5 Improving care pathways for elderly people

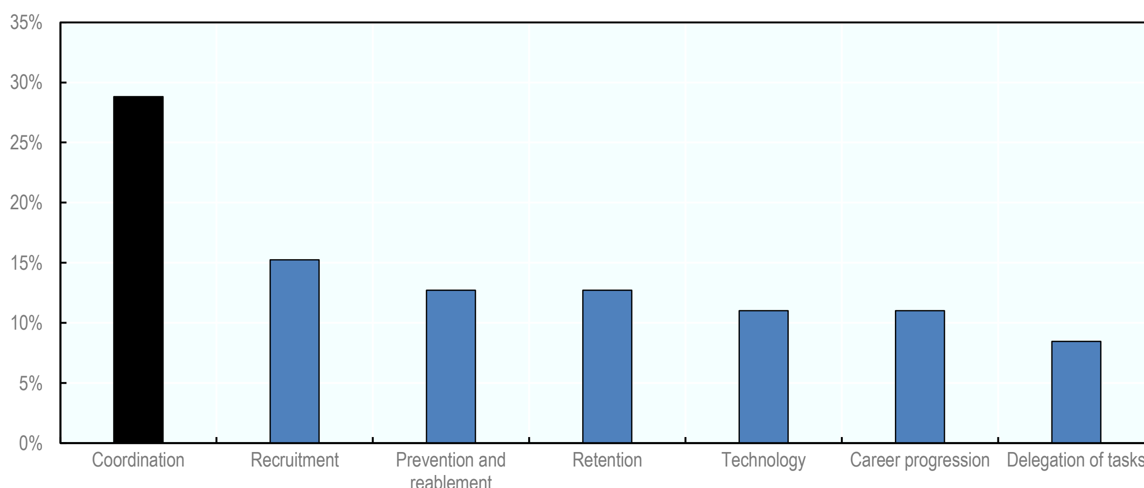
This chapter explores recent policy developments to improve co-ordination between the long-term care (LTC) and health care sectors, and their effect on the LTC workforce. In the coming years, LTC services will be more people-centred and organised nearer to communities; they will also require closer interaction with health services and family caregivers, as elderly people develop more complex needs and suffer more chronic diseases and other disabilities. The chapter discusses how countries are trying to provide more integrated care between hospital and home care, and what this means for workers in terms of their skills and care models. It also discusses the changes towards more teamwork and case management to provide LTC co-ordinated services at the community level. Finally, it highlights changes to leverage the help of family carers by increasing co-ordination with formal LTC workers and supporting family carers.

5.1. More integrated care is needed

In the future, LTC services should be more people-centred and organised closer to communities. Ensuring good care co-ordination is particularly important for elderly people. Support with activities of daily living (ADL) – such as bathing and dressing – and instrumental activities of daily living (IADL) – such as cooking and cleaning – will not be enough. Elderly individuals will also require attention to their complex medical needs for management of chronic conditions. This requires sustained efforts by care recipients and their families to understand and navigate the information and help needed within a fragmented health and care system. In addition, frail elderly people do not only want to see their remaining days maximised – they also want better quality of life in their later years.

Countries rated care co-ordination between health and social care workers as the most important policy in their LTC workforce agendas. Approximately one-third of OECD countries have policies in place to support better co-ordination of services provided by caregivers and to promote more integrated care (Figure 5.1). The majority of these policies aim to strengthen integration between health and social care services. Another important set of policies refers to initiatives promoting co-ordination between formal and informal workers. Informal caregivers – such as families, friends, neighbours and volunteers – represent an important proportion of care providers.

Figure 5.1. Co-ordination is the number one policy in countries' workforce agendas



Source: OECD Long-term care workforce questionnaire, 2018.

With population ageing, a growing share of elderly people are using acute hospital beds and needing both health and LTC services to manage their chronic conditions and activity limitations. Failure to provide more integrated care pathways for elderly people can push up hospital costs through unnecessarily long hospital stays because of delayed discharges (Suzuki, forthcoming[1]; Osterman, 2017[2]) and, after discharge, may result in hospital readmission (Fuji, Abbott and Norris, 2013[3]). Evidence from pilot programmes shows that integrated teams of health and social care workers led in some cases to reduced emergency care bed use and delayed transfers (World Bank, 2016[4]); meanwhile, use of residential and nursing homes fell and there was an increase in use of home care services (Thistlethwaite, 2011[5]). Lack of appropriate care support at home can also increase societal costs by placing a heavy burden on informal carers. Indirect costs of informal care include forgone employment or worse health for informal carers. The United States estimated the economic value of informal caregivers at about USD 350 billion in 2006 – the income forgone by caregivers due to time spent caregiving (Gibson and Houser, 2007[6]). In New Zealand, this value represented USD 10.8 billion or 5% of GDP in 2013 (Grimmon, 2014[7]).

In response, countries are implementing a number of programmes that support co-ordinated LTC services closer to home. Care co-ordination – i.e. system-wide efforts and/or formal policies to ensure that elderly people get people-centred services – can improve outcomes and avoid care fragmentation that may lead to safety issues and increases in costs. For instance, integrated care services for frail elderly people in Canada reduced the costs of institutional and home care and of acute hospitalisations (Béland et al., 2006[8]). Such integrated community care systems require new health and social integrated pathways, an expanded role for LTC professionals working in teams monitoring chronic conditions and better integration and support of informal carers.

Widespread evidence on the effectiveness of integrated care on outcomes other than quality of care is still inconclusive and depends on many organisational and training factors. Numerous obstacles hinder workers' and caregivers' ability to provide co-ordinated services at the community level. In the majority of countries, LTC funding is fragmented, and when care is funded from multiple institutional silos and different levels of government, it tends to inspire cost shifting instead of shared care provision by workers. In addition, regulations hinder workers from delivering services in an effective manner, when and where needed, and can confine what professionals can do or delegate to their peers.

Section 5.2 discusses measures to improve co-ordination between LTC at home and acute and hospital care. Section 5.3 explores how professionals are finding new ways of working together to deliver such co-ordination. Options for better integration and support of informal carers are discussed in Section 5.4.

Key findings

- Close to one-third of OECD countries ranked LTC co-ordination as the number one policy challenge within their workforce agendas. Elderly people want care services that satisfy their needs and preferences: care that is organised, co-ordinated and delivered closer to home in their community. However, elderly people – many of whom endure several chronic conditions – require attention from multiple providers across fragmented and poorly co-ordinated health and social care systems.
- Countries are developing integrated health and care pathways to avoid unnecessarily long hospitalisations for elderly people. For instance, Australia, Canada, the United Kingdom, France, Portugal and Spain are implementing mobile hospital-at-home services, either as follow-up hospital-level care at home after discharge of a dependent elderly person from a short hospital stay, or as a preventive way to avoid hospital admission. Some countries, such as Belgium, Australia and England, United Kingdom, are also developing geriatric knowledge in hospitals. The rationale is two-fold: to prevent hospitalisation worsening autonomy and to avoid people staying for unnecessarily long periods in hospitals or being readmitted soon after discharge.
- Prompt discharge from hospitals requires appropriate follow-up; "step-down" alternatives can ensure continuity of care at lower cost. There is scope for expanding the role of nurses and personal care workers to perform more duties in monitoring health conditions among elderly people, health coaching and assisting transitions from hospital to homes. In Portugal, for example, trained nurses can perform both care and cure, and received a good level of training, including in hospital-based management of medical conditions.
- There is also need for more geriatric expertise in the community and appropriate referrals between primary care and LTC. Geriatricians (elderly care physicians) in the Netherlands can address complex care needs at home. In England (United Kingdom), multispecialty community providers facilitate recovery at home and enhance home care services, with an enhanced role for community nurses. In Quebec (Canada), care recipients are assessed using a screening tool for autonomy and morbidity and are assigned a case manager, who refers them to LTC home services and co-ordinates with primary care and other services.

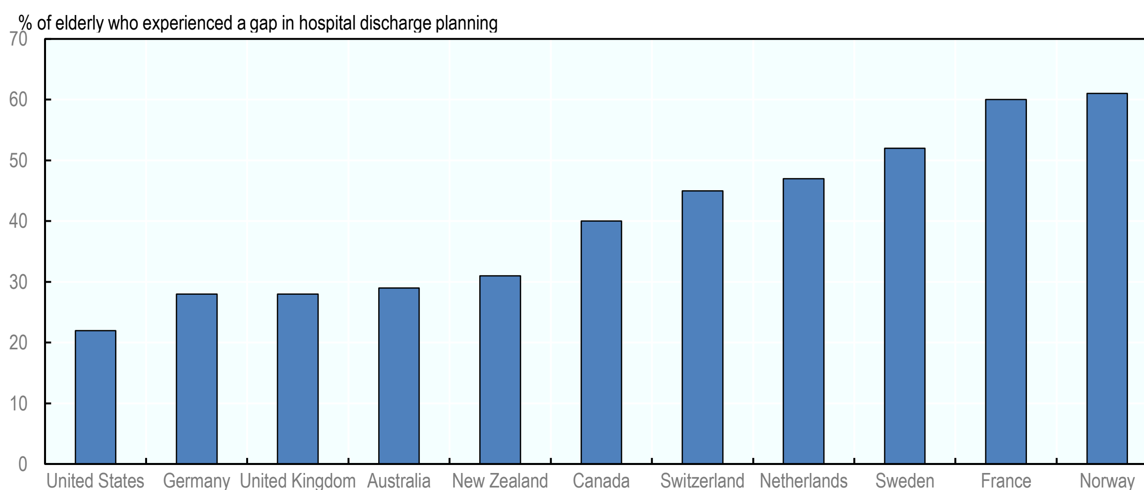
- Intermediate care facilities are offered in some countries such as Norway and the United Kingdom, as a model for facilitating better care co-ordination between acute and LTC services. There is evidence that using such intermediate care following hospital discharge may reduce a person's need for further LTC and hospital services.
- Care managers can help alleviate the administrative burden of LTC carers and help co-ordinate their needs and those of care recipients. In the majority of OECD and EU countries, nurses and personal care workers already conduct tasks supporting this role. For transfers from hospital care into the community, the transitional care nurse (TCN) model in the United States has shown positive results. For this to happen, professionals need to be trained in communication skills, leadership roles, ICT skills and more advanced clinical skills.
- In addition to care managers, complex care management requires multidisciplinary teams to help co-design and co-decide care plans. In Portugal and the United States, such teams are part of the health care system to help elderly people with complex needs. More training will be necessary for nurses and personal care workers to work in such teams.
- Given the potential shortage of formal workers in the LTC sector, facilitating collaboration between formal and unpaid family carers – including informal networks and associations – in the team will be essential. Certain OECD countries have started, as part of integrated care, to include carers as part of the care team. In Australia, for instance, family carers have access to shared care planning tools.
- Formal carers will also increasingly be asked to collaborate with family carers, providing skills training and directing family carers to the services available to them. Several OECD countries have improved recognition of family carers and their dual role as workers and carers, but better support is still needed. Without it, family carers are likely to feel overburdened, resulting in increased hospitalisations and emergency visits for their loved ones.
- Respite care, which is designed to offer caregivers a break from their regular duties, is often cited as an important component to ensure that carers can continue to care. Few countries have made access to overnight respite care a right for family carers. Germany offers legal entitlement to a maximum number of respite care and short-term care days per year. There is evidence that education, training and information interventions are effective. Beyond training, carers who spend a substantial amount of time out of the labour force would also benefit from recognition and certification of skills acquired as carers.

5.2. Some countries are developing integrated health and care pathways

Poor co-ordination between different professionals makes it more likely that elderly people go to hospital unnecessarily. This can contribute to unnecessarily long stays but also to a high risk of readmission. People aged 65 and over represent a high proportion of patients in acute care hospitals, and stay longer than younger patients (Suzuki, forthcoming[1]). In addition to longer lengths of stay, older people make up the vast majority of patients experiencing delayed discharge from hospital which are often due to the lack of appropriate care arrangements (Figure 5.2).

Figure 5.2. There are gaps in hospital discharge planning

Percentage of elderly people who experienced a gap in hospital discharge planning, 2016



Note: Gaps include: i) not discussing the purpose of taking each of the medications, ii) not having arrangements for follow-up care with a doctor or other health professional and iii) not receiving written information on what to do upon return home and what symptoms to watch for.
Source: 2016 Commonwealth Fund International Health Policy Survey (data refer to 2016).

There is some evidence of the cost-effectiveness of integrated care interventions. Ensuring that more cost-efficient care is provided through better co-ordination may well support controlling costs (Hofmarcher, Oxley and Rusticelli, 2007[9]). The opportunities to save costs through home-based care and nurse-led health promotion for older people at risk of being admitted to an institution are many, but there is almost no evidence supporting an incremental quality of additional years lived gain compared to normal care. Further, findings comparing costs of an integrated care intervention to costs of hospitalisation are also limited. Comprehensive discharge planning has been seen to reduce costs significantly compared to usual care (reductions of USD 359 in non-US trials and USD 536 in US trials) (Nolte and Pitchforth, 2014[10]).

5.2.1. Improving hospital experience and discharge are important to mitigate health problems for elderly people

For frail elderly people, care transitions between hospital and community services are particularly challenging. Lack of appropriate support can take a toll on an elderly person's health. Many older patients – by some estimates, close to half of patients aged 70 and over – may experience functional decline following a hospital stay. Long hospital stays have been associated with the onset of delirium among older patients, a complication further associated with higher risk of poor outcomes, including institutionalisation, dementia and overall mortality (Suzuki, forthcoming[1]). Staying in hospital longer has also been associated with frailty and a higher risk of mortality, compared with older patients who are not frail, and increases the risk that a patient will develop complications, including hospital-acquired infections. Providing some of the acute care at home or improving the hospital experience is important to preserve the health of elderly people.

Mobile hospital-at-home services can be beneficial for frail elderly people

Bringing hospital services close to home is an innovative way countries have found to fulfil elderly needs for specialised care. Hospital-level care can be provided to patients in their own homes, involving technical care of a more or less complex or intensive nature, without which hospitalisation would be required. This

model applies in one of two cases: as follow-up hospital-level care at home after discharge from a short hospital stay, or as a preventive way to avoid hospital admission when acute care beds are in short supply.

Mobile hospital-at-home services can offer a wide range of health care services: short-term medical treatments in response to acute clinical situations, continuous care in the case of chronic illnesses, palliative care and rehabilitation or functional therapies – all services identical to those provided at the hospital. However, their scope will vary across countries depending on the characteristics of the elderly people in the country and the supply of hospital services (Chevreul et al., 2004[11]). In Canada, for instance, home care services provide complex services such as intravenous therapy and dialysis, replacing acute hospital care while also providing LTC services. In Australia, hospital-at-home services have received strong political support, and laws have been changed to ensure that "private" insurance elderly persons can benefit from them. In the United Kingdom, hospital-at-home services are also quite diverse, varying according to objective (allowing early discharge or avoiding admission), pathology, clinical responsibility (allocated to hospital specialist or general practitioner (GP)) and provision of social services or lack thereof (Chevreul et al., 2004[11]).

Hospital-at-home care may save costs, improve patient satisfaction and reduce the probability of hospital-acquired infections and length of hospitalisation. Those cared for in the scheme tended to have higher satisfaction levels than those cared for in hospital (Shepperd et al., 2016[12]). By some accounts, pilots of the model have helped achieve savings of 30% per admission, for similar outcomes and fewer complications (Klein, Hostetter and McCarthy, 2016[13]). However, evidence on effectiveness and safety is mixed. Literature shows different results around the effect of hospital-at-home care on readmissions and significant differences in mortality (Farfan-Portet et al., 2015[14]). Given the demand for acute beds compared to the number available, hospital-at-home care can also be used as a preventive care model to avoid unnecessary hospital admissions. While previous evidence on the resulting avoidable hospitalisation was mixed, and hospital-at-home care may not have any effect on health outcomes per se, a more recent review shows it can increase the chances of living at home for six months.

Such services require strong co-ordination between the hospital team and health and LTC professionals in the community. For instance, in Portugal, in preparation for hospital discharge, a social worker from the care team conducts an evaluation of the patient's house and assesses the availability of an informal caregiver. Meanwhile, the hospital team (nurses, doctors, pharmacists, social workers and a nutritionist) assesses the patient thoroughly before discharge and provides a dossier including team contact details – available 24/7 – to take home. On the day of discharge, the patient receives a visit from a nurse; the following day, a home visit from the physician. Once settled in at home, follow-up is managed by nurses and personal carers attached to the primary care health centre, who co-ordinate care with the hospital.

There is often insufficient workforce capacity for hospital-at-home care to satisfy demand. The development of hospital-at-home options has been slow, relating in part to insufficient information for health professionals about the potential benefits and value added for patients. In France, health care professionals perceive it as a less attractive sector, with a higher workload and lower remuneration.

Adequate implementation of hospital-at-home care requires adaptations of skills to provide complex care in the home environment. In particular, if this is done by doctors or nurses from hospitals or primary care, such professionals will need to gain new expertise – this requires both new modules during baseline training and continuing education (such as basic training in palliative care, dementia and pharmacological intervention for nurses). Beyond acute care needs, development of hospital-at-home care is also linked to co-ordination with palliative care and end-of-life care services (Farfan-Portet et al., 2015[14]). Physician resistance and time constraints can represent a further barrier. Doctors at times still try to avoid referring patients for home care services as they want to ensure their patients are appropiately cared for. They may also hesitate to refer to such services as it takes time to make a comprehensive screening assessment – it is simpler just to admit patients to hospital (Klein, Hostetter and McCarthy, 2016[13]).

Geriatric knowledge in hospitals delays health deterioration for elderly people

Evidence shows that comprehensive assessment of elderly patients in hospitals can be of significant benefit (Oliver, Foot and Humphries, 2014[15]), but hospitals are not always well equipped to provide frail elderly people with high-quality care. This is particularly problematic for people with dementia, for instance. Many of the behavioural challenges of dementia, which can be exacerbated by distress at being in hospital, can be difficult for hospital staff to manage effectively.

With ageing populations, hospitals are also adapting departments and service lines to meet the needs of ageing patients. In this type of department, nurses are trained in geriatric illnesses and comorbidities. Alongside physicians, the care team includes a geriatric nurse navigator, a social worker, physical therapists and pharmacists when needed. All senior patients are screened for several geriatric conditions – dementia, delirium, dietary problems, depression and risk for falls. A patient identified as vulnerable to any of those conditions receives a thorough work-up and appropriate referrals (Flood and Allen, 2013[16]). Evaluations of special geriatric care units in Australia and Germany suggest that the care received can help to reduce negative outcomes of hospitalisation, including adverse events such as falls and reductions in capacity to perform ADL, though they may not reduce the length of stay in hospital (OECD, 2018[17]) (Deschodt et al., 2016[18]). Mobile interdisciplinary geriatric consultation teams are also used as an alternative to specific units for elderly people.

Belgium has long experience of hospital care for geriatric patients, starting in 1985. Regulations specify that each acute hospital must have either a care programme for geriatric patients or an established a collaboration agreement with another acute hospital offering such programme. Such programmes specify that any patient over 75 needs to be screened using a validated screening tool; if deemed at risk, the multidisciplinary team is consulted. Care programmes for geriatric care in Belgian hospitals are structured around five main components: a geriatric unit, an inpatient geriatric consultation team, an external geriatric consultation function, geriatric ambulatory consultations and geriatric day hospitals.

Another good practice example comes from England, United Kingdom. Many older people are admitted to hospital due to hip fractures, at an average age of 84. This outcome is often associated with frailty, bone fragility and multiple other comorbidities. While evidence-based treatment may be available, mortality at 12 months post admission is around 20%. To tackle this issue, in 2007 standards for management of patients with hip fracture and guidelines were drafted. A national hip fracture database was implemented in 2008, linking it to a national best practice in 2009. By 2013, 30-day mortality had fallen from 10% to 6%, the average overall length of hospital stay had been reduced, and an increased number of patients were leaving hospital having received comprehensive assessments and good preventive interventions (Oliver, Foot and Humphries, 2014[15]).

A number of countries have developed innovative new staff positions and teams working in hospitals to deal specifically with patients exhibiting symptoms of dementia. In Australia, the Dementia Behaviour Management Advisory Service is available in acute hospital settings to help deal with people with dementia exhibiting behavioural and psychiatric symptoms. In Ireland, a dementia nurse specialist role has been developed in acute hospital settings to serve as a link between hospital and community-based services. A similar role has been introduced in hospitals in Slovenia. Specialist mental health liaison teams in the United Kingdom also help to advise hospital staff on recognising and responding to delirium and dementia (OECD, 2018[17]).

One issue potentially impairing the performance of these programmes is the lack of geriatricians. In Belgium, only 28 physicians started geriatric training between 2010 and 2013, well below the minimum number of 80 places planned during those years, and this shortage is expected to worsen in future. There are fewer than four certified geriatricians in the United States per 10 000 75-year-old individuals. In addition, a career in geriatrics is chosen by less than 1% of US medical school graduates (Sorbero, 2012[19]). To tackle this, policy measures are being considered, such as imposing minimum enrolment in

geriatric training and increasing the attractiveness of this speciality (for example, by increasing the number of training places or rewards) (Deschodt et al., 2015[20]).

Proper planning for hospital discharge needs to be well supported to avoid readmission. This often requires a skilled multidisciplinary team that, together with the patient and family, discusses needs and agrees on a post-hospitalisation plan. In Sweden, before an elderly patient can be discharged from hospital (to go home or to a lower-acuity care setting), a physician from the hospital and a case worker from the municipal social services agency must jointly develop a plan to ensure the patient will receive follow-up services. This has enabled the country to reduce the number of patients kept in the hospital once they no longer need high-acuity treatment. In the Netherlands, a recent pilot programme has been developed where community nurses are placed in hospitals to conduct triage and check which patients are eligible for hospital care. If it is not required, the nurses redirect the patient to the right service in the community. When there is a need to attend hospital, the elderly are accompanied by professional aide.

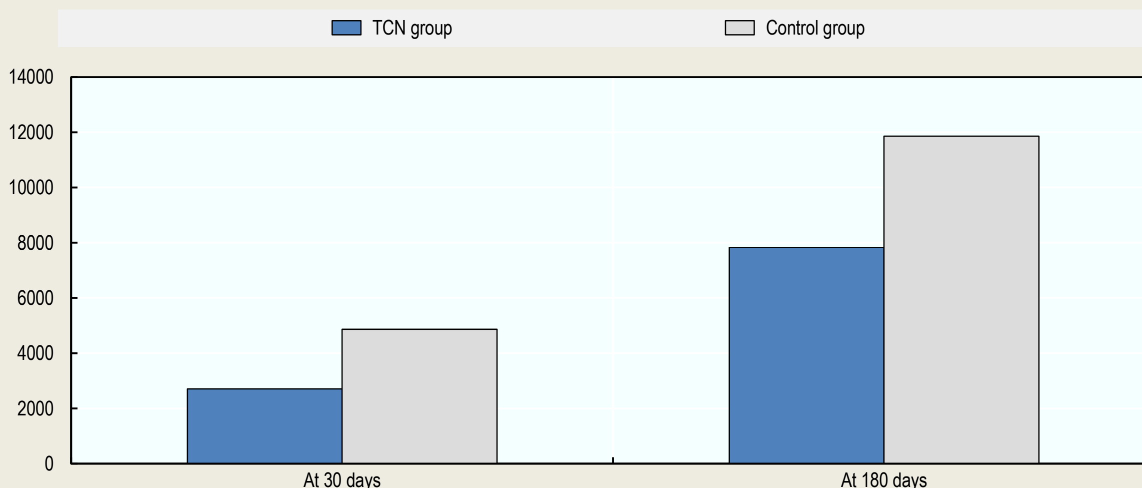
For transfers from hospital care into the community, the transitional care nurse (TCN) model in the United States has shown positive results. An advanced practice nurse or registered nurse supports comprehensive in-hospital planning and home follow-up for patients with multiple chronic diseases and complex therapeutic regimes, through which hospitalised patients receive 4-12 months of post-hospitalisation care. The TCN aims at long-term positive outcomes, ensuring that both patients and family caregivers are equipped with the knowledge and skills to deal with health issues. United States-based research used randomised controlled trials to show that this model improves acutely ill older adults' experiences of care, quality of life, patient safety and health outcomes (Occelli et al., 2016[21]) (Zhang et al., 2017[22]).

The TCN role is different from that of a nurse. In addition to typical nursing skills, the TCN has the competencies to act as a care manager and patient advocate, to manage complex cases and palliative care, to engage actively with family caregivers and to ensure inter-disciplinary care. The TCN does not work in isolation but collaborates with different physician specialists, other nurses, social workers and discharge planners, to name a few of the actors within the health care team. Usually, weekly clinical case conferencing sessions take place with a team of multidisciplinary experts for support in addressing the most complex issues (Box 5.1).

Box 5.1. A successful co-ordination model for complex patients, led by nurses

The TCN – usually an advanced practice nurse – has primary responsibility for ensuring care management of the elderly person throughout episodes of acute illness to avoid deterioration of health status and frequent hospital visits. A patient admitted to hospital is evaluated within 24-48 hours, based on screening and risk assessment. If the patient is eligible, a TCN will be in charge of providing individualised care, based on a tested protocol involving four areas of action: hospital visits, a series of post-discharge home visits, accompanying the patient on first visits to physicians and ensuring continuity of care post-transitional care. Randomised controlled trials on the TCN show significant results for avoidance of hospital readmission and emergency room visits, as well as reductions in total health care costs.

Figure 5.3. TCN's impact on total health care costs (in USD)



Source: Pauly et al. (2018[23]), "Cost impact of the transitional care model for hospitalized cognitively impaired older adults", https://doi.org/10.2217/cer-2018-0040.

5.2.2. Increasing geriatric expertise in the community will smooth care pathways

In addition to co-ordination at the hospital level, good discharge planning requires appropriate care at home or in the community, or sufficient intermediate care options to avoid a risk of hospital readmission in the future. Elderly patients with complex needs that span health and LTC may require an intensity of support that goes beyond what primary care physicians can deliver. For elderly people to stay at home as long as possible and prevent unnecessary hospital (re)admissions, more geriatric expertise in the community is needed. Hospital admission may follow any number of safety incidents, some of which could be avoided. It is estimated that the total cost of avoidable admissions to hospitals from LTC facilities in 2016 was almost USD 18 billion[1], according to an analysis using data from 25 OECD countries. This figure is equivalent to 2.5% of all spending on hospital inpatient care or 4.4% of all spending on LTC (de Bienassis, Llena Nozal and Klazinga, forthcoming[24]).

Several countries are enhancing the collaboration between professionals

A single access point for frail elderly people and co-ordination of services across acute, primary and LTC is important to provide appropriate follow-up for those with complex needs. The World Health Organization (WHO) has proposed the Integrated Care for Older People (ICOPE) approach: a people-centred approach to care that develops a continuum of care services for elderly people, ranging from prevention to rehabilitation (WHO, 2015[25]). This includes shared decision-making and goal setting; support for self-management; multidisciplinary teams; unified information or data-sharing systems; community linkages or integration; and supportive leadership, governance and financing mechanisms.

Several countries and regions have moved ahead in the integration of services or are at different stages of development in different parts of the country. In Scotland, United Kingdom, work has been under way since 2016 to integrate services across health and social care. The Czech Republic has started to integrate health and social care services in the Pardubice region to support individuals with reduced self-sufficiency. Saxony in Germany has introduced standard assessments and treatment pathways for geriatric patients with chronic conditions (EU, 2017[26]). Technological solutions and "continuity nurses" are used in Valencia

in Spain to facilitate treatment for elderly people. Sweden uses quality registers and benchmarking to improve co-operation between home care, primary care and hospital care to better co-ordinate care of the most ill older people.

Evaluation from integrated care models for the elderly shows positive results. The Program of Research to Integrate the Services for the Maintenance of Autonomy (PRISMA) in Quebec provides integrated care for elderly people through a single point of access and a shared clinical file. The case manager, usually a nurse or social worker, performs a basic assessment for autonomy loss, develops a care plan based on the needs of the elderly and family input, co-ordinates care with the primary care physicians, refers to other professionals as required and conducts periodic re-assessments (MacAdam, 2015[27]). The programme resulted in a decrease in the level of functional decline and there were also decreases in costs due to reductions in hospital readmissions and institutionalisation (Béland and Hollander, 2011[28]).

Geriatricians and district or community nurses can be important actors in co-ordination of care. Geriatricians specialise in treating patients with multiple chronic conditions, understanding patient preferences and having the competency to deal with frail elderly people and those at a risk of losing cognitive and functional abilities. Shortages of geriatricians reflect declining numbers of primary care and medical students choosing to study geriatrics. There is a need to incentive such specialisation. Financial incentives could be put in place for studies and establishing practices in the community. The Netherlands has tried to develop more elderly care expertise in the community. Elderly care teams are led by the GP and include an elderly care physician and an LTC nurse or social worker as a case manager. To address geriatrician shortages, some countries are providing exposure for medical students to geriatric medicine or promoting greater scope for advanced nurse practitioners. In the United States, the Medical Student Training in Aging Research is an example of such a programme. Nurse practitioners in Canada, the United States and the Netherlands have been effective in the care of older people and have improved physical function and reduced falls and hospital admission (Chavez, Dwyer and Ramelet, 2018[29]). In England, United Kingdom, district nurses operate in partnership with LTC services to delay and reduce the need for care and support, while also helping elderly people to recover from ill health and manage long-term conditions.

Increasing the expertise of LTC workers to detect health risks and manage health conditions appears promising

The United States has a programme to enhance the LTC workforce: the Health Resources and Services Administration Geriatrics Workforce Enhancement Program. This training programme seeks to integrate geriatrics and primary care models, to address gaps in health care for older adults, to promote age-friendly health systems and dementia-friendly communities, and to address the social determinants of health.

Nurses who are LTC workers can be a key element of enhanced integration between health and LTC services. For instance, LTC home care nurses in the Netherlands are part of the Transitional Care Bridge programme, which is used by 50% of hospitals to provide a smooth post-hospitalisation transition. They are also case managers as part of SamenOud or Embrace model, and provide advice on health conditions, housing adaptation and both health and social care.

Some specialists argue that personal care workers could also be trained in the necessary skills to observe health conditions, offer health coaching and assist in transitions from hospital to home (Osterman, 2017[2]). Personal care workers have the opportunity to observe the living environment, as well as slight changes in medical conditions or functioning that could be important for teams deciding on therapeutic interventions. As such, they can be key partners in the co-ordination of care. They also have the opportunity to observe and shape the home environment, such as by detecting and removing allergens, fall risks and social isolation. There are, of course, pros and cons to task delegation and risks that personal care workers are not well prepared for such roles (see Chapter 3).

Upskilling of personal care workers has been tried in several pilots across the United States with positive results. Additional training includes clinical topics to understand patients' health conditions, navigating transitions in care and supporting health-promoting behaviours. In New York, for the Mount Sinai Hospital Home Care Collaboration Solutions, personal care workers were trained as health coaches in a pilot programme to help improve patient transitions from hospital and to solve caregiving challenges; they also served as links to interdisciplinary teams. Evaluation suggests that the programme may improve patients' performance of health maintenance behaviours, such as diet and exercise, and their ability to manage symptoms, as well as reducing the number of emergency visits (Russell and Kurowski, 2015[30]). The Care Connections Senior Aide programme run by the Professional Healthcare Institute led to an 8% reduction in the rate of emergency department visits (Stone and Bryant, 2019[31]). The Enhanced Home Care pilot programme in California trained personal care workers in medication management, mental health nutrition and physical skills, resulting in better health results – in particular, a 40% improvement in medication compliance and a reduction in patients' unhealthy days (Service Employees International Union, 2014[32]).

Increased staffing of intermediate care facilities is reducing LTC needs and hospital readmissions

In many cases, frail elderly people may no longer require the intensity of care they receive in acute hospital care, but may nevertheless require a level of support they cannot obtain if discharged directly to home. In these cases, intermediate care facilities can offer an important "step-down" alternative to hospitalisation. Intermediate care can also help maintain elderly people's autonomy, focusing on rehabilitation and delivered by a combination of professional groups. Intermediate care beds are available in hospital and community hospital settings, nursing homes, residential rehabilitation units and, more recently, in day hospitals and at home.

There is evidence that using intermediate care following a hospital admission may reduce patients' need for further LTC and hospital services. Intermediate care facilities are intended to reduce avoidable hospital admissions while reducing length of hospital stay (OECD, 2014[33]). In Norway, a study of intermediate care use following hospital discharge found that patients who were transferred to intermediate care (rather than staying in hospital) required fewer days in nursing homes and less health care support at home (Herfjord et al., 2014[34])

There is significant cross-country variation in availability, and countries have moved to increase the capacity of intermediate and step-down care facilities. The 2012 Co-ordination Reform in Norway mandated that all municipalities develop intermediate care units by 2016 (OECD, 2014[33]), providing federal funding to support this. All municipalities have 24-hour care services to provide intermediate, short-term care, although capacities vary across municipalities. Availability of intermediate care facilities is also relatively widespread in the Netherlands, and has been credited with improved patient flow through hospitals and reduced hospital readmission rates (van der Brug, 2017[35]). However, a lack of standardisation means that relative capacity, settings and services can differ (OECD, 2014[33]).

In other countries, intermediate care facilities are not yet sufficient. In Scotland, United Kingdom, intermediate care facilities have been identified as an important approach to delivering care closer to home and reducing delayed discharge from hospital, although the development of new intermediate care beds has progressed more slowly than expected. In Sweden, waiting times to access beds in intermediate care are considered a major driver of delayed discharge from hospital.

Increasing beds in intermediate care facilities requires ensuring that intermediate care teams include staff from a broad range of disciplines. Trained nurses need to perform both care and cure and receive a good level of training, including hospital-based management of medical conditions. In addition, staffing needs include specialists for rehabilitation such as physiotherapists, occupational therapists, speech therapists and rehabilitation assistants, as well as nutritionists/dieticians psychologists and social workers. In addition to recruiting the right staff mix, the workforce needs to have skills to support people to optimise recovery

and regain as much independence as possible. Intermediate care staff will need training to be able to recognise and respond to chronic conditions such as diabetes, mental health and neurological conditions, to support needs in the areas of nutrition and hydration, and to evaluate deterioration in the care recipient's health or circumstances.

In Portugal, a major reform in 2006 contributed to preventing hospital stays and reducing their length (see Box 5.2). Following the reform, the number of public institution beds more than quadrupled to reach 8 400 beds in 2016 in convalescent units, rehabilitation units, maintenance units and palliative care units, up from 1 808 beds in 2007. A similar increase was observed for treatment places, as they went up from 1 660 in 2008 to 6 264 treatment places in 2016 (Lopes, Mateus and Hernandez-Quevedo, 2018[36]). These increases suggest that the reform filled a gap in the coverage of LTC by creating multiple types of care taking into account different care needs and freeing up hospital beds.

Box 5.2. National networks ensure co-ordination between home care and acute care services

In Portugal, in 2006, a major reform took place to create a network providing integrated LTC services: the National Network for Long-term Integrated Care. This aims to integrate health and social care as a way to prevent long stays in hospitals for elderly people, and to have both medical and social services provided under the same umbrella. The network provides integrated LTC at home and in institutions, as well as three types of intermediary care: convalescence beds for intensive rehabilitation for up to 30 days, funded entirely via the Ministry of Health; medium-term beds for between 31 and 90 days, funded by both the Ministry of Health and Ministry of Labour and Social Solidarity; and long-stay beds for care beyond 90 days, funded by both ministries, but with a greater contribution from the latter. In the future, the network will also provide day services to promote autonomy.

Source: 2018 OECD Long-term care interviews.

5.3. LTC workers will benefit from additional skills for integrated care

The lack of collaboration among different stakeholders can also become a burden for patients and families, who are left to manage the schedules of nurses and different specialists (Suzuki, forthcoming[1]). An increased role for case managers and greater integration of LTC workers with other health and social care professionals through use of multidisciplinary teams are avenues to help elderly people navigate the system better. Both require enhanced training for LTC workers and provide opportunities for specialisation and career development.

5.3.1. Case managers improve care pathways for the elderly

Case managers can help alleviate the administrative burden of LTC carers and help co-ordinate their needs and those of care recipient (Box 5.3). A case manager playing the role of a co-ordinator between different health and social services can simplify follow-up procedures significantly for both patient and informal caregivers. Effective case management can reduce the utilisation of hospital-based services, enable a cost-effective approach to cases and improve care outcomes (Ross, Curry and Goodwin, 2011[37]; Roland et al., 2012[38]). With case management, there was an increased use of home and health services which increase the probability of detecting deterioration before the need for acute hospital admission (Eklund and Wilhemson, 2009[39]). Surveys conducted in several countries have shown that case management supports care continuity and can reduce the need for institutionalisation by up to 50% (Paat and Merilain, 2010[40]).

Box 5.3. What is it case management and what does a case manager do?

Case management refers to the service co-ordinating the various system components to achieve a successful outcome. It entails assessment of a person's LTC needs and is followed by appropriate recommendations for care, monitoring and follow-up. Case management's primary goal is service provision for the elderly, not management of the system or its resources. This includes responsibility for referral, consultation, prescription of therapy, admission to hospital, follow-up care and (where necessary) prepayment approval of referred services. It includes responsibility for relocating, co-ordinating and monitoring all medical care on behalf of a patient. Case management essentially aims to limit health costs by reducing the need for hospitalisation and the use of emergency services by high-risk individuals. It is normally organised by case management doctors or nurses, often in consultation with an insurer.

Source: OECD Long-term care questionnaire and missions, 2018.

Case management of LTC for elderly people works differently across countries.

- In Austria, for instance, carers can enrol in local support centres, which put them in contact with a district nurse who assesses the carer's needs and directs them towards appropriate entities and services. Administrative and co-operative tasks are the primary focus of these institutions, but the services also act as brokers and contacts between the elderly and formal services. The aim is to avoid gaps between health and social care provision and empower carers with knowledge and skills to face the difficulties of caring duties.
- Japan created a new profession of LTC managers -which requires a license and a qualification exam- to co-ordinate provision of health and social services care needs for elderly individuals. Care managers carry primary responsibility for ensuring co-ordination of care for elderly individuals with complex needs, and are a first point of contact for such patients and their families. The profession is now highly systematised, with clear qualification criteria and need to renew their licence every five years to assure the quality of services. The role, competencies and responsibilities of care managers are clearly recognised as an important part of the solution to providing better-quality health and social care. Care managers in Japan come from a mix of professional backgrounds (including nurses, dentists and social workers) and their professional association, which has around 25 000 members, offers training, seminars and publications.
- In the Netherlands, the case manager helps care recipients who are no longer independent and have complex care needs. The role of case manager is still being developed, and is currently only implemented to aid those suffering from dementia but is planned to expand to other groups with LTC needs. Main tasks include counselling before and after diagnosis, mapping care needs of the elderly, providing information and advice on diagnosis, prognosis and consequences, co-ordinating care by offering information on processes, motivating elderly people who avoid care, and providing emotional and practical support.

Several countries use case managers to co-ordinate transitions within and between community settings and hospitals. In the large majority of OECD and EU countries, nurses and personal care workers already conduct tasks supporting this role (see Chapter 3). Evidence supports the use of nurses as case managers, as they can improve clinical outcomes and reduce costs. Nurses can co-ordinate care interventions (e.g. via telephone) to monitor conditions of those at risk of hospitalisation and to facilitate communication between and with other health professionals and informal caregivers (Kim, Marek and Coenen, 2016[41])

Case management requires that professionals hold a specific set of skills. Case managers need sound clinical training to identify health needs and design care plans, in consultation with other professionals.

The new bachelor's degree for nurses in the Netherlands incorporates a strong emphasis on enhancing analytical and critical thinking skills, as well as investigative skills. In addition, as part of the care plan, more countries require case managers to improve their skills in educating patients in self-management (Horntvedt et al., 2018[42]). Evidence-based practice is imperative to ensure patient safety. In addition, five core case management activities are assessment, planning, linking, monitoring and advocacy. They are very important to ensure information transfer between different caregivers.

In a few countries, nurses have received specific training in case management. While the module and competency set in the curriculum will depend on the type of case management, some of the areas most commonly found include communication and teamwork skills. Communication skills are an important element in ensuring satisfaction with services and that care is effective. Communication needs to be effective with other providers, but also with the elderly. The case manager needs to oversee follow-up consultations and focus on the care recipient and the family. Elderly people are sensitive to establishing a bond and trust with their case manager. This is particularly the case for patients suffering from multiple comorbidities, who display a need for case managers who help them deal with their emotional needs (Hjelm et al., 2015[43]).

In Norway, while case management is not formalised yet, an important financial envelope was allocated in 2018 to improve nurses' skills in communicating with formal and informal caregivers. Around NOK 360 million are being allocated to developing new competences of the workforce, among others. Nursing education is being revamped to increase improve interprofessional communication skills (formal and informal), manage budgets and use new technologies (such as GPS trackers). The goal is to continue to increase nurses' specialisation – around 18% of community nurses are specialised – and allow them to take on leadership roles.

In Germany, the Community-based support for primary care (or AGnES) care model – nurses acting as case managers when visiting elderly patients at home – provides specific training in case management. AGnES professionals can be qualified nurses or other assistants who have accumulated three years of professional experience; they receive training as a Medizinischen Fachangestellten and received an AGnES qualification. To work as case managers they undertake an additional training module on communication and conflict management. AGnES nurses are also trained to deal with inter-professional and inter-sectoral collaboration (i.e. network and system management, co-ordination and control of aids, quality assurance in case management) and basics for taking a leadership role in care: assessing needs, monitoring and evaluating a patient. The training emphasises the importance of dialogue with other professionals, as most tasks of a case manager relate to supporting co-ordination of appointments with specialists, co-ordinating LTC provision and rehabilitation after hospital stays and co-ordinating services with pharmacists.

5.3.2. Multidisciplinary teams are beneficial in LTC

Integrated multidisciplinary teams can help promote autonomy and reablement and therefore support patients to stay home for longer. These teams way of working involves professionals from different disciplines and with a multitude of skills co-design and co-decide care plans and their implementation instead of working alongside with the elderly. This goes beyond traditional teamwork in health and LTC settings in the way that it assumes integrated decision-making among different professionals. Typically, teams are composed of a set of professionals – e.g. nurses, personal care workers and occupational therapists – and professionals working part time – e.g. doctors, nutritionists and social workers.

Evidence of the impact of multidisciplinary teams working on LTC is limited but shows positive results. Research has shown that integrated multidisciplinary teams can contribute to fewer difficulties in IADL, greater self-efficacy, less fear of falling, fewer home hazards and greater use of adaptive strategies. They can reduce deterioration of health and functional ability, improve daily life activities, increase social

activities, decrease the length of hospital stays and delay readmission. Interdisciplinary teams can also contribute to patients' satisfaction with care (Socha-Dietrich, forthcoming[44]).

Team composition will depend on a number of factors such as care needs and local contexts. In countries like the Netherlands, composition of these teams is regulated by national policies; in others, like Norway, these are decided at the municipality level. The type of professionals in each team will vary depending on care needs, funding resources and availability of workers. It is, however, relevant that the elderly have a voice in deciding team composition. A high degree of rotation of the team members and the number of individuals see in a day can cause distress and make care recipients feel overwhelmed. Geographical misdistribution of health and social workers is one key challenge faced by LTC providers and governments. Rural areas normally face shortages of most qualified and skilled professionals, who may be reluctant to practise in socio-economically disadvantaged regions due to concerns regarding career, family and lifestyle (OECD, 2016[45]). The unequal distribution of professionals between metropolitan areas and rural/remote areas is one of the biggest workforce challenges in Australia.

There is some positive but still weak evidence of the impact of team training on the performance of multidisciplinary teams. In many instances, it is up to employers to ensure that teams work in an integrated manner (Buljac-Samardžić, 2012[46]). They enforce this by providing tailored theoretical or on-the-job training. Data collection from visits to a few nursing homes and home services companies in Norway, the Netherlands, Portugal and Germany shows that current themes for such training include understanding team dynamics, grasping the structure of multidisciplinary interventions and learning how to communicate in a team.

The United States, for instance, has been successful in operationalising fully integrated inter-professional teams at the primary care level, taking care of elderly patients with complex care needs. A number of managed care organisations have created inter-professional teams including primary care physicians, specialty trained nurses (for example, in diabetes), registered nurses, dieticians, speech therapists and social workers. Some of these teams comprise liaison community health workers responsible for outreach to underserved groups, such as indigenous populations, ethnic minorities or people with financial/housing difficulties. Recent developments within the integrated health systems and organisations show a trend towards further specialisation of inter-professional teams in care for specific groups of high-need patients. For instance, the Commonwealth Care Alliance launched a Senior Care Options programme, which provides primary care to elderly patients with complex needs through teams including geriatric social workers and palliative care clinicians, among the other usual categories of primary care professionals. Other inter-professional teams with a similar focus (for example, Community Aging in Place, which is active in 12 large cities) also include a handyman, who allows the team to make home modifications, helping elderly patients to navigate their homes more safely (Socha-Dietrich, forthcoming[44]).

5.4. Informal carers are also key actors in LTC services

In all OECD countries, both formal and informal caregivers provide LTC. Given the potential shortage of LTC workers, facilitating the work of carers and collaboration between formal and informal carers is essential. A move away from institutional care towards community-based care will require better integration of informal carers – whether family carers or other informal networks and associations – into the care team, and better support and compensation of informal carers so that they do not feel overburdened.

The role of formal care workers cannot be considered in isolation from informal care provision, and appropriate policies need to be in place for both types of worker to provide care that is more effective. Many countries rely heavily on informal carers to provide help to elderly people and are expanding formal care provision. Others are considering enhancing informal care, given financial pressures or difficulties with expanding the formal workforce. At the same time, co-ordination between formal and informal carers

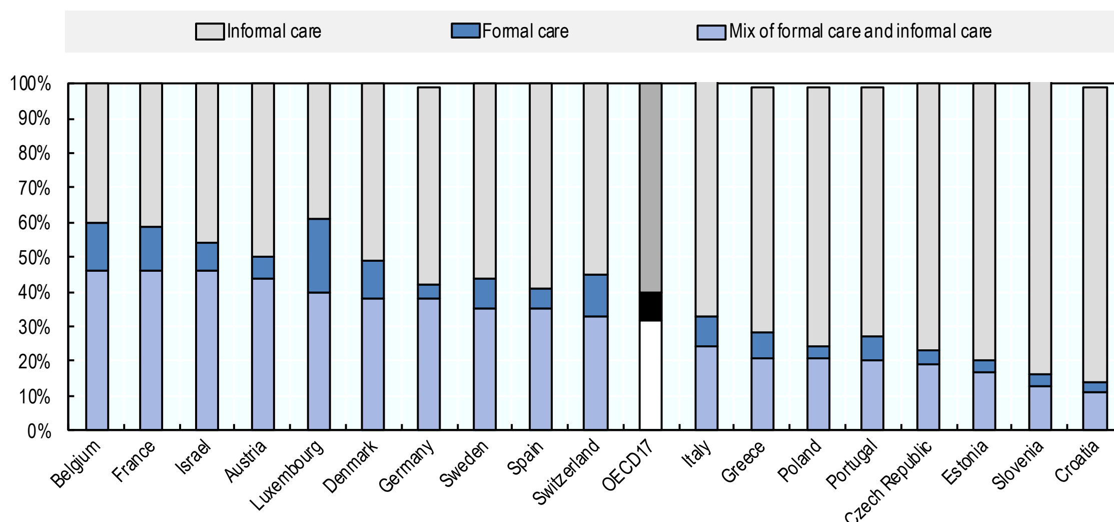
ranks low as a priority for countries. Less than half of OECD countries (45%) have implemented policies to strengthen co-ordination between formal and informal LTC workers.

This section analyses challenges that arise in co-ordinating informal and formal care workers. It suggests appropriate policy solutions to improve co-ordination, mainly in the area of incorporating informal carers as part of the care team and policies to improve the skills of informal carers and compensate them. Without better support, informal carers may be unable to sustain their care efforts, are more likely to have health problems themselves and may resort to emergency hospitalisation for their loved ones.

5.4.1. Changes in guidelines and incentives for formal carers can foster collaboration with informal carers

An average of 30% of people age 65 years and over receive both formal and informal care across OECD countries, ranging from as low as 13% in Slovenia to as high as 46% in Belgium. Care is shared between paid health care professionals and unpaid family caregivers (Figure 5.4). Coexistence of formal and informal care is more common in situations of greater need when both types of care become complementary (Litwin and Attias-Donfut, 2008[47]).

Figure 5.4. Receiving informal care alone is predominant but 30% of elderly people receive both formal and informal care



Source: OECD calculations based on the Survey of Health and Retirement Survey in Europe, wave 6 (data refer to 2015). The OECD average is unweighted.

Both types of care can either substitute for or complement each other, depending on the country and availability of various forms of formal care. Findings from the United States suggest that increased paid home care primarily went to people who were already receiving a greater amount of informal care from their adult children (Liu, Manton and Aragon, 2000[48]; Langa et al., 2001[49]). In Europe, informal care tends to be a substitute for formal home care and paid domestic help, and more informal care exists in countries where there is a lack of formal care (Van Houtven and Norton, 2004[50]; Bonsang, 2009[51]; Bolin, Lindgren and Lundborg, 2008[52]).

Formal and informal carers work in parallel and perform different tasks

Informal and formal caregivers are often dissatisfied with their collaboration. Formal caregivers may fail to recognise the contribution of informal carers and do not view them as partners in a shared care arrangement. This can result in informal carers being excluded from treatment decisions and care planning. In turn, formal care workers complain about being watched or asked to perform tasks that are beyond their duties (Sims-Gould et al., 2015[53]). This affects the satisfaction and turnover of formal caregivers (Carpentier and Grenier, 2012[54]).

There is scope for clarifying tasks and strengthening collaboration from the outset. Informal caregivers can provide help with IADL, while they may find provision of help with ADL – especially certain ADL such as hygiene, incontinence and cognitive impairments – more difficult, requiring help from formal carers.

Informal carers perform a variety of tasks, although the core of their activities is help with IADL or household care and emotional support. The majority of informal carers are heavily involved with practical care tasks or household care work: important IADL, such as shopping, cooking and doing laundry. Another task that falls to informal carers is administrative help, such as paying the bills. Large numbers of informal carers have a key role in providing company and emotional support, such as "keeping an eye" on the care recipient and making sure they are safe. In contrast, fewer informal carers perform personal care tasks and administer medication (Wanless, 2006[55]).

Roles and responsibilities of informal caregivers will become more complex and demanding. With delayed institutionalisation and higher numbers of elderly people staying at home with complex needs, especially with dementia, informal caregivers will have growing responsibilities and are likely to provide more tasks such as personal care and specialised medical care, including injections. It is also likely that they will become surrogate decision-makers for relatives who have suffered from physical or mental decline (Arber and Venn, 2011[56]). More frequent interaction should lead to a different collaboration, in which formal carers are trying not to fill gaps but to support informal carers in performing their tasks (Janse et al., 2018[57]).

Training and guidelines for formal care workers can improve collaboration with informal carers and efficiency in delivery

Collaborating with informal caregivers will require professionals to adopt a different way of working, in many instances. The current focus is mainly on the care recipient for whom they care, and not on the informal carers of the care recipient, even though they are an invaluable source of information about the needs of an elderly person. There is therefore a strong rationale to recognise the role and tasks performed by both formal and informal carers.

A way forward in the collaboration would be to include a training module for professional carers on how to work with informal carers. Research from the Netherlands concludes that such a module should be included in the curricula of allied health, nursing and social work education, and that similar training courses could be developed for the continuing education of personal care workers (Hengelaar et al., 2018[58]). Other forms of training suggested in Canada include case management conferences or in-service training sessions involving families, workers and managers, to gain shared understanding of the scope of the role and clear mechanisms for communication and conflict resolution (Sims-Gould et al., 2015[53]).

Regular communication between formal and informal carers is not always facilitated by current service provision. Professional care has a great deal to offer informal carers, such as advice, guidance, skills training and sharing of knowledge. Equally, professional carers benefit from good communications with the family caregiver. Rapid staff turnover and having different care providers with insufficient relays between them are obstacles to smooth collaboration. A permanent contact person, such as a case manager, might improve collaboration (Stephan et al., 2015[59]).

Informal carers are an indispensable but vulnerable link in the care chain, and more countries are seeking to give them stronger input into care. This includes consulting informal caregivers during creation of the care plan and directing them to available services (Jorgensen et al., 2010[60]). In the United Kingdom and Sweden, for instance, informal carers are entitled to a carers' assessment separate from the care recipient, and should be eligible for appropriate support services afterwards. In Finland, the law specifies that the informal carer must be able to provide care as certified by a GP through a health check. The new Care Plan in Norway notes that agreements made with family members and volunteers should be recorded in the case files and individual plans, both to co-ordinate these efforts with public care services and to assess relevant measures relating to training, guidance and relief from the caregiving burden.

Certain countries have started, as part of integrated care, to include informal carers as part of the care team. In Australia, for instance, informal carers have access to shared care planning tools. In Flanders, Belgium, the Informal Care Plan was adopted by the Flemish Parliament on 1 February 2017. The informal caregiver becomes a partner in the care and support plan, and professional care providers are encouraged to involve informal caregivers and respect their role in the care process and, where necessary, in care co-ordination. This will be further reinforced by planned modifications to the decrees on primary care, mental health care, local social policy and residential care, which should include the principle that the informal caregiver is a fully fledged partner in care.

5.4.2. Training and emotional support will help informal carers to perform their tasks better

Informal carers are the backbone of the system in many countries, yet they receive little training and psychological support, which results in lower quality of care. Psychosocial interventions have a positive impact on carers' well-being and mental health (Larkin, Henwood and Milne, 2019[61]).

Many informal carers request skill-building and LTC knowledge training

Because caregivers often experience anxiety and insecurity, and feel unprepared for their role, education and skills training can improve caregiver confidence. According to Eurocarers, training in the following skills is particularly useful: disease-specific knowledge; skills required to maintain the health status of the patient and, if possible, facilitate rehabilitation; skills to deal with management of symptoms; skills related to daily life activities; and management of emergency situations (Eurocarers, 2015[62]). Some practical nursing skills – mainly managing and administering medication, pain management and moving and handling techniques without suffering strain – are also needed.

Availability of training services is fragmented across OECD countries, and is often provided by civil society. Take-up tends to be low because training is not necessarily available nearby, there is a lack of information and carers do not always have the time to attend (Eurocarers, 2015[62]). One fruitful avenue is including formal care workers in the delivery of training, which can also help them understand better the challenges faced by carers (Johannessen, Engedal and Thorsen, 2016[63]; Eurocarers, 2015[62]). A training programme that is flexible for informal carers and contains a mixture of face-to-face learning and e-learning might also help.

More training and certification for informal carers will not only help them to improve the quality of care but will also assist with transferability of skills. For those carers who are interested in pursuing employment in the health and community services sectors, given the variety of skills they may have developed, it is important that they are able to supplement gaps and standardise their knowledge and ability.

Psychosocial interventions and counselling have also proved to have a positive impact on carers' capacity to deliver care. Addressing emotional strain by providing coping strategies such as self-care, stress management, problem-solving and decision-making guidance are fruitful avenues to reduce caregiver stress and improve quality of care (Brimblecombe et al., 2018[64]). Building carer resilience with techniques

for coping with demands, relaxation and reducing isolation through peer support are also valuable interventions (Larkin, Henwood and Milne, 2019[61]; Brimblecombe et al., 2018[64]). Examples of such interventions include, for instance, the municipal learning and mastery centres in Norway, which offer mastery courses to close family members to help them cope with their everyday lives.

Improved carer well-being strengthens their ability to care

The association between informal caring and poor health outcomes is well documented across studies (Thomas et al., 2015[65]; Stansfeld et al., 2014[66]). Caregivers are much more likely to report poorer subjective quality of life than similar adults who do not care for family or friends (Thomas et al., 2015[65]). Further, caregiver burden and ill health have also been associated with worse health outcomes for their care recipients. Higher caregiver burden has also been associated with a higher prevalence of falls among care recipients (Vaughon et al., 2018[67]).

Respite care, which is designed to offer caregivers a break from their regular duties, is often cited as an important component to ensure that carers can continue to care. Some respite care services are designed to offer short-term, often regular, breaks in care. These often included day care services delivered through municipalities and community organisations, or in-home care services. In addition to such day services, some countries offer caregivers the opportunity to take longer breaks from caring by offering temporary placements in residential care services, such as local nursing homes. Emergency respite care services, which offer caregivers respite at short notice, are less regularly available, although a number of countries have recognised the need to develop these programmes.

While many countries have overnight respite care services, their availability can vary greatly by municipality or local community. Overnight respite care is commonly provided by offering temporary residence in local nursing homes or other LTC institutions. Many municipalities have developed agreements with local nursing homes to use a designated number of beds for respite care, but availability can vary substantially by community. Co-ordination with formal carers is important to avoid the condition of care recipients, especially those with dementia, suffering a setback when they are taken away from their familiar environment.

Because of the high cost of providing respite services, some countries have determined legal maximums for the number of days carers may receive overnight respite care services. In New Zealand, respite care is funded to a maximum of 28 days per year, while in Israel, no more than two weeks are reimbursed. Few countries have made access to overnight respite care a right for informal carers, although Germany offers legal entitlement of six weeks per calendar year for respite care and eight weeks for short-term care, for which families can be reimbursed up to a fixed amount.

Innovative respite care services are also necessary to include either holiday breaks or mobile respite services at home. In Austria, a holiday respite care programme for people with dementia and their families integrates external care for people with dementia and training for carers into a holiday for the family. The municipality of Lyon is currently experimenting with respite care at home, although it tends to target mostly carers of people with disabilities. Mobile respite teams evaluate informal carers' needs and health, and provide appropriate solutions to reduce burnout, collaborating with health professionals and associations.

Although carers show satisfaction with breaks, there is little quantitative evidence of improvements to carers' emotional well-being and the cost-effectiveness of respite. Several meta-analyses show no evidence of the impact of respite on physical and mental health (Brimblecombe et al., 2018[64]). On the other hand, other research shows that respite care enabled 50% of carers to have more time for themselves, and that the health of those without access to respite care deteriorated more rapidly (Yeandle and Wigfield, 2012[68]). Part of the lack of evidence may be due to the lack of high-quality research in this area and the short-term services, which only offer temporary relief.

5.4.3. Compensating carers well and addressing their double burden will ensure more sustainable care

Individuals do not provide care in isolation from the other roles and responsibilities in their lives. Estimates from the Survey of Health and Retirement in Europe show that informal carers are less likely to work when providing care to a spouse. Across Europe, 45% of men aged 50-64 work if they are caring for their spouse, compared with 60% of those who are not carers; the equivalent figures are 34% and 52% for women. Quality of care requires reducing the double burden and stress of combining work and care by providing more flexibility at work – not only care leave but also the right to reduced working hours and flexi-time.

An effective contribution for informal carers also necessitates cushioning lifetime income losses. This could be done through either appropriate compensation when carers leave work or recognition of the role of carers with entitlements to pension rights and subsidies for social security contributions.

Informal carers need to balance work and caring responsibilities

Balancing the dual responsibilities of working and caring is difficult, but leave and flexible work can help. Informal carers in OECD countries have a 20% higher prevalence of mental health problems than those who do not provide care (Colombo et al., 2011[69]) and also tend to have worse physical health. Intensity and duration of care tend to lead to worse outcomes. Informal care also reduces the likelihood of being in paid employment because of the hours of work, and leads to higher chances of sickness absence. Care leave tends to limit the negative impact of caring on employment, especially in combination with flexible working conditions (Brimblecombe et al., 2018[64]).

Across OECD countries, there is growing commitment to support informal carers combining work and caring. Three-quarters of countries (30 countries) provide some rights to leave to care for a family member – either paid or unpaid – up from two-thirds of countries 10 years ago (Table 5.1). Currently, 19 countries offer some form of paid leave for caring, and four introduced paid care leave in the past decade.

However, in most countries offering paid leave for informal carers, it is only available for a limited duration – in most cases less than two weeks. Paid leave is also sometimes tied to an employee's sick leave allowance. Both Israel and New Zealand deduct time spent caring for sick family members from the carer's own allotted sick leave. In the Netherlands and Spain, employers are allowed to refuse requests for care leave if there is a strong business case for doing so. A number of countries have criteria based on employer size (Ontario, Canada, and the United States) or employment history (Canada, Ireland, New Zealand, the United States) that can exclude some carers from eligibility.

Care leave is still seldom used, through lack of awareness or fear of sending a negative signal to the employer, or because it is not adapted to the needs of the employee. Use of formal care leave arrangements is often limited, and caregivers prefer to use holidays or sick leave, or make individual arrangements with their supervisors (Colombo et al., 2011[69]; Oldenkamp et al., 2018[70]). Carers are often unaware of leave options, particularly those with lower education levels, and the opportunities available do not always match carers' needs. Formal care leave arrangements are more often used in cases of high intensity and burden of care, but when caring responsibilities are prolonged, they may be insufficient. While unpaid leave is often much longer, carers may be unable to afford such periods without income.

Programmes that allow for more work flexibility, including reducing hours and teleworking, may be better suited to supporting carers. Flexible working hours are critical to sustain the combination of work and caring, lower the chance of reduced working hours and increase employment prospects (Arksey and Glendinning, 2007[71]). In the United Kingdom (England), for example, all employees – including carers – may request a flexible working arrangement after an initial 26-week qualifying period. In Germany, a family care leave scheme was recently introduced for employees needing to support a relative with LTC needs. Employees may take up to six months off full-time work, or elect to work part time. Three months of leave is provided when caring for relatives at the end of life. In addition to the leave provided, employees have

the opportunity to access interest-free loans (conditional on employer size) to help support them while their income is reduced.

Table 5.1. More countries have leave entitlements to care for the sick than ten years ago

Country	Pension credits	Leave for carers	Paid leave available	Duration per year
Australia	–	Yes	Yes (100% of earnings)	10 days
Austria	Yes	Yes	Yes (100% of earnings)	1 week
Belgium	No	Yes	Yes (flat rate)	12 months per episode
Canada	–	Yes	Yes (for family members at risk of dying in the next 26 weeks; for employees who have worked ≥600 hours in the past year; 55% of earnings) Yes, family caregiver benefit for adults	Up to 26 weeks up to 15 weeks
Chile	–	–	–	–
Croatia		Yes	Yes (for spouse; 70% of earnings)	20 days per episode
Czech Republic	Yes	Yes	Yes (60% of earnings)	9 days
Cyprus	No	Yes	–	7 days
Denmark	Yes	–	–	
Estonia	–	Yes	Yes (80% of earnings)	7 days per episode
Finland	Yes	Yes	Unpaid but can depend on collective agreements	
France	No	Yes	Paid for terminal illness (payment for 3 weeks)	3 months
Germany	Yes	Yes	No but can receive short-term carer grant	6 months
Greece	No	Yes	–	6 days
Hungary	No	–	–	–
Iceland	–	–	–	–
Ireland	Yes	Yes	Yes (for close family member, when employee has worked for ≥12 months)	3 days
Israel	–	Yes	Yes (for spouse or parent)	6 days
Italy	Yes	Yes	Yes (100% of earnings)	2 days over their working life
Japan	–	Yes	Yes (40% of earnings)	93 days over their lifetime
Korea	–	Yes	–	90 days
Latvia	Yes	–	–	–
Lithuania	Yes	Yes	–	–
Luxembourg	Yes	–	–	–
Mexico	–	–	–	–
Netherlands	No	Yes	Yes (although employers can refuse "on serious business grounds"; 70% of earnings)	10 days
New Zealand	–	Yes	Yes (for employees who have worked for ≥26 weeks; 100% of earnings)	5 days taken from sick leave
Norway	Yes	Yes	–	10 days per episode
Poland	Yes	Yes	Yes (80% of earnings)	14 days
Portugal	–	Yes	–	15 days
Romania	–	No	–	–
Slovak Republic	–	Yes	Yes (55% of earnings)	10 days
Slovenia	Yes	Yes	Yes (for co-resident family members; 80% of earnings)	7 days (maximum 6 months if severely ill)
Spain	No	Yes	Yes (although employers can refuse on "serious business grounds"; 100% of earnings)	2 days
Sweden	No	Yes	Yes (80% of earnings)	100 days
Switzerland	–	Yes	–	–
Turkey	–	–	–	–
United Kingdom	Yes	Yes	–	–
United States	–	Yes	–	12 weeks

Source: OECD Family Database 2016 for leave; information on pension credits from Hamilton and Thomson (2017[72]), "Recognising unpaid care in private pension schemes", https://doi.org/10.1017/S1474746416000312.

In designing care leave for the future, countries need to balance the rights of working carers with eligibility conditions. Identification of who is the primary carer and the number of hours of caring are important when establishing entitlements to prevent an abuse of care leave. Similarly, a fine balance needs to be found between the amount of compensation and the length of leave to prevent the risk of early retirement or falling into a long period of inactivity, which would limit re-employment options.

Career loss compensation provides a forward-looking vision for carers

The majority of OECD and EU countries (two-thirds) provide care recipients with cash benefits for the person in need of care to support informal care, rather than supporting the informal carer directly (Table 5.2). While some countries require that care recipients make a formal contract with their caring relatives, most countries do not control what care recipients do with those cash benefits. A smaller number of countries support the informal carer directly financially – for example, Austria and the Netherlands. Finland and Belgium (Flanders) support informal carers in both ways, while Flanders and France support only care by adult children (care by spouses is not directly financially supported).

Table 5.2. Most countries have cash benefits for informal care

No support	Support the care recipient	Support the informal carer
Sweden	Belgium (Flanders)	Australia
Japan	Bulgaria	Austria
France (spouse)	Croatia	Belgium (Flanders)
Belgium (spouse)	Czech Republic	Canada (Nova Scotia)
Lithuania	England	Estonia
	Germany	Finland
	Finland	France
	Iceland	Hungary
	Israel	Ireland
	Italy	Netherlands
	Korea	Slovakia
	Latvia	
	Luxembourg	
	Netherlands	
	Poland	
	Portugal	
	Spain	
	Slovenia	
	United States	

Source: OECD Long-term care questionnaire.

Cash benefits for the care recipient include a number of benefits and drawbacks, especially from the point of view of informal carers. Cash benefits are used in several countries as a way to provide choice and flexibility for recipients and encourage care by a relative, which is often a preferred option. Such benefits avoid difficulties in identifying carers, which simplifies eligibility requirements and makes the financial contribution depend on needs. On the other hand, the benefit does not always go to the carer, leaving them dependent, and trapping informal caregivers in a low-paid role.

Carers are at risk of financial penalties with respect to accumulated retirement income for their second-tier pension (i.e. mandatory, contributory public or private savings for income replacement in old age) because of lower workforce participation. OECD countries have created “carer credits” for those with interrupted workforce histories, which take the form of an amount of time credited to the carer’s working record. To avoid those with fewer years of contributions receiving a lower pension, the government provides a credit

to their contribution record or reduces the required balance for a full contribution record. Carer credits can also be in the form of a financial credit to the pension account.

The social protection rights of informal carers for pension credits have improved by making credits more generous in value or duration and extending the rights. In Germany and Luxembourg, an increasing number of caregivers benefit from pension contributions. In Germany the value of the credit depends on the type of benefits and the constituting care level. It may reach 100% of the average wage, and caregivers are entitled to payment of pension contributions if they are not gainfully employed for more than 30 hours of care; they are also covered by unemployment and accident insurance. In Finland, France and the United Kingdom, credits have become easier to access (Hamilton and Thomson, 2017[72]). There is still a challenge in improving retirement income for women on low pay and those in precarious work, and in compensating those who work part time for care reasons with top-up credits, for instance. In addition, with the growing importance of occupational pensions, carer credits in mandatory private pension schemes will be needed because credits tend to be available for childcare only, with a few exceptions. Only in one country – the United Kingdom – do employers continue to contribute to the occupational pension on behalf on an employee during periods of care. In Sweden, while this is not mandatory, employers are encouraged to do so and most comply (OECD, 2011[73]).

Cash benefits and pension credits can alleviate poverty for families, but there are several reasons why governments would prefer to limit the generosity of cash benefits to carers. First, the benefit rarely constitutes remuneration for carers' full efforts and does not typically cover the full cost of care. It is rather a recognition that providing care involves costs for carers and compensation for the opportunity costs of caring – that is, for reduced working hours. Second, high compensation risks trapping carers in low-paid roles, with few incentives to participate in the formal labour market. Appropriate compensation for carers needs to be balanced against the potential side-effects on the labour supply of carers, acting as a disincentive to gainful employment. Previous analysis showed that carers' allowances can discourage work for low-skilled workers, especially if they are means-tested (Colombo et al., 2011[69]).

5.5. Conclusion

Improved co-ordination will require appropriate financial incentives and information-sharing mechanisms. Payment systems for complex patients need to be redesigned so that they reduce barriers to collaboration. Current funding mechanisms and payment incentives often exacerbate the problems of fragmented care. Integrated LTC budgets may also help to overcome co-ordination issues if decision-making power on funding allocation is spread across different levels of government and different ministries. In Portugal, the integrated care network receives funding from both the Ministry of Health and the Ministry of Social Protection. Funding is set for all professionals who are either part of local health units providing care at home or intermediate care facilities. In Scotland, United Kingdom, integration authorities are responsible for the governance, planning and resourcing of social care, primary and community health care and unscheduled hospital care for adults. It is important that workers treating an elderly person with complex needs are able to share important data about that patient in a timely way. A single electronic record, as used in Quebec for PRISMA for all the patient's medical care, will also facilitate the process.

The elderly would also benefit from a closer coordination across formal and informal carers. Part of this would necessitate a broader outlook in the care plans to include informal carers and ensure a sharing of tasks. In addition, informal carers will need a range of services to improve their wellbeing, compensate from their costs out of work and training options to enhance their roles as carers.

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Note

[1] USD 17 740.5, Millions, Current prices, current PPPs.

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