

Contents

Page

1. Background

3

1.1 Setting the scene

4

1. Background

1.1 Setting the scene - Understanding More about Epilepsy

Long term conditions are classified as a condition that is controlled by medication or other treatments which last over a number of years or decades (World Health Organisation, WHO, 2002). People with long term conditions can have their lives significantly altered (Department of Health, DoH, 2012). Epilepsy is a condition which affects approximately 50 million people worldwide (WHO, 2016), and about 600,000 in the UK (Epilepsy Action, 2016). Epilepsies are a common neurological disorder of childhood whereby they will have recurrent seizures. There are 3 in 1000 children with a diagnosis of epilepsy and are taking anti-epileptic medication aged 17 years or younger (NICE, 2012). For many children and young people, by taking medication seizures can be controlled. Managing seizures improves health outcomes and can help to minimise any detrimental impact on social, educational and employment activity (NICE, 2012).

Interestingly, as epilepsy is not a static condition, one of the comments families report as frustrating, appears to be a high level of uncertainty and unpredictability with regards to 'when the next seizure' is going to occur. As a result parents potentially demonstrate overprotective behaviour towards their children. The epilepsy in itself may be self-limiting in the way that the child may outgrow it; however, it is thought that the behavioural issues, such as low self-esteem and anxiety that occur as a result of over protective parental behaviour may continue long after seizures may have ceased (Reilly and Fenton, 2013).

The approach of this economic assessment will be to demonstrate both the cost avoided as well as the value added by an ENS. To do this, I have selected three case studies to illustrate the different levels of dependency for children with a diagnosis of epilepsy. Before doing so, I will outline the role of an ENS, the benefits of this role to staff; patients and to the trust followed by how I collected the data used in this economic assessment.

Home visits

By educating school personnel, and others involved with a child's care, there is increased potential for inclusion. I can reassure school staff as to how to manage a seizure when it occurs, often contributing to better school attendance, with the potential of improved educational attainment outcomes and later on improved employment opportunities.

I am able to provide advice about school inclusion post seizure which may improve patient/family quality of life. Parents are less likely to need to take time off work for example

I am able to liaise between the various hospital/community settings which contributes to improved patient outcome as people are aware of their current situation.

I am working using up-to-date evidence based practice leading to improved patient care

By providing all the family with epilepsy information this may help them deal with the condition more effectively, by understanding it further this could lead to a reduction in stress making family dynamics better.

1.3.3 Organisational outcomes

By having more contact with patients and providing them with information, for example on medicine compliance and when to call 999, they are empowered and understand when it would be appropriate to access health services; this understanding potentially reduces unnecessary A&E attendances.

By having direct access to patients and their families I am able to identify any safeguarding concerns and deal with this appropriately.

By mostly dealing with patients by telephone and providing advice this may reduce hospital admissions and will free up the consultants time

By providing a nurse-led service, I am able to support and improve self-management skills

2. Costs of the Service

Direct costs	Amount	Assumptions	Adjustments
Epilepsy Nurse Wage (wte 1)			

Indirect costs	Amount	Assumptions	Adjustments
Office Space inc telephones/computer	No additional cost	Already provided within the epilepsy nurse service	



3. Benefits of the Service

In the section I describe criteria I used to categorise patients in my caseload and the methods of peer review employed to validate my assessment. I then describe three cases from each dependency level to illustrate the potential economic impact of the service.

3.1 Epilepsy Nurse Case Load

The epilepsy nursing service currently has a caseload of approximately 170 children. The children vary in their dependency levels, and throughout my involvement with them they can change how dependent they are.

I categorised my caseload into 3 groups and colour coded each group. The red

- Those requiring emergency medication training /protocols

2- Medium level input – Orange (66 children)

- Those children that are going through transition
- Those having breakthrough seizures
- Those that may be having changes to medications
- Those that have infrequent seizures

3 – Low level input –green (87 children)

- Those children that are seizure free
- Those that need yearly reviews/ refresher training
- Those are needing infrequent epilepsy advice

The dependency of any one child can change on a regular basis in that a child may transition between the various levels of dependency throughout their time within the service.

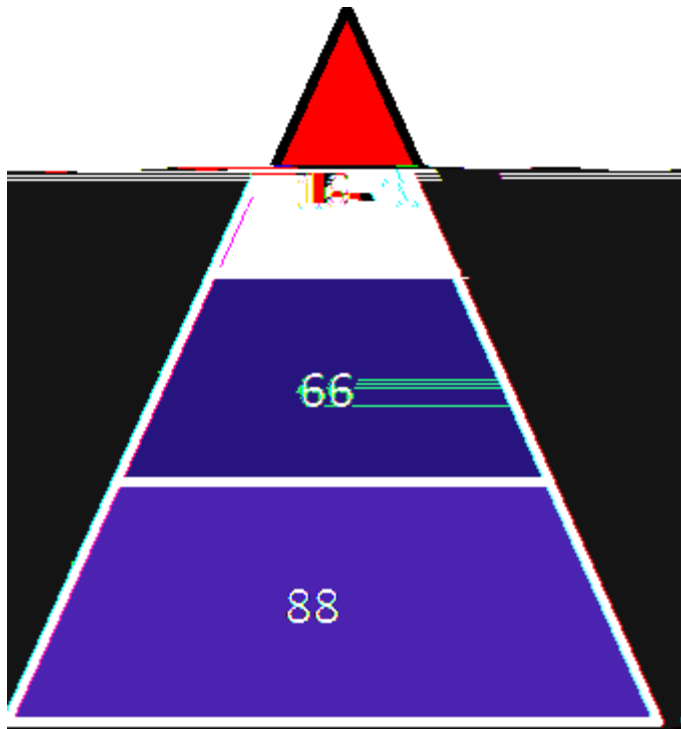


Fig 1: Diagram of Case load

In the next section I present three case studies, one from each dependency level. Although selected for convenience, each case was peer reviewed by an epilepsy nurse specialist from another Trust who confirmed they were representative of each dependency level.

3.2 Case Study 1 – A Boy aged 6 years (an example of a case requiring high level input)

This boy had been under our care about 4 years ago, and after two years of being seizure free he was weaned off medications and discharged.

Over summer 2017 he had had a seizure, was brought to hospital, and booked into the rapid access clinic in July. I was made aware of him by his doctor. The plan was to have an EEG done and booked back into clinic. After the test was completed, it was decided to give safety advice and to offer a follow-up appointment as this had been a single seizure.

George (not the patient's real name) was an inpatient on the children's ward following another seizure.

29/8/17 I called mum, to reintroduce myself. I ran through basic info, seizure management etc. (call length = 30 minutes). Mum was made aware that their clinic appointment would be brought forward.

30/8/17 – mum called me. Her son had had a further seizure. Description taken and reassurance given (25 minutes). They were going on holiday for a week.

8/9/17 – I left a message – trying to book into my clinic on same day as the consultant to minimise school disruption.

8/9/17 – text message from mum– they could not make my clinic, mum didn't want to take George out of school, as he has other clinic appointments at the hospital. Called to rearrange. Booked for 4/10 after school.

8/9/17 – text message received – school would like to meet up with me to do some training

8/9/17 – call to school booked training for 25/9/17

11/9 message left for mum to confirm that I have booked teaching session with school

11/9 – text from mum – she had received an email from school that I was going in.

12/9 – spoke to mum. She had text me to say George had another seizure overnight. Ran through history. Clear that George was still at home and well. I

advised that if he is ok, he needs to be

be avoided across my high dependency caseload over a 12 month period¹. However to avoid the risk of over inflating the cost avoided I have applied a sensitivity analysis. If George reflects 25% of my high dependency case load the cost avoided per annum could be £26,320. However, if George represents 75% of my high dependency case load, the cost avoided per annum could be £78,960. It may be reasonable therefore to attribute 50% of costs avoided to my service ie: **£52,640**.

This figure however does not take into account other costs avoided as a consequence of my intervention such as lost parental work time, rearranging childcare for siblings, extra hospital costs including parking, hospital food for parents.

By educating the family and school, I have prevented further missed school days. With an increased level of absence, there is an increased likelihood that children will not achieve, as high attainment outcomes compared to those that have a better attendance. For example at the end of KS2 and KS4, if a child has no school absences they are just over 3 times more likely to achieve a level 5 or more outcome compared to a child that has been absent for 10-15% of the time (Department of Education 2016).

¹ Analysis period is 3 months. Potential cost avoided is £1,645 over 3 months. Over a year, this equates to £6,580. 16 children in this category. 25% of 16 is 4, 50% is 8, and 75% of 16 is 12, so £6,580x4 = £26,320, £6,580x8 = £52,640 and £6,580x12 = £78,960.

By pupils being absent from school, the following figures have been obtained

(Institute of Fiscal Studies 2017):

Type of school	Spend per pupil per year
Primary	£4900
Secondary	£6300

Children are expected to attend school for 190 days per year, this equates to:

Type of School	Spend per pupil per day
Primary	£25.80 (£4900/190)
Secondary	£33.16 (£6300/190)

It is difficult to give an actual costing for each missed school day, as we can assume that the child would need further support from the teacher/learning support assistants on their return. This extra time would impact on the teaching staff over and beyond the day to day expectations of their role by providing this additional help.

As a result of George's seizures and his epilepsy over this three-month period he was absent for five days, two of these could not have been avoided from his initial inpatient stay plus hospital appointments. It may be reasonable to assume that the epilepsy nurse service contributed towards enabling school attendance. As a result of educating school staff on epilepsy and seizure management the remaining three days we may assume will not occur in the future months leading to an avoidance of up to twelve missed primary school days ($12 \times £25.80 = £309.60$) over a year.

I have not factored this figure

3.2 Case Study 2 – A 15 year old Girl

was feeling more tired as her daughter's dependency has increased with deteriorating health, requiring more input. Without the epilepsy nurse involvement, Sarah's school may not have the appropriate information to manage her seizures, leading to the possible reduction of mismanagement, allowing her to attend school. On recent occasions Sarah's mum when the school had called, had gone to pick her up, and as she felt the school did not properly understand her seizures. Sarah really enjoys going to school and hence the importance of this meeting being set up.

*Cost of nurse time on telephone calls/ ward visit @ 2.32 hours x £22.30/hour
=£51.74 (including + 22.5% on costs)*

*Estimated other time to include consultant discussion/leaving messages/
record keeping @ 0.58 hours x £22.30 = £12.93*

a direct route into the ESN service, which has the potential to build their confidence and trust.

4. Conclusion

The purpose of completing this economic assessment was to provide my primary audience evidence of the value of the epilepsy nurse service. The approach I undertook was to identify all elements of the role and how the service benefits patients, other staff and the organisation.

The report started by setting the scene, describing the working environment and the contribution of the epilepsy nurse specialist to the epilepsy service. It then set out the costs of the service at The Royal Surrey County Hospital and illustrated the impact of the service through three case studies representing the different patient/family dependencies within my caseload.

Based on the case studies, which are typical of the caseload, most of the epilepsy nurse time is spent with more complex epilepsies or with those families that are in a crisis for their own individual reasons. Providing a supportive service allows families not to feel isolated by their child's diagnosis which in itself has health benefits and leads to an overall better quality of life. They are able to understand the condition and to emotionally cope with potential changes in their lives.

The case studies are representative of the way the service runs, however, the dependency levels for each individual child are constantly changing due to the unpredictable o of2l2cre consta servpsy]TJETBT1 0 . 1 0 0 1 72.024 221.93 Tm[23(sTJ-3(p)-3(re)

as other health and educational costs, the service adds considerable value to patients and their families, the health service and the wider economy.

Through education and support, unnecessary hospital admissions are prevented and as a result significant costs are avoided. In addition to this, as a consequence of the ESN's intervention there has been significant value added to the lives of patients and their families.

In summary, the full economic cost of the Epilepsy Nursing Service is £52,640. By considering those greatest in need at any one time, this economic assessment indicates that costs avoided range from £26,320 - £78,960, with an average of £52,640. These estimates do not include the wider benefits to the economy such as school attendance and they sit within the context of the significant quality benefits the service realises.

By doing this course it has highlighted the value of the specialist nurse role. Without it I would not like to think how isolated some families would feel in dealing with their child's condition. The work that has been carried out has allowed me to evaluate the service and to look at the role from a strategic point of view. With this in mind, there may be potential to grow the service. In the absence of an adult epilepsy nurse within the Trust the feasibility of including young adults in the ESN service case load could be explored. This would have the potential of providing young adults with a

References

Office for National Statistics (2017) 'Sickness Absence in the Labour Market: 2016'

Available online from:

<https://www.ons.gov.uk/employmentandlabourmarket/peopleinwork/labourproductivity/articles/sicknessabsenceinthelabourmarket/2016> (Accessed 16.11.17)

This case study was undertaken by **Natalie Baines**, Children's Roald Dahl Sapphire Epilepsy Nurse Specialist, Royal Surrey County Hospital NHS Foundation Trust in 2017.

Natalie successfully completed an RCN leadership development programme commissioned by Roald Dahl's Marvellous Children's Charity.

The programme was designed to empower Roald Dahl specialist nurses to understand the principles of economic assessment and apply them in their practice in order to demonstrate the value and continuously transform their services.

Children's Epilepsy Nurse Service (Baines 2017)

Direct

- 1 WTE (made up of 2 band 7 nurses , 18.75 hours each)
- Equipment – telephones, computer
- Office space
- Photocopying
- Leaflets
- Mileage
- Travel time
- Training costs

- Nurse led clinics (every other month seeing 8 patients)
- To replace some home visits: new patients/support
- Education based training : epilepsy awareness; 1st aid training; rescue medication
- Sign posting to other services
- Student /medical training
- Evaluating / writing careplans
- Health promotion
- Counselling

For intervention

- New diagnosis/ Anxious families post first seizure providing support/Transition/Different syndrome type/under 2's/ pre-school age
- 1st seizures; febrile seizures
- Main stream/special educational needs schools/ nurseries/clubs

For partnership

- Other services: social care; education; charities; respite; MDT; Camhs
- As above
- Education setting
- MDT team

For delivery

Staff outcomes

- Improved management

