EFNA
EUROPEAN FEDERATION OF NEUROLOGICAL ASSOCIATIONS

TOWARDS A EUROPEAN NEUROLOGICAL HEALTH STRATEGY

EFNA'S POLICY ASKS FOR A LIFE-COURSE, RIGHTS-BASED AND IMPLEMENTATION-FOCUSED FRAMEWORK

EXECUTIVE MESSAGE

Neurological health must become a strategic European health, social and economic priority.

Neurological conditions are among Europe's major and growing causes of disability, premature mortality and reduced quality of life. The challenge is amplified by demographic change, but it is not an ageing-only issue: neurological conditions affect children, young people, working-age adults and older people.

Expert projections and data shared by organizations like the European Academy of Neurology (EAN) indicate that roughly 60% (or over 1 in 2) of the European population suffers from at least one neurological condition. This spectrum spans from common migraines and sleep disorders to neurodegenerative diseases like Alzheimer's, Parkinson's, and strokes. [1]

Figure 1

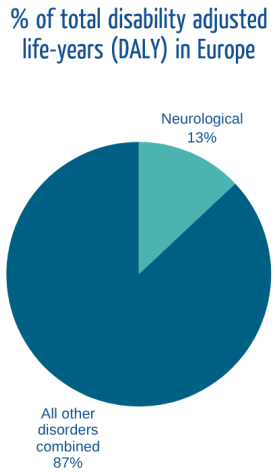

Figure 2

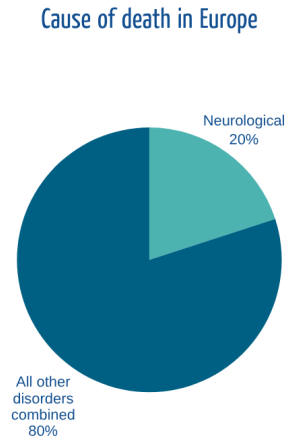

Figure 3

The evidence points to a dual challenge: a large and growing burden, and persistent gaps in diagnosis, treatment, rehabilitation, psychosocial support, social participation and care coordination. The European Parliament's 2026 briefing describes neurological disease as one of Europe's urgent and rapidly expanding health, social and economic challenges, citing an estimated €368 billion annual economic burden for a group of major neurological and neurodegenerative disorders in 2019, with more than half attributed to informal care. [2]

Europe has reached a pivotal moment for neurological health. The European Parliament's own-initiative report provides an opportunity to turn growing political recognition into a coherent European response.

The Strategy should be built around the three pillars as outlined by rapporteur MEP Catarina Martins —universal & equitable access; modern care models; research & innovation — with prevention and risk reduction as cross-cutting priorities, underpinned by unmet needs, a life-course approach, rights-based principles and effective implementation. [3]

The ultimate question is not how many neurological conditions Europe can name, nor how many services exist on paper. It is whether people can access earlier diagnosis, appropriate treatment, rehabilitation, psychosocial support and the opportunity to participate fully in society.

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The neurological health gap

A person can have a nominally available service and still experience unmet need because care is delayed, unaffordable, inaccessible, poorly coordinated, inappropriate or insufficient to address the full impact of the condition.

EFNA's European survey found that only 1 in 5 respondents reported access to affordable therapeutic interventions that satisfactorily managed their condition, while 92.4% would recommend psychological support or counselling as part of managing adjustment to life with a neurological condition. [4] EFNA's 2024 work, based on 4,800 respondents across Europe, reported 67% initially misdiagnosed, 56% having difficulty expressing symptoms to healthcare professionals and 85% reporting that medical professionals did not believe the extent or severity of symptoms. [5]

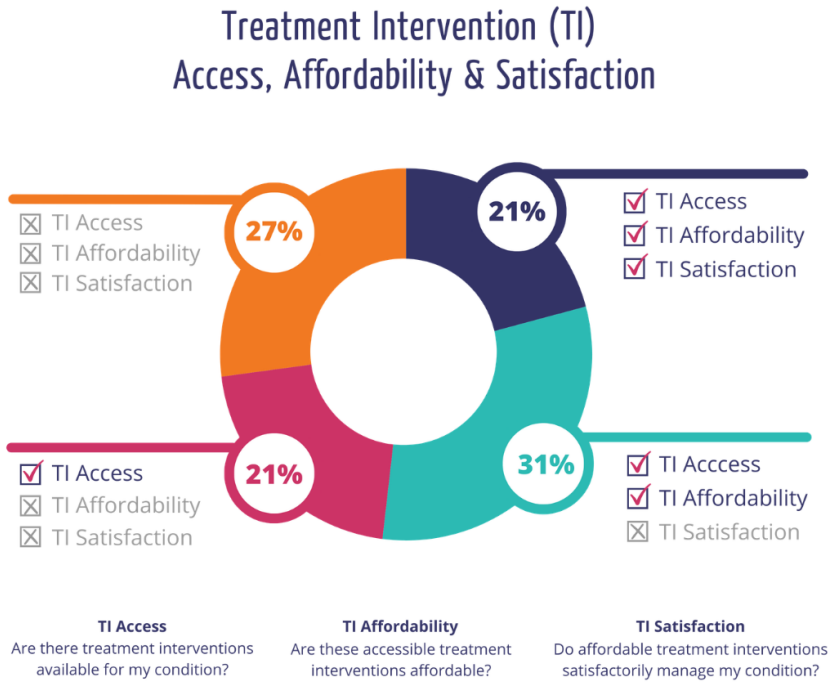

Figure 4

**These are patient-experience survey findings, not population prevalence estimates. They demonstrate the scale and nature of unmet need reported by respondents.*

A life-course, holistic and rights-based approach

EFNA proposes that neurological health be treated as a continuum: prevention and risk reduction → recognition → diagnosis → treatment → rehabilitation → psychological and social support → participation → long-term care and, where appropriate, palliative and supportive care.

Recognition	Diagnosis	Treatment	Rehabilitation	Psychosocial support	Participation	Long-term support
low awareness	delay / misdiagnosis	availability / affordability	waiting lists / fragmentation	mental health / stigma	education / work	community / carer support

Prevention should be embedded throughout the life course, combining action on modifiable risk factors, public awareness, health promotion and early intervention with measures to prevent avoidable complications, disability and the worsening of existing conditions. Prevention strategies should be evidence-based, equitable and accessible to all, while recognising that not all neurological conditions are preventable and avoiding blame or stigma towards people living with neurological conditions.

Life-course priorities

- **Children and young people:**
  Early identification, developmental support and safe transitions from paediatric to adult services.
- **Working-age adults:**
  Support to remain in or return to education and employment, with accessible services and social protection.
- **Older people:**
  Equitable neurological care without reducing neurological health to ageing, including multimorbidity and continuity.
- **Rare neurological conditions:**
  Specialist expertise, coordinated pathways and access to European networks and research infrastructures.
- **People with disabilities and complex needs:**
  Accessibility, communication support and full participation in decisions affecting their lives.

Gender equality and equity

Integrated gender-sensitive approach across the full continuum of neurological health, recognising how sex- and gender-related differences can influence risk factors, symptom presentation, diagnosis, treatment, care experiences and outcomes. It should address gender biases in research and clinical practice, inequalities in access to care, and the disproportionate burden of informal caring responsibilities, while recognising the intersection of gender with age, disability, socioeconomic status and other factors.

People living with neurological conditions should be recognised as patients, citizens, workers, students, parents and carers — not only as recipients of healthcare.

PILLAR I — UNIVERSAL AND EQUITABLE ACCESS

Equity means timely, affordable, accessible, appropriate and person-centred care.

EFNA calls for a broader definition of access. Formal availability is insufficient if people face long waits, travel barriers, out-of-pocket costs, disability-related barriers, health-literacy challenges or shortages of specialist and multidisciplinary staff.

Measure what matters

The Strategy should combine traditional health-system indicators — capacity, waiting times and service availability — with patient-reported outcomes, patient-reported experience measures and unmet-needs indicators.

> *A service should count as accessible only when the person can reach it, afford it, understand it, use it and benefit from it.*

EFNA calls for:

- Reduced diagnostic delays and misdiagnosis through workforce capability, health literacy and better referral pathways.
- Addressing of geographical inequalities in access to specialist neurological and rehabilitation services, particularly in rural and remote areas, also by leveraging telehealth solutions where appropriate to improve accessibility and continuity of care.
- Improved affordability and reduce financial barriers to medicines, technologies, rehabilitation and supportive services.
- Guaranteed access to multidisciplinary neurological care and neurorehabilitation, including community-based provision where appropriate.
- Strengthened continuity between hospital, primary, community, rehabilitation and social-care services.
- Use of accessible communication, reasonable accommodations and patient navigation to reduce disability and health-literacy barriers.
- Development of common European neurological indicators while respecting Member State responsibility for health-service organisation.

PILLAR II — MODERN CARE MODELS, PROTECTING PATIENT RIGHTS AND PROVIDING ROBUST SUPPORT TO CARERS

Neurological conditions frequently require long-term multidisciplinary support. Yet services remain fragmented between hospitals, primary care, rehabilitation, mental health, social care, education and employment. Modernisation should therefore focus on coordinated pathways and rights-based participation.

Families and informal carers make an essential contribution, but support for carers must complement — not replace — adequately funded professional health and social care. Particular attention should be paid to children and young people who take on caring responsibilities within their families. Healthcare professionals should be trained to recognise young carers, assess their needs and ensure appropriate support is available to reduce their sense of responsibility and prevent excessive emotional and practical burdens. There should also be recognition of the disproportionate burden of informal caring responsibilities placed on women and the impact that has.

Europe should judge neurological health policy by whether people's needs are actually met — not simply by whether a service exists. This should be assessed through robust implementation, regular evaluation and the systematic collection of feedback from people living with neurological conditions and their carers.

EFNA calls for:

- Promotion of integrated multidisciplinary neurological care with clear referral, coordination and follow-up responsibilities.
- Recognition of neurorehabilitation as an essential component of neurological care, not an optional add-on.
- Ensured access to psychological and psychosocial support as an integral part of care.
- Expanded community- and home-based services where clinically appropriate and preferred by the person.
- Support for self-management, care navigation, accessible information and shared decision-making.
- Embedded patient rights, reasonable accommodation, accessibility and non-discrimination across care pathways.
- Provision of palliative and supportive care where appropriate and aligned with the person's preferences.
- Identification and addressing of gender-related inequalities in the recognition, diagnosis, treatment and management of neurological conditions, including biases in clinical assessment and barriers to accessing appropriate care and support.
- Respite and replacement care; information and training; psychological support; financial protection; employment flexibility; recognition of young carers; and inclusion in care planning with the person's consent.
- Support for carers without shifting responsibility for adequate services from systems onto families.

PILLAR III — INVESTMENT IN RESEARCH AND CLINICAL INNOVATION

Investment in research and clinical innovation is essential to address the growing challenges associated with Europe's ageing population, while recognising that neurological conditions affect people at every stage of life.

The Strategy should promote prevention and risk reduction alongside early diagnosis, treatment and long-term care and broaden the definition of innovation beyond new medicines to include diagnostics, rehabilitation, care models, digital tools and implementation of science programmes.

Rare neurology: no neurological condition left behind

Rare neurological conditions should be explicitly visible within the Strategy. EFNA highlights diagnostic odysseys, fragmented care pathways and limited specialist expertise as persistent gaps. European Reference Networks, ERDERA (European Rare Diseases Research Alliance) and related infrastructures should be strengthened and well connected to the Strategy so that rarity does not become a reason for invisibility. [6]

EFNA calls for:

- Establishment of neurological health as a strategic European research priority, with strengthened synergies, coordination and complementarity across relevant EU programmes.
- Funding of research toward patient-identified unmet needs, including symptoms and quality of life that are not adequately addressed by disease-modifying treatments.
- Meaningful patient involvement throughout research priority-setting, study design, implementation and dissemination.
- Accelerated translation: basic research → translational research → trials → implementation → routine care → measurable patient outcomes.
- Support of responsible AI, digital biomarkers, remote monitoring and personalised approaches where they improve outcomes and equity.
- Improved access to clinical trials across Europe, including for people with rare and ultra-rare neurological conditions.
- Strengthened implementation of research on rehabilitation, integrated care, workforce models and health-system transformation.
- Integrated sex- and gender-sensitive approaches into neurological research, clinical trials and innovation, addressing evidence gaps, potential biases in diagnosis and treatment, and the underrepresentation of relevant populations in research.
- Strengthened research into the prevention of neurological conditions and the reduction of associated risks, including evidence-based interventions, modifiable risk factors, early intervention and strategies to prevent avoidable complications and disease progression.

EFNA'S 15 PRIORITY POLICY ASKS

1. Adopt a comprehensive European Neurological Health Strategy recognising neurological health as a strategic health, social and economic priority.
2. Build the Strategy around the three pillars: research and innovation; universal and equitable access; and modern, rights-based care models and carer support.
3. Make unmet needs a central measure of success across diagnosis, treatment, rehabilitation, psychological support, social care, participation and carers.
4. Embed a life-course approach covering children, young people, working-age adults and older people.
5. Adopt a holistic, gender-sensitive and intersectional approach approach addressing education, employment, poverty, social participation, stigma and disability and inequalities in neurological health and care.
6. Ensure no neurological condition is left behind, with explicit attention to rare and ultra-rare conditions.
7. Strengthen research and clinical innovation through relevant programmes and infrastrtuctures.
8. Improve early and accurate diagnosis, including health literacy, communication and workforce capability.
9. Guarantee access to multidisciplinary care and neurorehabilitation, including community-based and long-term support.
10. Recognise psychological and psychosocial support as integral to neurological care.
11. Strengthen support for informal carers, including respite, training, psychosocial support and financial/employment protections.
12. Measure what matters to people using patient-reported outcomes, patient-reported experience and unmet-needs indicators.
13. Establish a European Neurological Health Scorecard and implementation roadmap with responsibilities, milestones, funding pathways and reporting.
14. Use existing EU programmes and strategies strategically, embedding neurological health across relevant funding and policy instruments.
15. Ensure meaningful participation of people living with neurological conditions and their representative organisations in development, implementation, monitoring and evaluation.

A person living with a neurological condition should be able to access the right support earlier, affordably and without avoidable barriers — regardless of condition, age, circumstances or where in Europe they live.

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Figure 1: Adapted from Gustavsson *et al.* [9]. Comparators from Luengo-Fernandez *et al.* [10], Nichols *et al.* [11], and International Diabetes Federation [12].

Figures 2–3: Adapted from Deuschl *et al.* [8].

Figure 4: Adapted from EFNA [4].