House of Lords Parliamentary Debate
Wednesday 30 March 2011
Health: Polymyalgia Rheumatica and Giant Cell Arteritis

Question for Short Debate Asked By Lord Wills

To ask Her Majesty's Government what steps they are taking to encourage early diagnosis of polymyalgia rheumatica and giant cell arteritis and to ensure appropriate treatment.

Lord Wills: My Lords, the Government have said that their approach to the NHS is founded on the principle of doing more for less. I have asked for this debate today to suggest a way in which the Government might do this by preventing thousands of people in this country from going needlessly blind every year. Giant cell arteritis is the most common form of vasculitis: an inflammatory disease of blood vessels, most commonly of the arteries in the head. It is, in effect, a stroke in the eye. If diagnosed in time, it can be easily and cheaply treated with steroids; untreated, it leads to blindness in 25 per cent of cases. It is one of the most common causes of acute blindness in this country.

It has been estimated that around 3,000 people a year go blind needlessly as a result of giant cell arteritis, because their doctors failed to diagnose their condition in time and provide sufficiently rapid treatment. That is a tragedy for those afflicted and their families, so why is it happening? Why are thousands of these avoidable tragedies happening every year? The symptoms are everyday: headaches associated with scalp pain and pain in the jaw or tongue. It is also common to see systemic low-grade fever, weight loss, loss of appetite, depression and tiredness. Once symptoms present, an early temporal artery biopsy or ultrasound can effectively confirm a diagnosis of giant cell arteritis but urgent treatment needs to be started as soon as possible to prevent the risk of blindness.

However, far too often GPs miss the symptoms. This is often an affliction of older people and the symptoms are too commonly categorised as merely the aches and pains of ageing. Up to 3,000 people a year go blind as a result. Moreover, best clinical practice suggests that patients with suspected giant cell arteritis should be started immediately on high-dose steroids, not wait for specialist review. The precautionary approach is not usual practice for many general practitioners, not least because it is often not appropriate for other complaints. Far too often, patients are prescribed the wrong treatment and too late.

The problem arises from a combination of symptoms that, taken in isolation, could indicate a wide range of complaints, serious and less serious. There is the need for speed in treatment, which is required for few other complaints in the same way, and a precautionary approach which is not indicated in the same way for many other treatments. Yet there are such significant, differentiating characteristics about the symptoms so that giant cell arteritis ought to be easy to diagnose as long as GPs are sensitised to them. Headaches are common but sudden onset headaches and headaches over the temples are less common. Those categories of headache are key indicators for giant cell arteritis. Even in the minority of cases where headaches are not present, there will be other constitutional symptoms such as weight loss and loss of appetite. Jaw and tongue pain are red flag warnings. Visual disturbances such as double or blurred vision, or the transient loss of vision, are other powerful indicators for immediate treatment.

Dedicated clinicians and support groups have been working tirelessly to reduce the number of these avoidable incidents of blindness by raising awareness among clinicians. The British Society for Rheumatology, British Health Professionals in Rheumatology and the Royal College of Physicians produced guidelines for the management of giant cell arteritis 18 months ago, but the persistence of problems with diagnosis and appropriate treatment suggests that they need support if they are to make significant progress. I am afraid that they do not appear to be getting that.

Lord Wills: My Lords, before we were called to do our democratic duty, I was saying that the persistence of problems for the diagnosis and the treatment of giant cell arteritis suggests that all the good work being done by clinicians' bodies needs support if they are to be able to make significant progress, and they do not appear to be getting it. I asked the Government in a Written Question last October what steps they had taken to promote among general practitioners' knowledge and understanding of those guidelines. The reply stated:"All healthcare professionals are accountable, through their professional regulator, for keeping up to date with the professional guidance relevant to their area of clinical practice".-[*Official Report*, 6/10/10; col. *WA21*.] In other words, it was nothing to do with them.

Of course, government departments should be wary of interfering with the professional judgments of clinicians, but when there is such an obvious and persistent problem, government must not simply stand aside. Apart from all the human misery caused by this unnecessary blindness, it costs the NHS millions of pounds a year that could easily be saved. I asked the Government, again in October last year, what estimate they had made of the costs of such unnecessary blindness.

The reply stated:

"The department has made no estimate of the cost to the National Health Service of treating vision loss in those whose giant cell arteritis was not diagnosed early".-[*Official Report*, 6/10/10; col. *WA20*.]

I am surprised. Three thousand people a year are going blind unnecessarily and the department has not made any financial analysis of the problems.

Still, I shall try to help. The costs will include clinical treatment and social care, both for those afflicted and those who care for them or who were cared for by them. Some estimates have suggested that the annual cost to the Exchequer of blindness for an individual could exceed £20,000 a year. It could be considerably more than that, but let us take that figure. The cost of those 3,000 people going blind every year unnecessarily could run to around £60 million a year. In the absence of any calculation by the department, this is the figure that I am afraid we have to work with.

Of course, this cost accumulates year on year. Over the five-year period for which this Government are legislating for themselves to be in power, the total cost of such unnecessary blindness could come to nearly £1 billion. If we offset against that the cost of steroids-let us say £100 a year for two years for each patient-it still leaves a net cost to the taxpayer of around £900 million. Unless the Government act to help stop such unnecessary blindness, they run the risk of forcing taxpayers to go on paying costs running cumulatively into billions of pounds-not millions or hundreds of millions-while inflicting incalculable misery on those sufferers, mostly pensioners, who are already at the most vulnerable stage of their adult lives. I emphasise that this does not mean the loss of vision alone, although that is tragic enough. It also means, all too often, the loss of independence, with elderly people who had been able to live in their own homes being forced to go into residential care. I hope that the Minister will understand why I am today pleading with him to do more. I have four suggestions.

The Department of Health is conducting a consultation to expand the list of "never events". This is a welcome initiative and I congratulate the Government on taking it forward. Never events are defined as,"serious, largely preventable patient safety incidents that should not occur if the available preventative measures have been implemented by healthcare providers".

It is hard to imagine a better fit for this definition than blindness in giant cell arteritis. Causing blindness must qualify as "serious"; it is certainly "largely preventable"; and it clearly would not occur if the available preventive measures, early diagnosis and rapid treatment with steroids, had been "implemented by healthcare providers". I hope that the Minister can say now that his department will seriously consider making blindness from giant cell arteritis a never event. I should be grateful also if he could confirm to me today that if, when it has reached its conclusions after the consultation, his department decides not to make giant cell arteritis blindness a never event, he will write to me explaining why it has rejected this opportunity to prevent thousands of individual tragedies every year and to save the taxpayer millions of pounds.

My second request to the Minister is to ask NICE to make an appraisal of giant cell arteritis services in order to produce guidelines. As he is aware, NICE guidelines are mandatory for commissioning groups and acute trusts and, coupled with appropriate awareness programmes, this could transform consciousness of this illness and radically improve outcomes for those afflicted by it.

Thirdly, can the Minister please raise the profile of this issue by discussing it in a landmark speech? He has earned his reputation in your Lordships' House as an unusually thoughtful and conscientious Minister, and such a speech by him would only burnish that reputation.

Finally, can the Minister please communicate directly with GPs on the importance of early diagnosis of this disease through one or more of the mechanisms through which the Department of Health communicates to GPs, whether it is a "Dear colleague" letter, a Chief Medical Officer update or letter, or regular mention in the GP and practice team bulletins?

What impact might such consciousness-raising measures have? The best evidence comes from the treatment of strokes. In 2009, the Department of Health launched the Act FAST campaign to boost awareness of strokes, promoting a simple test to recognise the signs of strokes and act quickly. As the Minister will be aware, swift diagnosis and treatment can limit damage in the brain and increase the chances of survival. The Department of Health committed to a three-year £100 million stroke strategy in England.

When I asked in a Written Question last year what assessment the Government had made of the impact of the campaign, the Minister said that it, "successfully achieved a rapid change in behaviour. Within a year, an estimated 9,864 more people reached hospital faster, 642 of whom were saved from death or serious disability by receiving thrombolysis. The evidence demonstrated that the campaign achieved a payback of £3.16 for every £1 spent".-[*Official Report*, 9/12/10; col. *WA 86*.]

If the previous Government could take such impressive action on strokes, and if this Government can so commendably carry on that good work, I hope they can now take similar action over strokes in the eye. We now know from Act FAST that such consciousness-raising campaigns work. Such an approach to giant cell arteritis will save thousands of people going blind and could save the taxpayer up to £1 billion by the time of the next election. There really can be no possible excuse for the continuing inertia, and I look forward to hearing what commitments to improvement the Minister can make today.

In conclusion, I should be grateful if the Minister would agree to meet me, concerned professionals and representative patient groups to discuss what further measures might be possible.

Lord Black of Brentwood: My Lords, I am greatly indebted to the noble Lord, Lord Wills, for securing this debate. Polymyalgia rheumatica, on which I want to concentrate this afternoon, is an illness about which I have deep personal feelings, for reasons that I shall explain in a moment, and I am enormously grateful for the opportunity to say a few words on it.

Polymyalgia rheumatica is a dreadful condition which, I believe, has for far too long been overlooked. In answer to a Question that I tabled at the end of last year, the Minister-and I was very grateful to him for his reply-said that there were not even any central records about how many people were afflicted by this illness. He helpfully cited a review from the *British Medical Journal* of April 2008, which reported that the incidence of polymyalgia rheumatica in people over the age of 50 was about 100 per 100,000.

This is not therefore a very common illness. It impacts mainly on older women over the age of 70, and often on people who are already ill with other conditions such as osteoporosis, which is itself a dreadful scourge. Perhaps that is why we pay so little attention to it. However, we should, because my belief is that this condition is really a potential killer-not because the symptoms overwhelm the patient but because the treatment can. In itself, this illness is self-limiting and will disappear within two to three years, but my fear is that far too many people never get to that point because the steroids that are at the moment the only realistic treatment for this illness so weaken them over that time period.

If your Lordships will indulge me, I should like to tell the Committee about my personal experience. My mother had suffered from osteoporosis for many years. It was, as is so often the case, diagnosed too late because of the failure of GPs to recognise the condition. However, that is a matter for another day. In the summer of 2008, she fell ill with the excruciating pain in the joints that is the classic hallmark of polymyalgia rheumatica. A specialist diagnosed the illness and began her on a course of treatment with a corticosteroid called Prednisolone. Neither he, nor our GP, informed me or any of my mother's closest relatives about what the appalling consequences of prolonged treatment with this dreadful drug would be. We were told that this condition was easily manageable with these tablets. But we soon found out at first hand that it was not.

Within a month of being started on a high dose of this steroid, this normally slim lady put on a great deal of weight, placing burdens on her heart. Then, even more devastatingly, infections began in the chest and in the bladder. Each month a new one developed, with prolonged spells of hospitalisation, as her immune system was shredded by these steroids. Then injuries began in her legs as her skin became thinner and thinner. During one admission in Basildon hospital, she sustained an injury to her leg when a wheelchair was banged into her. The wound never healed.

Worse was to come. In what turned out to be her last Christmas, her personality began to change, as she became anxious, depressed, confused and irritable. It was not until I begged her doctors to reduce the high levels of Prednisolone that she regained her warm and ebullient personality. At the same time, these drugs took a blow torch to her osteoporosis, which rapidly worsened, causing her excruciating pain in her shoulders and legs.
Not long after, thanks no doubt to the weight she had gained and the trauma caused to her body, she suffered a heart attack. A few weeks after that she fell ill with her fourth chest infection in eight months and died in February 2009. Although it is not a killer disease, it was, I believe, polymyalgia which killed her. Not the illness but the only available treatment.

Since then, I have looked in much more depth as a lay person-I readily admit that I have no medical expertise-at the impact of Prednisolone, used over a prolonged period, on the human body. An article in the *Nursing Times* on 25 April 2006 set it out rather well. It mentioned that Cushing's syndrome, water retention, weight gain, acute risk of infection as a result of the attack on the immune system, gastric disturbance and peptic ulceration, skin changes and bruising, increased risk of osteoporosis-or a worsening in those that already have it-changes in mental state, inability to sleep, worsening arthritis and glaucoma and, of course, giant cell arteritis, are all side effects of the prolonged treatment that is necessary for polymyalgia. I know from first hand how devastating they can be. How many people have died? How many more will have to do so before we recognise this often overlooked condition and treat it as such?

I am not so naive as to believe that there are any easy answers to this question, but there are things which can and should be done. First, we should recognise that this is a life-threatening disease because of the way that it is currently treated. As an illness it can mean prolonged steroid use for up to three years, and that can be a death sentence in older people.

Secondly, I believe that GPs should be better trained to explain to polymyalgia sufferers and their relatives what the consequences of steroid use will be. There should be proper advice on how to mitigate those effects, including diet changes, the use of prophylactic antibiotics, or a pneumococcal vaccine to help prevent lung infections, none of which was offered to my own mother.

Thirdly, corticosteroids such as Prednisolone should come with much more serious warnings than they do about their harmful consequences. Doctors should be obliged to keep the doses of it as low as possible, seeing their patients every week if necessary to try to monitor their impact and to cut them down when they can. Finally, there should be more research into what causes this illness and how it can be prevented. As an illness of those in their twilight years, in those who are already ill, it is often overlooked. But if we could get to the root causes of it, and help to try to prevent it, many thousands of lives would be lived more fully than they currently are.

I have been able to relate today the experience of just one family. There are many more out there for whom it is already too late. But let our gift for the next regeneration be to redouble our efforts to deal far more effectively and humanely than we ever have before with this horrible illness.

Lord Alderdice: My Lords, as the noble Lord, Lord Black of Brentwood, said, we are all grateful to the noble Lord, Lord Wills, for attaining this debate. The two noble Lords who have preceded me in the debate have pointed out a number of the problems of dealing with these disorders. The terms of the debate are polymyalgia rheumatica and giant cell arteritis. Although they are related disorders, there are important differences as well as overlapping and connections.

In the case of the condition that the noble Lord, Lord Wills, was particularly exercised about, he was talking really about temporal arteritis, as giant cell arteritis can happen in other places, the aorta, and so on. The question of early, rapid and irreversible blindness is really a function of temporal arteritis. Indeed, many people who have temporal arteritis also have polymyalgia rheumatica and probably about 15 per cent of those with polymyalgia rheumatica have temporal arteritis. They are overlapping and we do not really know why they come about but the management is very different.

As the noble Lord, Lord Black of Brentwood, pointed out, there are significant problems with the treatment with Prednisolone, although there is not much in the way of an alternative. Very early diagnosis is difficult because there are other disorders that are similar in their symptoms. Indeed, a noble colleague remarked earlier that, listening to the list of symptoms, she began to become concerned about herself. There are many different disorders that can cause some of the symptoms of polymyalgia rheumatica-some even in my professional background in mental disorders. Rushing into treatment may not actually be the best thing and there is not a pathognomonic diagnostic tool. For temporal arteritis it is quite different because, as the noble Lord, Lord Wills, said, it is crucial to get on with the treatment very quickly. If you do not, the blindness supervenes. You might get a good diagnosis but it is all too late. There is a clear diagnostic tool, temporal artery biopsy. It can be done by a physician, surgeon, or whomever, and very quickly the dose of Prednisolone can be instituted. If at all possible, it is better if the biopsy can be done first, and then, even before the biopsy has been looked at carefully, you can start with the treatment. If you start with the treatment immediately it tends the make the diagnostic problems of a biopsy a little more difficult, but the key thing is stopping the blindness.

One of the problems with the difference, overlapping and so on, is how one gets the message across to medical practitioners on how to deal with things, which was the burden of what the noble Lord, Lord Wills, was bringing to your Lordships' and the Minister's attention. It is very important to focus on the fact that we are talking about temporal arteritis leading to the blindness. Even the very term itself tends to focus the general practitioner's mind on when he should become alerted to the range of symptoms, but focusing particularly on those things that might indicate temporal arteritis. In that case, he or she should quickly get a biopsy and start the treatment even before the results come back from the pathologist.

If you mix giant cell arteritis in general with polymyalgia rheumatica, you have a range of difficulties, disorders and treatment approaches that are complicated and cannot be diagnosed very clearly. There are lots of different tests that you might do, by which time the person is blind. That is exactly the kind of problem that the noble Lord has pointed out. The noble Lord suggested raising the profile and having the Minister make a speech-I wholly agree with his sentiments about the standing of the noble Earl and the beneficent way in which he deals with these matters. He made a number of valuable suggestions about reference to NICE, getting matters across, a "Dear colleague" letter from the CMO, and so on. But, if the main concern is early, rapid treatment to prevent blindness, we need to focus specifically on temporal arteritis and move on quickly to treatment. If the burden of our concern is

polymyalgia rheumatica, we ought to go a little more slowly and conservatively because there are other possible diagnoses. There are not obvious diagnostic tools and moving too quickly to treatment and not holding back can be, as the noble Lord Black of Brentwood, pointed out, more of a tragedy than the disorder itself.

Baroness Bakewell: My Lords, there was a tale told when I was first an advertising copywriter of a beggar sitting beside the road with an empty hat at his feet and a placard that read, "I am blind. Please help". An advertising man took the placard and amended the message to, "It is spring. I am blind. Please help". According to legend, the hat was soon filling with coins. It is spring: please help.

I support my noble friend's idea that there needs to be much greater awareness of giant cell arteritis in the community and among GPs. I do not have medical expertise, alas, and I am grateful not to have had the tragic experience of the noble Lord, Lord Black, with the death of his mother.

The added words were meant to bring home to all those who passed by just how terrible the affliction of blindness is. It is not only the buds on trees and the dancing daffodils that the blind cannot see-they cannot see the faces of those they love; they cannot easily move around the world, crossing roads, using the tube; in their own homes they cannot trace the multitude of things mislaid daily in life, they cannot read, watch television, cook or look out for domestic hazards such as gas taps left on and rugs awry. The sum total of all such difficulties is a life vastly curtailed from a life lived with full sight. That, as we have heard from the noble Lord, Lord Wills, is the predicated outcome for some 3,000 patients a year who suffer giant cell arteritis. The examples I have given were among the main problems that arise for older women. I understand that women over 50 are particularly vulnerable to giant cell arteritis.

In supporting my noble friend in urging the Government to take action, I want to describe a confluence of social circumstances that converge on the group most at risk from the threat of blindness. First, they are for the most part older patients. It is generally recognised that people of an older generation are often more tentative in their relationship with their GPs than younger, more assertive, generations. Older people turn up and describe their symptoms and, all too often, get from their doctors a response that amounts to little more than, "Well, what can you expect at your age?" It is the way in which society colludes to groom older people to expect their lives to be winding down. We do it far too often, far too early, and often with far too little medical authority. It is an expensive and depressing form of ageism, somehow implying to older patients that their aches and pains are of less significance than they were when they were younger.

I am careful to say "implying" because no doctor would articulate such a thought outright, but in the mood and way older patients are often treated, the "What can you expect at your age?" mentality can discourage them from pressing more insistently for the medical treatment they need and which would avoid their symptoms developing further. Nowhere is this more evidently the case than with giant cell arteritis.

The second circumstance that increases the chances that giant cell arteritis could be overlooked is that the symptoms are so humdrum: headaches, sudden onset headaches, headaches over the temples; loss of appetite, weight loss, depression, tiredness. All these symptoms crop up at every age but are more easily set aside when they happen to older people. What is more, our culture has come to expect the old to be complaining. We made a comedy television hero of Victor Meldrew, and we watch and laugh along with everyone at successive television series based on the notion of "grumpy old". The old are seen in these images as intrinsically irritable and complaining. It may just be television comedy, lightly meant and not to be taken too seriously, but such regular and amusing stereotypes colour our assumptions, sometimes to a dangerous degree. A patient presenting with a headache might just be one of them, but their complaint might be serious enough to need instant treatment and its neglect could, as we have heard, lead to total blindness that was totally avoidable.

A third consideration, related to all these, is that there is no time to be lost. With immediate diagnosis and treatment with high-dose steroids, and without waiting for a specialist report, the risk of blindness can be averted. Yet this is not how GPs go about their business; it is common practice to listen, weigh up symptoms and then recommend a first-stage range of treatments. In the case of giant cell arteritis, this will be damaging delay. When someone, especially an older person, goes blind, it is not only the individual who is afflicted. The social consequences in the life and care of such a person have a major impact, too, on the lives of their family, on those who have to cope with them, in where and how they live and in planning the social support for their rest of their lives.

It is becoming a truism of our ageing society that one of the most desirable patterns of living longer should be staying healthy for longer-desirable not only individually across a generation but in major financial savings to the state. Already, the system of social care for the old is woefully inadequate, leaving people isolated and neglected because the service is not fit for purpose. My noble friend Lord Wills has already detailed the further financial cost of 3,000 new patients each year suffering from acute blindness. I can suggest only the personal reality of those costs: already-stretched care workers with lists of visits to be made daily rushing in and out of people's homes, dumping unappetising food on their clients and offering them cursory hygiene and little in the way of friendship. Sometimes an older person may have several different carers coming and going, as the job turnover is high and its

wages low. I do not describe such social care to condemn the carers; the system forces such behaviour upon them.

Imagine how much more distressing and isolating it would be to receive such care if you were blind. That level of human misery is avoidable. If the Government take steps now strenuously to urge awareness of giant cell arteritis upon the medical profession, the blight can be averted. We know, as my noble friend has indicated, that raised awareness of symptoms among GPs already reduces the risk of damage caused by strokes. The gap between where we are now and the prospect of saving 3,000 people a year from going blind is a little one. It can be bridged, simply and soon. To do it is within our reach. It is spring.

Baroness Brinton: My Lords, I thank the noble Lord, Lord Wills, for calling this debate on a rare pair of diseases that have serious impacts on patients' lives. I also have a sense of déjà vu, having spoken in the previous debate about holistic services for those with life-limiting illnesses, based on my experience of physiotherapy services for rheumatoid arthritis. RA is much more common than polymyalgia rheumatica and giant cell arteritis, and I suspect that diagnosis of it is relatively easy. Today, I shall focus on PMR.

I say "relatively" because for most of the time the diagnosis of this family of auto-immune diseases is often a bit hit and miss, with much of it based on a subjective view of the GP on the level of stiffness of joints and pain that a patient is experiencing. That is particularly true for those who have seronegative rheumatology disease, which can be just as disabling for those with seropositive results. I know of sufferers who say that it took them a long time to get their GP to take their pain and stiffness seriously enough even to get a referral to a consultant. After all, is stiffness not just a bit inconvenient? For those without this type of arthritis it is impossible to convey the dread of waking up in the morning, knowing that that first move to get out of bed is like moving after having a night's sleep following a 20-mile hike the previous day. Yet that happens every morning and every joint screams at you as you start to move.

As your creaky joints start to loosen up, you are working out how on earth to get down those stairs. Your knees and ankles will not co-operate for at least the next hour, and your shoulders are so stiff that you cannot lift them to hold the banister. Yet you need to get downstairs because, while you cannot take your medication until you have eaten, you are desperate for the anti-inflammatory steroids and painkiller drugs. For patients trying to get a diagnosis, that must be absolutely terrifying. They may not have learnt the language of pain description, let alone have got access to pain clinics and effective pain control. The noble Lord, Lord Black of Brentwood, made the essential point about over-reliance on steroids. The Prednisolone bounce may give relief-I speak from personal experience-but its long-term use is worryingly dangerous. For PMR, the use of disease-modifying drugs such as Methotrexate should now be investigated as routine, as they are for RA, thus reducing the need for long reliance on steroids.

For PMR sufferers, there is also the further problem of disabling headaches, which are famously difficult to diagnose as they can be symptoms of a large range of problems, some serious and others not. Thirty years ago, many GPs would have put this down to stress. Perhaps some still do today.

As I mentioned in the previous debate, the NICE guidelines are very impressive, but there is an issue about GPs being aware of the detail and therefore ensuring that patients get early access to specialist physiotherapy, occupational therapy and so forth. I hope that the Minister will forgive me for briefly repeating the point that I made in the earlier debate. This early specialist intervention is absolutely vital. In my own case, I see a physiotherapist, a hand specialist and an orthotist, all of whom are there to ensure that I keep as much mobility and flexibility as possible.

Patients who do not get access to this specialist physio and OT support tend to lose mobility earlier and are more likely to give up working sooner than their colleagues who are getting that help. A substantial percentage of rheumatology patients are no longer able to work within five years of diagnosis. This is vital for the independence of patients but, frankly, it is also vital to the country because of the cost of supporting those patients. The same is true for PMR but, without the NICE guidelines, it is almost impossible.

Rare diseases need champions and I ask the Minister to ensure that PMR patients get access to the NICE guidelines or, while that is being sought, that they are deemed to be covered by the RA guidelines, many of which seem to cover the treatment needed for PMR. Reading through the drug regime, the physical needs and so forth, there is much overlap. I ask the Committee to forgive this non-clinician patient view of the world. I am sure that it is too simplistic but there are things that can be learnt from it. Surely access to the appropriate holistic services is as essential for PMR patients as for RA patients.

I want to end on a positive note. I asked the Minister privately some time ago about the status of these NICE guidelines under the proposed new healthcare changes emerging from the White Paper and the Bill. I was much encouraged with his response that the guidelines would take a stronger role for clinicians in their treatment and support for patients. What is important is that NICE has the capability to produce guidelines for the rarer diseases

in the rheumatology sector that rely on early diagnosis and treatment to protect the health of the patient and to prevent deterioration through active physiotherapy.

Baroness Thornton: My Lords, I congratulate my noble friend Lord Wills on calling this debate. These short debates are ideal for a discussion about something very specific and important such as the disease giant cell arteritis. It is always a challenge, therefore, to find anything new to say when the matter has been thoroughly explored with the eloquence of the experts who are here today. That never stopped anybody in the House of Lords from making a few remarks, but I will be brief.

To put this in the vernacular, the issue is a bit of a no-brainer. Indeed, when I was practising the pronunciation of polymyalgia rheumatica, about which I had no previous knowledge, one of my colleagues piped up that her mother had that, so I ran off a very helpful fact sheet about giant cell arteritis to give her.

As noble Lords have said, the problem with giant cell arteritis is that the symptoms are so commonplace-headaches, tenderness on both sides of the forehead, feeling unwell and so forth. The treatment is also relatively straightforward-urgent treatment with steroids, which will prevent the blindness that can occur and which is irreversible. Clearly, doctors and patients need to be aware of the risks of giant cell arteritis in people and should be on the lookout for symptoms of the disorder. That is the first point, which echoes what other noble Lords have said. If someone is diagnosed with polymyalgia rheumatica, doctors need to warn them that this is a possible consequence.

At this point, my noble friend read a list of requests for the Government, which were echoed by many other noble Lords. In many ways, I cannot better his action list, which, as ever, shows my noble friend's ability to analyse and put forward practical solutions that are also achievable. I hope that the Minister will undertake that his department will seriously consider making blindness from giant cell arteritis a never event and I hope that he will ask NICE to make an appraisal of giant cell arteritis services to produce guidelines.

Perhaps I may add one or two requests of my own. Have the Government estimated the cost of blindness caused by this condition, or does the Minister agree that my noble friend's estimate is in fact the true cost? Linked to that is the issue of research. Something that costs so much and which, I suspect, does not receive as much dedicated research as we would wish creates an imbalance that we ought to address. I should like to know what research is taking place into this condition-the noble Lord, Lord Black, made this point very eloquently-because we need to find new drugs to treat it. It is clear that that needs to happen because of the vulnerability of old people to massive doses of steroids.

As my noble friend Lady Bakewell said, "It is spring. Please help".

The Parliamentary Under-Secretary of State, Department of Health (Earl Howe): My Lords, I am grateful to the noble Lord, Lord Wills, as I am sure are all noble Lords, for raising the need for early diagnosis of polymyalgia rheumatica and giant cell arteritis and for making clear the serious results that can follow should the diagnosis be missed or appropriate treatment delayed.

In addressing his question, perhaps I may start with what may be the most obvious and important issue: namely, what is out there for clinicians in terms of commissioning support and training. As the noble Lord will be aware, there is already excellent guidance available on these related medical conditions, both for healthcare professionals and for patients. The British Society for Rheumatology, with partner organisations, has recently published clinical guidelines for both conditions. The society has an active strategy for disseminating these guidelines widely among healthcare professionals, including GPs. Summary information for GPs is available from Patient UK and from clinical knowledge summaries.

I am advised that the importance of prompt diagnosis of giant cell arteritis is underlined in both the undergraduate medical curriculum and in post-graduate training for GPs and relevant hospital specialists. Both NHS Direct and Patient UK carry information for patients.

This of course underlines that it is not the Government who improve the quality of patient care; it is clinicians. The role of government is to provide a framework that enables clinicians to get on with it, as the noble Lord, Lord Darzi, eloquently articulated in his publication in 2008, *High Quality Care for All*. Now, with the Health and Social Care Bill, we are breathing life into that framework. I genuinely believe that this will enable clinically-led quality improvement of the kind that the noble Lord is seeking for the care of polymyalgia rheumatica and giant cell arteritis as much as it will for other conditions.

Commissioners of healthcare are faced with a complex task. Determining the relative priorities between different clinical conditions requires a difficult and largely technical balance between a number of factors, including the strength of the evidence base, the size of the population affected, the impact of the disease if not properly treated, the disparity between current standards of provision and best practice. The commissioners also need to take into account their duties to promote patient choice, to promote public health and well-being and to tackle inequalities in health outcomes. It is a complex set of interlocking tasks that, again, cannot be managed from the centre.

What we can and should do from the centre is to set broad expectations for the NHS. In the national outcomes framework published in December, my right honourable friend the Secretary of State for Health made clear that we

would hold the NHS to account against five broad health outcomes: reducing premature mortality; improving the quality of life of people with long-term conditions; helping people to recover quickly from episodes of illness; improving their overall experience of healthcare services-

Earl Howe: My Lords, the last of the five health outcomes that I was listing is delivering safe care. Within these five domains we have signalled a number of major improvement areas where evidence suggests the need to improve current performance in the NHS. The National Commissioning Board will support the NHS in achieving these improvements in various ways, through setting tariffs and other financial incentives, such as commissioning guidance and setting a lower level commissioning outcomes framework against which local commissioners will be held to account. But below this level, it will be for local commissioning consortia to determine exactly which service improvements they need to prioritise to best improve the health outcomes for their populations. They will, of course, be working within health and well-being strategies agreed with local government partners on the basis of a joint strategic needs assessment. They will be accountable to the local HealthWatch and nationally to the commissioning board for the outcomes they achieve.

I turn to the specific suggestions of the noble Lord, Lord Wills. The first of his suggestions was that we should add blindness due to giant cell arteritis to the list of never events which, if they occur in the NHS, would result in contractual penalties. The noble Lord was kind enough to alert me in advance to this suggestion and we have considered it carefully. I am very sympathetic to its underlying intention. However, I am not convinced that it would be feasible. I say that because to qualify as a never event, an incident-in this case, a failure to diagnose giant cell arteritis-must meet a number of criteria. In particular, the incident must be easily defined and identified, and it must be largely preventable if the appropriate guidance is followed.

The problem is that the differential diagnosis of giant cell arteritis is not straightforward and would require a detailed case note review to establish whether a clinician was culpable for missing it in a particular instance. I am afraid that the proposed addition falls outside the criteria.

The noble Lord has also suggested that there is a need for NICE guidance. He will be pleased to hear that NICE is indeed considering, through its topic selection process, a potential short clinical guideline on the safe and effective use of steroids in the management of polymyalgia rheumatica and giant cell arteritis. As he will know, NICE has limited capacity for the development of guidance and there are many competing demands on its resources. While it would not be appropriate for me to circumvent the established process for identifying priorities, I can reassure him that the need for guidance in this area is being carefully considered.

He also suggested that I refer to the issues of giant cell arteritis in a landmark speech. I fear that he may have somewhat exaggerated the impact that a few words of mine are likely to have on the knowledge and skills of thousands of GPs across the country, but I am always willing to take up suggestions of this kind, where possible, and if I can give honourable mention to this specific condition in a speech I will certainly endeavour to do so.

Finally, the noble Lord suggested that we should use one of the Department of Health's regular channels of communication with the NHS to raise the profile of these two conditions-perhaps via the regular bulletin to GPs and practice staff.

The department has a variety of means for communicating directly with NHS professionals. I am happy to consider that idea. In general, the modes of communication tend to be used mainly for the most urgent or significant public health messages, and it would not be appropriate for the department to seek to give advice on clinical issues for NICE or the various professional organisations.

However, it would be possible in theory to use the GP bulletin to draw attention to professional guidance in this area, such as the excellent clinical guidelines developed by the British Society for Rheumatology and its partners. The department is already discussing with the society whether it would see this as a useful addition to its own means of dissemination.

We need to come back to a fundamental point. A liberated NHS should not wait for permission from Ministers to do anything. It should instead be listening directly to patients and their advocates-here, I include the noble Lord among the champions of these particular groups of patients. That is what the NHS will increasingly be doing.

The noble Lord asked me-he repeated the figure several times-whether the department accepted the estimate of 3,000 people a year going blind as a result of failure to diagnose giant cell arteritis. I made informal inquiries before the debate and, although he is absolutely right in all that he said about the devastating effects of this condition, I have been unable to verify the figure of 3,000 people, and experts whom we have consulted think that the true figure is quite a bit lower than that. I would be interested in any further information that the noble Lord has on that issue, and indeed on his statements around the failure by doctors to diagnose giant cell arteritis.

My advice is that the vast majority of GPs are already aware of the serious consequences of failure to diagnose giant cell arteritis, and I have already referred to the aspects of their training relating to that. It is a relatively rare condition; the average GP might see one case every two years. Picking up the occasional case of giant cell arteritis among many less serious conditions with superficially similar symptoms is therefore not straightforward. However, I believe that the great majority of GPs are sensitive to the need to pick up this serious condition.

The noble Baroness, Lady Thornton, asked me about research. As she well knows, there is a transparent process for determining research priorities, and I am sure that the professional organisations for rheumatological conditions will be familiar with the steps that they need to take, either in relation to research funding through the MRC or indeed, as regards clinical research, through the Department of Health.

My noble friend Lord Black referred in powerful terms to the adverse effect of steroids as treatment. He may like to know, if he does not already, that the standard guidance to GPs makes it clear that any dose of steroids should be progressively reduced over a fairly short period, so it is alarming to hear the experience that he recounted. He also said that GPs should warn patients of the adverse effect of drugs. I agree absolutely that that is a fundamental responsibility for all doctors, especially if drugs have potentially severe side effects. My noble friend Lord Alderdice pointed out the need to keep a focus on temporal arteritis, which should not be muddled up with polymyalgia rheumatica. That is clearly an issue for the professions, although he makes a valuable point. I undertake to draw his suggestions to the attention of the Royal College of General Practitioners.

My noble friend Lady Brinton suggested applying NICE rheumatoid arthritis guidelines to polymyalgia rheumatica. As many of the issues are the same I would be reluctant to tell NICE how to do its job. It is perhaps better to await the outcome of the topic selection process, which is already looking at PMR. The noble Baroness, Lady Bakewell, who is not in her place, spoke powerfully about ageism. I agree that any form of ageism is unacceptable. It is vital that education and training for GPs should address this issue and emphasise the specific signs for these diseases that are particularly prevalent in older people.

My time is up but I shall address the final question put to me by the noble Lord, Lord Wills, who asked whether I would agree to meet him to discuss these issues further. I would, of course, be happy to do so.