

West Berkshire Neurological Alliance

Representing people in Berkshire West affected by a neurological condition

Position statement. Recommendations to improve primary and secondary care health services in Berkshire West for people affected by a neurological condition.

September 2009

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1. Summary of main recommendations.

1. Ensure better access to timely and accurate diagnosis and treatment of neurological conditions.
2. Ensure better access to information and support for neurology patients.
3. Rebalance the local NHS workforce to include more neuro-specialists in a variety of roles and disciplines, linked to a unified care pathway.
4. Effectiveness of preventative activity should be audited at the individual level.
5. The audit and reward system that embraces neurology and allied services should ensure that neurology receives consistent attention from Commissioners and Directors of PCTs and Trusts.
6. The direction of change should be towards community-based services in preference to secondary care, wherever feasible.
7. Radical reform is needed of the systems and quality of care provided for neurology patients when in an acute setting.
8. An equitable approach is needed to NHS priority setting and funding overall.

2. About West Berkshire Neurological Alliance.

West Berkshire Neurological Alliance was formed in 1999. It is an association of local voluntary groups in the neurological sector, with some individual members with rare neurological conditions. Activities include information gathering, submission of evidence and justifications for change, developing and funding projects for neurological nursing, brain therapy and neuro-physical therapies, provision of neuro-education events and supporting the development of the local neurological voluntary sector.

3. Managing a neurological condition in the absence of a cure.

It is a priority for most neurology patients to find a cure, so in the absence of such cures most patients seek information to help them to manage and lead as normal a lifestyle as possible. Neurology patients often draw on a wide range of health and social care services. Frequently it is national charities that provide the most understandable and helpful information about living with a neurological condition.

4. Current deficiencies in services for neurology patients

Services for neurology patients are often variable in terms of access and quality. The process of diagnosis is variable, is often slow and is not always accurate. There are major gaps within specialist neuro-nursing, significant shortfalls in the capacity of neuro-physiotherapy and shortfalls in the speech & language service remit. There are gaps in both generalist and specialist pain management. A recurring concern is the lack of neuro-specific knowledge of some GPs. We receive reports from time to time of patients, in effect, being abandoned by GPs or Consultants at the time of diagnosis, with no information or support being offered to some patients. Neuro-rehabilitation services are established at only about two-thirds the recommended level.

We are aware locally of differential standards of funding within the region's wheelchair service, and inconsistent standards more locally within neuro-physiotherapy, hydrotherapy, continence advisory service, and occupational therapy

services. There are shortages in funding for neuro-physiotherapy, neuro speech & language, community neuro-rehabilitation, psychological support services, podiatry and neuro-specialist nursing. There are no local GPs with Special Interest in pain, headache or neurology. Services for people with MS and Parkinson's are relatively well developed locally, progress having been initiated mainly by the voluntary sector and Consultant physicians rather than by any co-ordinated process. Stroke services are improving due to Stroke recently becoming a national priority. Some who have other neurological conditions are envious of the services available for people with MS, Parkinson's and Stroke and aspire to receive a comparable level of service.

More could be done to keep neurology patients in good psychological condition by managing factors such as anxiety, depression, sleeplessness and self-esteem. More needs to be done to keep patients more mobile and to reduce accidents, falls, infections and pressure ulcers. Following hospital admission for an acute episode, often the poor in-hospital care of patients with an existing neurological condition can be in sharp contrast to the generally excellent attention given for the acute problem. Generically it is said that neurology patients occupy one in every five hospital beds and it is apparent that this ratio could be reduced locally.

Colleagues confirm similar patterns to the above in most Regional Health Authorities.

5. Some reasons for current deficiencies.

Neurology services, along with the other main services needed by neurology patients, are not priorities for NHS Boards of Directors. The Care Quality Commission knowingly has no system to assess neurology and allied services, the overall impact of which has been to take resources away from neurology and allied services.

The National Service Framework for Long Term Neurological Conditions is a document to which some NHS bodies have begun to aspire, but there is no strategy yet as to how this standard will be achieved in any PCT in our local Strategic Health Authority. This should change as Local Implementation Teams (LITs) begin to tackle the issues. Co-ordination at Strategic Health Authority level has not been successful.

The principal gaps in the preventative process arise from a lack of community based specialist neurology nurses, poor access to neuro-physiotherapy, almost total absence of access to psychological support talking therapies and a general lack of investment or specialisation in social care occupational therapy. However, there are exceptions and examples where local investment in such services has been effective. Major investment in NHS psychological services is expected by 2010.

Exacerbations of neurological conditions following acute hospitalisations occur regularly. It is unacceptable that some hospital Trusts have failed to tackle this problem effectively. The NHS is usually excellent at fixing medical crises, but has yet to establish ways of providing holistic care consistently in Secondary Care.

It is perverse that the NHS invests heavily in some other excellent services, to make them even better, while it invests only patchily in under-resourced neurology services.

6. National Service Framework for Long Term Neurological Conditions.

The NSF for Long Term Neurological Conditions (NSFLTNC) is the standard to meet, to ensure acceptable service outcomes for neurology patients. The NSFLTNC should be implemented before 2015. The Alliance is encouraging the NSF Local Implementation Team to accelerate its agenda, which is falling behind other localities.

7. Better access to information.

Any clinician asked for good quality information should ensure either that it is made available or be signposted. Where appropriate this should be in writing.

8. Existing workforce arrangements and service developments.

Locally there are four part-time Consultant Neurologists, each with a specialist interest, respectively in MS, movement disorders (Parkinson's), Epilepsy and Stroke. This is insufficient, evidenced by unacceptable waiting times and lack of follow-up capacity. The need for and justification for additional neurology nurse specialists is clear. The improvement that would arise through the appointment of a single care pathway that includes access to some GP Specialist posts is clear. Access to a skilled workforce should be at the centre of developments to implement the NSFLTNC.

Neurological Rehabilitation Services at the local Acute NHS Trust provide acute and intensive multi-disciplinary rehabilitation in 16 in-patient beds with some outpatient activity, serving a population of about 700,000. There are also five community neuro-rehabilitation beds. The number of staff in the Community Neuro-rehabilitation Team is insufficient and currently being increased. A much needed, new Talking Therapies service is being introduced on a rolling basis. Collectively these arrangements fall short of recommended levels and are insufficient overall to provide both a quality service and to meet current and growing demand.

9. Evidence base relating to impact of services.

There is considerable dissatisfaction about poor access to knowledgeable or specialist clinicians among patients and their carers. Evidence indicates particularly that the first need is to provide a thoughtfully structured and close to comprehensive Specialist Neurological Nurse team. Where impact studies exist, the evidence describes strong clinical and cost benefits in favour of specialist clinicians, of the order of 2:1 or 3:1.

A survey¹ in West Berkshire into how well clinicians understand how to help to manage a neurological condition indicated that specialist nurses are approximately twice as effective as other clinician groups.

Johnson et al² report improved satisfaction rates among MS patients and 3:1 return on cost, following the introduction of an MS Nurse Specialist post in Berkshire West.

Quinn³ reports better than 2:1 cost savings and improved satisfaction rates among patients with rare neurological conditions, following the introduction of a Rare Neurological Conditions Nurse Specialist in Berkshire West. Caseload excludes all

the common neurological conditions (Epilepsy, MS, Parkinson's, Stroke, Pain, Headache, Trauma, etc) and only includes such as Motor Neurone Disease, Huntington's, Myasthenia Gravis, Ataxia, Progressive Supranuclear Palsy, Multiple Systems Atrophy and Late effects of Polio.

Quinn⁴ reports similarly on improved cost savings and client satisfaction following the introduction of an MS Specialist Occupational Therapist post in West Berkshire.

A Berkshire West survey into MS and psychological impacts⁵, conducted in 2007, indicates that GPs are overly committed to prescribing relatively ineffective pharmacy for psychological problems and have little or no access to non-pharmacy alternatives. However 'grey quality' evidence indicates that psychological support therapists are highly clinically and cost effective, given suitable job descriptions and direction.

Whitaker et al⁶ have demonstrated the clinical and cost effectiveness of Dystonia Nurse Specialists treating such patients more cost effectively in the community rather than in a hospital environment.

Unpublished evidence about the clinical and cost effectiveness of Parkinson's and Epilepsy Nurse Specialist is consistent with the above.

The recommendations of the All Wales Physiotherapy Committee⁷ appear to be the most comprehensive on staffing levels suitable to provide physiotherapy services fit for purpose. However the recommendations refer mainly to staff/patient ratios rather than to staff/population ratios and costs are not considered.

The Association of British Neurologists⁸ recommends that the number of Consultant Neurologists should be 1:100,000 of population, based on clinical evidence only.

Recommendations of the British Society of Rehabilitation Medicine⁹ include a minimum of 6 WTE consultant specialists in rehabilitation medicine per million population including 3.6wte for district specialist inpatient rehabilitation services and their associated out-reach activities and 2.4wte for specialist community rehabilitation services. This would require three Rehabilitation Consultants for Berkshire West and 30 beds, some 50% greater than at present. Because the acute NHS Trust serves additional patients to those of Berkshire West PCT, commissioners should adjust numbers accordingly.

There is little other published cost effectiveness evidence for other disciplines.

10. Summary of recommended clinician to patient ratios.

The proportion of time spent by Neurology Nurse Specialists split between community and hospital activity will vary according to local need, but ideally would be mainly community based. The generally recommended ratios for **nurse specialists** to patient numbers are as follows:

Epilepsy Nurse Specialists. 1 Epilepsy Nurse Specialist per 100,000 population.
(Epilepsy Action)

Parkinson's Disease Nurse Specialists. 1 PD Nurse Specialist per 300 PD patients. (PD Society)

MS Nurse Specialists. 1 MS Nurse Specialist per 350 MS patients. (MS Society)

Dementia Nurse Specialists. 1 Admirals Nurse per 15,000 population over age 65. (Alzheimer's Society)

Dystonia Nurse or Therapy Specialists. 1 Dystonia Specialist per 300 with Dystonia. (Dystonia Society)

Rare Neurological Conditions Nurse Specialist. 1 Rare Neuro Conditions Nurse per 145,000 population, based on 50% community/50% in-hospital. (Quinn 2007)

Non-nursing recommendations include:

MS Specialist O/Ts. 1 MS O/T specialist per 145,000 population. (Located in Social Care.) (Quinn 2006)

Consultant Neurologists. 1 per 100,000 population. (ABN 2002)

GPs with Special Interest in Neurology, Pain or Headache. Recommendations on clinician/patient ratios have not been published, despite evident clinical success.

Neuro-rehabilitation Consultants. 6 per million (BSRM 2009)

11. The need for a workforce strategy and unified care pathway for neurology.

Replacing a generalist professional by a neuro-specialist will in general result in better quality care, a significant improvement in clinical outcomes, in particular lower hospitalisation rates and typically save around 2:1 or 3:1 on cost.

A good start point for workforce planning would be to establish an appropriately comprehensive structure of Neurological Nurse Specialist posts. This can be created and financed through a variety of means. It is estimated this alone would generate savings of approximately £5million pa in South Central Regional Health Authority. The appointment of at least one GpwSI would be a further appropriate development, all integral to the development of and ongoing adherence to a unified care pathway.

12. The need for better prevention.

Other than for some trauma injuries, the onset of a neurological condition is not in general preventable. However there are disease-modifying treatments available for several conditions including for MS, Parkinson's, Dystonia, Epilepsy and others. These should be provided in accordance with NICE Guidelines where these exist. 'Prevention' is a much-used word, but not enough preventative activity is yet in evidence, particularly as regards pressure sores, infections, falls and some other, preventable hospitalisations. Higher levels of prevention should be cost effective in reducing demand on secondary care services.

13. Acute hospitalisation.

Some neurology patients, particularly those with higher disability levels, identify that stays in hospital worsen their neurological condition and some express high levels of concern about their prospects there. Proper involvement of family carers, in the acute hospital setting, is sometimes sidelined, as can be the need to take long-term medications and other regular therapy. These matters should be given no less a priority than any treatment needed for short term/acute needs. Whereas many hospitals conduct detailed pre-admission checks, the necessary information about ongoing care needs does not always reach all ward staff. Resources on some wards sometimes are insufficient to look after patients with pre-existing conditions and lack of training of ward staff is evident in some cases.

14. Statutory funding.

There is major concern that the priorities set by the NHS tend to focus on expenditure to tackle self induced health problems caused by things such as smoking, poor diet, alcohol abuse, substance abuse and inappropriate sexual conduct rather than inherited or acquired health problems such as for the majority of neurological conditions. More effective public health activity is needed to deal with self-induced and avoidable health issues. This should then allow a transfer of NHS resources towards filling gaps in the services needed by those who develop ill health through natural causes.

15. In conclusion.

There is much to be done to achieve compliance with the NSFLTNC, locally and regionally. Services for neurology patients are variable in terms of access, timeliness, amount, funding and quality, from pre-diagnosis through to Palliative Care. There is a need for better access to information and support, a need for a more specialised and a generally better trained workforce and a need for a workable, effective and unified care pathway.

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