



*Making dementia a priority:
changing perceptions, practice and policy.*

Alzheimer Europe response to the Draft WHO Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders 2022-2030

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Overview of Alzheimer Europe response

Alzheimer Europe previously responded to the discussion paper in April 2021, outlining a number of concerns in relation to the proposed direction of the intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders 2022-2030 (Epilepsy GAP). Having reviewed the draft plan, we remain concerned about a number of these aspects and have reiterated these points in the sections below, with reference to specific sections within Epilepsy GAP.

We remain broadly in agreement with the scope, vision, goals, strategic objectives and the guiding principles as the basis of the Epilepsy GAP. As with the discussion paper, we are pleased to see the Global Action Plan grounded in a person-centred approach, focused on respecting the rights of individuals with neurological conditions. Furthermore, we recognise that there are a number of areas (e.g. risk reduction, better integration of care and support) where coordinated, joint actions, would offer potential value.

However, Alzheimer Europe continues to have reservations about the overall approach to grouping neurological conditions, noting that from a high-level policy perspective, the lack of detail and nuance risks overlooking the key challenges within countries (and for individuals living with such conditions). In particular, we have reservations about the move away from disease-specific approaches, believing that the distinct needs and challenges experienced by individuals living with dementia risk being overlooked.

From our perspective as an organisation representing people with dementia and their carers, whilst the action plan provides a welcome focus on neurological conditions, the specific actions and focus within it does not, in our view, strengthen the existing policies related to dementia, nor does it represent a substantive contribution to dementia-focused work already underway.

Feedback on specific sections of the Epilepsy GAP

Objective 1 (page 8)

In this section, we believe that sections 1.1 and 1.2 are overly broad in scope, proposing advocacy, policy and legislative responses which address neurological disorders e.g. through awareness raising campaigns. Whilst there is some reference for the need for this to be targeted, we believe that §29 is indicative of the problems of such an approach taken, as it envisages a neurological campaign encompassing all of the broad areas under the umbrella term of neurological disorders, including hygiene, food safety, child development etc. many of which are not directly relevant for the majority of dementias.

Similarly, the challenges and discrimination faced by people with dementia are likely to be vastly different to those who experience other neurological conditions such as migraines or ADHD. Public health interventions and policy responses must be targeted and focused on specific disease areas or groups of disease (e.g. neurodegenerative diseases).

Whilst we recognise that the implementation of such responses will be for Member States to decide themselves, we wish to see the point regarding the need for more disease-focused strands to be undertaken, to be explicitly mentioned in the plan.

As a result of the broader issues arising around the place of dementia as a condition, (a point we expand on in the following sections), we believe that §42 should be reworded. As we have highlighted in our previous response, dementia (and other neurological conditions) are sometimes included or addressed as mental health, sometimes non-communicable disease etc. Whilst understanding the intention of encouraging linkages between relevant disciplines,

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the current wording suggesting that neurological conditions be “integrated” into other areas, risks diminishing conditions and the importance of addressing them as serious health conditions (requiring targeted and specific responses) in their own right.

Objective 2 (page 12)

Alzheimer Europe agrees with the majority of provisions within this section, however, we believe that it equally demonstrates why the plan must specifically recognise neurodegenerative conditions. Neurodegenerative diseases are progressive, life-limiting conditions, with no curative treatment, which significantly impact the cognition and function of the individuals who experience them. This often requires increasing amounts of care and support for the individual affected, including informal carers who often undertake a significant portion of care and support. As such, this group of diseases have distinct and different needs from other chronic or manageable neurological conditions.

Within this section, and specifically under Care Pathways, there is little reference to long-term care. For people with dementia and others people with progressive conditions, long-term care is often a key issue to maintain the quality of life of the person with the condition to the fullest possible extent, whilst also ensuring that the health and wellbeing of the informal caregivers are protected.

Furthermore, whilst financing is covered under the previous objective, we believe that reimbursement and support for the financial cost of services, medications and other supports should be reiterated within this section.

We welcome the dedicated section (2.3) on the training and capacity building of healthcare workers, particularly in relation to professionals working within primary care settings. As noted elsewhere within this response, the role of primary care in the detection and diagnosis of neurological conditions, as well as the gatekeepers to more specialised care, means their understanding of neurological conditions and the care pathway, must be thorough and maintained on an ongoing basis.

Strategic Objectives and Global Targets

Alzheimer Europe, having raised this point in response to the discussion paper, believes that **SO1/Global Target 1.2** should be revised to provide clarity on the expectations of what a neurological campaign should contain.

It appears that the target is intended for governments to instigate a broad campaign which incorporates all neurological conditions. However, we stress that given the range of diseases covered under the umbrella term “neurological disorders”, as well as the diverse populations who are at greater or lesser risks of certain conditions, a single overarching campaign, unless focused on specific disease areas, is likely to be ineffective.

The Global Action Plan on the Public Health Response to Dementia 2017-2025 (Dementia GAP), awareness raising has been focused on raising awareness about dementia and challenging the specific stigma around the condition (as well as challenging misconceptions around the disease e.g. that it is a normal part of ageing). Without this level of focus, it is difficult to envisage the purpose and anticipated outcomes of an overarching neurological disorder awareness campaign.

In relation to **SO2/Global Target 2.2** we would suggest amending this to include diagnosis/detection (and ongoing management) of neurological conditions in primary care.

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Whilst understanding that specialist equipment and diagnostic methods (e.g. MRI scanning, PET scanning etc.) requires the involvement of specialists working in hospitals or specialist centres, for many countries, primary care is the first line of contact for many patients and often acts as a gatekeeper to more specialised services. As such, it would be useful for their role in the detection and diagnosis to be included within the target.

Whilst understanding that the rationale behind **SO5/Global Target 5** is to provide a metric for epilepsy that does not currently exist within other strategic policy documents, the broader focus of much of the rest of the document is on neurological disorders. As such, we would suggest broadening this to refer to increase service coverage for neurological disorders as a whole or, alternatively, including an equivalent metric for neurological disorders under **SO2**.

Furthermore, the global targets and key indicators within the SOs and key indicators are high level and do not necessarily reflect how measurement of some of the details will be monitored (e.g. SO2 and its global targets make no reference to carers). It is possible these will be finalised as the document progresses, however, we would have welcomed the opportunity to provide feedback on these in the draft plan.

Overarching feedback on Epilepsy GAP

Alignment with other work programmes

Alzheimer Europe is still unclear how this Global Action Plan will fit in with other WHO programmes of work. Within the draft document, a large number of other work programmes and strategic documents are referred to within **Table 1** and some of the targets from these are included under **SO3/global target 3.2**.

However, it is not apparent how these strategic documents align and reinforce each other. For example, dementia is mentioned throughout the draft plan (as an example, in most cases), and the Dementia GAP is referenced in **Table 1**. However, it is not clear in what way the existing targets and objectives of the Dementia GAP contribute to this intersectoral plan for epilepsy. In return, it is not evident how the Epilepsy GAP contributes to the objectives of the Dementia GAP, as some of the SOs seem duplicative (although referring to neurological disorders instead of dementia).

As we have previously suggested, it would be helpful for the Epilepsy GAP to more explicitly explain the connections between the documents, highlighting where existing goals, targets or outcomes exist and will be used, whilst identifying new actions.

Disease-specific vs. Brain health/catch-all approaches

Alzheimer Europe welcomes the public health approach emphasising the importance of brain health throughout the life course, recognising the necessity of a shift, as well as the key role of the WHO in identifying good practice examples of the most effective means for implementation.

Furthermore, we recognise that in the areas of prevention and integrated care (both between health and social care, and between general and specialist services) there are undoubtedly commonalities between disease areas, which would benefit from cooperation and alignment in some areas of work.

However, Alzheimer Europe remains concerned that Epilepsy GAP incorporates diseases and conditions which are distinct and diverse in nature, including:

- Highly variable symptoms

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- Significant differences in function and needs
- Availability of treatment and medicines
- The duration (and progression) of conditions
- The populations affected and the age of development.

Unlike many of the neurological disorders referenced in the draft action plan, dementia is a condition which most frequently presents in later life, more frequently in women and is progressive in nature. There is no curative treatment, therefore it requires significant levels of care and support for individuals living with the condition, especially as it progresses and the needs of individuals increase.

Despite this, there is a single mention of neurodegenerative diseases in the draft plan and little reference to the nature of these conditions, in particular, in relation to the increased complexity in the provision and coordination of care and support.

As such, for dementia (and likely for other neurodegenerative conditions), the needs of people with the condition and their carers across the fields of care, treatment, support and research, must be addressed with these specific points in mind.

We strongly suggest a dedicated sub-section on neurodegenerative conditions (as has been included for epilepsy) within the plan, addressing the distinct challenges associated with these conditions.

The categorisation of dementia – globally and nationally

It is perhaps also useful to note that within the Epilepsy GAP, particularly in relation to diagnosis, supports and services, there is a strong focus on the role of neurology and specialist neurology services. For dementia, this is slightly more challenging, as whilst dementia is a neurodegenerative condition, its place within policy and clinical practice varies widely, across (Old Age) Psychiatry, Geriatric Medicine and Neurology. Indeed, under the WHO's own work, dementia sits under Brain Health, which itself sits under the broader remit of Mental Health.

In making this point, we wish to reiterate that dementia is still not well supported or accommodated in policy or medical terms under a single area.

Whilst this specific point is unlikely to be resolved by Epilepsy GAP, it remains a key difficulty associated with in the diagnosis, care and treatment of the condition. This ultimately impacts upon the quality of life of people living with the dementia and their carers. We would welcome the WHO addressing this specific point within the plan.