

A response by EDCON

EDCON, based at the Madariaga European Foundation in Brussels, is a network of European experts in the field of dementia. It was created to identify controversial issues concerning the care for people with dementia, to build consensus among all concerned on these issues and to promote recommendations developed on the basis of this consensus so as to improve care for patients and their caregivers. By this we want to improve the communication between the scientific community and the wider audience of policy makers and the public in one of the most important topics for the ageing population.

EDCON welcomes the Commission initiative and the opportunity to underline a number of important issues in relation to demographic changes, particularly in relation to challenges brought about by the increasing number of older people.

We are pleased to see the Green Paper's approach to the ageing of society, which -quite rightly- emphasises the *challenges* brought about by demographic ageing. The consequences of this development for the structure of the labour market, the sustainability of social security and the provision of care are indeed crucial for the social coherence of society. But where most other policy documents stop there, and underline the negative side of societal ageing only, the Green Paper also notes that *not all* older people are inactive or in need of care, and that this healthy group of older people has a vast societal contribution to make.

This is strongly in line with EDCON's view, i.e. that the fact that people live longer, healthier and more active lives is one of the most powerful success stories of the last century.

However, EDCON would like to share some concerns in relation to the way the Green Paper addresses the growing need for care and areas where possible solutions ti fulfil this need could be sought. This issue is of particular importance to EDCON, as the chance of being affected by a form of dementia increases with age, and the rising number of people suffering from a dementia represents one of the most serious challenges to health and care systems for the coming years.

The Green Paper underlines the crucial role of the family in care provision, and hence the need to support families in their care tasks (according to the Green Paper, measures should be put in place that will facilitate families having more children). On the other hand, it makes a powerful case for the need for increasing labour market participation by women (the main providers of family care).

There are two issues EDCON would like to raise in this respect.

Firstly, it is clear that, changing demography and working conditions are accompanied by changes in family life and roles. Due to demographic pressures - such as smaller and more dispersed families (lower fertility), increasing female labour market participation and increasing mobility - family care provision is under threat. EDCON would therefore advocate the strong need to implement policies that would make it easier for families to *continue* to provide this care. An example would be offering support by putting in place more family friendly labour market policies, enabling family carers to combine their care tasks with their work responsibilities.

Increasing the labour market participation of women (the main providers of family care) will further undermine the family care potential, if improved policies for reconciliation of work and family life are not put in place.

Attention should also be paid to intra-generational support systems.

Secondly, the Green Paper only focuses on informal (family) care provision. However, health systems need to adapt their <u>formal</u> care provision as well to the specific –and growing – care needs of frail older people, and ways need to be found for formal and informal care providers to cooperate better and be mutually supportive.

This is in line with the priorities of EDCON as demonstrated by two of the consensus statements we are elaborating at this point in time, i.e. improving standards of dementia care and access to diagnostic evaluation and medical treatment for dementia. Improving standards of dementia care will make a concrete contribution to improved quality of life for older people and their carers. Better access to diagnostic evaluation and medical treatment will also help to alleviate the burden on care provision, both in a formal as well as in an informal sense.

The Green Paper asks the question whether the issues it raises should be addressed at European Union level. EDCON is of the opinion that, since all Member States are currently trying to find solutions to these challenges, the EU has a crucial role to play in facilitating the exchange of experience and practice. This will enable health stakeholders to learn from each other and improve cooperation in these vital matters.

EDCON is currently in the process of developing links with the main EU health stakeholders, in order to ensure that issues related to dementia become part of the European health, social and research policy agendas, and we look forward to the outcome and next steps in this vital consultation initiative.

Yours sincerely,

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EDCON Chair

