Structuring Epilepsy Services; Psychology is more help than Nursing?

Clare Harrisson
Epilepsy Nurse Specialist
Young Epilepsy
Don’t just ‘listen to Matron’ this is the evidence from a wide range of sources supporting the role of Epilepsy Nurse Specialists.
What do Epilepsy Nurse Specialists actually do?

• Strive to make epilepsy what children have and NOT who they are
• Provide high quality, effective, holistic assessments and care for children, families and carers
• Work collaboratively with other professionals and agencies to ensure a seamless service around the child and family
• Develop services and practices that are child focussed and in line with research
• Educate the child, family, school, respite services etc about the full impact of epilepsy and practical management including emergency medication, seizure first aid and SUDEP
• Encourage and support young people to take ownership of their epilepsy thereby hopefully reducing non compliance issues
• Build and sustain long term relationships with the child and family
• Facilitate a smooth, planned and timely transition process
• Ensure the child and parents understand the information they have been given by other professionals (decoding)
• Ensure any information the child or family may have accessed via the Internet or other sources is of high quality and validated
• Devise Individual Health Care Plans that address the needs of the child in all areas of their life thereby expanding their world not shrinking it
• Provide a readily accessible point of contact for the child and family
• Provide practical advice re medication administration and safety devices for instance
• Address any issues arising within the larger family including very importantly those of any siblings
• Aim to minimise the psychosocial impact of epilepsy for the child through education and empowerment.
Child epilepsy care ‘varies in UK’

Royal College of Nursing chief executive and general secretary Dr Peter Carter added: "Epilepsy is clearly being treated very well in many parts of the country, and specialist nurses have led the way in helping children and their families to manage epilepsy. However, it is a matter of profound concern to us that this is not the case everywhere. "The recommendation that all children have access to a specialist nurse is there for a reason - the nurse can offer an unparalleled combination of expert clinical advice alongside practical help for children and their families. Epilepsy can be a very distressing and worrying illness for a child to have. Therefore, having a specialist nurse who is on hand to answer questions and give advice on avoiding complications can make all the difference to how well the condition is managed."
NICE 2012

At the review, children, young people and adults should have access to: written and visual information; counselling services; information about voluntary organisations; epilepsy specialist nurses; timely and appropriate investigations; referral to tertiary services including surgery, where appropriate. [2004]

Evidence statements
There is some evidence that epilepsy specialist nurses improve clinically important outcomes such as knowledge, anxiety and depression for people with epilepsy in secondary and tertiary care. (III)

What process of care has been proposed to improve outcomes for adults and children with epilepsy in secondary/tertiary care?
Specific epilepsy/seizure clinics
Epilepsy Nurse Specialists
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 guidance. 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.
best care:
The value of epilepsy specialist nurses
A report on a study by researchers at Liverpool John Moores University on behalf of Epilepsy Action, June 2010
The evidence that we offer from this study is nicely captured by the words of a consultant neurologist who took part in our study and said… “ESNs are the saving grace of our work... The ESNs service is not just down to improving quality and luxury, it is an essential service.”

Professor Fiona Irvine
Research Lead at Liverpool John Moores University
“People with long term neurological conditions have improved health outcomes and a better quality of life when they are able to access prompt and ongoing advice and support from practitioners with dedicated neurological expertise, such as specialist nurses. This can cover: managing their medicines; treatment of specific symptoms; help to understand their condition and its current and future management. Specialist advice and treatment can be cost neutral and may reduce admissions and length of stay and improve wellbeing”

*The National Service Framework for Long Term Neurological Conditions (DH 2005)*
Epilepsy Action estimates that by reducing waiting times to see a specialist or general neurological consultant epilepsy specialist nurses save health trusts £80,000 per year. In Surrey PCT, a new specialist epilepsy nurse reduced attendances at A&E by nearly half in 2005.

This represents a saving of £17,136 a year.

Epilepsy misdiagnosis (which happens in 20-31 per cent of cases, or over 100,000 people) in England costs £23 million and the non-medical cost was £111 million. A specialist epilepsy service could help combat this and a randomised controlled trial (NHS National Workforce Project) found that patients consulting a specialist nurse and a neurologist were less likely to visit their GP, which led to a saving of £184 per patient per year.
Reduction in A&E attendances

In February 2005 an adult epilepsy specialist nurse came to post, working for Surrey PCT. Prior to this, there was no epilepsy specialist nurse in post. Data from the Royal Surrey County Hospital shows a reduction in attendances for people with epilepsy at A&E from an average of 29 a month in 2005 to 15 a month in 2007. This results in an average of 14 less a month and 168 a year. Under Payment by Results this would attract the tariff of £102 giving a saving of £17,136 a year.
The epilepsy specialist nurse achieved these outcomes by:
• Managing medication
• Adjusting medication
• Educating people with epilepsy - self management
• Educating carers and family in the use of rescue medication
• Interception through telephone clinics
• Educating ambulance technicians.
Specialist nurses have been a fantastic development over the last few decades bringing better outcomes, better quality and saving money. It is time to appreciate what a contribution they can make when money is tight.

Shadow Health Minister, Anne Milton MP
February 2010
Patient Education and Counseling

Promoting self-care in epilepsy: the views of patients on the advice they had received from specialists, family doctors and an epilepsy nurse

L. Ridsdale, M. Morgan, C. O'Connor

Accepted 25 May 1998
A recurring theme from interview data was that patients perceived the doctors' time as too limited to explain the condition and how to manage it, whilst the nurse had the time and expertise to do so. Overall the nurse trained in epilepsy care was valued highly for providing advice and support, especially in explaining the social aspects of epilepsy. Patients expressed the belief that they would have benefited most by seeing a special nurse at the time when epilepsy was first diagnosed.
Our paediatrician put us in touch with an epilepsy specialist nurse. This was around the time that Jessica was making the transition from nursery school, to primary school and going into reception class. When Jessica had seizures in school, in her first week, no one really knew what to do. I got in touch with our nurse and she went straight into school, did a training session with staff and wrote a care plan for Jessica. We would be completely lost without our nurse now. She has been so very supportive, helpful, understanding and caring.

It’s sad to see that so many children and young people don’t have an epilepsy specialist nurse to help them. I know, that if we didn’t have the support of our nurse, we wouldn’t cope as well as we do with Jessica’s epilepsy.
In conclusion

If it's improving the lives of children with epilepsy and their families by developing services

Professionals with wide and diverse range of roles and responsibilities

Reduction in costs

Increasing the scope of the understanding of the full impact of childhood epilepsy

Ensuring children with epilepsy are able to live their lives to the full

Epilepsy Nurse Specialists are the people that are needed!!!!