The economics of healthy and active ageing series

# HEALTH AND SOCIAL CARE NEAR THE END OF LIFE

Can policies reduce costs and improve outcomes?

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### About this brief

This brief reviews the evidence on health and social care needs and expenditures at the end of life. End of life costs are the main reason for high per person spending levels observed at older ages in many European countries. However, there is huge variation between individuals, with estimates suggesting that just 10% of people near the end of life are responsible for over 60% of total end of life health and social care expenditures. High-cost individuals tend to be frail people with multiple chronic illnesses who use considerable hospital and social care services.

In most European countries, there will be large increases in annual deaths in the coming years as the 'baby boom' generation ages and improved survival ultimately leads to more deaths each year. This will inevitably lead to growth in end of life needs and, ultimately, spending levels. However, there are a number of strategies available to address these challenges. Some end of life needs can be reduced with more active public health measures and active rehabilitation, much of which can be very cost-effective. More active assessment of care needs can also significantly improve the experiences of patients and families, reduce unnecessary tests and interventions, will not shorten survival, and can help to limit the growth in costs.

### About the series

Population ageing is often perceived negatively from an economic standpoint. Yet taking a more balanced view, it becomes evident that a growing older population is not necessarily very costly to care for, and that older people provide significant economic and societal benefits – particularly if they are healthy and active. This is the broad perspective of the Economics of Healthy and Active Ageing series: to inspire a 're-think' of the economic consequences of population ageing.

In this series we investigate key policy questions associated with population ageing, bringing together findings from research and country experiences. We review what is known about the health and long-term care costs of older people, and consider many of the economic and societal benefits of healthy ageing. We also explore policy options within the health and long-term care sectors, as well as other areas beyond the care sector, which either minimize avoidable health and long-term care costs, support older people so that they can continue to contribute meaningfully to society, or otherwise contribute to the sustainability of care systems in the context of changing demographics.

The outputs of this study series take a variety of brief formats that are accessible, policy-relevant and can be rapidly disseminated.

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### Acronyms

	ADL	activity of daily living
10	EU	European Union
	GDP	gross domestic product
11	IADL	instrumental activity of daily living
	TILDA	The Irish Longitudinal Study on Agei
11	WHO	World Health Organization

### **Key messages**

In most European countries, the number of deaths each year will increase as the 'baby boomer' generation ages and approaches the end of life. Better strategies for managing care at the end of life are therefore of great importance, both to ensure the financial sustainability of health and social care systems and to enable people to die with dignity.

- Population ageing in itself has little impact on growth in health care expenditures and only modest effects on social care expenditures, but end of life care remains a main reason that health and social care spending is higher on average among older people than younger people.
- Growth in expenditures as the number of deaths increase can be managed while also improving outcomes for patients and their families. To do this, decision-makers need to have a good understanding of:
  - o the drivers of end of life expenditures;
  - o future death rates (and the age people die); and
  - o the appropriate mix of end of life services including the balance between treating disease directly and managing symptoms at the end of life.
- Expenditures for people near the end of life are highly variable. A small share of users typically frail with multiple chronic conditions, often including dementia account for the bulk of costs (in Ireland for example nearly two-thirds of total end of life health and social care spending was on 10% of decedents, while the lowest-cost 50% accounted for only 7% of spending).
- Hospital care is the largest component of end of life care expenditures, but not all of it is necessary or appropriate: many admissions can be prevented, while some hospital care is inappropriate for people with complex needs and multiple chronic diseases.
- The experiences of patients and families can be improved by skilled and careful assessment of needs and by supporting people when making difficult choices.
  Experience shows that such assessments and support can also reduce the costs of care.
- There are challenges in helping people make choices about their care that are in line with their goals. Issues to address include:
  - Finding better ways to prospectively identify those at risk of receiving high-cost care that is unlikely to lead to much longer life or to a good quality of life.
  - Improving the understanding of palliative approaches so that a shift from treating diseases is not seen as giving up on curative care, but rather as giving people a choice to live as well as possible.
  - Adjustments to care provision in recognition of patient preferences and the fact that changing the balance from more curative to more palliative care does not normally shorten life, and in some cases may extend it.

### **Executive summary**

Concerns about the impact of population ageing on health and social care systems have included fears in some countries that expenditures will rise rapidly and that there may be a shortage of younger people to support the needs of the ageing population. It has been shown elsewhere in the European Observatory's *Economics of Healthy and Active Ageing series* though that such fears are exaggerated and population ageing itself will lead to only slow and modest increases in care needs and costs. It has also been shown that a key driver of higher care costs of older people is expenditure near the end of life.

This policy brief focuses on: patterns of needs and related expenditures at the end of life; how these are likely to change with population ageing and an increasing number of deaths; how we can use a better understanding of needs and cost drivers to improve experiences of patients and families, and to limit growth in expenditures. This will involve careful assessment of needs for services that aim to treat disease and the complementary palliative care that aims to reduce symptoms and improve quality of life.

### High per person health and social care expenditures at older ages are not simply a consequence of 'getting older' – they are driven by expenditures at the end of life

Although expenditure on health and social care is typically higher for older people than younger people on average in most European countries, this is mostly driven by high costs near the end of life. Evidence suggests that there is negligible direct effect of calendar age itself on health care expenditures, but social care expenditures do increase with age as well as with proximity to death. The additional costs of health care near the end of life reduce with death at the oldest ages, but additional costs of social care remain high for older people approaching death.

In most countries in the European Region, the number of deaths each year is increasing as the 'baby boomer' generation ages and approaches the end of life. While ageing may have little direct effect on costs, this rise in the number of deaths will drive increased needs and expenditures in the short to medium term.

Although most people prefer not to die in hospital, hospital care is typically the largest component of end of life care costs, often being more than 50% of the total. While in many cases this care is appropriate and necessary, there is increasing evidence that many hospital admissions can be prevented, and that some of the care provided in hospital is inappropriate for people with complex needs and multiple chronic diseases at the end of life.

Careful examination of the patterns of end of life costs shows that they are highly variable and skewed. It has been shown that, in Ireland, the most expensive 10% of decedents account for nearly two-thirds of end of life health and social care spending. The least expensive half of decedents account for only 7%. It follows that policies to improve care and contain costs need to factor in who the high-cost decedents are, and to what extent this high expenditure represents effective and cost-effective care. The high-cost decedents are typically frail and have multiple chronic conditions, often including dementia.

### Developing better strategies for care near the end of life

It is possible in many cases to retain greater independence and reduce disability in older age. Some prevention and rehabilitation interventions have been shown to be costeffective too. Policies to achieve healthy and active ageing throughout the life course may therefore also slow the growth in care needs and costs at the end of life.

There is growing evidence that skilled and careful assessment of needs, as well as support for patients (that is, older people with care and support needs at the end of life) and families in making choices, can improve the experiences of patients and their families, and may reduce costs of care. While such assessments are expensive to carry out, the associated savings can be substantial. Better support has also been shown to improve outcomes. The twin challenges are to find better ways to identify early those at risk of high-cost and low-value care, and to assist people to make good choices in line with their goals. A shift in the balance of intent from treating diseases to more palliative approaches should not be seen as giving up on curative care, but rather a choice to live as well as possible. Evidence shows that such a shift is often in line with patient preferences. Changing the balance from more curative to more palliative care does not normally shorten life, and in some cases may extend it. Better assessment and support for better choices is particularly useful when the patient has complex needs.

Understanding the drivers of end of life care and knowledge of how policies may help to support better choices can improve experiences and quality of life near the end of life – and may also slow the rate of expenditure growth.

### POLICY BRIEF

### Introduction: Why is this brief important?

Populations are ageing in most countries due to rapid increases in life expectancy, especially for men, and declines in birth rates below replacement levels. As a result, there is a fear in some countries that there will not be enough people of working age to support the needs of older people. An overview of the various policy issues arising from population ageing and the options available to policy-makers can be found in the first introductory policy brief in this series on the *Economics of Healthy and Active Ageing* [1].

A key concern related to population ageing is how it will impact health and social care use and expenditure trends. The belief that older people are more costly for health and social care systems than younger people is pervasive, and so the logic goes that having a larger share of the population at older ages may unsustainably accelerate growth in public health care spending. In reality, the evidence suggests that the effects of ageing on health care spending will be modest and growth will be slow [1,2], but there will naturally be some additional care needs.

Health and social care expenditures can, nevertheless, be particularly high for people near the end of life. In fact, the costs associated with end of life care largely explain why health and social care expenditures per person, on average, are often higher for older people than for younger people, since most people die at older ages. Taken together, this raises important questions including:

- What drives high end of life health and social care use and costs?
- Do all (or most) people experience high use and cost of health and social care at the end of life?
- How will population ageing affect end of life care use and spending in the future?
- Are there interventions that can keep end of life costs manageable without sacrificing quality of care?

This policy brief reviews the evidence on patterns of service use and costs of care at the end of life. It will show that spending near the end of life varies greatly across individuals and that high overall costs are driven by service use by a small proportion of decedents. Although the numbers of people with needs for palliative and end of life care will rise with population ageing, it is possible to reduce the volume and intensity of service use, lower costs, and improve patient experiences with well-designed palliative and end of life care interventions.

As a part of the *Economics of Healthy and Active Ageing* series, this brief does not aim to provide detailed guidance on the organization and delivery of palliative or end of life care (see Box 1 to understand the distinction between the two). Rather it aims to provide a better understanding of: the effects of population ageing on the need for care at the end of life; the evidence on how different approaches to

provision of care may affect the experiences of patients and families; and the likely effects on patterns and costs of care associated with different policies and strategies.

### Box 1: What is palliative care (and how is it distinct from end of life care)?

While 'palliative care' and 'end of life care' are terms that are often used almost interchangeably, they are not synonymous. Palliative care is a whole approach that gives focus to managing symptoms and quality of life, while end of life care relates to a phase, normally defined as the expected last six months or year of life. The World Health Organization (WHO) defines palliative care [3] as follows:

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with lifethreatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten nor postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient's illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

Parts of a palliative approach can be appropriate at many different stages of illness, but the balance of effort tends to move from more disease-modifying approaches to more palliative approaches as disease progresses and the end of life comes closer. The decision to embrace a palliative approach is not necessarily a decision not to provide treatment that aims to reverse or slow down the progress of a disease, and in many instances interventions (such as radiotherapy), which affect the underlying disease, also have useful effects on symptoms. While a palliative approach does not specifically aim to lengthen or shorten life, decisions to focus on symptoms and quality of life can shorten life (but with less distress), may have no effect on survival, or in some cases may lengthen life expectancy by avoiding interventions that might be poorly tolerated by a very sick patient [4].

Palliative care in many countries has been associated with managing the symptoms of late-stage cancers, but the underlying approaches are, in principle, relevant to all people whose illnesses lead to pain or distress. In addition to pain, common symptoms may include fatigue, breathlessness and delirium, as well as psychological problems for the patients and families. Hence, good palliative care tends to be inclusive, individual and wide-ranging. It can be provided by specialized health care professionals (including medical, nursing and allied health professionals and carers) or as part of a broader package of treatments provided by health care professionals from other disciplines.

#### Health and social care expenditures increase by age

In most countries with well-developed health systems there is an observable relationship between calendar age and per person health and social care spending levels, such that average per capita expenditure typically increases with age. As an illustration, Figure 1 contains average health spending per person data across European Union (EU) countries, which shows this prototypical pattern.

Although spending per person is typically higher at older ages, expenditure levels often decline for the very old (e.g. above 90 years) [5–13]. Costs increase steadily above the age of 50, with a more rapid rise for those in their 80s. As will be discussed below, much of this pattern can be understood in terms of expenditures near the end of life.

Per person spending on long-term care, sometimes referred to as social care, also tends to increase with age, particularly among older adults. The fact that social care spending in aggregate continues to rise for people above the age of 80 is largely explained by the higher number of people in residential care or those living at home with high levels of domiciliary support. The pattern of costs of social care is shown in Figure 2 using an example from Canada. There is some evidence that annual care costs plateau and may fall for the very old, but the numbers are comparatively small and there is variation between countries. It should also be noted that these data refer only to formal, paid services. Evidence shows that much of the cost of social care falls on informal carers and families – in many cases around half of total costs [14]. It is therefore important to ensure that what appear to be cost savings from changes in models of care are not simply cost shifting from formal to informal care.

### Why do per person health and social care spending levels increase with age?

A good understanding of what drives cost increases is important as it can help to guide policy development to ensure both better experiences in older age and moderate increases in costs. While taken together, the data above demonstrate that health and social care spending typically increases with age, a more detailed analysis of these expenditure patterns indicates that although age is a correlate of spending, it is not itself the main driver of per person spending increases (see Box 2).

It turns out that much of the high costs of health and social care for older people occurs near the end of their life, with little or no link to age itself [5–13,15–25]. Health care spending for those near the end of life is much higher than spending for people of the same age who do not die that year [14], as shown in Figure 3 using data from Canada.



#### Figure 1: Per person health care expenditures, 2016, in selected EU countries by age group as percentage of per person GDP

Source: Data from the European Commission Ageing Working Group (not published).











Source: Data taken from [6].

#### Box 2: Does ageing drive health and social care spending?

Despite the apparently strong relationship between calendar age and health care costs, analyses have consistently shown that population ageing in itself will not have a major impact on health expenditure patterns in the future [1,2]. Health expenditure growth attributable to population ageing is unlikely significantly to exceed increases in resources that come from economic growth. This is because:

- Ageing is a very slow process, so any change in expenditures due to ageing will also be slow [1,15,25].
- Research has shown that factors such as policy decisions regarding entitlements and costs related to the adoption of new technologies have a larger effect on spending [13,15,16].
- Costs of care are much higher near the end of life, and since most people die at older ages this gives the appearance of costs rising with age.

When proximity to death is taken into account, most studies show no significant effect of calendar age on health care spending. Further, although social care expenditures increase with age as well as in the time period immediately before death, social care costs generally comprise a relatively small share of health and social care expenditures overall. While investments to improve quality and accessibility of social care will inevitably increase spending levels, social care expenditures are likely to remain well below that of health care.

Several points are clear from the data in Figure 3. First, health care spending near the end of life is much higher than spending for people of a similar age who survive; at the age of 65 spending is 18 times higher, and it is five times higher at 90. In addition, health care spending is modest for survivors, and among survivors rises only gradually with age. Lastly, spending near the end of life falls with age above 65. Per person spending in this study was more than one-third lower at the end of life for decedents over 90 as compared to those who died at 65.

There is some debate about the mechanisms that drive health care expenditure patterns near the end of life, with some arguing that this is really a proxy for morbidity and complexity of illness [13,24,26]. Multimorbidity increases with age, and is very common near the end of life. As the management of chronic diseases improves, the numbers living well with multiple health conditions may rise, with associated care costs. Much depends on whether ageing at a population level is associated with better health at any age, or living longer but in worse health [27]. Another reason for high end of life costs is the (ultimately unsuccessful, and often inappropriate) hospital treatment of the primary cause(s) of death.



### Figure 4: Mean drug spending in last year of life (NZ\$)

Source: Data taken from [11].

While most of the evidence on health spending near the end of life comes from studies of hospital care, similar patterns have been found in costs of other components of health care, such as medications prescribed outside of hospital [10,11]. There is no direct effect of age on the price of medications, but people near the end of life use many more. Again, it is interesting to note that the additional drug spending near the end of life declines with age (Figure 4). This is not because older decedents use fewer drugs than younger ones, but rather because they tend to use lowerpriced drugs.

Social care spending is also much higher for decedents than for survivors, although the difference is smaller than it is for health care spending (Figure 5). Social care spending for decedents is, on average, more than double that for survivors. According to data from Canada, the first rapid rise in spending occurs roughly between ages 75 and 85, with a further near doubling of spending between 85 and 90 for survivors. Studies suggest that the key determinants of individuals' social care expenditures are their instrumental activities of daily living (IADL), which include the capacity to shop and cook, as well as more basic activity of daily living (ADL) care needs [28,29]. Near the end of life, many people often become very frail, and this may help explain the higher costs. The concept of frailty aims to measure resilience and the capacity to withstand and recover from illnesses or other pressures [30], and has been shown to be useful in understanding needs and social care use. It has also been shown that expenditure levels are highly variable within countries for apparently similar needs [31], suggesting different levels of informal care support.





### What services are responsible for high health care costs at the end of life?

Unsurprisingly, the costs in the last year of life are dominated by the costs of hospital care and of time in care homes. According to Figure 6, in Ireland, hospital care accounts for 56% of costs in the last year and residential care homes 29%, so 85% of total costs come from these two. Primary care accounts for only 4% of costs, and care in the home for 11%. There is evidence that patterns of costs at the end of life are similar in other Western countries [1], although the breakdown between different elements of non-hospital costs differs.

Evidence for cancer patients in Israel shows that the main difference between decedents and survivors is in the intensity of hospital care in the last year of life [32]. This is consistent with the fact that people near the end of life tend to have multiple chronic diseases and tend to be frail. Hospital admissions are often the result of a failure of community-based services to support the person at home, leading to a hospital admission, but in many cases these people require few clinical interventions. Higher end of life costs for younger decedents (also reflected in Figure 3) may reflect the larger potential for extending life in younger patients, as well as greater effort to treat disease. It has also been found in an international collaborative study that high levels of attendances at hospital emergency departments are the result of inaccessibility of community health care, perceived barriers to community health care and poorly coordinated care [33].

# How will population ageing and greater numbers of decedents affect end of life care use and expenditures in the future?

A number of factors will affect end of life spending in the future, although among the most important factors is the change in the number of deaths per year [34,35]. The number of people near the end of life is expected to increase considerably in European countries over the next 30 years as the 'baby boomer' generation reaches older ages and the number of annual deaths increases. However, given the lower end of life health care costs in older decedents, average costs should fall as life expectancy increases and more people die at older ages [6]. At the same time, there is likely to be an increase in end of life spending on social care as people die at older ages, as well as a rise in social care spending for survivors as more will be older and at higher risk of dementia and its associated costs [31,36–38]. Expanding entitlements and better social care coverage will also result in some increases in end of life social care spending.

Detailed studies of future demands for end of life care have been carried out in only a few countries. However, some countries project large increases in annual deaths, which suggests there will be greater end of life care needs. These increases in the number of deaths vary across the European Region, with a rise by 2050 of around 13% projected for Germany, 26% for France, 15% for Czechia and 82% for Azerbaijan (Source: authors' calculations from UN data; [39]). In some countries this is against a projected fall in overall population levels. Romania is one of the few



#### Figure 6: Costs in the last year of life, Ireland

Source: Data taken from the Irish Longitudinal Study on Ageing covering deaths between 2009 and 2018.

countries to project no change in annual deaths by 2050. A key issue for planning for end of life care is therefore to look carefully at projections of numbers of deaths.

This increase in annual deaths is a result of rapidly increasing life expectancy and the related substantial fall in deaths in recent years. This has the inevitable consequence that the future death rate will rise as the cohort of longer survivors reach the end of life. As reported by May et al. [33], a large part of the increase in future medical care needs will have a more palliative, symptom management intent rather than a more curative one. In most European countries, the future number of deaths will be a more important driver of needs for end of life care (and potentially spending) than population ageing on its own.

Etkind and colleagues [32] provide projections of need for palliative and end of life care for England and Wales based on projected deaths and morbidity patterns. England and Wales is expected to experience 25% more deaths per year in 2040 than in 2014. Cancer deaths will rise by a third and the numbers with dementia will rise nearly fourfold, leading to an overall projection of a rise of 42% in the numbers needing palliative care by 2040.

May et al. [33] show that the number of annual deaths in Ireland is expected to rise by 68% between 2016 and 2046, with an associated increase in numbers approaching the end of life. In addition, the authors look at the likely increases in health conditions (such as dementia) that will require palliative care as deaths are put off until progressively older ages. Overall, this study estimates that palliative care needs will nearly double by 2046. However, this increase in palliative care needs may be offset to some extent by a fall in spending on other (often more expensive and sometimes ineffective) health care services.

### Do most people experience high use and cost of health and social care at the end of life?

An important factor in understanding high costs at the end of life is that these are in fact driven by very high costs for a relatively small proportion of decedents [37,40]. The distribution of end of life costs is wide and skewed. Figure 7 shows the distribution of spending on hospital and ambulatory health care in the last year of life for Ireland, using data from The Irish Longitudinal Study on Ageing (TILDA).

As can be seen, nearly 80% of total spending on care is accounted for by the most expensive 10% of decedents. The top 20% in terms of cost account for over 85% of total spending. The lower cost 50% of the decedents account for less than 5% of the total.

When social care costs are added, the distribution of spending in the last year of life is nearly as skewed, as shown in Figure 8.



#### Figure 7: Percentage of total health care costs in last year of life by cost decile (Ireland)

Source: Authors' own calculations based on data from the Irish Longitudinal Study on Ageing covering deaths between 2009 and 2018.



#### Figure 8: Percentage of total health and social care costs in last year of life by cost decile (Ireland)

Source: Authors' own calculations based on data from the Irish Longitudinal Study on Ageing covering deaths between 2009 and 2018.

### What are the characteristics of those with very high end of life costs, and how can we provide appropriate and cost-effective care?

The analysis in this policy brief suggests that we need to look closely at the characteristics of those with high health and social care costs at the end of life. What are the characteristics of these very high-cost decedents? Can we identify those at risk of high-cost care?

### What are the characteristics of these very high-cost decedents?

It is known that the highest-cost decedents tend to have multiple chronic diseases (often including dementias) and are frail. They are at high risk of futile and possibly harmful investigations and treatments [26]. They are likely to have many inpatient days in hospital, and are likely to require high levels of support at home or in residential care facilities. As shown in Figure 6 above, 85% of the costs of care near the end of life is for hospital (56%) and residential care (29%). Research is ongoing to develop tools to identify early those who might benefit most from skilled interventions to improve the care trajectory.

Evidence [38] shows that the main drivers of increasing social care costs, including costs near the end of life, are disabilities as measured by ADL and IADL scores [38]. Reducing admissions to (high-cost) residential care will require a focus both on reducing disabilities and also on ways to reduce the impact of disabilities on the viability of care at home. In contrast to health spending, age remains a determinant of social care spending even when disability is taken into account. Costs of social care are also higher in those who are living alone in older age than those in households with two or more people [38]. Recent trends in life expectancy, with men gaining more rapidly than women, mean that households are more likely to have two or more people. Households with two or more residents are better able to withstand shocks and crises. Therefore, there is likely to be some offsetting effect on the growth in social care spending. The proportion of older people living in single-person households is falling, although in most countries the absolute number of single-person elderly households continues to rise.

### Can we identify those at risk of high-cost care?

While we know the features of people who are likely to have high-cost and poor experiences, there remains a challenge in how to identify them in a timely way as they pass through the care system. While most high-cost patients are frail, there are many frail people who do not have high costs. There are currently several research programmes that aim to improve our ability to identify early those who are at risk of high-cost and futile interventions. There is some emerging evidence that adding a mortality risk score [27] to information on multimorbidity can help in identifying people at high risk of high cost. However, given that a large part of the cost comes from hospital admissions, an obvious place to identify those with complex needs and potentially inappropriate care is at the point of access to acute hospital care. The limited available evidence suggests that interventions at the point of hospital access can improve the care experience and lower cost [41].

### Developing better strategies for care near the end of life

Policies to manage the growth in health care spending need to focus mainly on high-cost decedents and determine whether there are better, more cost-effective ways to provide health and social care services and other forms of support.

## How appropriate is current care and are there alternatives that may achieve more and/or cost less?

Given the scale of high end of life costs as compared to costs for survivors, it is clear that we need to understand better the drivers of these high costs and the extent to which they represent good value in terms both of longer life and good quality of life in this period.

There have long been concerns in many countries that patients and families have poor experiences near the end of life, and some of these relate to inadequate or inappropriate care. A common indicator has been place of death, with a large difference between preferred and actual location [28,38]. While it is clear that in some cases the death in hospital occurs as a result of changed circumstances, it remains the case that many people, who could die at home, end their lives in hospital settings.

There is other evidence that current resources are not used to their best effect at the end of life [38,42]. Results from longitudinal ageing studies show that under-treatment of pain and depression was reported in nearly half of deaths [39]. A study of preferences for care amongst patients and informal caregivers revealed a mismatch between what was wanted and what was provided [43]. Some of the dissatisfaction was with the poor process of care delivery as well as the content.

Concerns that care near the end of life was failing to provide the services that would be most appropriate and costeffective have led to a series of studies of team-based assessments to improve understanding of needs and better plan the care trajectory [4,41,44–45]. The underlying hypothesis is that failure to take into account all the relevant circumstances facing the patient, along with a failure to be clear about the goals of care, can lead to unnecessary and sometimes inappropriate investigations and treatments. A multidisciplinary team with a range of skills and perspectives can help the patient to choose a better pathway and more appropriate care.

It has been shown for some categories of patients with lifelimiting illness that it is possible to improve the experience and lower costs of care, suggesting that, in such cases, current provision is neither appropriate nor efficient. Reduced costs come from fewer investigations, fewer interventions and fewer days in hospital, with some evidence that experiences and outcomes are also better.

#### How can we ensure the best care pathway?

The mechanisms that have been shown to change care trajectories involve careful multi-professional assessment and support for better choices by patients and carers. This has

been shown to work in inpatient and emergency department settings. It is likely that similar approaches in different care settings can also improve the care pathway. Studies have shown that more careful assessment and planning can reduce interventions, reduce costs and improve outcomes [4,41,44–45]. For patients with very complex needs and a cancer diagnosis, the savings for a single hospital stay were around \$10,000 and a study of palliative care assessments in the emergency department setting showed reductions in length of hospital stay of nearly 11 days [41]. Although assessment by multi-professional teams is expensive, this has been shown to be more than offset by costs savings for many patient groups. Savings come from a combination of shorter hospital stays, fewer investigations and less treatment that has a disease-modifying purpose [46].

In one study [4] it was shown that palliative care team assessments were associated with increased life expectancy for people with life-limiting disease. There are understandable and reasonable concerns that the choice to shift the balance from interventions that aim to change the course of the disease to ones that aim to achieve better symptom management is a decision to give up. However, it is known that many interventions that aim to extend life do not succeed and may lead to an earlier death. Better management of symptoms and quality of life can extend life, so that 'giving up on curative treatment' is not really a useful way to characterize the choices. A better understanding is that the balance of effort should change as the best outcomes and experiences warrant a shift from a narrow focus on treating the disease to a broader one which includes better symptom management.

Until recently, Medicare patients in the USA were faced with the choice between palliative care or services that treat the disease more directly. The rules that accompanied the Medicare Hospice Benefit, in its original form, required beneficiaries to forego the option of curative interventions, making it a choice between palliative or curative care [47]. As suggested above, this choice rules out the much better pathway of a gradual change in the goals of care and the balance between curative and palliative intent.

The (well-intentioned) development and application of the Liverpool Care Pathway may have reinforced the perception that these different types of care are mutually exclusive [48]. It is now clear that planning appropriate support and care near the end of life needs to allow for flexibility and wellinformed changes, and to support choices that will achieve the goals of care. It needs to take account of the evidence on what patients want and what their goals are, as well as the evidence on how this can differ from goals pursued by relatives and informal carers (see Box 3 below).

There are three key findings from studies on improved assessment and planning. Change is greatest when:

- there are more chronic diseases diagnosed, making the choices about which diseases to treat and how best to treat them complex
- the assessment is early in the care trajectory
- the patient has a cancer diagnosis.

In the absence of more detailed information, it is likely that detailed assessment should be focused on patients who have complex needs, and attempts should be made to provide this service as early as is feasible.

#### Box 3: What do service users want?

A number of themes emerge from the research on preferences relating to end of life care. There is strong evidence that people may have their overall experiences improved by facing as few barriers as possible to accessing the services they need. However, there are important differences in patterns of preferences for services and place of care among patients and caregivers, which are influenced by factors such as age and personal circumstances. A difficulty in understanding user preferences in palliative and end of life care is that service users (and indeed the general public) often have a limited understanding of what is (or could be) available, and about the goals of different types of care [43]. This is made more challenging by common misconceptions about the purposes and roles of palliative care (and indeed in some settings the name itself is a problem). For example, it has been shown that patients' expressed preferences reflect their direct knowledge and experience of what is (locally) available [49]. Where specialist palliative care is more fully developed, and understood by service users, the preferences against hospital care at the end of life are more pronounced [43,49].

Overall, there is evidence of strong preferences for care that is coordinated, continuous and accessible, even if some potentially useful services are not available. Process and experiences of patients can be as important as content [38,43,49,50]. Patients are keen to ensure that their symptoms are managed as well as is feasible [50]. This means they display strong preferences for ensuring ease and efficiency of access to care *even when they do not currently need to gain access* [43,50]. There was recognition that services have a cost and someone has to pay, but there was a clear preference against financial barriers to care at the point of use.

Both patients and caregivers prioritize supportive processes of care, so that people feel they can get information and advice quickly [43]. The tendency to be frequently referred on from one professional to another without the problem being resolved is particularly disliked [43]. Interestingly, there is a good understanding by patients that some problems cannot easily be resolved. Patients and caregivers alike are not unrealistic about the possibly limited options for useful interventions, so the attitude and approach taken is of more importance than success in resolving problems. Caregivers tend to have a stronger preference for attempts to change the disease trajectory compared to patients, while patients focus more on effective symptom management.

There is consistent evidence concerning places of care, including the location of death [38,43,49]. There is a general preference for death at home over death in an institutional setting, but in some cases these preferences change among older people with care needs as their diseases progress and the burden of caregiving increases. In a recent study of people with life-limiting illness across Ireland, England and the USA, the stated preferred place of death was home (56%), followed by a hospice setting [38]. There was no significant difference in the preferences between the countries despite the different health and social care systems.

Where data are available it is clear that, in most countries, a large proportion of people do not die in their preferred location. There is a particular preference against death in an acute hospital setting, but this is often the outcome [49]. While death in hospital cannot be avoided in all cases, and it may be the only feasible setting in some circumstances, it is often the result of pursuing inappropriate and unrealistic goals of care, and can be associated with poor quality of life near the end of life.

As we develop a better understanding of what drives costs near the end of life, and of the mismatch between what people want and what people get, there is clearly scope to use end of life care resources to better effect and to avoid some costs [25].

### Are there interventions that might prevent the development of these very high-cost needs?

The conceptual framework for the *Economics of Healthy and Active Ageing* series highlights the role of policies to promote healthy and active ageing. There is good evidence that it is possible to improve ADL scores in people with lifelimiting illness [51], with improved experiences for patients and, in some cases, lower costs. Evidence exists for many care groups in many settings [52], and in some instances it has been shown to be very cost-effective. As with other interventions in end of life care, it has generally been shown that earlier interventions are more effective than later ones, but later ones are nevertheless often effective and costeffective. Interventions to reduce limitations to ADL and IADL are of particular importance in reducing social care needs and costs.

Whilst there is a need for further studies, in particular those that track the whole trajectory of care from the team assessment to the end of life, the existing evidence shows clearly that careful and well-informed assessment, taking account of the goals of both the patient and their family, will significantly change patterns of care and costs, with an improvement in the experience of patients and families. The effects of skilled assessments is greater where the patient has complex needs, normally with multiple health conditions. These people are typically frail and in all circumstances are likely to require high-cost care, but this can be better and sometimes cheaper if carefully planned (see Box 4 below).

The evidence suggests that the effects of skilled assessments is greater when there is a diagnosis of cancer (even though this may not be the primary life-limiting illness). This is probably because futile interventions in this group that aim to change the course of the cancer may be expensive as well as sometimes poorly tolerated by the patient.

The evidence also suggests that there will be more limited savings where the life-limiting illnesses are respiratory or circulatory. This is probably because such people tend to experience a gradual decline in capacities for ADL, whereas people with cancer often retain such capacities until late into the final stages of the disease.

#### Box 4: Palliative care team or unit interventions

The logic of palliative care team or palliative care unit interventions is that meeting complex needs of people with complex problems requires careful and considered assessment, identification of options for care, and support for patient and family decision-making, when available. Teams are normally comprised of a range of skilled professionals from medicine, nursing, allied health professions and social care, who work together to assemble the best information to support better choices. Palliative care units differ in that they bring the patient to the service rather than the service to the patient, thereby providing a calm setting. There is some evidence that this approach is slightly more successful than that of teams working in the normal hospital setting.

### Discussion: The way forward for improving services towards the end of life

The evidence on the current pattern of needs and likely growth in demand for good care near the end of life can inform the development of better strategies. As has been demonstrated, a large part of the high cost of dying is driven by the needs of a relatively small number of people with complex needs and typically high-cost care. These are also the people who are most likely to have their care improved by more careful assessment of their needs. The challenge is to have in place ways to identify these people and to work with them to make better choices.

Hospital care is mainly organized around specific illnesses and types of intervention. While this has led to improved standards of care for each disease, it has tended to underplay the role of concurrent chronic diseases. Care is often organized with short consultations, frequently carried out by someone from a single profession or discipline. The evidence shows that there is value to be gained for the patient and family in supporting decisions more slowly, and through drawing on a range of perspectives. To some extent this has been the approach in primary care and specialized care services for older people. Given the high costs and often poor experiences of care resulting from an excessive focus on disease-modifying approaches, more considered choices can improve experiences and may also lower costs.

The evidence on the feasibility and usefulness of better support for choices, along with that on preferences, provides a good basis for improved services near the end of life.

There are a range of key actions to improve the use of resources and experiences of services users:

- As numbers of patients with complex needs are likely to increase rapidly, with increasing numbers nearing the end of life, so the capacity to provide care services will need to increase.
- Mechanisms are required in social care, primary care and hospitals to identify people with complex needs and refer them to teams that can provide skilled support for better (and continuous) decision-making.
- Whatever the main financing mechanisms for health and social care are in a particular country, it is important to remove financial barriers to access to services at the point of use, since this increases stress for both patients and families, and may ultimately lead to greater spending.
- Since continuity is highly valued and frequent referral is disliked, it is important to ensure that points of access to services are well understood and that navigating the system is made easier.
- Care pathways need to be flexible and allow for choices to change as needs and preferences evolve.

While growing numbers of people with complex needs and people near the end of life mean that some additional resources will be needed in order to provide good care [53], some of the increase can be funded from the reduced use of services that are currently driving high costs and poor outcomes for many patients. Overall, the takeaway message is that rethinking and developing the approach to health and social care services for people near the end of life has the potential to both improve quality of life and slow the rate of expenditure growth.

### References

- Cylus J, Figueras J, Normand C (2019). Will population ageing spell the end of the welfare state? A review of evidence and policy options. Economics of Healthy and Active Ageing series. Copenhagen, European Observatory on Health Systems and Policies (https://www.ncbi.nlm.nih.gov/books/NBK550573, accessed 20 October 2021).
- European Commission (2015). The 2015 Ageing Report: Economics and budgetary projections for the 28 EU member states (2013–2060). European Economy Series, 3. Brussels, European Commission (https://ec.europa.eu/economy\_finance/publications/eur opean\_economy/2015/pdf/ee3\_en.pdf, accessed 20 October 2021).
- 3. WHO (2020). *Palliative care*. Geneva, World Health Organization (https://www.who.int/cancer/palliative/definition/en, accessed 24 March 2020).
- 4. Temel JS et al. (2017). Effects of early integrated palliative care in patients with lung and GI cancer: A randomized clinical trial. *Journal of Clinical Oncology*, 35(8):834–841; doi: 10.1200/JCO.2016.70.5046.
- Zweifel P, Felder S, Meiers M (1999). Ageing of population and health care expenditure: A red herring? *Health Economics*, 8(6):485–496; doi: 10.1002/(sici)1099-1050(199909)8:6<485::aidhec461>3.0.co;2-4.
- McGrail K et al. (2000). Age, costs of acute and longterm care and proximity to death: Evidence for 1987–88 and 1994–95 in British Columbia. Age and Ageing, 29(3):249–253; doi: 10.1093/ageing/29.3.249.
- Lubitz J et al. (2003). Health, life expectancy, and health care spending among the elderly. *New England Journal of Medicine*, 349(11):1048–1055; doi: 10.1056/NEJMsa020614.
- Seshamani M, Gray AM (2004). Time to death and health expenditure: an improved model for the impact of demographic change on health care costs. *Age and Ageing*, 33(6):556–561; doi: org/10.1093/ageing/afh187.
- Seshamani M, Gray AM (2004). A longitudinal study of the effects of age and time to death on hospital costs. *Journal of Health Economics*, 23(2):217–235; doi: 10.1016/j.jhealeco.2003.08.004.
- Moore PV, Bennett K, Normand C (2017). Counting the time lived, the time left or illness? Age, proximity to death, morbidity and prescribing expenditures. *Social Science & Medicine*, 184:1–14; doi: 10.1016/j.socscimed.2017.04.038.

- Moore PV, Bennett K, Normand C (2014). The importance of proximity to death in modelling community medication expenditures for older people: Evidence from New Zealand. *Applied Health Economics and Health Policy*, 12(6):623–633; doi: 10.1007/s40258-014-0121-x.
- Blakely T et al. (2015). Updated New Zealand health system cost estimates from health events by sex, age and proximity to death: Further improvements in the age of 'big data'. New Zealand Medical Journal, 128(1422):13–23.
- 13. Howdon D, Rice N (2018). Health care expenditures, age, proximity to death and morbidity: Implications for an ageing population. *Journal of Health Economics*, 57:60–74; doi: 10.1016/j.jhealeco.2017.11.001.
- 14. Pammolli F, Riccaboni M, Magazzini L (2012). The sustainability of European health care systems: Beyond income and aging. *European Journal of Health Economics*, 13(5):623–634; doi: 10.1007/s10198-011-0337-8.
- Martín Martín JJ et al. (2011). Review of the literature on the determinants of healthcare expenditure. *Applied Economics*, 43(1):19–46; doi.org/10.1080/00036841003689754.
- Spillman B, Lubitz J (2000). The effect of longevity on spending for acute and long-term care. *New England Journal of Medicine*, 342(19):1409–1415; doi: 10.1056/NEJM200005113421906.
- 17. Häkkinen U et al. (2008). Aging, health expenditure, proximity to death, and income in Finland. *Health Economics, Policy, and Law*, 3(2):165–195; doi: 10.1017/S174413310800443X.
- Breyer F, Felder S (2006). Life expectancy and health care expenditures: A new calculation for Germany using the costs of dying. *Health Policy*, 75(2):178–186; doi: 10.1016/j.healthpol.2005.03.011.
- 19. Reinhardt UE (2003). Does the aging of the population really drive the demand for health care? *Health Affairs* (*Millwood*), 22(6):27–39; doi: 10.1377/hlthaff.22.6.27.
- Dormont B, Grignon M, Huber H (2006). Health expenditure growth: Reassessing the threat of ageing. *Health Economics*, 15(9):947–963; doi: 10.1002/hec.1165.
- 21. Anderson GF, Hussey PS. Population aging: a comparison among industrialized countries. *Health Affairs (Millwood)*, 19(3):191–203; doi: 10.1377/hlthaff.19.3.191.
- 22. Cylus J et al. (2019). Sustainable health financing with an ageing population: Implications of different revenue raising mechanisms and policy options. European Observatory Policy Briefs. Copenhagen, European Observatory on Health Systems and Policies (https://apps.who.int/iris/handle/10665/331977, accessed 20 October 2021).

- 23. Hazra NC, Rudisill C, Gulliford MC (2018). Determinants of health care costs in the senior elderly: Age, comorbidity, impairment, or proximity to death? *European Journal of Health Economics*, 19(6):831–842; doi: 10.1007/s10198-017-0926-2.
- 24. Barer ML, Evans RG, Hertzman C (1995). Avalanche or glacier? Healthcare and demographic rhetoric. *Canadian Journal on Aging*, 14(2):193–224.
- Yi D et al. (2020). Drivers of care costs and quality in the last 3 months of life among older people receiving palliative care: A multinational mortality follow-back survey across England, Ireland and the United States. *Palliative Medicine*, 34(4):513–523; doi: 10.1177/0269216319896745.
- Rechel B, Jagger C, McKee M (2020). Living longer but in better or worse health? Economics of Healthy and Active Ageing series. Copenhagen, European Observatory on Health Systems and Policies (https://eurohealthobservatory.who.int/publications/i/livi ng-longer-but-in-better-or-worse-health, accessed 20 October 2021).
- 27. Lee SJ et al. (2006). Development and validation of a prognostic index for 4-year mortality in older adults. *JAMA*, 295(7):801–808; doi: 10.1001/jama.295.7.801.
- Gomes B, Higginson IJ (2004). Home or hospital? Choices at the end of life. *Journal of the Royal Society* of *Medicine*, 97(9):413–414; doi: 10.1258/jrsm.97.9.413.
- 29. Murphy CM, Whelan BJ, Normand C (2015). Formal home-care utilisation by older adults in Ireland: Evidence from the Irish Longitudinal Study on Ageing (TILDA). *Health and Social Care in the Community*, 23(4):408–418; doi: 10.1111/hsc.12157.
- Zeltzer D et al. Why is end-of-life spending so high? Evidence from cancer patients. Working Paper 28162. Cambridge, MA, National Bureau of Economic Research (http://www.nber.org/papers/w28162, accessed 20 October 2021).
- Rockwood K, Andrew M, Mitnitski A (2007). A comparison of two approaches to measuring frailty in elderly people. *Journal of Gerontology, Series A: Biological Sciences*, 62(7):738–743; doi: 10.1093/gerona/62.7.738.
- 32. Etkind SN et al. (2017). How many people will need palliative care in 2040? Past trends, future projections and implications for services. *BMC Medicine*, 15(1):102; doi: 10.1186/s12916-017-0860-2.
- 33. May P et al. (2019). Population-based palliative care planning in Ireland: How many people will live and die with serious illness to 2046? *HRB Open Research*, 2:35; doi: 10.12688/hrbopenres.12975.1.

- Normand C (2015). Analysis of the health system in Slovenia: Long-term care. Final report. Copenhagen, European Observatory on Health Systems and Policies; Government of Slovenia (http://www.euro.who.int/\_\_data/assets/pdf\_file/0003/3 36396/Long-term-care-report-Slovenia.pdf?ua=1, accessed 20 October 2021).
- Prince M et al. (2015). World Alzheimer Report 2015: The global impact of dementia – An analysis of prevalence, incidence, cost and trends. London, Alzheimer's Disease International (https://www.alzint.org/u/WorldAlzheimerReport2015.p df, accessed 20 October 2021).
- Connolly S et al. (2014). Estimating the economic and social costs of dementia in Ireland. *Dementia*, 13(1):5– 22; doi: 10.1177/1471301212442453.
- 37 UN Data (2021). Number of deaths, both sexes combined. New York, NY, United Nations Population Division (http://data.un.org/Data.aspx?d=PopDiv&f=variableID% 3a64, accessed accessed 6 September 2021).
- Higginson IJ et al. Social and clinical determinants of preferences and their achievement at the end of life: Prospective cohort study of older adults receiving palliative care in three countries. *BMC Geriatrics*, 17(1):271; doi: 10.1186/s12877-017-0648-4.
- 39. May P et al. (2020). End-of-life experience for older adults in Ireland: Results from the Irish longitudinal study on ageing (TILDA). *BMC Health Services Research*, 20(118); doi.org/10.1186/s12913-020-4978-0.
- 40. Aldridge MD, Kelley AS (2015). The myth regarding the high cost of end-of-life care. *American Journal of Public Health*, 105(12):2411–2415; doi: 10.2105/AJPH.2015.302889.
- Tiernan E et al. (2019). A quasi-experimental evaluation of an intervention to increase palliative medicine referral in the emergency department. Journal of Health Services Research & Policy, 24(3):155–163; doi: 10.1177/1355819619839087.
- Bone AE et al. (2021). Influences on emergency department attendance among frail older people with deteriorating health: A multicentre prospective cohort study. *Public Health*, 194:4–10; doi: 10.1016/j.puhe.2021.02.031.
- Johnston BJ (2018). Patients' and carers' perceptions of palliative care. Dublin, Trinity College Dublin (http://www.beaumont.ie/media/PatientandFamiliesPerc eptionsofpalliativeCare1.pdf, accessed 21 October 2021).
- 44. May P, Normand C, Morrison RS (2020). Economics of palliative care for cancer: Interpreting current evidence, mapping future priorities for research. *Journal of Clinical Oncology*, 38(9); doi: 10.1200/JCO.18.02294.

- 45. May P (2018). Economics of palliative care for hospitalized adults with serious illness: A meta-analysis. *JAMA Internal Medicine*, 178(6):820–829; doi: 10.1001/jamainternmed.2018.0750.
- 46. May P et al. (2017). Cost analysis of a prospective multi-site cohort study of palliative care consultation teams for adults with advanced cancer: Where do cost-savings come from? *Palliative Medicine*, 31(4):378–386; doi:10.1177/0269216317690098.
- 47. Connor SR (2009). U.S. hospice benefits. *Journal of Pain and Symptom Management*, 38(1):105–109; doi: 10.1016/j.jpainsymman.2009.04.012.
- Seymore J, Clark D (2018). The Liverpool Care Pathway for the Dying Patient: A critical analysis of its rise, demise and legacy in England. Verson 2. Wellcome Open Research, 3:15; doi: 10.12688/wellcomeopenres.13940.2.
- 49. Brick A et al. (2015). Economic evaluation of palliative care in Ireland. Dublin, Trinity College Dublin (http://www.tara.tcd.ie/bitstream/handle/2262/75734/Fi nal-report-July-2015.pdf?sequence=1&isAllowed=y, accessed 20 October 2021).
- Douglas HR et al. A new approach to eliciting patients' preferences for palliative day care: The choice experiment method. *Journal of Pain and Symptom Management*, 29(5):435–445; doi: 10.1016/j.jpainsymman.2004.08.017.
- 51. Patel S et al. (2020). Supervised pulmonary rehabilitation using minimal or specialist exercise equipment in COPD: A propensity-matched analysis. *Thorax*, 76(3); doi: 10.1136/thoraxjnl-2020-215281, online ahead of print.
- Rahja M et al. (2021). Some gain for a small investment: An economic evaluation of an exercise program for people living in residential aged care. *Australasian Journal on Ageing*, 40(2):e116–e124; doi: 10.1111/ajag.12875.
- Cicely Saunders International (2021). You matter because you are you. An action plan for better palliative care. London, Cicely Saunders International (https://csiweb.pos-pal.co.uk/csicontent/uploads/2021/01/Cicely-Saunders-Manifesto-A 4-multipage\_Jan2021-2.pdf, accessed 20 October 2021).

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