
THE EUROPEAN PARKINSON'S DISEASE STANDARDS OF CARE CONSENSUS STATEMENT

Volume I, 2011

This Consensus Statement is the first of three volumes.

Volumes II (2012) and III (2013) will appear after the results of the second and third Move for Change surveys have been published. See pages 19-21 for more information.

CONTENTS

4	Executive summary
6	The cost of Parkinson's disease in Europe
8	Background to Parkinson's disease
	What is Parkinson's?
	Epidemiology
	Symptoms
	Multidisciplinary teams
	Stigma and discrimination
	The cost of Parkinson's
13	The Consensus Statement
	How people with Parkinson's should be managed
	What European policymakers need to do
18	About the EPDA
19	The EPDA and the need for a Consensus Statement
21	Further information
22	References
25	Evidence
	Summarised evidence of Parkinson's on quality of life
	The economic impact of Parkinson's
28	Glossary
30	Contributors

EXECUTIVE SUMMARY

THE FACTS ARE STARTLING. More than one million people live with Parkinson's disease (Parkinson's) in Europe today and this number is forecast to double by 2030 (Dorsey 2007). It is the second most common neurodegenerative disease (after Alzheimer's disease) and its prevalence will continue to grow as the population ages. And the economic impact of the disease is enormous – the annual European cost is estimated at €13.9 billion (Gustavsson et al 2011). Yet Parkinson's is just one of many neurodegenerative disorders, which will surpass cancer as the most common group of medical conditions by 2040 (WHO 2004).

THE EPDA

As a result of these facts, the European Parkinson's Disease Association (EPDA) – the only European Parkinson's umbrella organisation (representing 45 member organisations as of 2011) – exists to raise the profile of the disease in order to effect change at a European political level.

The EPDA's ultimate vision is to enable the 1.2 million people with Parkinson's in Europe (Andlin-Sobocki 2005) to live a full life while supporting the search for a cure. In order to do this, it aims to

become the leading voice for Parkinson's in Europe – providing innovative leadership, information and resources to national Parkinson's associations, European policymakers, the treatment industry, healthcare professionals and the media. In achieving these aims, the EPDA hopes to raise the profile of Parkinson's and enable people living with the disease to be treated effectively and equally throughout Europe.

CHALLENGES

Unfortunately, there are major obstacles to achieving these aims. Both the direct costs of the disease (such as consultations and medication) and the indirect costs (such as reduced working hours and institutionalisation) are a great cause for concern – as are the diverse and numerous motor and non-motor aspects of Parkinson's – while hospitalisation and healthcare utilisation rates are dangerously high.

Medication is another major challenge. It is currently considered to be the cornerstone of Parkinson's disease management but the right treatment for the right person is not consistently available across Europe. In addition, medication on its own is not sufficient to enhance and improve a person with Parkinson's quality of life. They also need access to other therapies – such as physio, speech and language, and occupational. It is the combination of all these elements that ensures holistic treatment, and they need to be made available to everyone.

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OPPORTUNITIES

Opportunities do exist, however, to improve the care for people with Parkinson’s in both the treatment and management of the disease. Early and appropriate pharmacological intervention has been shown to not only reduce the economic impact to both the individual and to society but also enable people living with the disease to remain in the workplace for longer, thereby enabling them to contribute to society.

CONSENSUS

Despite the fact that Parkinson’s affects so many people and represents such a significant economic threat to European society, there is not – and has never been – a ‘consensus’ on Parkinson’s management or an agreed definition of what should constitute good-quality Parkinson’s care. Until now.

The European Parkinson’s Disease Standards of Care Consensus Statement combines the evidence of the economic and emotional cost of Parkinson’s across Europe with the specialised knowledge of a host of Parkinson’s experts. These experts include neurologists, geriatricians

and members of the various multidisciplinary teams as well as people with Parkinson’s and their carers. Together, in a unified voice for the first time, they define a model for European policymakers to follow that will ensure the optimum management of Parkinson’s. In short, policymakers need to:

- support initiatives ensuring equal access for people with Parkinson’s to good-quality, specialised care across Europe
- reduce inequalities in the treatment and management of Parkinson’s
- improve funding for Parkinson’s research and define research priorities
- invest in optimum treatment and maintenance strategies
- increase public and professional awareness of Parkinson’s
- minimise stigma and discrimination
- strengthen the level of neurological care within European healthcare systems
- provide adequate funding that supports the continued work of national Parkinson’s organisations.

A UNITED FRONT

The European Parkinson’s Disease Standards of Care Consensus Statement is unique. It is the first document of its kind to support and encourage the drive for equality and optimisation of Parkinson’s treatment at both a European and a national level. It has been developed, reviewed and endorsed by European Parkinson’s specialists, people with Parkinson’s, carers and 45 national Parkinson’s organisations. For a full list of contributors, see page 30.

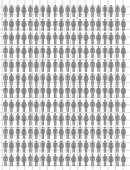
THE COST OF PARKINSON'S DISEASE IN EUROPE

The UK

In 2003, the annual cost of care per person for all people with Parkinson's by age was £5,993 (€9,975). A move from the home to residential care was associated with an estimated 500% cost increase.



=€4,421



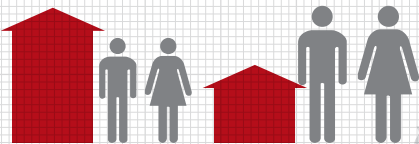
=€354m

France

In 1999, the average yearly cost of treating Parkinson's was estimated at €4,421 per person, resulting in an approximate expenditure of €354 million across the estimated 80,000 people with Parkinson's living in France.

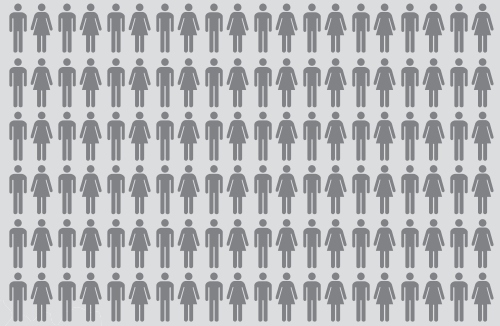
Spain

Direct costs were significantly higher in 2009 among younger people with Parkinson's and those with a greater severity of disease.



Sweden

Total direct costs of Parkinson's were €8,328 per person in 2011, of which only 21% were drug costs.

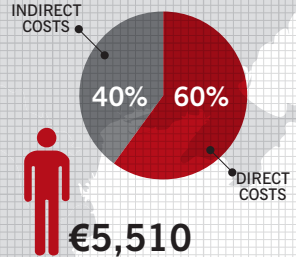


1,200,000+

The amount of people living with Parkinson's in Europe, according to the latest estimates (from 2005). This number is forecast to double by 2030.

The Czech Republic

Total semi-annual costs of Parkinson's were €5,510 per person in 2010. Direct costs accounted for 60%, while indirect costs accounted for 40%.



Germany

A 2010 German study revealed that the costs per person range from €18,660 for Hoehn and Yahr stages 1-2, and €31,660 for Hoehn and Yahr stages 2-5.

€18,660

STAGES 1-2

€31,660

STAGES 2-5



The severity of Parkinson's differs from person to person and every case is different.

€13.9 billion

The estimated annual European cost of Parkinson's. The economic impact of the disease is enormous.

BACKGROUND TO PARKINSON'S DISEASE

PARKINSON'S IS A PROGRESSIVE, chronic and complex neurodegenerative disease that has no cure. It affects all aspects of daily living and is the most common neurodegenerative disease after Alzheimer's disease. The incidence of Parkinson's is forecast to double by 2030 (Dorsey 2007) primarily as a result of the ageing population. Treatment and management is available for a number of aspects of the disease but is not yet accessible to all. Ongoing research has resulted in significant improvements but more is needed to delay, stop or even reverse the disease.

WHAT IS PARKINSON'S?

Parkinson's occurs as a result of the destruction of the nerve cells that produce the neurotransmitter dopamine in the pars compacta region of the substantia nigra in the brain (Chaudhuri 2006). Due to this lack of dopamine, messages in the brain fail to transmit smoothly to the muscles, resulting in difficulties controlling movement (Jankovic 2008). A similar destruction occurs naturally with ageing, but in Parkinson's the process is accelerated.

Although a complex disorder (Keus 2009), it is widely accepted that motor and some non-motor symptoms result from the greatly reduced activity of these dopamine-secreting cells due to premature cell death. In addition to dopaminergic cell loss, further lesions in non-dopaminergic systems are also common in Parkinson's, helping to cause the non-motor features of the disease (Lees et al 2009).

EPIDEMIOLOGY

There are more than 1.2 million people living with Parkinson's (Andlin-Sobocki 2005) in Europe. The average age of onset is 60 years, although more than one in 10 people are diagnosed before the age of 50 (Tanner 2002). Parkinson's is more prevalent in men than women, and may affect people of all ethnicities. It is important to remember that Parkinson's can affect anyone.

SYMPTOMS

Parkinson's is predominantly characterised by problems with body movements – known as motor symptoms. These symptoms include tremor, rigidity, bradykinesia and postural instability (Pankratz 2009, Reichmann 2010). However, Parkinson's is also associated with symptoms that are not directly related to movement – known as non-motor symptoms – which include loss of taste and sense of smell, sleep disturbances, gastrointestinal complications, constipation, swallowing

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disorders, anxiety, pain, fatigue, depression, sexual dysfunction, hallucinations and psychosis, impulse control disorders, cognitive impairment and dementia (Barone et al 2009; Aarsland et al 2009; Menza 2010; Wood 2010). These non-motor symptoms often result in the need for additional care outside that of the specialist neurologist or geriatrician (Hayes 2010). They may also be associated with dopaminergic and non-dopaminergic pathologies and some are specifically induced by dopaminergic treatment (Chaudhuri et al 2010; Rektorova 2010).

It is important to remember that both the motor and non-motor symptoms can bring on hospitalisation, which results in an increase in healthcare utilisation and a significant escalation of economic burden (Keus 2009, Lökk 2011).

While motor symptoms have long been thought of as the fundamental symptoms of the disease, the non-motor symptoms are increasingly being recognised as common and important components. Despite the fact that non-motor

symptoms are often poorly recognised (Chaudhuri 2006), they cause a significant impact on the quality of life of people with Parkinson's (Gómez-Esteban 2010; Martinez-Martin 2011; Soh 2011) and remain a major cause of hospitalisation (Muzerengi 2007). (See Table 1 on page 25 for data from three studies that indicate the impact of Parkinson's on quality of life at different stages of the disease and highlight the correlation with disease severity.)

The severity of Parkinson's will differ from person to person as every case is different. However, a person's disease severity is most commonly determined using the Hoehn and Yahr scale, where stage 0 shows no symptoms of the disease and stage 5 is the most severe form. While people with Parkinson's may not experience certain disease symptoms at all, others' symptoms are likely to vary from one day to the next (Politis 2010). Nevertheless, the effects of Parkinson's invariably involve the physical, cognitive and psychological domains and impact across nearly every cultural, social and economic boundary.

MULTIDISCIPLINARY TEAMS

Traditionally, the management of Parkinson's involved a single medical specialist – most commonly a neurologist or geriatrician. In some European countries, the situation has changed over the last two decades as it has been recognised that there is the need for a broad range of expertise to

optimally manage the disease. However, for the majority of countries this is not the case. Despite this fact, all people with Parkinson's and their carers should be involved in their own disease management and work with a variety of professionals – known as the 'multidisciplinary team' or 'support services' (Aragon 2010). Multidisciplinary teams may include:

- ! general practitioners
- ! neurologists
- ! geriatricians
- ! physiotherapists
- ! Parkinson's disease nurse specialists
- ! speech and language therapists
- ! occupational therapists
- ! nutritionists
- ! psychologists, ideally specialised in Parkinson's
- ! pharmacists
- ! complementary therapists.

A multidisciplinary team approach – including safety within the home appropriate to the stage of the disease as well as combining both pharmacological and non-pharmacological treatments – is the optimum approach for such a complex and multifaceted disease (Van der Marck 2009, Aragon 2010). It has been shown that Parkinson's disease nurse specialists form a key part of the multidisciplinary workforce (MacMahon 2006) and that the quality of life of people living with the disease can be improved with their support. In the same way, enhanced training for other healthcare

professionals would provide the specialist knowledge needed to recognise Parkinson's symptoms as early as possible. Unfortunately, however, the current delivery of healthcare services is inadequate and many people who require such care are not being referred to the relevant specialist (Keus 2009), although guidelines do exist that state the importance of such referrals (Royal Dutch Society for Physical Therapy 2004).

STIGMA AND DISCRIMINATION

Canadian-born sociologist Erving Goffman defined stigma in 1963 as “the situation of the individual who is disqualified from full social acceptance”. Since then, several studies have demonstrated that depression and anxiety – key Parkinson's non-motor symptoms – are associated with stigma (Tickle-Degnen 2011). Equally, the World Health Organisation states:

“**Public awareness of Parkinson's as a priority health challenge needs to increase. This would then reduce stigma and discrimination**”

“Barriers to effective care include the lack of resources, lack of trained providers, and the social stigma associated with mental disorders including depression.”

For people with Parkinson's, stigma and discrimination often results from a lack of public and professional awareness of the disease. Data from the EPDA's 2009 Perceptions of Parkinson's survey (which interviewed more than 5,000 members of the general public across Europe) indicated that although four in 10 people know someone with Parkinson's, two thirds of the population do not know how widespread the disease is or understand its challenges or impact. Therefore, there is a need to increase public awareness of Parkinson's as a priority health challenge, which would, in turn, reduce its stigma and remove discrimination against people with Parkinson's in the workplace.

In short, there are currently not enough employer strategies that support people with Parkinson's in the workplace – such as encouraging the provision of occupational therapy, granting flexibility to attend medical appointments, and giving employees with Parkinson's the option to work from home. Encouraging these actions is essential to increase disease awareness – both among employers and employees – and enable them to feel more accepted by society.

THE COST OF PARKINSON'S

The economic consequences of Parkinson's across Europe are considerable. The estimated annual total cost of the disease is €13.9 billion (Gustavsson et al 2011) and this figure will increase as the number of people with Parkinson's in Europe continues to grow.

It has frequently been shown that the annual cost of Parkinson's per person increases as the disease becomes more severe. A German study revealed that Parkinson's costs rose from €18,660 (for Hoehn and Yahr stages 1-2) to €31,660 (for Hoehn and Yahr stages 2-5 (Winter 2010). UK figures, meanwhile, support this view. A report stated that the annual cost per person with Parkinson's at Hoehn and Yahr stages 3-5 was approximately €72,277 (Findley

2011). Such costs are divided into direct costs (which include consultations, hospital admissions, tests and investigations) and indirect costs (which include early retirement, reduced working hours for carers and institutionalisation) (Hagell 2002, Lindgren 2004, Andlin-Sobocki 2005).

In addition, it costs approximately €8,300 more in healthcare bills for each person with Parkinson's compared to those who do not have the disease. This additional cost is attributed to longer stays in hospital, more days in long-term care (such as nursing homes) and increased

€13.9bn
The estimated annual cost of Parkinson's in Europe. This figure will continue to grow as the population ages.
See pages 6-7 for more on the cost of Parkinson's

numbers of prescriptions (Chen 2008). A UK study revealed that moving a person with Parkinson's from their home into residential care was associated with an approximate 500 per cent cost increase (Findley 2003). Similar studies have also shown significant increases in expenditure as symptoms progress (Hagell 2002, Dodel 2008, Findley 2007 and 2011. See also table 1 on page 25), while non-motor symptoms are a major source of hospitalisation and institutionalisation – both key cost-drivers in Parkinson's care – and have an impact on continuing employment (Dodel 2008).

It is important to note, however, that these figures do not represent the full picture. For example, indirect costs increase due to reduced earnings of both the person with Parkinson's and their family carer(s) combined with the hidden costs associated with the resulting loss of productivity (Chen 2008). (Table 2 on pages 26-27 provides a detailed summary of the economic cost of Parkinson's.)

In contrast, studies have shown that early drug treatment combined with therapeutic interventions can reduce the economic impact of Parkinson's – and in some cases delay the progression of the disease, which maintains a person's quality of life for a longer period of time (Olanow 2009). Other benefits that can stem from such proactive approaches include reduced hospital admissions, relapse rates and symptom severity (Bird 2010). Of course, improved quality of life is not only an economic requirement – it is also a goal in itself.

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THE CONSENSUS STATEMENT

THINGS NEED TO CHANGE. BUT we, the Parkinson's community, cannot implement these changes alone. We need the support of national and European policymakers to ensure that the already immense economic and societal burden does not accelerate further as our population continues to age (see tables and statistics on the economic impact of Parkinson's on pages 6-7 and 25-27).

Opportunities for change do exist. This unique *Consensus Statement* – endorsed by European Parkinson's specialists, people with Parkinson's, carers and 45 national Parkinson's organisations – provides guidelines for policymakers on:

- how people with Parkinson's should be managed to ensure their effective participation within society
- the areas that need to be focused on to make the above a reality.

HOW PEOPLE WITH PARKINSON'S SHOULD BE MANAGED

People with Parkinson's should be referred to a doctor with a special interest in Parkinson's

A doctor with a specialist interest in Parkinson's will give the most reliable diagnosis due to their greater familiarity and experience with the disease (Pahwa 2010) – particularly its motor and non-motor symptoms. However, referrals to a Parkinson's specialist can be a lengthy process and access is historically very limited (Chaudhuri 2004). A reason for this is that the number of people a general practitioner sees with Parkinson's would be a fraction of those seen by a specialist neurologist (Galvin 2009) and, consequently, they will be less likely to be familiar with the symptoms and necessary procedures of care (Ghosh 2010).

In addition, non-motor symptoms are often inadequately treated by neurologists, and in more than 50 per cent of consultations they remain unidentified. They require different treatments and, most importantly, have different prognoses (Chaudhuri 2010). Non-motor symptoms can occur at any stage, and many can precede motor symptoms by more than a decade. Specialist Parkinson's doctors are therefore more likely to detect these symptoms and maintain a more holistic approach to the disease's

treatment and management (Engstrom 1994, Chaudhuri 2004 and 2010).

Non-motor symptoms are wide ranging and varied. They include bladder complications, visual hallucinations, dementia, psychosis, falls, gastrointestinal complications, swallowing disorders and cognitive impairment. The most common of these symptoms are sleep disturbances, which are unrecognised in more than 40 per cent of people with Parkinson's. Many of these symptoms often require treatment from other specialist areas – for example, bladder complications would require assistance from a urologist (Fowler 2010).

People with Parkinson's should receive an accurate diagnosis

The telling of a diagnosis of Parkinson's will have a long-term impact on every aspect of a person's life (Schrag 2000) and those of their family (Chrischilles 1998). However, there is no simple or accessible diagnostic test for Parkinson's due to the disease's complexity. A clinical diagnosis is always required, which relies on an expert's clinical assessment (Jankovic 2008, Pankratz 2009). To complicate matters further, Parkinson's is a difficult disease to diagnose as it can present itself in many different ways, especially in the early stages when its signs and symptoms are subtle (Koller 1997). In such cases, the use of established diagnostic tools that detect the loss of dopamine in the brain may be useful.

It is therefore essential that:

■ specialist advice is made available to

people as soon as the early signs and symptoms of Parkinson's are detected so that treatment options can be explored (Bird 2010, Pahwa 2010). An unwelcome consequence for European governments is that inaccurate diagnoses – that result in unnecessary or incorrect diagnostic tests – dramatically increase their already oversubscribed healthcare costs

- the doctor – or ideally the specialist team – allocate enough time to ensure the person with Parkinson's and their family fully comprehends what they are being told and what implications the news holds for them. Evidence from the Global Parkinson's Disease Survey Steering Committee (2002) also revealed that the satisfaction (or lack of it) with the explanation of the disease at the time of diagnosis has a significant impact on a person with Parkinson's later life
- a diagnosis is accurate and fully explained. When this is achieved, most people with Parkinson's are able to achieve a good quality of life for many years
- people with Parkinson's are prescribed medication as early as possible. This will improve their quality of life – and in some cases might even delay the progression of the disease (Olanow 2009)
- the multidisciplinary team be involved as soon as the disease has been diagnosed. This could delay the development of further complications, therefore reducing hospital admissions, relapse rates and symptom severity,

which would in turn reduce the disease's economic impact on both the individual and society (Bird 2010).

In short, earlier intervention is more cost effective for individuals and society.

People with Parkinson's should receive access to support services

Support services – namely access to a multidisciplinary team – when used in conjunction with medical treatments in the early stages of the disease can help people with Parkinson's live a full life, work for a greater length of time and stay at home longer despite their symptoms (Vossius 2009). It is vital that all of these

support services are available to every person with Parkinson's in Europe.

An optimum multidisciplinary team approach should also include the carers' needs. For example, occupational therapy may help carers cope with people with Parkinson's more complex situations, thereby delaying the need for assisted or residential care (Dyck 2009, Van der Marck 2009) and reducing associated costs. However, a vital but unacknowledged consideration is that the family and carers often carry the physical and emotional strain of day-to-day care. As a result, psychosocial disturbances, particularly depression and anxiety, have been known to develop for carers (Di Luca 2011), a reality that needs to change.

In addition, national Parkinson's disease organisations play an integral role in supporting people with Parkinson's, their families and carers, healthcare professionals and healthcare systems. As many of their resources are often very limited, however, much of their potential often fails to be realised. These organisations can provide an important link between all those impacted by Parkinson's and the healthcare providers who are committed to improving their care. There is scope to build the capacity of these organisations across Europe, which would ensure their development as well-informed and effective patient representatives and advocates. Even modest funding would be translated into tangible results in improving awareness and education in Parkinson's.

A strong network of national

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”

Parkinson’s organisations would raise awareness and provide education about the disease, enabling people with Parkinson’s and their carers to continue to participate effectively within society.

People with Parkinson’s should receive continuous care

A wide range of treatments and support services is required to ensure that the journey from diagnosis to the end stages of the disease is as smooth as possible for each person with Parkinson’s and their families (Ghosh 2010).

Where possible, every person with Parkinson’s in Europe should:

- remain under the same care team for the duration of their treatment, thereby ensuring that a consistent and supportive relationship can develop between the person, their doctor and the other members of the team, as well as encouraging improved disease management and better communication (WHO 2003, Hudson 2006, Giles 2009)
- expect – and be entitled to receive – the optimum treatment available, which should include access to the four most

commonly prescribed drug classes: levodopa (l-dopa); standard-release or controlled-release dopamine agonists; monoamine oxidase-B (MAO-B) inhibitors; and catechol-O-methyltransferase (COMT inhibitors). Ensuring doctors and their patients have access to the full range of medicines that are licensed and approved for the use in the treatment of Parkinson’s allows for a greater individualisation of treatment

- have the option of receiving surgical opinion, infusion treatments and any future treatment intervention that has been proven to be efficacious and safe
- be considered for support from palliative care specialists and the multidisciplinary team (Bunting-Perry 2006). People with Parkinson’s have not traditionally been considered for support from palliative care specialists despite having the same palliative care needs as many others – such as people with advanced cancer. Indeed, the nature of Parkinson’s and its physical and psychological challenges suggest that a palliative care approach may be extremely beneficial (Lanoix 2009).

People with Parkinson’s should take part in managing their illness

When diagnosed with Parkinson’s, people can struggle to come to terms with the loss of independence and control that the disease brings. By being fully involved in the choice of treatment and therapy from the beginning, however, they can increase their compliance to therapy, regain their

confidence and control, and participate more fully in society (WHO 2003).

Doctors who actively engage with people with Parkinson's – by increasing their understanding of the disease process and explaining how it may affect them in the future – succeed in improving their quality of life.

For example, a Japanese study showed there was a clear correlation between patient quality of life and patient knowledge about Parkinson's (Shimbo 2004). Similarly, a Scottish study identified a significant positive parallel between quality of life and the satisfaction of the person with Parkinson's. The researchers claimed that the more involved a patient was in the administration of their own treatment, the more satisfied they became (Grosset 2005). By being able to make decisions regarding their own treatment, therefore, people with Parkinson's will be in a position to regain control of their lives and feel able to remain in employment longer, thereby financially contributing to society.

Similarly, non-compliance to treatment is common in Parkinson's (Leopold 2004, Davis 2010, Grosset 2010, Tarrants 2010). However, fully involving patients in their treatment and therapy decisions helps improve compliance and leads to a greater understanding of the disease (WHO 2003) and improved management (Kulkarni 2008). Evidence has also shown that efforts to promote medication adherence in Parkinson's may lead to cost savings for managed care systems (Davis 2010).

WHAT EUROPEAN POLICYMAKERS NEED TO DO

- 1 Support initiatives that ensure equal access to good-quality, specialised Parkinson's care across Europe.
- 2 Reduce inequalities in the treatment and management of Parkinson's.
- 3 Improve funding for Parkinson's research and define research priorities.
- 4 Invest in optimum treatment and maintenance strategies.
- 5 Increase public and professional awareness of Parkinson's.
- 6 Minimise stigma and discrimination.
- 7 Strengthen the level of neurological care within European healthcare systems.
- 8 Provide adequate funding that supports the continued work of national Parkinson's organisations.

ABOUT THE EPDA

THE EPDA IS THE ONLY European Parkinson's disease umbrella organisation. It represents 45 member organisations and advocates for the rights and needs of more than 1.2 million people with Parkinson's and their families.

WHAT DOES THE EPDA DO?

By working with its 45 member organisations – who represent the needs of individual people with Parkinson's and their families at a national level – the EPDA aims to:

- ensure equal and timely access to prompt diagnosis and good-quality Parkinson's care across Europe by raising standards and reducing existing inequalities
- increase public awareness of Parkinson's as a priority health challenge
- help reduce stigma and remove discrimination against people with Parkinson's
- support the development of national Parkinson's organisations throughout Europe.



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Member
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Ireland

THE EPDA VISION

To enable all people with Parkinson's in Europe to live a full life while supporting the search for a cure.

THE EPDA MISSION

In order to achieve its vision, the EPDA aims to become the leading voice for Parkinson's in Europe – providing innovative leadership, information and resources to national Parkinson's associations, European policymakers, the treatment industry, healthcare professionals and the media. In achieving these aims, the EPDA hopes to raise the profile of Parkinson's and enable people living with the disease to be treated effectively and equally throughout Europe.

www.epda.eu.com

THE EPDA AND THE NEED FOR A CONSENSUS STATEMENT

THE EPDA'S CHARTER FOR PEOPLE WITH PARKINSON'S DISEASE

The EPDA's Charter for People with Parkinson's (www.epda.eu.com/epdacharter) was launched in April 1997 in an attempt to raise the profile of Parkinson's and enhance the public's awareness of the disease. The Charter provides a framework for managing Parkinson's – from the initial screening and diagnosis, through to treatment, management and palliative care. The Charter states that all people with Parkinson's have the right to:

- be referred to a doctor with a special interest in Parkinson's
- receive an accurate diagnosis
- have access to support services
- receive continuous care
- take part in managing the illness.

The Charter and its principles were supported by the World Health Organisation (WHO) and other notable individuals, including Pope John Paul II, Luciano Pavarotti, Princess Diana, Muhammad Ali, various UK prime

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The evidence suggests that standards are not being met across Europe and people with Parkinson's are not receiving the care they are entitled to
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ministers and other influential people from around the world. The Charter led to the creation and launch of the Global Declaration on Parkinson's Disease by the WHO Working Group on Parkinson's Disease in 2003 (www.epda.eu.com/globalDeclaration), which was subsequently signed and supported by numerous high-profile figures including Archbishop Desmond Tutu, Michael J Fox, Muhammad Ali and Janet Reno. The Global Declaration aims to improve the lives of people with Parkinson's by encouraging the implementation of the EPDA Charter.

Unfortunately, the evidence suggests that the Charter's criteria are still not being satisfactorily met across Europe and people with Parkinson's are **NOT** receiving the standard of care they are entitled to.

THE EPDA'S MOVE FOR CHANGE CAMPAIGN

In 2010, the EPDA launched its Move for Change campaign – a three-year, three-part pan-European online survey (translated into 24 European languages)

that asks people with Parkinson's whether their lives have improved since the launch of the Charter in 1997.

Each year, the survey seeks frank responses from participants on one or two specific points from the Charter. The data received from the first survey has provided invaluable evidence for this *Consensus Statement* and supports the fact that the management of people with Parkinson's must improve throughout Europe. The results from the first part of the campaign were published in the October 2011 issue of the *European Journal of Neurology*.

This report, which was authored by two distinguished neurologists and can be downloaded online (see page 21 for more details), reveals areas where progress has been made to ensure the best possible care for people with Parkinson's but also highlights those areas where much more work is required.

Interestingly, information from patient organisations was rated much more positively than the resources that are generally available from doctors. Some positive examples from the report include:

- the majority of people with Parkinson's across Europe received their diagnosis within one year
- the family doctor has a very important role in the ongoing care of a person with Parkinson's who visits the doctor on a regular basis
- the importance of the neurologist with regards to diagnosis and post-operative care.

However, the majority of responses were negative. For example:

- people with Parkinson's expressed concern over the manner in which their diagnosis was delivered. Many felt they were treated abruptly or impersonally. The poorest scores were given when the diagnosis was handled by a neurologist or hospital doctor, and the best scores were given when dealing with a family doctor
- hospital doctors had only a minor role to play in people with Parkinson's management, while geriatricians were even less involved. A lack of relevant or practical information from professionals about Parkinson's was also a recurring theme in respondents' comments
- the involvement from a Parkinson's specialist was at its highest in Eastern and Southern Europe, and noticeably lower in Northern and Western Europe.

The data from the final two surveys will be used in the same way as the first: the results will be analysed by the EPDA and a manuscript will then be prepared for submission in a peer-reviewed neurological journal. The article will then be used as a tool alongside the *Consensus Statement* (which will be updated on an annual basis to coincide with the additional Move for Change supporting data). Together, they will be used as tools to campaign for the improved management and care of people with Parkinson's, which will enable their effective participation within society.

FURTHER INFORMATION

EPDA WEBSITE

A list of European and international Parkinson's organisations is available on the EPDA website.

www.epda.eu.com/members

MOVE FOR CHANGE CAMPAIGN

For full details of the Move for Change campaign, see pages 19 and 20. The results from the first survey (published in the October 2011 issue of the *European Journal of Neurology*) can be downloaded at www.epda.eu.com/news/2011-10-03-epda. For more information, visit the website.

www.epda.eu.com/projects/move-for-change

LIFE WITH PARKINSON'S AWARENESS CAMPAIGN

The EPDA's Life with Parkinson's awareness campaign aims to highlight the lack of understanding and knowledge concerning Parkinson's that exists throughout Europe today through the provision of educational booklets and an accompanying DVD. The campaign also seeks to highlight the need to reduce the economic impact of Parkinson's and ensure that all people with Parkinson's have access to the right management and the right treatment at the right time.

The campaign materials contain

personal testimonies from around the world that describe challenges experienced by people with Parkinson's and their families, and the consequences of these challenges on their daily living. In addition, international Parkinson's opinion leaders explain the disease's symptoms and provide the facts that are linked to the various testimonies. All materials are available in multiple languages.

www.parkinsonsawareness.eu.com

PARKINSON'S DECISION AID

The Parkinson's Decision Aid website aims to help people with Parkinson's thrive while living with the disease. The website is based not only on medical opinion but also on real-life experiences. It explains what options are available and provides information on who can help, how they can help and when.

www.parkinsonsdecisionaid.eu.com

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EVIDENCE

Table 1: Summarised evidence of Parkinson's on quality of life

REFERENCE	COUNTRY	STUDY TYPE	SAMPLE SIZE	INSTRUMENT USED	RESULTS/FINDINGS
Schrag et al. 2000	UK	Population-based	124	PDQ-39 EQ-5D SF-36	In all assessments, regardless which instrument used, quality of life (QoL) was significantly decreased by increasing disease severity (summary index). <ul style="list-style-type: none"> • PDQ-39: HY 1: 10.5 versus HY 5: 66.7 • EQ-5D (summary index): HY 1: 0.96 versus HY 5: -0.21 • SF-36 (physical): HY 1: 48.6 versus HY 5: 20.8 • SF-36 (mental): HY 1: 48.0 versus HY 5: 37.3
Keränen et al. 2003	Finland	Cost of Illness	260	PDQ-39 EQ-5D 15D	The correlation between utility score assessed on two instruments (15D and EQ-5D) and severity was 0.51 and 0.45 respectively. The correlation between QoL and Parkinson's severity was 0.5, when QoL was measured with PDQ-39. A strong correlation between QoL, cost of illness and disease severity was reported. The QoL of Parkinson's patients with motor fluctuations was also lower than that of patients without motor fluctuations.
Pechevis et al. 2005	Europe	Observational		PDQL SF-36	Both instruments showed significant reductions of QoL scores with increasing severity of dyskinesias. The effect of dyskinesias appeared to be in addition to that of motor fluctuations and disease severity.

Notes

PDQ-39: 39-item Parkinson's disease questionnaire; PDQL: Parkinson's disease quality of life measure; SF-36: Study short form 36; EQ-5D: EuroQoL 5D; HY 1: Hoehn and Yahr stage 1; HY 5: Hoehn and Yahr stage 5

Table 2: The economic impact of Parkinson's

STUDY	KEY FINDINGS
3-month prospective analysis of the economic impact of Parkinson's in Germany (Dodel et al 1998)	<ul style="list-style-type: none"> • 3-monthly direct cost of Parkinson's per person was €2,664. • Progression of symptoms (as measured via HY stage) increased expenditure (HY 1=€987; HY 5=€4,980). • The onset of motor complications parallels an increase in costs.
Prospective study of direct and indirect healthcare costs in France (LePen et al 1999)	<ul style="list-style-type: none"> • The annual indirect cost per person was €6,984. • Average yearly cost of treating Parkinson's in France is estimated at €4,421 per person, resulting in an approximate expenditure of €354 million across the estimated 80,000 people with Parkinson's.
Direct and indirect cost analysis in Swedish people with Parkinson's (Hagell et al 2002)	<ul style="list-style-type: none"> • Total annual costs for Parkinson's were €13,800 per person. • Direct costs were €7,899 per person.
Prospective study of direct healthcare costs in the UK (Findley et al 2003)	<ul style="list-style-type: none"> • Annual cost of care per person for all people with Parkinson's by age was £5,993 (€9,975). • Progression of symptoms (as measured via HY stage) significantly increased expenditure. • A move from the home to residential care was associated with an estimated 500% cost increase.
A Cross-sectional study of the economic burden of Parkinson's in Finland (Keränen et al 2003)	<ul style="list-style-type: none"> • Total costs were €11,800 per person. The annual direct costs were €4,900 per person. • A strong correlation was made between quality of life, cost of illness and severity of Parkinson's.
Six-month observational study to evaluate the health economic burden of Parkinson's in Germany (Spottko et al 2005)	<ul style="list-style-type: none"> • Total medical and non-medical direct costs from the perspective of statutory health insurance (GKV) amounted to €3,380 ± €4,230. • Total indirect costs amounted to €3,180 ± €6,480. • Multivariate analyses of the direct costs revealed disease severity and health-related quality of life to be significant predictors of increased cost.
Three-year study of the economic aspects of Parkinson's in Germany (Dengler et al 2006)	<ul style="list-style-type: none"> • Total average cost per person with Parkinson's per month amounted to €1,007.55 (€603.33 as direct costs and €404.22 as indirect costs). • Costs increased in proportion to HY stage, declining with stages 4 and 5.
Summary of the incidence and costs of Parkinson's in Australia in 2005 (Access Economics 2007)	<ul style="list-style-type: none"> • Costs increased in proportion to HY stage: annual cost per person with Parkinson's in HY 1 equated to €2,481, compared with €7,585 for those in HY 5. • These estimates were developed by applying the weighted average of ratios developed from both Findley et al (2003) and Spottko et al (2005).

Table 2: The economic impact of Parkinson's (continued)

STUDY	KEY FINDINGS
Evaluation of costs and health-related quality of life in patients with Parkinson's in Europe – Health economics survey, Germany (Dodel et al 2008)	<ul style="list-style-type: none"> • Total annual costs per person of €20,860 (including direct costs of €3,720 excluding medications, drug costs of €3,840 and indirect costs of €6,360). • Progressive symptoms increase treatment costs. Patients with dyskinesia; costs almost double (€10,760) compared to patients without. Also, motor fluctuations increased by €5,000 to €11,040. • Indirect costs are significantly higher than the direct costs associated with Parkinson's.
A cross-sectional study to evaluate the health-related economic burden of Parkinson's in Spain (Cubo et al 2009)	<ul style="list-style-type: none"> • Average total 3-month direct cost amounted to €2,631 per person. • Medical treatment accounted for 34% of the total cost, with an average cost per person of €669. • Direct costs were significantly higher among younger patients, those with a higher HY stage and greater severity of disease.
A cohort study investigating the costs of Parkinson's in the Czech Republic (Winter et al 2010)	<ul style="list-style-type: none"> • Total semi-annual costs of Parkinson's were €5,510 per person. • Direct costs accounted for 60% of the total costs, indirect costs accounted for 40%. • People with Parkinson's treatment expenditure accounted for 40% of their income. • Study demonstrates a considerable economic burden of Parkinson's in the Czech Republic.
Analysis of an advanced Parkinson's UK patient dataset, with regard to the economic burden of the disease (Findley et al 2011)	<ul style="list-style-type: none"> • Average 12-monthly total costs increased depending on the amount of time per day a patient spent in an 'off' state: <25% of their waking hours = €29,808; >75% of their waking hours = €72,277 (HY stages 3–5). • Overall, 7% of costs were attributed to direct medical care, 50% were attributed to direct non-medical care and 43% to indirect informal care.
Direct cost analysis in Swedish people with Parkinson's (Lökk et al 2011)	<ul style="list-style-type: none"> • Total direct costs for Parkinson's were €8,328 per person, of which drug costs were only 21%.

Note

HY 1: Hoehn and Yahr stage 1; HY 3: Hoehn and Yahr stage 3; HY 5: Hoehn and Yahr stage 5.
The euro values in these studies were calculated as per the conversion rates at the time

GLOSSARY

Biomarker	A substance measured in blood whose concentration reflects the severity or presence of a disease state
Bradykinesia	Abnormal slowness of movement; sluggishness of physical and mental responses
Carers	A carer is someone who takes regular, ongoing care of a family member or friend who needs help due to illness, age or disability. A carer can be anyone – of either sex, or any age – and is generally unpaid
Cognitive impairment	Affects brain functions relating to thought processes such as thinking, reasoning and judgement, remembering, imagining, learning, intuition, sense and perception, and understanding
Compliance	Consistently taking the right amount of medication at the right time
COMT inhibitors	Catechol-O-methyltransferase inhibitors – a group of drugs used as a treatment for Parkinson’s. COMT inhibitors are given alongside levodopa to prevent it being broken down in the body and brain
Dopamine	A neurotransmitter that is produced in several areas of the brain, including the substantia nigra. When dopamine is given as a drug it does not directly affect the central nervous system because it cannot cross the blood-brain barrier. To increase the amount of dopamine in the brain, levodopa – the precursor of dopamine – can be used because it can cross the blood-brain barrier
Dopamine agonists	Dopamine receptor agonists are drugs that have a structure very similar to dopamine. Because of this similarity, they are able to mimic the action of dopamine rather than replenish the inadequate supply of dopamine in the way levodopa does. Unlike levodopa, they do not need to be converted by the brain cells first
EPDA	European Parkinson’s Disease Association
GP	General practitioner
Hoehn & Yahr	The Hoehn & Yahr (HY) scale is a system used to rate Parkinson’s as one of five stages. Stage 0 represents no symptoms and stage 5 means the most severe disease stage

L-DOPA	Levodopa (L-3,4-dihydroxyphenylalanine) – the precursor to the neurotransmitters dopamine, noradrenaline and adrenaline – is used in the clinical treatment of Parkinson’s and dopamine-responsive dystonia
MAO-B inhibitors	Monoamine oxidase B inhibitors are a class of drugs that are used to treat the symptoms of early Parkinson’s as well as to treat levodopa-induced motor fluctuations in more advanced disease. They work by stopping dopamine being broken down in the brain
Neurotransmitter	A chemical that is present in the nervous system to carry messages between different nerve cells. Examples of neurotransmitters include dopamine, acetylcholine, noradrenaline and serotonin (the ‘feel good’ chemical). Dopamine is not the only neurotransmitter that is involved in Parkinson’s
‘Off-stage Parkinson’s	It is one of the stages in the ‘on-off’ phenomenon experienced by some people with Parkinson’s. This phenomenon can best be described as an unpredictable shift from mobility (‘on’) to a sudden inability to move (‘off’). The ‘on-off’ attacks are unpredictable fluctuations in response to medication, which may last up to several hours
Palliative care	Palliative care is any medical treatment that aims to make life more comfortable for people with an advanced chronic, progressive condition. It includes the management of pain and symptoms, together with emotional, psychological and spiritual support
Parkinsonism	Parkinsonism is the generic name given to a group of conditions that feature the main characteristics of Parkinson’s: tremors, rigidity of muscles, mobility problems and bradykinesia (slowness of movement)
Pars compacta	A portion of the substantia nigra
Progressive disorder	A condition that becomes worse over time
Substantia nigra	A brain structure located in the midbrain that plays an important role in reward, addiction and movement. Parkinson’s is caused by the destruction of dopaminergic neurons in the substantia nigra

CONTRIBUTORS

This *Consensus Statement* has been developed and reviewed by a number of European key opinion leaders in the field of Parkinson's as well as Parkinson's patient organisations. Each of the following contributors has worked with the EPDA to try to standardise the care, treatment and management of the disease and therefore improve the quality of life of people with Parkinson's throughout Europe.

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