



*Working for people living with brain disorders*

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A Guide of good practice for cooperation between doctors  
and Patient Associations for chronic neurological disorders  
in Europe.

The present guide was officially launched at the congress of the European Federation of Neurological Societies (EFNS) in Madrid on August 26<sup>th</sup>, 2008 and will be subject to regular updating.



## Introduction

The guide is based on the principles of the European Parkinson's Disease Association (EPDA) Charter for people with Parkinson's disease and the satellite symposium held in Luxembourg on 23 March 2007 organized by the European Board of Neurology, section of the Union Européenne des Médecins Spécialistes (UEMS) with representatives of the European Federation of Neurological Associations, the European Parkinson's Disease Association, Alzheimer Europe and the European Headache Alliance.

Patient Associations are Non Governmental Associations named in the document PA/NGOs formed around the needs of patients with a specific medical (neurological) condition or a group of related medical (neurological) conditions. The different neurological PA/NGOs have activities specific to the conditions they represent, the present documents deals with needs, aims and objectives common to all PA/NGOs. The guide's aims at promoting and addressing the principles of cooperation between Medical Organizations or individual doctors with PA/NGOs at national and international level within Europe.

The principles of the cooperation are based on mutual respect and partnership, high ethical standards and avoidance of conflicts of interest. The common aim is the improvement of care and quality of life of the persons affected by the various neurological conditions and to promote research in brain disease.

The value of a good cooperation in partnership is mutual for patients and doctors and eventually beneficial for society at large. Brain disease represents a huge burden on society and is likely to increase with an aging population and better control of other conditions like cardiovascular disease and cancer.

It should lead to enhanced public awareness of the impact of neurological conditions on society and to a less negative public attitude to chronic neurological illnesses and reduce stigmatisation and discrimination by the general public.

The guide should help to promote a better understanding between patients and doctors, improve information for the patients about the various conditions and help PA/NGO to develop strategic approaches and tactical decisions according to current medical insights, opportunities and new developments. The cooperation can help to identify outcome measures from 'the patient's point of view' in the development of guidelines and protocols and incorporate 'the patient's view' in research projects.

## Guide:

Patients with a chronic neurological condition have

the right to:

- Be referred to a doctor with a special interest in their condition
- Receive an accurate diagnosis
- Have access to support services
- Receive continuous care; and
- Take part in managing the illness

### At the moment of diagnosis

- Have the right to a correct diagnosis and access to a doctor with an interest in their condition
- To be informed of the diagnosis (unless the patient has stated previously that they do not wish to be informed)
- Receive support for the patient and carer, following the diagnosis.

### Improving communication between doctors and patients

- Skills in ‘how to break bad news’ should be developed and understanding encouraged of the initial shock experienced by patients when diagnosed
- Dialogue between doctors and patients improved to ensure that patients are informed in a way that corresponds to their needs and expectations
- Patients need to be educated to ask their doctor the right questions i.e. Patients Decision Aid
- Doctors need to ask the right questions to ensure that they can provide the right answers concerning improving quality of life and providing respect to the patients’ knowledge and experience of their particular condition i.e. Patient Decision Aid.

### Providing Continuous care by:

- Receiving continuous and appropriate care by a doctor and team of healthcare professionals who have an interest in their condition
- Encouraging the development of multidisciplinary teams to improve disease management
- Ensuring that carers are involved and consulted in the management (with the consent of the patient)
- Arranging care across the full spectrum of the conditions, structured in accordance with the results of cost effectiveness studies
- Improving informed consent procedures and promoting that patients take part in the management of their illness.

### Providing accurate information by:

- Creating information resources for patients which are accessible, honest and validated
- Campaigning against treatment procedures that do not respond to patients’ real needs.

### Enhancing awareness of stigma and discrimination by:

- Increasing public awareness and overcoming society’s negative attitudes towards chronic neurological and psychiatric illness, through education, thereby reducing stigma and removing discrimination
- Supporting partnership between doctors and other health care professionals with PA/NGOs representing patient interests to promote better understanding of the various conditions.

Education and research:

- Contributing in the identification of relevant outcome measures in research
- Encouraging participation of European PA/NGOs in the dialogue between researchers, academia and governments
- Contributing to the development of practice guidelines and their implementation
- Encouraging research in brain disorders
- Lobbying for funding with authorities and industry for support and research
- Encouraging the support of PA/NGOs with funding applications to the European Commission.

To achieve these goals:

- PA/NGOs to work in partnership with doctors, healthcare professionals, industry, academia and politicians.

The aim of the partnership being:

- To encourage legitimate, good and trustworthy cooperation between doctors and PA/NGOs utilising their complementary roles.

NGOs remit:

- A nationally or European registered association
- Work to an agreed Memorandum & Articles of Association
- Have an Elected Board (numbers determined by the Memorandum & Articles of Association) and publicise
- Appoint a Medical Advisory Board and publicise
- Hold a Bank Account and produce annual audited accounts
- Hold an annual General Assembly
- Clear Aims and Objectives of what they wish to achieve within a specified timescale (Business Plan)
- PA/NGO representatives should be free of conflicts of interest regarding industry, public or private health insurance or health care providers
- Develop a Code of Practice that supports the ethos of the organisation
- Debate financial support with industry and other external organisations ensuring that Code of Practice is maintained
- Ensure transparency with regard to all funding and support received
- Legitimacy demonstrated by its Business Plan, work programme and record of activities.

Medical Advisory Board

- PA/NGOs should have a Medical Advisory Board
- The doctors appointed to the Medical Advisory Board should have a special interest and be opinion leaders (nationally respectively at European level) in the condition represented by the NGO
- Should receive an official endorsement of their professional or scientific association.

Responsibility and accountability of Medical Advisory Board

- To provide the PA/NGOs with the benefit of their professional and scientific knowledge
- Provide validation of information and educational material produced by PA/NGOs
- Collaborate with the PA/NGOs Board in the development of educational and research projects of mutual interest
- PA/NGOs meetings i.e. conferences should not be misused by the patients to seek personal consultations with the doctors present

- As a general rule it is recommended that doctors do not stand for election as a Board member of a national or European organisation unless retired.

#### Medical Research Grant application

- All Grant applications need to be discussed by the elected Board and appropriate Research Panel
- Should a member of the PA/NGO Medical Advisory Board be a participant in the Grant application, they should be given the opportunity to resign from the Panel or resign from the application
- This ensures that the professionalism and profile of the PA/NGO and doctor are not compromised.

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