

MULTIDISCIPLINARY APPROACHES IN PROGRESSIVE NEUROLOGICAL DISEASE: CAN WE DO BETTER?

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Progressive neurological disease (PND) is an important cause of disability in the community and hence a focus for the forthcoming National Service Framework on long term conditions.¹ About 300 per 100 000 are affected by the two most common conditions in the group, multiple sclerosis (MS) and idiopathic Parkinson's disease (PD). PND produces complex patterns of physical and cognitive impairment.

We will first consider the needs of people with PND. How can rehabilitation concepts be applied to people with PND? What problems do they face? The second section will outline the resources relevant to neurological rehabilitation and we will conclude by considering how services should be integrated. Inevitably, the article will highlight shortcomings in current services. Can we do better?

MEETING THE NEEDS OF PEOPLE WITH PROGRESSIVE NEUROLOGICAL DISEASES

What do people with PND need? To understand the needs of any patient group we require a conceptual framework. Two questions arise. How can we use the term rehabilitation in PND? What should be expected from clinical neurologists?

Applying rehabilitation concepts in progressive disease

Two principles apply to all forms of rehabilitation (see Barnes on p iv3). Firstly, rehabilitation is an active process, distinguished both from spontaneous improvement in the patient (recuperation or convalescence) and from services supplied to the non-participating patient (care). Secondly, rehabilitation achieves change through person centred goals. Note that not everyone will desire change to the same extent, or in the same way. Professionals must be aware that most disabled people seek support and care without wishing for any form of rehabilitation, and many will have quite different aspirations from those conceived by their neurologist. With these principles in mind, we will now consider some of the special characteristics of rehabilitation in PND. Many characteristics are common to specific patient groups—for example, MS,² neuromuscular disorders,³ and PD.⁴

Disease management or self management

Far from being an optional add-on, the rehabilitation approach is fundamental to the management of progressive diseases. Treatment should always be relevant to the individual's practical goals. In line with modern thinking about healthcare the patient should, where possible, take the lead in drug and treatment decisions. However, individuals will differ in the extent to which they wish or are able to take on such responsibilities. One of the skills required in working with patients with PND is to enable them to have their desired degree of control over management decisions.

Recurrent programmes of rehabilitation

Rehabilitation in progressive disease is never "one-off". A person newly diagnosed with PD or MS may have goals concerning employment, driving, or financial planning. Later, multidisciplinary assessments and interventions may be required in response to emergent disabilities. The challenge in PND is to be helpful rather than intrusive.

Prevention as part of rehabilitation

Rehabilitation programmes aim to reduce risks of unwanted complications as well as to improve function in the short term. In PD, neurologists readily weigh the risk of future drug related complications against the functional benefits of starting levodopa treatment. In the same way, they must gear their advice to a whole range of other avoidable physical and social problems—for example, contractures or depression, unemployment, or carer ill-health.

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The intertwining of rehabilitation and care

Needs are constantly changing in PND, so that rehabilitation and care must be simultaneous rather than sequential. The rehabilitation approach entails repeated review of the way in which care is delivered. Do care systems maximise independence, or the reverse? Are care resources adequate to prevent complications? Equally, care providers must be actively engaged with rehabilitation goals so as to promote activity and participation.

Shifting the focus from impairment to the environment

The goal of drug treatment is to alleviate impairments. As the literature on physiotherapy in PD demonstrates, therapy interventions often have the same aim.⁵ However, campaigners for disability rights point out that impairment is not the sole source of disablement. They have shifted the focus from individuals to their environments: a classic example is the way steps restrict the lives of wheelchair users. Hence environmental factors have been incorporated into the World Health Organization's revised framework, the International Classification of Functioning, Disability and Health (ICF)⁶ (see Barnes, p iv3). We call diseases progressive when medical measures fail to control impairments. Environmental changes—and we include items of equipment in this category—can have striking benefits at all stages of disease. For the right person, a wheeled walking frame can improve mobility at least as dramatically as any drug. Clinicians must constantly watch for opportunities to advise on improvements to the physical or social environment; needs may arise either in the home or in the workplace.

Is rehabilitation compatible with neurological practice?

In neurology, symptoms and signs are primarily markers of pathology: monocular visual loss with pain suggests optic neuritis, perhaps multiple sclerosis; hemiplegia suggests a hemispheric lesion, perhaps a stroke; and so on. In rehabilitation medicine, the primary significance of symptoms and signs is functional. How will monocular blindness affect driving ability? How will hemiplegia affect independence in the toilet? Neurology classically asks two questions: "Where?" (what is the site of the lesion?); and "What?" (what is the pathological basis?). Rehabilitation entails a third question, "So what?". Determining "Where?" and "What?" may require only one or two clinical encounters lasting as little as 10 or 20 minutes. To ask "So what?" is to open a can of time consuming worms.

Outpatient neurology depends on a relationship between a doctor and a patient; by contrast, rehabilitation is less doctor centred. In helping people to manage a progressive disease, information must be shared between professionals and all must be aware of the limitations of any one point of view. Rehabilitation inevitably strays into non-medical domains, concerning itself with banalities such as garages and toilets which are not discussed in medical textbooks. This has discouraged many neurologists from what they see as a misuse of their specialised training.

Despite these differences of emphasis, the fact remains that most neurology is practised in the outpatient clinic, where chronic disease predominates. Whether or not they are trained or resourced to do so, neurologists must inevitably play a role in responding to the ever changing needs of patients and families. Many neurologists recognise this

responsibility even though substantial numbers do not. A survey in 1996 of 226 British neurologists showed that 49% had "attended case conferences which are multidisciplinary (that is, not solely involving nurses) and attended by a patient plus family" recently, but 18% had never done so. Over a fifth had "visit(ed) patients outside the hospital for rehabilitation assessment" at least occasionally, but nearly half had never done so. A minority of respondents regarded rehabilitation as irrelevant to general neurology, but most considered that it deserved more prominence among neurological services and lamented the lack of current resources.

Evidence on met and unmet need

Surveys of organisations such as the Parkinson's Disease Society provide useful information on needs. One consistent message is that people need information at the time of diagnosis and also subsequently. Doctors have key roles as patient educators, but must often be signposts rather than information providers themselves. In a survey of people with PND in Derbyshire we found that an average of 25% were ignorant of information sources for 10 topics, ranging from the medical condition to financial planning. General practitioners (GPs) and other professionals were equally unaware of information resources: many were unaware, for example, that the local employment service could advise disabled people about job retention as well as re-employment. The information sources most valued by patients over the course of their illnesses were not doctors but self help organisations.

A common complaint is the failure of GPs and consultants to refer to other services appropriately ("if only I'd known then what I know now..."). We acquired evidence on this point from a sample of 114 people with PND resident in Nottingham. During the previous 12 months over a quarter of the sample had urinary incontinence but only one person had had contact with a continence advisory nurse; half the sample had fallen but only one in seven reported contact with an occupational therapist. People reporting specific difficulties such as in rising from a chair had not been offered equipment which could have been helpful, and none of those scoring highest for risk of skin sores was using a pressure relieving mattress. A large majority of the sample had seen a GP, and 85% had seen a consultant in the previous 12 months, but without triggering appropriate referrals. Where referrals are made, the rationale is often poorly specified—for example, patients and their medical advisors often request physiotherapy without clear objectives.

RESOURCES FOR PEOPLE WITH PROGRESSIVE NEUROLOGICAL DISORDERS

The large array of services available for people with PND can be divided into: (1) specialist medical services (excluding neurology, which we have already discussed); (2) specialist non-medical services including information resources; and (3) generic services available at community level.

Specialist medical services Rehabilitation medicine

Consultants in rehabilitation medicine work within multidisciplinary teams to provide inpatient and outpatient services for people with complex and changing disabilities; their clientele is largely neurological although they also provide specialist services to other diagnostic groups. Rehabilitation medicine services are often appropriate in PND because of the complexity of physical and cognitive

impairments and also on account of the need to coordinate multidisciplinary interventions and to work between the hospital and the community.

Psychiatry

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Ongoing psychiatric advice is often useful for patients with PND. In some areas, the service for Huntington's disease (HD) is led by psychiatrists. In areas where there is no special interest in HD, general psychiatrists are called on in times of crisis but their neuropsychiatric expertise is necessarily limited. The same difficulties arise in other progressive conditions, and also in traumatic brain injury, where neuropsychiatric complications are common.

Community mental health teams (CMHTs) may be more or less integrated with consultant psychiatrists and can be accessed directly. Community psychiatric nurses can monitor and support people with disorders of mood or behaviour in their homes, as well as accessing specialist community facilities such as day centres.

Dementia is an important problem in PND. MS is the most common cause of progressive dementia in adults aged less than 65, and 20–30% of people with PD have dementia; cognitive failure is a feature of several less common progressive conditions, notably HD. Services for younger adults with dementia are poorly developed in the UK. Where they have developed, they are usually led by psychogeriatricians, who acquire extensive experience of the interplay between neurological disease and behaviour.

Clinical genetics

Genetic counsellors, who are often but not invariably nurse trained, work closely with consultants in clinical genetics. Having been involved with families at critical times such as during diagnosis, pre-symptomatic genetic testing or pregnancy, genetic counsellors develop close relationships which provide insights into wider issues. They cannot, however, remain indefinitely involved and require other services such as psychiatry, rehabilitation medicine, or neurology for onward referral.

Specialist non-medical resources

Diagnosis specific services

Specialist nurses are increasingly advocated for MS and PD, where the potential case loads are large enough to justify a service at district general hospital (DGH) level. It has been recognised recently that therapists or other health professionals may be alternatives to nurses. Typically, a specialist nurse will have a hospital base and will be in direct contact with individual patients and their families both in the clinic and at home. An important role is to educate other professionals, notably the primary care team. As they gain experience, specialist nurses become useful advisors on all aspects of the disease, including options for drug treatment.

The Huntington's Disease Association, the Motor Neurone Disease Association, and the Muscular Dystrophy Campaign all fund advisors who fulfil similar roles across larger catchment areas. These support workers sometimes come from professional backgrounds such as social work and hence have a somewhat different range of functions from specialist nurses. However, through working closely with health professionals they become well informed about such matters as enteral feeding and equipment.

Although outside the scope of this article, mention should be made of specialist traumatic brain injury teams, which

provide support for patients and families living in the community. The teams include therapists but some are led by non-medical case managers.

Neurology specific services

Alternatives to diagnosis specific nurses include specialist rehabilitation outreach nurses and social services or joint funded staff with special responsibilities for people with neurological disabilities.

There is increasing specialisation within the therapy professions. Neurological physiotherapy and neurological occupational therapy require a set of skills and a range of experience not shared by therapists who are either generic or have other specialisms such as musculoskeletal or respiratory disease. Within speech and language therapy, those who treat adults are increasingly subspecialising either in speech or in swallowing.

Other specialist services

Rehabilitation of people with chronic disease is supported by specialist teams such as those advising on continence, nutrition and enteral feeding, tissue viability, and pain. These are typically DGH based services led by specialist nurses who network with colleagues in the community.

Epilepsy nurses are usually hospital based and their remit in many ways parallels that of the MS and PD specialists, and may occasionally interact with them.

Some patients with non-malignant terminal conditions require input from palliative medicine consultants, while a larger number will benefit from less specialist nurse led palliative services which are accessed through primary health.

Information resources

There is no shortage of information resources. In our Derbyshire survey respondents identified 44 locally available information resources; admittedly, one of these was the window cleaner but there were no less than three specialist information providers in the locality. By far the most important sources were the national self help organisations, which provide literature, helplines, and internet services. Other important locally available sources of non-statutory information and advice include the Citizens Advice Bureau and disability organisations such as DIAL. Information on equipment is available from demonstration facilities such as disability living centres.

Generic community services

Space does not permit us to describe community services comprehensively, especially since there is considerable variation in local arrangements.

Primary health care services

The term "primary health care" now embraces GPs, practice nurses, the separately organised community nurses, and also podiatry (chiropody) and dentistry. In addition to hospital based services such as dietetics, physiotherapy, and occupational and speech therapy, a range of services provided by primary care or community trusts are often available to deliver treatment in the home setting. In PND, community physiotherapists are among those who often have sustained relationships with patients and can thus function as well informed key workers.

Local authority and other statutory services

Social services are the pivotal local authority agency, since assessments by occupational therapists and community care workers based in social services are the gateway to provision of a range of equipment for daily living, minor adaptations, and major home adaptations, although the latter are funded separately. Referral to social services can also trigger a review of benefits (although these are administered by a different government department, the Benefits Agency) and of domiciliary services, as well as an assessment of transport, respite, housing, and carer needs.

Social services care managers provide a system of ongoing review for severely disabled people with complex needs. They organise regular multidisciplinary reviews using a standardised format which should take account of health as well as social needs. Regrettably, no such system exists for people who have significant disabilities but who do not require the intensive level of social services support which triggers care management.

Several other local authority services are provided specifically for disabled people—for example housing, leisure services, education, and new supporting people schemes.

The two government agencies most often involved with disabled people are the Benefits Agency and the Employment Service, which have offices in each locality.

Equipment services

Equipment services are complex, although the forthcoming Integrated Community Equipment Services will unify provision of non-specialised equipment including communication aids, with a single point of access for patients and professionals. Wheelchairs remain a separate service, usually National Health Service (NHS) based, with a specialist component for people with complex needs. Electronic environmental controls are usually provided by a specialist, NHS based service. Each of the above equipment services is supported by specialist occupational therapists and by rehabilitation engineers, and specialist services also have support from rehabilitation medicine consultants. Specialised communication aids are often provided ad hoc, with special funding sought by speech and language therapists. Unfortunately not all appropriate items of equipment are funded by existing services. Additional needs can sometimes be met by charitable organisations.

Residential and respite care

Residential and respite care are an important but neglected component of services for people with PND. Many patients gravitate towards nursing homes at various stages of disease progression. Residential care often fails to meet the expectations of professionals and patients. People with PD are particularly troubled by a lack of understanding of specific problems such as fluctuations in mobility. Staff responses to the behavioural problems of patients with conditions such as HD may be ill informed and unhelpful. Many non-specialist homes claim to provide activities or even in-house therapy, but specialist therapy input is uncommon. Most such homes provide adequate nursing care and little more; medical supervision is provided by local GPs, with no special access to specialist advice. At the top end of the market, there are homes which command higher fees on the basis of a claim to be specialist. Often, this is little more than evidence of some degree of experience with particular types of resident such as those with HD or traumatic brain injury. Rehabilitation is

rarely provided, and there is no financial incentive to render residents more independent.

It is a sad reality that while people with PND often require a period of respite care either for themselves or to give a carer a rest, such care can have a negative effect on the person's independence. An alternative solution is the provision of additional care at home, particularly when a carer wishes to be absent for a period of respite.

CAN WE DO BETTER?

“Go it alone” rehabilitation

The neurology clinic often provides support during the early stages of disease, while other services “inherit” the patient with the advent of significant disabilities. Perhaps the greatest difficulty with this model is making the judgement regarding the timing of referrals. Detecting opportunities to benefit from rehabilitative interventions requires specialist experience and skill. In practice, many patients go through a clearly unsatisfactory three stage process, being discharged from the neurology clinic when no problems are perceived or anticipated, only to be referred back to neurology or to another service some time after a crisis has developed.

Neurologists who discharge outpatients with conditions such as MS may well imagine that “the community” houses a comprehensive system of health and social care, in which GPs and social services are rapidly alerted to the onset of new disabilities. This utopian vision is far from reality. Most GP services are reactive to patient complaints. District nurses are also largely reactive to specific problems. Nurses are only in a position to monitor chronic problems in the few patients who are receiving routine input for tasks such as bowel care. Despite the term “primary health care team”, many GP practices hold few if any multidisciplinary meetings.

Like health services, social services are principally reactive, often responding to individual referrals and then “closing the file” unless care management is in place. Care managers have a financial interest in being proactive, since avoidable complications such as falls and sores can increase the cost of care.

Occupational therapists can crucially enhance independence and quality of life but as we have seen, their services are dispersed between social services and a variety of NHS funded services. Other services are equally fragmented and usually without formal links between them.

Bearing in mind the complexity of services, we suggest that neurologists who wish to be involved in the rehabilitation and preventive management of disabled people should:

- ▶ educate patients so that they can recognise problems and potential problems when they arise
- ▶ point patients towards information about locally available services—local branches of self-help groups are best positioned to provide such information
- ▶ assume that their patients will not be monitored proactively, unless there is a specific plan in place
- ▶ assume that one service will not communicate with another, unless there is evidence to the contrary
- ▶ where appropriate, identify and communicate with a community based professional who is well linked with other services
- ▶ where appropriate, make use of specialist rehabilitation medicine services

However, equity, efficiency, and effectiveness would be enhanced by more systematic services, which we discuss in the next section.

Towards an integrated service Diagnosis led services

There are considerable attractions in developing services around specific diagnostic groups. This can work well for PD and MS, where a diagnosis specific clinic is served by specialist consultants and a specialist nurse provides a bridge with the community. Patients and patient led organisations usually support this model, which establishes a service with a clear mission and ethos. The team progressively acquires a high level of expertise and research, teaching, and fundraising are facilitated. The more specialised the team, however, the less easily it can be closely linked with the community, although outreach workers can provide such links and can continue to support patients who are too disabled to attend the clinic. These difficulties become more acute for less common conditions. Thus, the model works well for regional care and research centres funded by the Motor Neurone Disease Association, but seamless transition to community services is required when patients become more disabled. Another difficulty is that rarer conditions such as the progressive ataxias cannot easily be accommodated.

Neurological community services

Several centres have established successful multidisciplinary, community based teams in which much of the work concerns PND although, in order to achieve critical mass and to remain locality based, they are not diagnosis specific. If funds are available, one or more locally based neurological therapists can work effectively within such a team, referring to more specialist services as necessary. Such teams can facilitate inter-agency communication although they will typically be NHS funded. However, teams which do not have continuous access to medical expertise are seriously disadvantaged.

The approach we have taken in Derby is to work towards greater integration of existing services. The special features of our model, which is led by a neurologically orientated rehabilitation medicine service, include:

- ▶ outreach neurological therapy and nursing posts
- ▶ two social services funded specialist care manager posts for people with PND
- ▶ a rehabilitation communication group meeting regularly in each of the primary care trust areas, attended by social services staff, community therapists, rehabilitation medicine staff and others, to exchange information on clients with PND who have complex needs. These meetings help keep professionals up to date with available resources, provide a forum for service improvements, and encourage joint assessments and services.

In addition, there are plans for a specialist MS nurse and we already have a specialist PD nurse. Patients with motor neurone disease are transferred to the service from the nearby regional care and research centre with which we are

closely linked. There is also a service for HD run jointly by rehabilitation medicine and clinical genetics.

An unusual feature in Derby is the specific commitment of social services to people with PND. This has been facilitated by strong grass roots communication links between NHS neurological rehabilitation services and social services. Care management is exceptionally well developed in both Derby and Derbyshire. Specialist posts funded for PND by the two local authorities have demonstrated the ability of specialists who are not health professionals to make strong contributions to multidisciplinary rehabilitation processes. Another recent development in Derby is a local authority funded short stay and day care facility for people with PND.

Can we do better?

As we have indicated, people with PND can potentially benefit from a vast range of services. Under-funding is a problem, but the main difficulty they face is a lack of integration of services. In fact, people with motor neurone disease, and their carers, are sometimes overwhelmed by the plethora of services that beat paths to their door, but which frequently seem unaware of each other. Referrals and interventions will be more effective and more timely where health and social services are working together as a team. Clinical neurology is an important part of such a team, alongside other expertise. Platitudes apart, the prerequisite for doing better is to challenge traditional models of clinical practice.

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