

Natalie Baines  
Children's Roald Dahl Epilepsy Nurse  
Specialist

Royal Surrey County Hospital  
NHS Foundation Trust

Economic Assessment – Demonstrating  
the Value of the Specialist Nurse



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## 1. Background

This report is an economic assessment of the paediatric epilepsy nurse service within a district general hospital. The primary audience for this report are the hospital managers, my line manager and the consultants within the epilepsy service. The approach I have taken is to identify all elements of the role initially and how they benefit patients, other staff and the organisation.

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

## 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).

Austin (1996) wrote about a 'model of family adaptation to new onset childhood epilepsy'. It was found that parental stress as a result of the diagnosis was long term more detrimental than the seizures per se. This model went on to suggest that the

anxiety shown by parents was likely to lead to childhood behavioural problems, and this was still seen even after the seizures were controlled. From this study it was concluded that those parents able to adapt well to the diagnosis had a much more positive impact on their child. Chapieski et al. (2005), looked at 56 mothers with children aged between 6 and 12 years that had had a diagnosis of epilepsy within the previous 6 months. The study revealed increased overprotective behaviour by the mothers, such as controlling what the child does, or not letting them meet/go to friends' houses, due to maternal fear of the seizure itself. Maternal anxiety was shown to have more of a negative impact than their child's own anxiety on seizure occurrence. Although this was a fairly small sample group, it does demonstrate the value of Epilepsy Nurse Specialists (ENS) in supporting families.

It appears that an ENS may be the most appropriate person to deal with these psychosocial elements leading to an improvement in patient and hopefully parental satisfaction (Wilson et al, 2012). By using an unhurried approach when discussing issues relating to epilepsy and their child, this improves parental satisfaction and shows a warmth, connection and sympathetic approach which reduce parental stress (Cunningham et al, 2002). It is extremely difficult to distinguish whether the anxieties shown are: as a result of the diagnosis of epilepsy; or if it is a parental personality trait or a build-up of events at that particularly time that causes an inability to properly deal with an extra factor in their life (Patterson and McCubbin, 1983). Epilepsy specialist nurses are certainly able to offer this approach. NICE (2012) suggests that children and young people with epilepsy are seen by an epilepsy specialist nurse who they can contact between scheduled reviews. This is something that is carried out in practice.

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.

## 1.2 Epilepsy Nurse Role:

I have worked at the Royal Surrey Hospital, which is a district general hospital in Guildford, Surrey for almost 5 years. Initially I was employed on part-time hours as a band 6 to assist the existing band 8a epilepsy specialist nurse. My colleague was initially employed with the funding help of the Roald Dahl Marvellous Children's Charity. After my colleague's retirement, for a short period of time I worked part time hours covering the role. Approximately 18 months ago I was successful in my interview to become a band 7, and at the same time another band 7 part-time nurse was employed to job share with me. We both work 18.75 hours each. We have a case load of approximately 170 patients over a large geographical area, which fluctuates slightly above and below this figure as children enter and leave the service.

Within our team we have one lead consultant with a special interest in epilepsy, and then patients are managed by 4 other doctors with further epilepsy training. Children and young people will be seen initially in a rapid access seizure clinic by one of the doctors, further investigations may then be done, and upon diagnosis of epilepsy they inform me by way of conversation and referral letter.

My role encompasses:

- Telephone consultations – on average between 5 and 20 per day. Each varying in length with the average being approximately 11 minutes
- Clinics – twice a month, with one new patient and 2 follow ups being seen on each occasion
- School training – on average 3 per month – taking on average 1.5 hours per session (including travel time)

- Home visits – on average 4 per month – taking on average 2 hours per visit (including travel time)
- Transition support
- Rescue medication training to parents, carers, schools
- Ward visits – when possible to visit inpatients (these visits can be time consuming trying to sort out medical issues, discharge concerns, or providing reassurance, lasting between 20 minutes and 2 hours – 1 or 2 times per month)
- Multidisciplinary meetings
- Care plan writing
- Sign posting families to other services
- Health promotion
- Medical /student / new ward and existing ward staff training

### 1.3 Benefits of the Epilepsy Nurse Role

#### 1.3.1 Staff Outcomes

- By supporting families, they will have a better understanding of their condition and as a result empower them to recognise when to get in contact with the epilepsy nurses in between clinic appointments. Without this service the consultant would book extra clinics for patients when they may not be necessary.
- I am able to assess a patient's needs/provide medication advice/ check medicine compliance which improves their quality of life, results in less seizures and frees up the time of other professionals such as a pharmacist.

#### 1.3.2 Patient outcomes

- When patients have medication compliance issues, I can provide solutions/strategies to help which potentially can lead to reduced hospital/A&E admissions due to potential increased seizures; this in turn leads to less clinical risk, such as injuries which would lead to a better quality of life.
- I am easier to make contact with than hospital consultants or GPs, for example, and can respond to patient enquiries rapidly, which minimises patient anxieties, leading to reduced hospital visits, and reduces financial costs for travel etc. as well as time issues, for example time off work. By having an epilepsy nurse service this frees up consultants time by not having to respond to extra phone calls or having to arrange further clinics.
- By providing the patient and their families with the opportunity to call me if they have any concerns/further questions this leads to more reassurance and improved self-confidence with their epilepsy and how to manage it.

- 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 with the potential to improve mental health outcomes for the patient and family. This in turn may lead to less A&E attendances.

#### 1.4 Method of collecting data

This was a laborious activity. Initially I started to look through and audit the nurse-led service, with the intention of working towards the Trust's goal of transformation and increasing clinic appointments. It had already been identified that there was a high 'do not attend' rate not just for the nurse led clinic, but also for other professionals within the Trust. The geographical area for the Trust is large with the hospital being located towards the north of this area. I initially felt that perhaps setting up an outreach clinic in the southern part of our catchment may help to reduce our DNA rate. I asked our IT department to identify those patients from our internal patient record database that lived in this proposed area.

When I examined the data however, there were very few DNA's by the patients that lived closer to the proposed outreach clinic location. This was a useful exercise to test my initial assumption. After this, I returned to IT and requested a list of all epilepsy patients that had been seen in one of the epilepsy clinics over the last 12 months. I was provided with a list of 400 patients. I knew this was not correct. The list included all patients booked into various consultants' clinics. I manually filtered out those patients that were non-epilepsy related and after a considerable amount of time, I identified approximately 170 patients. This serves to illustrate some of the challenges encountered when seeking to make informed decisions based on NHS data.

Whilst this figure (170) may be representative of my caseload size, the caseload itself is not static as there is movement of patients with new diagnosis, discharged patients, those moving into or out of area and deaths etc.

Next, I sorted my then current caseload into age order, and included other relevant information about each patient to provide myself and the team an up to date database of patients. I then categorised my caseload according to the level of input they receive from the epilepsy nurses; this will be discussed further later.

I also approached the finance department to request local data on the costs of running the epilepsy nurse service to include telephone costs. In addition to this I asked for the local costs of A&E attendances, as well as hospital admissions. Having been put in contact with one employee within finance, I was then passed onto various other people in the department, and after numerous emails I unfortunately did not receive this information. Consequently, this economic assessment is based on proxy figures.

In addition to this, I carried out a brief survey of families perceptions of the epilepsy nurse service. Families were all very positive about how efficient, reliable and swift the service is. With this in mind, if the service was not available, these patients may not have their queries answered leading them to access other professionals such as the consultants or their GP.

## 2. Costs of the Service

<b>Direct costs</b>	<b>Amount</b>	<b>Assumptions</b>	<b>Adjustments</b>
Epilepsy Nurse Wage (wte 1) @Band 7 (x2 0.5 wte nurses)	£35,891 (£18.20/hour)	Annual leave of 33 days + 8 days public holiday entitlement. 4.3 days per year sickness	<b>£43,966</b> (includes 22.5% on costs)
Secretarial support 7 hours /week. Band 4. Midpoint	£21,263 7 x £10.87/ hour = £74.62 per week	If service was unavailable, there would be extra time needed to pass on messages between parents and consultant. 260 working days per year minus annual leave entitlement, equates to 43.8 working weeks per year, multiplied by 7 hours allocated per week.	£26,047 (inc + 22.5% on costs) Cost to epilepsy nurse service <b>£4,004</b> (£74.62 + 22.5% x 43.8 weeks worked per year)
Nurse visits	£869.05 per year	Nurse travels 1337 miles per year. Nurse receives £0.65/mile travelled	
Staff training Epilepsy Update courses		Time taken from nurse's week.	
Consultant time discussing patients' approx 2 hours per week (midpoint)	£83,972 (£43/hour)= £ 86	Annual leave of 33 days + 8 days public holiday entitlement	£102,866 (inc. +22.5% on costs) Cost to epilepsy nurse service <b>£4614.33</b> (86 + 22.5% x 43.8 weeks worked per year)
		<b>Total Cost of Epilepsy Nurse Service</b>	<b>£52,584</b>

<b>Indirect costs</b>	<b>Amount</b>	<b>Assumptions</b>	<b>Adjustments</b>
Office Space inc telephones/computer	No additional cost	Already provided within the epilepsy nurse service	
Telephone call charges	Amount unavailable.	On a contract with the telephone company paying a monthly amount	
Staff training Epilepsy Update courses	Up to £500 per year	Provided by Roald Dahl Children's Charity.	
Meeting with paediatric matron	No additional cost	Monthly meetings held lasting an hour	

Royal college of Nursing, RCN (2017), Department of Health (2016); ONS (2017)

Unfortunately, when undertaking this economic assessment I was unable to obtain any figures relating to telephone costs. Although identified here as an indirect costs it would have been insightful to have known the details regarding telephone usage as these 'hidden costs' underpin a significant part of the service, which I illustrate later through case studies.

### 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 category are the children identified as having a high dependency level; the orange group have a medium dependency level and the green group are identified as low dependency patients. These categories and the rationale behind them were peer reviewed and discussed with other epilepsy nurses within the south-east region of the country.

#### Epilepsy nurse grading

- 1 – High level input –Red (16 children)

For example:

- Those children that have been newly diagnosed (maybe for 2-6 months) or new to the area
- Children with complex needs
- Those that are having frequent seizures

- 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. This diagram therefore reflects my caseload at the time of undertaking this economic assessment and may be indicative of the caseload at any one time.

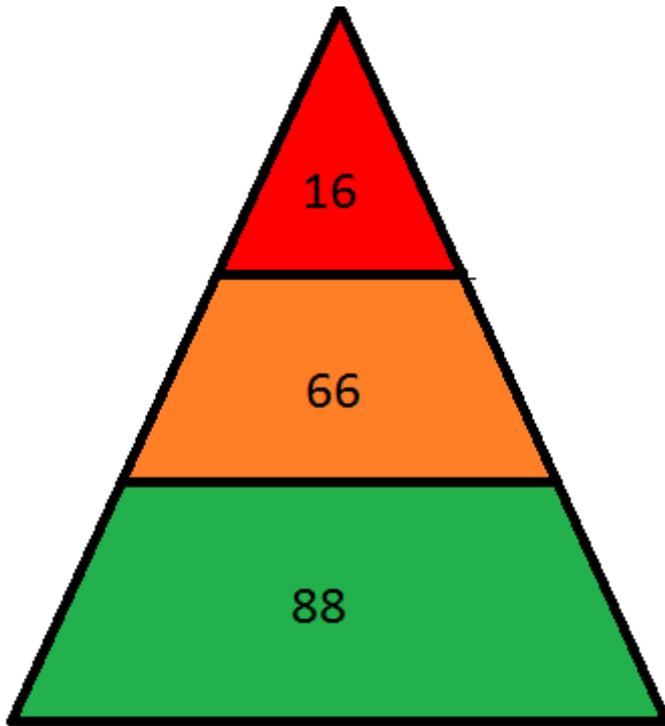


Fig 1: Diagram of Case load

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 in school. Mum happy with plan (30 minutes).

- 12/9 – discussion with consultant re: other seizures. Plan to increase meds.
- 12/9 – call to mum – to explain meds increase. Mum asking about behaviour of son, reassured and gave advice – parenting class (25 minutes).
- 12/9 – text later that evening from mum. George went back to school and was ok. Also, had forgotten to say he had had a seizure a few weeks back, before holiday, similar to previous presentation. Mum felt he was a little anxious about going on holiday.
- 13/9 – mum called, unsure about meds increase, wanted to clarify (20 minutes).
- 14/9 – text from mum. George had a seizure this morning. School were worried to have him there, has got a cold now. He has started his medication increase.
- 14/9 – call to mum to check on details. Mum reports he is unwell and prefers to keep him at home (20 minutes).
- 14/9 – call to school – to explain that no reason for him not to attend school after a seizure if well. Covered first aid (20 minutes).
- 14/9 – text from mum – asking what to do if he gets a temperature.
- 14/9 – call to mum to explain what to do re: temperature /illness advice. When to give anti-pyretics etc.(20 minutes).
- 14/9 – text from mum - they did some school work whilst he was off from school today
- 18/9 –Clinic Appt. Was asked to chat to mum. Long chat about history of recent seizures. Covered first aid again, when to call ambulance, safety (30 minutes)
- 18/9 – text from mum in the evening- what to do about repeat prescriptions
- 19/9 – text back to mum, to explain letter from clinic will go to GP so they know what to do.
- 19/9 –text from to mum to say that GP have asked for a form to be filled out for repeat prescription.

- 21/9 – text from mum, doesn't think she will have enough medicine for the weekend.
- 21/9 – working from home, call to work, to ask for consultant letter to be typed today and sent out to GP. Asked for a call back when done so I could reassure mum. Email to consultant to let him know. He was not informed about shortage of meds in clinic earlier in the week.
- 21/9 – further texts from mum, with different scenarios – should mum go to fill out form at gp, will it get faxed across, and will they get told when it was there.
- 21/9 – mess left for mum to explain what was being done
- 21/9 – mess left for mum, to advise that letter has been sent to GP
- 21/9 – text from mum , asking if she should call GP tomorrow to make sure it is there
- 21/9 – mess left , advised to go there this afternoon
- 21/9 – care plan written
- 22/9 – text from mum. Not at work today. She had had a call from school to say he had had a tightening in his hand today, and that they were keeping an eye on him
- 23/9 – abnormal EEG – generalised epilepsy
- 25/9 – teaching session at school – 45 minutes + 40 minutes travel time (9 miles)
- 25/9 – text from mum asking if school visit went well
- 26/9 – text from mum – to say school had said they were all trained up now
- 28/9 – text from mum – have received care plan I have done
- 2/10 – text from mum – with example of recent behaviour
- 2/10 – call to mum – call to run through school visit, and to see how George is doing. Seizure free for last 10 days or so. Mentioned about issue she has with behaviour, ran through some management of this (18 minutes).
- 4/10 – text from mum at 7 am. George had 2 x seizures yesterday. Mum recorded these and will show me later as visiting them.

- 4/10 – home visit completed. Explained to George about epilepsy. Ran through checklist with mum, answered questions. Watched videos. 1.5 hours plus 50 mins total travelling (9 miles)
- 4/10 - email sent to consultant to explain about visit and video, asking if wanted to increase meds further in light of more seizures.
- 9/10 – discussion with consultant, plan to increase meds
- 9/10 – call to mum to explain and meds increase (6 minutes). Letter dictated.
- 9/10 – text from mum later that day, to let me know that his performance at school went well.

This is an example of a high level input, where I put a lot of time into the family's needs over a 3 month period. Without the epilepsy nurse service, school would not have been as willing to have George attend, post seizure. This leading to more days off, as school had expressed their feels of how to manage a child with epilepsy. As a direct result of my input and expertise, George benefits by attending school as he is learning and socialising with his peers. In addition, George's parents feel reassured as they now do not call an ambulance and are happy to manage his seizures at home. Without the education I have provided to the family and further support my assumption would be there would have been unnecessary A&E attendances. Parents would not have known how to go about receiving repeat prescriptions, perhaps leading to the GP needing to call them to explain the process or unnecessary GP appointments made.

Not only have I supported the family with regards to George's epilepsy. I have since provided George's mum with help for herself as she suffers from anxiety issues in signposting her to various local services to try and improve her wellbeing.

Using the above figures I have calculated my direct involvement costs plus cost avoidances based on this one case study which represents one of 16 high level input patients.

- *Total time recorded for my input = 7.7 hours*
- *Extra unrecorded time for messages/texts /discussion with consultant/ dictating letters, I have made assumptions made this equates to 1.4 hours*
- *Total time = 9.1 hours*
- *Cost of time = 9.1 x £22.30/hour =£202.93 ( this includes 22.5% on costs)*
- *Mileage costs for school visit @ 22 miles x 0.65p = £14.30*
- *Mileage costs for home visit @ 21 miles x 0.65p = £13.65*

By having a nurse-led epilepsy service, we can assume that there has been a reduction in 999 calls/ambulance call-outs/hospital attendance/possible inpatient stay/GP intervention/missed school days.

For the purpose of this economic assessment I have used national reference data, as local figures were not available. The Department of Health, DoH (2016) suggest the following costs relating to 999 and ambulance intervention:

999 call	£7
999 – hear and treat or refer	£34
999 – see and treat or refer	£181
999 – see and treat and convey	£236

As well as the following for inpatient costs (DoH, 2016):

Non – elective inpatient	£1609
Excess bed days	£306
A&E attendance	£138

The amount of £1609 is representative of the average cost of a non-elective adult admission. I was unable to uncover the precise figure from my Trust nor identify any

national figures for the paediatric equivalent, and acknowledge the limitations of this proxy data.

By assuming my input has resulted in preventing one hospital admission using this case study as an example, this has potentially avoided up to £1609 per patient,

In addition, we can also assume that there is a GP appointment cost avoidance of £36 for an average 9.22 minute consultation (PSSRU, 2017), as at one point during this case study example, George’s mum would have called the GP for an appointment if the ESN was unavailable.

Therefore, based on the assumptions above the estimated costs avoided in the three months George required intensive input were:

	<b>Cost</b>	<b>Freq.</b>	<b>Total</b>	<b>Cumulative</b>
<b>Costs avoided: Organisational</b>				
Hospital admission	£1609	1	£1609	<b>£1609</b>
<b>Costs avoided: Primary Care</b>				
GP attendance	£36	1	£36	<b>£1645</b>

This figure £1645 represents estimated costs avoided assumed to be a consequence of my input over three months, with one high dependency patient.

Based on the assumption, tested out through peer review, that George is typical of my high dependency patients it may be reasonable to assume that these costs may

be avoided across my high dependency caseload over a 12 month period<sup>1</sup>. 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).

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<sup>1</sup> 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 for missed school days into the costs avoided across the ENS, as more detailed work would be required to look at the wider impact of the ENS on school attendance.

### 3.2 Case Study 2 – A 15 year old Girl

Sarah (not her real name) has complex medical needs with multiple diagnoses. She is a young lady with complex epilepsy which tends to cluster which worsen when she is unwell. Sarah has been and does fluctuate between being a high and medium input patient. For the purpose of this case study, and at the time of writing this, Sarah represents a medium level dependency, and looks at the value added by the intervention of the ENS service.

- 25/9 - Call from mum, school has given her Buccolam rescue medication, four times since starting school (20 minutes). This is extremely unusual for her. Mum happy for me to call school. Mum has taken Sarah to the GP and has been commenced on oral antibiotics.
- 25/9 - Call to school – ran through history, seemed like followed protocol. Questions about whether continuous seizure, post-ictal moments or respiratory issues. They had mentioned Sarah required oxygen. Gathering info. Offered to come in to run through things, school felt they were ok at the moment, asked if protocol was clear, as sometimes especially for the complex ones they are difficult to write (15 minutes).
- 27/9 - D/W consultant. Explained situation. ? To change protocol to include just one type of seizure rather than for multiple types.
- 27/9 - spoke to mum on the ward, Sarah is an inpatient for increased respiratory rate and concerns about a possible chest infection. Explained about phone call to school, and discussion with consultant. Mum wonders whether it should be taken away, and they call mum if concerned about seizures. Discussions around alternatives, also about trying to get a meeting, mum keen (30 minutes). (Return journey would be 42 miles plus 1 hour meeting time and approximately 1 hour 20 minutes travelling time)
- 28/9 - call to lead nurse at school. Ran through situation again, and descriptions of seizures. She felt Buccolam was needed. She wondered it maybe a progression of epilepsy. I suggested meeting after Sarah was well and out of hospital. They have a checklist of alternative methods to try and distract her out of seizure (25 minutes).

- 3/10- call to mum; she had emailed me with suggestions/concerns about Buccolam in school (30 minutes). In respite this weekend, rewrote rescue medication protocol.
- 3/10 - call to school, trying to arrange a school meeting next week. They will call back/email to confirm.
- 3/10 - call from SW, had dad call him as keeping off school due to concerns about how they look after daughter. Was told school not keen to take my advice. Explained that this was not the case, misunderstanding perhaps, as initially school felt they were ok with the information they have. As things have progressed meeting now being arranged. (7 minutes)
- 4/10 - call to mum advised that meeting should be next week
- 9/10 - message received from school, meeting on 11/10
- 9/10 - call to mum to confirm (3 minutes).
- 11/10 - message on answer phone from mum: unable to make meeting as unwell.
- 11/10 - call to mum, to see how they are. Have colds. Explained will try for next week.
- 11/10 - call from school to say meeting has been postponed, suggested alternative dates (4 minutes)
- 11/10 - call back from school, unable to arrange for those dates, to rearrange for after half term (5 minutes)
- 12/10 - call to mum to find out availability, message left. Found out Sarah is an inpatient

This is a current example of a medium level dependency for the ENS service.

Sarah's parents are not keen for her to attend school, until a meeting takes place as they had concerns over her epilepsy management. From the time Sarah was unwell up to the meeting date this totalled 14 missed school days. This was putting extra pressure on the parents. Mum doesn't work, however, she had mentioned that she

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*
- *School visit cost, 2.5 hours x £22.30/hour = £55.75*
- *Total cost of nurses time = £120.42*
- *Mileage for school visit @ 40 miles x 0.65p/mile= £26*
- *Missed school days = £33.16 per day*
- *Total missed school day spend 14 x £33.16 = £464.24*

As a result of educating the school staff, and the ENS intervention with Sarah and her family I have worked to support Sarah's reintegration back into the education system. We can assume that if it was not for my intervention, this scenario may have worsened. As a result of my involvement we can assume for Sarah that year on year her level of absence could have improved leading to greater attendance. Not only has improved Sarah's quality of life but also those of her family.

For many of the high and medium level patients, they are offered a much more timely reply to their queries; with some information being provided that would not necessarily have been done so by consultants due to their other commitments. These patients are time consuming as illustrated by these first two case studies. Certain queries such as increasing medications can be done in between clinic appointments, and this would subsequently improve the patients and families quality of life as well as free up clinic spaces for those patients that need them.

### 3.4 Case Study 3 – 3 year old Boy

- David (not boy's real name) had had a history of blank episodes
- A referral came via his GP into the service
- Seen in the rapid access clinic
- Investigations including EEG done
- Childhood Absence Epilepsy Diagnosed
- David was started on medication
- Seen by epilepsy nurse to run through diagnosis and management in more detail
- Call by epilepsy nurse to parent one month later to see how things are
- Reviewed again by consultant 3 months later

This is a good example of a low input patient, after the initial support following diagnosis; management is undertaken by the parents, with little/rare contact between clinic appointments. I had spent time visiting the family, approximately 2 hours including travel.

*Cost would be 2.1 hours @ 22.30 hour = £46.83 (including + 22.5% on costs)*

*Travel of 8 miles (return) 8 x 56p = £4.48*

Although this example illustrates a low level dependency, as epilepsy can be an unpredictable condition, a case like David's may at any time transition between the dependency levels. However, by having this beneficial first introduction and managing this stage well, I become the point of contact when families have queries or are a point of crisis as illustrated in case study 1 and 2. The patient and families know me and will contact me which again adds value to the ESN service. They have

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 nature of epilepsy.

It has been beneficial to create and maintain a database of patients, from which further audits and evaluations can be undertaken. Unfortunately, this was not straight forward; however, as a result of this economic assessment more reliable caseload data has been achieved. By avoiding hospital admissions, consultant's time as well

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 crucial support network to guide them into and through their adult lives.

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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.

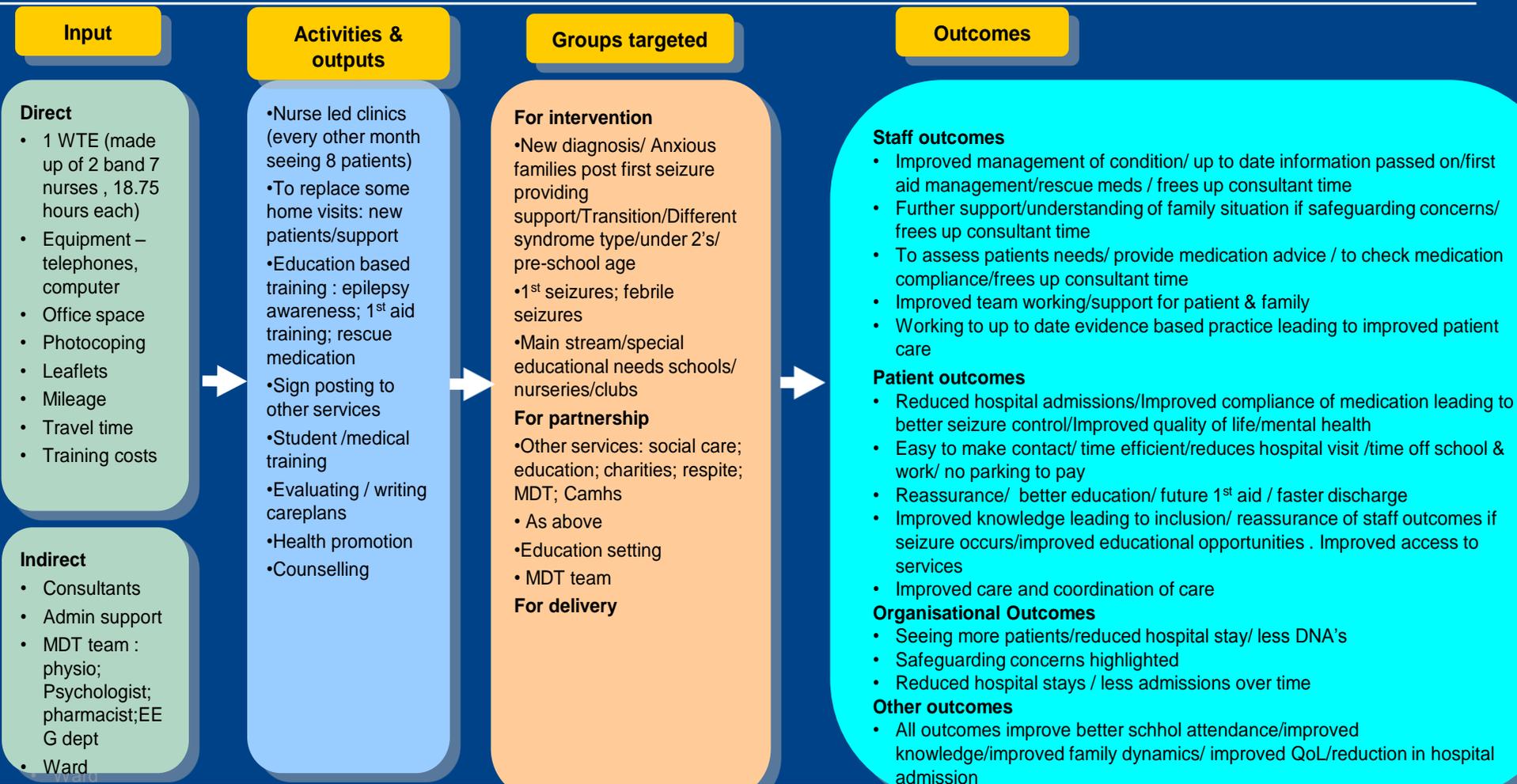
Natalie successfully completed an RCN leadership development programme commissioned by Roald Dahl's Marvellous Children's Charity.

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.

The programme is endorsed by the Institute of Leadership and Management.

You can contact Natalie by email [nataliebaines@nhs.net](mailto:nataliebaines@nhs.net)

# Children's Epilepsy Nurse Service (Baines 2017)



# Clinical Nurse Specialist – Children’s Epilepsy Service (Baines 2017)

## Inputs

### Investment

#### Direct

- › 1 WTE Band 7 nurse @ £43966 p.a (inc + 22.5% on costs)
- › Secretarial support 7 hours p.w @ £4,004 p.a (inc + 22.5% on costs)
- › Training - £500 from Roald Dahl Children’s charity
- › Travel costs – approx 1330 per year / £0.65 per mile £869.05
- › Consultant time – approx. 2 hours per week £4614 p.a (inc + 22.5% on costs)

#### Indirect

- › Office space & supplies/equipment
- › Monthly meeting with Paediatric Matron for 1 hour
- › Resources – provided free by charities/ pharmaceutical company
- › Telephone call charges – on average 12 calls per day.

## The Service

### Journey through Service

#### Activities

##### Clinics/home visits/telephone

- › Expert clinical assessment
- › management plan
- › New diagnosis
- › Rescue medication discussions/training
- › Care plan writing and reviews
- › Patient/ carer/ professional education
- › Transition support
- › Referral/signposting to other services
- › Health promotion
- › Counselling

#### Groups Targeted

- › Children aged 0-18 years who have a diagnosis of epilepsy/febrile convulsions/1<sup>st</sup> fit
- › Transition aged children from 14 years
- › Carers of those children above
- › Other healthcare professionals of those children
- › Education professionals

#### Source of referral

- › Hospital Consultant
- › GP
- › 1-2 new referrals per month
- › Current active caseload of 170 patients
  - › 16 high input
  - › 66 medium input
  - › 88 low input

## Summary of Benefits

#### For patients/carers

- › Reduction in anxiety
- › Better management of condition
- › Prevent school/social exclusion
- › Expert care provision
- › Reduced need for hospital admission/clinic appointment
- › Up to date evidence based information
- › Reduction of GP involvement
- › Improved medication compliance
- › Improved academic achievement
- › Better family dynamics

#### For healthcare system

- › The full economic cost of the epilepsy nurse service is £52640 for the high level input patients. Costs avoided range from £26320 to £78960. These figures do not take into account the wider benefits to the economy such as school attendance and they sit within the context of the significant quality benefits the service realises.

#### For other local services

- › Improved school attendance
- › Staff provide better support for their pupils with epilepsy

#### Opportunities for service development

- › To expand the service to include young adults in the absence of an adult epilepsy nurse within the trust