



EUROCARERS

EUROPEAN ASSOCIATION
WORKING FOR CARERS

EC Communication on effective, accessible and resilient health systems

Comments from Eurocarers

1. Introduction

Eurocarers is a European organisation representing informal, unpaid carers and their organisations, with the aim to advance their interests, irrespective of the particular health need of the person they are caring for.

We warmly welcome this Communication, which underlines the European Commission's commitment to support member states in their efforts to put in place functional health systems that work for patients as well as for society and the economy.

This short paper serves to make the case for –EU and national level - initiatives in this area to explicitly include carers and their issues and actively seek to ensure that carers are enabled to care.

2. Why do carers matter to health systems?

Carers are persons of all ages who provide care (usually unpaid) to someone with a chronic illness, disability or other long lasting health or care need, outside a professional or formal employment framework. Research has pointed out that approximately 80% of care across the EU is provided by families (spouses and children) and friends, predominantly within the home environment. Even in countries with a well-developed supply of formal long term care, the number of informal carers is estimated to be at least twice as large as the formal care workforce.

Estimates also suggest that the economic value of unpaid informal care - as a percentage of the overall cost of formal long-term care provision - in EU Member States ranges from 50 % to 90 %. For example, in the UK, it has been calculated that the value of informal care equals £ 119 billion (€141.2 billion)¹ – a huge contribution in times of austerity and tight health and social budgets. Therefore, carers constitute an enormous resource - to patients, to society and to the economy.

This precious resource is under pressure, however: the combination of various demographic and socio-economic developments – such as lower birth rates, the trend towards smaller families, increasing mobility (leading to greater physical distances between relatives), the rising number of women entering the labour market² and a prolonged working life due to delayed retirement (partly following explicit policies aiming at increasing labour force participation of women and older workers) – is rapidly leading to increased strain on carers, as a result of the decreasing unpaid care potentials. Moreover, these developments are being

¹ Royal College of Practitioners report 2013

² Actively encouraged by the EU itself, with its target of a female employment rate of 75 % by 2020.

compounded by increasing shortages of formal caregivers, and this is rapidly becoming a major issue in the majority of EU Member States

3. Some general comments on the Communication

The Communication contains a number of positive notions, such as:

- The common values with respect to health across the EU - as recognised by the Council of Health Ministers in 2006, i.e. universality, access to good quality care, equity and solidarity.
- The need to strengthen cooperation between health systems in view of common challenges such as *'increasing cost of healthcare, population ageing associated with a rise of chronic diseases and multi-morbidity leading to growing demand for healthcare, shortages and uneven distribution of health professionals, health inequalities and inequities in access to healthcare'*.
- The fact that health has now gained a firm place on the EU health agenda, as underlined by inclusion of health and health issues in a number of overarching policies and initiatives such as the European Semester, the Annual Growth Survey and Europe2020
- The important role of innovation in the health care sector
- The three main principles of the Communication, i.e.
 - strengthen the effectiveness of health systems
 - Increase the accessibility of healthcare
 - Improve the resilience of health systems

Other positive issues relate to:

- The Commission's intention to pay more attention to the patient experience.
- Eurocarers would like to urge the Commission to include the carers experience in this future work as an essential partner in the health/care team
- The need to better measure the effectiveness of health systems, and to gathering information on the comparative effectiveness of health systems. The role and contribution of carers, in terms of e.g. compliance, would also need to be taken into account.
- The need for health systems to be accessible, and the various factors that influence & inhibit this accessibility. Eurocarers would like to underline that this accessibility need also holds true for carers as it often comes down to carers to navigate the healthcare system on behalf of the person cared for. Affordability is quite rightly mentioned as one of the barriers in accessing health care, as many carers can experience financial difficulties as a result of their caring responsibilities (out of pocket expenses and in many cases, income loss due to the difficulty of combining paid work with care responsibilities). Availability of care services is another important factor for carers, as they will need the support of formal care services in order to be able to care.
- The need for less separation between health professions and putting in place multidisciplinary teams. Carers should be considered as part of these multidisciplinary teams, as good cooperation between formal and informal care providers is crucial to the quality of life of the cared for persons.
- The need for health systems to be sustainable. Eurocarers would again like to underline the huge personal and financial contribution made to health care systems. Without the 80 % of all care being provided, mostly free of charge, clearly health systems would collapse without the continuation of informal carers.

4. Adding carers to the EU agenda for effective, accessible and resilient health systems

The Communication lists a number of actions it has taken or is intending to take that can support Member States, including:

- A report on *quality of care and patient safety* presenting the implementation of the Council recommendation on patient safety, with a view to further action in this field. Eurocarers will follow these developments with interest and will continue to make the case for inclusion of carers in this work.
- Work on *Integration of care* 'between different levels of healthcare (primary care, hospital care, etc.) and between health and social care, particularly with regard to elderly people or people with chronic illnesses'. Under this heading the Commission refers to the opportunity to exchange learning experiences on questions relating to which patients can be treated better or equally well outside hospital and how to successfully reduce hospitalisations. It is clear that both these questions have a strong bearing on carers and what they contribute, as reductions in hospital care will inevitably lead to increases in the demand for care at home. While shortening stays in hospital may be beneficial to patients and health systems, it frequently increases the burden on family carers. A shift from intramural to community/home based care will be hard to accomplish without putting in place adequate support measures for carers at the same time. *Training of carers will be indispensable as well*, as carers increasingly administer and monitor complex medication prescriptions, implement and manage complex medical procedures (dialyses, peg feeding etc.) and work with modern technology within the home environment, often with minimum training or support. Training and support will also benefit the persons cared for.
- The need to develop *eHealth applications*. In this respect, Eurocarers would like to point out that, apart from the need for products and services that could support patients, there is a need for products and services that support carers. Not only will this decrease the care burden, it will also contribute to a higher quality of life and increased independence of the persons cared for.

While we welcome the above plans and intentions, Eurocarers would like to urge the Commission to take the following into account in relation to health and healthcare provision policy development as well:

- Better awareness and recognition of the contribution and the resource represented by carers to patients, society and the economy, in particular sustainable health care systems;
- The preventative aspects of well-trained and well-supported family care to avoid or delay hospital admission and long-term institutional care;
- Accessible and reliable information and advice to promote self-care and self-management solutions in family care;
- Respite breaks for carers, essential both to the carer and the cared-for-person, especially where care is provided for most of each day of the week;
- Health promotion and protection for carers in health services and delivery (e.g. need for a systematic health and social assessment of carers and of their caring work);
- Training, especially in core caring skills e.g. manual handling, coping with caring, knowledge of conditions and in situations where carers need to administer and monitor complex medication prescriptions, implement and manage complex medical procedures;
- Assisted Ambient Living (AAL) and Information and Communication Technology (ICT) products and services that support carers, e.g. to decrease the care burden, to contribute to a higher quality of life and increase the independence of the persons cared for;
- Integrated provision of services at home as well as in care institutions and hospitals, but also between health and social care systems. Privately-hired domestic care workers can provide an important support to carers; recognised training is important in this respect;
- Recognition by and training of formal care service (including homecare) providers with regard to the central role of carers and acknowledgment of them as equal partners in care.

In more practical terms, Eurocarers would like to suggest a number of current EU health initiatives where carers and their issues could be included or strengthened:

- The European Innovation Partnership on Active and Healthy Ageing Partnership;
- The Health Programme;
- The Joint Action on Mental Health;
- The Joint Action on Chronic Disease;
- Actions on health inequalities and access to health care;
- Strand 'health, demographic change and well-being' of the Horizon2020 programme
- Participation of carers organisations in the European Health Policy Forum

5. Conclusions

It is clear that carers are an inherent as well as an indispensable part of the provision, organisation and sustainability of health and social care systems. They will become even more important in view of the changing health and care needs, due to the ageing of society and the increasing prevalence of frailty and chronic disease. They currently are the largest contributors to the sustainability of our health and social systems.

Despite the obvious importance of the contribution of carers, their interests are rarely considered in policies that impact on them in a consistent and across-the-board manner, including health and health care policies. This is one of the reasons why Eurocarers, together with the European Parliament Interest Group on Carers, has developed a template for an EU level carer's strategy, which could be part of the Commission's proposed agenda in the field of improving the effectiveness, accessibility and resilience of health care services. Apart from sharing the same challenges and despite the variations between the individual health systems, all member states need the resource provided by informal carers to prevent a collapse of the entire care system. All member states need to take account of carers and their support needs. A copy of the template strategy is attached for your information.

Providing care can be a source of personal satisfaction and emotional gratification. But, if not adequately supported – caring can bring many challenging consequences for carers. While these challenges occur in many different areas (employment, work/life balance, finances, social inclusion...), it can also have a strong impact on the (physical and mental) health and well-being of carers themselves, leading to higher health and welfare care costs for society and the economy.

Therefore, if carers are expected to keep providing care – and they are – their needs and requirements should be an inherent part of health and social policy development, and their contribution properly considered as part of the economic equation.