

Why is care at the end of life not matching people's preferences?

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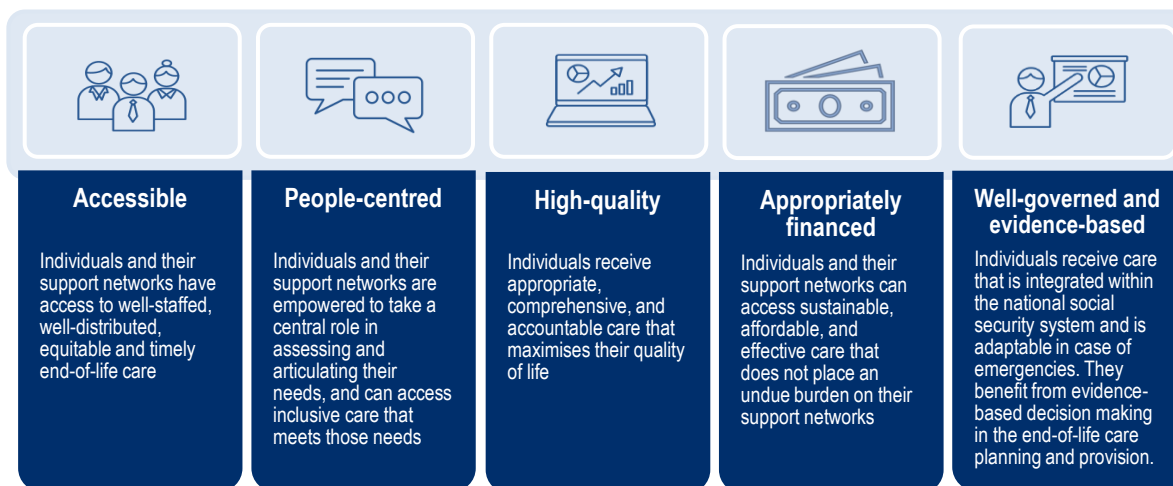
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A growing number of people need support at the end of their life

As populations age and the burden of chronic conditions rises, a higher number of people will require support towards the end of their life. Out of almost 11 million deaths happening across OECD countries in 2019, around 7 million people would have benefitted from end-of-life care according to OECD estimates (OECD, 2023^[1]). Ensuring adequate care at the end of life is therefore emerging as a priority across OECD countries. Over the period from 1960 to 2021, the share of people aged 65 and above has doubled from 9% to 18% and it is expected to reach 27% in 2050 (OECD, 2020^[2]).

The OECD framework of end-of-life care includes five dimensions to measure country's efforts and performance on end-of-life care: accessibility, people centredness, high-quality, appropriate financing and well-governed and evidence-based policy making. The framework highlights the importance of providing individuals and their support networks with access to well-staffed, well-distributed, equitable and timely end-of-life care, which is adequate to people's needs, while ensuring that people play a central role and receive care that is in line with their wishes. Furthermore, the framework also highlights the importance of ensuring adequate funding and financing of end-of-life care services, so that care is affordable and available in all settings. Finally, the OECD framework points out to the importance of a good governance of end-of-life care services, which are evidence based and resilient to shocks (Figure 1).

Figure 1. The OECD framework of end-of-life care



Source: OECD (2023^[1]), *Time for Better Care at the End of Life*, <https://doi.org/10.1787/722b927a-en>.

Most people would like to die where they live, but home care services are scarce

Assessing the quality of the care and support that people receive in the last phase of their life is not straightforward, but examining where individuals die and the nature of care they receive during their final months are reliable indicators. The place where people are cared for and die is often related to how accessible end-of-life care is in some settings, to what extent health systems are people centred,

respecting people's preferences, and whether end-of-life care is appropriately financed. Public funding mostly geared towards end-of-life care services in hospital and scarce availability of services to support the last moments of life at home may represent an obstacle to dying in the place of preference.

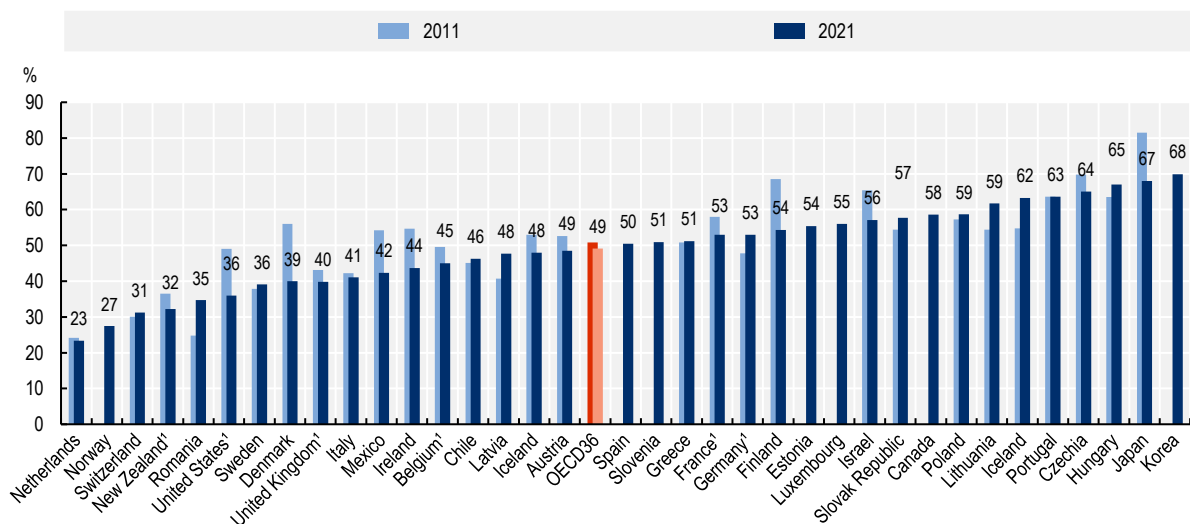
Most people prefer to die at home, yet hospitals remain the most common place of death

Preferences on place of death can vary among individuals and across countries due to personal characteristics and cultural differences. Yet, a growing body of research has explored people's preferences for place of death, showing that people might have a preference to die in the place where they live. Non-hospital healthcare facilities are often indicated as the least preferred place of death (e.g. in Italy, the Netherlands and Spain), while home is most often indicated as the preferred place of death across countries (OECD, 2023^[1]; Billingham and Billingham, 2013^[3]; Gomes et al., 2013^[4]; Higginson, 2017^[5]). International studies have indicated that the share of people reporting their home as their preferred place of death ranges from 51% in Portugal to 84% in the Netherlands (OECD, 2023^[1]).

Despite a preference to die at home, most people currently die in hospitals. In 2021, half of the deaths across OECD countries took place in hospitals. Such data refer to deaths happening for any cause of death, excluding external causes of mortality such as accidents and injuries (i.e. it includes all International Classification of Diseases, tenth revision (ICD-10) codes except V00-Y99). In some countries like the Netherlands, Norway, Switzerland and New Zealand, the proportion of deaths occurring in hospitals is notably lower, at around one-third or less. This is likely attributable to the prominent role played by nursing homes, hospices, or other long-term care facilities, which serve as the primary place of death in those countries. On the opposite end, Czechia, Hungary, Japan and Korea witness 65% or more of deaths occurring within hospital. The share of deaths taking place in hospital decreased in the decade between 2011 and 2021, with part of the change driven by increased in-home deaths during the COVID-19 pandemic due to a lack of access to services in institutional settings (OECD, 2023^[6]; 2023^[1]).

Figure 2. Trends in hospital death rates, 2011 and 2021 (or nearest year)

Share of people dying in hospital



1. Latest data refer to the pre pandemic period.

Note: Data for Belgium refer to the Flanders region. Data for the Czechia, Finland, Poland and Portugal might include deaths that occurred in other non-hospital inpatient institutions. Data from Finland, Greece, Hungary, Italy, Mexico, Poland and Portugal come from the EOLINPLACE Project funded by the European Research Council under the EU's Horizon 2020 Research and Innovation Programme, using data from national providers. Source: OECD (2023^[6]), *Health at a Glance 2023: OECD Indicators*, <https://doi.org/10.1787/7a7afb35-en>.

Resources for end-of-life care services at home are scarce, hampering people's choice on the place of death

Dying at home with adequate support at the end of life might not be an option for some people, as adequate end-of-life care in non-hospital settings is not widely accessible for people approaching death. Previous OECD analysis have highlighted that, across OECD countries, the distribution of spending and human resources in palliative care¹ tends to be geared towards hospitals and might, for some people, preclude the possibility to be cared for at home. Hospital expenditure represents between 32% and 67% of end-of-life care expenditure. Furthermore, none of the OECD countries for which data is available currently reaches the rate of 1 palliative home care team per 100 000 inhabitants, recommended by the European Association for Palliative Care² (OECD, 2023_[11]).

Higher availability of long-term care and palliative care at home, and the support of family caregivers can support people to die at home

Existing evidence has shown that in countries where governments spend more on home long-term care³ (LTC) services and where home-based palliative care services are more widely available, people are more likely to die at home. People who have relatives living with them or nearby are also more likely to die at home.

Spending on home long-term care is strongly associated with higher probability of dying at home

As of 2023, across OECD countries, public funding for long-term care ranged between less than 1% of GDP and more than 2% of GDP. Around half of the 20 OECD countries for which data is available spend less than 1% of their GDP on long-term care, while in some countries (e.g. Belgium, the Netherlands and Sweden), spending for long-term care services exceeds 2% of GDP. Further variation exists in the allocation of spending to home-based vs. non-home-based⁴ care services. While Austria, Germany and Poland allocate more than half of their total public long-term care funding to home-based services, 8 out of the 20 OECD countries analysed allocate between one-third and half of the total long-term care funding to home-based services (OECD, 2023_[7]).

¹ Palliative care entails physical, emotional, social, and spiritual support with a particular emphasis on symptoms management such as pain but also emotional support and mental health care and bereavement care for families.

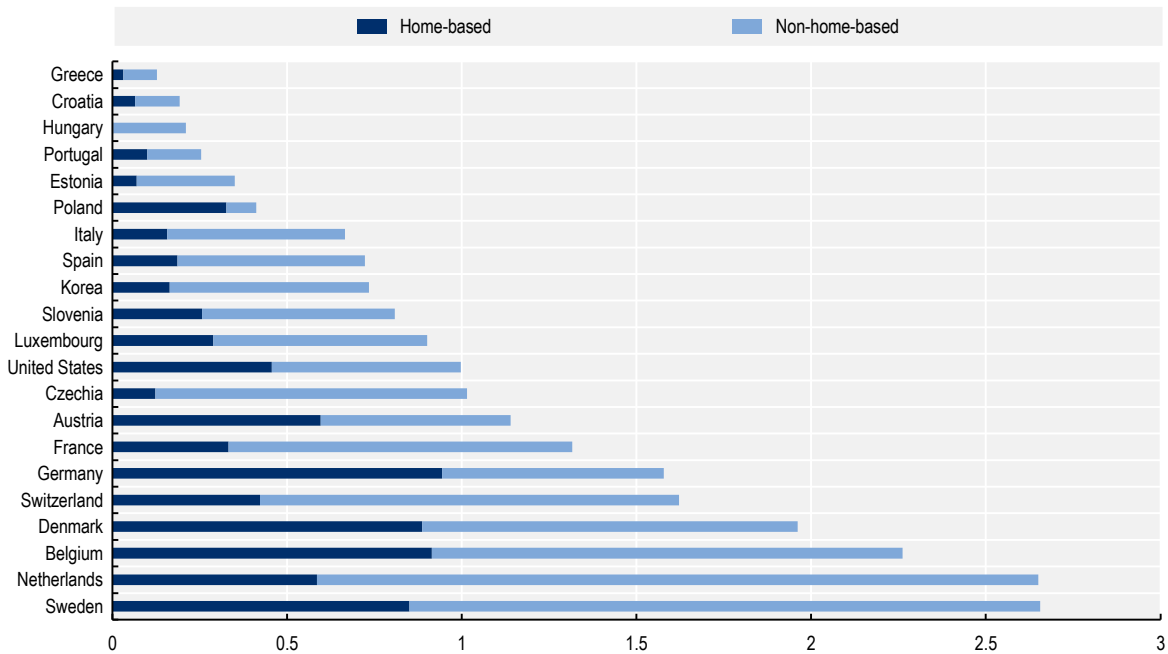
² Following a Delphi technique, the European Association for Palliative Care recommends 1 hospital support team and 1 inpatient palliative care team per 200 000 inhabitants and 1 home care team per 100 000 inhabitants (Arias-Casais, 2019_[22]; Payne et al., 2022_[23]).

³ The OECD defines long-term care (health and social) as a range of medical, personal care and assistance services that are provided with the primary goal of alleviating pain and reducing or managing the deterioration in health status for people with a degree of long-term dependency, assisting them with their personal care (through help for activities of daily living, ADL, such as eating, washing and dressing) and assisting them to live independently (through help for instrumental activities of daily living, IADL, such as cooking, shopping and managing finances) (OECD, 2023_[24]).

⁴ Non-home-based spending refers to spending for LTC inpatient care, day care and outpatient care.

Figure 3. Around half of OECD countries spend less than 1% of their GDP on long-term care

Spending from government and compulsory schemes on home-based and non-home-based long term care as a share of GDP, 2019 or latest year available



Source: OECD Health Statistics 2024.

Previous evidence had shown that the share of GDP allocated to long-term care spending was negatively correlated with the share of deaths taking place in hospital (Orlovic, Marti and Mossialos, 2017^[8]). New analysis by the OECD and the University of Southern California confirms that public spending for long-term care influences the place of death and finds that LTC spending is significantly associated with the probability of dying at home, depending on whether long-term care spending is home-based or not. An increase of 1% in home-based long-term care spending is in fact associated with increased home deaths by 0.14% and reduced deaths in hospital by 0.15%. On the other hand, a 1% increase in non-home-based long-term care spending is associated with higher institutional deaths by 0.075% (Casanova et al., 2024^[9]).

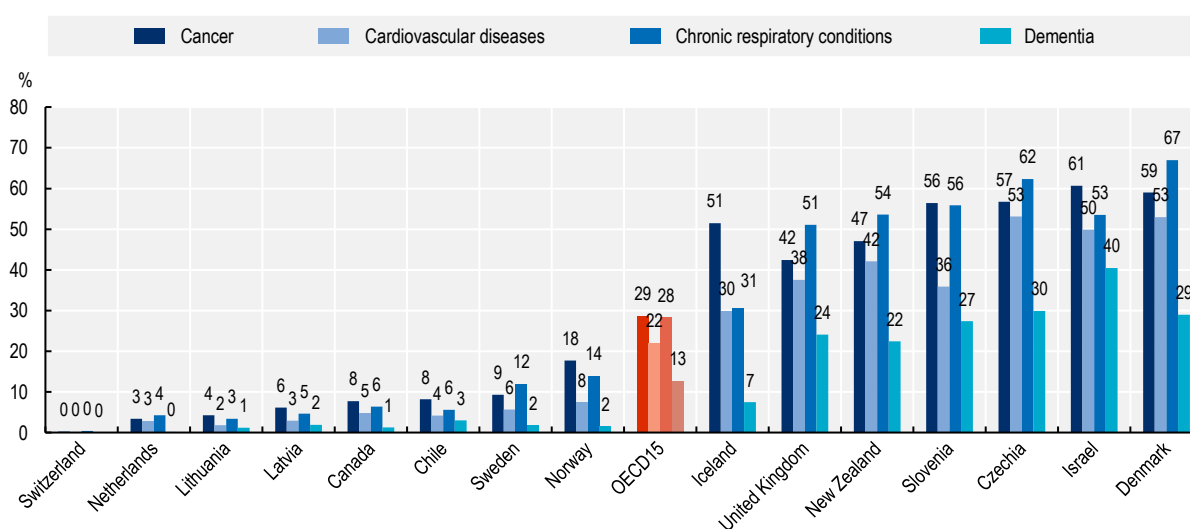
Higher availability of palliative care teams is associated with dying at home, particularly among younger people and those with non-cognitive related causes of death

The availability of palliative home care teams is also associated with a shift of deaths from hospital to the person's home. According to OECD/University of California analysis, overall, a 1% increase in the availability of home-based palliative care teams is associated with a 0.12% increase in deaths at home and a 0.096% decrease in the share of deaths in hospital. The effect spans across all age groups, although it is higher for relatively younger people. Furthermore, the cause of death seems to mediate the effect of increased home care teams' availability. The analysis shows that higher availability of home palliative care teams results into more deaths at home instead of hospital for individuals who died from cancer, cardiovascular disease, and other non-cognitive-related conditions (Casanova et al., 2024^[9]). This is also in line with previous literature showing that people with memory-related conditions such as dementia are more likely to be institutionalised, compared to people with other type of diseases (Joling, 2020^[10]; Luppá et al., 2008^[11]; Nihtila et al., 2007^[12]; Schulze et al., 2014^[13]). Once people are institutionalised, transitioning from the institutions back home in the last period of life is uncommon, likely giving people little choice on where to die.

Access to palliative care remains low and people do not always receive adequate symptom relief, while they also have unplanned hospitalisations. Across OECD countries for which data was available, less than 40% of those dying in need of palliative care receive such services (OECD, 2023^[11]). Available data shows that people in their last months of life, particularly in their last 30 days of life, experience admissions to the hospital for urgent/unplanned care as they may not be able to receive adequate care in the place where they live. The share of people being admitted to hospital in an urgent/unplanned way during the last 30 days of life varies significantly across OECD countries, ranging from values around 0 in Switzerland, to almost 70% in Denmark, suggesting that the choice on whether to hospitalise a person at the end of their life might be more heavily influenced by the characteristics and resources of the health system in a country, than by the person's needs and preferences (Figure 4).

Figure 4. People experience unplanned admissions to inpatient settings at the end of their life

Share of deceased people who, during their last 30 days of life, experienced more than one unplanned or urgent inpatient admission, by cause of death, 2021 (or nearest year)



Note: Data for New Zealand refer to 2018.

Source: OECD (2023^[6]), *Health at a Glance 2023: OECD Indicators*, <https://doi.org/10.1787/7a7afb35-en>.

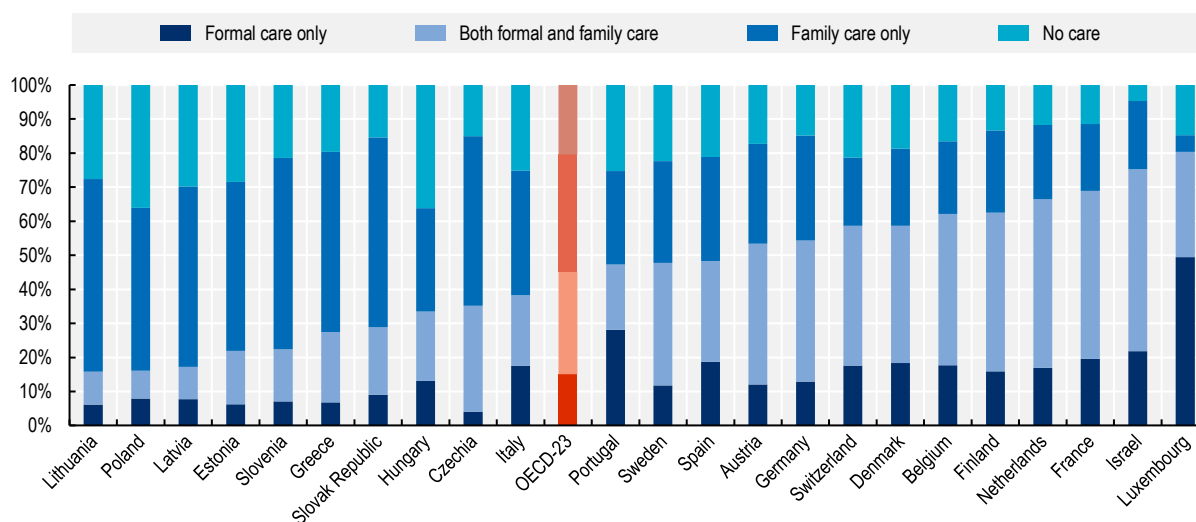
Living close to potential caregivers supports people to die at home

There appears to be a positive association between living with someone or having a family carer and dying at home, while living alone, particularly with no offspring nearby, is associated with a lower likelihood of dying at home (Ailshire et al., 2020^[14]; Costa, 2014^[15]; Houttekier et al., 2009^[16]; Gomes and Higginson, 2006^[17]). The analysis by OECD and University of Southern California finds that co-residing with a carer improve the likelihood of dying at home by 0.48% when it is the partner and by 0.13% when co-residing with adult children. A potential support network therefore seems to facilitate people to age and die in place.

Informal carers provide the bulk of care when it comes to long-term care needs among older people and therefore represent a valuable resource that countries are increasingly recognising and supporting. The majority of people with care needs currently receive informal care, either alone or as a mix with formal care. As of 2022, the share of people aged 65 or older with at least three limitations in activities of daily living or instrumental activities of daily living receiving only informal care equalled 34% across 23 OECD countries, with an additional 30% receiving both formal and informal care (Figure 5).

Figure 5. Around half of older people with care needs receive informal care

Share of the population 65+ with at least three ADL or IADL limitations, by type of care received



Note: Family care is received from family and friends; formal care is delivered by paid carers. Countries are sorted by the number of people receiving formal care. Data from Luxembourg is based on Survey of Health, Ageing and Retirement in Europe Wave 8; data from other countries is based on Survey of Health, Ageing and Retirement in Europe wave 9.

Source: Survey of Health, Ageing and Retirement in Europe (wave 8 and 9) (SHARE, 2024^[18]; 2024^[19]).

While informal carers are an important resource for the provision of home care, balancing their personal and professional life with caregiving duties is sometimes not sustainable, leading carers to drop out of the labour market or experience physical and mental health issues. The European Union directives on work-life balance, published in 2019, require that people who provide informal care services for a family member must take at least 5 days of annual leave from work to be able to dedicate themselves to care activities. The majority of OECD countries are currently supporting informal carers through paid or unpaid carer leave and cash benefits (two-thirds of the 33 studied OECD countries). Less widespread policies to support carers are the availability of counselling and training and respite care services (Rocard and Llana-Nozal, 2022^[20]).

Policies can support people to die in the place of their choice

This brief defines a set of policies to make end-of-life care more *accessible*, *high-quality*, *people-centred* and *well financed*, in line with the OECD framework of end-of-life care (OECD, 2023^[11]). Such policies will allow people to be more active decision-makers of their end-of-life by choosing to die in their preferred place, and provide people with adequate and high-quality end of life care services in all settings. Furthermore, these policies support more *accessible* and *well-financed* end-of-life care, by rethinking and redistributing funding mechanisms across all settings of care, making services affordable and available to all people in need, in their preferred place of care.

Data on preferences for place of death show that most people prefer to die in their home and existing evidence shows that home care at the end of life can be supported by higher spending on home long-term care, higher availability of palliative care teams at home and the availability of family carers living nearby the person at the end of life. Governments can support people to die in their preferred place of death by improving the distribution of public funding for long-term care across different settings, increasing the availability of home palliative care staff and supporting family carers.

Improving the distribution of resources for long-term care across different settings can increase funding for long-term care at home. Higher funding for care outside of hospitals would expand access to such care, making home care accessible and affordable to everyone in need. Higher availability of long-term care across all settings would support people to die in their preferred place, receiving adequate support in the last period of their life.

Better distribution of resources and better access to end-of-life care in all settings could be achieved by:

- Increasing the coverage of public spending for end-of-life care services in all settings, reducing out-of-pocket costs and improving the affordability of services
- Ensuring appropriate funding and skilled human resources providing care at home
- Improving the availability of care and support 24 hours a day in all settings, which can support people living at home

Increasing the availability of home palliative care staff can support people to age and die at home, should they wish to. It would allow people to receive specialised and adequate care at home, avoiding unplanned hospital admissions at the end of life.

To increase the availability of home palliative care staff, governments can invest on:

- Widening the types of professionals having sufficient general palliative care knowledge and improving the availability of trained staff in non-hospital settings, especially in primary and long-term care
- Increasing the rate of specialised home palliative care teams to ensure the availability of a sufficient number of trained specialists to support people at home in the last period of their life
- Promoting better working conditions, including higher salaries, a healthier work environment through better occupational health and safety, and improved flexibility in work schedules, which can make the long-term care and end-of-life care sectors more attractive and reduce the existing high rates of absenteeism and turnover

Recognising the utmost importance of the role of informal carers at the end of life and supporting them can facilitate carers' ability to juggle their responsibilities, providing adequate support for people at the end of life, to allow people to age and die in their preferred and most adequate place.

Support to family carers can be improved by:

- Providing carers with paid and/or unpaid leave, cash benefits and respite care, to facilitate balancing personal, professional and care responsibilities
- Supporting informal carers with counselling and training opportunities, to allow them to provide adequate and high-quality support to the person at the end of life
- Involving individuals at the end of life and their support network in the decision-making process throughout the entire care path, up until the end of life, to ensure that people receive care that is in line with their needs and wishes

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