

EVALUATION OF A NEW POST: THE WEST BERKSHIRE CLINICAL NURSE SPECIALIST FOR RARE NEUROLOGICAL CONDITIONS

Evaluation Summary

This specialist nursing post was funded by 4 Berkshire charities: the West Berkshire Neurological Alliance, the Motor Neurone Disease Association (Reading and West Berkshire), British Polio Fellowship (Berkshire branch) and Huntington's Disease Association (Reading branch).

It established a clinical nurse specialist (CNS) for neurodisabilities, based within the Royal Berkshire hospital NHS Foundation trust, to work with patients across the Berkshire West area who have rare, complex neurological conditions.

A multimethod evaluation of the post was undertaken by staff from the University of Reading.

Findings

The evaluation found that the post met the outcomes desired by the funders:

- It provided rapid and timely access to specialist knowledge and services
- Patients and carers reported greater satisfaction with health services
- Patients' length of stay in hospital was reduced.

Patients and carers were extremely positive about the post, indicating that the CNS helped meet national and local policy objectives, providing:

- A patient centred service, with patients offered information about their condition
- Rehabilitation, advice and support to meet continuing and changing needs
- Support for family and carers
- Care during admission to hospital or other health and social care settings, ensuring patients neurological needs are met when they are having care for any other reason
- Appropriate speed and flexibility of service delivery, within and across professional and agency boundaries

The post was highly cost-effective. Cost savings from the reduction in bed stay more than covered the cost of the post. Savings in 2006 (the year following the appointment of the CNS) were of the order of twice the cost of the post – ranging from 165% to 274% of the post costs, depending on method of calculation. This is likely to be an underestimate of the cost benefit, since it does not include any additional income to the hospital trust from freed capacity to increase the number of hospital admissions.

Patients and carers valued the post highly. The majority believed there was little improvement to be made to the service, beyond ensuring it was continued. In the words of a carer asked to choose something to improve the service:

she [CNS] is wonderful. She gives me so much support, which without I don't think I could cope. My wife (of over 50 years) only wish is to stay at home, and [CNS] gets us all the help we need. Her job is vital, she cannot be done without. FOR HER: more money, more help with her workload.

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Background

This specialist nursing post was funded by 4 Berkshire charities: the West Berkshire Neurological Alliance, the Motor Neurone Disease Association (Reading and West Berkshire), British Polio Fellowship (Berkshire branch) and Huntington's Disease Association (Reading branch). The post was funded for 2 years in the first instance, from October 2005. It established a clinical nurse specialist (CNS) post for neurodisabilities, based within the Royal Berkshire NHS Foundation trust, to work with those patients across the Berkshire West area who have rare complex neurological conditions. Although hospital based, the majority of the work was to be within the community. The project proposal is attached (Appendix 1).

The progressive, neurodegenerative diseases included were: Motor neurone disease, Huntington's disease, Myasthenia gravis, Multiple systems atrophy, Progressive supranuclear palsy, Post polio syndrome and Ataxia. Other patients who presented with complex neurological conditions would also be considered for the service in exceptional cases. Neurological conditions such as Parkinson's disease, Multiple sclerosis, Stroke, Epilepsy and Dementia were specifically excluded since there were separate services already available within the Trust.

It was anticipated that the nurse would have a caseload of up to 50 patients.

Evaluation of the post was also funded by the same 4 charities with the aim of identifying the impact of the post. It was also expected that, if the impact was positive, the evaluation would then provide evidence to support a case for the Royal Berkshire NHS Foundation Trust to continue funding the post.

Evaluation

A multi method evaluation of this post was undertaken by staff from the University of Reading.

The evaluation aimed

1. to document both the process and the outcomes of the postholder's work
2. to analyse the costs and benefits of the post

Outcomes investigated were drawn from the 'anticipated measures of success' in the *Project proposal* (Appendix 1):

- rapid access by patients and carers to specialist knowledge and services
- better quality of life for patients in the community setting
- reduction in hospital admission and length of stay

Outcomes known¹ to be important to people affected by neurological illness - both patients and carers – were also explored:

- time available

¹ Department of Health *National Service Framework for Long-term Conditions*

Motor Neurone Disease Association(2000) *Standards of Care*

Quinn, A (2006) *Evaluation of MS specialist post in West Berkshire* University of Reading;

- specialist expertise
- co-ordination of health and social care services

There were 2 stages to the evaluation:

1. Questionnaires sent to patients and carers who had contact with the Clinical Nurse Specialist
2. Analysis of service statistics

Stage 1: Questionnaires to Patients & Carers

In the first phase of the evaluation, questionnaires were sent to all 29 patients currently receiving a service from the Clinical Nurse Specialist, and to 9 patients who had minimal contact. 22 of the 29 current patients responded (a 76% response rate), and for of the 9 'minimal contact' patients (44%); the total response rate for patients was thus 68%. A breakdown of the CNS's caseload in December 2006 and February 2007 is attached (Appendix 2).

Patients were requested to pass a copy of the questionnaire onto their carer, if any.

Responses were received from 16 carers of current patients, plus 1 carer of a minimal contact patient. In addition, questionnaires were sent to 12 bereaved carers; responses were received from 9 (75%).

Questionnaire responses are detailed in Appendices 3 and 4, and questionnaires are attached (Appendices 6 and 7).

Findings from first evaluation phase

1. **Patients and carers who have contact with the Clinical Nurse Specialist are very positive about the post.** The high level of satisfaction was reflected in the agreement by all that the clinical nurse specialist made a real difference and should be available to everyone affected by a rare neurological illness. All patients and carers who responded to the questionnaires thought she had a good understanding of neurological illness. (*Appendix 3, Table 2 responses 1 and 5; Appendix 4, Table 3, responses 9 and 13*)
2. **Patients and carers are more satisfied with the health services provided now they have contact with the Clinical Nurse Specialist.** Most were satisfied with services previously (though individuals distinguished between satisfaction with the GP and neurology services, and less satisfaction with hospital services more generally). However, satisfaction was increased with involvement of the CNS. (*Appendix 3, Table 2 response 8; Appendix 4, Table 3 responses 15 and 16*)
3. **Patients receive and value a wide range of support from the Clinical Nurse Specialist.** 85% of respondents agreed that it gave them confidence knowing there was someone to call when they needed help. Regarded as most important was that the CNS responded quickly to requests for help, organised any necessary help, and provided a single point of contact for information and help. (*Appendix 3, Table 2 responses 3 and 4*)
4. **Carers similarly receive and value a wide range of support from the Clinical Nurse Specialist.** For carers, the most important elements were the confidence gained by knowing there was someone to call if needed, and the provision of a single point of contact (*Appendix 4, Table 3 response 12*)
5. **There is some confusion about carers' assessments.** Only a third of carers responded that they had received an assessment. The majority of carers said that they had not been offered a carers' assessment or were uncertain about this. Those

who had received an assessment tended to find it helpful. (*Appendix 4, Table 1 responses 18 and 19; Appendix 4, table 2*)

Stage 2: Analysis of service statistics

It was envisaged that the Clinical Nurse Specialist would have a caseload of 50. At the time of the first stage of the evaluation (December 2006) her overall case load was exactly 50: 38 current cases (9 with minimal contact), and 12 deceased cases. By the end of February 2007, overall case numbers had risen to 68.

As anticipated, the largest diagnostic group in her caseload was Motor neurone disease (37%) followed by Huntington's disease (26%) and Myasthenia gravis (16%). (*Appendix 2*)

Findings from second evaluation phase

1. **There was a decrease in the length of time patients with rare neurological conditions were treated as hospital inpatients in 2006, the year following the appointment of the Clinical Nurse Specialist.** Average length of hospital stay for patients with rare neurological conditions in 2005 (15.15 days) compared to 2006 (9.54 days) demonstrate a substantial decrease of 37% in 2006. This is substantially in excess of the reduction in average length of stay across all specialities for the same period (approximately 3%). (*Appendix 5, tables 2 and 5*)
2. **The decreased length of stay in 2006 represents a cost saving comfortably in excess of the cost of the CNS post.** Calculating the bed cost at £303 per day² the savings range from £62,418 to £103,689 – 165% to 274% of the cost of the CNS post (£37,840 for 2006).
 - a) **The decreased length of stay in 2006 represents a cost saving of £62,418 (comparing the number of inpatient bed days in 2006 with the number of bed days in 2005).** In 2006, 61 patients with rare neurological conditions were admitted for an average 9.54 days, totalling 582 days; in 2005, 52 patients were admitted for an average 15.15 days, totalling 788 days. The total reduction in bed days was thus 206. At a cost of £303 per bed per day, this represents a saving of £62,418, or 165% of the cost of the CNS post.
 - b) **The decreased length of stay in 2006 represents a cost saving of £103,689 (based on the reduction in bed days for patients in 2006).** If the 61 patients in 2006 had a hospital stay of 15.15 days (the 2005 bed stay average for patients with a rare neurological disorder) the cost at £303 per bed day would be £280,017. Instead, their stay was reduced to 9.54 days on average, resulting in a cost of £176,328. This represents a saving of £103,689 and equates to 274% of the cost of the CNS post.
3. **The number of admissions and readmissions for patients with rare neurological conditions were reduced in 2006 compared to 2005, when admissions for the primary diagnoses are considered.** The number of admissions with a primary diagnosis of a rare neurological condition halved between 2005 and 2006, reducing from 20 to 10. This reduction was primarily accounted for by reduced admissions for people with Motor neurone disease from 16 admissions in 2005 to 6 admissions in 2006 – a 69% reduction. Readmissions with a primary diagnosis of a rare neurological condition remained stable at 1 readmission in each of 2005 and 2006. (*Appendix 5, tables 1 and 3*)

² £303 is the cost day of a neuro-rehabilitation bed in 2006. While patients were admitted to a range of different wards, it represents a realistic figure acknowledging the difficulties in calculating an average figure for the bed cost to the hospital trust.

4. **There was a slight increase in the overall number of admissions and readmissions for patients with rare neurological conditions in 2006 compared to 2005, accounted for by an increase in the number of admissions for which a rare neurological condition was the secondary diagnosis.** The number of admissions overall increased from 52 to 61, an increase of 17%. Admissions for which the neurological condition was a secondary diagnosis increased from 32 to 51, an increase of 37%; this was predominantly accounted for by an increase in the number of admissions for which Myasthenia gravis was the secondary diagnosis, increasing from 9 in 2005 to 23 in 2006. There was an overall increase in re-admissions from 6 to 9, equivalent to an increase in re-admission rates from 11.5% to 14.8% between 2005 and 2006. This increase in re-admissions is entirely accounted for by secondary diagnoses. (*Appendix 5, tables 1 and 3*)
5. **There was little change in the numbers of admissions via casualty or to the local hospice between 2005 and 2006.** This probably reflects the very low numbers of patients with rare neurological conditions who attend either Accident and Emergency or Duchess of Kent House. It nevertheless indicates that the reduced length of stay has not led to admissions elsewhere within the health system.

Summary

The questionnaire feedback from patients and carers is extremely positive about the post. They indicate that the Clinical Nurse Specialist is helping to meet the requirements of the National Service Framework for long-term neurological conditions, the Motor Neurone Disease Association standards for care, and the outcomes and priority objectives of the Berkshire West Integrated Services Improvement Plan for long term conditions. In particular, the post helps provide

- A patient centred service, with patients offered information about their condition (*NSF quality requirement 1*)
- Rehabilitation, advice and support to meet continuing and changing needs (*NSF quality requirement 5*)
- Support for family and carers (*NSF quality requirement 10*)
- Care during admission to hospital or other health and social care settings, ensuring patients neurological needs are met when they are having care for any other reason (*NSF quality requirement 11*)
- Appropriate speed and flexibility of service delivery, within and across professional and agency boundaries (*MND Association standard 3c*)

The commitment of the particular post holder was frequently acknowledged. The following comment from a bereaved carer is echoed by other carers and patients, many of whom believe that the service could not be improved upon:

If I had a magic wand I would make another Carol Allen. You cannot improve the fantastic commitment she gave to our family. Could not have coped without her, she was our guardian angel. (BC7, Appendix 4, table 4)

Average length of hospital stay for patients with rare neurological illnesses fell in the year following the Clinical Nurse Specialist appointment (2006), compared to the year leading up to the appointment (2005). Comments from patients and carers suggest that the CNS's ability to negotiate with a range of health and social care services on behalf of patients could be the means of influencing the length of stay in hospital:

[She is] able to influence the timescale of things that need to happen. (C16, Appendix 4, table 4)

As well as contributing to increased quality of life for both patients and carers, reduced length of hospital stay has a financial benefit for the Royal Berkshire NHS Foundation Trust from cost savings. Hospital financial data demonstrate a high benefit to cost ratio of the Clinical Nurse Specialist post. The cost saving to the hospital trust from the reduced length of stay equate to approximately twice the cost of the post, ranging from 165% to 274% of the post's annual cost depending on the method of calculation. This is likely to be an underestimate, as it does not include any calculation of the additional income to the hospital trust obtained by freeing the capacity for an increased number of hospital admissions (with the national tariff system based predominantly on PCT payment by hospital 'spell' rather than per day). Additional benefits derive from the expedited discharge, enabling beds to be used more efficiently and appropriately.

Evidence from other NHS staff, including the Neurology and Neurorehabilitation Consultants indicates that input from the CNS has freed their time to offer further services to those with neurological conditions as well as providing an additional service to patients and carers.

The evaluation findings demonstrate that the post is highly valued by patients and carers, meets national and local policy objectives, and is cost-effective.

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APPENDIX 1: Project proposal

West Berkshire Neurological Alliance

Representing all West Berkshire people with a neurological condition.

Project proposal.

A Specialist Nurse for rare and complex neurological conditions for the West of Berkshire.

1. Name of the scheme. Specialist Nurse for rare and complex neurological conditions for patients in the West of Berkshire.

2. Purpose. To provide to best professional standards a community based (80%) and hospital based (20%) specialist nurse service for any person registered with a GP as a patient in the geographical area covered by the Primary Care Trusts of Newbury & Community, Reading and Wokingham, (known collectively as The West of Berkshire), for patients affected by any of the conditions listed below.

3. Neurological conditions to be covered. Ataxia, Huntington's Disease, Late Effects of Polio, Motor Neurone Disease, Multiple System Atrophy, Myasthenia Gravis, and Progressive Supranuclear Palsy. In exceptional cases where other patients present with a rare, complex neurological condition, such patients may also receive service.

4. Neurological conditions specifically excluded. As there are existing, separate services for such people, patients with the following neurological conditions are specifically excluded from this service: Alzheimer's Disease, Dementia, Epilepsy, Multiple Sclerosis, Parkinson's Disease, and Stroke, unless such patients also have one of the conditions listed in section 3 above.

5. General aims.

- * To inform, train and support patients with the conditions listed above in their own care.
- * To inform, train and support family and friends of such patients similarly.
- * To inform and train professional colleagues involved in the treatment and care of such patients.
- * To provide rapid, holistic, expert assessments, information and support.
- * To provide prompt, appropriate, well co-ordinated statutory services.
- * To stimulate the development of effective multi-disciplinary services for such patients.
- * To ensure patients are at the centre of their own treatment and destiny.
- * To improve the quality of health care services for such patients.
- * To strive for equitable access to statutory services for all such patients.
- * To expand the numbers of specialist neurology staff within the NHS.
- * To develop and evaluate the scheme as a possible model for wider dissemination.

The anticipated measures of success are that there should be more rapid access by patients and their carers to the specialist knowledge and services they need, leading to less stress and anxiety and greater levels of independence and self management. Patients should enjoy a better quality of life and be more fulfilled within their own community setting. The rate of infections, hospitalisations, and accidents should reduce. There should be faster discharge back into the community for those who become hospitalised.

6. Outline of the project. A new, full time post shall be created, a specialist nurse with training in neurology. The post shall be based at Battle or Royal Berkshire Hospital's (RBBH) Neuro-rehabilitation department under the clinical leadership of Dr Christine Collin or her successors.

Voluntary sector funding shall finance the post for two years, and pay for independent monitoring of the impact that it has, which is intended to provide the evidence that ongoing funding should be by the NHS.

Patients with a confirmed diagnosis of one of the listed conditions shall be able to self refer to the nurse, or be referred through GPs, Consultants or other clinicians.

It is envisaged that, once established, around 50 individuals may comprise the current patient portfolio, and these shall only come from patients listed above, unless a patient with some other rare/complex neurological condition presents and is in clinical need.

7. Who qualifies to receive service? Patients with a confirmed diagnosis as described in section 3 above, and either registered with a GP in the West of Berkshire or referred, diagnosed or managed by the Reading Neurology and Neuro-rehabilitation service, and who are likely to benefit from such a service.

If the service is over subscribed a process of prioritisation shall be established by the qualified professional staff connected with the scheme.

8. Standards. Service and support to patients will be holistic and to standards consistent with the National Service Framework for Long Term Conditions, and with the Motor Neurone Disease Association's published 'Standards of Care'.

Where appropriate, patients shall be offered referral to other NHS disciplines for assessments/treatments in a multi-disciplinary context.

9. Staff requirements. This is a single staff post appointment, and a pilot scheme. The size of patient population that can be given a beneficial service has been estimated. There is no budgetary provision for holiday, sickness or other absence. One aim of the project is to monitor activities, demand and impact (clinical and cost), to aid future service planning.

10. Staff appointment level. Grade H nurse.

11. Qualifications and training. Graduate. RGN, ENB 998/City & Guilds 730/SLICE. Post basic qualification in a relevant neurology speciality.

12. Outline job responsibilities. See Draft job description August 2004.

13. Hours of work. This is a full time position, expected to be 80% community based, 20% hospital based, requiring a flexible approach to working hours to suit the location and needs of patients.

14. Project oversight. A Steering Group shall have overall responsibility for the scheme. Membership shall be: Dr Christine Collin or her nominee, one substitutable representative from each main funding partner, the nominee of Royal Berks. & Battle Hospital Trust, and one user representative elected by users. Up to one other person may be co-opted by agreement. The members shall appoint a Chairman from amongst themselves, and may determine any matter in relation to this scheme by mutual agreement.

The Steering Group will have specific responsibility for ensuring that:

* The budget is agreed.

- * Funding partners comply with their funding commitments.
- * Funding partners are given evidence that the scheme is running efficiently and meeting its broad aims.
- * The service provider has an up to date service level agreement.
- * The service provider is generally in compliance with the service level agreement.
- * The service provider is paid for the service given.
- * All money provided by the scheme is spent only on the scheme.
- * The scheme is transferred smoothly into mainstream NHS funding at the end of its 2 year life, or brought to an orderly conclusion if this is not possible.

The Steering Group has the authority to increase or reduce the size of the scheme or to suspend or terminate it, being bound by any service contract that any post holder may properly have been given. This group may review any matter and determine any changes to the scheme which may be necessary while always maintaining the original aims.

At all times the need for the scheme to remain solvent and the needs of patients with the conditions covered by the scheme shall be held paramount. The Steering Group is free to appoint other Funding Partners if so desired.

3 weeks notice by any member by any medium shall be required to convene a Steering Group meeting. The quorum for voting is 4. Simple majority voting shall apply.

15. The Service Provider. RBBH is appointed as the provider of the service. It shall:

- * Provide office facilities, suitably equipped.
- * Recruit and retain staff suitably qualified to provide this service.
- * Ensure that staff understand the purposes of the scheme.
- * Provide appropriate training and peer group support.
- * Enable the scheme to function and develop.
- * Ensure that the service is used only by people who meet the eligibility criteria of neurological conditions and residence.
- * Monitor standards, including safety and confidentiality.
- * Produce regular reports on the effectiveness of the scheme.
- * Make recommendations as to how the scheme can be improved.
- * Keep within budget at all times.
- * Liaise with the Steering Group on any aspect as appropriate.
- * Ensure that the post holder is paid, and otherwise act as payroll facilitator.
- * Receive and disburse all money due for providing the service to those with a right to it.
- * Return any money incorrectly invoiced or sent or not properly spent on the scheme.

16. Appointing personnel. An open recruitment policy will apply. RBBH shall advertise for, interview and select staff. The Steering Group may nominate up to two representatives to be present and take part at any interviews. The recruitment budget must not be exceeded without the prior permission of the Steering Group.

17. Equipment. A minor equipment budget may be established once needs are clarified.

18. Insurance. The service provider, being a part of the NHS shall ensure and indemnify that NHS insurance covers the scheme in the same way as if the NHS was also funding the service. Nothing in this agreement makes the main funding parties responsible for uninsured matters arising from the provision of this service. The Steering Group may take out insurance with respect to default of any individual or party in respect to this scheme.

19. Publicising the project. Publicity shall be generated, to bring awareness of the scheme to all West of Berkshire GPs. Participating voluntary groups may publicise the scheme to their members as appropriate.

20. Confidentiality. Records of activity shall be kept in a way that assists the process of reviewing the success of the project. All user records shall be kept secure and confidential according to standard practice, and in compliance with the requirements of The Data Protection Act, as amended. Where records are analysed for statistical purposes any data which is published shall be in a format whereby it is not possible to identify any individual.

21. Patient management. Patients are free to accept or reject this service, and the reasons for rejection of it should be monitored.

22. Quality systems monitoring. The Line Manager shall make arrangements for a regular internal quality audit to ensure the scheme and its methods are operating as intended and that the recorded data is capable of withstanding statistical analysis if required.

23. Audit arrangements. (Subject to confirmation), Reading University shall be appointed to monitor the impact of the scheme in terms of clinical and cost benefit and patient satisfaction. They shall recommend how the scheme should be monitored, and the Steering Group shall determine the extent to which this is likely to satisfy budget holders who are the ones expected to adopt responsibility of the funding after the project budget is spent.

A multi-method evaluation shall include an audit of the baseline service, to measure the impact of the service on standards; an audit of the nurse's role and patient health and satisfaction.. The Post holder and lead managers shall be expected to participate in the evaluation programme.

24. Limits of the scheme. Nothing in this scheme shall prevent it or other schemes being developed if such may be expected to benefit other neurology patients.

25. Expectation. The main funding partners expect that the West of Berkshire PCTs or their successor organisation(s) will take responsibility for long term funding once the 2 year term has expired. Funding Partners expect to see a reference to this in the PCT's service and financial plans, in advance of the end of the pilot.

26. Finance agreement. The scheme has a provisional budget (See Appendix) of £90,106 spread over 2 years. Annual inflation is assumed at 3%.

The two main funding partners, (namely West Berkshire Neurological Alliance (WBNA) and Motor Neurone Disease Association, Reading and West Berkshire, (MNDARWB) are separately responsible for raising the funds that they have separately pledged to the scheme. Where third parties have made pledges to the main funding partners it is the responsibility of the main funding partners to call on those pledges such that funds shall be sufficiently in place to pay any invoices presented and due.

The two main funding partners agree to pay, against itemised invoices, on a quarterly basis an amount up to and not exceeding £5,625.00 each, only for items covered by the agreed budget headings, and actually spent on the service. WBNA agrees to make any additional payment in connection with any start up costs of the scheme, subject to the final value of all money being payable by them being not more than £45,106.00. MNDARWB shall not pay more than a total of £45,000. No invoice shall be settled by either funding partner for any item not agreed, or for any overspend in connection with the scheme for whatever reason unless specifically agreed in writing prior to such event.

RBBH shall present their invoices within 3 weeks of the end of each quarter and properly incurred costs of

the service shall be settled within 4 weeks of receipt of invoices. The first invoice date shall be three calendar months following the date that the post holder commences in post.

If non-qualifying people receive any service, such service is not part of this scheme and shall be at the cost of the Service Provider. If the scheme is terminated, or if for any other reason there is any surplus money or other assets these shall be retained by the Main Funding Partners in whatever proportion they shall mutually agree. If the Service Provider has incurred costs without authorisation or above those the Commissioning Group has committed in connection with this service, the Service Provider shall be liable to settle these costs without recourse to the Main Funding Partners.

27. Notice to quit period. Main Funding Partners have the right and obligation to give 4 months notice to withdraw funding from the scheme, if this is their intention.

The Service Provider agrees to provide the service for two years, subject to the availability of funding.

28. Main funding partners:

1. West Berkshire Neurological Alliance,
2, Clayhill Crescent,
Newbury,
Berkshire
RG14 2NP

Main contact: Mr John Holt, Secretary. Tel: 01635 33582

2. Motor Neurone Disease Association (Reading and West Berkshire)
51, St Peter's Avenue,
Caversham
RG4 7DL

Main contact: Margaret Moss, Chairman. Tel: 0118 947 0871

29. Acceptance of the agreement. I agree to the above and am authorised to sign on behalf of:

West Berkshire Neurological Alliance

Name Position

Signed Date

Motor Neurone Disease Association (Reading and West Berkshire)

Name Position

Signed Date

Royal Berks. & Battle Hospital Trust

Name Position

Signed Date

Neuro-rehabilitation Department, Reading

Name Position

Signed Date

APPENDIX 2

Table 1: CNS Caseload

December 2006		February 2007	
DIAGNOSIS	NO.	DIAGNOSIS	NO.
Motor neurone disease	15	Motor neurone disease	25
Huntington's disease	6	Huntington's disease	18
Myasthenia gravis	2	Myasthenia gravis	11
Progressive SN palsy	2	Multiple systems atrophy	6
Post polio syndrome	1	Progressive SN palsy	2
Ataxia	1	Post polio syndrome	1
Other	2	Ataxia	1
Subtotal	29	Other	5
Minimal contact		TOTAL	69
Motor neurone disease	3		
Myasthenia gravis	3		
Huntington's disease	2		
Multiple systems atrophy	1		
Subtotal	9		
Deceased			
Motor neurone disease	10		
Multiple systems atrophy	1		
Other	1		
Subtotal	12		
TOTAL	50		

APPENDIX 3
QUESTIONNAIRE FINDINGS, PEOPLE WITH A RARE NEUROLOGICAL ILLNESS

Table I: Patient and services information

	CURRENT CASELOAD <i>22 people</i>		MINIMAL CONTACT <i>4 people</i>		TOTAL <i>26 people</i>	
1. Age group						
18 – 40	2	9 %	1	25%	3	12%
41-64	9	41%	2	50%	11	42%
65+	11	50%	1	25%	12	46%
2. Living						
Alone	4	18%	3	75%	7	27%
Spouse/friend etc	18	82%	1	25%	19	73%
Paid carer	-		-		-	
3. Time since neurological diagnosis						
0-6 months	3	14%	1	25%	4	15%
7-12 months	7	32%	2	50%	9	35%
1-2 years	1	5%	-		1	4%
2 years+	11	50%	1-	25%	12	46%
4. Living in Berkshire West at diagnosis						
Yes	18	82%	4	100%	22	85%
No	3	14%	-		3	12%
<i>Nil response</i>	1	5%	-		1	4%
5. Information at diagnosis						
Yes	17	77%	4	100%	21	81%
No	5	23%	-		5	19%
			-			
6. Given contact at diagnosis						
Yes	19	86%	2	50%	21	81%
No	3	14%	2	50%	5	19%
7. Receive necessary help from health services						
Yes	18	82%	3	75%	21	81%
No	4	18%	-		4	15%
<i>Nil response</i>	-		1	25%	1	4%
8. Services received						
Help with physical symptoms	12	55%	-		12	46%
Help with PEG feeding	9	41%	-		9	35%
Help with CPAP machines	4	18%	-		4	15%
Physiotherapy	12	55%	-		12	46%
Occupational therapy	12	55%	1	25%	13	50%
Speech & language therapy	17	77%	2	50%	19	73%
Wheelchair clinic	11	50%	-		11	42%
Support, advice & information	18	82%	2	50%	20	77%
Social Services referral/ liaison	12	55%	-		12	46%
Charities referral/ liaison	12	55%	3	75%	15	58%
<i>Mean number of services received</i>	5.4		2		5	

Appendix 3, Table 2: Patient contact with Clinical Nurse Specialist (CNS)

	CURRENT CASELOAD 22 people		MINIMAL CONTACT 4 people		TOTAL 26 people	
1. CNS has good understanding of neurological illness						
Yes	22	100%	4	100%	26	100%
No	-		-		-	
2. Time since meeting CNS						
0 – 6 months	6	27%	1	25%	7	27%
7 – 12 months	11	50%	3	75%	14	54%
more than 12 months	5	23%	-		5	19%
3. The CNS						
Responded quickly	19	86%	2	50%	21	81%
Organised help	19	86%	-		19	73%
Provided single point of contact	16	73%	2	50%	18	69%
Helped manage illness	13	59%	-		13	50%
Helped keep independence	14	64%	-		14	54%
Gave information as needed	17	77%	2	50%	19	73%
Helped others understand	15	68%	-		15	58%
Helped with physical symptoms	15	68%	-		15	58%
Gave confidence	19	86%	3	75%	22	85%
Helped to improve quality of life	14	64%	-		14	54%
Linked with other services	14	64%	2	50%	16	62%
4. Most important						
Responded quickly	5	23%	1	25%	6	23%
Organised help	4	18%	-		4	15%
Provided single point of contact	3	14%	1	25%	4	15%
Helped keep independence	1	5%	-		1	4%
Helped others understand	2	9%	-		2	8%
Helped with physical symptoms	1	5%	-		1	4%
Gave confidence	2	9%	1	25%	3	12%
Helped to improve quality of life	1	5%	-		1	4%
Linked with other services	-		1	25%	1	4%
<i>Nil response</i>	3	14%	-		3	12%
5. CNS makes a real difference and should be available to all						
Strongly agree	19	86%	2	50%	21	81%
Agree	3	14%	2	50%	5	19%
Neither agree nor disagree	-		-		-	
Disagree	-		-		-	
Strongly disagree	-		-		-	
6. Previous contact with health service?						
Yes	18	82%	2	50%	20	77%
No	4	18%	2	50%	6	23%

Appendix 3, Table 2: Patient contact with Clinical Nurse Specialist (CNS) *continued*

	CURRENT CASELOAD <i>22 people</i>		MINIMAL CONTACT <i>4 people</i>		TOTAL <i>26 people</i>	
7. Happy with previous service?*						
Very satisfied	5	28%	-		5	25%
Satisfied	10	56%	2	100%	12	60%
Neither satisfied nor dissatisfied	3	17%	-		3	15%
Dissatisfied	-		-		-	
Very dissatisfied	-		-		-	
8. More satisfied with CNS?						
Yes	20	91%	3	75%	23	88%
No	1	5%	-		1	4%
<i>Nil response</i>	1	5%	1	25%	2	8%

* percentages are given as the percentage of those who had prior contact with health services (18 people from current caseload, 2 with minimal contact)

Table 3: chose 1 thing to improve CNS service

1. Current caseload

- find a cure *P1*
- can't actually think how the service could be improved but I think the hours are long so you're dependent on the postholder and how many extra hours she/he is prepared to put in - so maybe more postholders would be the answer, funded by NHS and available countrywide *P3*
- I want to keep my nurse as I'm lost without her *P4*
- provide a back up nurse to assist Carol *P6*
- increase the staff *P9*
- nothing *P10*
- no need to improve, she has got the job just right *P11*
- she is wonderful. She gives me so much support, which without I don't think I could cope. My wife (of over 50 years) only wish is to stay at home, and Carol gets us all the help we need. Her job is vital, she cannot be done without. FOR HER: more money, more help with her workload *P12*
- regular contact to ask how I am *P14*
- just having the knowledge that she can be contacted anytime with a query and sort it is good enough *P15*
- make me well again *P17*
- keep a good level of experienced staff with commensurate salary *P18*
- make sure that she will be a permanent fixture *P19*
- luckily my MND is comparatively slowly progressing and I am still largely independent so my needs for the nurse have been limited so far. However, from what I have seen her support role becomes more and more valuable as the disease progresses. My only other comment is that it should be funded by the NHS (rather than by volunteer fundraising) *P21*
- I would like to see more of Carol even though we have moved to Winchester *P22*

2. Minimal contact patients

- perhaps more time *MP3*

APPENDIX 4

QUESTIONNAIRE FINDINGS, CARERS OF PEOPLE WITH A RARE NEUROLOGICAL ILLNESS

Table 1: Carer and services information

	CURRENT CARERS <i>17 people</i> <i>(*includes 1 with minimal contact)</i>		BEREAVED CARERS <i>9 people</i>		TOTAL <i>26 people</i>	
9. Age group						
18 – 40	2	12%	-		2	8%
41-64	8*	47%	4	44%	12	46%
65+	7	41%	5	56%	12	46%
10. Living together						
Yes	16	94%	7	78%	23	88%
No	1	6 %	2	22%	3	12%
11. Proportion of time spent as carer						
Full time	8	47%	7	78%	15	58%
Half time	6*	35%	1	11%	7	27%
Less than half time	3	18%	1	11%	4	15%
12. Time since neurological diagnosis						
0-6 months	3	18%	1	11%	4	15%
7-12 months	5*	29%	1	11%	6	23%
1-2 years	3	18%	2	22%	5	19%
2 years+	6	35%	5	56%	11	42%
13. Living in Berkshire West at diagnosis						
Yes	13	76%	7	78%	20	77%
No	3*	18%	2	-22%	5	19%
Nil response	1	6%	-		1	4%
14. Information at diagnosis						
Yes	15	88%	4	44%	19	73%
No	1	6%	4	44%	5	19%
Nil response	1	6%	1	11%	2	8%
15. Given contact at diagnosis						
Yes	13*	76%	4	44%	17	65%
No	3	18%	4	44%	7	27%
Nil response	1	6%	1	11%	2	8%
16. Receive necessary help from health services						
Yes	14*	82%	6	67%	20	77%
No	3	18%	1	11%	4	15%
Nil response	-		2	22%	2	8%

Appendix 4, Table 1: Carer and services information ^{continued}

	CURRENT CARERS <i>17 people</i> <i>(*includes 1 with minimal contact)</i>		BEREAVED CARERS <i>9 people</i>		TOTAL <i>26 people</i>	
17. Services received						
Help with physical symptoms	7	41%	6	67%	13	50%
Help with PEG feeding	1	6%	6	67%	7	27%
Help with CPAP machines	6	35%	2	22%	8	31%
Physiotherapy	8	47%	6	67%	14	54%
Occupational therapy	9	53%	7	78%	16	62%
Speech & language therapy	11	65%	7	78%	18	69%
Wheelchair clinic	9	53%	7	78%	16	62%
Support, advice & information	12*	71%	7	78%	19	73%
Social Services referral/ liaison	10	59%	8	89%	18	69%
Charities referral/ liaison	13*	76%	6	67%	19	73%
<i>Mean number of services received</i>	<i>5.2</i>		<i>7</i>		<i>5.8</i>	
18. Received carers' assessment						
Yes	4	24%	4	44%	8	31%
No	7*	41%	3	33%	10	38%
<i>Nil response/ Don't know</i>	<i>6</i>	<i>35%</i>	<i>2</i>	<i>22%</i>	<i>8</i>	<i>31%</i>
19. Offered a carers' assessment**						
Yes	2	15%	-		2	11%
No	6*	46%	4	80%	10	56%
<i>Nil response</i>	<i>5</i>	<i>38%</i>	<i>1</i>	<i>20%</i>	<i>6</i>	<i>33%</i>

** percentages are given as the percentage of those who had not received a carers' assessment (13 carers from current caseload, 5 bereaved carers, 18 in total)

Table 2: Outcome of any carers' assessment by Social Services

Current carers:

Do not qualify *C10*

Had several, all well done & aids around home installed *C16*

Now getting carers allowance *C22*

A comprehensive care package to allow me to pursue other things. Funding to join gym. Basically, they were of the opinion that it was too great a responsibility for 1 person *C23*

Bereaved carers

Help to be provided with personal care and this was increased as his condition worsened.

BC3

Providing the patient with the necessary equipment such as special bed, wheelchair, hoist, home help, restbite (*sic: respite*) etc. This was followed by regular meetings. *BC4*

Allocated a social services care manager who organised equipment, respite care and other things necessary *BC6*

Not particularly useful - merely documented what was known already. Suggested doing things that were not realistic (eg give up work) *BC9*

Appendix 4, Table 3: Carer contact with Clinical Nurse Specialist (CNS)

	CURRENT CARERS 17 people (includes 1 with minimal contact)		BEREAVED CARERS 9 people		TOTAL 26 people	
9. CNS has good understanding of neurological illness						
Yes	15*	88%	9	100%	24	92%
No	-		-		-	
<i>Nil response</i>	2	12%			2	8%
10. Time since meeting CNS						
0 – 6 months	5	29%	4	44%	9	35%
7 – 12 months	10*	59%	4	44%	14	54%
more than 12 months	1	6%	1	11%	2	8%
<i>Nil response</i>	1.....	6%	-		1	4%
11. The CNS						
Responded quickly	13*	76%	8	89%	21	81%
Organised help	13*	76%	8	89%	21	81%
Provided single point of contact	11	65%	7	78%	18	69%
Helped cope with illness	12*	71%	8	89%	13	50%
Gave information as needed	11*	65%	8	89%	19	73%
Helped get home aids, adaptations	11	65%	8	89%	19	73%
Gave confidence	14*	82%	8	89%	22	85%
Helped to improve quality of life	5	29%	5	56%	10	38%
Linked with other services	8	47%	6	67%	14	54%
Introduced to other carers	6	35%	-		6	23%
12. Most important						
Responded quickly	2	12%	-		2	8%
Organised help	1	6%	-		1	4%
Provided single point of contact	4	24%	2	22%	6	23%
Helped cope with illness	1	6%	2	22%	3	12%
Gave information as needed	-		-		-	
Helped get home aids, adaptations	-		-		-	
Gave confidence	6*	35%	1	11%	7	27%
Helped to improve quality of life	-		-		-	
Linked with other services	-		4	44%	4	15%
Introduced to other carers	-		-		-	
<i>Nil response</i>	3	18%	-		3	12%
13. CNS makes a real difference and should be available to all						
Strongly agree	12	71%	8	89%	20	77%
Agree	5*	29%	1	11%	6	23%
Neither agree nor disagree	-		-		-	
Disagree	-		-		-	
Strongly disagree	-		-		-	
14. Previous contact with health service?						
Yes	13*	76%	9	100%	22	85%
No	4	24%	-		4	15%

Appendix 4, Table 3: Carer contact with Clinical Nurse Specialist (CNS) ^{continued}

	CURRENT CARERS <i>17 people (includes 1 with minimal contact)</i>		BEREAVED CARERS <i>9 people</i>		TOTAL <i>26 people</i>	
15. Happy with previous service?*						
Very satisfied	2	15%	2	22%	4	18%
Satisfied	8*	62%	2	22%	10	45%
Neither satisfied nor dissatisfied	2	15%	2	22%	4	18%
Dissatisfied	1	8%	1	11%	2	9%
Very dissatisfied	-		2	22%	2	9%
16. More satisfied with CNS?*						
Yes	13	100%	9	100%	22	100%
No	-		-		-	

** percentages are given as the percentage of those who had prior contact with health services (18 (13 carers from current caseload, 9 bereaved carers, 22 in total)

Table 4: chose 1 thing to improve CNS service

Current carers

- more support for her with specialist carers C1
- continuity of service C4
- being completely satisfied by the service provided by the Clinical Nurse Specialist I cannot think of anything C10
- scheduled visits to monitor situation & assess progress, check, resolve issues C13
- if time allowed it then regular home visits would be a good thing but we realize the workload doesn't allow for this so to keep in touch by email is of great help C15
- ensure the post is maintained on a long-term basis and is available for everybody who has neurological illness C16
- ensure that it is a permanent position C19
- I am really happy with the service that is provided C20
- now that we have moved to Hampshire I wish that the service was available here as Carol is invaluable and I always feel better after her visits C22
- make sure that she has adequate support. Better yet, I'd clone her to make sure that she was not overworked and always available C23

Bereaved carers

- to jump into the situation at the diagnosis time, to relieve the DN or community nurses of arranging carers agencies, a care manager, OT& respite. Maybe these are not the specialist jobs?! BC1
- At the point in time when the consultant neurologist determines the illness (in our case, Multiple Systems Atrophy) then the Clinical Nurse Specialist is brought in immediately BC2
- ensure that the appointment is made permanent and will continue BC3
- no magic wand please. This would only make what is already done superficial.

Appendix 4, Table 4: chose 1 thing to improve CNS service continued

Bereaved carers continued

Carol Allen has placed us on a firm foundation, proving she has arrived at a level where she is highly esteemed. Carol Allen has helped us in what is the real world, this special gift has its own special qualities in caring for people who need special help and doesn't need improvement.

BC4

make the services of a Clinical Nurse Specialist available to more people who need that kind of support. Note: The most difficult thing after the diagnosis was that my wife's GP did not understand the disease or what my wife was going through. And it was so important that the Clinical Nurse Specialist could give us the information and reassurance and help that we needed. *BC6*

If I had a magic wand I would make another Carol Allen. You cannot improve the fantastic commitment she gave to our family. Could not have coped without her, she was our guardian angel. *BC7*

that the role be higher profile and for all health professionals and local GPs to be aware of the role and to listen to advice given *BC8*

provide funding to allow: a) cover during periods of absence or unavailability of the Clinical Nurse Specialist to improve their work/life balance *BC9*

APPENDIX 5:Table 1: Admission statistics for patients with rare neurological illnesses

Code	Diagnosis	2005			2006		
		Prim	Sec	All	Prim	Sec	All
B91X	Sequela of poliomyelitis		3	3		4	4
G10X	Huntingtons disease	1	2	3		2	2
G111	Early-onset cerebellar ataxia			0		2	2
G114	Hereditary spastic paraplegia		1	1			0
G119	Hereditary ataxia, unspecified	1	4	5	1	1	2
G120	Infantile spinal muscular atrophy, type I -Werdnig-Hoffman		1	1			0
G122	Motor neuron disease	16	11	27	5	10	15
G129	Spinal muscular atrophy, unspecified			0		3	3
G700	Myasthenia gravis	2	9	11	4	23	27
G708	Other specified myoneural disorders		1	1			0
G709	Myoneural disorder, unspecified			0		1	1
G903	Multi-system degeneration			0		5	5
		20	32	52	10	51	61

Appendix 5, Table 2 Average Length of stay for patients with rare neurological illnesses

Code	Diagnosis	2005			2006		
		Prim	Sec	All	Prim	Sec	All
B91X	Sequela of poliomyelitis		11	11		15	15
G10X	Huntingtons disease	28	13	17.67		0.5	0.5
G111	Early-onset cerebellar ataxia					1.5	1.5
G114	Hereditary spastic paraplegia		4	4			
G119	Hereditary ataxia, unspecified	10	19	16.8		0	0
G120	Infantile spinal muscular atrophy, type I-[WerdnigHoffman		1	1			
G122	Motor neuron disease	17.25	6.3	12.78	12.4	7.6	9.2
G129	Spinal muscular atrophy, unspecified					11.67	11.67
G700	Myasthenia gravis	86	9.1	23.09	43.25	4.1	9.93
G708	Other specified myoneural disorders		14	14			
G709	Myoneural disorder, unspecified					7	7
G903	Multi-system degeneration					14	14
		24.3	9.4	15.15	23.5	6.8	9.54

Appendix 5, Table 3 Readmissions for patients with rare neurological illnesses

Code	Diagnosis	2005			2006		
		Prim	Sec	All	Prim	Sec	All
B91X	Sequelae of poliomyelitis		2	2			0
G10X	Huntingtons disease			0			0
G111	Early-onset cerebellar ataxia			0			0
G114	Hereditary spastic paraplegia			0			0
G119	Hereditary ataxia, unspecified			0			0
G120	Infantile spinal muscular atrophy, type I [Werdnig-Hoffman]			0			0
G122	Motor neuron disease	1	2	3	1	3	4
G129	Spinal muscular atrophy, unspecified			0		2	2
G700	Myasthenia gravis		1	1		1	1
G708	Other specified myoneural disorders			0			0
G709	Myoneural disorder, unspecified			0		1	1
G903	Multi-system degeneration			0		1	1
		1	5	6	1	8	9

Appendix 5, Table 4, Readmission Rates for patients with rare neurological illnesses

Code	Diagnosis	2005			2006		
		Prim	Sec	All	Prim	Sec	All
B91X	Sequelae of poliomyelitis		66.7%	66.7%			
G10X	Huntingtons disease						
G111	Early-onset cerebellar ataxia						
G114	Hereditary spastic paraplegia						
G119	Hereditary ataxia, unspecified						
G120	Infantile spinal muscular atrophy, type I [Werdnig-Hoffman]						
G122	Motor neuron disease	6.3%	18.2%	11.1%	20.0%	30.0%	26.7%
G129	Spinal muscular atrophy, unspecified					66.7%	66.7%
G700	Myasthenia gravis	0.0%	11.1%	9.1%	0.0%	4.3%	3.7%
G708	Other specified myoneural disorders						
G709	Myoneural disorder, unspecified					100.0%	100.0%
G903	Multi-system degeneration					20.0%	20.0%
		5.0%	15.6%	11.5%	10.0%	15.7%	14.8%

Appendix 5 Table 5

AVERAGE LENGTH OF STAY BY CALENDAR YEAR, ALL SPECIALITIES (EXCLUDING DAY CARE)

CalYear	Type	Number admitted	Total LoS	Average LoS	Average LoS	Reduction in LoS
2005	Emergency	41988	182942	4.357		
2005	Elective I/P	9982	43757	4.384		
2005 Total		51970	226699	4.362	4.362	
2006	Emergency	41757	178595	4.277		
2006	Elective I/P	10219	42088	4.119		
2006 Total		51976	220683	4.246	4.246	2.665%

**APPENDIX 6
QUESTIONNAIRE FOR PATIENTS**

Evaluation of the Clinical Nurse Specialist post
Questionnaire for people with a rare neurological illness

Please answer the questions by ticking the appropriate boxes

1. First, a few questions about you

Which age group are you? 18-40 41-64 65 or over

Please tell us who you live with:

I live alone
 I live with spouse/partner/family/friend
 I live with a paid live in carer

2. Questions about the time you were diagnosed with a neurological illness

How long ago were you diagnosed with a neurological illness?

0-6 months 7-12 months 1-2 years More than 2 years ago

Were you living in West Berkshire at this time?

Yes No

When you were diagnosed did you get the information you needed about your illness?

Yes No

When you were diagnosed were you told who to contact if you needed further help?

Yes No

3. Questions about health services in general

Do you believe that you have the help you need from the health services?

Yes No

Below is a list of some available help from health services. Please tick the services that you have received. Tick as many boxes as apply.

- Help with physical symptoms (such as breathlessness, fatigue or nausea etc.)
- Help with PEG feeding tubes (PEG = Percutaneous Endoscopically-guided Gastrostomy)
- Help with CPAP machines (CPAP = Continuous Positive Airway Pressure)
- Physiotherapy
- Occupational therapy
- Speech and Language therapy
- Wheelchair clinic
- Support, advice and information
- Referral to or liaison with Social Services
- Referral to or liaison with charitable organisations

4. Questions about the Clinical Nurse Specialist

Do you feel the Clinical Nurse Specialist has a good understanding of neurological illness?

- Yes No

How long is it since you first met the Clinical Nurse Specialist?

- 0-6 months 7-12 months More than 12 months

Please read the statement below and tick any that you agree with.

The Clinical Nurse Specialist:

- a) Responded quickly when I asked for help
- b) Helped to organise the help I needed
- c) Provided a single point of contact for information and help
- d) Helped me to manage my illness
- e) Helped me to keep as much independence as possible
- f) Gave me information about my neurological illness as and when I needed it
- g) Helped the professionals/family/friends who support me to understand my neurological illness
- h) Helped me with physical symptoms

- i) Gave me confidence knowing there was someone to call when I need help
- j) Helped me to improve my quality of life
- k) Referred to or linked me with other services/organisations

If you had to pick just one from the above list, which would you say has been most important to you.

Please give letter a – k.

Please read the following statement:

The Clinical Nurse Specialist makes a real difference and should be available to everyone affected by a rare neurological illness.

Please tick the box that most closely matches your response to this statement.

Strongly Agree	Agree	Neither Agree or Disagree	Disagree	Strongly Disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

5. Questions about Contact with Health Services

Did you have contact with health services in relation to your neurological illness before you met the Clinical Nurse Specialist?

Yes No

If YES, how happy were you with the services provided?

Please tick the appropriate box for you.

Very Satisfied	Satisfied	Neither Satisfied or Dissatisfied	Very Dissatisfied	Dissatisfied
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Are you more satisfied with the service provided now you have a Clinical Nurse Specialist?

Yes No

6. Final Question

If you could choose just one thing (imagine you have a magic wand) what would you do to improve the Clinical Nurse Specialist service?

To develop a better understanding of how the Clinical Nurse Specialist role improves the lives of people affected by rare neurological illness, we would like to interview some people.

Are you willing to be interviewed? Yes No

Interviews can be held in your own home or at an appropriate alternative venue. If you agree to be interviewed, we will contact you by telephone or email to arrange this. Could you please let us have your name, and telephone number or email address.

Thank you for taking the time to fill in this questionnaire.
Please return it to the research team, in the envelope provided.

**APPENDIX 7
QUESTIONNAIRE FOR CARERS**

Evaluation of the Clinical Nurse Specialist post

Questionnaire for informal carers of people with a rare neurological illness

(By informal carer we mean a relative, partner or friend who spends time supporting and helping a person who has a rare neurological illness)

1. First, a few questions about you

Which age group are you? 18-40 41-64 65 or over

Do you live with the person you care for? Yes No

What proportion of your time is spent as a carer for the person with neurological illness? Full time Half Time Less than Half Time

2. Questions about the time the person you care for was diagnosed with neurological illness

How long ago was he/she diagnosed with neurological illness?
 0-6 months 7-12 months 1-2 years More than 2 years ago

Were you involved with the person you care for at the time of diagnosis?
 Yes No

If NO please move onto question 3.

If YES:

At the time of diagnosis did you get the information you needed?
 Yes No

At the time of diagnosis were you told who to contact if you needed further help?
 Yes No

Was the person you care for living in West Berkshire at the time of diagnosis?
 Yes No

3. Carers' Assessments

Have you had a carers' assessment by Social Services?

If YES, what was the outcome of this assessment? Please comment.

If NO, have you been offered a carers' assessment by Social Services?

Yes

No

4. Questions about the health service

Do you believe that you and the person you care for have the help you need?

Yes

No

Below is a list of some available help from health services. Please tick the services that you or the person you care for have received. Tick as many boxes as apply. (The list is continued on page 3).

<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>

Help with physical symptoms (such as breathlessness, fatigue or nausea etc.)

Help with PEG feeding tubes (PEG = Percutaneous Endoscopically-guided Gastrostomy)

Help with CPAP machines (CPAP = Continuous Positive Airway Pressure)

Physiotherapy

Occupational therapy

Speech and Language therapy

Wheelchair clinic

Support, advice and information

Referral to or liaison with Social Services

Referral to or liaison with charitable organisations

5. Questions about the Clinical Nurse Specialist

Do you feel the Clinical Nurse Specialist has a good understanding of neurological illness?

Yes

No

Please read the statements below and tick any that you agree with.
The Clinical Nurse Specialist:

- a) Responded quickly when I asked for help
- b) Helped to organise the help I needed
- c) Provided a single point of contact for information and help
- d) Helped me to cope with and understand the illness and its symptoms
- e) Gave me information about neurological illness as and when I needed it
- f) Helped to get aids, equipment or adaptations for the home
- g) Gave me confidence knowing there was someone to call when I needed help
- h) Helped me to improve my quality of life
- i) Referred to or linked me with other services/organisations
- j) Introduced me to carers' groups/other carers

If you had to pick just one from the above list, which would you say has been most important to you?

Please give letter a – j.

Please read the following statement:

The Clinical Nurse Specialist makes a real difference and should be available to everyone affected by a rare neurological illness.

Please tick the box that most closely matches your response to this statement.

Strongly Agree	Agree	Neither Agree or Disagree	Disagree	Strongly Disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

5. Questions about contact with the health service

Did you have contact with health services before you met the Clinical Nurse Specialist?

Yes No

If yes, how happy were you with the services provided?
Please tick the appropriate box for you.

Neither Satisfied Very

Very Satisfied Satisfied or Dissatisfied Dissatisfied Dissatisfied

Are you more satisfied with the service provided now you have a Clinical Nurse Specialist?

Yes No

How long is it since you first met the Clinical Nurse Specialist?

0-6 months 7-12 months More than 12 months

6. Final Question

If you could choose just one thing (imagine you have a magic wand) what would you do to improve the Clinical Nurse Specialist service?

To develop a better understanding of how the Clinical Nurse Specialist role improves the lives of people affected by a rare neurological illness, we would like to interview some carers.

Are you willing to be interviewed? Yes No

Interviews can be held in your own home or at an appropriate alternative venue. If you agree to be interviewed, we will contact you by telephone or email to arrange this. Could you please let us have your name, and telephone number or email address.

Thank you for taking the time to fill in this questionnaire.
Please return it to the research team, in the envelope provided.