

An economic assessment of the children's epilepsy nurse specialist role.

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As a Roald Dahl Sapphire Epilepsy Nurse Specialist the partnership between myself and the children, young people, parents and carers enables me to recognise the benefits of the service provided. This is demonstrated by improved health outcomes, reduced use of acute services, increased participation and customer satisfaction. Presenting these benefits to persuade further investment allowing the service to further develop and improve without compelling evidence of their economic value is a challenge.

Anand, Dinika; Anand, Rajiv (2014) found that epilepsy is more distressing in cases of children with uncontrolled, recurrent seizures as well as for girls with epilepsy. The need for providing adequate psychological support and assistance to parents and children was highlighted. The critical value of a holistic approach to the treatment of epilepsy particularly was established.

Chiou, Hua-Huei; Hsieh, Liang-Po (2008) study compared parental stress of those whose child had asthma and those with a child with epilepsy. Overall, results showed that parental stress was higher in the epilepsy group. Possible explanations for a higher level of parenting stress in the epilepsy group were discrimination, poor child adaptation, the threat of unpredictability of the seizures, and neurological dysfunction.

The NICE Quality statement 27 (2013, reviewed 2017) recommends that children and young people with epilepsy are seen by a Children's Epilepsy Nurse Specialist who they can contact between scheduled reviews. It is felt that the Children's Epilepsy Nurse Specialists play a key role in supporting continuity of care between settings for people with epilepsy. There is some evidence that Children's Epilepsy Nurse Specialists improve clinically important outcomes such as knowledge, reduces anxiety and depression for people with epilepsy in secondary and tertiary care.

An audit by Epilepsy 12 (2015) revealed that the ability to contact a professional at the point of need significantly improved service user's satisfaction.

There is evidence that access to the Epilepsy Nurse Specialist can reduce use of acute services. Kirsten Johnson (2010) was appointed to work with children with epilepsy and their families at King's Mill Hospital in Nottinghamshire in 2007. Since then, the number of admissions for children with epilepsy has fallen from an average of four a month to two. Ladikos P.D.; Oren C.L.; Heys M. (2016) felt that almost half of all A&E attendances for children and young people with epilepsy may be avoidable and they identified a need for improvements to the Paediatric Epilepsy Service.

Although this acknowledges the quality related benefit of the Children's Epilepsy Nurse Specialist, it does not demonstrate any economic benefit.

The Roald Dahl Sapphire Epilepsy Nurse Specialist at King's Mill Hospital

The Roald Dahl Sapphire Epilepsy Nurse Specialist post was established at King's Mill Hospital on 30th April 2007. The role was funded for 1 year by Roald Dahl's Marvellous Children's Charity, with support from Epilepsy Action, and has been fully funded by the NHS Trust since that time. There was no epilepsy nurse service at the Trust prior to this post. The post has been challenged at times by the threat of dis-establishment and also redeployment to ward duties. The lack of evidence of economic benefit from the role means it is difficult for those working outside of the service to fully understand its value.

I have been in post as the Roald Dahl Sapphire Epilepsy Nurse Specialist for 10 years. I began as a novice practitioner and now practice as a competent practitioner. I am the only specialist nurse for this service. I work full time as a Band 6 with a salary of £35,577 (Appendix 2). My case load is approximately 300 children over a large demographic area. Epilepsy Action and the Royal College of Nursing recommend a maximum caseload of 250. Many of these children are cared for by our consultant paediatrician with a special interest in epilepsy but the remainder will be cared for by any one of the other 12 consultants in our paediatric service.

The role from its outset has involved establishing and developing the specialist nurse service. Service activity is diverse but at its heart aims to provide care at the point of need to a group of complex children and young people and their families. This includes:

- The 'Hot Line' service which involves answering telephone calls or texts from young people, parents, carers, and schools at the point of need and responding to that concern. This may be about seizure activity, medication/side effects, behaviour or learning, activities and inclusion. Each contact requires time, documentation and often further planning and liaison with another professional. This then requires further contact with the client and documentation. Calls may be straight forward with a clear request and outcome but often this is not the case. Epilepsy can be a very frightening and complex condition for parents to manage and when they contact the service at their point of need they may be upset, frightened or angry. This requires a competent practitioner to listen, question and understand what is needed at that time and provide the appropriate care.
- Telephone consultations to support those with a new diagnosis, new medicine plan or having difficulty managing epilepsy for any reason. Also telephone contact to those families who have not brought their child to their clinic appointment. Vigilance is required to support and protect these children and young people. All contact is documented.
- If available I will visit any child attending Emergency Department or admitted to the children's ward. I can support their journey, assist in their plan of care and often reduce the time they spend in that setting. I will follow up this contact with a telephone consultation when the child is discharged.

- Emergency Department and the children's ward try to make me aware of any child that has been admitted with seizure activity so if I am not available at that time I can make contact with the family by telephone to review.
- Our service provides weekly nurse-led seizure clinics at King's Mill Hospital and Newark hospital. These clinics provide care to children with a new or established diagnosis and focus on epilepsy education, medicines management, safety, lifestyle and moving towards self-management. There is a weekly seizure clinic that is consultant-led and a monthly teenage seizure clinic. There is a seizure clinic for children with additional needs four times a year and a visiting neurology clinic five times a year. The Epilepsy Nurse Specialist is in attendance for all these clinics and may also be invited to see children with an epilepsy attending a general paediatric clinic.
- The Epilepsy Nurse Specialist provides care outside of the hospital setting and can support children and families by visiting them at home. This can be very helpful in understanding the challenges that some families face and avoid additional stresses that time off work, travelling and the hospital environment may bring to that family. Additional teaching such as emergency medicine teaching is sometimes done in the family home.
- The Epilepsy Nurse Specialist provides education to support an individual child and this includes epilepsy teaching, emergency medicine teaching and vagal nerve stimulation teaching for families, educational settings and other care setting as required. The Epilepsy Nurse Specialist provides emergency medicine teaching yearly for families and other settings that have taken on that responsibility while the child requires access to this. The Epilepsy Nurse Specialist provided 85 school visits from April 2016 to April 2017.
- The Epilepsy Nurse Specialist provides individual healthcare plans to support a child with an epilepsy in school and also emergency medicine plans for home and other settings as required once training has been delivered.
- Liaison with multiple other services is a vital part of the role as education and sharing of information ensures appropriate, safe care for the child or young person.
- The Epilepsy Nurse Specialist regularly provides education about epilepsy, epilepsy care and emergency care to medical and nursing staff in the Trust.
- To ensure that the Epilepsy Nurse Specialist's knowledge and practice continues to evolve and improve it is important that further study and training is accessed. Mandatory training is provided by the Trust. Specialist education is sought by the nurse specialist. Funding is often accessed externally and time to attend is provided by the Trust.

Plans for Children's Epilepsy Nurse Service at King's Mill Hospital

The current workload of the Roald Dahl Sapphire Epilepsy Nurse Specialist is in excess of that recommended by the Royal College of Nursing. As the lead and only Epilepsy Nurse Specialist I am responsible for providing continued case management for a large case load whose level of need fluctuates and at times can be intense. The role includes continued service development. There are no plans to expand the nurse specialist service. There is no service available at weekends or

when the Roald Dahl Sapphire Epilepsy Nurse Specialist is on leave. Support would be accessed by contacting the Consultant's personal assistant or by accessing acute services.

The personal assistant supporting this service works 24 hours per week. Her hourly rate is £17.29 (Appendix 2). In a usual week between 2 and 5 hours of her time is related to Epilepsy Nurse Specialist activity. She reports she spends more time related to epilepsy nurse specialist activity when the nurse specialist is not available as patient concerns more often come to her at that time. She felt that each call would take 10 to 15 minutes to manage. Taking this call and ensuring that appropriate action is taken impacts significantly on her time.

There are some additions to services available in the Trust that will support the children's epilepsy service. Working in partnership with Nottinghamshire County Council the Trust has access to a youth work team to address mental health provision for children and young people in hospital. A youth worker is aiming to be available for teenage clinics to support young people with chronic illness as mental health concerns are known comorbidities. She is developing a resource pack that will help to signpost children and young people to other services to support their emotional and physical health, relationships, education and employment.

A Community Children's Training Team has recently been established that will work county wide, training schools and outside agencies about many health conditions and procedures. They can provide epilepsy awareness training for schools and care facilities but information or care about an individual child or young person will continue to be provided by the Roald Dahl Sapphire Epilepsy Nurse Specialist.

Groups like Epilepsy 12 continue to evaluate children's epilepsy services nationally. The group was established in 2009 and undertake national clinical audit with the aim of helping epilepsy services, and those who commission health services, to measure and improve the quality of care for children and young people with seizures and epilepsies.

Nationally within the NHS there is a move towards reducing hospital admissions and the length of stay. At King's Mill Hospital we don't currently have a target to reduce paediatric admissions. There is on-going work with implementation of the Sustainability and Transformation Plans which overall are looking for a reduction in the number of referrals that come into the Trust. In the future there will be a specific plan for paediatrics.

There is a triaging service within paediatrics which looks at all new referrals, considering their appropriateness and ensuring they are directed to the correct service. It is expected that this system will reduce referrals by around 10% but this is related to their appropriateness rather than stopping or reducing an admission.

The Children's Admissions Unit has recently been established which ensures children attending the unit are assessed, admitted or discharged in a timely way.

HM Treasury (2003), as set out in The Green Book, states that 'the economic, financial, social and environmental assessments of a proposal should be combined and aims to ensure consistency and transparency in the appraisal process throughout government.' Some of these principles include the true economic costs, who incurs what costs, whether benefits can be attributed to the service and who benefits from what.

For this economic assessment I have elected to focus on one aspect of my service - the telephone contact service. I will consider the costs of providing this aspect of the service and the costs avoided as a consequence of my interventions. Much of the cost data was sourced from the Trust. This includes the service set up costs, salaries of the Epilepsy Nurse Specialist, consultant, personal assistant, clinic costs, emergency department attendance and ward admission. Where this was not available costs were obtained from national figures, for example the cost of attending the GP and ambulance attendance costs. (Appendix 2). I have taken two approaches to this economic assessment. The first is based on a 3 month audit of the service where the costs avoided are based on my professional judgement. To support my assumptions I have also considered a case study of a patient with complex needs and subjected my assumptions to the peer review of my colleagues (paediatric consultant and personal assistant) who would have had to manage these contacts in my absence and other Epilepsy Nurse Specialists (Appendix 3). First I will set the scene by outlining the telephone contact service.

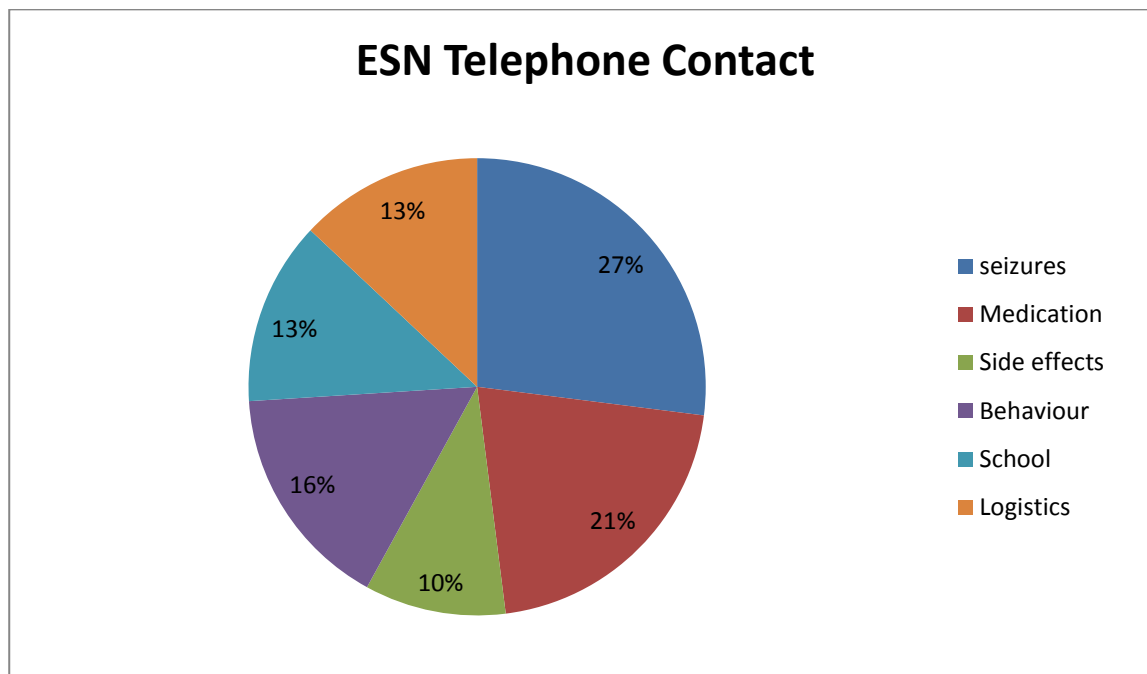
Telephone contact service

The significance of the telephone service became evident to me in the second year of my practice. As a Roald Dahl Sapphire Epilepsy Nurse Specialist it is a requirement to send a report to the supporting charities. To facilitate this I audited my clinical activity. In my first year of practice I had recorded 263 telephone contacts. In the second year I had recorded 619 telephone contacts.

This has increased year on year and between April 2016 and April 2017 there were a recorded 1207 telephone contacts and 1876 text messages received. In an average week I will receive 26 telephone calls and 41 text messages requiring clinical activity. A personal aim for my service is that all patient care related contacts are actioned on the same or next day.

80% of telephone contact is unplanned. Up to 18 hours per working week can be attributed to telephone contact with or relating to a client. Some conversations are very brief and others lengthy but the mean duration of calls are 5.5 minutes. The time attributed to telephone contact

does not represent or reflect the complexity of the concern or the level of knowledge and clinical activity needed to achieve an outcome for that child and family's concern. The chart below demonstrated the concerns of the client group.



Outcomes from telephone contact

There are many patient outcomes from these interventions. The timely management of a concern reduces the risk of escalation of concerns or symptoms which may lead to a hospital attendance. The prompt response provided by telephone contact reduces client/parent anxiety that left unmanaged may also lead to them contacting other services or a hospital attendance.

Telephone contact regarding seizure activity and medication are the most frequent concerns and together relate to nearly half of all contacts. Many contacts are considered rescue discussions about seizures. We will discuss seizure activity, triggers and adherence allowing the Epilepsy Nurse Specialist to understand the concerns of the client or parent. This will then allow the Epilepsy Nurse Specialist, client or parent to discuss medicine management which may include adherence, side effects and adjustment of medicine plans. This contact will improve the parent and child's knowledge about their epilepsy, first aid and managing risks as these are discussed as part of the conversation.

Telephone contact can often be in relation to mood and behaviour and it is vital that the Epilepsy Nurse Specialist recognises vulnerable children, parents and safeguarding concerns. Liaison or signposting to other services is often required. Contact at the time of the concern ensures that difficulties are managed in a timely way minimising their impact on the child and family. Seizure

management is optimised, risk and safety is rationalised and school and social inclusion is maintained.

The Epilepsy Nurse Specialist is vigilant and contacts families who have not brought their child to clinic appointments or who are not managing their care. I can also provide the link to additional services as I am usually a known person to the family and aware of the challenges that can be a barrier to them accessing services. This liaison will promote good epilepsy management for the child. It will promote attendance to clinic appointments and adherence to medication so reducing wasted clinic time and reducing medicine wastage.

Staff outcome

Contact with the Epilepsy Nurse Specialist at the point of need ensures that children and families do not need to seek support from other sources such as the personal assistant, GP, Emergency Department or the Children's Ward so reducing the pressure on those staff. It also ensures that extra outpatient clinic appointments are not requested. This reduces the workload of administrative staff managing clinic booking and the Paediatric Consultant who is attending clinic. All of these actions have a cost implication. Disruption for the child and family is minimised by the concern being managed out of hospital.

Organisational outcomes

The telephone contact service benefits the organisation as it ensures that Emergency Department, Children's Ward and outpatient clinic use is optimised. It avoids unplanned or unnecessary outpatient appointments so assists the Trust to achieve targets for 18 week wait and avoid sanctions if this is breached. It ensures that extra clinic and consultant time is avoided. Medicine wastage is minimised. Safeguarding and Sudden Unexpected Death in Epilepsy (SUDEP) is considered as part of the Epilepsy Nurse Specialist contract. The organisation further benefits from service user satisfaction.

Retrospective diary review of telephone contact

Retrospectively I reviewed telephone contacts between 1st April 2017 and 30th June 2017 and made assumptions about what would have happened if the Epilepsy Nurse Specialist was not available. I have considered the cost of this contact being managed in a different way. I have referenced the sources of what can be monetised in Appendix 1.

250 telephone contacts were reviewed.

All 250 calls are likely to have been received by the personal assistant and the concern redirected to the Consultant. The personal assistant reports taking a call and resulting activity usually takes 10 minutes. £720.41

- a)** The assumption was that 186 would require Consultant opinion and this may be a telephone call from the Consultant or an outpatient appointment made. Neither of these responses would happen in a timely way and I question if the concern would be escalated and then families seek a different route such as attending Emergency Department or GP for advice. I have made assumptions based on my knowledge of the families and service and also used peer review to test my assumptions about the outcomes for these children.
 - a. 56 families would have a call back from the Consultant. Taking into account that he is only likely to spend 5 minutes on each call this would cost £350
 - b. 66 families would be offered an outpatient appointment after the consultant had considered their concern. When reviewing the families that contacted the service 11 children presented more than once. Presuming that their concerns were managed on the first outpatient appointment I have costed for 51 outpatient appointments costing £10,047. Administration time/cost should also be considered as these children would be additions to the clinic.
 - c. 24 may attend Emergency Department because of escalating concerns at a cost of £4,800. If an ambulance was required there would be an addition cost of £254 per attendance.
 - d. 14 families may present to the children's ward. £5,376.
 - e. 26 families may attend their GP's, costing £1,170.
- b)** 28 of the contacts may have attended their GP. The GP may not be willing to adjust care for this specialist group of children and young people and refer back to the hospital delaying the response further. The GP may adjust care in an inappropriate way which could escalate concerns.
 - a. Attending the GP cost £1,260.
- c)** The personal assistant often receives patient related calls and when the specialist nurse is in work they will be redirected to that service to be managed. As part of this review, 26 of the contacts could have been managed by the Consultant's personal assistant as they related to administrative concerns about appointments or communications with GP or other services.
 - a. Assuming the time taken for each contact is 10 minutes including administrative work the cost would be £74.92 (this cost has already been included in the figure representing all calls taken by the personal assistant).
- d)** 5 contacts would have presented at the Emergency Department AND
- e)** 5 would have sought admission to the Children's Ward.
 - a. This would have been an inappropriate and costly use of services. The attendance would involve waiting time and interventions for the child both of which may be anxiety provoking or frustrating for them. It is unlikely that the child and family would see a known professional. Although the family may be reassured by seeing a health professional, care may not be adjusted. They may be discharged with

instruction to contact the Epilepsy Nurse Specialist or an outpatient appointment with the child's Consultant so adding several more steps to the patient journey before the goal is achieved.

- b. Attending Emergency Department £1,000.
- c. Attending the Children's ward £1,920.
- d. If an ambulance was required there would be an addition cost of £254.57 per attendance.

This represents just a quarter of the yearly activity. Potentially the cost of managing patient concerns without the availability of the Epilepsy Nurse Specialist over a year would be:

- Consultant call £1,400
- Seizure clinic attendance £40,188
- Emergency Department attendance £23,200
- Children's ward attendance £29,184
- GP attendance £9,720
- Personal assistant's time £2,881

Total cost over a twelve month period £106,573.

It is worth noting that this cost is based on the assumption that the 3 months period audited (April – June 2017) is representative of 12 months activity. In reality the Epilepsy Nurse Specialist's telephone activity was known to be greater than 1000 contacts per annum, so in excess of these figures. In the year April 2016 to April 2017 the Epilepsy Nurse Specialist received 1207 telephone calls and 1876 text message, which suggest that overall the costs avoided here is a relatively conservative estimate.

Previous audit demonstrates that the Epilepsy Nurse Specialist spends 18 hours of her working week managing telephone contact. This is nearly 50% of her time. The full economic cost of the Epilepsy Nurse Specialist is £43,581 (Appendix 2), 50% of which is £21,790.50. Estimated cost avoided by Epilepsy Nurse Specialist availability for this service is £84,778.

These figures do not take into account the wider economic benefits including the quality benefits to the family and their costs avoided. Research supports that children and young people with an epilepsy present with co-morbidities. These can affect their physical and emotional health, learning and behaviour, leading to missed school days and increased hospital admissions. This in turn impacts on parents and families affecting their physical and emotional health and relationships. It will affect their ability to work, which impacts on the family's financial stability and also makes it difficult to maintain social networks.

I will now consider a case study involving the same child and family during an intense 2 week period, documenting 6 different telephone contacts with the Epilepsy Nurse Specialist. I will demonstrate the cost of delivering this service and the cost avoided as a consequence of this service availability. This case study demonstrates the wider benefits of Epilepsy Nurse Specialist input as several layers of support are apparent in these contacts. I will then consider how these

concerns would be managed if the Epilepsy Nurse Specialist telephone service was not available and the cost of providing this level of support in a different way. I have made assumptions based on my experiences with this family about the choices they would make if they could not make contact with the Epilepsy Nurse Specialist. I will seek the opinion of colleagues and peers to check my assumptions.

I have presented this case study to the lead paediatric consultant for epilepsy, the personal assistant supporting my service and also a group of epilepsy nurse specialists attending the epilepsy nurse specialist regional meeting. I have asked for their opinion on how these concerns would be managed if the Epilepsy Nurse Specialist telephone service was not available.

Case study – setting the scene

Leah, aged 9yrs, was admitted acutely via the Emergency Department with clusters of focal seizures. She was not known to the service and did not have a diagnosis of epilepsy. Leah was reported to be above average academically, competitive, sporty and loved to dance.

Focal seizures progressed to a generalised tonic clonic seizure that did not respond to treatment. Leah was sedated and ventilated and transferred to the Paediatric Intensive Care Unit at the local tertiary centre. Leah remained sedated and ventilated for 4 weeks. The Electroencephalogram showed continued seizure activity. It was felt she had a viral tonsillitis causing viral encephalitis.

When Leah was woken up she had difficulties with memory and speech. She had left sciatic nerve pain causing pain in her leg and limiting mobilisation. Focal seizure activity continued and she was taking 3 different antiepileptic medications. She remained on the children's ward at the tertiary centre for a further 6 weeks and then was transferred back to our care as an outpatient.

The telephone contacts I have described were between 2nd and 16th June 2017. Leah is now 12 years old. She has tried 6 different antiepileptic medications. Her longest period of seizure freedom is 8 days. Seizure activity is varied and unpredictable.

She attends senior school on a part time timetable and has 1:1 support. I have worked very closely with school to initiate and maintain inclusion. She is below her peers academically and continues to have difficulties with processing information and memory. Her mobility is much improved and Leah would like to participate in sports but her mum feels that physical activity and tiredness triggers seizure activity so she does not participate at present.

The impact of Leah's illness and epilepsy on the family has been huge. Her parents remain traumatised by her initial illness and admission to PICU. They are grieving as Leah is a changed child and the aspirations they had for her no longer seem achievable. They are angry, upset and sometimes frightened. Leah's parents feel that they do not fully understand why this happened to Leah and how to manage epilepsy. Professionals are sometimes not able to give them definitive answers to their questions. The frequency and unpredictability of seizures mean they often feel confused and not in control. Managing Leah's epilepsy dominates their daily lives. Although they

need frequent hospital outpatient appointments and school reviews they find these very upsetting as they are forced to recognise that Leah does not have the same abilities that she once had.

Leah has times where she recognises she has changed following her illness. Her time in hospital and her epilepsy is not discussed with her as her parents worry this will frighten and upset her. They have allowed conversations between Leah and the Epilepsy Nurse Specialist about epilepsy and seizures but often Leah cannot remember these. She does worry about her health and her different ability. She is also aware of how worried her parents are and this worries her too. Her competitive nature is still apparent and drives her learning in school. She is very keen to take part in sports and dance as these were activities she previously excelled in. She is very frustrated that she is not allowed to participate and cannot understand the reasoning around these decisions. Leah wants to be in school and do all the things her peers are doing without one to one support.

Leah's younger sister misses the big sister she remembers. She is frightened by the seizures and is confused by the difficulties Leah now has with her learning and abilities. She is spending a lot of time with her grandmother because of Leah's needs. She sometimes feels jealous of the attention and time Leah receives.

Leah's mum has given up her career to care for Leah. She finds seizures very upsetting and stigmatising. She will not take her daughters out on her own in case Leah has a seizure as she does not feel able to manage this outside of the home. She does not want people to stare at Leah and is fiercely protective of her. The family manage day to day activity by one parent staying at home with Leah while the other takes her sister out. Leah's grandmother will often do the school run with her sister. On-line shopping is utilised. They rarely do things as a family. Both girls used to regularly stay overnight with grandparents. Leah is not able to do this now because of fears about seizures and safety. Leah's dad has had some concerns with his employment because of time off due to Leah's illness and appointments. He has had to leave work at short notice on occasion because of Leah's seizure activity. His employers are not as understanding as they once were.

Since Leah has returned to our care I have had telephone contact with the family on a weekly basis. The family have benefited from having access to a consistent known professional who is knowledgeable about their child's condition and care. They have been able to discuss complex issues and concerns at length at their point of need and achieve some understanding and clarity. This level of contact has allowed Leah's parents to care for her at home and have confidence in her attending school. They have often had a high level of concern and anxiety about antiepileptic medications and the opportunity to discuss and rationalise these concerns has enabled them to maintain Leah's treatment plan. Over time we have established a good relationship, demonstrating trust and rapport.

Telephone contact with the Epilepsy Nurse Specialist

2nd June 2017

Leah's parent is reporting concerns about seizure activity and wetting with the seizures, which is a new challenge. We have discussed seizures type and frequency. We have discussed medication and seizure management. I have emailed Leah's consultant.

Follow up call from me with Consultants opinion. The advice is to increase Clobazam. Parent very concerned about any change in medication. We have discussed parents concern regarding increase/side effects. What other options are available? What we will do if this plan does not work? We have agreed a plan. Written plan provided. Letter provided for the GP.

Conversation time 27 minutes

Administration time 10 minutes

Patient benefit

Leah's care-planning happened at the point of need ensuring the best epilepsy management. Child's and parents' anxiety is minimised because of timely response so their concern is less likely to escalate to the use of other services such as attending the Emergency Department or children's ward. We have been able to talk through any concerns, ensuring adherence to medicine plan.

We have not needed to request an outpatient appointment. The family have been able to access information so are well informed and able to maintain Leah's safety.

Leah continues to attend school.

Staff benefit

A call to the personal assistant from parent asking for consultant advice has been avoided.

The consultant time has been protected as he did not have to contact parent. (He may have offered outpatient appointment).

Organisational benefits

Outpatient clinic, Ward and Emergency Department use optimised.

Service user satisfaction.

Cost of Epilepsy Nurse Specialist

£15.92

Estimated cost avoided

Call to Personal Assistant £2.88

Call back from Consultant £6.25

Parents may request outpatient appointment £197.

5th June 2017

Parents are reporting that Leah's seizures have been more difficult over the weekend. They have made the decision to increase Lamotrigine. They have not increased Clobazam as discussed and agreed 2nd June. We have discussed the medicine plan. Parents are more comfortable with Lamotrigine, so we will continue with that and have a plan to increase if required. First aid and night time monitoring discussed. I have emailed Leah's consultant. I have provided a medicine plan for Lamotrigine and written to GP.

Conversation time 18 minutes.

Administration time 10 minutes.

Patient benefit

Leah's care-planning happened at the point of need ensuring the best epilepsy management. Child's and parents' anxiety is minimised because of timely response so their concern is less likely to escalate to the use of other services such as attending the Emergency Department or children's ward.

We have not needed to request an out patients appointment. The family have been able to access information so are well informed and able to maintain Leah's safety.

Leah continues to attend school.

Staff benefit

A call to the personal assistant from parent asking for consultant advice has been avoided.

The consultant time has been protected as he did not have to contact parent. (He may have offered an outpatient appointment).

Organisational benefit

Outpatient clinic, Ward and Emergency Department use optimised.

Service user satisfaction.

Cost of Epilepsy Nurse Specialist

£12.00

Estimated cost avoided

Call to Personal Assistant £2.88

Call back from Consultant £6.25

9th June 2017

Leah has fallen and fractured wrist. Surgery required to insert k wires. I have visited Leah on the ward prior to discharge.

12th June 2017

Leah is experiencing increased seizure activity. I have advised an increase in Lamotrigine as per plan. Lamotrigine has been tolerated well but mum is not happy to increase. We have discussed her concerns and mum feels happy to increase the dose as per plan. Possible adverse effects discussed. Mum asked what the next plan would be. We have also discussed pain in relation to Leah's recent fracture and how this may be impacting on seizure activity. We have discussed pain relief. We have discussed first aid for seizures considering Leah's fracture. Conversation documented on Leah's electronic record.

Conversation time 24 minutes.

Administration time 5 minutes.

Patient benefit

Leah's care-planning happened at the point of need ensuring the best epilepsy management. Child's and parents' anxiety is minimised because of timely response so their concern is less likely to escalate to the use of other services such as attending the Emergency Department or children's ward.

We have not needed to request an out patients appointment. The family have been able to access information so are well informed and able to maintain Leah's safety.

Leah continues to attend school.

Staff benefit

A call to the personal assistant from parent asking for consultant advice has been avoided.

The consultant time has been protected as he did not have to contact parent. (He may have offered an outpatient appointment).

Organisational benefit

Outpatient clinic, Ward and Emergency Department use optimised.

Service user satisfaction.

Cost of Epilepsy Nurse Specialist

£12.48

Estimate cost avoided

Re-admission to children's ward for pain and seizure management. £384 average cost per day.

14th June 2017

Leah is still experiencing frequent seizure activity. Number of seizures this week is greater than last week. Medicine plan is already in place. We have discussed possible cause of increase in seizures. We have discussed analgesia in relation to Leah's fracture. I have suggested increasing

Lamotrigine as per plan. There is some reluctance to do this because of concern about adverse effects. We have discussed this and rationalised in relation to Leah's tolerance of Lamotrigine up to this point. Parent questioned about what to do next if this doesn't work. We have discussed this and agreed on continued telephone contact to support. Conversation documented on Leah's electronic record and consultant made aware.

Conversation time 22 minutes.

Administration time 5 minutes.

Patient benefit

Leah's care- planning happened at the point of need ensuring the best epilepsy management. Child's and parents' anxiety is minimised because of timely response so their concern is less likely to escalate to the use of other services such as attending the Emergency Department or children's ward.

We have not needed to request an out patients appointment. The family have been able to access information so are well informed and able to maintain Leah's safety.

Leah continues to attend school.

Staff benefit

A call to the personal assistant from parent asking for consultant advice has been avoided.

The consultant time has been protected as he did not have to contact parent. (He may have offered an outpatient appointment).

Organisational benefit

Outpatient clinic, Ward and Emergency Department use optimised

Service user satisfaction.

Cost of Epilepsy Nurse Specialist

£11.62

Estimated cost avoided

Call to Personal Assistant £4.32

Call back from Consultant £6.25

Parents may have requested outpatient appointment £197

15th June 2017

Leah's seizure activity has increased and is now during the night as well as daytime. Parents report focal seizures and 1 convulsive seizure. We have discussed first aid and night time monitoring. Parents are sleep deprived and mum is worried about dad working when he has had so little sleep.

We have discussed the medication and plan. Medication has not been increased as per plan as parent worried about adverse effects. We have talked about those concerns and the impact of this increased seizure activity on Leah and the family.

Parents are now seeing non epileptic events. These have happened before and responded well to the plan we implemented. That plan is now difficult to follow because of Leah's fracture and having a cast on her arm.

Leah takes the progesterone pill to stop her periods as parents felt that seizure activity was worse around the time of menstruation. Parents are now worried about impact of this. We have discussed this.

Conversation documented on Leah's electronic record.

We had a neurology clinic that pm so I discussed these concerns with Leah's consultant and neurologist who cared for her at the tertiary centre. Appointment planned.

I have contacted parents with advice and appointment details.

Conversation time 35 minutes

Administration time 16 minutes

Patient benefit

Leah's care- planning happened at the point of need ensuring the best epilepsy management. Child's and parents' anxiety is minimised because of timely response. Concerns addressed and information and a plan of care given. Appointment provided so their concern is less likely to escalate to the use of other services such as attending the Emergency Department or children's ward.

We have not needed to request an out patients appointment. The family have been able to access information so are well informed and able to maintain Leah's safety.

Leah continues to attend school.

My assumption is that the family would have attended the Emergency Department on this occasion if telephone with the specialist nurse had not been achieved.

Staff benefit

A call to the personal assistant from parent asking for consultant advice has been avoided.

The consultant time has been protected as he did not have to contact parent. (He would have offered an outpatient appointment).

Organisational benefit

Outpatient clinic, Ward and Emergency Department use optimised.

Service user satisfaction.

Cost of Epilepsy Nurse Specialist

£21.95

Outpatient appointment given £197

Estimated cost avoided

Call to Personal Assistant £4.32

Call back from Consultant £6.25

Possible escalation due to parental anxiety to Emergency Department attendance £200 (average cost).

16th June 2017

Leah experienced a short convulsive seizure this morning. Managed at home. Parents are worried about what to do if there are more seizures. First aid and emergency medicine plan discussed. Step by step approach talked through. Family have this in writing.

Discussed medicine plan and this is going well. Further telephone contact planned. Conversation documented on Leah's electronic record.

Outpatient appointment as planned 19th June 2017.

Conversation time 20 minutes.

Administration time 5 minutes.

Patient benefit

Leah's care- planning happened at the point of need ensuring the best epilepsy management. Child's and parents' anxiety is minimised because of timely response. Concerns addressed and information and a plan of care given. Appointment provided so their concern is less likely to escalate to the use of other services such as attending the Emergency Department or children's ward.

We have not needed to request an out patients appointment. The family have been able to access information so are well informed and able to maintain Leah's safety.

Leah continues to attend school.

My assumption is that the family would have attended the Emergency Department on this occasion if telephone with the specialist nurse had not been achieved.

Staff benefit

A call to the personal assistant from parent asking for consultant advice has been avoided

The consultant time has been protected as he did not have to contact parent. (He may have offered outpatient appointment).

Organisational benefit

Outpatient clinic, Ward and Emergency Department use optimised.

Service user satisfaction.

Cost of Epilepsy Nurse Specialist

£10.76

Estimated cost avoided

Call to Personal Assistant £2.88

Call back from Consultant £6.25

Possible attendance at Emergency Department if concern escalates £200 (average cost).

Total epilepsy nurse specialist time spent on conversation and administration

- 197 minutes x £25.83 per hour = £84.80

Total £84.80

Estimated costs avoided by epilepsy nurse specialist intervention

- Personal assistant time £14.04
- Consultant time £31.25
- Outpatient appointments £394
- Ward admission £384
- Emergency department attendance £400

Total £1,223.27

This demonstrates an estimated saving of £1,138.47 (£1,223.27 - £84.80) to the Trust.

There are also a range of quality benefits to Leah and her family from these costs avoided. Leah's care-planning happens at the point of need ensuring the best epilepsy management. The timely response ensures concerns are discussed, anxiety is reduced and knowledge and resilience is increased. Leah is able to be cared for in her own home. She is able to attend school. Leah's sister is able to stay at home instead of being cared for by grandparents. Her dad does not need to take time away from work to be in hospital with her or attend extra outpatient appointments. There could be an economic value attached to all these quality benefits.

Peer review of the case study

I have sought peer review from the Paediatric Consultant with a special interest in epilepsy, the personal assistant and colleagues at the regional epilepsy nurse specialist meeting.

All review groups felt that the family's first contact is likely to be the personal assistant if the epilepsy nurse specialist is not available. All agreed that if contact was not possible with the personal assistant or, if following that contact the Consultant was not able to call back in a timely way, the concern would quickly escalate and the family would attend the Emergency Department.

For at least 2 of the contacts it was felt that the family would present at Emergency Department as their first response.

The personal assistant always advises any family that contacts with a concern to contact their GP or Emergency Department if they felt they needed an urgent response as she is aware that it may be a few days before the consultant is able to call them back.

The Consultant feels it would be unusual for him to spend more than five minutes managing a concern when he phones a family back. This brief intervention would address the presenting concern but is unlikely to include additional information. This additional information that is part of the conversations with the Specialist Nurse illuminates the parents' existing knowledge and provides further education or support enabling the family to feel more confident to continue caring for their daughter at home.

The consultant cannot be available to manage concerns at the time that they present. Our service's experience with many families is when the specialist nurse is not available they will contact several different people such as the personal assistant, the children's ward or pharmacy in an effort to get advice. It may not be appropriate for the people contacted to give advice or they may not have information available to them about the child to allow them to manage the concern. This results in several people trying to communicate to manage the concern. In this situation there is often confusion, an escalation of the concern and frustration and upset for the child and family.

Conclusion

My intention when undertaking this work was to demonstrate the economic value of the Roald Dahl Sapphire Epilepsy Nurse Specialist so retaining and supporting the role without risk of disestablishment or re-deployment. It is hoped that service planners maintain robust epilepsy care pathways to sustain and support the role, ensuring continued quality care to children and young people with an epilepsy and their families. Considering the large caseload of the Roald Dahl Sapphire Epilepsy Nurse Specialist future plans should include more nurse capacity allowing the service to improve and develop. This would be beneficial in the adult epilepsy service also so transitional care could become collaborative.

I have raised my profile in lots of small ways while producing this document. I have liaised with colleagues working in finance, management and communications to seek out the information I required. They have endeavoured to answer my questions and have often provided additional information that has supported my study. It has been very interesting to discover how finance, management and communications colleagues support my service and about new initiatives to drive continuing improvement.

The telephone contact documented demonstrates that this contact is avoiding use of other services thus avoiding costs. A cost saved is as good as a contribution. The experience, knowledge and skills required to manage these telephone concerns is evident. The relationship between the specialist nurse and family adds an extra layer of value to the care received by the family. The service offered by other professionals when the Roald Dahl Sapphire Epilepsy Nurse is not available is not cohesive or timely. This leaves the family unsupported.

When I consider the families that contact me at their point of need, my contribution and the outcome, I am not thinking about my economic value or a cost saved. I am thinking about keeping a child well, safe and included. I am providing parents and schools with the skills and knowledge to manage epilepsy so they can help that child achieve those things. Completing this work has made me look at what consequences we would see if this service was not available. What would be the impact on that child and family's physical and mental wellbeing? What would be the impact on their quality of life? We must also consider the impact on other services that would then be tasked with managing these concerns, the GP, Emergency Department, Children's Ward, Outpatient Department, Consultant and Personal Assistant. The Roald Dahl Epilepsy Nurse Specialist is an essential part of NHS children's epilepsy services with proven economic value.

Recognising that all the components of Epilepsy Nurse Specialist activity can have an economic value applied hasn't changed the way that I nurse but it has provided me with the skill to communicate my achievements and demonstrate my value in a bespoke way depending on my focus. The skills and methods used for this study will be applied to further study demonstrating the value of the Roald Dahl Sapphire Epilepsy Nurse Specialist.

This case study was completed by Kirsten Johnson, Roald Dahl Sapphire Epilepsy Nurse Specialist, Sherwood Forest Hospitals NHS Trust in 2017. Kirsten 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 of and continuously transform their services.

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

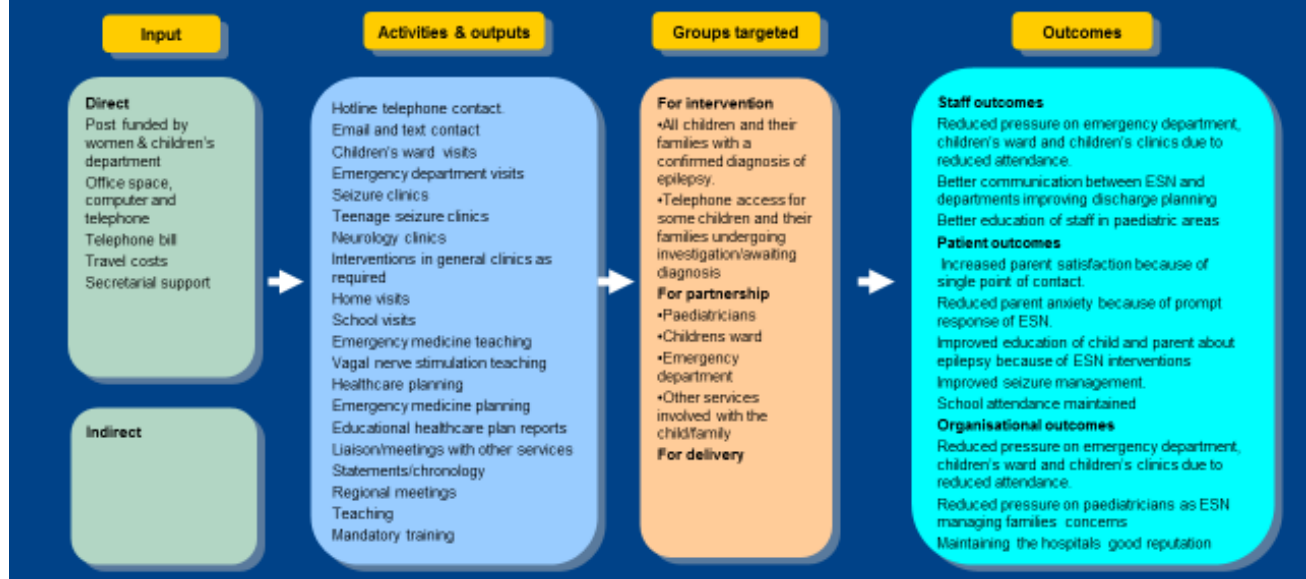
You can contact Kirsten by email Kirsten.johnson@sfh-tr.nhs.uk

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Appendix 1

Children's epilepsy nurse specialist



Appendix 2

What can be monetised?

Costs obtained from Hospital Trust sources

- Epilepsy Nurse Specialist. Band 6. Full time. £35,577 +22.5% =£43,581 (37.5 x 45 = 1.687). £43,581/1.687 = £25.83 per hour.
- Consultant time for telephone contact £103,490 + 22.5% = £126,775 (37.5 x 45= 1.687) £75per hour.
- Personal assistant (not allocated any specific hours to support my service. Just added in to duties) Time 2 to 5 hrs per week on activity related to specialist nurse. Salary £15,245 + 22.5% = £18,675 (24 x 45 = 1.080) Hourly rate = £17.29.
- Consultant led seizure clinic. New patient £251.67. Follow up £197.00.
- Nurse led seizure clinic. New patient £213.51. Follow up £135.12.

Note: With regards to the tariff vs costs question. In theory the tariff we get should equal all the costs. However, we know this isn't the case for many services. We are in the process of implementing PLICS (Patient Level Information Costing System) which given time will identify the true costs of a service which helps calculate the national tariff. We are not at the stage yet for it to give us any usable data. Paediatrics is one of the pilot areas for the system.

Cost if breaching. If this is a consultant led clinic, under the 18 week Referral to Treatment Time, we do have a sanction against this. However it is currently suspended whilst we're under the sustainability and transformation fund. The Referral To Treatment standard is set at 92%. If breaches increase to cause activity to drop below the standard, then we would be charged £300 for each and every patient that is below the 92%. For instance, if we have 100 patients and only 8 have breached, then we would not be charged. However, if 9 have breached, we would then be charged £300 for that patient, if 10 breached then we would be charged £600, and so on.

- Emergency department attendance £131-£234 depending on level of intervention required
- Children's ward admission £384
- Computer £700. Considered a set-up cost
- Land line telephone (no information available). No cost attributed to paediatrics. (Further info sought)
- Mobile phone Monthly cost including £3.75 contact = £22.69 - £52.88

Number of calls to service. 1207 incoming calls. 1876 text messages.

Costs obtained from national figures

- Attending GP £45
- Ambulance attending home and transferring to hospital £254.57

Appendix 3

Peer review of case study to demonstrate economic value of the Epilepsy Nurse Specialist

Epilepsy lead, Consultant Paediatrician's opinion

For the first three telephone contacts the Consultant felt that the family would contact his personal assistant with the concern. It is likely that it would take two to four days for the Consultant to contact the family so in the meantime they may have attended their GP or the Emergency Department.

For the fourth telephone contact the Consultant would have asked for an urgent outpatient appointment to be made. As this appointment would not happen on the day the concern presented he felt that the concern may escalate and the family may seek an opinion elsewhere. He also felt that these concerns would affect Leah's school attendance impacting on her social and educational inclusion. This would have an impact on Leah's emotion health and may exacerbate non epileptic events.

For the fifth telephone contact the Consultant felt the family would present at the Emergency Department.

The Consultant feels it would be unusual for him to spend more than five minutes managing a concern when he phones a family back. The Consultant reports his hourly rate is £55 so each five minute phone call would cost £4.60. This brief intervention would address the concern but is unlikely to include addition information about seizure management, first aid, night monitoring, emotional concerns, parental concerns and future planning and review. These additions that are part of the conversations with the Specialist Nurse illuminate the parents existing knowledge and provides further education or support which enables the family to feel more confident to continue caring for their daughter at home.

The consultant cannot be available to manage concerns at the time that they present. Our service's experience with many families is when the specialist nurse is not available they will contact several different people such as the personal assistant, the children's ward or pharmacy in an effort to get advice. It may not be appropriate for the people contacted to give advice or they may not have information available to them about the child to allow them to manage the concern. This results in several people trying to communicate to manage the concern. In this situation there is often confusion, an escalation of the concern and frustration and up-set for the child and family.

Personal assistant's opinion

The personal assistant works 24 hours per week. Her hourly rate is £23.38. In a usual week, 2 hours of her time is related to Epilepsy Nurse Specialist activity. This can increase to 5 hours per week and she reports she spends more time related to specialist nurse activity when the specialist nurse is not available. When the specialist nurse is not available telephone concerns more often

come to her. Taking this call and ensuring that appropriate action is taking impacts significantly on her time.

The personal assistant felt it was likely that the telephone contacts would come to her if I was not available.

For each contact she felt she would need to email the child's consultant with their concern. She would advise the family to wait for the consultant to get in touch with them. She felt that it was unlikely the consultant would be able to get back to them on the same day of contact.

She would advise the family to contact their GP or Emergency Department if they felt they needed an urgent response.

If she had not had a response from the consultant by the end of the working day she would email again.

In most cases she felt the consultant would email her to arrange a review on the ward or an outpatient appointment which she would arrange and then contact the family to let them know.

Peer review of telephone contact

The peer group felt that if the Epilepsy Nurse Specialist telephone contact had not been available the child and family would have presented to the Emergency Department on four occasions. From one of the contacts they felt she would have been admitted to the children's ward for assessment. For one contact the peer group felt that the family would contact the consultant's personal assistant to request consultant call back or an earlier outpatient review. This may not happen in a timely way so concerns could escalate.