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Parkinson disease

A public health approach

Technical brief

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Introduction

Globally, disability and death due to Parkinson disease (PD) are increasing faster than for any other neurological disorder (1). PD is a degenerative condition of the brain associated with motor symptoms (slow movement, tremor, rigidity, walking and imbalance) and a wide variety of non-motor complications (neuropsychiatric and autonomic symptoms, disorders of sleep and wakefulness, pain and other sensory disturbances). Progression of these symptoms and complications markedly decrease functioning, and quality of life and result in high rates of disability and care requirements (2). The main risk factor for PD is increasing age, although younger people can be affected as well (3). Despite the significant impact of PD, there is global inequality in the availability of neurological resources to manage the disease, with poor availability especially in low- and middle-income countries (LMIC) (4).

The prevalence of PD has doubled in the past 25 years (1). The numbers are likely even higher when the many people living with various forms of parkinsonism are included, such as those caused by degenerative conditions (atypical parkinsonism), vascular lesions in the brain or adverse effects of medications such as neuroleptics. The data on incidence and prevalence are inconsistent, particularly for LMIC (5-7) and for ethnic minorities in high-income countries (HIC) (8-10), because of financial and geographical barriers to health care, underreporting of cases, misdiagnosis, lack of awareness of PD and incorrect perceptions that the decline associated with PD (e.g., slowing down or becoming stooped) is part of “normal” ageing (11-16). The inconsistent data make it difficult to estimate the global impact of PD accurately. Current estimates suggest that, in 2019, PD resulted in 5.8 million disability-adjusted life years, an increase of 81% since 2000, and caused 329,000 deaths, an increase of over 100% since 2000. (17).



Globally, disability and death due to Parkinson disease are increasing faster than for any other neurological disorder.

In 2017, PD was estimated to cost US\$ 52 billion per year in the USA (18), which will continue to increase as the incidence and prevalence of PD rise. Large scale, rigorous economic data on the cost of PD in LMIC is lacking (19).

Despite substantial development of drugs to treat PD, none have proven to be effective in slowing progression. Levodopa remains the most effective drug for improving most motor and various non-motor symptoms of PD and for improving functioning and quality of life, although it cannot halt the neurodegenerative process. Data on the potential causes of PD and opportunities for risk reduction are, however, accumulating. The possible causes include environmental (e.g.: exposure to pesticides, solvents and air pollution throughout life) (20) and genetic risk factors (e.g., *LRRK2* polymorphisms or mutations) (21).

Levodopa is on the WHO Model Lists of Essential Medicines (22); however, it is not accessible, available, or affordable everywhere, particularly in LMIC. Although optimal PD care also requires an integrated interdisciplinary approach (3, 23), appropriate treatment, rehabilitation and palliative care provided by interdisciplinary teams with expertise in neurological disorders (4) are lacking in many parts of the world.

In the context of providing universal health coverage, an urgent public health response is necessary to meet the health and social requirements of people with PD and to improve functioning, quality of life and prevent disability as global longevity increases. A pressing need for effective preventive actions is also needed to slow the rising incidence of PD before the burden and costs of treatment overwhelm country health services. In line with the WHO's Intersectoral global action plan on epilepsy and other neurological disorders (24), this brief, targeted to policy-makers, health programme managers and planners, health-care providers, researchers,


people with PD, carers and other stakeholders, outlines the crucial areas for intervention in PD and several areas for action, including:

- global health policies to implement strategies focused on PD
- prevention and reduction of risks for PD including education and awareness;
- assured access to treatment and care, including access to and education of an interdisciplinary workforce trained in neurological disorders; and
- delivery of services and the management of PD at various levels of health systems.

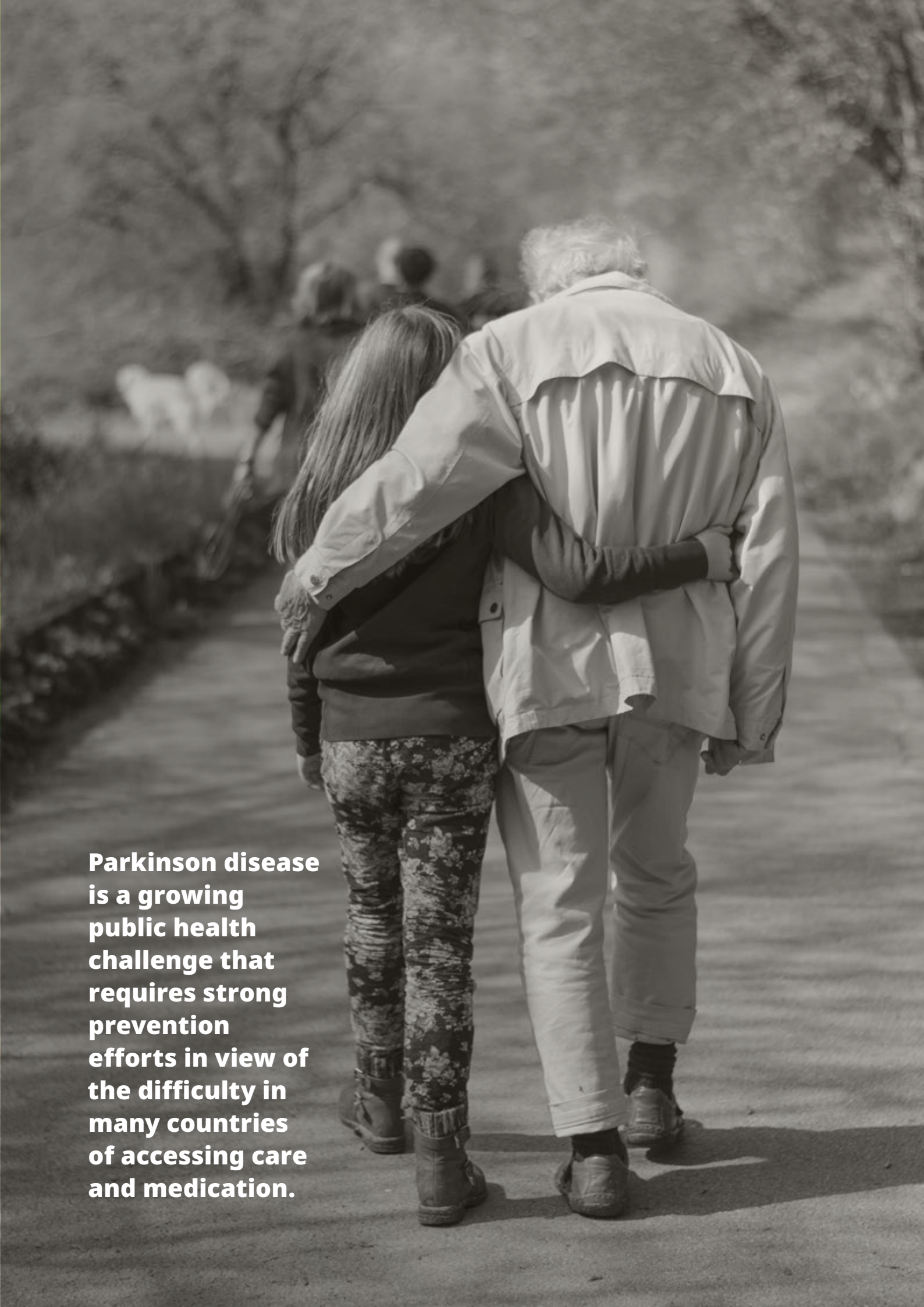


Methods

This technical brief is based on evidence from a WHO-commissioned literature review and a 2-day consultation with international experts on global policy, considerations for implementation and the research agenda for PD, with a focus on LMIC.



Although optimal PD care requires an integrated interdisciplinary approach, appropriate treatment, rehabilitation and palliative care provided by interdisciplinary teams with expertise in neurological disorders are lacking in many parts of the world.



Parkinson disease is a growing public health challenge that requires strong prevention efforts in view of the difficulty in many countries of accessing care and medication.

Review of the evidence

Disease prevention and risk reduction

PD is a growing public health challenge that requires strong prevention efforts (25); however, the health-care workforce, policy-makers and the general public are not adequately aware of the importance of reducing risk. Genetic predisposition is the causal factor in only a relatively small sub-group of cases (3), and a number of studies have shown that environmental factors, including pesticides (26–29), air pollution (30, 31) and industrial solvents (32) could increase the risk of PD. Measures used to protect users from exposure to pesticides (e.g., personal protective equipment (PPE), safe application equipment), often are not feasible in LMIC (e.g., too costly or impractical in hot climates) (33) and while less hazardous alternatives often exist and are available, they are not utilized (34). Genetic predisposition may further increase the risk of PD after exposure to environmental toxins (35, 36). As social standing can affect exposure to risk factors, addressing social inequalities would also reduce the development of PD. Some studies suggest that certain lifestyle factors protect against PD, including regular physical exercise (37, 38), a Mediterranean diet (39, 40) and consumption of caffeine (41).



Environmental factors, including pesticides, could increase the risk of Parkinson disease.

Essential health services in an interdisciplinary approach to care can improve functioning and the quality of life of people with PD and reduce the strain on carers. As PD progresses, rehabilitation to improve and maintain functioning and quality of life, to prevent complications and to minimize long-term disability (42–45) and palliative care (46, 47) are considered essential. These interventions are not, however, available everywhere, particularly in LMIC.

Gaps and challenges



23%
of countries
worldwide had
neurologists in
rural areas.

Interdisciplinary care teams, considered to be essential for optimal management of PD, are also lacking in low-resource settings.

NEUROLOGICAL WORKFORCE AND TREATMENT ACCESS

While PD is best diagnosed by specialists with expertise in movement disorders (48), very few such specialists work in LMIC (49, 50) and even fewer in rural areas around the world. The WHO Neurology Atlas provides estimates of 0.03 neurologists per 100 000 population in low-income countries and 4.74 per 100 000 population in HIC, and only 23% of countries worldwide had neurologists in rural areas in 2017 (4). Interdisciplinary care teams, considered to be essential for optimal management of PD (3), are also lacking in low-resource settings (51), where there is limited access to affordable PD nurses or ancillary services such as physiotherapists, occupational therapists, speech and language therapists, and psychologists (7). For example, specialized PD nurses are available in only two countries in Africa and PD speech programmes in only one (52). Clinical diagnosis of PD by trained, non-specialized health-care workers and simplified treatment guidelines could offer better management in primary care where specialist neurological treatment, rehabilitation and palliation provided by interdisciplinary teams are unavailable. Telemedicine might also be used to provide care to people with PD living in underserved areas of the world with geographical and financial barriers to care (53–57).

Government expenditure on health in developing countries is often inadequate, and lack of health insurance coverage means that people with PD must pay out-of-pocket for basic health care and medication (4, 52). The WHO Neurology Atlas reported that

levodopa, which remains the most effective medication for PD (58, 59), was consistently available in primary care in only 34% of the 110 countries surveyed, none of which were low-income countries (4). Limited access to levodopa means that people living with PD cannot be given even the most basic therapy to improve their quality of life. When levodopa is available, it is often unaffordable or is not subsidized by public health-care systems because of poor health insurance coverage (7, 60, 61).

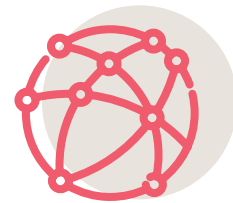
Advanced treatment options for PD, such as deep brain stimulation, can reduce drug intake and costs and improve health and functioning and has been shown to be cost-effective in the long-term (62). Use of deep brain stimulation in LMIC is, however, limited because of the high cost (15) and lack of facilities and expertise (7, 15). Inequitable access and gender disparities are also seen in HIC, where women are much less likely to receive this treatment than men (63, 64). Another treatment for patients with advancing disease in HIC is infusions of dopaminergic medications; however, these are even more costly and thus unavailable for most people with PD (15, 65).

The needs of people with neurological disorders for rehabilitation are also generally not met: only 16% of 105 countries reported specialized neurorehabilitation services and 17% reported neurorehabilitation in general rehabilitation units in 2017 (4). Motor impairments, such as dyskinesias (involuntary movements) and dystonias (painful involuntary muscle contractions) (66) contribute to limitations in speech, mobility and thus, restrictions in many life areas. This underscores the need for a more holistic and interdisciplinary approach, combining the use of medication and non-pharmacological interventions, including interventions for rehabilitation such as yoga (67, 68) and speech or swallowing occupational therapy. Despite increasing recognition of the importance of palliative care services (47), they are lacking in many LMIC. A study published in 2013 reported that only 20 countries in the world (8.5%) have integrated palliative care in health services (69).



16%

of countries
reported specialized
neurorehabilitation
services.



8.5%

of countries
have integrated
palliative care
in health services.



Resources and educational material in local languages are rarely available so many people with Parkinson disease and their families are unaware of the disease.

AWARENESS AND EDUCATION

Globally, the population and also non-specialist health-care professionals are generally poorly informed about PD (16), which can result in erroneous assumptions, such as contributing it to a contagious illness, a form of insanity or a “normal” part of aging (70, 71). Such assumptions can contribute to stigmatization, particularly if the symptoms are obvious, and can delay presentation to health-care services and initiation of treatment, often after several misdiagnoses. Little information about PD, such as resources and educational materials in local languages, is available, so that many people with PD and their families are unaware of the disease and its symptoms and do not seek appropriate care (72). Integrated media and public education campaigns could be conducted to avoid stigmatizing perceptions of PD and to create awareness.

Opportunities for service delivery and management in health systems

As PD is a progressive disease, people living with the condition frequently require long-term care. An interdisciplinary approach will ensure optimal disease management (3, 23, 76–78). Providing holistic care may be daunting in low-resource settings, where limited resources impede building an integrated system of care along a continuum of services that includes diagnosis, treatment, rehabilitation and palliative care.

PRIMARY CARE

Primary care, the entry point to health care in most communities, is the logical setting for addressing PD in LMIC where access to specialist services is lacking. PD is most often diagnosed by clinical evaluation (3), with little or no need for ancillary testing. Diagnosis may therefore be done in primary care facilities by trained health-care workers, including general practitioners and specialist nurses. Complex cases could be triaged to secondary

care for further, specialized assessment, for example, by neurologists, when available. Telemedicine, including sharing of videotaped neurological examinations, is a flexible option and is effective for consulting experts elsewhere and for improving local diagnostic skills (55, 57, 79). Use of telemedicine is in accordance with the WHO Global strategy on digital health 2020–2025 (80). Interventions for rehabilitation, including physiotherapy, occupational, speech and language therapy, diet management and psychological interventions, should be available at all service levels, depending on country context.

Increasing the number of health-care professionals who enrol in specialized neurology training could bridge the gap in access to care for PD, particularly in LMIC.

INTERDISCIPLINARY CARE AND MANAGEMENT

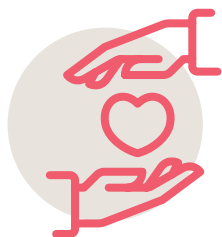
As with many degenerative neurologic disorders, nonpharmacological management can offer symptomatic relief of motor or non-motor symptoms in PD. Several studies have investigated specific forms and approaches to physiotherapy including strength training, gait and balance training, intense rehabilitation training and hydrotherapy (23, 76, 77, 78). Occupational therapy can help people with PD better manage their problems in daily functioning such as swallow therapies which are important adjunctive treatments in PD and are especially important in preventing complications of pulmonary aspiration.

Planning for palliative care might have to start at diagnosis (46) and not just at crises, although such discussions may be difficult (83–85). Little attention has been paid to the provision of palliative care and therefore improvements in the quality of life of people with PD (47, 86). Palliative services are not common in LMIC. Primary health-care workers with appropriate understanding of PD could be given the relevant training to discuss the benefits of advance planning of palliative care with people with PD and their carers including due consideration of local and cultural perspectives about the end of life. Development of resources and programmes that can be delivered by carers of people with advancing PD could also overcome limited access to palliative care (87, 88).



Diagnosis of Parkinson disease can be done in primary care facilities by trained health-care workers.





Effective delivery of care for Parkinson disease should include support for carers.

SUPPORT FOR CARERS AND SELF-MANAGEMENT

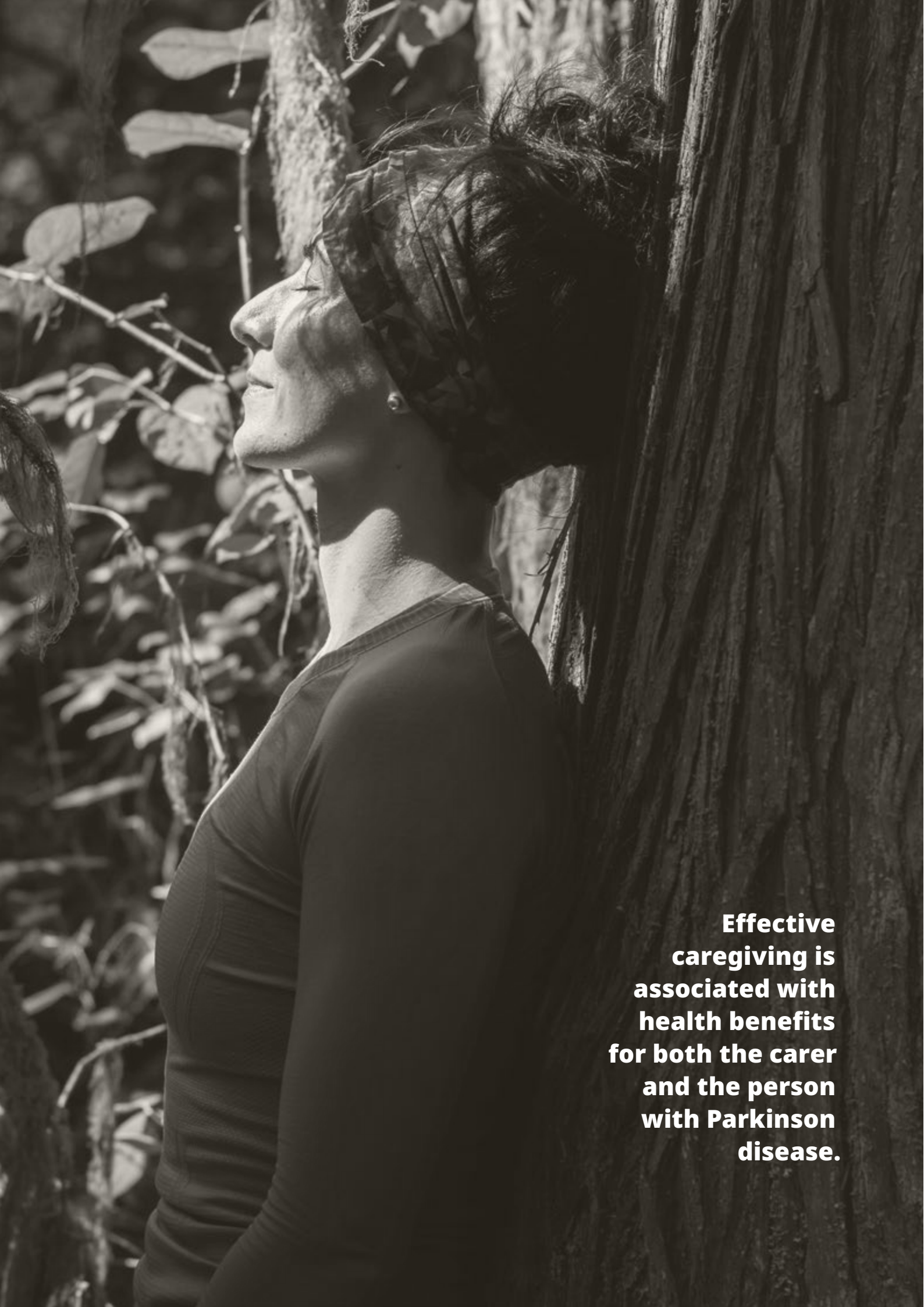
Self-management is an important component of care for PD, as progression of the disease requires management of motor and non-motor symptoms, such as lack of balance with a propensity to falls and cognitive and behavioural problems. These symptoms in people with advanced disease add to the stress and burden of carers (81). Effective delivery of care for PD should therefore include support for carers (82). Support groups of people with PD (both in-person and virtual) are beneficial for learning and communicating and provide emotional and social support for both people with PD and their families. Support groups also offer opportunities for local advocacy, combatting stigmatization in communities and educating people about PD. They may also contribute to global advocacy and awareness (72).

Models of care, educational programmes and advocacy in LMIC

Examples of community care, educational programmes and advocacy initiatives in low-resource settings (73) have shown that access to treatment and awareness can be improved.

In India, a community model of care developed in 2005 by the Parkinson's Disease and Movement Disorder Society, has helped overcome barriers to access to and affordability of health care by using and building community resources. The interdisciplinary model is delivered in 65 support centres and has served over 50 000 people with PD and their families, promoting self-management to improve independence and quality of life and to reduce the burden and stress of carers (74).

In Uruguay, a therapeutic, rehabilitative and educational programme was established in 2007 to bridge gaps in access to PD care (75). Professionals deliver rehabilitation and provide mental health support and counselling to people with PD and their families and carers. Medical professionals can also attend educational lectures. By the end of 2018, the programme had reached 423 people with PD and 431 family members. These initiatives demonstrate the importance of the community in the management of PD.



**Effective
caregiving is
associated with
health benefits
for both the carer
and the person
with Parkinson
disease.**

Key actions

As the prevalence of PD is increasing globally, it is a challenge to many populations. Political commitment will be required to develop strategies, programmes and services that are effective for people with PD and their families and carers. The key actions identified in this brief are: global health policies to implement PD strategies; advocacy and awareness-raising; prevention and risk reduction; ensuring the availability of basic drugs and interdisciplinary therapies such as rehabilitation and palliative care; strengthening health and social systems and building capacity; and research on PD.

Global health policies to implement PD strategies

- leverage the momentum of the Intersectoral global action plan on epilepsy and other neurological disorders to advance the agenda of PD in all settings;
- include civil society organizations, people with PD and their support networks to increase the success and impact of PD strategies.

Advocacy and awareness-raising

- facilitate global action to change local, national and international policy to improve care and services for PD;
- improve awareness among people with PD, their families and society (with local, population-level solutions) to increase understanding of PD and to change public attitudes and practices, particularly stigmatization and discrimination; and
- promote the establishment of local PD support groups and community initiatives.



Prevention and risk reduction

- ban pesticides (e.g.: paraquat and chlorpyrifos) and chemicals (e.g.: trichloroethylene) which have been linked to PD and develop safer alternatives as per WHO guidance (89–91);
- accelerate action to reduce levels of and exposure to air pollution, an important risk factor for PD and other noncommunicable diseases, including Alzheimer disease, respiratory disease, heart disease and stroke;
- further understand and address modifiable risk factors through public education and changes to policy and legislation;
- increase access to and promotion of healthy behaviour (i.e., exercise and diet) along the life-course to reduce the risk for PD and to enhance potentially protective factors;
- encourage links for prevention of PD with promotion of healthy living, working and environmental conditions; and
- identify synergies between PD, other neurological disorders and noncommunicable diseases to facilitate prevention.

Ensuring the availability of medicines

- increase access to and the affordability of therapies for PD of any severity, including motor and non-motor features;
- promote rational selection of medicines for training, supply and reimbursement including updates of national essential medicine lists;
- adapt/modify local legislation to enable the production and increase access to generic PD medicines;
- promote and support local manufacture of PD drugs and therapies in LMIC;
- generate evidence to feed into the national assessment of procurement and supply chain management;
- inform and support national planners/ partners to prepare risk management plans for managing essential health product supply chains and for maintaining equitable availability, access, and appropriate distribution of medicines for PD;
- register PD medicines (e.g., levodopa) with relevant pharmaceutical registration boards in LMIC to improve its availability;
- review and revise the WHO Essential Medicines list to include dopaminergic and other medications (e.g., amantadine); and
- negotiate with pharmaceutical and device companies to ensure that treatments are affordable for more people with PD.



Political commitment will be required to develop strategies, programmes and services that are effective for people with Parkinson disease.

Strengthening health and social systems and building capacity

- build the capacity of primary healthcare, social workers, rehabilitation and palliative care;
- develop career tracks for the neurological workforce by strengthening postgraduate training and working in partnership with medical societies to raise awareness of PD;
- promote educational programmes within the PD interdisciplinary health and rehabilitation workforce and create networks for referrals;
- provide education and training of primary health-care providers, including allied health professionals, and shift tasks to community settings;
- strengthen information systems for better recording of the numbers of people affected by PD globally, particularly in low-resource settings and in various population groups;
- provide educational materials for better diagnosis, communicating the diagnosis and follow-up care, including support;
- increase innovations for specialist support (e.g.: telemedicine) to offer remote interdisciplinary support for people with PD, with respect for their privacy and security (in accordance with the WHO Global strategy on digital health 2020–2025);
- integrate diagnosis, treatment, rehabilitation and palliative services into interdisciplinary teams within universal health coverage;
- ensure good health financing and social protection to prevent catastrophic out-of-pocket payments and early retirement.

Carer support

- increase awareness of the impact of caring for people with PD, including the need to protect carers from discrimination, support their ability to continue to provide care throughout the disease progression, and promote self-advocacy;
- provide accessible and evidence-based information on available resources in the community, such as training programmes, respite care, mental health services and other resources tailored to the needs of carers of people with PD;
- assist in implementing culturally sensitive, context-specific and person-centred training programmes for carers and families to promote well-being and enhance knowledge and caregiving skills throughout the progression of PD, starting with existing resources such as WHO's iSupport (92) and mhGAP (93).

Research on Parkinson disease

- promote and extend global funding for PD research;
- generate additional knowledge and evidence to inform policy, planning and programming for PD;
- increase investment in biomedical, clinical, implementation and translational research into new diagnostics and treatments in direct response to the needs of people with PD;

- collect robust, standardized, easily accessible data, specifically prevalence, incidence and risk factors in representative populations, from routine health information systems;
- develop better regulatory frameworks to allow more efficient and secure sharing of data between sectors and across countries and regions;
- improve coordination of multi-stakeholder, multi-centre, cross-regional research collaborations and to build research capacity, particularly in LMIC;
- improve representation of LMIC in PD research through cost-effective, locally relevant strategies;
- promote diversity, equity and inclusion in all areas of PD research and care;
- involve and support people with PD, their families and carers by active participation in and guidance of research on innovative solutions with a meaningful impact;
- evaluate the feasibility and effectiveness of community models of care for people with PD; and
- support not-for-profit organizations financially in the design, implementation and documentation of action research to build models of care that can be replicated.

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An urgent public health response is necessary to meet the health and social requirements of people with Parkinson disease and to improve functioning, quality of life and prevent disability, in the context of providing universal health coverage.



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