EURO CARERS

European Association Working for Carers

ENABLING CARERS TO CARE

An EU Strategy to support and empower informal carers

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TERMINOLOGY

A range of terms are used to describe a person who cares for another including: an 'unpaid carer', a 'family carer', an 'informal carer', a "caregiver" or simply a 'carer'. As part of the development of this EU strategy, Eurocarers members have chosen to use the term 'informal carer', which reflects a widespread option in existing policy documents of relevance to carers. In this document though, we often abbreviate 'informal carer' to 'carer,' as do many organisations and carers themselves. Eurocarers defines carers as "persons of all ages who provide care (usually unpaid) to family members, other relatives, partners, friends and neighbours with a long-term illness, disability or other long-lasting health or care need, outside a professional or formal employment framework". It is important that carers are not confused with paid workers, who are sometimes called carers too: paid carers are care workers. Equally, carers are not volunteers. There may well be volunteers supporting the cared-for person and/or the carer, but they are not the carer.

WHY CARERS COUNT

Europe's overall increase in life expectancy and ageing demographic is generating a growing incidence of age-related conditions, a growing demand for care in all age groups and a serious sustainability challenge for care systems. This is exacerbated by an ageing EU health and social care workforce, problems with staff retention due to demanding working conditions and relatively low pay in some occupations, as well as the need for new skills and competences as a result of new care patterns and the rise in new technologies. These challenges are consistent across EU member states.

Against this backdrop, community care has become a prominent EU priority in the last few years and the shift towards home-based care is seen as a practical measure to contain the costs of services while also supporting widespread preferences among (older) people[1]. All of this puts more and more pressure on informal carers who - in most European countries – already provide a large part of Long-Term Care for dependent people.

In Europe, 80% of Long-Term Care (LTC) is provided by informal carer[s] and estimates of the economic value of this unpaid care - as a percentage of the overall cost of formal Long-Term Care provision in the EU - ranges from 50 to 90 %[3]. The projected budgetary impact of a progressive shift from informal to formal care by 2070 would imply an increase of the share of GDP devoted to Long-Term Care by 130% on average for the EU[4].

The value of informal care in Europe is not only a matter of finances. Informal care and solidarity also have an intrinsic value from a moral standpoint, i.e. standing and caring for vulnerable groups (e.g. people who are chronically ill, persons with disabilities and frail older people) not because of any personal interest, but because they need this support. Caring, and its impact on both those who carry out the role and those who receive care, engages civil, political as well as socio-economic rights. The provision of the latter in particular, requires positive actions by the State and investment of public resources[5].

From the above, 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 demographic ageing and the increasing prevalence of frailty and chronic conditions.

Informal care can be a source of great personal satisfaction. But in many cases – and even more so when people have limited choice in their caring roles or when no adequate support is available – informal care can be a determinant of negative health outcomes, a barrier to education and employment, and a driver of discrimination, social exclusion and poverty. The welcome shift from residential and institutional care settings to care at home must not place additional burdens on carers or prevent them from working, learning or having a life outside of caring. Policies that affect carers should therefore never assume that people innately want or choose to be carers. While it is clear that carers will be essential to meet the challenges posed by ageing societies, free choice and personal autonomy should therefore remain at the core of any initiative targeting them. This Strategy is based on the idea that carers, whatever their circumstances, should enjoy the same opportunities in life as other people without caring responsibilities and should be able to achieve their full potential as citizens.

Consequently, people should have the **right to choose freely** whether they want to be – and remain - a carer, and to what extent they want to be involved in caring; people needing care should have the right to choose who they wish to be their carers. **Carers who want to care for their dependent relatives/friends should receive the recognition they deserve for the central role they play in community care, and this should be reflected in all policies affecting carers.** Without the vital contribution of carers, European care systems would not be sustained. Informal care should therefore be 'normalised' by ensuring that carers are seen as equal partners in the planning and delivery of care and have access to the financial, practical and emotional support they require. Initiatives targeting carers should focus on identifying, assessing and supporting them in a personalised and outcome-focused way and in a consistent and comprehensive manner.

In contrast, **people who do NOT want – or are not able - to be involved in the provision of care to their relatives or who only want to play a limited role in these activities should be able to rely on affordable and professional care options of good quality, in particular home-care and community-based services.** Demographic ageing as well as recent changes in society which have altered family structures (e.g. smaller families, greater physical distances between relatives, rising number of women entering the labour market, a prolonged working life, etc.) will put more pressure on informal carers in

Europe, and so informal care should be seen as an important component but not as THE only central element of care systems in Europe. Member States should therefore invest in the development of long-term care services (in particular homecare and community-based services) which are universally accessible. They should aim to move from a primarily reactive to an increasingly proactive policy approach, which seeks to reduce care demand and boost cost-effective care provision. This shift of approach should build on:

➡ Preventive measures to reduce the consistent and cumulative number of people needing long term care;

➡ Better detection of persons in need of care and their informal carers;

➡ Targeted interventions to manage functional decline and frailty;

➡ Rehabilitation and re-enablement to improve people's ability to live independently;

➡ Realising the full potential of technology to help people remain at home, to raise the efficiency of care services and to compensate for the expected decline in the number of informal carers;

➡ Better coordination of health and social care to improve the effectiveness of care overall;

➡ Measures to improve the supply and retention of formal carers and informal carers, including by helping informal carers to reconcile work with family and care responsibilities;

➡ The promotion of age-friendly environments which facilitate independent living;

➡ Measures to boost the efficiency, accessibility and affordability of long-term care (and particularly community-based and home care services); and

➡ Measures to improve the quality and responsiveness of care services.

Too often though, the lack of care options meeting these criteria leads to situations where informal

care becomes the default element in the care chain, with a severe impact on carers' ability to experience equal opportunities in their everyday social and professional life. Actions targeting care-recipients, carers and communities should be seen as complementary and co-dependent, particularly at the time of addressing inequalities in health.

THE RATIONALE FOR AN EU STRATEGY ON CARERS

Over the last few years, much has been achieved in taking forward the carers' agenda at international, EU and – to some extent – national and regional level. However, the success of initiatives aiming to address the needs and preference of carers largely depends on the interplay between a broad set of policies in the social, health and employment fields. Yet, policy developments of relevance for carers have often been implemented in a fragmented and uneven manner and have therefore not always resulted in real improvements in carer support, leading - sometimes - to a breakdown in trust between carers and decision-makers and service planners.

Much more needs to be done to achieve practical support on an all-inclusive and multidimensional basis, to connect the dots between existing EU, national and regional policy initiatives and to trigger new ones in support of carers. This strategy therefore presents a coordinated set of steps to be taken in order to:

➜ **Contribute to the provision of affordable long-term care services of good quality, in particular homecare and community-based services for all across the EU. In this, carers should be recognised as partners in care and not as passive recipients of health, care and other support services; and**

➜ **Put in place support measures that enables carers to maximise their life prospects and maintain an active and productive life while continuing to care, should this be their choice.**

WHO DOES THIS STRATEGY CONCERN?

This strategy will be of interest to those who can improve the lives of carers, in partnership with them, and who can influence the support provided to carers. It is for decision-makers, managers and practitioners, especially in local authorities, community-based care teams, and all statutory agencies involved in supporting carers. The strategy will also interest carer Organisations, condition-specific organisations and others in the Third Sector. Last but not least, the strategy will also be of interest to informal carers across Europe. Carers know all too well what caring means but it is important to change how services and support are planned and delivered at international, EU, and national/regional level in order to contribute to improving carers' wellbeing, confidence, ability to combine caring responsibilities with an active social and professional life, protect themselves from disadvantage or discrimination (including financial hardship, as a result of caring), and get involved in the planning and shaping of the services required for them as well as care recipients.

The 10 steps towards carer-friendly societies across Europe

STEP 1	Define and acknowledge Carers
STEP 2	Identify your Carers
STEP 3	Assess the needs of your Carers
STEP 4	Support multisectoral care partnerships for integrated and community-based care services
STEP 5	Facilitate carers' access to information and advice about care, caring and care-life balance
STEP 6	Pay attention to carers' health and prevent negative health outcomes
STEP 7	Give Carers a break
STEP 8	Provide Carers with access to training and recognise their skills
STEP 9	Prevent Carers' poverty and allow them to maintain an active professional/educational life
STEP 10	Adopt the Carers' perspective in all relevant policies

Define and acknowledge Carers

Informal carers are vital, both to the care of people with long-term conditions and disabilities in the community and the economy of EU countries. Yet, decision makers often fail to meet their needs either due to the use of narrow-focused definitions of informal care or the absence of such definitions in the legislation. The first step in making a decision or addressing an issue is to define it.

A broad and inclusive definition of informal care and carers should be adopted as the basis of any resolute action aiming to develop a comprehensive and consistent carer-friendly policy framework. Public authorities at International/EU, National and regional level should seek to agree on a clear and inclusive definition of informal care, along the lines of the definition used by Eurocarers – i.e. carers are persons of all ages who provide care (usually unpaid) to family members, other relatives, partners, friends and neighbours with a long-term illness, disability or other long-lasting health or care need, outside a professional or formal employment framework - is suggested. This definition should be the starting point of a more systematic and proactive approach aiming to consolidate and flesh out carers' existing legal rights and to set out key principles for carer support both now and in the future.

Identify carers

Taking on the care of another person may be a swift process but carers do not immediately identify with being a 'carer' – preferring to think of themselves in relational terms to the person with a long-term condition or disabilities e.g. partner, sibling, son, daughter or friend. Besides, there is a widespread view that caring for or looking after someone, particularly a family member, is 'what you do.' It can also be difficult to determine when 'the caring journey' starts, depending, for example, on the condition of the would-be carer's relative or friend, who may initially keep quite good health.

As people become older, frailer, sicker, and/or increasingly disabled, become addicted to alcohol and/or illegal drugs or have a diagnosed mental health problem, the role of carer becomes more apparent. As the cared-for person's condition deteriorates, the caring role often becomes all-encompassing so that carers are managing competing demands, and feel unable to look after their own needs as well as those of the cared-for person. Many people who support family members with mental health problems or drug or alcohol addiction do not seek to identify themselves as carers as there is still a stigma attached to this role. In addition, the person with care needs may deny that they need or are getting support from a family member or partner. Some, in particular younger carers, are not known to be carers. They do not tell relatives, friends or health and care professionals about their responsibilities because of a fear of separation, guilt, pride or other reasons.

There is substantial evidence that unfavourable socio-economic circumstances are strongly related to high morbidity and mortality, that socio-economic differences in health persist into old age, and that health status is one of the strongest predictors of the use of both formal and informal care. The general understanding is that people in low socio-economic status (SES) groups receive more informal and formal care because of their relatively high need for assistance, as most overtly indicated by their poor health. However, socio-economic inequalities in the use of informal care tend to be greater than those for formal care.

In many countries, formal care services are means-tested, i.e. individuals with low income pay less for formal care. Because people in low SES groups are less able to purchase privately-paid care and their use of formal services is subsidised, they are the most likely to use both informal and public-sector care. As a result, socio-economic inequalities in the use of informal care can be observed across Europe[6]. It is therefore important to pay specific attention to lower socio-economic groups when identifying carers and assessing their needs. Measures targeting carers should be put in place in a universal manner, but with a scale and intensity that is proportionate to the level of disadvantage.

Finally, there are hard-to-reach carers, including Black and Minority Ethnic (BME) and LGBTI carers. For BME carers, problems of language and communication may make self-identification more difficult. Professional attitudes and beliefs such as 'they look after their own' can also impact on how BME carers are identified by practitioners. As a result of all of the above, one of the biggest challenges is to identify hidden carers. Carer identification is the first important step to a proper assessment of carer's needs, the definition of tasks that they are prepared to take upon themselves and the provision of support.

Measures should be put in place to collect information about the number and typology of carers and their specific needs. Steps should also be taken to help professionals in the health and social care workforce to identify and interact with carers. Efforts should be stepped up to raise awareness about informal care and carers and to collect data about the number, typology and needs of carers in Europe. To do so, a few existing tools and initiatives have already demonstrated their added value. For example, a (limited) number of public authorities have introduced questions about informal care in their national census and population surveys in order to capture to situation of carers. These very laudable and useful practices should be rolled out across Europe. More generally, all relevant stakeholders (civil society organisations, care professionals, carers' organisations, condition-specific organisations, etc.) have an important role to play in raising awareness about care and caring and in collecting data about carers at their level. Self-identification tools should also be put in place in order to encourage carers to identify themselves more proactively. This nevertheless calls for vigorous information campaigns about the issues faced by carers and available support, the identification and training of professionals providing a secure and safe environment where carers have the confidence to identify themselves and the provision of appropriate opportunities for carers to self-identify.

Furthermore, given their contact with care recipients and their families, it is widely recognised that health and social care professionals are best placed to identify informal carers and encourage them to consider themselves as such. Care professionals should therefore be better informed and trained about the role, challenges and added value of carers in order to integrate carer identification into their core professional role. Members of the health and social care workforce who are 'carer-aware' have an important signposting role to play in the implementation of effective carer-friendly support measures. Many things can be done by the care workforce to support informal carers – most of which are neither time consuming nor expensive in terms of resources. They can acknowledge carers, include them in discussions about the person they care for in order to develop or adapt the care plan, perform a regular follow-up, give them a choice about the tasks they are prepared to take upon themselves, enquire about their health and overall wellbeing, provide them with information about the condition of the person they care for or inform them about their rights and the support measures that are available to them. Measures to train and allow care professionals to actively support carers should therefore be put in place without delay.

A broad and inclusive definition of informal care and carers should be adopted as the basis of any resolute action aiming to develop a comprehensive and consistent carer-friendly policy framework. Public authorities at International/EU, National and regional level should seek to agree on a clear and inclusive definition of informal care, along the lines of the definition used by Eurocarers – i.e. carers are persons of all ages who provide care (usually unpaid) to family members, other relatives, partners, friends and neighbours with a long-term illness, disability or other long-lasting health or care need, outside a professional or formal employment framework - is suggested. This definition should be the starting point of a more systematic and proactive approach aiming to consolidate and flesh out carers' existing legal rights and to set out key principles for carer support both now and in the future.

Assess the needs of carers

A carer's assessment is an opportunity to discuss with the social services what support or services he/she needs. The assessment should look at how caring affects the carer's life, including for example, physical, mental and emotional needs, and whether the carer is able or willing to carry on caring.

Steps should be taken to develop and – when already in existence - improve the uptake and quality of carers assessments/carer support plans which allow to develop personalised support measures. Carers should be entitled to an assessment regardless of the amount or type of care they provide, their financial means or their level of need for support. It should be available to carers even if the person that they care for is not eligible themselves for statutory care and support. They should not necessarily have to live with the person they are looking after or be caring full-time to have an assessment.

When a carer is sharing caring responsibilities with another person, or more than one person, including a child under 18, each should have an assessment (although for a child under 18 the assessment should be different). For young carers, the local authority should have a duty to assess 'on the appearance of need' (i.e. without a 'request' having to be made). They should also be required to take reasonable steps to identify young carers in their area.

Some people indeed start giving care at a very young age and do not really realise they are carers. Other young people become carers overnight. If someone in the family needs to be looked after, kids may really want to help them. But young carers should not be involved in similar activities as adult carers. Nor should they be spending their time caring for someone at the detriment of their educational attainment and social life. It is important for young carers to be able to decide whether they are the right person to provide the care needed by the cared-for person, how much and what type of care they are willing or able to give, or whether they should be a carer at all.

The child with caring responsibilities, their parents and any other person the young carer requests should therefore be involved in the assessment process. The assessment itself should look at whether or not the young carer wishes to continue caring, and whether it is appropriate for them to continue caring. When doing this, any education, training, work or recreational activities the young carer is or wishes to participate in should be considered.

Where a young carer's eligible needs are identified as requiring support, local authorities should either:

➜ **Provide support directly to the young carer or**

➜ **Demonstrate that the 'cared for person's' assessment has provided adequate care and support to prevent inappropriate care being required from the young carer.**

The particular needs of specific groups of carers, e.g. older or young carers, carers from lower socio-economic status backgrounds, Black and Minority Ethnic or Lesbian, Gay, Bisexual and Transgender carers, and carers with disabilities/illnesses, should be taken into consideration.

Carers organisations have a vital role to play in supporting the development of assessment plans and the provision of personalised support measures to carers - they should therefore be supported and nurtured.

EQUALITY GROUPS

Research has highlighted socio-economic differences in the use of informal and formal help. Because of their relatively poor health and lack of social and material resources, people in low socio-economic status groups tend to receive more informal and formal care than those in the high socio-economic status group. This is particularly true in the case of informal care, which underlines the profoundly inequitable dimension of care systems that excessively rely on informal care. Investment in accessible formal care services therefore remain the central element of universal and carer-friendly care systems.

Preventing inequalities on the ground of "race" or "ethnicity", disability, gender or sexual orientation, age or religion means ensuring opportunity for all carers to access suitable resources and support. Carers may be excluded from support because there is no recognition of their particular caring situation. The result may be lack of opportunity, difficulty in accessing provision or unresponsive services.

Carers' centres should deliver support to partners and be careful about advertising themselves to families only, which might be off-putting to LGBTI carers. Health and social care professionals need to be sensitive to caring relationships and the different forms these may take.

LONG-DISTANCE CAREGIVING[7]

In most European countries labour market mobility and changing family patterns are increasing while the number of family carers in close proximity decreases. For example, data from the Survey of Health, Ageing and Retirement in Europe (SHARE) indicates that in 15-30 % of all cases, the own mother lives more than 100 kilometres away. In this context, it can also be assumed that a number of European citizens have a national but, in some cases, also a cross-border long distance to overcome.

According to the current literature (mainly from the U.S.), distance carers are predominately female, married with children, belong to the age group 40-50 years and report a high socio-economic status. However, the group of 'distance carers' shows a higher proportion of male carers compared with family carers living nearby – possibly due to their main function as 'secondary caregivers' from the distance. Distance carers provide a lower amount of hands-on care (10h/week vs. 3-6/day as proximate carers) but perform typical care tasks from far away, such as monitoring care, management care, emotional care and motivation. This leads over to the question of a broader definition of 'care' beside 'hands-on'-care, which acknowledges also emotional and cognitive dimensions of help. Care recipients are mostly parents and/or parents-in-law, supported by their own children living far away. According to the MetLife Study, one third of the distance carers also get help from other siblings or other close relatives as well as from their own spouses. Professional help and help from friends or neighbours are also important for local support. The findings therefore highlight the social embeddedness of distance care-arrangements.

CARING IN REMOTE AND RURAL AREAS

Providing support to carers in remote and rural areas has an equality dimension to the extent that carers living in these areas may not have access to the same support than other carers. The accessibility of healthcare services for the person with care needs can be a significant issue for this particular group of carers.

Another key issue is transport. Many carers in remote and rural areas have to travel long distances and there are issues about the lack of adequate transport or the high costs of transportation. There are other key issues relevant to caring in remote and rural areas. As a result of having to travel long distances, it can be difficult to keep hospital and GP appointments. Innovative solutions are needed to help make life more straightforward for carers in rural areas. ICT-based solutions (e.g. Telehealth care) are very relevant to caring situations in remote and rural areas and they should therefore be explored further.

The carer's assessment/carer support plan should be the gateway to support and services. However, carers who do not have a carer's assessment/plan should also be able to access support even if the carer's assessment is the preferred route to support. There are many forms of support available to carers over and above that provided, in some cases, by other family members, friends and neighbours.

In the delivery of support, it is important to take into account that a person's caring situation can change quite dramatically, even in a short space of time. People can continue to be carers, in a different way, for example, when the person they are caring for moves on to independent living or into a care home. Caring at end-of-life is particularly difficult and the carer may need support after their relative dies.

Carers frequently report the difficulties they encounter and the barriers they face in their day-to-day caring role. Some say they have benefited from support which is then withdrawn or that there is a disjointed approach to the delivery of support from different professionals. Carers themselves often have to use their limited and precious time and energy to facilitate the connections to be made amongst the various professionals.

Support multisectoral partnerships for integrated community-based care services

Integrating care, services and supporting activities means that the design and delivery of care is made in a more effective manner, so that users receive a continuum of preventive, curative, rehabilitative, and support interventions throughout the life course which are suited to their needs over time and are seamlessly available across different levels and areas of health and social systems.

Multisectoral Care teams, including carers and organisations that represent them, should be established in order to implement the principles of integrated people-centred care. Carers are central to the planning, shaping and delivery of services for the people with care needs and in relation to support for themselves. Carers, when approached by other actors of the care pathway (i.e. care professionals) as equal partners in the delivery of care, enable people with illnesses or disabilities to remain at home and in their own communities safely, independently and with dignity. Carers can, for example, prevent avoidable hospital admissions and contribute to people's overall health and wellbeing. The inclusion of carers and organisations that represent them in Integrated Care Partnerships can allow to release the full potential for synergies across services, better allocates resources and avoids overlaps and the negative effects and costs of service disruptions on health status.

ICT-based solutions for care offer great potential in the context of integrated care services. When it comes to carers, ICT can support their social integration, provide them with social, emotional and peer support, facilitate their participation in aspects of life outside the home and thus improving their quality of life. The appropriate and targeted use of telecare – i.e. the remote or enhanced delivery of care services to people in their own home or a community setting by means of telecommunications and computerised service - can help carers by: providing affordable access to support and assistance round the clock; supporting individual, personalised services; achieving fewer days in hospital and care homes and less Accident and Emergency admissions; reducing stress and providing peace of mind; enabling a good night's sleep; helping some carers to combine work and care; providing some with an opportunity for a life outside of caring; and

providing early intervention. Telecare usually refers to sensors and alerts which provide automatic and remote monitoring of care emergencies and lifestyle changes, to trigger human responses or shut down equipment to prevent hazards.

Equipment and adaptations can also play an important part in supporting the role of carers. Having the right equipment or adaptations in the home allows the cared-for person to remain at home for longer. It also reduces the pressure on, and risks to, the carer and it can help prevent hospital admissions. The provision of equipment and adaptations can also provide physical relief, particularly with regard to back strain. Financial measures should therefore be put in place to ensure that the required equipment and home adaptations are affordable.

Facilitate carers' access to information and advice about care, caring and care-life balance

Carers often struggle to access - sometimes basic - information about the condition of the person they care for, the services and supports that are available to them and ways of maintaining their own health and wellbeing. Carers frequently say that they would like the right type of information at the right time, depending on their particular circumstances. They also want up-to-date information, as sometimes they are provided with information on services that is out-of-date. Carers who are new to caring often say that the priority for them is to have information and advice about the condition or illness of the person for whom they are caring. They may require a different type of information as the illness or condition changes.

Measure should be taken to facilitate carers' access to information and advice about care, caring and care-life balance. Health professionals can play an important role in providing condition-specific information that can help carers to understand and deal with difficult or challenging symptoms. Many carers say that to receive information from GPs and other care staff on the condition of the person they care for would help them in their caring role. They believe that they would be better equipped to care for their relative if, for example, the GP involved them in the consultation or appointment with the cared-for person. The role of other care professionals has already been discussed hereabove. They can assist carers with navigating in and around both statutory and non-statutory services and organisations.

National carer organisations and – when these do not exist - other civil society organisations, including patients' groups and condition-specific organisations, can provide a lot of information for carers through their publications and websites, including information packs tailored to different caring situations, benefits advice and guidance on health and wellbeing. The central part played by national and local carers organisations should be supported and the emergence of new carers organisations fostered.

Pay more attention to carers' health and prevent negative health outcomes

Caring can impact heavily on a carer's physical and/or mental health and wellbeing, when not adequately supported.

The health literature shows that physical health outcomes can be linked to informal caregiving through the following dynamics:

➜ Caregiving often requires physically demanding work over a long duration, which might cause musculoskeletal injuries and aggravation of arthritis and other chronic illnesses;

➜ Carers tend to neglect a healthy lifestyle (e.g., diet and exercise); and

➜ Caregiving increases stress and lowers psychological health, which is likely to manifest in such physical outcomes as hypertension and cardiovascular condition[8]. Some studies demonstrate that mortality rates are higher among carers who report emotional strain than among non-carers[9].

The majority of studies suggests that carers tend to show an above-average level of psychiatric symptoms. Behavioural problems (e.g., disruptive and aggressive behaviour), physical and cognitive impairment, and the time spent on caregiving seem to place a burden on the carer and increase symptoms of depression. Overall, the prevalence of mental health problems among carers is 20% higher than among non-carers[10].

More attention should be paid to carers' health in order to prevent negative health outcomes as a result of informal care. Early identification and support have a positive impact on carers' overall health. A good service response to changed circumstances in caring is also beneficial to their health. Many carers are concerned that they cannot afford to be ill, and some feel unable to continue with their caring role. Carers who do say they are able to cope often raise concerns about increasing age and their own personal health problems. Carers can become socially isolated and ground down by trying to get services in place for the person they care for. Moreover, disability, illness, and long-term conditions often change family relationships.

Access to emotional support through a carers centre or provided by a condition-specific organisation or through the GP – or other primary care professionals - can help. Some carers need more intensive interventions such as counselling. Good advice and person-centred training on moving and handling can help with the physical aspects of caring. So too can having the right services in place for the cared-for person to lessen the physical burden, which can sometimes be extreme. Tailor-made resource on issues relating to stress and caring should therefore be produced and actively promoted. Health checks should be organised more systematically to assess carers' wellbeing. These should be correlated to the level of intensity of the caregiving responsibilities (e.g. carers of people with mental health problems, neurodegenerative condition or with high-level functional limitations) and – therefore - risk of adverse health outcomes. Health promotion, counselling and training offer great potential to prevent negative health outcomes among informal carers as well as the risk of abuse towards care recipients. Key drivers for change also include tackling the social determinants of health for carers (access to professional support, access to information, training and respite care, household income, etc.), improving people's health literacy, maximising and promoting employment and lifelong learning opportunities.

Give carers a break

The provision of short breaks or respite is hugely important to carers. It is often perceived as the most important and common form of support to alleviate caregiving burden and stress. Respite care can provide carers a break from normal caring duties for a short period or a longer time. Without respite, carers may face serious health and social risks due to the stress associated with continuous caregiving, and may also enjoy little time for leisure or feel isolated.

Policies and practices ensuring ease of access to suitable respite should be developed.
Carers are often reluctant to take such breaks because of uncertainties about the quality of respite care and financial difficulties. Policies ensuring ease of access to suitable respite, for example via financial support to pay for such breaks, geographical proximity and sufficient availability of respite services, are thus important. Respite care may refer to very different types of interventions providing temporary ease from the burden of care. Often, the objective of such breaks is to increase or restore the carer's ability to bear this load. The most common forms of respite care include Day-care services; In-home respite; and Institutional respite. An important element of respite care definition is the length of respite. Some of the services offer short stays (such as day-care services) and others consider longer periods of time (vacation breaks for carers, emergency care etc.). Both duration and frequency of respite breaks (every day or week) are relevant when assessing the importance for the carer and the care recipient. Some countries offer more diversified "packages" of support (combining both short and long-term breaks) in order to better meet the needs of the carer. The provision of respite breaks can be provided in various settings, such as community care or institutions, and by various actors, such as family and friends, and nurses.

Respite care services are the most common type of services provided to carers across the EU. Carers say that access to personalised, flexible short breaks provision is crucial. Short breaks help to recharge batteries and sustain carers in their caring role. They can be a lifesaver for some. Carers can have a life of their own through the provision of suitable short breaks. Many carers do benefit from short breaks which meet their needs entirely. It gives them a good-quality break from the stressful demands of supporting someone with a disability or long-term condition or dementia or another condition or illness. It makes life easier for the carer (and also for the person with care needs).

Many carers want planned breaks from caring. Carers also need to be able to mix and match different options, at different times and for different reasons. There should at all times be an emphasis on choice, flexibility and availability of break when needed. It is also important to recognise that some groups of carers may have particular difficulties in using mainstream short break services.

Local authorities should seek to provide (in collaboration with all relevant partners), and support access to, short breaks and respite stays adapted to both the care recipient and their carer(s). Investments should therefore be made to provide innovative breaks, which can be delivered in partnership with the voluntary sector. Both home-based and institutional respite should be available.

Provide carers with access to training and recognise their skills

Carer training promotes carer confidence and enables carers to provide better quality care for longer and in better conditions for themselves and the person for whom they care. Carers who receive training feel better supported in their caring role and more confident. The preventive aspects of well-trained and well-supported informal carers in avoiding or delaying hospital admission and long-term institutional care are well documented.

Training, especially in core caring skills e.g. manual handling, coping with caring, knowledge of conditions and in situations where carers need to manage and monitor complex medication prescriptions, coordinate and implement complex medical procedures is essential in this respect. Training in stress-management techniques is also useful to prevent informal carers' burn-out and therefore unwanted and unprepared institutional care. Finally, it can also contribute to preventing mistreatment by raising awareness about Human Rights issues related to caregiving, but also by breaking carers' isolation and by drawing their attention to their own well-being and life satisfaction.

Informal carers gain a great amount of – sometimes very technical - skills while performing their caregiving tasks. These include personal care (bathing, washing, feeding, dressing, managing incontinence…) as well as specific medical care (e.g. home-based dialyses, management of oxygen/nebulisers, monitoring of blood and insulin levels in the case of diabetes, tracheotomy patient care, blood pressure monitoring, colostomy bag management, administration of medication, diet monitoring, etc.). In addition, carers also develop a wide range of communication skills and often have to deal with challenging behaviours in the context of demanding care needs (e.g. dementia or other mental illnesses). Besides, informal carers also acquire important transversal skills,

as they tend to organise and manage care arrangements for their loved ones, involving a range of health and social care professionals, while also managing their own professional and family responsibilities. Planning, managing competing priorities, sharing information, coordinating, using digital tools are among the skills they apply in their everyday life.

Yet, these skills are generally undervalued even though they could be an important instrument to improve the caring experience both for carers and their caree and to secure carers' crucial contribution to long-term care systems. Moreover, valuing and strengthening informal carers' skills may prove promising to counter their social exclusion and to improve their chances of maintaining an active professional life or to re-enter the labour market. It should be added that the difficult working conditions in the care sector, the challenges of retaining staff and attracting young professionals, and - consequently - the potential shortage of care professional lead many families to rely on migrant carers hired on the informal market to provide care to their dependent relatives. Compared to other industries undeclared work is indeed particularly prevalent in Long-Term Care (LTC) and many EU countries are seeking to overcome the insufficient supply of domestic LTC workers through employment of migrant care workers. In this context, validating the skills of informal carers and taking stock of their experience as part of pathways to achieve recognised professional

qualification in the field of care, could contribute to addressing this shortage in the care workforce and opening opportunities for informal carers who wish to return to the labour market. **Public authorities should take initiatives to support the training of carers and the recognition of their skills.** Recognising, developing and validating the skills of informal carers is therefore not only useful to improve the quality of life of carers and their caree, but also to contribute to the sustainability of our care systems and to the EU (female) employment objectives.

Investments in carer training should therefore be made in order to improve carers' skills and maximise their opportunities to maintain work-life balance and exercise their skills beyond their caregiving stretch. Consideration should also be given to the training needs of specific groups of carers such as first-generation migrant family carers. This can easily be implemented through better (financial) support to carer organisations which often already have a lot of expertise in the topic.

Prevent carers' poverty and allow them to maintain an active social, professional and educational life

A wide range of issues impacts on carers' level of income. Carers can experience significant financial hardship as a consequence of their caring role. They are often faced with additional costs as a result of the illness or disability of the person they care for, and their caring responsibilities can act as a barrier to entering education and paid employment.

Many working carers have to perform a difficult balancing act – even more so in the case of "sandwich" carers (i.e. people having to care for both children and older relatives). They can face practical challenges such as finding and securing support for their "caree" and themselves or having to interrupt working days to cope with care needs. They can also experience mental problems given the added stress of juggling caregiving with professional duties: they can feel guilty for "abandoning" their caree, isolated and anxious due to the perception that they may be viewed differently, less ambitious and motivated perhaps than other employees. As a result, when not adequately supported, carers may be compelled to reduce their working hours (involuntary part-timers) or eventually give up paid employment, thereby reducing their income and pension entitlements.

The gender dimension of this phenomenon is particularly significant since it is mostly women who give up paid jobs or reduce working hours in order to fulfil caregiving responsibilities. This is due to the deeply engrained cultural perception of caring roles in our societies, but also to the fact that care duty is often taken on by family members with the least opportunity costs (and, across the EU, women still form the vast majority of second income earners). Consequently, long term care responsibilities tend to aggravate the gender pay and pension gaps – already present because of childcare responsibilities.

Caring also affects the type of work which carers are able to undertake. Some carers may benefit from more limited opportunities for career advancement due to geographical and time constrains or to discrimination in the workplace as a result of their caregiving responsibilities. Many find local, flexible, often low-skilled and low-paid jobs which can be adapted to their caregiving schedule, with side effects on carers' earnings. In turn, poverty and worries about finances can have an adverse impact on carers' health, wellbeing and quality of life. For those carers who find themselves exiting the labour market altogether to fulfil a caring role, re-entry can prove difficult, particularly when the care period was long.

Altogether 12% of people of working age (18–64 years) are involved in providing regular care for a disabled or infirm person – 9% of men and 15% of women. The employment rate of male regular carers is 73% (72% for men of working age who were not regular carers); among women of working age, 54% of regular carers but 63% of others are in employment[11].

Young carers[12] and young adult carers[13] are still a largely invisible group but the tremendous impact of informal care on their daily life is well documented. They may undertake a wide range of caring responsibilities including practical tasks (such as cooking, housework and shopping); physical and personal care (such as helping someone out of bed or helping someone dress); emotional support and supervision;

managing the family budget and collecting prescriptions; helping to give medicine; or helping someone communicate. Being a carer can affect a young person's health, social life and self-confidence – over 45% report a mental health problem. Many struggle to manage their education, working life and caring role which can cause pressure and stress.

The most common worries expressed by young carers concern the health of the person being cared for, their own health, school work, money, bullying and having no friends. Their most common problems relate to sleeping, suicidal thoughts, self-harm and eating disorders. Research has also highlighted a high level of concern regarding young carers and education. The major educational difficulties identified concern punctuality, attendance and problems with homework/coursework. Additional problems cited were difficulties joining in extracurricular activities, low attainment, anxiety and fatigue[14]. Young carers who leave education and training early are bound to lack skills and qualifications, and in turn face a higher risk of unemployment, social exclusion and poverty.

Taking on a caring role should not mean that people have to face financial hardship and social exclusion or give up work or education to care. Measures should therefore be taken to anticipate the negative impact of informal care on carers' equal opportunities to live a rewarding social, educational and professional life. The benefits of education and employment to individuals in society (for example, income, responsibility and respect) should extend to carers. Carers who want and are able to study or work should be enabled to do so, and should not be discriminated against. They should be supported at school/university and in the workplace to maintain their employment status. Carers should also have access to lifelong learning opportunities, further and higher education and skills development in ways which take account of their caring responsibilities.

The precondition for good work-life balance is the availability of high quality, affordable and accessible formal long-term care services. Investment in these should therefore be regarded as a priority. Policies that aim to assist working carers should include appropriate income support and other "flexicurity" measures for carers (teleworking, part-time, flexible working time, carer's leave paid at an adequate level, etc.), rights and regulations in the employment field as well as practical measures that can be implemented by employers at company level. Counselling has proven extremely beneficial to carers who are combining work and care provided that they have access to it as early as possible in their caregiving journey. Counselling should focus on the potential impact of informal care on carers' career, their financial means, their pension entitlements, as well as their health and wellbeing. The information provided should be adjusted to the life phase they are in. Many employers have developed carer-friendly policies and effective workplace practices, enabling carers to remain in, or to return to, work. These should be identified and supported. Furthermore, in order to create a carer-friendly professional ecosystem, all stakeholders (workers, employers, social partners and public authorities) must be involved in shaping and implementing legislative and practical measures. Carer-friendly employment practices should therefore be encouraged and promoted.

Carers who have left the labour market or reduced their working time to care should be included in active inclusion programmes and their specific needs should be taken into consideration. Employment services should be made aware of the challenges facing carers and being involved in caring should be seen by professionals of the sector as more than just "staying at home".

A large number of countries provide financial support to carers through cash benefits either paid to those in need of care, part of which may be used to compensate family carers (the most common option) or paid directly to carers through a carer allowance. A carers' allowance recognises that providing care involves costs for carers. It may help carers to juggle their responsibilities by having some income to compensate for reduced working hours or for additional expenses incurred as a result of caring. In addition, it also provides a strong signal that carers' play an important social role and should be acknowledged by providing a financial reward for their

efforts. Care allowances provided to dependent people or to carers may support, or on the contrary disincentivise, family carers' employment, depending on the level of the benefit, its rules of use, the national culture of care, the traditional or legal obligation to care for dependent family members and the income of both the cared-for person and the carer.

Countries with direct payments to carers have very different compensation and eligibility conditions. Two main approaches emerge: countries providing remuneration to family carers who are formally employed; and countries with means-tested allowances. In addition, some countries provide other types of allowances to carers, such as flat-rate allowances. Typically, such cash allowances involve a number of eligibility requirements with a view to define an eligible carer (e.g. primary carer), the level of care effort (e.g. number of hours of care per week), the relationship between the carer and the care recipient (e.g. certain relatives, co-residency) as well as the care level of an eligible care recipient (e.g. high care need).

Cash benefits for dependants are often advocated as a good approach to maximise the independence of the care recipient and have become more prominent in recent years. In many cases, such cash schemes allow the use of the allowance to support family carers or even to hire family members formally. While the primary aim of cash for care schemes is often to expand choice and flexibility for the care recipient, compensating or encouraging family carers can be seen as a secondary aim. This type of support may present several advantages for carers and policy makers. First, eligibility requirements for carers might be simpler since policy makers avoid the difficulties of defining who are primary carers and interfering with family relations in that way. Many carers do not identify themselves as carers and do not necessarily apply for a specific allowance while carers may be reached via a cash benefit targeting the user. In addition, such cash benefits can be used by elderly carers since they do not constitute wages as in the case of carer's allowances in northern Europe. They can also provide more generous benefits than the means-tested direct allowances given to carers. Finally, a fairer allocation of

cash resources is likely to be achieved if allocated to the care recipient since the amount of the allowance depends on needs.

On the other hand, cash benefits given to the dependent person might not always be used to pay family carers and may generate financial dependence of the carer. The allowance might compensate for the additional care expenses and may be used to supplement family income if there is no specific provision to pay for family carer. This leaves carers dependent on the care recipient in terms of the compensation for their efforts or to buy formal care services for breaks. Certain countries have gone around this problem by having relatives employed through a formal contract if they provide care above a certain number of hours per week. Holidays rights are also included in the conditions of employment. This still leaves carers financially vulnerable if the person needs to receive long-term care in an institution or dies[15].

Overall, there is a risk of care allowances, when not regulated as formal wages within formal work contracts, creating very precarious workers – be they family members or not – in a new grey economy of home-based care services. According to various studies, this semi-formal labour market is often staffed by migrant workers, particularly, but by no means exclusively, in the Southern European countries, where, with the help of care allowances unregulated in their use, migrants are increasingly standing in for missing Long-Term Care services and declining availability of informal carers[16].

This being said, care allowances and cash benefits that can be passed on to carers are usually way under the average wage in most countries. More attention should therefore be paid to ensure carers do not fall into poverty, even after receiving financial support.

Young carers often have to resolve a particularly acute tension between their right to self-determination and their roles and responsibilities in their family. Hence, for those young carers who are involved in informal care, it is important to ensure that no inappropriate or excessive caring takes place and that their caring role does not prevent them from enjoying their rights as

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children. Consequently, policies and practices seeking to recognise and support young carers across Europe should aim to allow them to move from a situation of vulnerability to one of growth, where they can flourish as human beings.

The two best avenues to meet the needs of young (adult) carers concern:

→ The provision of direct support through training, counselling, psychological and emotional support, following an initial needs assessment by formal services, based on a 'whole family approach[17]', and

→ Boosting the provision of more adequate and intensive formal care services to the cared-for person as it enables respite and better time management of the young carer - the level of impairment of the cared-for person (usually a parent) and the lack of formal care services being amongst the root causes of young people assuming a caring role.

Young carers should be identified as early as possible (via improved vigilance and screening tools of professionals), their needs should be addressed and the needs of the whole family should be assessed. This requires good joint working between adult and children's services. Schools play a vital role in both early identification and in the provision of support for young carers and their families. The desired outcome is that children and young people are able to engage fully with the educational and social opportunities available to them. A key focus should therefore be in developing work with schools. A range of strategies can be used to raise awareness of young carers in schools, identify potential hidden young carers and provide appropriate support

Adopt the carers' perspective in all relevant policies

There is a clear need for better strategic planning and collaborative working between a wide range of policies in the health and social sectors.

Adopt a comprehensive and multidimensional carer-friendly approach by considering the perspective of carers in all relevant policies at international, national and regional level. Public authorities should proactively ensure that this happens so that carers do not have to negotiate the boundaries of different services in the future. Such an approach emphasizes the consequences of public policies on the daily life of carers and aims to improve the accountability of policy-makers for the impacts of their decision at all levels of policy-making.

IMPLEMENTATION AT EU LEVEL

Although most of the policies that affect the daily life of carers are designed and implemented at national and regional level, the steps listed in this Strategy can be reflected at EU level. While care provision differs greatly between (and sometimes within) Member States, it is indeed clear that all countries need the resource provided by informal carers to prevent a collapse of the entire care system. Fortunately, recognition of the importance of carers and their contribution to care and well-being, society and the economy as a whole, is on the increase.

In recent years, the European Parliament has actively supported direct references to carers in various important initiatives, including the EU's EaSI programme budget lines since 2011, the EP Report on care services in the EU for improved gender equality and the EP Report on women domestic workers and carers in the EU. The European Parliament Interest Group on Carers is continuing to act as a forum for discussion on EU policy, assessing the impact of EU policy developments on carers.

As far as the European Commission is concerned, many recent initiatives and documents refer explicitly to carers, namely:

➜ The European Pillar of Social Rights and the related initiative on Work/life balance for parents of carers are prime examples of the capacity to improve the life of carers through EU-level initiatives. The Pillar affirms for the first time at Union level the right to long-term care services for persons who are reliant on care (See Eurocarers' Policy Briefing 'The EU Pillar of Social Right - What does it all mean for carers across Europe?');

➜ The Ageing Report 2018 states that improving the efficiency of LTC systems is necessary in order to respond to the increasing need for care. The measures required to do this include improving governance, targeting care at those that need it most and can least afford to pay

it, ensuring availability of carers, supporting informal carers, as well as health promotion and rehabilitation;

➜ The European Social Policy Network's reports on the Challenges in long-term care in Europe and on Work-life balance measures for persons of working age with dependent relatives in Europe affirms that the provisions of care to the dependent person represent the cornerstone of all national LTC systems and too little attention has been paid to the role of the carer[18, 19];

➜ The SPC report on "Adequate social protection against Long-term Care risks"[20] states that there are solid equity and efficiency reasons for Member States to support to informal carers, including through a better recognition of care duties in labour law and corporate practice;

➜ The EPC Joint Report on Health and Long-Term Care Systems & Fiscal Sustainability underlines that Informal care helps increase the sustainability of LTC systems but can have a significant personal impact on the carers themselves[21];

➜ The Employment Package[22], more notably the Staff Working Document on the employment potential of household and personal services, which contains a number of relevant statistics on carers and the need to ensure high quality and sustainable care provision;

➜ The European Innovation Partnership on Active and Healthy Ageing[23]: this Partnership explicitly targets carers as one of the main stakeholder groups;

➜ The Social Investment Package and its Staff Working Document on Long Term Care[24] explicitly recognise the huge contribution of carers and acknowledges their main issues and challenges;

→ The Blueprint on Digital Transformation of Health and Care for the Ageing Society reiterates that Patients, carers and healthcare professionals should be placed at the centre of healthcare innovation and policy reforms[25].

These initiatives contain many references to carers, which highlight:

→ That a substantial part of long-term care is provided by mostly untrained informal carers, and that long-term care provision should be seen as a combination of informal and formal care;

→ The strong gender issues in relation to long term care provision, since women are the main recipients as well as the main providers of care;

→ The increasing need for long-term care, on the one hand, and a shrinking informal care potential, on the other;

→ The need for better and more comparable European data on the current provision of formal and informal long-term care;

→ That informal care provision involves costs for the economy and the public budgets: informal carers may not be able to find or stay in formal work, which means that they do not contribute to taxes and social contributions;

→ Some of the issues and challenges faced by carers, as already outlined above in section 2.

Importantly, the Commission underlines the 'huge potential benefits of EU-level collaboration and policy coordination in this complex area'[26]; in other words, the added value of EU-level action in this field is acknowledged. The fact that great variation exists between Member States in terms of care provision models and the roles of formal and informal care within these means that there is a huge potential for exchange of experiences and ideas and good (as well as bad) practice.

LOOKING FORWARD

As the impact of being a carer can be felt in many different areas and at different times of life and work, a comprehensive EU level initiative on carers should be multi-dimensional and longitudinal.

The following areas are all highly relevant to enable European citizens to continue caring during their life course in the future:

Awareness and recognition of the contribution of carers to society

Specific EU-level activities should be put in place to ensure an effective and coordinated exchange of information, experience and good practice between Member States and relevant stakeholders about care and caring. Several EU advisory committees (e.g. the Social Protection Committee, the Economic Policy Committee, the European Social Policy Network, the Expert Panel on effective ways of investing in health, etc.) offer great potential to align priorities and raise awareness about the topic. Another possibility would be to designate one of the coming years as the **European Year of Care and caring**.

Development of national action plans on carers

The EU level's remit in the field of health and long-term care provision is limited; EU countries hold primary responsibility for organising and

delivering care services. EU policy can nevertheless be used to complement and coordinate national policies aiming to provide access to affordable and good quality care for all across Europe while addressing the negative impact of informal care on carers themselves, the people they care for and society as a whole. Although care is an area in which diversity amongst member states is greatest, the 4 main challenges facing care systems - i.e. a growing demand, a declining supply of potential (professional and informal) carers, quality as well as financing challenges - are consistent across all member states. This Strategy to support and empower informal carers across Europe should therefore be used by EU institutions to stimulate the development of comprehensive and consistent national/regional action plans seeking to drive the development of good policy and practice to provide carers with choice, to support and empower them in the context of effective and sustainable care systems, in particular homecare and community-based services. The EU Semester as well as ESF+ offer great potential to help EU member states adopt the multidimensional approach described in this Strategy. The measures to be put in place should focus on:

→ Social inclusion and societal participation of carers (or organisations that represent them) in different fields and throughout the life course.

→ 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

→ Emotional support and counselling to alleviate the emotional impact of caring and the impact on changing relationships.

→ Measures to offer practical support to carers.

→ 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 care burden).

→ Measures that enable working carers to combine their care and work responsibilities, so that carers can continue to contribute to the economy, the labour market and can earn their own living.

→ Measures to ensure that carers do not lose their financial and social security rights as a result of their caring responsibilities, e.g. by losing out on pension rights when giving up paid employment to care (leading to poverty in old age), or suffer financial hardship through out of pocket expenses related to the person cared for.

→ Possibilities and facilities for carers of working age who have left the labour market in order to care to update their professional qualifications when they are ready to re-join the labour force.

→ 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.

→ 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; 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.

→ Empowerment and capacity building of carers and of their representative organisations.

→ 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.

→ Take account of the variety of different situations e.g. specific needs and challenges of the many young carers as well as those that are very old, mostly partners.

Research, data collection and monitoring

Research should help build a more comprehensive picture of carers and their issues throughout Europe. Despite a growing and important momentum around care and caring in recent years, and although the information and data at disposal is already sufficient to trigger resolute action in favour of carers, much remains to be done to collect comparable data about the number, typology, needs and preferences of carers across Europe. More research could also be useful to collect information and good practice on cost-effective and responsive ways of providing training and education to carers, on formal employment for carers of working age, on carers' social inclusion and societal participation, on the situation of particularly disadvantaged groups of carers, on cultural change in health and social care systems, on policy aspects of carers' situation, etc.

Future calls for proposals under the EU research programmes (Horizon Europe, Erasmus+, ESF+) offer great potential for specific research opportunities aiming to further document care and caring in Europe. This research could be built on earlier major EU-funded research projects such as EUROFAMCARE[27, 28]. Comparable data and indicators on Long-Term Care and informal care in Europe should also be developed in order to assess the situation and monitor change. EU institutions can also play a leading role in the policy dialogues related to the definition of informal care and caring, the typology of informal carers across Europe and the collection of data through population surveys, for example.

Legislative measures

Most of the legislative competence in the policy areas affecting carers are shared with member states. However, there are some areas where legislative action could be taken. The EC proposal for a Directive on Work/life balance for parents and carers is a prime example of the EU capacity to positively impact the daily life of carers. Action in other areas could be explored and experiences disseminated between countries, while recognising and respecting the principle of subsidiarity.

Systematic inclusion of carers issues in EU health and social policy development: mainstreaming

Carers are increasingly being recognised in EU-level policy development. The European Pillar of Social Rights and the related initiative on Work/life balance are positive examples of this trend (as illustrated in Eurocarers' Policy Briefing 'The EU Pillar of Social Right - What does it all mean for carers across Europe?'). However, a number of other current EU policy domains offer great potential to (better) take account of carers, such as:

→ Social policy (European Semester, Em-

ployment Guidelines, ESF+, Disability Strategy, Gender Equality initiatives, poverty and social exclusion initiatives...),

➡ Health policy (State of Health in the EU, Health Programme, Initiatives on chronic conditions, ICT initiatives, Horizon Europe research programme),

➡ Youth policy (young carers),

➡ Justice, economic and employment policy (e.g. the Pan-European Personal Pension Product PEPP).

These should be used more actively to address the needs of carers, prevent them from facing negative social and health outcomes as a result of their caregiving responsibilities and promote their rights across Europe.

Financial support

A number of the above-listed EU initiatives (e.g. EaSI Programme, Health Programme, Erasmus+, AAL Programme, ESF+) hold the potential for funding. This funding could contribute to the capacity building of carers through to the provision of support (e.g. practical and emotional support, good practice exchange, training, information) and advocacy (e.g. policy development, practical solutions). It could also support research, networking as well as the development of in-country organisations working with and for carers.

Inclusion of carers in relevant EU-level consultations, fora and advisory boards

Carers of all ages and their representative organisations could be included in social and health consultations as well as in relevant fora and advisory boards (e.g. the Health Policy Platform) as a relevant stakeholder. This could help assess proposed policies and initiatives for their impact on carers and their cared for persons.

IMPLEMENTATION AT INTERNATIONAL LEVEL

At international level, we warmly encourage decision-makers to consider the implementation of this strategy as part of:

The European Strategy for the implementation of the Sustainable Development Goals (SDGs)[29];

The Millennium Declaration and Millennium Development Goals (MDGs), which expired at the end of 2015, have made an enormous contribution in raising public awareness, increasing political will and mobilising resources for the fight to end poverty. The 2030 Agenda for Sustainable Development (link is external) builds on this experience and goes further. The 2030 Agenda addresses both poverty eradication and the economic, social and environmental dimensions of sustainable development in a balanced and integrated manner.

The 2030 Agenda also addresses issues which were reflected in Millennium Declaration but not the MDGs, including issues such as effective institutions, good governance, the rule of law and peaceful societies. A new departure is the universality of the 2030 Agenda – meaning that it applies to all countries at all levels of development, taking into account their different capacities and circumstances.

The following SDGs are of particular relevance for the daily life of carers across Europe and globally:

➡ **Goal 1**. End poverty in all its forms everywhere;

➡ **Goal 3**. Ensure healthy lives and promote well-being for all at all ages;

➡ **Goal 4**. Ensure inclusive and equitable quality education and promote lifelong learning opportunities for all;

➡ **Goal 5**. Achieve gender equality and empower all women and girls;

➡ **Goal 8**. Promote sustained, inclusive and sustainable economic growth, full and productive employment and decent work for all; and

➡ **Goal 10**. Reduce inequality within and among countries.

The WHO Framework on integrated, people-centred health services[30];

The Framework defines people-centred care as an approach to care that consciously adopts individuals', carers', families' and communities' perspectives as participants in, and beneficiaries of, trusted health systems that are organized around the comprehensive needs of people rather than individual conditions, and respects social preferences. People-centred care also requires that people with long-term conditions or disabilities have the education and support they need to make decisions and participate in their own care and that carers are able to attain maximal function within a supportive working environment. People-centred care is broader than patient and person-centred care, encompassing not only clinical encounters, but also including attention to the health of people in their communities and their crucial role in shaping health policy and health services.

The Framework calls for reforms to reorient health services, putting individuals, families, carers and communities at their centre, supported by responsive services that better meet their needs, and that are coordinated both within and beyond the health sector, irrespective of country setting or development status. It sets forth a compelling vision in which "all people have equal access to quality health services that are co-produced in a way that meets their life course needs, are coordinated across the continuum of care, and are comprehensive, safe, effective, timely, efficient and acceptable; and all carers are motivated, skilled and operate in a supportive environment". Among other things, this entails empowering individuals to make effective decisions about their own health and to enable communities to become actively engaged in co-producing healthy environments, and to provide informal carers with the necessary education to optimize their performance and support in order to continue in their role. Empowering and engaging people is also about reaching the underserved and marginalized groups of the population in order to guarantee universal access to and benefit from quality services that are co-produced according to their specific needs. Carers must receive adequate training in order to be able to provide high quality interventions, and to serve as advocates for the recipients of care, both within the health system and at the policy level. Additionally, carers have their own needs for personal fulfilment and require emotional support to sustain their role.

The work of the WHO Europe Primary Health Care Advisory Group[31].

The concept of primary health care (PHC), and its fundamental importance in strengthening health systems, was first enunciated in the Declaration of Alma-Ata, adopted at the Inter-

national Conference on Primary Health Care held in Almaty, Kazakhstan on 6–12 September 1978. It expressed the need for urgent action to protect the health of all people through PHC via universal health coverage, equity in health, use of appropriate technology, intersectoral collaboration and community participation.

Across WHO European Region Member States at present, there is a renewed commitment to uphold the vision of a PHC approach. The WHO European Centre on Primary Health Care acts as a hub of excellence in Primary Health Care and services delivery, setting out to ensure that the WHO Regional Office for Europe is equipped to work closely with Member States in their efforts to transform services delivery.

As shown here-above, the leading role played by informal carers in European Long-Term Care systems highlights that future models should better support informal care with the information, counselling and training they need. Primary Health Care (PHC) has a strong role to play in acknowledging the partnership role in LTC with patients and informal carers, not least because they know their patients and their patients' principal carers and providers. PHC professionals therefore, need to champion carers across the health and social care sectors, help them with their education and rights, and support them with the resilience to cope and respond to their mental health needs. The role of carers is fully recognised by WHO, but what is needed is a change in culture and mindset. More work needs to be done to actively involve people with long-term conditions or disabilities, carers and communities and improved governance and accountability is needed to bring together multi-professional providers to support PHC coherently.

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