

# HOUSE OF COMMONS HANSARD DEBATES FOR 6 March 2001

## Westminster Hall

### Neurology

10.59 am

**Mr. Paul Burstow (Sutton and Cheam):** I suspect that this is the first debate on neurology in the House for many years, and possibly ever. I have not double-checked that with the Library, but the House does not seem to have given much consideration to services provided to people with neurological conditions. On the day that I received notice from the Speaker's Office that I had secured the debate after several weeks of applications, I was delighted to hear that the Secretary of State for Health had declared the Government's intention to draw up a national service framework for long-term health conditions, with a special focus on neurological conditions.

Three million people in the United Kingdom suffer from neurological conditions--only heart disease and cancer affect more people--and one in five of all admissions to medical wards are accounted for by acute neurological cases. Despite those facts, neurology has been something of a Cinderella service in the national health service--in part because until recently little could be done beyond diagnosis and amelioration of symptoms. However, that is changing, so now is a good time to have a debate in this Chamber and to turn the spotlight on neurological services with the aim of raising them to the standard of the very best NHS services. We need to improve the standard of excellence in neurology across the whole country, so that everyone has access to good quality services on a level playing field.

Neurological conditions result from damage caused by illness or accident to the brain, spinal column or nerves. They have many causes, many of which are not yet known, and they affect young and old, rich and poor, men and women and people from all cultures and ethnicities. Some neurological conditions, such as epilepsy, are life-long and people can experience their onset at any time of life; some, such as cerebral palsy, are present from birth; some, such as muscular dystrophy, commonly appear in early childhood; and some, such as Alzheimer's disease and Parkinson's disease, affect mainly older people. Certain conditions have a sudden onset owing to accident or illness, such as head injury, stroke or cancers of the brain and spine.

Neurodegenerative conditions, such as multiple sclerosis and motor neurone disease, can affect people at any age and often cause a slow deterioration of a person's quality of life and ability to live independently.

Of those conditions, some can be life threatening, most severely affect people's quality of life and many cause long-term disability. Their impact often extends far beyond the individual concerned, because they have knock-on effects on family members and others who have a caring role. Caring for someone with a debilitating illness is often such an onerous task that carers have to give up their own employment. That, added to the inability of the person with the condition to continue to be economically active, can have a devastating impact on a family's quality of life, financial circumstances and long-term well-being.

Today's debate is not about the needs of carers, but we should bear in mind that they carry a massive burden, especially where neurological conditions are involved, and their role is often unstated, unrecognised and undervalued. It is important to say, however, that some of the Government's initiatives on carers' grants and respite care are making a difference to many of our constituents.

Neurological conditions are poorly understood. Public awareness is low, even of relatively common conditions such as epilepsy. Many rare conditions are largely unheard of and poorly

understood, even by non-specialist health professionals. That can lead to problems with the quality of initial diagnosis and the care pathways down which people are directed.

My interest in the topic has developed over the past three and a half years. It started with my constituency mailbag, through helping constituents who were battling to be prescribed beta interferon for their relapsing-remitting MS. I approach the debate from a Back Bencher's perspective, having been struck by the patchiness of the provision of services across the country. There are wide variations in access to services, not only for MS, but for the whole spectrum of neurological conditions.

That interest led me to undertake a survey of NHS trusts last year. I am grateful for the support given to me by the Neurological Alliance, especially Nicky Joules, and for the advice of the **Association of British Neurologists** in drafting the survey. Their support and advice ensured that the information gained was useful and could inform the debate about how neurological services might be better provided.

I found wide regional variations in access to neurological services--it is yet another postcode lottery. Two out of three patients wait for more than 13 weeks to see a neurologist and the average waiting time in non-urgent cases is 25 weeks. In 44 per cent. of hospitals, patients wait for as long as six months for an out-patient appointment; the worst waits to see a consultant neurologist lasted up to two years. My survey also found that six out of 10 hospitals could not offer a 24-hour response to a neurological emergency. Yet early diagnosis and treatment can make all the difference to a person's chances of recovery and a better quality of life.

The reason that access to services is so patchy is quite simple: there is a lack of capacity, with not enough neurologists to meet demand. I am sure that the Minister will acknowledge that a key bottleneck is the shortage of training places, which are needed to expand the work force and fill vacancies for neurologists throughout the country. My survey found that, on average across England and Wales, there is one neurologist for every 165,641 people. In Wales, the south-west, the north-west and the north-east, the number of neurologists is less than one per 200,000 people. Recently, a neurologist told me:

"If the UK was to have the same provision of neurologists for the population as the United State there would have to be 2,000 consultants; for the same provision as Europe (excluding the UK obviously) 1,000 would be required. In fact we have just over 200 (allowing for part time academic posts etc). Quite how this situation has been allowed to go on for decades is beyond me; we appear to be where the US and Europe were at the end of WW2. The shortage will take decades to correct."

It is hardly surprising that most patients' groups to which I spoke said that, if it does nothing else, the national service framework must address the serious shortage of neurological consultants.

**The Association of British Neurologists** and the Neurological Alliance recommend that the number of neurologists must rise to a minimum of between 600 and 700--roughly double the current number--if the service is to start to improve.

Access to specialists can make an enormous difference to how an individual copes with diagnosis, especially as the specialist can explain the progression of the condition and the options for treatment. That shortage, however, masks a deeper problem: the shortage of sub-specialists. There are only 60 consultants in the whole country who have specific expertise in Parkinson's disease, and fewer than 40 who specialise in treating MS. The rarer the condition, the scarcer the expertise. I wonder, for example, how many neurologists specialise in progressive supranuclear palsy.

In neurology, access to specialist centres is a key way to make effective use of NHS resources and give patients the chance to receive the best possible care. I hope that the national service framework will address that. The current out-of-area treatment scheme, OATS, is often an obstacle to appropriate treatment. Many trusts have suspended specialist procedures unless they are under contract or being paid for privately. Many patients who have been referred to

Some patients' home health authorities have offered to pay for operations, but trusts refuse to perform them because there is no mechanism for funds to be transferred to them. Occasionally, trusts agree to undertake an operation, but only after much correspondence and often when hon. Members and others have lobbied on the patient's behalf. Operations have been suspended not because of lack of funds, but because of bureaucracy. I hope that that problem can be resolved, because it has put services at risk, and they are being run down. Last April, the Department of Health announced a review of OATS. It will help if the Minister can shed some light on the timing of that review and the publication of its results, so that we can see what reforms are planned and what issues are to be addressed.

In anticipation of the national service framework, I should like to raise a few issues. First, the Department of Health has asked the Medical Research Council for trials to test the treatment of Parkinson's disease through deep brain stimulation therapy. Will the regional specialised commissioning groups have complete responsibility for commissioning specialised neurosurgery? Will that be governed or monitored nationally and will it be reflected in the national service framework in future? Is there a timetable for the trials and will they account for all deep brain stimulation therapy during the trial period? Will those who opt out of them still have access to deep brain stimulation therapy? People with Parkinson's disease and the Parkinson's Disease Society of the United Kingdom will appreciate clarity on those issues. Secondly, a few years ago, Scope conducted research into the effects of ageing on people with cerebral palsy and found that few sufferers visited their doctors for regular check-ups. The majority had not seen a consultant since leaving school and had not seen a physiotherapist for at least five years. General practitioners, physiotherapists, social workers and occupational therapists are often insufficiently familiar with cerebral palsy and, in short, many sufferers simply give up on treatment in the belief that they cannot be helped. That underlines the fact that the national service framework must address social and primary care as much as secondary and tertiary services. Primary care begins from the time of the initial referral and, alongside social services, has a long-term role after diagnosis.

The third issue relates to multiple sclerosis, which originally drew my attention to neurology. The Minister will know that new and emerging treatments can slow the progress of neurological conditions and may pave the way for even more effective treatments. For most people with multiple sclerosis, the national service framework offers the prospect of improved multi-disciplinary working and enforceable standards of service. However, it will not deliver the improvements that one group is looking for. It appears likely that the National Institute for Clinical Excellence will deny access to disease modifying drugs to all or most people with multiple sclerosis who would benefit. The national service framework holds out the promise of better services for such people once they are disabled, but does not offer the hope of a brake on the progression of their disease.

At 3 o'clock on the day before the Christmas holidays began last year, after most people had gone home to start celebrating, NICE smuggled out an announcement 10 days before its pre-programmed date for the release of the decision from its appraisal committee which effectively kicked into the long grass its decisions on beta interferon. We will not know now whether beta interferon and copaxon will be available on the NHS until July at the earliest, and a final resolution will probably not emerge until even later. That is not acceptable. I hope that the Minister will look closely at the conduct of NICE on that day in December and its behaviour in respect of assessment of treatments. It appears to have ignored the voice of the patients, who have not been allowed to come to the table and express an opinion.

Fourthly, the Minister will know of the value that patients and patients' groups place on access to specialist nurses. The MS Society and the Parkinson's Disease Society contribute to the funding of a growing network of specialist nurses. That network should force us to examine how such nurses are supported, trained and funded in the NHS. While it is welcome that charities make

contributions to the funding of such posts--in many cases, they fund them fully--in the long run, the NHS, in the context of neurology, must properly support the service.

The Department is addressing the recruitment and training of specialist nurses and considering how to ensure that commissioning bodies take such matters into account. Will the Minister say what progress has been made in the review of the consideration of specialist nurses? When is that review likely to be concluded? Will it be affected in any way--I hope that it will not--by the national service framework? Time is pressing and clarity is needed sooner rather than later. The national service framework, which will be published in 2005, is welcome, but too far in the future.

Fifthly, I have received strong representations from several groups in respect of pain management in the NHS, about which, as the Minister may recall, the House had a debate last year--although it was held late in the evening and was therefore almost as well attended as today's debate. The issue is important, but not often debated in the House. The point has been made to me forcefully that chronic pain should be included within the national service framework. Given the prevalence of chronic pain in the UK, it is surprising how poorly co-ordinated services remain. At best, a person can hope to be referred to a pain management course after a long wait; at worst, he can find himself being passed around the specialists and offered a range of different medications on a trial and error basis until something turns up that might alleviate the pain.

My final point relates to the prevalence of neurological conditions generally. I mentioned at the beginning of my contribution that 3 million people in this country suffer from neurological conditions, but the truth is that we do not know precisely how many there are, because no method exists for recording the diagnosis of neurological conditions. There is no disease register or systematic means of capturing such information, even though that information would be invaluable to effective research and deepening our understanding of such conditions, and must be central to effective commissioning of services at a local level. As a starting point, the national service framework must include better recording of prevalence in the population, so that we can allocate resources appropriate to need.

Patients' groups have an important role to play in the development of all national service frameworks, not least in the context of the national service framework for long-term conditions. Umbrella organisations play a key role in that work by bringing together the disparate interests that a national service framework often covers. I suspect that that will be the case when the Government and the Department begin their detailed work on the national service framework. The Secretary of State has given a welcome indication of willingness to provide extra support for umbrella organisations, to facilitate their task of engaging in robust and real dialogue with Government, but it would be useful to know whether the Department and Secretary of State would be minded to provide additional resources to facilitate the involvement of non-governmental organisations in the preparation of national service frameworks. That would be helpful to the Neurological Alliance and other NGOs with interests in other national service frameworks.

As the national service framework under discussion is likely to cut across already existing national service frameworks--especially those covering older people--it will be important to have cross-sector interests represented in the process to deal with those concerns. We must make sure that there are no gaps between the various national service frameworks. It will be interesting to hear how the Government will ensure that such gaps are not created.

I understand that the national service framework is unlikely to be published until 2004, and that it is intended that it will be implemented from 2005. It is essential that the Government's commitment to producing that national service framework in no way derails existing work that will benefit people with neurological conditions. I shall cite three examples. First, in a debate a couple of years ago, the Minister of State, the hon. Member for Barrow and Furness (Mr.

groups on the commissioning of neurological services. Publication of that compendium is a year overdue; when will it be published? It will be an invaluable aid to primary care trusts and others who have a responsibility for commissioning, and the sooner it is being used, the better. Secondly, the National Institute for Clinical Excellence is to begin work on clinical management guidelines for MS for publication in 2002. I have made some representations about the pace at which NICE intends to proceed. Given the range that must be covered, it is important that its work is not lost within the work on the national service framework. Thirdly, I have referred to the Department considering specialist nurses in neurology; it will be useful if the Minister can say when that work will be promulgated.

The national service framework and the other work that is in train within the Department are welcome. I introduced today's debate because the findings from surveys show that we have a long way to travel to reach the standard of service that the Government and all hon. Members want for people with neurological conditions. We need a people-centred approach that develops services around individuals and builds on the ideas in the national health service plan. We must ensure that an appropriate multi-disciplinary range of services follow people throughout their lives, and that services are at all times tailored to be appropriate to their needs and those of their carers.

#### **11.21 am**

**Dr. Peter Brand (Isle of Wight):** I congratulate my hon. Friend the Member for Sutton and Cheam (Mr. Burstow) not only on securing the debate, but on setting out the reasons behind it so clearly and excellently. I am disappointed that there has not been an enormous Back-Bench contribution to the debate, but his speech makes up for that.

**Mr. Desmond Swayne (New Forest, West):** It is quality that counts.

**Dr. Brand :** It is.

My hon. Friend has made many valuable points, but I shall concentrate on a few. The national service framework is welcome, but I hope that it is not an alibi for not proceeding with the planning and thinking surrounding the diagnosis and treatment of neurological conditions. Over the past few years, the world of neurology has moved on tremendously. Some 30 years ago, when I trained, cerebral doctors who seldom handled patients considered it to be an intellectual exercise. That was probably appropriate because there was little that they could do.

Neurologists tend to be people who wear extremely expensive suits and silk ties and spend much of their time in Harley street. In fact, the man who taught me the Babinsky reflex, which is the awful test where doctors tickle the sole of a person's foot to see which way the toe goes, said that the only implement that should be used to carry out such a test satisfactorily was a Bentley key. Since then, I have never aspired to neurology, or to a Bentley, given that I did not think that owning such a key was appropriate.

My hon. Friend was right to point out that neurology covers a wide range of diagnoses. Neurological illness can result from catastrophic events, accidents, intercranial bleeds, nerve injuries during accidents and conditions that are either contracted in utero or around birth, such as cerebral palsy. Indeed, some conditions that appear in the first six to 12 months after birth are difficult to distinguish from the effects of immunisations going wrong. Many neurological diseases are neurodegenerative diseases, such as Parkinson's disease, MS, motor neurone disease and the big condition of Alzheimer's, which is not a uniform disease and requires diagnosis. It is important to recognise that, although much more can now be done about neurological conditions, it is no good taking a scatter-gun approach to treatment. A precise diagnosis is required. In that sense, we have progressed tremendously over the past 10 to 20 years. It is no longer acceptable for a condition such as epilepsy to be treated by taking the approach that might be taken in cookery: trial and error, starting with a dollop of phenobarbitone, going on to a

has a significant place, but only an appropriately skilled neurophysician can establish which patients are suitable for treatment and the form that that treatment should take.

My hon. Friend is right to point out that we are woefully short of capacity in diagnosis and treatment. Liberal Democrat Members have highlighted not only neurologists but the role of nurse practitioners. I commend to the Minister the role of nurse practitioners, who should be funded more meaningfully. One of our practice nurses trained as a nurse practitioner in epilepsy services, but it is difficult to secure meaningful funding for her, so that she may use the expertise that she has acquired.

Much of the work that nurse practitioners might do can also be done by nurse assistants under supervision. I shall return to that matter when I deal with the long-term care proposals that are being considered in another place.

In addition to nurse practitioners, in providing treatment, we desperately need more speech therapists. Many neurological conditions have as sequelae significant communication problems. Speech therapy has moved a long way in targeting treatment for particular conditions. It now involves not only speech therapy in the traditional sense but access to modern communication aids. A lot of electronic equipment can now be extraordinarily helpful to people with degenerative neurological diseases, but it remains hard to get hold of. When I first became involved in the matter, we had regional funds for environmental aids. That budget has now been dispersed, and in dispersal seems to have been virtually lost. I am sure that all hon. Members encounter cases in which people are denied what should be standard equipment to help with communication.

In addition to speech therapists, it is important to have access to psychologists who understand degenerative neurological conditions. Some conditions can be difficult to diagnose, especially degenerative brain diseases such as Alzheimer's or Korsakov's encephalopathy. The different causes of the disease are not always clear except through expert assessment such as neuropsychology.

Once a diagnosis has been made, patients should have access to a physiotherapist with a special interest in neurology, which is especially important for children suffering from cerebral palsy. It is not good enough for a small child to be assessed once and to be referred again only three years later. Much of a physiotherapist's work could be carried out by physiotherapist assistants or other carers, but expert supervision is required to check that the correct treatment is given.

I am enormously concerned about the Government's definition of what treatment is allowable under the new long-term care regulations. The Government do not recognise how the world has moved on. Care is now delivered through therapeutic teams. They may be headed by a registered nurse, but much of the work may be carried out by another health professional. It is ridiculous that only time spent by the registered nurse qualifies for funding through the national health service, not work carried out by care assistants, whether with children or with those at the other end of the age spectrum. I hope that the Government will think again about their definition because it makes no intellectual or practical sense.

We have not yet mentioned the great strides forward in diagnostic imaging. In the past, my neurological colleague with his sharp suit and Bentley key was required to perform all sorts of magic--there was also a test involving gold coins but I have forgotten what it was. We can now be somewhat more scientific and specific by using appropriate scanning techniques. However, we still rely too heavily on charities and voluntary organisations to equip communities and district general hospitals with the necessary imaging equipment. Throughout the country, many scanners that were bought with funds raised through an extraordinary amount of hard voluntary work are coming to the end of their useful lives.

I hope that the Government will conduct an audit of available equipment to determine whether it is available in the strategic places in which it is required. Access to good scanning equipment is just as important as access to good cancer services or cardiology; indeed, scanning equipment is

necessary for those services. There is no evidence at present of a sensible national or even regional framework for ensuring that such facilities are available.

I present a good example of how things have moved forward. There used to be a rare treatment for a strange condition called torticollis that gave one a wry neck. What I am now doing is difficult for the *Hansard* writers to report, but the condition gives one an uncontrollable twitch. It is treatable through injections of botulism. It is amazing that that treatment is carried out predominantly in the private sector for cosmetic reasons--to get rid of wrinkles--yet in the national health service, there is an enormous waiting list for operations for genuinely distressing conditions.

I hope that the Minister will consider what is available and what can be done within the national health service framework. We should ensure that people who rely on the national health service for treatment of real conditions have priority over those who simply opt for "botulism-injection tea parties", as I recently saw them described, attended for three months by middle-aged ladies who want to have their wrinkles controlled. Personally, I like wrinkles, as they suggest a degree of experience.

The abolition of extra-contractual referrals has had a dramatic effect. In the past, money would follow the patient and specialist centres would vie for that patient. The mechanism ensured that patients were referred and accepted. The out-of-area treatment scheme, which replaced ECRs, does not do the same job. Payments are often delayed. One may have to guess how many rare conditions are likely to occur in one's district and place a contract that may be unnecessary. When some years ago I challenged the Secretary of State on the effect of the introduction of the OATS arrangements, he assured me that doctors could still refer patients anywhere within the United Kingdom. Doctors can do that, of course, but the hospital to which a patient is referred is under no obligation to accept the referral. Hospitals are increasingly turning down patients because they are not sure that they will be funded for the work.

A process such as neurosurgery for epilepsy, for example, is complicated and expensive. The diagnosis must be firm, the lesion causing the epilepsy must be identified through specialist techniques and the patient must be prepared psychologically for such a dramatic operation. On the other hand, the results of such surgery can be dramatically good. Patients may be able to come off a complex drug regime and begin to function anew--they may, in a sense, wake up. Those operations are worth while, therefore, but the few centres that perform them are working to capacity and unwilling to expand and to increase their work load, owing to the uncertainty over funding.

I pay tribute to carers and patients themselves. Doctors, like all other health professionals, are good at networking and learning about conditions in which they have an interest. That is positive and useful, but it is high time that patients and carers do more networking, so that they become aware of the treatment available and adjust their expectations. Patients with neurological conditions have for too long accepted that they are suffering from a Cinderella condition and that they cannot do much about it, apart from swallowing a few tablets. Much can be done, however, and through patient education and empowerment we can hope for a change in the present position, which is very much top down. Patients may begin to make reasonable and achievable demands, which are currently held back because of the restraint on resources.

**11.39 am**

**Mr. Desmond Swayne (New Forest, West):** It is always a privilege to speak after my neighbour across the western Solent, the hon. Member for Isle of Wight (Dr. Brand), who brings his professional expertise, wisdom and plain common sense to debates.

I congratulate the hon. Member for Sutton and Cheam (Mr. Burstow) on securing this timely and important debate, which has produced speeches of high quality. I congratulate him, too, on the

achievement for an ordinary Back Bencher, who does not enjoy a great deal of administrative support, to provide such a high quality document, backed up by a significant amount of research. I am glad that the debate so far has concentrated not only on neurologists, because the matter goes beyond their numbers. The hon. Members for Isle of Wight and for Sutton and Cheam referred at length to the failure of the out-of-area treatment system. That system is log-jammed, so an increase in neurologists alone will not necessarily address the problem. The OAT arrangements deserve attention.

The hon. Member for Isle of Wight drew attention to speech therapists, thereby raising the question of rehabilitation in general and of strokes and similar conditions in particular. If patient outcomes are to improve, such specialist provision must be made. All the evidence suggests that establishing specific rehabilitation centres and facilities are the best way in which to achieve that. As for the provision of drug treatments, I share the concern that was expressed by the hon. Member for Sutton and Cheam with respect to beta interferon. I entirely agree with his analysis of the history and the behaviour of the National Institute for Clinical Excellence. It is 19 months to the day since NICE was asked to investigate and appraise the situation as regards beta interferon. On 6 February, at Health Questions, we were told that guidance was expected from NICE in November; by that date, it will be 26 months since the matter was referred to the organisation. In the announcement that foreshadowed the creation of NICE, we were told that it would provide a mechanism by which the arrival of new drugs in the health service could be speeded up. In that role, however, the body has not covered itself in glory.

We are told that more economic modelling is required by NICE. I am not against that, in principle; one of the things that we do badly in this country is clinical appraisal, which should be accompanied by economic modelling. Many clinicians agree with that. They sometimes take a cynical view of the media-to-market approach--as they term it--of some pharmaceutical companies, and would like there to be a much more robust means of testing and appraising the value of drugs. However, I question whether, when the process has already been going on for so long, we should consider yet more evidence for beta interferon, given that it is no longer a new drug. Prescribing habits in the United States and in continental Europe are much wider than they are here. It is legitimate to ask how many patients who would have benefited from beta interferon have lost their window of opportunity as a result of the delays.

**Dr. Brand :** Is it not essential that, when a decision is made about making a drug available, the economic modelling should include the effects outside the national health service, for instance on benefits and the provision of social services? Would the hon. Gentleman not agree that that economic modelling should be done by the Government collectively rather than by NICE?

**Mr. Barry Jones (in the Chair ):** Order. Both hon. Gentlemen are on the edge of being out of order on this issue.

**Mr. Swayne :** There is much force in what the hon. Member for Isle of Wight says.

To return to the subject of neurological conditions, will the Minister answer the question posed by my hon. Friend the Member for Buckingham (Mr. Bercow) on 6 February, which the Minister of State, the hon. Member for Southampton, Itchen (Mr. Denham), failed to answer--why is copaxone being treated as an interferon when it is chemically and pharmacologically different? It has been tested for eight years and has reduced relapses by 70 per cent. In addition, what stage has been reached with respect to treatments for Alzheimer's disease, especially donepezil and rivastigmine. When will we know the outcome of an expensive trial that has been conducted in the west midlands with respect to donepezil?

I shall not dwell on Conservative policy in respect of NICE for fear of you bringing me sharply to order, Mr. Jones. However, we want a radically different approach to the problem. We want an exceptional medicines fund, with prescribing criteria laid down by a committee serving that fund. We want to remove from NICE's responsibility consideration of what we would regard as

political matter, and a Minister should decide what is available for the exceptional medicines fund.

I come now to another issue raised by the hon. Member for Sutton and Cheam concerning the provision of specialist nursing, and I want to illustrate a point that he made. Currently, one of the log-jams in the system is a significant shortage of specialist nurses. I have in my possession a letter from Mr. Palmer, the consultant neurosurgeon at Derriford hospital, dated 17 November. In the letter, he warns his colleagues about the effects of having to devote time and resources to train overseas nurses to fill the vacancies. He stresses that

"All elective admissions have been cancelled until probably at least February." He wrote that in November. The letter continues:

"The neurosurgical unit can no longer provide a secondary referral service for Derriford Hospital. We will not accept direct emergency admissions from GP practices or receive referrals from the Accident and Emergency staff directly. Only tertiary referrals will be accepted i.e. from an admitting consultant team. We will provide 24 hours notice of return to secondary care but need the hospital's support to take these patients back into the admitting consultant's service without delay. When patients are not accepted back further emergency referrals will only be accepted on the agreement to swap with our blocked bed. If this is not possible the only option would be a transfer to another neurosurgical unit." In respect of transfer to another unit, his letter states:

"We know that the neurological units in Bristol, Southampton and Oxford are in similar crisis precluding transfer of care." If that is the situation in the acute neurological service, it requires urgent attention. Perhaps the Minister, in her response, will say what the Government have in mind.

If I were to summarise and simplify the report produced by the hon. Member for Sutton and Cheam, its key feature is that it draws attention to unacceptable waiting times for neurological disciplines. Its principle recommendation is that we must increase the number of neurologists by 60 per cent. That might be true, but I have a slightly different focus. We are increasingly moving toward evidence-based medicine and so my focus, along with that of many other commentators, is on patient outcomes rather than becoming fixated by our input into that process. Of course, inputs are important because they largely determine patient outcomes. Nevertheless, it is important to focus primarily on outcomes rather than on inputs.

An interesting fact that comes out of the hon. Gentleman's report is that in Denmark there are 100 neurologists for every 1 million of the population, in the United States there are 40, in Germany there are 12, but in the United Kingdom there are only six. The question that immediately occurs to me is: what about patient outcomes for the neurological conditions to which those figures relate? Why are there this extraordinary number of neurologists in Denmark? Are patient outcomes in Denmark much better than in the US or Germany, which has only 12 neurologists per 1 million of the population? With half their number of neurologists we do not compare too badly with Germany, which poses some interesting questions.

There is a nice line in the report when the hon. Gentleman refers to the British Brain and Spine Foundation stating that UK patients are half as likely to wake up with a neurological condition and find that there is a neurosurgeon at the bottom of their bed than they are in the rest of the developed world. To my mind, the key question is not who is standing at the bottom of the bed, but whether one is likely to wake up. Patient outcome is the key issue, so the discipline of the consultant who is responsible for care does not matter to the patient, so long as he or she is capable of delivering the best care available. It may be that it is vital that a neurosurgeon or neurologist should be at the bottom of the bed, but that is an issue about which we must acquire more evidence.

My conversations with neurologists have revealed that we function differently in the United Kingdom. Traditionally, neurologists have avoided dealing with the commonest causes of brain failure, be they stroke, dementia or sequelae of head injury; geriatricians and other physicians have made up the shortfall. The conditions upon which neurologists have traditionally had a therapeutic impact are epilepsy, Parkinson's disease and other rare disorders such as myasthenia gravis and post-infectious demyelinating polyneuropathy. I read about an hon. Member who had an episode of myasthenia gravis, although I must say that he has subsequently functioned as an outstanding parliamentarian, so he is clearly over that.

The diagnostic skills of neurologists have been useful traditionally in the diagnosis of multiple sclerosis, motor neurone disease and peripheral neuropathies, spongiform encephalopathy and a host of rare and esoteric disorders. The hon. Member for Isle of Wight drew attention to the fact that there has been a great increase in our ability to deal with many of those conditions in the past 10 years and longer. I know that, for patients, those conditions are not esoteric at all. However, many neurologists say that, in dealing with some of those conditions, their impact is quite limited, and neurology is predominantly an out-patient discipline.

One of the complaints made by neurologists performing that out-patient role is that many of the referrals that they receive from general practitioners arise because the GPs are themselves least comfortable with their own neurological diagnostic skills. Consequently, many neurologists find their case load taken up by people suffering from tension headaches and those who believe that their symptoms are indicative of a brain tumour or some other disease. Perhaps addressing the diagnostic skills of general practitioners would have an impact on at least some of the out-patient problem. I hope that, within primary care groups, there will be an exchange of patients, and a cross-referral between general practitioners who are becoming more specialist in particular conditions. That might relieve some of the pressure on secondary care referrals to hospitals.

**Dr. Brand :** The hon. Gentleman is confident that general practitioners can become more expert, but he must recognise that, if we are to meet the Government's own standards in accessing general practitioners, we need an extra 10,000. Giving them an extra job in this area will not solve the overall problems in the national health service.

**Mr. Swayne :** I acknowledge what the hon. Gentleman says and the difficulties facing general practitioners involved in primary care, and I recognise the need for more of them to meet the demands of the national plan. We are now talking about the huge shortage of neurologists, which raises the question of which issue to address first, or which should be given the greatest leverage for an improved patient outcome.

Most patients with serious conditions, for example, multiple sclerosis or motor neurone disease, are relatively easy to diagnose on clinical grounds alone. As the hon. Member for Isle of Wight said, we now use a great deal of high-tech equipment to confirm such diagnoses. About 40 years ago, it might have cost just a few pounds to diagnose a multiple sclerosis sufferer. Given the remarks of the hon. Member for Isle of Wight when describing his teachers, it might be more appropriate to say that it would have cost a few guineas all those years ago to diagnose someone suffering from multiple sclerosis. Now, it might cost as much as £1,000, using high-tech equipment. It is legitimate for us to ask by how much our skill and ability in diagnosing these conditions has improved.

I was particularly enthusiastic about paragraph 3.8 of the report in which the hon. Member for Sutton and Cheam drew attention to the importance of speed of diagnosis and stated:

"A large number of neurologists and stroke physicians ... are now saying treating stroke as a medical emergency the way a heart attack is would improve survival after stroke, reduce post attack depression ... and the risk of being institutionalised." That bears out what my hon.

Friend the Member for Runnymede and Weybridge (Mr. Hammond) was told when he visited the Royal Hallamshire hospital on Friday last week.

We all understand that a heart attack is an emergency and requires rapid treatment. The public

especially among the public, about strokes, which also require swift treatment? All district general hospitals have coronary care units and they are successful in terms of patient outcome, but not all district general hospitals have stroke units, although experience shows that they can also achieve successful results.

Whether stroke units need to be staffed by neurologists or geriatricians, as they largely are now, is not a matter on which I have the expertise to make a judgment. It may be right to encourage a greater supply of neurologists to take on that work, but I would want to see the clinical evidence of improved patient outcome before huge resources were diverted to such an end.

I come to the national service framework announced by the Government, which, significantly, the hon. Member for Sutton and Cheam called for on 3 January. It was a notable success for him to have secured such a swift response from the Government, and one that he deserves.

We favour a national service framework, but we have some reservations and want to ensure that it does not become over-prescriptive. However, we are confident that it will improve matters. Hon. Members are entirely right when they say that the national service framework, which may be in place in 2005, must not be allowed to delay development in the meantime. There is a tendency to produce a report, put a framework in place and believe that the problem has been dealt with. I remind the Chamber of Florence Nightingale's words when she drew a problem to the attention of a senior officer in the Crimea who assured her that it was unnecessary for her to trouble herself with it because there was already a report on it. Her response was that in her experience such reports were not necessarily self-implementing.

### **12.3 pm**

**The Parliamentary Under-Secretary of State for Health (Ms Gisela Stuart ):** I confess that I am too young to recall the words of Florence Nightingale, but I congratulate the hon. Member for New Forest, West (Mr. Swayne) on a polished close to his speech.

It is customary to congratulate an hon. Member on securing a debate, but the hon. Member for Sutton and Cheam (Mr. Burstow) should also be congratulated on the timing of his thoughtful debate. I agree that it is the quality and not the quantity of hon. Members in the Chamber that matters.

Hon. Members have raised a number of specific issues. If, inadvertently, I do not provide specific answers, I shall certainly return to them in more detail. However, I was somewhat surprised that the hon. Member for Sutton and Cheam referred to a national crisis in neurological services. I do not agree that there is such a crisis, but I accept that there are problems, which are more severe in some areas than in others. Our stated aim is that the worst services must make progress to deliver the best, but that will take time.

Hon. Members will be aware that the NHS was in survival mode for many years, but we are turning the corner and it is now in expansion mode. There is record investment and we are working towards shorter waiting lists. In many ways, the debate has illustrated why we need national frameworks and coherence in respect of the services that we deliver. It has also demonstrated that we need an expansion in staff. Virtually every hon. Member mentioned shortages in certain areas and the practical problems that arise when nurses are recruited and trained as specialists.

The hon. Member for Sutton and Cheam has made a number of points about waiting times, and it is important that I clarify them for the record. He said in January that waiting times for appointments are horrendous--up to two years--but that is not the case. For in-patients, the maximum wait is 18 months. Since 1997, no patient in England has waited more than 18 months for neurology treatment. The average in-patient waiting time in England is 9.48 weeks. The vast majority of out-patients--about 95 per cent.--are seen within 26 weeks and the average waiting time in England is 10.6 weeks.

that 44 per cent. of hospitals make patients wait longer than 26 weeks. Again, that is not the case. More than 85 per cent. of hospitals are able to give appointments within 13 weeks.

**Dr. Brand** *rose--*

**Mr. Burstow** *rose--*

**Ms Stuart** : May I finish my point about waiting times before giving way? According to the press release that was issued by the hon. Member for Sutton and Cheam, the number of neurologists in England and Wales would have to be increased by 60 per cent. to reduce waiting times to meet the Government's target of three months. However, it is not clear to which target the press release refers. There are two different targets in respect of the three-month maximum waiting time: one for in-patients and another for out-patients. The NHS plan refers to reducing the maximum waiting time for out-patient appointments to three months by the end of 2005, and reducing the maximum waiting time for in-patient treatment to three months by 2008. We are confident that those targets are achievable.

**Mr. Burstow** : I will look at the figures that the Minister has given today with some interest, but I hope that she will accept that the report is a faithful representation of the results of a survey of NHS trusts. The information was not converted or altered--we merely reported what we found.

**Ms Stuart** : I accept that the hon. Gentleman desires to do nothing other than act on the basis of his findings. I echo the comments of the hon. Member for New Forest, West by congratulating the hon. Gentleman on his efforts as a Back Bencher. I simply want to put on the record the findings of our survey, which is, I hope, more reliable and thorough. I hope that the hon. Gentleman is satisfied with that.

**Dr. Brand** : When the Minister conducts her surveys, does she ask each trust whether it defers putting people on the waiting list, especially in respect of out-patient appointments? In my experience, it is not uncommon for

**6 Mar 2001 : Column 36WH**

patients to be sent a letter stating, "We have received your referral, but we are not in a position to put you on our waiting list as yet. You will hear from us in about six months' time."

**Mr. Nicholas Winterton (in the Chair)** : I call Dr. Gisela Stuart--

**Ms Stuart** : There are some doctors in the Stuart family, Mr. Winterton, but I am not one of them. People should not be put on a waiting list for a waiting list, so I will take up the hon. Gentleman's point.

The hon. Member for Sutton and Cheam described the wide variations in waiting times throughout England and Wales as a postcode lottery for neurological services. As he knows, waiting times in Wales are a matter for the Welsh Assembly. Waiting times in England do vary. We recognise that patients can wait a long time for neurology treatment. The NHS plan says that all patients will have a maximum wait of three months for out-patient appointments and six months for in-patient appointments. We are confident that we will be able to meet those targets. The hon. Gentleman said that the figures show that the non-urgent average waiting time to see a consultant neurologist is 25 weeks, with 44 per cent. of hospitals having to make patients wait longer than six months for an out-patient appointment. That is not the information that I have been given. The national average out-patient waiting time for neurology is 10.6 weeks. In December 2000, only 12 per cent. of neurology out-patients had waited as long as six months for an appointment.

We all accept, however, that that is not good enough. We need to make progress in a co-ordinated manner. Some hon. Members have expressed a fear that the national service framework would be a hindrance to further progress. It will not be--far from it--but the various initiatives must go hand in hand in dealing with the situation in the short term and in the long term. It is essential that they work in tandem.

I thank the hon. Member for Isle of Wight (Dr. Brand) for his enlightening anecdote about the Bentley key, and I am delighted to say that we have moved on from that. Funding for diagnostic

scanners, 50 additional CT scanners and 50 additional MRI--magnetic resonance imaging--scanners will be funded by 2004. Those will be used in the diagnosis of cancer and other diseases, including neurological diseases. The hon. Gentleman said that we must consider strategic availability. Again, we must ensure that immediate and long-term strategies develop in tandem.

Reference was made to deep brain stimulation therapy. The Medical Research Council is considering a trial of the effectiveness of such therapy. We are also working closely with the Parkinson's Disease Society and others. I understand that the trial would cost about £1.3 million over three years.

Hon. Members mentioned nurse practitioners and the availability of specialist nurses. The NHS has huge capacity problems. We simply do not have enough doctors and nurses of any specialisation. We must address long-term problems through more training and short-term problems through putting the available work force to best use.

The hon. Member for Isle of Wight referred not only to nurse practitioners, but to speech therapists and physiotherapists. I am delighted that the Multiple Sclerosis Society is working with the NHS to provide more specialist nurses. The further development of a specialist nursing post is an integral part of neurological services. It will be addressed with NHS commissioners and providers. Specialist nurses will be important stakeholders in developing the national service framework.

**Mr. Burstow** : The Department is considering the recruitment and training of specialist nurses. Will that work be concluded before the implementation of the national service framework?

**Ms Stuart** : If there is information about precise dates, I will pass it on to the hon. Gentleman. We must invest extra money. Hon. Members will acknowledge that we are dealing with that matter, not only through extra funding this year, but thereafter. I am pleased that the debate has not been a sterile discussion about solving the problem with pockets of money here and there. The problem is more fundamental than that.

The creation of national service frameworks to deal with the huge divergence of services is an important development. Hon. Members have rightly pointed out that there is a danger of creating various channels. We do not want that to happen. Other Government policy allows close working, for example with social services. The Bill to establish care trusts will facilitate such working together. I hope that hon. Members will be reassured that those are all parts of a jigsaw, which will be fitted together carefully.

Neurology covers a huge range of complex issues and conditions. Some neurological disorders are rare, but others are common, such as epilepsy, which affects more than 400,000 people in the United Kingdom, and multiple sclerosis, which affects a further 85,000 people. Most neurological disorders are chronic and disabling and have a profound impact on the lives of individuals and their families. One third of the British population lives with a long-term health condition. Therefore, our decision about the national service framework for such conditions, which was announced on 28 February, is important to people with neurological conditions and to their families and carers. Hon. Members have drawn attention, rightly, to the needs of carers and to the need to take their experiences into account in developing the national service framework. The national service framework will focus on the needs of people with neurological diseases of the brain and with spinal injuries. It will include services for people with epilepsy, multiple sclerosis, Parkinson's disease or similar conditions. The question has been raised of whether the treatment of chronic pain will be included in the framework. What place that will have within the framework will be addressed during the consultation with stakeholders.

The aim of the national service framework is to overcome the lottery in care and to ensure that health and social services work together in all parts of the country to provide the right level of care and treatment for people who live with long-term health conditions.

Many such people are poor, or live in the poorest parts of the country. There is an especially

epilepsy, as well as a fundamental and consistent link between poverty and ill health. The Government have a responsibility to break that link.

The Government have been successful in developing and publishing national service frameworks for mental health, for coronary heart disease and the national cancer plan. Those frameworks have helped our programme to deal with inequalities and race standards and to reduce unacceptable variations in NHS services. Later this year, a national service framework will be introduced for older people and for diabetes. The illnesses covered by the five national service frameworks account for half total NHS spending. The frameworks are part of the Government's commitment to ensuring that patients have fair access to high standards of care, wherever they live. The NHS plans commit us to developing more of them.

Each national service framework is developed with the assistance of an external reference group that brings together health and social care professionals and managers, service users and carers, partner agencies and other advocates. That inclusive process ensures that a range of views is heard and can contribute to the development process. A decision on the chair of the national service framework for long-term health conditions and on its scope and membership will be announced in due course.

I pay tribute to the constructive and important work of voluntary organisations. The Neurological Alliance has given an unequivocal welcome to the national service framework for long-term health conditions and is looking forward to collaborating with the Department of Health to produce a framework that will benefit people in that neglected area. The hon. Member for Sutton and Cheam paid tribute to the support that he received in producing his report.

With long-term health conditions, patients are the specialists in how best they can receive care: whether it is best to receive it in the acute sector or at home. The Government recognise the important role of the voluntary sector and specialist patient representative bodies not just in being advocates for patients, but in bringing extraordinary expertise to the debate. That is why we work closely with the voluntary sector in other areas of neurology.

**Mr. Burstow** : That point provides the opportunity to seek clarification from the Minister, who rightly welcomes the important work and support provided by non-government organisations in supporting patients and so on. I specifically asked her about the Secretary of State's indication that the value of such work might be recognised with additional funding for umbrella organisations. Might that translate into additional support for the Neurological Alliance and, particularly, the work on the national service framework?

**Ms Stuart** : Of course, we are all optimists and everything is possible. If my brief is correct, the hon. Gentleman may be referring to applications by the Neurological Alliance under section 64 of the Health Services and Public Health Act 1968. We are considering those applications to allow services to be expanded. I am sure that his representations will be heard, but it would not be right and proper for me to make an announcement now and he would not expect me to.

I refer to our work with Epilepsy Bereaved and the comprehensive clinical audit to investigate the unexplained death of people with epilepsy. Tragically, some 1,000 people with epilepsy die every year. That audit should allow us to move forward in a more co-ordinated way. Hon.

Members have recognised that some conditions are rare, but we must try to develop an understanding of them. We are working with the Human BSE Foundation to provide standards of care for people with new variant Creutzfeldt-Jakob disease. We are also working with the Parkinson's Disease Society, which has just received £36,000 for advice helplines. Only a couple of months ago, the society launched a fascinating CD-ROM, which took patients through the adaptations that they could ask for in their houses. We work with and support the voluntary sector. I put on the record that it is uniquely able to do something that neither the Government nor the NHS can do.

I turn to whether we have enough neurologists. I am grateful to the hon. Member for New Forest, West, who graphically illustrated that ultimate numbers do not necessarily show us the picture,

neurological disorders account for up to 17 per cent. of all general practice visits and almost 20 per cent. of all acute hospital admissions. Studies suggest that up to 2,000 people in a population of 100,000 will have a disabling neurological condition. More than one quarter of those will require daily help to remain living at home.

There have been difficulties in filling consultant neurologist posts in some areas. The Speciality Workforce Advisory Group has reviewed the number of consultants in neurology annually. The average length of training in the speciality is six years and past recommendations by SWAG take time to be felt on the ground. Current trainees in neurology will provide approximately 90 additional trained specialists by 2006: an increase of almost one third between 1999 and 2006. We shall continue to keep the speciality under review with the Royal College of Physicians and NHS management. In particular, we want to find ways of resolving local shortages that have been reported in some areas.

We are aware that most neurological conditions have no cure at present. Often, their causes are not fully understood and the diagnosis of individual conditions is difficult. That is why, in improving our understanding of how to treat and manage such conditions, it is important to consider research, too, hence the Government's support for the Medical Research Council, the NHS health technology assessment programme and other research streams that help us in our drive to understand the causes of neurological diseases. In England, the main Government agency for research is the Medical Research Council, which receives funding via the Department of Trade and Industry.

The Government keep their priorities for research under review. NHS priorities are identified through widespread consultation with those using, delivering and managing services. Account is taken of the burden of disease, potential benefits and Government objectives as well as the responsibilities and work of other funders. It is a long-standing and important principle of successive Governments not to prescribe to individual research councils the detail of how they should distribute resources between competing priorities. That is best decided by researchers and research users. The MRC will take all such factors into account when it decides whether it wishes to fund research projects into neurological and other conditions. I remind hon. Members that, in 1999-2000, the MRC provided about £18.6 million for research into neurological conditions. That research will help to improve our understanding of such conditions and aid the development of treatments for them.

I was not surprised that hon. Members raised the issue of beta-interferon and multiple sclerosis. Although we shall have divergent views about the language with which we described the action that NICE has taken, it is probably best to put on record why it has asked for more evidence. There seems to be genuine uncertainty about the appropriate use of beta-interferon. That was reflected in the different prescribing patterns throughout the country. We therefore asked NICE to conduct an authoritative appraisal of the evidence on beta-interferon as part of its first appraisal programme. To us, that is a high priority.

I stress that NICE has not yet issued guidance on the use of beta-interferon for multiple sclerosis. As part of its appraisal process, NICE circulated its final appraisal determination to patient groups, professional groups and manufacturers. All were given 10 days to appeal. NICE rejected eight appeals against the FAD. An appeal panel considered the appeals on 22 and 23 September 2000. Part of the appeals were upheld and, as a result, NICE's appraisal committee reconsidered its guidance on 13 December 2000.

During its appraisal of beta-interferon and a similar drug, glatiramer acetate, NICE considered evidence that included economic models supplied by manufacturers and independent researchers, including data not previously submitted. Those models are used to inform NICE's judgment on the cost-effectiveness of beta-interferon. The evidence relating to the cost-effectiveness of those medicines is critical to NICE's appraisal of the drugs. NICE considered those models and concluded that such detailed examination raised several issues, which its appraisal committee,

After considering the deliberations of the appraisal committee, NICE commissioned further economic modelling. It advised that the commissioning, construction and evaluation of a further economic model will take some months. It is therefore extending the time scale of its appraisal of both beta-interferon and glatiramer acetate to enable further research to be undertaken. It anticipates that the appraisal committee will reconsider the evidence, which will consist of a new model and any other new material available at the time, in July 2001. Unless there are further appeals, NICE expects to issue its guidance by November 2001. We shall have to wait for that final guidance. I do not wish to pre-empt what it might say.

I hope that today's debate, which has been informed and welcome, has reassured hon. Members that we acknowledge the great importance of neurological services. The development of the national service framework will mean that good service will be available wherever in the country a patient must call upon it. However, sometimes long-term solutions will be needed to get that right and improvements may be made more quickly in other areas. That will happen, but, as ever, our biggest present constraint is the work force, the training of whom will take time.

**Mr. Nicholas Winterton (in the Chair ):** I thank the Minister for her reply. We move to the next debate, initiated by the hon. Member for Clydebank and Milngavie (Mr. Worthington).

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[Next Section](#)

[Index](#)

[Home Page](#)