

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

acknowledgements

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The Liverpool John Moores University epilepsy specialist nurse evaluation team:

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Mrs Sylvia Williams and family

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And most of all, all the epilepsy specialist nurses throughout the UK

Editorial control rests with Epilepsy Action

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foreword



Dr Peter Carter,
Chief Executive and
General Secretary of the
Royal College of Nursing

Specialist nurses are at the heart of caring for millions of people in the UK with a long-term or complex condition. These experts improve the standard of care and the quality of life of patients with a diverse range of needs.

Nearly half a million people in the UK have epilepsy. It is essential that the NHS offers the level of care and expertise that epilepsy patients deserve. Epilepsy Action has been carrying out excellent work in promoting the benefits of epilepsy specialist nurses (ESNs) and in supporting staff in these roles.

As the largest nursing union in the world, the Royal College of Nursing is pleased to support this publication, which proves that specialist nurses change lives and save money. Driving patient-led care and guiding innovation, ESNs are rich in the knowledge and experience that is essential for delivering high standards of care.

The RCN recently ran its 'Nursing counts' campaign in which we outlined our priorities for the new government. As part of this, we explored the vast benefits of specialist nurses. Working in collaboration with nearly 40 healthcare organisations including Epilepsy Action, we promoted the work of these nursing specialists. Epilepsy Action continues to offer vital nursing support to individuals with epilepsy and has invested both time and money into providing this crucial lifeline for patients.

This publication proves that in the face of efficiency drives, perhaps now more than ever, we need to safeguard ESNs. This will mean not only defending the posts that already exist, but also ensuring continued investment in services which make a huge difference for the many thousands of people in the UK.

A handwritten signature in black ink, appearing to read 'P. Carter'.

Dr Peter Carter
Chief Executive and General Secretary of the Royal College
of Nursing

introduction



Professor Fiona Irvine,
Research Lead at Liverpool
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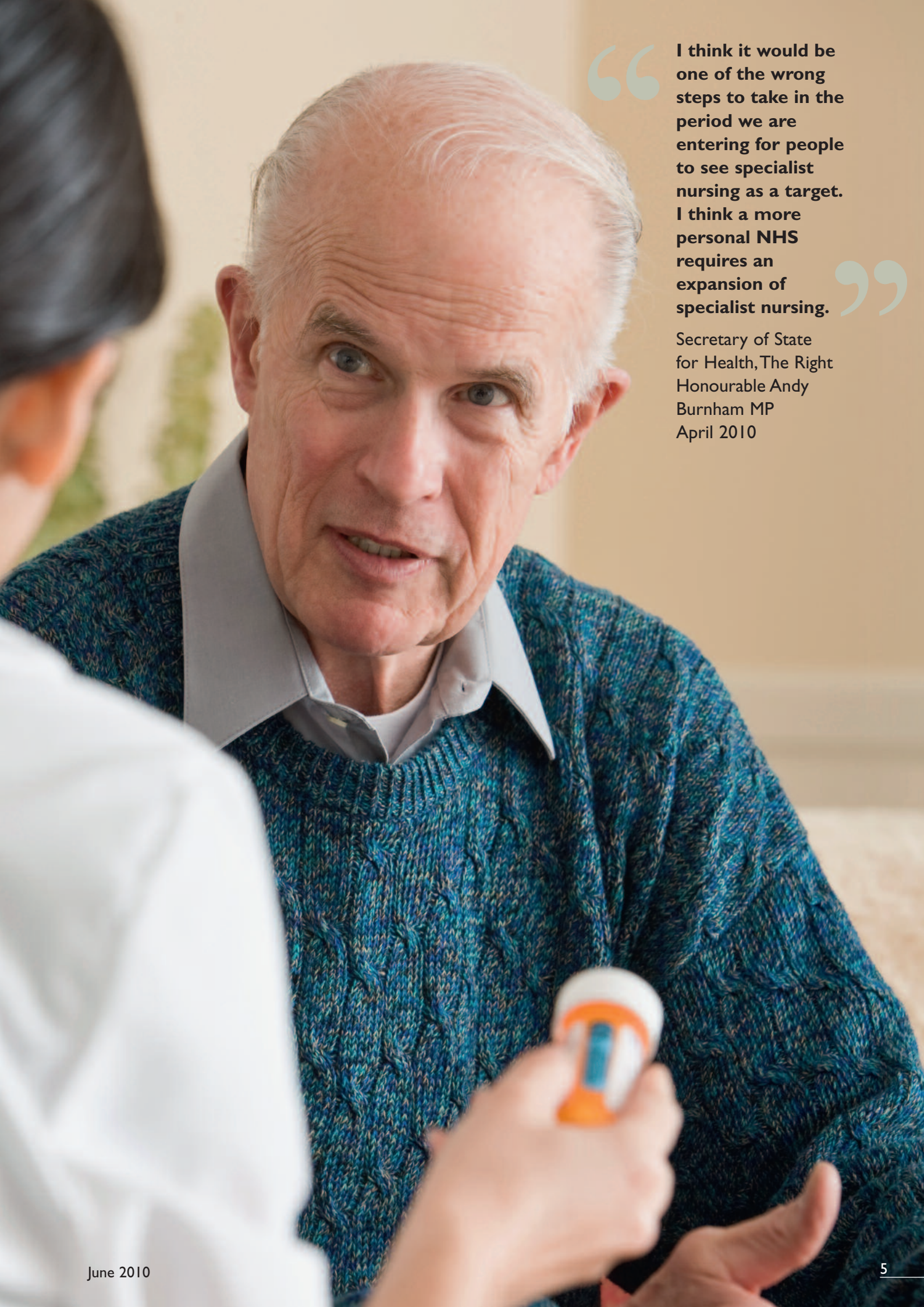
The role of the epilepsy specialist nurse (ESN) has developed significantly over the past twenty years. It is clear that patients have a great appreciation of the ESN and find the service invaluable. Yet there is limited evidence that explores the main elements of the role or that highlights the contribution that ESNs make to neurological services. In this uncertain economic climate it is particularly important that service users, professional colleagues and service managers have a full understanding of the many elements of ESNs' work. Their contribution to the service needs to be fully recognised, so the role can continue to gain support and development. Thus it is opportune that our research study produces sound evidence of the worth of the ESN that can be used to justify their role.

I led a team of research, academic and clinical experts to undertake this study in 2009. We completed a detailed and rigorous process of mapping the work of ESNs and considering their value in terms of productivity, economics and contribution to team work. This culminated in a detailed report to Epilepsy Action, which clearly demonstrates the pivotal position of ESNs in providing high quality, cost effective care for patients with epilepsy and their families. We are delighted to be able to report on our work. We hope that the findings will be used by ESNs, neurologists, patients and commissioners to make clear the necessity of the role in epilepsy services. 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."*

F. Irvine

Professor Fiona Irvine
Research Lead at Liverpool John Moores University

For a copy of the full Liverpool John Moores University research report, email campaigns@epilepsy.org.uk or call the Epilepsy Action campaigns team 0113 210 8800.



“

I think it would be one of the wrong steps to take in the period we are entering for people to see specialist nursing as a target. I think a more personal NHS requires an expansion of specialist nursing.

”

Secretary of State
for Health, The Right
Honourable Andy
Burnham MP
April 2010

executive summary

Epilepsy is a complex, long-term condition that can affect individuals in very different ways. Because of this, at least 60 per cent of people with epilepsy (nearly 280,000 people in the UK) will require ongoing access to an adult, paediatric or learning disability epilepsy specialist nurse (ESN).

ESNs are an expert and essential part of a multi-disciplinary team providing clinical and psychosocial information and support for individuals with epilepsy. Epilepsy Action has supported the introduction of ESNs into the health service across the UK for 15 years, investing over two million pounds in nurse posts through its Sapphire Nurse Scheme.

Despite NICE¹ and SIGN² guidance recommending all patients with epilepsy should have access to an ESN, there are currently no clear national standards on service delivery and coverage is inconsistent. Currently there are only around 250 ESNs across the UK despite a need for 1,100. A number of these posts are under threat with reduced hours or posts being cut altogether.

This research was commissioned by Epilepsy Action to evaluate the role of the ESN and establish the costs and benefits of the ESN service. It centres on adult ESNs but the principles equally apply to paediatric and learning disability ESNs. The research was undertaken between January and December 2009, by a team of researchers at Liverpool John Moores University.

¹Clinical Guideline 20. The epilepsies: diagnosis and management of the epilepsies in adults and children. National Institute for Clinical Excellence guideline, 2004.

²Guideline No. 70 Diagnosis and Management of Epilepsy in Adults. Scottish Intercollegiate Guideline Network, 2003.

Key findings

- ESNs act as a central cog in the care of people with epilepsy.
- Adequate resourcing of the ESN service is crucial to the delivery of high quality care for people with epilepsy – limited resources lead to compromised and fragmented care.
- ESNs undertake a wide range of valuable, mainly patient-related activities in various settings. In the absence of ESNs this work would either fall to consultants or simply be overlooked.
- The ESN service is about improving quality of care. It is an essential service, not a luxury, to ensure patients are ‘moved-on’ and receive best, not basic, care.
- ESNs are good value for money and the work ESNs do cannot be done by less experienced staff.
- ESNs reduce a consultant’s workload. This can lead to cost savings since nurse-led care does not carry the high salary costs associated with consultant-led care.
- Primary care based ESNs can optimise and standardise care for individuals with epilepsy and support and reduce the burden of care for GP colleagues.

Recommendations

Epilepsy Action is calling on the Departments of Health and healthcare commissioners to:

- Acknowledge the importance of the NICE and SIGN guidelines which say that ESNs should be an integral part of the network of care of individuals with epilepsy.
- Recognise the value of epilepsy specialist nurses and commit to protecting existing ESN posts from redundancy or secondment to generic duties.
- Ensure that the minimum required number of 1,100 ESNs is met by 2015.
- Develop guidelines on the appropriate caseload and responsibilities of an ESN.
- Direct trusts to collect meaningful and comparable epilepsy-related hospital activity data so that the true extent of the economic value of ESNs can be fully demonstrated.

ESNs' pivotal role

NICE guidelines state that epilepsy specialist nurses should be an integral part of the team providing care to a person with epilepsy. The findings of this study clearly demonstrate that, where nurses exist, they are central to the quality of care provided.

The majority of an ESN's time is spent in patient-related activities. Their work is complex and varied and includes various clinical interventions, as well as providing psychological and social support to patients and their families.

Many ESNs fear that essential elements of the service they provide would simply not take place without an ESN in post. In particular, education of patients and families on issues such as safety, and patient counselling, would fall by the wayside.

In a primary care setting, ESNs provide a level of specialist knowledge not available from a GP. The research project revealed that ESNs not only underpin a GP's ability to support their patients, they also help them review medication and identify when to refer back to acute services. An earlier study found that GPs were unhappy with the level of access they had to neurologists. Ninety-five per cent believed that an ESN service would help to alleviate this.³

Finally, ESNs provide crucial assistance in areas that are generally neglected, such as the transition from paediatric to adult care and pre-conception counselling for women of child-bearing age. NICE guidelines state that the transition from paediatric to adult care should be managed by a named clinician. Despite this, only a third of trusts have transition services in place.⁴ Similarly, NICE guidelines state that all women with epilepsy should be given pre-conception counselling, yet only 21 per cent of women actually receive it.⁵ ESNs are perfectly placed to plug these important gaps.

The research concludes that ESNs are pivotal in ensuring the seamless provision of care by different health and social care providers, essentially acting as the care manager for patients with epilepsy.

³Neligan A, Renganathan R, Sweeney BJ (2006) Management of epilepsy in the community. *Irish Medical Journal* 99 (2) 52-54.

⁴Epilepsy in England: time for change, Epilepsy Action, 2009.

⁵Mothers in mind, Epilepsy Action, 2008.

ESN activity – supporting consultants

The study revealed that 70 per cent of an ESN's time is spent on patient-related activities. The remainder of their time is spent on teaching, admin, continuous professional development, research and managing others. All the ESNs involved in the study provided telephone consultations and most (92 per cent) worked in outpatient clinics. More than two-thirds (68 per cent) provided home visits. Ninety seven per cent of interactions recorded in the study were with patients with uncontrolled epilepsy.

ESNs perform many of the same activities as a consultant, including drug reviews, clinical assessment, and education of patients about their condition. Almost all (94 per cent) were involved in monitoring and changing drug dose and regime on a daily basis. This is crucial to supporting, obtaining, and maintaining the best possible seizure control while minimising side effects – the key goal of epilepsy treatment.

The only activities performed by consultants that ESNs are not usually involved in are diagnosis and the ordering and interpretation of diagnostic tests. By assisting with changes to drug regimes or education of people with epilepsy, an ESN frees up a consultant's time, allowing them to spend more time on complex cases.

“ If there were no ESNs then my workload would increase hugely and the number of patients I could help would decrease by about 25 per cent. ”

Consultant

It is clear from the study that consultants value ESNs a great deal. Eighty per cent felt that ESNs reduced patient demands on their time, allowing them to see more complex cases. Those who felt their ESNs resulted in increased demands on their time recognised that this was due to an increase in appropriate referrals.

“ They see most of my returns and reduce time I have to spend on info and advice. ”

Consultant

quality of care

People with epilepsy may have complex and long-term needs. These are hard to predict, plan and to design a commissioning pathway for. Many consultants in the study were keen to emphasise that improving quality of care is central to the service ESNs provide.

The ESN improves quality of care through easy access to expert authoritative advice, information, counselling.

Consultant

ESNs are highly experienced and well qualified professionals. The ESNs involved in the study believe they are the sole professional group that specifically offer education to patients' families. Indeed, were there no ESNs in post, respondents indicate that this would be the most likely area of care to be neglected.

The study identified core values that helped to define the role of the ESN, which included holistic care, proactive and responsive management style, continuity of care and time for patients.

Sylvia Williams is the mother of Tim, who has epilepsy. She describes the difference that Teresa Smith, an epilepsy specialist nurse, has made to Tim and his family.

Tim attends Musgrove Park Hospital in Taunton, Somerset. Tim could go to a hospital much closer in Exeter but, out of choice, he prefers to make the journey to Musgrove Park 30 miles away because of the attention he receives. Within that attention is indeed a jewel – a Sapphire Nurse [ESN] by the name of Teresa Smith.

Tim is 28 and had his first seizure in 1999. He was diagnosed with epilepsy a year later and for those first six years we felt we were out in the wilderness. In the early days it can be so scary and no one tells you much at all. We had many questions but were frightened to ask because we were fearful of what the answers might be.



In 2006 Tim was transferred to the service in Taunton, which is where we met the wonderful consultant who would introduce us to Teresa two years later. Teresa arranged a house visit and we could not believe that this person was in our house. She stayed for two hours and we asked her all the questions we had never been able to ask before. When she left she gave us two telephone numbers so that we could get hold of her whenever we needed her.

Teresa has helped us to make sense of Tim's epilepsy and she makes us feel safe that we can ask any question and will be able to cope with the answer. She always gives us the time we need and calmly gives us information without ever pushing Tim to do anything he isn't sure about.

It makes such a difference to the whole family to have someone giving you what you need at the right time. Tim was made redundant for six months until he found his current job with the local water board. Just before he started, Teresa told us about the Access to Work scheme, which we had never heard of before. We got in touch with the scheme and I couldn't believe my eyes when, on his first day of work, a taxi pulled up to take him safely to work and brought him back again later. I cried all day because my son was finally receiving the help he needed to live a normal life. We wouldn't have known this was possible without our nurse.

We really cannot believe our luck regarding the service Teresa provides, and we are just one family among many. As far as I am aware Teresa is the only epilepsy specialist nurse in the department, but I suspect her boundaries for visits must have elastic sides!

I positively boast about our Sapphire Nurse – it's always interesting to watch people's faces as they realise they don't know very much at all about such a vital service.

Teresa has made a huge difference to all our lives. I don't know what we would do without her.



Sylvia Williams

value for money

When examining the outcomes of the work of an ESN, the emphasis should always be on quality of care. However, it is interesting to note that almost all consultants agreed that ESNs are good value for money. Few felt that the work ESNs do could be done by less experienced staff.

“ **They don't just save money they provide admin/support/ information to patients. The argument for specialist nurses is first (for me) about increasing quality of life. Not just about saving money and my time.** ”

Consultant

This research study specifically indicated a number of cost savings. One area in which ESNs are surprisingly active is patient consultation by telephone, a setting of care which is offered by all 98 respondents to the ESN questionnaire. Seventy-eight per cent of interactions examined in the case study part of the project were conducted by telephone. In the current economic climate, where justifying costs is inevitably important, engagement with patients by telephone seems an appropriate means of providing low cost care. At the same time, it reduces the burden on patients who often do not need or wish to travel to hospital (for example) to speak to the ESN. However, to enable this valuable activity to continue, it needs to be recognised and properly reimbursed by commissioners.

“ **Consider the consultant and secretary time lost in dealing with the many patient/GP questions that come up in any busy epilepsy service.** ”

Consultant

The study further concludes that the relatively inexpensive provision of education for families by ESNs will help to prevent future crises that require costly healthcare intervention.

“When the nursing is good, the care is good. It is the quality of nursing that determines the quality of care.”

Leader of the Conservative Party, The Right Honourable David Cameron MP
May 2010

Image courtesy of www.iStockphoto.com/alvar



“Reductions in hospital admissions for chronic epilepsy services demonstrated in our area since [the] ESN [has been] in place.”

Consultant

Other studies of ESNs support these findings. An NHS National Workforce Project included a case study of a new specialist nurse appointment at Royal Surrey County Hospital.⁶ This hospital found accident and emergency attendances for people with epilepsy dropped from an average 29 a month (2005) to 15 a month (2007) after a nurse was appointed. Under the Payment by Results tariff at the time (£102), this represented an annual saving of £17,136. The saving was mainly attributed to:

- Managing and adjusting medication
- Educating people with epilepsy (greater self-management)
- Educating carers and family on the use of rescue medication
- Interception through telephone clinics
- Educating other general medical staff, including ambulance technicians

A nurse specialist for epilepsy at NHS band 7 would command a salary of between £30-40,000. Meanwhile a consultant's salary would fall between £74-176,000, making a specialist nurse a cost-effective choice to complement a neurologist's work.

⁶Long Term Neurological Conditions: A good practice guide to the development of the multidisciplinary team and the value of the specialist nurse. NHS National Workforce Projects, 2008.

challenges

The study revealed a number of challenges facing ESNs as they try to define and defend their roles in the face of mounting pressures to cut costs.

An issue of resources

There are approximately 250 ESNs who provide a service for people with epilepsy in the UK, despite a need for 1,100. As a bare minimum, a primary care trust area should have four adult ESNs, one paediatric ESN and one learning disability ESN. Epilepsy Action's recent *Time for change* report showed that the majority of primary care trust areas do not have even one epilepsy specialist nurse.

Due to financial and other constraints, their continued employment may be threatened. Some NHS trusts want to prove that ESN services are value for money and will reduce overall costs before creating new posts. This report demonstrates the indisputable value of ESNs in providing a good epilepsy service.

Inadequate numbers of ESNs mean unacceptably high caseloads. New patients are accommodated but many existing patients are hard to discharge because of the complexity and long-term nature of their cases. The ESNs in the study had an average caseload of 570 patients. Some had caseloads of up to 2,400. Epilepsy Action recommends a maximum active caseload of 250.

Identity crisis

ESNs broadly perform the same functions from trust to trust. However since they operate to various models without a set of clear, agreed national standards on service delivery, many feel their position is weakened.

Professional identity has been further compromised in those cases where ESNs have been asked to take on non-specialist roles such as shifts on wards. ESNs are being diverted from their normal roles to take on work that could be done by staff on lower pay bands. Not only does this represent poor value for money, it also means that ESNs are able to give less of their time to their specialist role in epilepsy care. This ultimately lowers the level of intervention they are able to offer their patients with epilepsy.



Jo Geldard, Sapphire Nurse,
Leeds General Infirmary

ESNs in the study also raised concerns in relation to the provider/commissioner split. Since the provider arm of the service may be viewed as a business, measures of success could be driven by the number of patients seen rather than the quality of care they receive. This flies in the face of the organisational and operational principles and the vision of an NHS that puts quality of care centre stage.

“ **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

The essential service of the epilepsy specialist nurse

The work of an ESN is complex and varied. ESNs operate to various models without a set of clear, agreed national standards on service delivery. Here is an outline of the activities an ESN may be responsible for.



Fewer seizures and side effects

ESNs undertake medicines management. They review seizure history and patterns, review treatment and drug regimes and make or advise on necessary changes. They may also issue prescriptions.

Increased awareness

ESNs provide education and training about epilepsy to other health professionals, social services, schools, colleges, employers and the wider community.

Empowerment

ESNs provide people with epilepsy and their carers with advice and information on issues such as driving, first aid and benefits. They also signpost them to other services.

Tailored care

ESNs provide specialised clinics covering contraception, pre-conception, transition from paediatric to adult care and learning disabilities.

Reduced misdiagnosis

ESNs may hold first seizure clinics, take seizure histories and refer suspected misdiagnoses to the consultant.

Improved quality of life

ESNs provide counselling and support on lifestyle issues, relationships, employment and prejudice.

Continuity of care

Through liaison with other agencies, ESNs oversee care plan management and act as an advocate for the person with epilepsy. They provide a link between primary and secondary healthcare and between healthcare and social care.

Better self-management

ESNs are an accessible point of contact for the person with epilepsy through a combination of telephone clinics, home visits and emergency support.

Fewer epilepsy-related deaths and accidents

ESNs help people manage their risk of sudden unexpected death in epilepsy (SUDEP) and improve safety at work, at home and in leisure activities.

conclusion

This research was originally commissioned by Epilepsy Action because ESNs were being challenged to prove their worth to commissioners. It followed a period when ESNs were being asked to do reduced hours in their speciality and a number of posts were under threat. At that time, Epilepsy Action campaigned successfully to save the threatened posts and reinforce the importance of their specialist work. The publication of this report comes at a time when, sadly, such problems appear to have returned.

In these times of economic uncertainty and budget restraint, the NHS is understandably looking to make savings. It is for this reason that we believe it is important to highlight the invaluable contribution of ESNs and demonstrate that they represent excellent value for money. Epilepsy specialist nurses form the foundations of an epilepsy service. Employing an ESN is the single most important thing an NHS organisation can do to improve its services for people with epilepsy.

Nurses dramatically improve the quality of patient care.

- We need the government to recognise that nurses are integral to the care of people with epilepsy.
- We need a commitment from government to protect and support those already in place.
- We need to see a strategic plan for increasing the numbers of nurse posts to the minimum required to serve the population of people with epilepsy in UK.

It is time that epilepsy specialist nurses were valued and appreciated as much by the NHS as they are by their patients.

methodology

The research comprised of four studies. The researchers undertook a large questionnaire survey of ESNs, three focus group interviews with ESNs working in various clinical settings and a questionnaire survey of neurologists. Finally, they examined detailed case studies of NHS trusts, where comparisons were made between trusts who employed ESNs and a trust that had no ESN service.

Epilepsy Action's – Sapphire Nurse Scheme



To help create new epilepsy specialist nurse posts, Epilepsy Action runs the Sapphire Nurse Scheme. This scheme provides NHS organisations with a financial grant to set up an epilepsy specialist service in their area.

The scheme started in 1995, our organisation's sapphire anniversary from which the scheme takes its name. As of June 2010, the Sapphire Scheme has helped create over 100 new epilepsy specialist nurse posts.

Epilepsy Action can provide the funding to support the employment of a Sapphire Nurse, at NHS band 6 or 7. Each application is assessed on its own merits and in the light of the money available at the time.

Funding is provided to a maximum of full salary funding for one year or part salary funding for two years.

Supplies of Epilepsy Action patient information materials, such as leaflets, booklets and support for the nurse by Epilepsy Action staff, are offered free of charge, ongoing beyond the initial funding period.

Epilepsy Action's funding for the cost of the nurse post comes from pharmaceutical companies, charitable foundations and general donations to Epilepsy Action. The Roald Dahl Foundation supports the majority of paediatric Sapphire Nurse posts.

For further information about the scheme, and how to apply for funding, please contact the Sapphire Scheme Co-ordinator, at sapphire@epilepsy.org.uk or 0113 210 8800.

Epilepsy Action aims to improve the quality of life and promote the interests of people living with epilepsy.

Our work includes:

- providing information to anyone with an interest in epilepsy
- improving the understanding of epilepsy in schools and raising educational standards
- working to give people with epilepsy a fair chance of finding and keeping a job
- raising standards of care through contact with doctors, nurses, social workers, government and other organisations
- promoting equality of access to quality care

How can Epilepsy Action help?

We have a range of expertise and resources to help a review of epilepsy services. We can provide advice on designing services, care pathways and epilepsy generally. We have a network of local branches and a large database of members to provide local input in to service redesign. To find out more contact the epilepsy services manager at services@epilepsy.org.uk or call 0113 210 8800.

Getting more information

Call our **Epilepsy Helpline:**

freephone 0808 800 5050 **text** 07797 805 390

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