health promotion within the specialist area.

Management

- Manages own caseload, and co-ordinates patient journey across divisions and organisational boundaries.
- Works in close collaboration with other health care professionals across organisational boundaries to ensure the service meets patient's needs.
- Assists with the recruitment and initialising of new staff.
- Acts as a clinical supervisor to staff within the department.
- Acts as a mentor to pre- and post-registration nurses, assisting in meeting their learning needs.
- Contributes to the development of local policies, protocols and procedures in accordance with local and national standards in relation to specialist area of expertise.

Research

- Participates in/undertakes clinical audit, and contributes to development of knowledge within specialist field of practice.
- Participates in undertaking research in relation to specialist area of practice.
- Undertakes evidence-based practice and ensures dissemination of relevant research and best practice.
- Supports and advises junior staff who may wish to undertake audit and research in specialist field.

Professional

- Is a member of a relevant professional association and attends regional/national meetings and conferences as required.
- Identifies personal learning needs and takes steps to pursue personal development plan.
- Maintains practice within the context of NMC Code of Conduct, Scope of Professional Practice/relevant professional body and policies laid down by the trust.

- Maintains a comprehensive portfolio and demonstrates appropriate professional development to post-registration education and practice standards.
- Evaluates professional performance and identifies the implications for practice.
- Ensures the promotion of safety, wellbeing and the interests of patients, staff and visitors to the department.

Teaching

- Assists in the planning, implementation and evaluation of education programmes involving all members of the team, liaising with the training department as appropriate.
- Participates in programmes of induction and orientation for new staff requiring community epilepsy experience.
- Participates in programmes of education for pre-registration students to demonstrate the application of theory to practice.

Information management and technology

- Analyses patient information to aid assessment planning and implementation of appropriate of care.
- Prioritises own workload to ensure delivery of patient service outcomes are met.
- Maintains accurate personal and professional records, adhering to Nursing and Midwifery Council and trust policy and guidelines.
- To report accidents/incidents of patients or self which occur whilst on duty, and completes appropriate forms immediately. Participates in any investigations as necessary.
- Maintains all aspects of trust clinical governance strategy and requirements.

General trust requirements such as infection control and confidentiality (not listed here).

Grade 7

| | | | |
|------------------------|--|--|------------------|
| JOB TITLE: | Children's community nurse: epilepsy nurse specialist | | |
| GRADE: | Band 7 once full competencies achieved | | |
| QUALIFICATIONS: | Child branch or registered sick children's nurse (RSCN): | | Essential |
| | Recognised teaching qualification eg ENB 998 Teaching and Assessing in Clinical Practice programme: | | Essential |
| | Specialist qualification eg British Paediatric Neurology Association Paediatric Epilepsy Training Level 1 (or willingness to work towards): | | Essential |
| | Experience of nursing CYP with epilepsy and/or community nursing: | | Essential |
| | Nurse prescriber (or willingness to work towards): | | Essential |
| | Relevant degree (or willingness to work towards): | | Essential |
| RESPONSIBLE TO: | Lead epilepsy nurse specialist | | |

Job purpose

- Responsibility for providing specialist nursing skills, knowledge and expertise in the care and management of children and young people with epilepsy.
- Carries out clinical assessment of children and young people's needs and plans and implements packages of care accordingly.
- Supports the child, family and carers holistically, in response to their specific needs, maximising their independence and quality of life.
- Is a member of the Epilepsy Nursing Service, working across all teams, with clinical responsibility for a group of clients within a defined caseload, liaising and acting as a specialist resource within the multidisciplinary and multi-agency team.

- Acknowledges the specific cultural needs of children and families and ensures that care is delivered in a way that is sensitive to such needs.
- Acts as a key worker within the guidance of the Common Assessment Framework when appropriate, in line with the recommendations directed nationally and locally such as Every Child Matters 2004, and the National Service Framework for Children and Young People 2005.

Key responsibilities

Clinical and professional

1. Uses key skills of assessment, interpretation, and analysis of findings, utilising clinical expertise and judgement to:
 - prevent inappropriate hospital admissions and promote effective hospital discharge planning, wherever possible
 - provide and co-ordinate support to children and young people with epilepsy, implementing health promotion as appropriate
 - teach children and young people, families and carers to competently carry out specific nursing care and procedures as required.
2. Plans, develops, co-ordinates and manages service provision for children and young people with epilepsy.
3. Assesses patients, plans and implements appropriate models of care, provides specialist advice and maintains contemporaneous and accurate records.
4. Works as a key member within the multidisciplinary and multi-agency teams, leading and promoting care within the hospital.
5. Is competent in performing advanced clinical nursing skills appropriate to the caseload including:
 - participating in joint consultant and nurse-led clinics to support the child or young person with epilepsy
 - uses clinic-based tools for the assessment, diagnosis and management of children with epilepsy
 - provides direct and telephone advice to children, young people and their parents and carers with respect to seizure control and management
 - liaises, where appropriate, with primary, secondary and tertiary care centres neurological and neurosurgical management.
6. Liaises with epilepsy management support structures within Birmingham Children's Hospital and across the region and:
 - supports the implementation of NICE guidance to support the care of the child or young person with epilepsy and their families
 - supports the development of medication management protocols
 - develops training information and literature and provides training to young people, parents, carers, health, education and social care staff, in seizure prevention and management.
7. Effectively communicates complex and sensitive information to children, families and carers, such as supporting diagnosis, breaking bad news, palliative care and bereavement.
8. Supports palliative care and provides symptom management in end of life care, advising and guiding other professionals as required.
9. Is aware of, and adheres to, local safeguarding and child protection policies and procedures.
10. Supervises development of, and delegation to, nominated junior and unqualified staff.
11. Leads and participates in clinical audit and the development of procedures and protocols including drugs and epilepsy devices and disseminates research findings as appropriate.
12. Maintains a non-judgemental approach regardless of circumstances when working within the home environment and in all aspects of their work.

Education

1. Contributes to the development and implementation of training programmes, protocols and care pathways within Birmingham Children's Hospital and across the region.
2. Provides up-to-date education and expert advice for the multidisciplinary team and works closely with the multidisciplinary team.
3. Attends and participates in induction, in-service training and mandatory study days as identified.
4. Is responsible for maintaining and improving own professional knowledge and competence in accordance with PREP.
5. Keeps up to date with relevant developments in epilepsy and epilepsy surgery.
6. Contributes to and participates in clinical supervision of team members.
7. Acts as an assessor, mentor or supervise of pre- and post-registration of nursing and medical staff.
8. Supports the development of resource materials related to the care of the child with epilepsy and its management.

General trust requirements such as infection control and confidentiality (not listed here).

Grade 8

JOB TITLE: Northern Children's Epilepsy Surgery Network – lead nurse
BAND: 8a
REPORTS TO: Clinical lead of the Epilepsy Surgical Network (NorCESS)
PROFESSIONAL
ACCOUNTABILITY TO: Lead nurse

Key relationships

- Children, young people, parents families and carers.
- Patient support groups including Epilepsy Action.
- Clinical directors, directorate managers, lead nurses, tertiary/specialist and district general hospital neurology and epilepsy teams, allied health professionals, hospital managers, team managers, ward teams, co-operate nursing teams, divisional managers, social workers, community nurse teams and general practitioners within the Northern Epilepsy Surgical Service (NorCESS) area.

Role summary

- Acts as a recognised expert in the field of epilepsy nursing and provides professional leadership in all aspects of practice in supporting colleagues to promote excellence in care.
- Plans, implements and evaluates new and existing policies in epilepsy nursing and epilepsy surgical practice and service delivery in line with local and national guidance.
- Contributes to training for nurses and other health professionals and support workers in the care of patients throughout the NorCESS network.
- Develops and contributes to the strategic planning of the NorCESS network and nursing practice.
- Represents the NorCESS network at national and regional meetings and events.
- Promotes organisational change and supports the implementation of the national epilepsy surgical arrangements, including the quality standards with particular emphasis on nursing care and surgical practice.
- Supports the development of clinical pathways across the network in partnership with the clinicians to ensure best practice.
- Liaises with key professionals involved in treatment and care within the NorCESS area to promote equity of standards in service delivery across the network.

- Attends and participates in the local committee and network and centre meetings.
- Is an integral member of the NorCESS team, providing advice and guidance on best practice, and supporting local teams to deliver and meet agreed standards.
- Takes the lead work in patient experience, safety and clinical effectiveness.
- Acts in accordance to the NMC Code of Professional Conduct.
- Has a responsibility to ensure all information processed for patients and staff is kept confidential, accurate and in line with the Data Protection Act 1998 and Caldecott Policy.

Key result areas

Leadership

- Provides effective clinical and professional leadership acting as a role model for all staff within the network.
- Provides leadership and management support to the epilepsy surgical ward lead nurses at both NorCESS centres.
- Demonstrates a high level of networking skills to avoid conflict and encourage team working.
- In conjunction with clinical director and network manager, describes the service objectives to clinical teams and monitors compliance and effectiveness to ensure best outcomes for patients.
- Ensures effective communication systems, written and verbal, and supports the use of information technology to ensure that it is embedded in the network.
- Liaises with all services and departments to ensure that they are meeting the needs of patients in the clinical areas.
- Facilitates and negotiates change and new ways of working where necessary to support new care delivery processes within the network.
- In conjunction with the clinical director and network manager plus the senior nurses, contributes to the development of an action plan for the implementation of the '10 key roles for nurses', building on current skills, expertise and practice.
- Represents NorCESS at professional and academic forums as required.

Management

- Leads on policy development for the service in liaison with lead nurses and senior nursing managers across the network.
- Ensures guidelines and protocols relating to epilepsy and epilepsy surgery are evidence-based and reflect national guidance.
- Ensures the views of patients, parents and carers are incorporated into all aspects of service provision.
- Responsibility for defined projects within the network.
- Supports any visits from regulatory bodies to achieve accreditation, such as the Care Quality Commission.

Clinical

- Ensures all documentation is appropriate, accountable and defensible.
- Provides advice on role competencies and contributes to the development of competencies for nurses and students that support the safe care and treatment.
- Ensures all epilepsy nursing and epilepsy surgical practice is evidence-based and contributes to the development of nursing competences to ensure appropriate delivery of nursing care.
- Supports the development of clinical pathways across the network in partnership with the clinicians to ensure best practice.
- Maintains own clinical and professional competence and credibility. Utilises clinical sessions to exemplify high standards of care and expected behaviour to measure agreed standards of nursing practice, and gain additional accessibility to both patients/families and members of staff.

- Leads work in relation to patient experience, safety and clinical effectiveness such as complaints or investigations of clinical incidents.
- Takes responsibility for personal and professional development, participating in the trust KSF reviews with the lead nurses.
- Provides a visible presence in clinical areas and is accessible to patients, families and staff to provide expert epilepsy knowledge.
- Ensures all nurses comply with NMC regulations and work within their scope of practice.

Research audit

- Participates in capacity building for research and development for clinical staff.
- Contributes to clinical audit and research projects ensuring compliance with research governance.
- Actively seeks to improve practice through the application of research evidence, the promotion and initiation of research, and the auditing of chemotherapy practice.
- In conjunction with the clinical director and network manager develops a programme of epilepsy-related audits.

Education and training

- In partnership with the lead nurse, validates changes in roles and practices within the network ensuring changes are in line with key policy and quality standards initiatives.
- Contributes to the development, provision and evaluation of training.
- Ensures that network arrangements support an environment that is conducive to teaching, education, training and development for all staff.

General trust requirements such as infection control and safeguarding (not listed here).

| PERSON SPECIFICATION | | | |
|---------------------------------|--|--|--|
| FACTORS | ESSENTIAL (Necessary for safe and effective performance in the job) | DESIRABLE (Contributes to improved job performance) | METHOD OF ASSESSMENT |
| Qualifications | RN Child/RSCN and Adult. Graduate – health related studies. Teaching qualification. Qualified in specialty. | Management qualification. Relevant Master’s degree. Qualified in specialty. Non-medical prescribing. Clinical assessment skills. | Application form. CV. Interview answers. |
| Experience | Experience in a senior clinical position in speciality area. Experience of successfully managing the implementation of change. Evidence of professional leadership, leading to innovation in practice. Experience of devising, delivering and evaluating teaching programmes. Evidence of continuous professional development. Experience in clinical audit and benchmarking. | Line management experience. Experience in workforce planning. Experience in setting establishments and using workforce toolkits including dependency tools. Experience in research and development. Experience in complaints management. | Application form. CV. Interview answers. |
| Skills, abilities and knowledge | Communication skills. Presentation skills. Report writing skills. Negotiating and influencing skills. | Strong analytical skills. Ability to consider the wider picture. IT and word processing skills. Able to demonstrate contribution of nursing role to clinical governance. | Application form. CV. Interview answers. Asking questions at interview. |
| Personality | Honest. Open minded. Treats colleagues with dignity and respect. Capacity to work with clinicians and staff at all levels. Exemplary personal standards of conduct and behaviour. Inspires others and leads by example. | | Asking questions at interview. |

Appendix 2

References and further reading

Department of Health (2006) *Modernising Nursing Careers: Setting the direction*. Available from: www.scotland.gov.uk/Publications (accessed 13 November 2013).

Epilepsy Action (2013) *A Critical Time for Epilepsy in England*. Available from: www.epilepsy.org.uk/involved (accessed 13 November 2013).

Global Campaign Against Epilepsy (2011) *Epilepsy in the WHO European region: Fostering epilepsy care in Europe*. Available from: www.globalcampaignagainstepilepsy.org/epilepsy-in-the-who-fostering-epilepsy-care-in-europe/ (accessed 18 November 2013).

Lagae L (2011) Clinical Practice: the treatment of acute convulsive seizures in children, *European Journal of Paediatrics*, 170(4), pp.413-8.

NHS Employers (2010) *Simplified KSF*. Available from: www.nhsemployers.org/PayAndContracts (accessed 13 November 2013).

NHS Employers (2011) *How Agenda for Change Works*. Available from: www.nhsemployers.org/PayAndContracts (accessed 13 November 2013).

NICE (2012) *The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care*. Clinical Guideline 137. Available from: <http://guidance.nice.org.uk/cg137> (accessed 13 November 2013).

NICE (2013a) *Diagnosis and management of the epilepsies in adults, children and young people*. Available from: <http://publications.nice.org.uk/diagnosis-and-management-of-the-epilepsies-in-adults-children-and-young-people-cmg47> (accessed 13 November 2013).

NICE (2013b) *QS27 Quality standard for the epilepsies in children and young people*. Available from: <http://publications.nice.org.uk/quality-standard-for-the-epilepsies-in-children-and-young-people-qs27/> (accessed 13 November 2013).

Royal College of Nursing (2009) *Integrated core career and competency framework for registered nurses*. Available from: www.rcn.org.uk/publications (accessed 13 November 2013).

Royal College of Nursing (2011) *Children's and young people's cardiac nursing: guidance on roles, career pathway and competence development*. Available from: www.rcn.org.uk/publications (accessed 13 November 2013).

Royal College of Nursing (2012) *Core competences for nursing children and young people*. Available from: www.rcn.org.uk/publications (accessed 13 November 2013).

Royal College of Paediatrics and Child Health (2012) *Epilepsy12 Results*. Available from: www.rcpch.ac.uk/child-health (accessed 13 November 2013).

Scottish Paediatric Epilepsy Network *SPEN Scottish Paediatric Epilepsy Network*. Available from: www.spen.scot.nhs.uk/index.html (accessed 13 November 2013).

SIGN (2005) *Diagnosis and management of epilepsies in children and young people (81)*. Available from: www.sign.ac.uk/pdf/sign81.pdf (accessed 13 November 2013).

ViroPharma *The Perfect Initiative: Practices in Emergency Rescue medication For Epilepsy managed with Community administered Therapy*. Available from: www.viropharma.eu/PERFECTInitiative.aspx (accessed 13 November 2013).

| Educational and professional networks | |
|--|--|
| Epilepsy Action | www.epilepsy.org.uk/professionals/healthcare/professional-epilepsy-training |
| Epilepsy Society | www.epilepsysociety.org.uk/WhatWeDo/Trainingandseminars |
| ESNA – Epilepsy Nurses Association | www.esna-online.org.uk/ |
| Paediatric Epilepsy Training (PET) courses | www.bpna.org.uk/pet/ |
| Scottish Paediatric Epilepsy Network | www.spenn.scot.nhs.uk |
| Young Epilepsy | http://youngepilepsy.org.uk/what-we-do/epilepsy-training-days |

| Information for children, young people and families (and professionals) | |
|--|--|
| Epilepsy Action | http://kids.epilepsy.org.uk/ and www.epilepsy.org.uk/info |
| Young Epilepsy | http://youngepilepsy.org.uk/ |
| Sudden Unexpected Death in Epilepsy (SUDEP) | www.sudepaware.org/ |
| Joint Epilepsy Council | www.jointepilepsycouncil.org.uk/ |
| Matthew's Friends | http://site.matthewsfriends.org/ |

| Clinical guidance | |
|---------------------------|--|
| NICE Guideline | http://guidance.nice.org.uk/cg137 |
| SIGN Guideline | www.sign.ac.uk/pdf/sign81.pdf |
| SANAD trials publications | www.hta.ac.uk/project/1031.asp |



Royal College
of Nursing

The RCN represents nurses and nursing, promotes excellence in practice and shapes health policies

August 2008
Updated December 2013

RCN Online
www.rcn.org.uk

RCN Direct
www.rcn.org.uk/direct
0345 772 6100

Published by the Royal College of Nursing
20 Cavendish Square
London
W1G 0RN

020 7409 3333

Publication code: 004 514

ISBN: 978-1-910066-13-3