

A photograph of two women sitting and reading a brochure together. The woman on the left has short white hair and is wearing a blue sweater and tan trousers. The woman on the right has short curly brown hair and is wearing a grey pinstriped suit jacket and a necklace. They are both smiling and looking at the brochure. The brochure has the title 'Parkinson's and you' and several small photos of people. The background is a plain white wall.

# Taking Control: our right to information

People with neurological conditions speak out

A report by the Neurological Alliance, the Association of the British Pharmaceutical Industry (ABPI) and Ask About Medicines - September 2008

People with long-term neurological conditions are to have the information they need to make informed decisions about their care and treatment and, where appropriate, to support them to manage their condition themselves.

National Service Framework for Long-term Conditions

Quality Requirement 1

March 2005

By 2008, we would expect everyone with a long-term condition and/or long-term need for support — and their carers — to routinely be offered information about their condition.

Our Health Our Care Our Say,

White Paper, 2006

# Contents

Summary	3
Neurological conditions	4
The National Service Framework for Long-term (neurological) Conditions	5
Information prescriptions	6
The Taking Control Survey	7
The information shortfall	9
Why information matters	9
The importance of timely information	9
Emotional support	11
System failure	12
Good information, poor access	13
The voluntary sector	13
Specialists and health professionals	16
Specialist doctors	17
Specialist nurses	17
The internet	18
Action must be taken	19
Solving the problem	21
Campaign partners	24



# Summary

Living with a neurological condition is a challenge. Consistent access to high quality, reliable information is fundamental to people's ability to manage their condition effectively and maintain the best possible quality of life. Yet despite the fact that a clear policy exists, and has been set out since 2005 in the National Service Framework (NSF) for Long-Term (neurological) Conditions, the reality is still very far from those aspirations.

This report is based on the findings of two pieces of research commissioned by the campaign partners: the Taking Control survey and a series of focus groups of people with neurological conditions. We found that the problem is not that the information does not exist, but that it is not getting into the hands of the people who need it. It is clear that the opportunity exists for healthcare providers to bring about dramatic improvements in the situation, by ensuring that people with neurological conditions can easily find consistently high quality, reliable and accessible information about their condition and its treatment. This should be a priority from the first time they seek support for their neurological symptoms and throughout their illness.

Someone in the UK is diagnosed with a neurological condition every minute and this figure is on the rise. There is no excuse for further failure to implement the NSF commitment on information. It could be done rapidly, at minimal cost and to significant effect. We urge all those involved in the care of people with neurological conditions to take action now.

**We believe that, as a minimum, people with a neurological condition should be able to expect:**

1. To be treated by health professionals who attach priority to giving information to patients
2. To leave the appointment at which their diagnosis is suggested or made with a minimum information pack consisting of:
  - adequate information about their condition and their treatment in a format which suits them
  - a copy of the Ask About Medicines guide **Finding and Using Information about Health and Medicines**
  - a copy of the Neurological Alliance's guide **Getting the Best from Neurological Services**
  - contact details for a specialist team
  - contact details for a relevant patient support group
  - a date for a follow-up appointment at which there will be an opportunity to discuss the condition and its treatment in greater detail and to ask questions
3. To have a single, well-informed and accessible point of contact for on-going information about their condition and treatment

# Neurological conditions

A neurological condition is a disorder that affects the central nervous system (brain and spinal cord, the autonomic nervous system, or the peripheral nervous system). These conditions are the most widespread cause of major disability and they have a significant, although frequently undervalued, impact on health and social services.

Neurological conditions affect people of all ages. They can begin at any time in a person's life. Many neurological conditions cannot be foreseen or prevented.

There are many different neurological conditions. Well known examples include Parkinson's disease, multiple sclerosis, motor neurone disease, epilepsy and muscular dystrophy.

## The prevalence of neurological conditions

- 600,000 people in the UK are diagnosed with a neurological condition every year; this means that more than one person is diagnosed with a neurological condition every minute.
- There are over 10 million people in the UK living with a neurological condition which has a significant impact on their lives.
- Over one million people (over 2% of the UK population) are disabled by their neurological condition. They may need some help with daily tasks, and are likely to be out of full-time employment.
- Approximately 350,000 people require help for their daily activities because of a neurological condition.

These figures may be underestimated, as the NHS does not collect prevalence information. It should.<sup>1</sup>

1. Source: Neurological Alliance.

See also "Filling the Void: how real life health information builds better services", Sue Ryder Care, 2007

# The National Service Framework for Long-term (neurological) Conditions

Published in 2005 by the Department of Health, the National Service Framework (NSF) for Long-term (neurological) Conditions is a key tool for delivering the government's strategy to support people with long-term conditions in England. The NSF aims to build on changes in NHS management and commissioning to bring about a structured and systematic approach to delivering treatment and care for people with long-term conditions. The NSF applies to health and social care services working with local agencies involved in supporting people to live independently, such as providers of transport, housing, employment, education, benefits and pensions. It aims for more joined-up, responsive social care services that will enable people to live independently in the community.

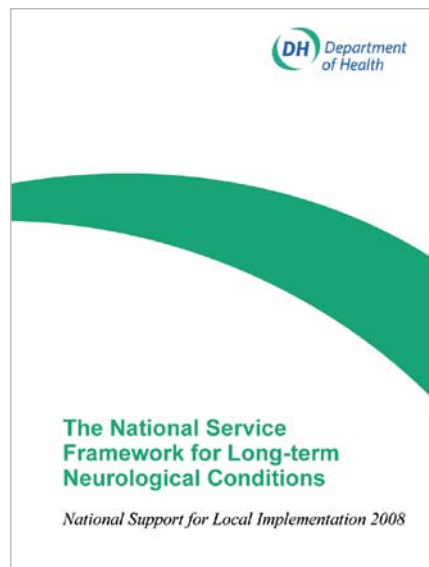
At the heart of the NSF are 11 quality requirements (QRs), based on available evidence that included what people with long-term neurological conditions had reported about their experiences and needs. The QRs are focused on ensuring:

- A person-centred service
- Early recognition, prompt diagnosis and treatment
- Emergency and acute management
- Early and specialist rehabilitation
- Community rehabilitation and support
- Vocational rehabilitation
- Provision of equipment and accommodation
- Provision of personal care and support
- Palliative care
- Support for family and carers
- Care for people with neurological conditions in hospital or other health and social care settings.

The QRs are to be fully implemented by 2015.

The NSF does not address individual neurological conditions separately, as there are so many elements of service provision common to different conditions. However, the QRs are designed to put the individual at the heart of care and to provide a service that is efficient, supportive and appropriate at every stage from diagnosis to end of life. The emphasis throughout the NSF is on supporting people to live with long-term neurological conditions, improving their quality of life and providing services to support independent living.

The NSF is supported by a web-based NSF Good Practice Guide, an NSF Information Strategy, a leaflet for the public and a glossary of terms (see [www.dh.gov.uk/longtermnsf](http://www.dh.gov.uk/longtermnsf)).



# Information prescriptions

In the 2006 White Paper, *Our Health Our Care Our Say*, the Government published its commitment that:

“By 2008, we would expect everyone with a long-term condition and/or long-term need for support – and their carers – to routinely be offered information about their condition...”

The White Paper explains that:

“The information will be given to people using services and their carers by health and social care professionals (for example GPs, social workers and district nurses) to signpost people to further information and advice to help them take care of their own condition.”

Subsequently, between January 2007 and January 2008, the Department of Health piloted information prescriptions in twenty sites in England, to inform implementation across the country. At the time of publication it remains unclear how and to what extent information prescriptions will become part of the routine practice of all health and social care professionals. And as there is no national strategy for implementation, there is a strong likelihood of variation in local provision.





# The Taking Control Survey

In order to gain a deeper understanding of the information needs of people with neurological conditions, a partnership between the Neurological Alliance<sup>2</sup>, the ABPI<sup>3</sup> and Ask About Medicines<sup>4</sup> commissioned the Taking Control survey and conducted a series of focus groups with people with neurological conditions.

Key findings from the survey<sup>5</sup> included:

**only half** (51%) understood what their diagnosis meant when they first received it

---

**70%** were given no advice at diagnosis about where to seek further information on their condition

---

**fewer than a fifth** (18%) say they have enough information about medicines for their condition

---

**only a third** (34%) feel confident asking questions about medicines for their condition

---

**more than 4 in 10** (43%) do not have the name and telephone number of a specialist team whom they can call to ask questions.

---

The research also confirmed that patient groups, other people with the same condition, specialist doctors and specialist nurses are all sources of useful information for people with neurological conditions, but people are not routinely given advice about where to obtain information, and access to specialists is limited. The amount of contact with their neurologist after diagnosis is varied, and many patients search for information on their own rather than relying on regular appointments as a source of information.



- 2 The umbrella group linking over 50 brain and spine charities
- 3 The trade association for more than 75 companies in the UK producing prescription medicines
- 4 The independent campaign to increase people's involvement in decisions about their use of medicines
- 5 Conducted by the Neurological Alliance among 1001 people with neurological conditions, November 2007.



Getting the best from neurological services

# The information shortfall

## Why information matters

Neurological conditions are often debilitating, frequently permanent, often progressive and always life-changing. In many cases the treatments on offer are limited. High-quality information allows people to navigate their way through complex, fluctuating conditions and disjointed services, enables them to make informed choices and helps to reduce fear and isolation. Crucially, it also supports effective partnership between healthcare professionals and patients.

Conversely, lack of information can lead to people with neurological conditions being denied access to care that could improve their quality of life and slow down the progression of their condition.

## The importance of timely information

People with neurological conditions need different information at different stages in their journey to help them navigate the many aspects of their condition, including:

- identifying potential symptoms or having them detected
- diagnostic tests
- diagnosis
- medicines
- other treatment options (e.g. physiotherapy, surgery, lifestyle changes)
- clinical trials
- experimental treatments
- side effects
- managing symptoms (e.g. pain control)
- day-to-day living
- communication with and reactions of friends and family
- emotional issues
- employment and financial issues
- self help
- end of active treatment or the transition from active to palliative care.

Focus group participants talked about their desire for information about side effects, drug interactions, and the availability of treatments, especially new ones.

Diagnosis is a particularly important time. Receiving a neurological diagnosis can be a shocking experience, and it happens to someone every minute<sup>1</sup>.

The Taking Control survey found that

**only half** (51%) of those surveyed understood their diagnosis

**67%** did not feel they had asked the doctor who made the diagnosis the questions they needed to ask

**70%** were given no advice at diagnosis about where to seek further information on their condition.

“At diagnosis my GP did not offer me any information on my condition to take home to digest and pass on to my family. In the end I turned to the internet and have learned more from other sufferers than the experts. As far as my GP goes he just gives me a repeat prescription and that is that!”  
Person with trigeminal neuralgia.

It is perhaps not surprising that people are often too confused to ask a range of questions straight away. But it does mean that everyone who receives a diagnosis should leave with the assurance that there will be a follow-up appointment and the contact details of a source of information (ideally both a patient organisation and the specialist team).

Findings from the Taking Control survey and focus groups also illustrate how people vary in their reaction to diagnosis. Many, even if they are aware of the condition, are shocked and unable to take in information immediately.

“At our first meeting, my consultant came straight out and said he thought I had Parkinson’s disease. I was there on my own and in a state of shock. He sent me to have a blood test and an appointment was made for six months time. I really don’t remember much more about that afternoon or how I arrived home, it felt like my life was over, I couldn’t take it all in and very briefly I thought about suicide.”

Woman with Parkinson’s disease



1. Source: Neurological Alliance

## Emotional support

The need for emotional support in accepting diagnosis, communicating with friends and family, and living with a long-term health condition should not be underestimated. The focus groups provided the opportunity to explore this.

“There is not enough support given about the emotional side of the illness.”

Woman with Parkinson’s disease

Some people who had suffered undiagnosed for years had found the diagnosis an enormous relief, as it offered them the hope that they could find treatment and get on with their lives at last.

“Being fit I put MS on the backburner, I didn’t want to know what I had and was in complete denial ... I didn’t want any drugs ... didn’t want anything.”

Man with multiple sclerosis

Experience suggests that not having good information about the benefits of taking medication can lead people to ignore their condition and avoid taking any treatments until their symptoms worsen, with potential longer-term effects on progression of the condition and on their quality of life. People with neurological conditions need to be encouraged to ask questions about their medicines and any alternative options that might be available to them.

Participants were eloquent about their need for information and advice to come to terms with both their diagnosis and how it will change their lives in the longer term.

Alternatively, others described not wanting to face up to the diagnosis and going into denial as a coping strategy.

“I am an intelligent person who is struggling to cope with a condition which has taken away my independence. I put on a brave face for everyone else but it feels like I am living in two worlds. I go to work but am not as able as my colleagues, which isolates me, but am not so disabled that I can’t mix in that world. My husband is physically supportive and so are my friends, but they have their own lives. I hate being so dependent.”

Woman with muscular dystrophy

“I was treated as if the symptoms were all in my head for the last ten years, so it is a great relief to finally have been diagnosed.”

Man with multiple sclerosis



## System failure

The Taking Control survey shows high demand for information from people with neurological conditions, and it is widely recognised that improved outcomes can very often be achieved if those affected are involved in the management of their condition. The NSF Quality Requirement 1 acknowledges this in describing high-quality information as the “core requirement” which “underpins all the other QRs”. It is all the more disappointing, therefore, that the Taking Control survey found that:

**only 18%** of respondents have as much information as they need about their condition

---

**only a third** (35%) know how to find information about medicines for their condition

---

**over a third** (36%) received no information at all from their GP

---

**43%** do not have the name and telephone number of a specialist nurse or doctor team whom they can call to ask questions about their condition or treatment.

---

“Having been diagnosed at an early age at 37 I feel I am left to get on with my illness. I am now pregnant and I can hardly find any information on pregnancy and PD – it is a case of shut my eyes and hope for the best.”

Woman with Parkinson's disease

Findings from the focus groups echoed the survey findings and specifically contrasted the strong desire people have for information with the difficulty many of them experience in getting it from specialists and healthcare professionals, leaving people unguided and often frightened.

“On diagnosis I was given no information at all about my type of MS, what it might mean to me, nor was I directed towards any information sources. Only on speaking to a friend did I realise that my worst imaginings would not necessarily come true.”

Woman with multiple sclerosis

The Taking Control research suggests that, so far, little progress has been made in implementing the admirable sentiments expressed in the NSF Quality Requirement 1. Indeed, it appears that the healthcare system is failing people with neurological conditions by neglecting to ensure access to the promised high-quality information and specialist advice.



# Good information, poor access

## The voluntary sector

The irony is that there is no shortage of information sources to which people could easily be referred. Patient groups, other patients, specialist doctors and specialist nurses are all sources of useful and valued information for people with neurological conditions. Yet people are not routinely given advice about where to obtain information, and access to specialists is limited.

The voluntary sector is a rich and vibrant source that could and should be used much more consistently. As well as producing a wealth of high quality information concerning diagnosis, treatment options and support services, patient organisations are able to put people in touch with others with the same condition. Standards are high – medical information is normally checked by medical advisers or scientific committees – and the value of the practical tips and emotional support that people can gain from others who are in the same boat is considerable, as well as being very much in tune with the Government's emphasis on patient expertise.

"It took five years to find a local group ... found it by fluke."

Person with multiple sclerosis

It ought to be routine for specialists and GPs to give people with neurological conditions information about contacting the relevant patient organisation. All too often this is not done, meaning that people who lack the skills, confidence or tools to search for such information miss out on the support and advice they could gain. Health inequalities are reinforced when information and support are not freely available to all.

"Transverse myelitis is a rare disease and therefore not many people have heard of it or have experience of it. Thankfully, the TM Society is working hard to create greater awareness and redress the balance somewhat. They are great at circulating information and offering support. Apart from the society there is very little out there to support sufferers of TM."

Person with transverse myelitis



The survey and focus group work showed how important the information provided by patient organisations, and the opportunity to speak to other people with their condition, are for people with neurological conditions.

According to the survey,

**94%** of people who got information from patient organisations, and **89%** of those who got information from other patients, described it as very useful or quite useful.

Focus group participants echoed these results repeatedly. This highlights why it is so important that people are given contact details for patient organisations immediately on diagnosis. Yet

**69%** of survey respondents said they had been given no advice about where to seek further information on their condition at diagnosis

**32%** had not had information from a patient organisation

“I was born with Tourette’s syndrome but was turned away by my GP constantly until I was 23 years old and contacted MIND for help. Whenever I discussed my symptoms with my GP he was rude and uninterested, once he actually told me to ‘go away and sort my life out’. My schooling suffered, my work life suffered and three suicide attempts later my GP still wasn’t interested. Luckily MIND gave me the information that would pave the way to a proper diagnosis. The Tourette’s Syndrome (UK) Association and my specialist have also been a godsend to me. Local health authorities ought to be ashamed of themselves. Unfortunately I still feel bitter about the way I was treated for most of my life by my local practice and local hospital. Still, I got there in the end!”

**Man with Tourette’s syndrome**

Focus group participants acknowledged that they had found real value in talking to other people with the same condition, and carers.

“I wouldn’t accept my injury for the first year. I was only 22 and had my whole life in front of me. It wasn’t until Headway got in touch and talked me through it that I started to believe that I was living with a brain injury and that it wouldn’t stop me doing the usual life things – it is thanks to them for the person that I am today.”

**Woman with severe brain injury**



“I have not been given any rehab treatment whatsoever and when I phoned the hospital at the early stages to try and ask about the situation, I was informed by the registrar that had attended me that he was busy and had really sick people to see. The only real support I have is through the TM Support Group, and the love and help of my family and colleagues.”

**Woman with transverse myelitis**



Focus group participants felt that specialists and healthcare professionals could do more to put patients in touch with relevant voluntary organisations.

“For some reason in my experience as a person with MS and as a committee member now of an MS Society Branch not one health care professional in 11 years ever recommended I turn to these purpose built organisations for help. Why is this? Furthermore the GPs in my area in the main do not know we have an MS nurse or how to contact her.”

Woman with multiple sclerosis

“It always struck me that people who suffer from the disease know more as a group. GPs don’t always think about the support groups.”

Man with Parkinson’s disease

“The only information I received was from the MS Society, which I orchestrated myself. When I was first diagnosed I asked the neurologist if there was anything for me to read, he said no and never mentioned anything about the MS Society.”

Person with multiple sclerosis

“If someone had introduced me to other young able-bodied people with MS it would have helped me out of my denial and to deal with the diagnosis. It was a really big weight off my shoulders when I had the opportunity to meet other normal people with the same condition through a support group.”

Woman with multiple sclerosis



## Specialists and health professionals

The survey demonstrated how much people with neurological conditions value getting information from specialists, and how patchy their ability to do so is. According to respondents:

**36%** did not get a chance to see a specialist doctor or nurse to ask more questions after diagnosis

---

Of those who got information from specialist doctors, **79%** found it very useful or quite useful

yet **27%** of respondents had not seen a specialist doctor in the last 12 months

---

Of those who got information from specialist nurses, **86%** found it very useful or quite useful

yet **61%** of respondents had not seen a specialist nurse in the last 12 months

and **46%** had had no information from specialist nurses

---

Disappointingly, potential information sources close to home are not proving as forthcoming or as useful as ought to be expected:

**36%** had had no information from their GPs

and only **58%** of those who did get information from this source said they found it very useful or quite useful

---

**66%** had had no information from pharmacists

and only **58%** of those who did get information from this source said they found it very useful or quite useful.

---



## Specialist doctors

The survey finding that 27% of respondents had not seen a specialist doctor in the past 12 months was echoed by focus group participants.

“Living in North East Hants, there is a lack of services for MS patients, no MS nurses and what’s a neurologist? I have no primary point of contact. I would recommend that any one with MS doesn’t take up residence in this area.”

Man with multiple sclerosis

“My GP told me that neurologists don’t want to be bothered by people like me, so he would not refer me to one. My condition has worsened considerably and I have developed some very distressing symptoms but I can’t get anyone to take me seriously. Sometimes I am patronised and pacified by the medical profession but mostly I am ignored, mocked and derided.”

Woman with myalgic encephalomyelitis (ME)

## Specialist nurses

“My MS nurse Sheila is amazing – she is my safety net, as I know I can always turn to her. If any problem occurs, one call and the problem is discussed and 99% of the time resolved. She also gives me information on medicines so that I am able to have a voice in choosing which medication I would like to take.”

Woman with multiple sclerosis

Neurological conditions are a multidisciplinary concern, and different professionals play a role at different times in the patient journey. Nurse specialists could make a significant contribution to the organisation and development of services to help people with neurological conditions, and they are likely to be pivotal in innovating and co-ordinating the provision of patient information.



It is cause for concern, therefore, that according to the Taking Control survey:

**only 40%** of respondents saw a nurse specialist in the last year

**nearly half** (46%) had obtained no information from a specialist nurse

yet **86%** of those who did get information from specialist nurses found it very useful or quite useful.

Specialist nurses often play a central role in facilitating communication and the flow of information across the healthcare team, before, after and between appointments with consultants. They provide expert advice, support and advocacy for people with neurological conditions throughout their journey and so may be ideally placed to co-ordinate their information needs as they change. It is essential that people with neurological conditions can access effective help and advice when problems or concerns arise between scheduled appointments, and contact with nurse specialists is one important way that information can be provided. There are already not enough nurse specialists and it is deeply worrying that some of those posts that do exist are under threat.

## The internet

Most of the focus group participants got further information about their condition by their own research, mainly via the internet. The internet can be an excellent source of health information, and many websites offer high quality, evidence-based information. But it should not be the only place where people with neurological conditions can go to find the information they need.

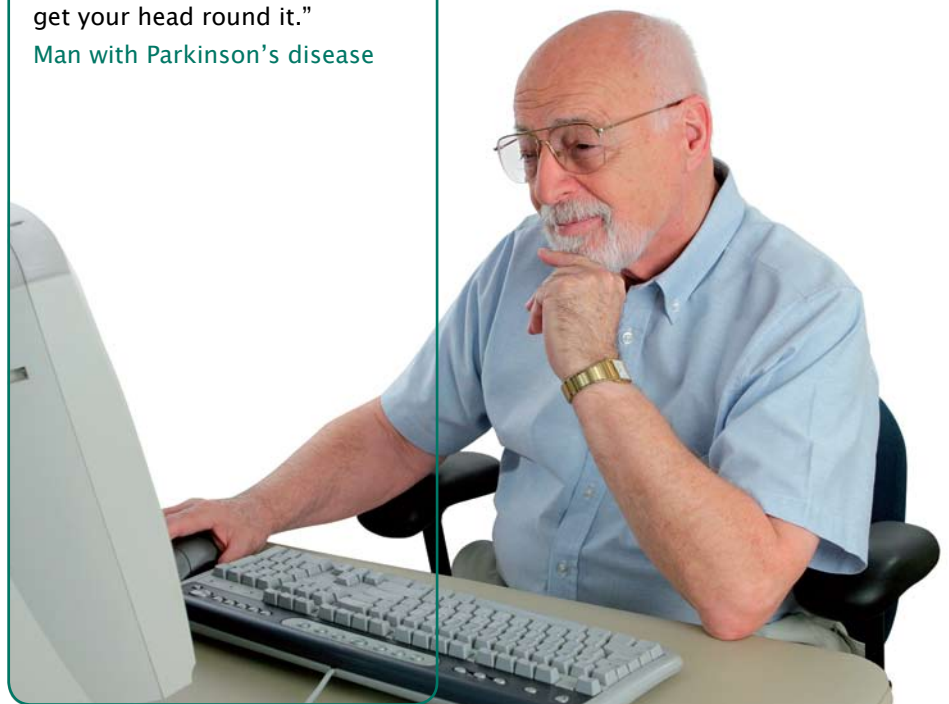
One of the major barriers to understanding neurological problems is the diversity of each condition. People can have very different experiences of the same condition, and interpreting general information in a way that is relevant to the individual case is often a challenge.

Additionally, not all online information is reliable, and people's fears may be exacerbated, or their hopes unfairly raised, if they are not able to discuss what they have read with a professional who is familiar with their circumstances.

The Ask About Medicines guide, **Finding and Using Information about Health and Medicines**<sup>6</sup>, is an example of the kind of guidance that can be given to people to help make their individual research a truly informative process.

"The internet can drown you in dubious information and you end up convinced you are more ill than you really are. Maximum help is needed immediately on diagnosis – it shatters your world until you get your head round it."

Man with Parkinson's disease



# Action must be taken

It is simply not acceptable that the situation described in this report should continue. The more that people understand about their condition and the treatments that are available, the better equipped they are to make informed choices about treatment and therapies. There is a growing and diverse evidence base which collectively supports the argument that when doctors and nurses work together with patients in decision-making about medicines, medicines are used more effectively.

According to the Task Force on Medicines Partnership:

- **Patients must have enough information about their illness and treatment options to take an active role in decision making.**

This information must be clear, accurate and sufficiently detailed, and tailored to their individual needs<sup>7</sup>.

- **Prescribing consultations must involve patients as partners, to the extent that they want.**

During the consultation, patients should be asked about their views and beliefs about their illness and treatment, and these must be explored fully before a decision on treatment is reached jointly between the health professional and the patient<sup>8,9</sup>.

- **After a medicine has been prescribed, patients should have access to ongoing support so that any problems or questions that may arise can be addressed.**

Health professionals should use all opportunities to talk with patients about how their treatment is progressing and resolve any practical difficulties, and medicines should be reviewed regularly, with patients.

Research from the Picker Institute shows that having access to good quality information in suitable formats, particularly when supported by guidance from a health professional, can have a number of positive effects, including increased levels of confidence and involvement in decision-making processes, reduced anxiety and isolation, and improved self-care behaviours and clinical outcomes. The authors emphasise that patient information is likely to be a critical component of successful approaches to improving the well-being of patients with low health literacy<sup>10</sup>.

The role of good quality information in improving the health and well-being of people with neurological conditions is clear. Action must be taken to implement, for all people with neurological conditions, the promise made in 2005 in the National Service Framework.

7 Dickinson D, Raynor DK: Ask the patients—they may want to know more than you think: *BMJ* 2003;327:861,

8 Makoul G, Arntson P, Schofield T (1995): Health promotion in primary care: physician-patient communication and decision making about prescription medications. *Soc Sci Med*; 41 (9): 1241–1254.

9 Barry C, Bradley C, Britten N, Stevenson F, Barber N: Patients' unvoiced agendas in general practice consultations: qualitative study *BMJ* 2000;320:1246–1250

10 Coulter A, Ellins J et al: Assessing the quality of information to support people in making decisions about their health and healthcare: Picker Institute Europe, 2006.



**Parkinson's Disease Society**

**Kinetic crisis pain is usually improved by treatment with levodopa drugs.**

**Headaches in Parkinson's** are rarely severe and normally over the counter painkillers are adequate. People with Parkinson's should care not to take a large number of tablets together at one time, particularly if they are taking medication for high blood pressure or heart problems. The tablets need to be spaced out as together they may, in fact, cause headaches. Severe, drug resistant headaches are rare in Parkinson's and if present need to be investigated by a neurologist.

**Muscle cramps** will often be alleviated by treatment for Parkinson's. For example, night-time cramps may be helped by prolonging the action of levodopa and using a controlled release preparation. Otherwise soluble levodopa dissolved in fizzy orange juice may help, taken when cramps are painful. In some situations, when there is severe off-period-related bowel cramps, spongy sulphate tablets are often prescribed. Quinine sulphate tablets are often prescribed for cramps, but caution is required as these tablets may sometimes lead to abnormal low levels of blood cells and so require monitoring. Some tonic waters contain quinine and may help if taken at night. However check that the drink

**Parkinson's Disease Society**  
 215 Watford Street Road London W11 1NF UK  
 Tel: 020 7614 9688 Fax: 020 7223 0662  
 Helpline: 0800 857 0013 Telephone: 020 7662 3100  
 Email: [enquiries@parkinsons.org.uk](mailto:enquiries@parkinsons.org.uk)

© Parkinson's Disease Society of the United Kingdom (2008)  
 Registered Charity No. 292197 A company limited by guarantee  
 Registered No. 448379 (England)  
 Registered office: 215 Watford Street Road London W11 1NF UK  
 Registered May 2008

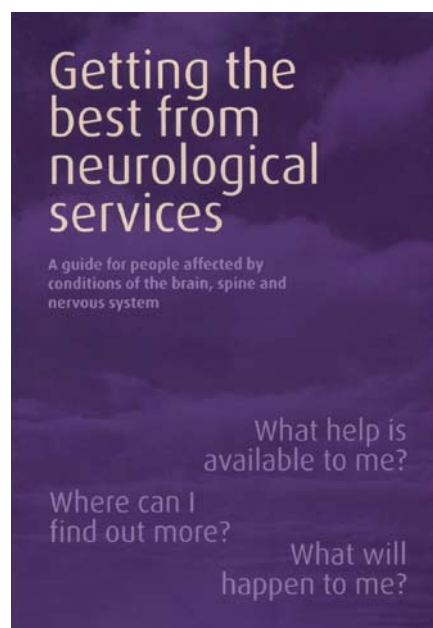
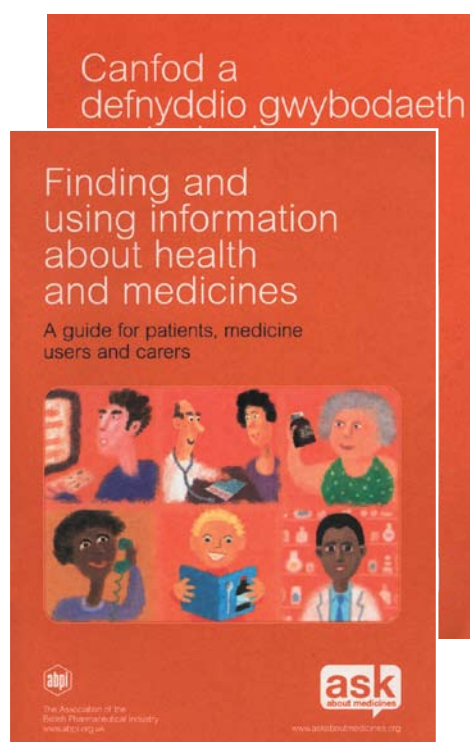
© Parkinson's Disease Society of the United Kingdom  
 Registered office: 215 Watford Street Road London W11 1NF UK  
 Registered No. 448379 (England)  
 Registered May 2008

# Solving the problem

The NSF and the “Our Health Our Care Our Say” white paper have given us the policy. Patient organisations and campaign groups have produced effective guides to help people access good quality information. There is no real need for people with neurological conditions to go uninformed.

**As a minimum, someone with a neurological condition should be able to expect:**

1. To be treated by health professionals who attach priority to giving information to patients
2. To leave the appointment at which their diagnosis is suggested or made with a minimum information pack consisting of:
  - adequate information about their condition and their treatment in a format which suits them
  - a copy of the Ask About Medicines guide **Finding and Using Information about Health and Medicines**
  - a copy of the Neurological Alliance’s guide **Getting the Best from Neurological Services**
  - contact details for a specialist team
  - contact details for a relevant patient organisation
  - a date for a follow-up appointment at which there will be an opportunity to discuss the condition and its treatment in greater detail and to ask questions
3. To have a single, well-informed and accessible point of contact for on-going information about their condition and treatment.



We believe that, with commitment from all sides, it is possible to take huge steps towards solving this problem rapidly. This is one part of the NSF that can be implemented quickly and at low cost.

#### Solutions may lie in:

- Promoting the use of model questions, information prescriptions and guides to information sources
- Ensuring GPs can readily access information about neurological conditions and know when to refer people to specialist services
- Ensuring effective distribution of **Getting the Best from Neurological Services** (which guides people with a neurological condition through the different services they may need at different times)
- Patient organisations ensuring that their information and contact details are easily accessible
- Promoting wider use of the Brain and Spine Foundation's **Information Access Toolkit**
- Building a greater communication module into the training of neurologists
- Working with the Association of British Neurologists to ensure that every neurologist understands the value of the minimum information pack and has access to the core documents
- Ensuring health and social care professionals pass on information about relevant patient organisations as early as possible after diagnosis
- Developing the neurological conditions content of the NHS Choices website and encouraging healthcare professionals and patients to use this resource
- Promoting wider use of the Ask About Medicines guide **Finding and Using Information about Health and Medicines**

The campaign partners are committed to tackling this problem without delay, by bringing together a Task Force of motivated stakeholders – including specialists, health professionals, commissioners and managers of services, and people with neurological conditions – to develop and then monitor a practical Action Plan that can be implemented rapidly.





# Campaign partners



## **The Neurological Alliance**

is the campaigning group of over 50 national and local third sector organisations fighting to improve services for people with a neurological condition.

[www.neural.org.uk](http://www.neural.org.uk)



## **The Association of the British Pharmaceutical Industry**

is the trade association for about 75 companies in the UK that produce prescription medicines. As part of their role, they have encouraged Datapharm to develop and publish medicines information for patients, which is available online at [www.medicines.org.uk](http://www.medicines.org.uk).

[www.abpi.org.uk](http://www.abpi.org.uk)



## **Ask About Medicines**

is the independent campaign to increase people's involvement in decisions about their use of medicines.

[www.askaboutmedicines.org](http://www.askaboutmedicines.org)



People with long-term neurological conditions are to have the information they need to make informed decisions about their care and treatment and, where appropriate, to support them to manage their condition themselves.

National Service Framework for Long-term Conditions

Quality Requirement 1

March 2005

## Taking Control: our right to information

People with neurological conditions speak out

A report by the Neurological Alliance, the Association of the British Pharmaceutical Industry (ABPI) and Ask About Medicines – September 2008

