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

Alzheimer Europe contribution – European Commission consultation on the Green Paper on Ageing

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Laying the foundations (chapter 2 of the green paper)

1. How can healthy and active ageing policies be promoted from an early age and throughout the life span for everyone? How can children and young people be better equipped for the prospect of a longer life expectancy? What kind of support can the EU provide to the Member States?

In relation to dementia, improving health literacy amongst the population, as well as raising awareness of the condition and the lifestyle factors which increase the risk of developing dementia, is a key component of prevention activities.

This requires greater understanding of the condition amongst both the public and medical professionals, to support efforts to reduce the prevalence of the condition (in a similar manner to approaches taken for cancer, cardio-vascular disease etc.). As many countries begin to move towards "brain health" as a conceptual approach throughout the life of an individual, the EU's must support initiatives and work to embed this approach.

Dementia is comparatively poorly understood when compared to other non-communicable diseases. Although the causes of the underlying diseases which cause dementia are not fully understood, the biological and physiological changes which take place in an individual, occur decades before symptoms emerge.

The Lancet Commissions on "Dementia prevention, intervention, and care" published in 2020 showed that 12 potentially modifiable risk factors throughout the life-course (including smoking, alcohol consumption, education, social isolation etc) are linked to around 40% of worldwide dementias.

As the EU has committed to spending 20% of the budget of EU4Health programme on prevention, we believe this must include dedicated funding on dementia prevention, including activities such as awareness-raising and education programmes which improve societal understanding of the condition. However, this cannot be purely focused on primary prevention and must also include secondary and tertiary prevention.

In addition, funding programmes such as European Regional Development Funding and European Social Fund Plus should be used to ensure that Member States have skilled and trained professionals working within health systems, who understand dementia and can support the agenda around brain health and prevention.

2. What are the most significant obstacles to life-long learning across the life-cycle? At what stage in life could addressing those obstacles make most difference? How should this be tackled specifically in rural and remote areas?

Alzheimer Europe cannot address issues around life-long learning across the life cycle.

However, we would like to address learning in later life and for people with cognitive impairments. These two groups often face a stigma, as assumptions are often made about their ability to learn new skills or knowledge, particularly where digital and technological resources are involved.

Through our engagement with our members and our European Working Group of People with Dementia, we have found this to be far from the case. During the COVID-19 pandemic, many older people and people with dementia have adapted to circumstances whereby services, supports and resources have moved to online or digital formats. Whilst people may need

support and training to help them adapt to using such technologies, it should not be assumed that this group has not capacity to do so.

In addition to the stigma which people face regarding their capacity to learn, the availability and format of training often does not accommodate the needs and circumstances of people with dementia. This should be addressed through dedicated resources and training which address some of the additional challenges experienced by these populations, as well as involving them in the process of designing and development.

Whilst we do not have additional suggestions beyond digital and online resources for rural areas in terms of learning, we believe it is important to reiterate here that some of these communities are often poorly served by internet and mobile connections. If these are envisaged as the primary means of improving learning in rural and remote areas, the EU should provide support to Member States to boost coverage for these areas.

Making the most of our working lives (chapter 3 of the green paper)

3. What innovative policy measures to improve participation in the labour market, in particular by older workers, should be considered more closely?

Similar to the provisions of the UNCRPD for persons with disabilities, there should be a focus on employers providing "reasonable accommodations", which allow older people to continue to participate in the labour market. This should include the ability to continue working, carrying out tasks in keeping with an individual's ability as they age. In cases of cognitive impairment, whilst many people will choose to stop working as a result of their condition, it should also be possible for individuals to transition into a new role or for adaptations to be made to an existing role, in line with their abilities, where the individual wishes to continue to do so. For older persons, additional measures such as guarantees for flexible working arrangements and phased retirement, could support people to continue in the labour market longer than they would otherwise be able to do so, as well as opening the potential to participate in voluntary work.

This survey does not address an important issue, which pertains to participation in the labour market. As populations age, more people will require care and support from unpaid informal caregivers, which will, in many cases, be delivered by persons of a working age. As such, ensuring that these individuals are well supported and given the opportunity for flexible and accommodating working conditions is essential. Additionally, health, social care and social security systems should ensure that a balance can be struck for people with caring responsibilities, to ensure there is flexible support which allows them to continue to work, without losing out financially or experiencing detriment to their own health and wellbeing.

There has been some progress in this regard following the EU's passage of the of the Work-life balance directive, however, the support included within this support is extremely limited. It is imperative that the EU goes further to support informal carers and ensures that the implementation of existing measures is monitored closely.

4. Is there a need for more policies and action at EU level that support senior entrepreneurship? What type of support is needed at EU level and how can we build on the successful social innovation examples of mentorship between young and older entrepreneurs?

Alzheimer Europe has no contribution on this question.

5. How can EU policies help less developed regions and rural areas to manage

ageing and depopulation? How can EU territories affected by the twin depopulation and ageing challenges make better use of the silver economy?

Alzheimer Europe has no contribution to make regarding depopulation.

Older people and people with dementia in less developed and/or rural areas are affected to a greater extent than their counterparts in developed and/or urban areas, often as a result of fewer supports and services (including health and social care) being available. Opportunities for socialising, interactions and amenities, all of which have a significant role in a person's quality of life may also be reduced.

As such, the role of the EU must be to support Member States in ensuring that these populations have access to supports and services which meets their needs, both in relation to health and social care, but also in more community-orientated services.

For health and care services, this must include the EU4Health programme working to strengthen healthcare systems, including the identification of how services and supports can be introduced into these areas, as well as made sustainable in the long-term. In addition, the EU4Health programme can also support the sharing of resources, information and best-practice examples to facilitate this.

As per question two, there may be opportunities for digital and online services which may have a role to play in providing support to older people and people with dementia in such communities. However, these cannot be a replacement for in person supports and services which continue to be vital for these populations.

There is also a need for further research to be carried out in this area in identifying good practices in health and social care systems, which would align with the health cluster of Horizon Europe. Specifically, examining the epidemiology surrounding ageing populations (and the distribution of dementia across Europe), the provision of services in rural areas and the (health) economics surrounding the provision of services and supports, would add vital knowledge to help inform the direction of the EU's support, for the EU4Health programme and other cohesion funds.

New opportunities and challenges in retirement (chapter 4 of the green paper)

6. How could volunteering by older people and intergenerational learning be better supported, including across borders, to foster knowledge sharing and civic engagement? What role could a digital platform or other initiatives at EU level play and to whom should such initiatives be addressed? How could volunteering by young people together with and towards older people be combined into cross generational initiatives?

In the context of dementia, and in line with our comments in question one, we believe that the key to fostering better involvement and inclusion of people with dementia within their societies is improved societal understanding and awareness of the condition. In doing so, societies respond with policies and practices which help keep people with dementia active within their communities.

There are excellent examples of initiatives at a local, regional and national levels relating to dementia, including through initiatives such as Dementia Friends and Dementia Friendly Communities. Furthermore, in relation to these aspects, a number of examples of intergenerational work were evaluated and shared as part of the second Joint Action on Dementia (2016-2019), which was funded by the EU.

Using the previous two examples, civil society and non-governmental organisations often have a leading role to play, both in the development and implementation of such approaches. This is primarily as a result of the strong connections they have within their communities, as well as often working closely with people with lived experience, thus allowing them to better understand the needs of their specific populations.

As such, we would suggest that the role of the EU should primarily be focused on the provision of funding which makes such schemes possible, as well as support for platforms which allow for the exchange of knowledge and information between European countries. As part of this, we believe there is a need for the EU to not only provide financial support for innovative and new models of working but to examine how long-term sustainability and support can be provided for such vital work.

7. Which services and enabling environment would need to be put in place or improved in order to ensure the autonomy, independence and rights of older people and enable their participation in society?

There are a number of societal aspects which are important in order to ensure the autonomy, independence and rights of older people. There is no single model which enables this, rather a complex mix of services, supports, policy and legal frameworks are required, which responds to the context of a broad range of populations and communities.

However, we believe that there are overarching and broad categories of supports which should be included and which are fundamental for improving the quality of life of older people and more specifically, for people with dementia.

A basic foundation for all communities is access to affordable health and social care services, regardless of where an individual lives. These services, must of high quality, affordable and respond to the needs of people living with chronic and other conditions. As part of this, support for unpaid familial carers is an essential component, including respite care etc.

Communities should have activities and supports which encourage older people to maintain active and participate in their societies. This includes activities and groups which allow individuals to interact with their peers, as well as ensuring that urban design and development is done so with the principles of accessibility, so that older persons and people with mobility issues are not faced with additional barriers within the built environment. These two aspects combined are essential to reducing loneliness and isolation in people with dementia and their carers, which can have significant detrimental effects on the mental health and cognitive function of individuals.

To apply these broad principles in practice, stakeholders (including governments, municipalities, civil society etc.) must work together to agree how implementation should take place. It is imperative that older people, people with dementia and carers etc., are involved in the planning, design and decision-making processes.

8. How can the EU support vulnerable older persons who are not in a position to protect their own financial and personal interests, in particular in cross-border situations?

At present, there is considerable variation between Member States in relation to the level of protections for persons who are not deemed to have capacity to manage their own personal, financial and legal affairs.

Alzheimer Europe recently published "Legal capacity and decision making: The ethical implications of lack of legal capacity on the lives of people with dementia", which explored these issues in depth and made a number of recommendations, including in relation to guardianship.

Existing international covenants, including the United Nations Convention on the Rights of Persons with Disabilities, the European Charter on Fundamental Rights, the European Convention on Human Rights, the Charter of Social Rights, amongst others, outline and provide guidance on how countries should proceed in relation to matters concerning the protection of vulnerable adults, as well as matters pertaining to guardianship.

The underlying approach should be one whereby existing capacity is maximised and no automatic loss of loss of legal capacity is applied. However, these matters are ethically and legally complex, with issues around the concept of supported, shared and substitute decision making being subject to ongoing debate and scrutiny, particularly in relation to how they should be applied in practice.

The role of the EU in this regard should be one of high-level oversight, with support for the sharing of good-practice in this area. As a signatory to the UNCRPD and the author of other policy drivers outlined above, the EU has an obligation to support Member States to ensure their laws and policies are compliant with such international agreements. Alzheimer Europe also believes that Member States should be encouraged to sign up to the Hague Convention on the protection of vulnerable adults, with compliance with the Convention supported at an EU level.

The European Union Agency for Fundamental Rights (FRA) has previously focused on issues around the UNCRPD and voting for persons with reduced capacity. Therefore, we believe that there is a role for the FRA to more closely monitor and report on issues relating to legal capacity and guardianship, outlining the different approaches of countries and providing recommendations for countries should improve their legal and policy structures. In addition, the EU could include this as part of its work around the European Semester Process.

9. How can the EU support Member States' efforts to ensure more fairness in the social protection systems across generations, gender, age and income groups, ensuring that they remain fiscally sound?

Alzheimer Europe believes that a major inequity in the current social protection systems relates to the lack of recognition for years spent in informal caring roles. In relation to this, we believe that the time spent in an informal caring role should be included in the determination of pension provision, especially where a person has had to reduce or give up employment as a result of their caregiving role. Furthermore, Alzheimer Europe is of the view that social protection systems must improve support for informal carers during the duration of their role, including provision of adequate carers allowances, flexible working time for individuals still in the workforce. Whilst the Work Life Balance Directive was a good first step in this regard, this must be built upon, to ensure that informal carers are adequately supported.

Furthermore, we believe that the recognition of long-term care needs as part of a health care insurance and social protections should be prioritised as an issue. As Alzheimer Europe demonstrated in its recent Dementia Monitor 2020 report, not only is there a shortage in the availability in many long-term care and support services across Europe, a considerable number

are either self-funded by the individual or are co-funded. For progressive conditions such as dementia, where long-term care and supports are vital to maintaining the health and wellbeing of individuals, resulting in them paying thousands of Euros in care costs. As such, it is vital for the EU to work with Member States to ensure that long-term care is more readily available and affordable, making social protection systems fairer and equitable.

10. How can the risks of poverty in old age be reduced and addressed?

Dementia is an illness which disproportionately affects women, both as a result of those diagnosed with the condition (approximately two thirds are women) and the disproportionate number of informal carers of people with dementia (the majority of whom are also women). As women are often in lower-paid, part-time jobs and have lower pensions than men, they are often at greater risk of poverty, which is exacerbated by a diagnosis of dementia (either to themselves or a loved one).

It is therefore essential that social protections across the EU provide adequate welfare supports, both for the individual with dementia and to their carers, to eliminate their risk of falling into poverty as a result of loss of income and inability to work.

In addition, people with dementia are likely to require health and social care services to support their health and wellbeing. However, these supports are not universally available across Europe and often are subject to co-funding arrangements (in some case with means testing) or self-funding by the individual. As such, addressing these expenses to individuals, would go some way to alleviating the financial burden and reducing their risk of falling into poverty as a result of their illness.

The matters relating to health should be addressed specifically through the EU4Health programme and could be a significant focus of its work around health inequalities. Both health matters and social protections should be monitored by the EU as part of the European Semester Process.

11. How can we ensure adequate pensions for those (mainly women) who spend large periods of their working life in unremunerated work (often care provision)?

Alzheimer Europe addresses this matter in question 10.

12. What role could supplementary pensions play in ensuring adequate retirement incomes? How could they be extended throughout the EU and what would be the EU's role in this process?

Alzheimer Europe has no contribution on this question.

Meeting the growing needs of an ageing population (chapter 5 of the green paper)

13. How can the EU support Member States' efforts to reconcile adequate and affordable healthcare and long-term care coverage with fiscal and financial sustainability?

Alzheimer Europe has outlined in questions one, five and ten, the role of the EU4Health programme in reshaping the health and social care systems to ensure that they are sustainable and provide support for people with dementia and their carers, alleviating the burden of care costs on individuals. As part of this, we believe that the European Semester process should

monitor this, both in relation to the extent of costs to individuals, as well as the sustainability of health and long-term care in Member States.

Public health approaches which focus on primary, secondary and tertiary prevention are key to addressing some of the challenges around health and long-term care coverage. The 2020 Lancet Commission on Dementia showed that around 40% of dementias are the result of modifiable risk factors, such as diet, early life education etc. which are areas which are within the EU's remit to address, for example, as part of the EU4Health's budget, which has allocated 20% for preventative spending.

In addition, the Health Cluster of the Horizon Europe research programme should dedicate resources to funding research which examines how health systems, with particular regard to dementia, can ensure that their health and long-term care systems are both affordable to individuals, as well as remaining financially sustainable. This should include funding for health economic-based studies which can demonstrate the benefit of preventative approaches, as well as exploring new public health and clinical interventions, which could then be rolled out to Member States.

14. How could the EU support Member States in addressing common long-term care challenges? What objectives and measures should be pursued through an EU policy framework addressing challenges such as accessibility, quality, affordability or working conditions? What are the considerations to be made for areas with low population density?

As noted in previous answers, there are a number of areas in relation to health and long-term care, which should be addressed, including:

- Accessibility/availability/affordability of services between countries – there is a clear divide between countries in Europe in relation to the availability and affordability of services
- Urban/rural disparity – within countries, there are often fewer services available in rural or areas of lower population density
- Quality of care – best practice should be researched and shared amongst Member States, with support given for implementation of new ways of working or to facilitate changes within health systems.

Alzheimer Europe has outlined in previous answers how we believe the EU should use funding mechanisms (such as cohesion funding), policy processes (such as the European Semester), as well as investing in further Europe-wide initiatives (such as the Joint Actions on Dementia), to ensure that people with dementia, regardless of the country in which they live, have access to high quality care and support.

An additional consideration underpinning these aspects is the need for increased numbers of educated and skilled individuals working across the health and care sectors in response to increased demand for supports and services. Member states must begin to introduce structural changes which incentivise people to undertake careers in the health and care sectors, with an additional focus in ensuring staff retention. This is a crucial element of establishing the necessary capacity of health and care systems for the future.

15. How can older people reap the benefits of the digitalisation of mobility and health services? How can the accessibility, availability, affordability and safety of public transport options for older persons, notably in rural and remote areas, be

improved?

The COVID-19 pandemic has demonstrated the possibilities for the digitisation of some forms of health and care support, particularly at a time when in-person services and supports have not been able to continue. Examples of which we are aware include telemedicine, peer supports in online groups and online counselling. Alzheimer Europe has been able to continue involving people with dementia in our activities, ensuring that the voices of people with dementia continue to be heard.

From our own experiences and those of our members, we are aware of many challenges in the use of digital technologies, especially for older people or people with cognitive impairments where the person may not have support or resources to help them learn and make use of such technologies.

As such, we wish to make two key points:

- In relation to care and support services in health and social care, digital services should not be considered as replacements for in-person services, merely as a supplementary form of support
- The gradual digitisation of services, across all areas, risks excluding and making life more difficult for those with poorer digital skills, where digital services are poorly designed (and thus inaccessible) and where infrastructure is lacking.

The use of services and supports in a digital way must framed within policy drivers and other work as additional or complementary services. Furthermore, technology and digitisation of services should be in response to an identified need and wish of people who use services; the focus should not simply be to drive an uptake of technology.

When digital supports and services are introduced, it is imperative that resources and training (in suitable formats) are also provided to support people to learn and make use of these new ways of working.

16. Are we sufficiently aware of the causes of and impacts of loneliness in our policy making? Which steps could be taken to help prevent loneliness and social isolation among older people? Which support can the EU give?

People with dementia and their carers can often experience isolation and loneliness following a diagnosis, for a number of reasons. For individuals with dementia, socialising may become more challenging as a result of symptoms or as a result of the stigma which often accompanies the condition. In addition, carers often have less time to continue normal social activities as their caregiving role often takes up a significant portion of their time.

During the COVID-19 pandemic, problems with isolation and loneliness have been exacerbated by lockdown measures, which have significantly impacted upon the mental health of people with dementia and carers, with evidence emerging of significant cognitive decline in persons with dementia during these periods.

Whilst introduced at a time of great uncertainty, with an immediate focus on reducing the spread of COVID-19, there was a demonstrable negative impact of such blanket approach, which did not have significant regard to the effect on individuals in the most vulnerable of situations, including people with dementia and carers. The EU and governments of Members States should consider how the needs of vulnerable populations are taken into consideration, both in

the context of the current pandemic, but more importantly, for any future actions, to ensure that similar mistakes are not repeated.

We consider the EU's contribution in this area should focus on two key areas:

- The EU should use its funds to support Member States development of communities, environments, supports and services which keep people engaged and able to participate in their communities, regardless of their age, disability etc.
- The EU should use its policy drivers, through the European Semester process, European Disability Rights Strategy, Accessibility Act etc. to ensure that countries are taking steps to reduce loneliness and social isolation, and remove barriers which may exacerbate them.

17. Which role can multigenerational living and housing play in urban and rural planning in addressing the challenges of an ageing population? How could it be better harnessed?

Alzheimer Europe has co contribution on this question.