



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

Alzheimer Europe contribution - WHO Global Action Plan on Epilepsy and other neurological disorders discussion paper

2 April 2021

Overview of Alzheimer Europe response

As the discussion paper is the first stage in the process of the development of the World Health Organization (WHO) Global Action Plan on Epilepsy and other neurological conditions, Alzheimer Europe will contribute some broad points for consideration, then use further opportunities during the consultation phases to make more specific points.

Alzheimer Europe agrees with the scope, vision, goal, strategic objectives and the guiding principles of the discussion paper and supports these as the basis of the Global Action Plan on epilepsy and other neurological conditions. In particular, we are pleased that the discussion paper references the importance of taking a person-centred approach, grounded in 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 a coordinated, joint actions are potentially incredibly valuable.

Whilst backing the broader principles which underpin the discussion paper, Alzheimer Europe's has concerns that the broad approach to neurological conditions, from a high-level policy perspective, lacks the detail and nuance to address 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 conditions, are at risk of being overlooked.

Whilst we understand that more detailed actions and targets will be developed at a later stage, and that country/disease specific issues will be addressed as the WHO supports countries in implementing the Global Action Plan, we believe that it would be helpful for there to be more clearly defined actions and targets within the paper, including greater detail on how the plan will support alignment between different areas of work.

Alignment with other work programmes

Alzheimer Europe would welcome further information about how the plan will fit with other WHO programmes of work, particular the Global Action Plan on Dementia. The discussion paper provides a table of related policy initiatives and work programmes, however, it is not clear how these will interact or fit together.

For example, within the discussion paper, the need for awareness raising campaigns and societal awareness of neurological conditions is highlighted as an area for action. However, this creates two key issues:

- It is unclear whether the intended action is for governments to instigate a broad campaign which incorporates all neurological conditions or if it is intended to drive the creation of multiple disease-specific campaigns
- The second is the overlap with the Dementia GAP which contains a specific target for awareness raising under the Dementia Friendly Communities – as before, we would be concerned that the focus on dementia may be lessened, were it to be included in a broader campaign.

For each section and subsection, it would perhaps be useful for the Global Action Plan to identify the areas in other plans and programmes of work, identifying where there are existing goals, targets or outcomes set by other plans, whilst identifying new actions which are specific to this strategy.

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

Alzheimer Europe believes there is a need for clarification on the approach of the Global Action Plan for Epilepsy and other neurological conditions. From the discussion paper, it would seem that there are two overarching aims (in line with the WHA 73 resolution):

- To create an impetus for change around the current policies and approaches to epilepsy diagnosis, treatment and care
- To align common themes and areas for action amongst neurological conditions.

Whilst understanding the need to align with the WHA resolution, we believe there is a contradiction in the document in advocating for non-disease-specific approaches (e.g. as outlined in line 15), whilst on the other hand providing a specific focus on system responses for the diagnosis, treatment and care of epilepsy (e.g. as outlined in line 17).

We believe there would be value in structuring the document in such a way as to provide specific focus and actions related to epilepsy, whilst using separate sections for the broader measures which are common and applicable across all neurological conditions.

Furthermore, adopting public health approaches which emphasise the importance of brain health throughout the life course is important and the support of the WHO in identifying the most effective means for the implementation of the policies and measures to realise this in practice is incredibly valuable. For issues such as prevention, integrated care (both between health and social care, and between general and specialist services) and ant-stigma and awareness raising campaigns, there is undoubtedly some commonality between disease areas, which would benefit from cooperation and alignment in some areas of work.

However, we stress that the range of neurological conditions included under the global action plan is broad, incorporating diseases and conditions which are distinct and diverse in nature, including:

- Highly variable symptoms
- 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 other neurological conditions, dementia is a condition which most frequently presents in later life, more frequently in women and is progressive in nature. There is no cure, nor is there a disease modifying treatment, therefore requiring significant levels of care and support to support individuals living with the condition, especially as it progresses and the needs of individuals increase.

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.

The categorisation of dementia – globally and nationally

It is perhaps also useful to note that within the paper, 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

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(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 this Global Action Plan, we believe that it underlines the difficulty and reiterates the challenges faced by people with dementia and their carers in receiving support. Therefore, the global action plan's and objectives in relation to diagnosis, care pathways and integrated care must include consideration of this point when setting objectives in this area.

Specific points in the discussion paper

As previous noted, Alzheimer Europe broadly supports the overarching aims and objectives of the Global Action Plan. We welcome that the plan identifies the considerable scale of the challenge posed by dementia, as the third biggest cause of neurological DALYs in 2016. Alzheimer Europe believe there would also be value in including acknowledgement of the mortality associated with neurological conditions. For example, in 2019, dementia was the 7th leading cause of mortality in 2019 (3rd leading cause in Europe).

Alzheimer Europe notes that within the discussion paper, there is only a single reference to neurodegenerative diseases (line 13), which identifies it as falling under the bracket of neurological conditions. If the WHO intends to avoid disease-specific actions within this plan, we suggest, as a minimum, that there should be additional specificity in the plan, recognising that progressive neurodegenerative conditions have distinct challenges, particularly in relation to the ongoing management, care and support of individuals and carers of individuals living with such a condition.