



## **INTRODUCTION**

The European Institute of Women's Health (EIWH) welcomes the European Commission Communication on a European initiative on Alzheimer's disease.

We are all aware that during their lifespan, the health of women is influenced by several factors : their education and their socio-economic or geographical background. However, as women age, other external factors influence their health and well-being : dementia affecting a close relative is a factor that may change the life of a woman, both from a health and from a socio-economic point of view.

Failing to properly include the specific needs of women in this European action on Alzheimer's disease can have societal and economic costs that could be avoided if adequate and timely decisions were made.

Rather than being seen as a social or economic burden to society, ageing women must be seen as a potential resource for society. They play an active role in their families and in the community, as care-givers.

The EIWH will support the European action on Alzheimer's disease and ensure it will duly recognize women as sufferers of dementia as well as the collateral health consequences dementia has on the female carers.

The EIWH is also looking forward to the engagement of other European Commission DGs in this EU action on Alzheimer's disease as it encompasses many sectors : health, employment and social affairs, research, digital agenda, fundamental rights and citizenship, education.

## **BACKGROUND**

Dementia affects over 7 million people in the European Union and Alzheimer's disease is the most common form of dementia.

Alzheimer's disease is a neurodegenerative disease with progressive damage of the brain cells. The result is a slow but continuous loss of cognitive and intellectual functions (memory, thinking, judgment and autonomy). While a small number of young people may be concerned, the prevalence is higher in people over 65 and in women (4.9 million women and 2.4 million men).

The incidence of Alzheimer's disease is deemed to increase along with the increase in life

expectancy. It is thus foreseen that the number of people with the disease will double, even treble by 2050.

Alzheimer's disease is the first cause of dependency in Europe. It has collateral effects on the carers who are very often a close member of the family. It is estimated that – on average – three persons in every family directly bear the burden. It is reckoned that some 19 million Europeans are directly affected by the disease. At the late stage, the carer of a person with dementia can dedicate over 10 hours per day to the person with dementia. Access to home care, residential care and respite care is most unequal across the EU. Very often the carers are not aware of their existence or cannot afford them.

Alzheimer's disease is a costly disease. It is estimated that the total direct and informal care cost of Alzheimer's disease is € 21,000 per patient/year across the 27 Member States (56% of this amount relating to informal care).

Some risk factors have been identified (age, hypertension, hypercholesterolemia, diabetes mellitus). Nevertheless, very few studies have concentrated on the gender differences in dementia risk factors.

To-date, no cure has been found to halt or treat the disease. Treatments that delay progression or alleviate the symptoms exist but are unequally accessible across the Member States.

It is obvious that dementia, and in particular Alzheimer's disease, have a dramatic impact on the current and future healthcare and social budgets. Research remains fragmented and underfunded compared to other as prevalent diseases. It is urgent to address these issues in a timely manner. This is even more crucial as we sail through an unprecedented economic crisis.

Health must remain a top priority, both at EU level and at national level. It calls for due recognition and must be put in the context of new research and development opportunities as well as social and financial opportunities within the context of the EU 2020 strategy.

## **EU ACTION ON ALZHEIMER'S DISEASE POLICY RECOMMENDATIONS**

- **EU action to include a gender perspective as well as a health and gender impact assessment.**

This recommendation is based on two facts : Alzheimer's disease mainly affects women (who on average live 7 years longer than men) and women play an important caring role in the society (starting with the care of young children to the care of elderly relatives while, very often, looking after a husband).

Between 50% and 80% of the people with dementia are cared for at home usually by a close family member, very often a women. As the patient's function deteriorates, the burden on caregiving increases (the caregivers can spend over 10 hours a day caring for a person with dementia). As a consequence, the informal carer very often has to leave a paid job to fully engage in a caring activity.

It must also be taken into account that, because of this caring role, women tend to neglect their own health. It is therefore important that all new EU policies include a gender perspective and recognise the role women play in society.

- **Medical and socio-economic EU research to have a specific focus on Alzheimer's disease and include a specific gender perspective.**

It is well-recognised that women are not duly represented in clinical trials. Clinical trials for dementia drugs must include a fair proportion of women.

The Joint Programming Initiative of research to combat neurodegenerative diseases (JPND) must include a specific focus on women.

Equally, future FP8 must have a strand on dementia, including gender-specific research into Alzheimer's disease.

The newly created Gender Institute must be a partner in collecting disaggregated socio-economic data that will support the development of innovative EU socio-economic policies.

- **EU health, education and information policies to help increase awareness, break the stigma about the disease and increase prevention.**

All too often, the people affected by dementia do not recognise the symptoms and consult a doctor at an advanced stage of the disease.

EU awareness campaigns must be put in place (around World Alzheimer's Day, for instance) and the EIWH supports the European Parliament Resolution on the JPND that calls for a European Year of the Brain in order to raise awareness about brain-related diseases associated with ageing, and measures to prevent them.

Alongside early diagnosis, prevention must also be at the chore of these awareness campaigns.

- **Flexible work policies must be considered**

Very often, as dementia progresses, the vast majority of informal carers may have no other alternative than leave a paid job to look after the person with dementia. It is thus essential that the Member States officially recognise the role of informal carers of elderly, often dependant, people.

To follow the development of the disease, gradual measures may be offered : first, flexible work policies to answer the specific needs of the people with dementia (who need to stay in a familiar environment) and those of the informal carer who needs some time off work to care while retaining a paid job.

Second, the Member States should introduce an official paid leave for people caring for a dependant person, inspired from the existing parental leaves in place. This is important to fight women's poverty and bring equity in the system : the carers of elderly, dependant persons must get the same recognition and compensation as parents taking some time off for their children.

To ease the carers' burden and meet the EU 2020 objectives of full employment and new job creations, the introduction of flexible work policies must be an integral part of the European action on dementia to ease carers' burden and help meet the EU 2020 objectives of full employment.

- **The EU action on Alzheimer's disease bring new job perspectives**

Once again, the Member States must recognise the role of informal carers and see this as a positive development.

As dementia is a multifaceted disease with dramatic behavioural changes and cognitive impairment that leave the informal carer in disarray, this informal carer should benefit from adequate training to be better prepared and act appropriately, in a timely manner.

When one correlates the lack of future carers due to a dwindling number of young people who

could take over and the increase in the need of carers of people affected by dementia over the coming years, the carers skills can later be used in the community, thus possibly creating new job opportunities for these people who have had to stop a career some years before.

- **Appropriate pension schemes**

Pensions is another area on which the EU action on Alzheimer's disease must focus : women who have stopped a paid work to care for a dependant person lose on their pensions. Women poverty is a fact that needs to be overcome.

The EU action on Alzheimer's disease must pay specific attention to the carers and provide them with a pension to recognize the years spent looking after a dependant person.

The European Commission's Green Paper on pensions is a vehicle to push the agenda forward and the EIWH will contribute to the consultation.

- **Access to and financing care**

To enable women who become informal carers stay active in employment longer, the Member States must develop tailored quality care facilities for people with dementia : there is a sharp need in more day care centres, home care, respite care facilities...

Due recognition of the geographical constraints faced by people with dementia and their carers must be duly taken into account too (rural area, small towns, transport facilities...).

Tailored, high quality long-term care (LTC) facilities are another area that the EU action on Alzheimer's disease must consider. Gender criteria must be included when setting up these facilities to respect the individual.

The bureaucratic, administrative and financial barriers that can be encountered when resorting to long-term care must be an integral part of the action and be overcome.

It goes without saying that the care facilities be of high quality, with trained staff and the staff performances be regularly evaluated.

The gender perspective is relevant when considering access to Long Term Care(LTC) services, as women are the main providers of LTC, especially informal care, and the main users of LTC services as they live longer than men.

- **Promote ICT and assistive technologies**

While keeping the people with dementia in their familiar environment and relieving the carers' plight, ICT and assistive technologies must be developed and seen as a positive development.

Stimulating this new technological and economic sector can on the one hand help economic recovery and answer the patients and the carers needs.

It is imperative that these new technologies respect the individual's privacy and integrity.

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