Module 1- Recognising and Supporting Informal Carers

Module 1 Introduction

This module introduces participants to the context of long-term care in Europe, with a focus on the differences between formal and informal care and types of services available on national level in each partner country. It highlights the demographic trends leading to the increasing need for care, and the reliance on family members to fill existing gaps in national care systems.

The module also explores the impact of informal caregiving on various aspects of individuals' lives, such as physical and mental health, employment / professional development, recognition and training, and economic stability. By combining theoretical content with interactive activities, the module aims to raise awareness among managers, employers and HR specialists, encourage reflection and help build practical strategies for supporting informal carers.

Learning objectives

The learning objectives of this module are:

- To understand the distinction between formal and informal care.
- To gain awareness of the limitations of existing formal long-term care services in partner countries.
- To gain awareness of the demographic changes that lead to growing demand for long-term care.
- To understand the importance of community-based services and of family in long-term care and why informal long-term care in necessary.
- To recognise the challenges faced by informal carers in terms of employment, physical health, emotional wellbeing, and financial stability.

- To explore the positive aspects of caregiving, such as personal fulfilment and skills development.
- To identify ways in which employers, managers, and HR professionals can support employees with caring responsibilities.

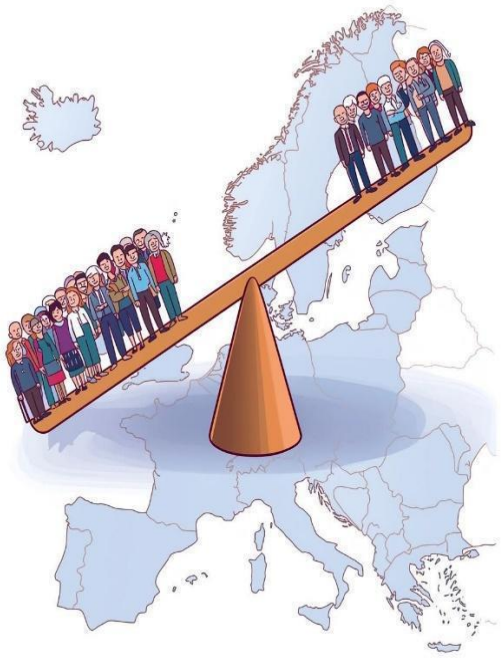
Unit 1.1: Long-Term Care: A General Overview

This unit provides a general overview of long-term care (LTC) in Europe, placing the topic within the broader demographic, social, and economic context. The unit begins by examining the demographic crisis in Europe driven by population ageing, together with its social, economic, and health-related consequences. It then highlights national trends in partner countries, with examples from Romania, Cyprus, Greece, Spain, and Italy. Next, the unit addresses the growing care needs of vulnerable populations, focusing on older people who increasingly experience chronic illnesses and limitations in daily activities. Then it addresses the distinction between formal and informal long-term care, and the limitations of current formal care systems, particularly regarding availability, affordability, and quality, which often lead to increased reliance on informal care. The latter is also an important topic addressed by this unit, with a focus on the essential role of family caregivers and the challenges they face in the absence of adequate recognition and support.
Finally, the unit concludes with interactive activities that encourage participants to reflect on the importance of LTC and to engage with realistic care scenarios.

Theoretical Content

Demographic Crisis in Europe

Advances in healthcare and technology in recent decades have led to the demographic phenomenon of population ageing, with individuals aged 65 and above growing in number and even outnumbering younger people.



Eurostat (2024a) defines demographic ageing as **the shrinking proportion of people of working age in the EU alongside the expansion of the older population**.

- The population of older people in the EU-27 is expected to grow from 90.5 million in 2019 to nearly 130 million by 2050 (Eurostat, 2020).
- Life expectancy has increased, but healthy life expectancy has not kept pace: in 2022, the number of healthy life years at birth were 62.8 years for women and 62.4 years for men, indicating that most of the later years of older individuals tend to be lived with activity limitations (European Commission, 2024). This demographic trend has broad social, economic, and

healthcare consequences, requiring adaptation of care systems to ensure good quality life for older populations.

Social consequences

- The growing number of older persons will result in **more single-person households** and, consequently, a **higher risk of social isolation**.
- Between 2015 and 2024 the number of single-adult households in the EU increased by 16.9%, compared to 5.8% growth in all households (Eurostat, 2024b).
- In 2024, nearly **one third of people aged 65 or older in the EU were living alone**, highlighting the increased vulnerability of older adults to social isolation and loneliness (Eurostat, 2024b).

This trend will reshape community structures and increase the need for both formal and informal support.

Economic consequences

- The **shrinking active population** will put pressure on labour markets and productivity.
- The **old-age dependency ratio** in the EU rose from 27.7% in 2013 to 33.9% in 2024, meaning there are already fewer than 3 people of working age for every person aged 65 and over (Eurostat, 2024c).
- Projections show that by 2100 the old-age dependency ratio may reach 59.7% placing **unprecedented strain on pension systems and public budgets** (Eurostat 2024c).

Health and care-related consequences

- Demand for health and long-term care services will also rise (Houggard Jensen, Pinkus & Ruer, 2024; OECD, 2025).
- At the same time, **shortages of qualified personnel** in these systems are expected to intensify (Eurofound, 2020).
- The share of people aged 85 and above – the group most likely to require intensive care - has already reached almost 3% of the population in 2022 and it is projected to double in the next decades (Eurostat, 2024d).
- **Chronic diseases** and **age-related disabilities** will therefore become major challenges for both healthcare providers and informal carers (Daly, 2025).

Policy implications

Governments will need to adapt pension, healthcare, and social care systems to these new realities. This will require:

- Stronger policies to promote active ageing (preventive healthcare, promotion of physical activity, healthy diets, lifelong learning programmes etc.) (Malley & Zigante, 2025).
- Greater social inclusion through measures aimed at reducing loneliness and isolation among older adults (e.g. intergenerational programmes, age-friendly communities etc.) (Eurofound, 2024).
- Digitalization of healthcare and social services in order to improve accessibility and reduce exclusion among older people (e.g. telemedicine, electronic health records, online appointments, online platforms for applying for social support, etc.) (World Health Organization, 2021).
- Labour market adaptation in order to keep older workers longer in employment (e.g. incentives such as flexible contracts, part-time opportunities) combined with anti-age discrimination measures (Eurostat, 2020).
- Pension system reform by gradually adjusting retirement ages in line with life expectancy and promoting private pension schemes (OECD, 2023).

- Formal recognition and support for informal caregiving, which remains a crucial component of long-term care provision (financial compensation for carers, carers' leave and flexible working arrangements, respite services, training and counselling for carers etc.) (Costa-Font & Vilaprana-Pietro, 2025).
- Investment in formal care (in long-term workforce, improving working conditions, integrated care models, public-private partnerships in LTC, use of technology in care etc.) (Barber et al. 2021; Cés & Coster, 2019).
- Community-based care models which are less costly and more sustainable than institutional care models.

National Trends in Partner Countries

Romania

- In 2024, 20% of the population was 65+ (Eurostat, 2025c).
- The 65-79 age group increased by 34% between 2001 and 2024, higher than the EU average.
- The age group 80 years and above presented the second highest increase at EU level, representing 144.4% compared to 79.4% for EU27 (Eurostat, 2024e).

Cyprus

- In 2024, almost 18% of the population was aged 65 or older (Eurostat, 2025c).
- By 2060, almost 32% of the population will be 65+ (Trading Economics, 2024).
- Disability-free life expectancy is 62.4 years for women and 62 years for men, close to the EU average (Eurocarers, 2023).

Greece

- In 2024, 23.3% of the population was 65+ (Eurostat, 2025c)
- By 2050 the proportion of Greeks aged 65 or older will exceed 32%, leading to an inevitable demographic crisis (Pavlopoulos & Rachiotis, 2024).

Spain

- In 2024 20,3% of the population was 65 years old or over (Eurostat, 2025c).
- By 2035 the life expectancy at birth will be 83.2 years for men and 87.7 years for women (Instituto Nacional de Estatística, 2022).

Italy

- In 2024, 24,3% of the population was 65 years old or over (Eurostat, 2025c).
- It has one of the highest ageing indices worldwide: in 2023, for every child there were nearly 6 older people (Istituto Nazionale di Statistica [ISTAT], 2023).
- By 2023, the old age index reached 200% (Istituto Nazionale di Statistica, 2025).

Growing Need for Care in Vulnerable Populations

Older people are more likely to experience chronic illness, functional limitations, and challenges in self-care routines (e.g. bathing, dressing, eating, using the toilet, etc.) or in carrying out activities of daily living (preparing meals, shopping, taking medication, going to the doctor, etc.) (Cleveland Clinic, 2024).

Due to the increasing number of people in the "fourth age" (80+) the care demands have also intensified.

Statistical evidence

- Across the EU, in 2018, almost half of the people aged 65 and over reported difficulties with at least one personal care or household activity.
- 46.6 % of the EU's older population with an increased difficulty in personal care or household activities reported a lack of assistance with those activities (Eurostat, 2022).

- Almost 30 % of the EU's older population with difficulties in personal care or household activities used home care services for personal needs (Eurostat, 2022).

Long-Term Care: Formal and Informal Dimensions

Definitions

Long-term care (LTC): a range of health, social, and personal services and support provided to individuals who, due to ageing, chronic illness, disability, are unable to fully manage the activities of daily living over an extended period of time. It is not limited to medical treatment, it includes assistance with personal care (such as bathing, dressing, eating, mobility), household activities (such as meal preparation, cleaning and shopping), as well as emotional support and social participation. LTC can take two forms, formal and informal (World Health Organization, 2022).

- **Formal care** relates to paid care services provided by trained healthcare professionals or medical institutions (Li & Song, 2019):
  - Unlike informal care provided by family and friends, formal care is delivered by paid professionals or organizations.
  - It can be provided across various settings, including community-based services, residential facilities, and individuals' homes.
  - The support includes services from nurses, home health aides, physical therapists, and other trained professionals.
  - Across the EU, there are 6.3 million people who work in the formal LTC sector (Eurofound, 2020).
- **Informal care** typically involves unpaid support provided by non-professional caregivers, including family members, friends or neighbours (Li & Song, 2019):
  - Informal LTC plays a central role in addressing the caregiving needs of the population.
  - Across Europe, as much as 80% of all care is provided by informal carers (European Commission, 2021)
  - At least 44 million people (12% of the adult population) provide informal care on a regular basis (Eurocarers, 2021)
  - A clear gender divide exists in informal care, with an average of 59% of informal caregivers in the EU being women (Eurocarers, 2021)

    - Most long-term carers are spouses, daughters or daughters-in-law who provide such care to their family members on an unpaid basis, invisibly supporting paid and unpaid care work everywhere (UN Women, 2024).
- **Mixed care** represents a hybrid model where formal and informal care are combined to meet the comprehensive needs of care recipients (Sörensen & Pinquart, 2002; Lee et al., 2020):
    - In practice, many LTC arrangements involve both professional services and family support working together, rather than functioning as entirely separate systems (Kemp et al., 2013; Kerpershoek et al., 2016).
    - Mixed care models allow families to maintain their caregiving role while receiving professional support for more complex medical or personal care tasks (Pfaff et al., 2024).
    - This approach can help prevent caregiver burnout among informal carers while ensuring that care recipients receive specialized professional attention when needed (Gérain & Zech, 2019; ASPE, 1993).
    - The integration of formal and informal care can provide more flexible and responsive care arrangements that adapt to changing needs over time (Kemp et al., 2013).

Limitations of formal long-term care

The formal long-term care system, while crucial for many, presents significant limitations related to the **availability**, **affordability**, and **quality** of the services provided. These challenges often create substantial barriers for individuals and families seeking necessary support.

1. Availability

Access to formal long-term care services is influenced by a multifaceted array of geographic, infrastructural, and systemic factors. Even in densely populated urban centres, individuals may confront significant barriers such as extended waiting lists, limited facility capacity, and complex administrative processes required for admission (Scott et al, 2024)

Who is most affected? → Vulnerable groups, including individuals with disabilities, low-income households, members of linguistic or cultural minorities, are particularly susceptible to these gaps in service provision (OECD, 2024).

Trends in the EU

- Despite most EU Member States having deinstitutionalisation strategies in place, the number of individuals (children, adults with disabilities, and older people) in residential facilities has risen in the 10 years up to 2022–2023 in the EU (Eurofound, 2024).
- Thus, the need for LTC is increasing, which means that formal care services and provisions are experiencing higher demand (Eurocares, 2021; Eurofound, 2024).
- The observed limitations of formal LTC services lead to heavy reliance on informal care (European Commission, 2022). Most countries examined operate a fragmented, mixed LTC system, balancing public, private, and family resources (OECD, 2025).

Role of informal carers

- The family is still the backbone of LTC, though demographic shifts (ageing population, fewer births) make this model increasingly unsustainable.
- Informal caregivers play a definite role as the primary support system for the LTC of older adults, supporting many individuals to continue living at home (National Institute on Aging, 2023).
- Informal caregivers provide care for persons with whom they have a personal connection, such as a family member, friend or neighbour.

- Their support mainly involves assisting with personal tasks, including activities of daily living (ADLs) like bathing, dressing, mobility, eating, toileting, continence and other chores such as housekeeping, laundry, meal preparation, medication management, shopping, handling finances, transportation and using communication devices (Edemekong et al., 2025).

Additional barriers in rural/remote areas

In rural and remote settings, these obstacles are frequently intensified. Many regions face:

- *Insufficient long-term care facilities*, with some regions lacking fundamental residential or respite services altogether (OECD, 2020).
- *Shortage of specialized professionals*, including geriatric nurses, physiotherapists, and occupational therapists, often necessitates that residents travel considerable distances to obtain necessary care, if it is available at all. Such circumstances complicate logistics for families and may discourage consistent engagement with essential health and social support services.
- *Infrastructure constraints,* which further aggravate these issues. In certain instances, the condition of existing facilities, characterized by aging structures, insufficient equipment, or inadequate accessibility, can compromise both the quality and safety of care provision.
- *Persistent difficulties in attracting and retaining qualified staff*, partially due to funding limitations. These contribute to variability in service delivery, limiting some organizations' ability to provide comprehensive, individualized care.
- *Policy and regulatory environments* have a decisive impact on the availability of services. Regulatory restrictions on the development of new facilities, rigorous licensing requirements, or inadequate public investment can impede the expansion of long-term care networks and heighten regional disparities.

Consequences

- Where formal care options are scarce, families and communities often bear increased responsibility for supporting older adults, children/ adults with disabilities and those with chronic illnesses.
- While this dynamic can foster community cohesion and interpersonal support, it also imposes substantial demands on informal caregivers, who may lack necessary training, resources, or opportunities for respite.

Formal LTC systems are currently struggling to meet the growing demand of the ageing populations, leaving many individuals without the support they need, opting for informal care provision from their loved ones, mainly women in the family.

2. Affordability

Affordability can present a significant challenge in accessing formal long-term care, influencing the choices of many individuals and families (OECD, 2024). Affordability pressures are intensifying amid rapid demographic change and limited public provision.

Key facts

- Long-term care is the fastest-growing area of social spending in the EU, projected to rise from 1.7% to 2.5% of GDP between 2019 and 2050. Yet years of under-investment have left deep structural gaps that strain families, workers, and providers alike (European Commission, 2022).
- The growing demand for LTC services has created a significant care gap that, if not addressed, will negatively impact quality of life in old age and place additional pressure on declining labour forces as more people, particularly women, must provide unpaid care (Hougaard et al., 2024).

Types of Costs in Long-Term Care

Direct costs for services

- residential care homes
- in-home nursing
- day programs
- specialised therapies
- various indirect and less visible costs that may accumulate over time (OECD, 2024).

Direct costs generally encompass:

- monthly or daily rates for residential facilities
- payments to professional caregivers or nurses
- fees for therapies or medical treatments not covered by public healthcare plans (Barber et al., 2021).

These costs vary substantially based on factors such as location, the level and complexity of care required, and the facility's reputation or specialty. Private long-term care facilities can, in some cases, be so expensive per month, that they may significantly affect household savings or force families to liquidate assets (Barber et al., 2021).

Indirect/hidden costs (less visible, but equally important) include:

- caregivers' reduced work hours and wages,
- earlier retirement
- increased morbidity and stress
- opportunity costs and externalities to other family members (Costa-Font & Vilaplana-Prieto, 2025).

Who needs care?

- In 2019 in the EU, almost half of the people aged 65 and over reported difficulties with at least one personal care or household activity (Eurostat, 2022).
- 46.6 % of the EU's older population with an increased difficulty in personal care or household activities reported a lack of assistance with those activities.
- Almost 30 % of the EU's older population with difficulties in personal care or household activities used home care services for personal needs (Eurostat, 2022).

Affordability barriers disproportionately affect vulnerable populations, creating social inequalities in access to care.

LTC needs to significantly increase the risk of household poverty, particularly in Mediterranean and Eastern European countries where public service provision is traditionally limited and families bear primary care responsibility (Casanova et al., 2024).

Care has a strong gender dimension:

- Women comprise nearly all the formal care workforce
- Care responsibilities keep significantly more women than men out of the labour market
- Women are more likely to need long-term care but less able to afford it.

Living in already disadvantaged conditions further heightens the probability of sliding into poverty when long-term care needs arise, exacerbating existing social inequalities (European Commission, 2022).

3. Quality

The quality of formal long-term care varies across providers and national regulations (Dayly, 2025; Malley & Zigante, 2025). Staff-to-patient ratios, training standards, regulatory oversight, and resource availability play roles in determining the standard of care provided (Cés, & Coster, 2019).

Issues such as understaffing, insufficient training, or limited funding may affect the well-being and dignity of individuals receiving care (Raffnson, Shankar &S Steptoel, 2015).

Achieving consistently high-quality, person-centred services continues to present challenges for long-term care systems (Daly, 2025).

Cross-country differences in the EU

Significant differences across EU member states regarding specific features and policies in the field of long-term care (LTC) make it difficult to establish meaningful comparisons in terms of service quality (Daly, 2025).

Still, the European Strategy on LTC highlights four common challenges, all closely related to the quality of services (Daly, 2025):

- ensuring adequate access to LTC for all those in need;
- guaranteeing the provision of high-quality LTC services;
- securing an adequate and sustainable workforce while supporting informal carers;
- financing LTC in accordance with the growing demand for such services.

Assessing quality in long-term care

Assessing the quality of long-term care services generally requires the examination of their key dimensions and the identification of appropriate indicators to capture the situation under evaluation (Malley & Zigante, 2025). The earliest models of LTC quality assessment derive from frameworks developed within medical sciences.

Different frameworks are used to evaluate LTC quality

- Donabedian model (1980, cited in Malley & Zigante, 2025): distinguishes between *outcomes* (the effects on the beneficiary health), *processes* (the interaction between the patients and services providers, and *structures* (the context of care, such as facilities, equipment or staff involved in providing care). The model remains a cornerstone reference in the field.
- OECD framework (2013), proposes evaluating LTC quality across four main dimensions (Malley & Zigante, 2025):
    - care effectiveness,
    - user safety,
    - person-centredness, responsiveness and empowerment,
    - care coordination and integration.
- INTERRAI Quality Indicators: Developed by the interRAI research collaborative[1], uses standardised assessment tools to generate quality indicators for LTC facilities. It enables benchmarking and monitoring of care processes and outcomes internationally and is based on specific quality indicators for home care, institutional care and mental health services.
- European Quality Framework for Long-Term Care: Developed by the European Quality Framework for Social Services[2], it focuses on rights-based, person-centred care, promoting dignity, autonomy, and participation of service users. It emphasises the involvement of users and families in service planning and delivery.

Key factors influencing quality

[1] https://interrai.org/

[2] https://www.age-platform.eu/

At the individual level, quality in formal long-term care is influenced by multiple interrelated factors that affect the experiences of residents and service users (Zigante & King, 2019):

- *Staff-to-patient ratios*; when staffing levels are insufficient, carers may have less capacity to provide individualized attention, respond promptly, or sustain a therapeutic environment. Adequate staffing supports continuity of care, relationship-building, and early identification of health issues.
- *Training and qualifications of care personnel*. High-quality care environments often emphasize ongoing professional development so that staff stay current with best practices, including dementia care, palliative care, infection control, and communication. Ongoing training enables staff to address complex needs, enhances their confidence, and reduces risks of errors or adverse outcomes (Zigante & King, 2019).
- *Regulatory oversight and enforcement of standards* serve as mechanisms to help maintain quality Licensing bodies and health authorities conduct inspections, assess compliance with health and safety requirements, and monitor care outcomes. Facilities meeting consistent benchmarks typically deliver higher standards of person-centred care, while lapses in oversight or inconsistent enforcement may permit substandard practices, impacting resident safety and public confidence (Malley & Zigante, 2025).
- *Resource availability*. Facilities with access to modern medical equipment, mobility aids, and recreational spaces are more capable of supporting overall well-being and independence. Financial limitations, especially in underfunded or rural areas, can limit access to these resources and may influence nutrition, cleanliness, maintenance, and variety of activities available, which all contribute to quality of life (Zigante & King, 2019; Raffnson, Shankar &S Steptoel, 2015).
- *Communication and cooperation among care teams*, residents, and families also affect the care experience. Transparent decision-making, regular updates, and including residents and advocates in planning support autonomy and respect for preferences. Inadequate communication may lead to misunderstandings and unmet needs.

Quality in LTC depends not only on regulations, professional standards, and resources, but also on adequate staffing – both in terms of numbers and qualifications – as well as the involvement of care teams, residents, and families.

The Role of Families

Families often provide essential long-term care, especially where formal options are limited. Their contribution covers a wide range of daily and emotional needs:

Main caregiving responsibilities:

- Assistance with hygiene, meals, medication,
- Support with appointments, finances, and household tasks
- Companionship and emotional support (Eurocareres, 2021; European Commission, 2021).

Challenges faced by families

Due to the significant costs associated with formal long-term care services, many families encounter a complex array of financial, emotional, and logistical challenges (European Commission, 2021).

Financial challenges

- Services such as residential care facilities, in-home nursing, and specialised therapies involve high costs
- Insurance coverage or public subsidies often fail to fully cover expenses (OECD, 2024).

- Consequently, family members often make considerable personal sacrifices, including reducing paid employment, foregoing leisure pursuits, or utilising personal savings and assets to finance care needs (Eurofound, 2025).

Emotional and logistical challenges

- In addition to financial considerations, families provide essential support grounded in trust, affection, and cultural norms (Costa & Vilaplana-Pietro, 2025). Across various societies, there exists a strong tradition of intergenerational solidarity, wherein younger members are expected to care for elders as a demonstration of duty and respect.

While such arrangements can strengthen familial bonds and foster mutual appreciation, they may also impose significant strain on caregivers, particularly when care demands are substantial and resources for respite or assistance are inadequate (Gérain & Zech, 2019; Raffnson, Shankar &S Steptoel, 2015).Furthermore, the vital yet often unrecognized contributions of family caregivers remain largely overlooked in social policy and public discourse (Costa-Font & Villaprana-Pietro, 2025).

The value of this unpaid labour is considerable, supporting the viability of health and social care systems by addressing gaps in formal service provision.

Insufficient recognition and support can contribute to caregiver burnout, compromised health, and social isolation.

Comprehensive long-term care strategies must recognize and address the pivotal role played by families, ensuring they receive adequate resources, respite opportunities, and acknowledgment for their contributions (Kemp, Ball & Perkins, 2019).

Interactive Activities

Activity 1: Professional Role Reflection - Understanding Formal Long-Term Care Systems

Aim

- To initiate group engagement and cultivate participants' awareness of LTC delivery systems and professional caregiving roles
- To encourage participants to reflect on and share their understanding of institutional care environments, regulatory frameworks, and interdisciplinary collaboration

Materials needed

- Flipchart or whiteboard
- Markers
- Notepads
- Pens
- Optional: printed case studies featuring formal care settings or organizational charts

Format A: individual reflection and group sharing

Step 1 Brief introduction to formal LTC systems, including residential facilities, home care agencies, day care centres, and the roles of professional caregivers within these structures.

Step 2 Participants are presented with a case study from a formal care setting (e.g., “an elderly care centre has 45 residents. Ana, a registered nurse, coordinates care with three care

assistants, a physiotherapist, and a social worker. Today, she must manage medication schedules, a family meeting about end-of-life care, and staff training on new infection control protocols.")

Step 3 Each participant answers reflection questions individually about professional responsibilities, care coordination, and regulatory compliance.

Step 4 Group roundtable: participants share responses to foster discussion about the diversity of formal care settings and professional challenges.

Step 5 Facilitator summarizes common themes and differences on a flipchart or whiteboard, highlighting the complexity of formal care delivery.

Format B: Role mapping and system analysis

Step 1 Participants identify and describe formal care settings they have experience with (nursing homes, home care agencies, hospice programs, adult day centres).

Step 2 Each participant presents their setting, explaining the organizational structure, staffing models, and regulatory requirements.

Step 3 Group discussion to map out the range of formal care environments, professional roles, and quality standards.

Step 4 Visual mapping on a flipchart/whiteboard to create an organizational ecosystem showing how different formal care services interconnect.

Links and resources

- European Foundation for the Improvement of Living and Working Conditions resources on LTC workforce
- National quality standards for residential care facilities
- Professional competency frameworks for formal caregivers
- Guidance on interdisciplinary team collaboration

Instructions for trainers

- Open the session by emphasizing the professionalism and complexity of formal LTC delivery systems.
- Explain both activity formats and choose the one that best suits group size and professional experience level.
- Distribute reflection questions focused on organizational challenges, ethical dilemmas, and professional boundaries.
- Facilitate group discussion, ensuring representation from different care settings and professional roles.
- Wrap up by highlighting common challenges such as staffing shortages, regulatory compliance, documentation requirements, and quality improvement initiatives.

Trainer notes

- Emphasize the diversity of formal care settings: nursing homes, home care agencies, rehabilitation centres, palliative care units, adult day programs.
- Highlight the interdisciplinary nature of formal care: nurses, care assistants, social workers, therapists, physicians, administrators.

- Address professional boundaries, burnout prevention, and the importance of self-care for formal caregivers.
- Discuss the intersection between organizational policies, professional standards, and regulatory frameworks.

Expected outcomes

- Participants identify formal LTC as professionally delivered, regulated care provided through institutional or agency-based settings
- Participants understand the organizational structures, staffing models, and regulatory requirements governing formal care
- Participants recognize key challenges including workforce shortages, high turnover, documentation burdens, regulatory compliance, and resource constraints
- Group mapping uncovers shared themes (e.g., documentation demands, staff coordination) and setting-specific perspectives (e.g., residential vs. home care challenges)
- Participants appreciate the importance of interdisciplinary collaboration and professional development in formal care settings

Activity 2: Professional Case Analysis - Managing Complex Care in Formal Settings

Aim

- To build practical skills in care coordination, interdisciplinary collaboration, and professional decision-making
- To encourage critical thinking about regulatory compliance, quality standards, and ethical issues in formal care environments

Materials

- Scenario handouts featuring formal care settings
- Pens
- Flipchart and markers
- Whiteboard for recording care plans and coordination strategies

Steps

Step 1 Present the scenario

Provide participants with a scenario from a formal care setting (see scenarios below). Distribute scenario handouts and allow time for participants to review the professional challenges presented

Step 2 Role assignment and set-up

Divide participants into interdisciplinary teams (ideally 4-6 people per group). Assign professional roles: charge nurse, care assistant, social worker, physiotherapist, family liaison, facility administrator. Briefly clarify the responsibilities, scope of practice, and perspectives of each role

Step 3 Professional assessment

Encourage participants to assess the situation from their assigned professional perspective. Prompt them to consider care needs, risk factors, regulatory requirements,

and organizational constraints. Allow 10-15 minutes for initial assessment and discussion within each team

Step 4 Develop care plan
Ask each team to develop a comprehensive, interdisciplinary care plan that addresses medical needs, safety concerns, quality of life, and family communication. Teams should document their plan using standard care planning formats. Record key elements on flipchart for presentation

Step 5 Identify resources and protocols
Invite teams to identify relevant organizational policies, clinical protocols, regulatory standards, and external resources. Discuss how formal care settings must balance person-centred care with institutional requirements and safety standards

Step 6 Coordination and communication
Guide teams in discussing how to coordinate care across shifts and disciplines. Consider strategies for effective handoffs, documentation, family meetings, and communication with external providers. Develop a communication plan that ensures continuity of care

Step 7 Anticipate professional challenges
Prompt each team to identify potential challenges such as staffing limitations, conflicting family requests, regulatory compliance issues, ethical dilemmas, or resource constraints. Discuss how organizational policies and professional standards guide decision-making

Step 8 Quality and safety analysis
Encourage teams to analyse quality indicators and safety risks. Identify opportunities for quality improvement and risk mitigation. Consider how documentation and monitoring support accountability and continuous improvement

Step 9 Present and debrief
Invite each team to present their care plan and coordination strategy. Facilitate discussion about different approaches, ethical considerations, and lessons learned. Reflect on how professional roles complement each other in formal care settings

Expected outcomes

- Greater confidence in interdisciplinary care coordination and professional collaboration
- Enhanced understanding of regulatory requirements and quality standards in formal care
- Improved ability to balance person-centred care with organizational and safety requirements
- Opportunity to practice professional communication and collaborative problem-solving

SCENARIO 1: BEHAVIORAL CRISIS IN A NURSING HOME

Setting: 120-bed skilled nursing facility with memory care unit

Background:

Mr. Adrian, 78, recently admitted to the memory care unit, has moderate dementia and a history of anxiety. Over the past week, he has become increasingly agitated during evening shifts, shouting, refusing care, and attempting to leave the unit. Last night, he pushed a care assistant. The family is upset, staff members are concerned about safety, and the facility must comply with restraint-minimization regulations while ensuring everyone's safety.

Professional considerations:

- Care team includes charge nurse, three care assistants, activities director, social worker, and consulting psychiatrist
- Facility policy requires behavioural intervention plans and family consultation
- Regulatory standards prohibit chemical or physical restraints except as last resort
- Staff express fear and request additional support

Care coordination challenges:

- Inconsistent documentation of triggers and interventions across shifts
- Family requests immediate medication to "control" behaviour
- Care assistants report feeling unprepared to manage aggressive behaviour
- Administration concerned about liability and regulatory compliance

Decision points:

- How to conduct comprehensive behavioural assessment across disciplines
- Developing non-pharmacological interventions and environmental modifications
- Coordinating care plan across three shifts with consistent implementation
- Communication strategy with family about realistic expectations and care approach
- Staff training and support needs
- When and how to involve physician or psychiatric consultant

Reflection prompts:

- What assessment data should each professional role contribute with?
- How can the team balance safety with person-centerer, least-restrictive care?
- What documentation is needed to support clinical decisions and regulatory compliance?
- How should the team address staff concerns and prevent burnout?

SCENARIO 2: COMPLEX DISCHARGE PLANNING

Setting: Rehabilitation unit in a long-term care facility

Background:

Mrs. Elena, 82, admitted following hip replacement surgery six weeks ago. She has made good physical progress but has diabetes, early cognitive decline, and lives alone. The interdisciplinary team disagrees about discharge readiness. Physical therapy believes she can manage at home with supports. Nursing team is concerned about medication management and safety. Social work team has identified limited family support and financial constraints. Medicare coverage is ending, and the family is pressuring for discharge.

Professional considerations:

- Interdisciplinary team includes nurse case manager, physical therapist, occupational therapist, social worker, dietician, and physician
- Discharge planning must consider safety, regulatory requirements, liability, and patient preferences
- Multiple external agencies involved: home health, meals on wheels, outpatient therapy
- Documentation must justify continued stay or support safe discharge

Care coordination challenges:

- Conflicting assessments of discharge readiness among team members
- Patient expresses desire to go home but demonstrates poor safety awareness
- Family unable to provide hands-on support but opposed to assisted living

- Limited home health services available in patient's rural area
- Insurance and financial constraints affecting options

Decision points:

- How to facilitate effective interdisciplinary communication and consensus
- Balancing professional judgments with patient autonomy and family preferences
- Coordinating transition of care across multiple providers and settings
- Managing risk while supporting independence
- Documentation to support clinical decisions if adverse events occur post-discharge

Reflection prompts:

- How should the teams resolve professional disagreements about risk and readiness?
- What is each professional's responsibility in discharge planning and risk assessment?
- How can formal care providers support patient choice while maintaining professional standards?
- What follow-up and communication systems ensure continuity after discharge?

SCENARIO 3: STAFFING CRISIS AND QUALITY CARE

Setting: 60-bed assisted living facility

Background:

A public assisted living facility is experiencing severe staffing shortages. Three care assistants called in sick for the evening shift, leaving one nurse and two assistants for 60 residents. Several residents require significant assistance with medications, mobility, and personal care. One resident has fallen twice recently. Families are complaining about delayed responses to emergency calls. Administration cannot find replacement staff. The remaining team must prioritize care, maintain safety, and meet regulatory requirements while managing their own stress and fatigue.

Professional considerations:

- Charge nurse must triage needs and delegate appropriately
- Staff members working beyond safe ratios and feeling overwhelmed
- Regulatory requirements for medication administration, documentation, and supervision remain unchanged
- Risk of errors, injuries, and burnout is high
- Facility reputation and licensing at stake

Care coordination challenges:

- Insufficient staff to provide usual standard of care
- Must prioritize essential care and defer non-urgent tasks
- Communication with families about service limitations
- Supporting staff morale and preventing burnout
- Maintaining documentation despite time pressures
- Determining when situation becomes unsafe and requires intervention

Decision points:

- How to prioritize and triage resident needs ethically and safely
- What tasks can be safely deferred or modified?
- When and how to escalate concerns to administration

- Communication strategies with residents and families
- Documentation of staffing situation and clinical decisions
- Self-care and mutual support among remaining staff
- Longer-term advocacy for adequate staffing and working conditions

Reflection prompts:

- How do professional standards and ethics guide decision-making in under-resourced situations?
- What is each team member's responsibility when staffing is unsafe?
- How can formal caregivers advocate for systemic changes while managing immediate demands?
- What organizational supports would prevent or mitigate staffing crises?

Unit 1.2: The Impact of Informal Caregiving and the Need for Support for Carers

This unit provides information on the effects of informal caregiving on carers and their need for support. The first section examines the impact of informal care on carers' well-being, taking into account key areas of their lives—employment, physical health, emotional well-being, and economic stability. With regard to employment, data are presented both at the European level and nationally for Romania, Cyprus, Greece, Spain, and Italy.

In contrast, the second section discusses the positive impact of informal caregiving, highlighting benefits such as personal fulfilment and sense of duty, stronger family bonds and emotional rewards, the development of new skills and personal growth, as well as contributions to society and advocacy for carers' rights.

Finally, the unit addresses the crucial need for support from employers, emphasising that recognising the needs of employees with caregiving responsibilities brings multiple benefits. It also presents examples of carer-friendly practices such as flexible work arrangements, leave and financial support, empowerment and recognition, training, and skills development.

The unit concludes with interactive activities designed to raise awareness about the challenges faced by employees with caring responsibilities in the workplace, foster empathy, and support the identification of carer-friendly practices.

Theoretical Content

Effects of Informal Caring on Carers' Wellbeing

Caregiving responsibilities have an impact on multiple dimensions of carers' everyday life, and their effects often extend beyond the immediate period of providing care. This section explores how informal caregiving affects key domains in the lives of informal carers – employment and economic sustainability, physical health, and emotional wellbeing.

Employment

Employment is one of the life domains most affected by informal caregiving responsibilities.

Source: Image generated by the authors using Canva AI (2025)

- Balancing paid work with unpaid care generates significant challenges for people with caregiving responsibilities.
- These challenges are not equally distributed: women are far more likely to adjust their careers in order to meet caregiving demands.
- Care work is unevenly distributed between men and women, reinforcing gender inequalities and traditional gender roles (EIGE, 2023; European Commission, 2021). Caregiving roles are traditionally assigned to women to a much greater extent than to men (World Bank, 2022; Guga & Șindreșan, 2021).

Impact on employment choices

Caregiving can influence employment in multiple ways:

- Reducing working hours
- Moving into part-time or flexible jobs
- Declining promotions
- Leaving the labour market entirely

Women are more likely to reduce working hours, change to part-time jobs, or retire early to provide care (European Commission, 2021).

Consequences

- Over time, these adjustments contribute to gender inequalities in income, career growth, and pension entitlements.
- At the same time, employers and economies face lower productivity levels and reduced labour force participation, especially as the population ages and the demand for care increases.

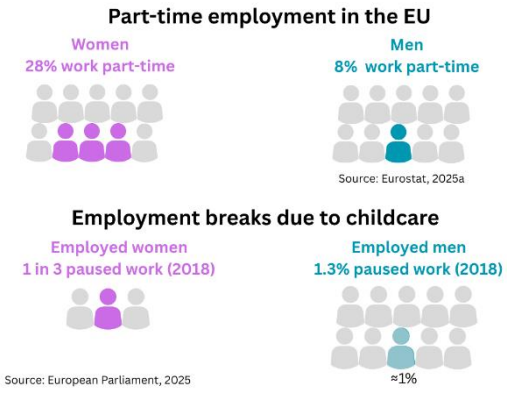
Differences across Europe

The effects of informal caregiving on employment vary across Europe, depending on welfare regimes, labour market structures, and the availability of formal long-term care services.

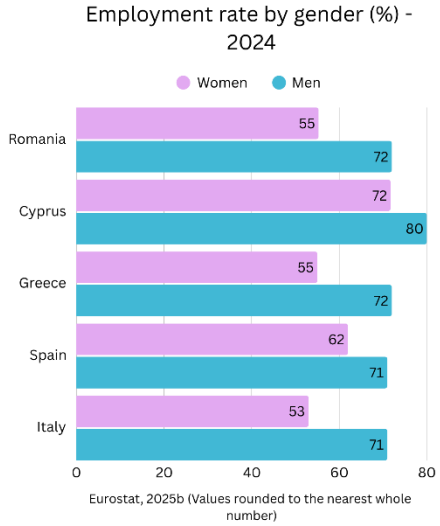
In countries where public support for care is limited, families—and especially women—carry a larger share of the burden, leading to gender gaps in employment.

EU level data

- Nearly **28% of women work part-time**, compared to just 8% of men (Eurostat, 2025a).
- **1 in 3 employed women** paused their work due to childcare, compared to only 1.3% of men (2018) (European Parliament, 2025).
- Informal LTC providers are often below retirement age, which creates strong work-life conflicts (European Parliament, 2025).



National level data



Women's employment rates remain significantly lower than men's across all five countries.

Gender gaps range from around 9 percentage points in Spain, to over 15 points in Romania and Greece, and nearly 20 points in Italy.

These differences reflect both structural barriers and the **unequal distribution of care responsibilities between men and women**.

In addition, national data reveal specific vulnerabilities among women carers and older female workers:

- In **Cyprus**, only 21% of women carers aged 50-64 are employed, compared to 62% of men in the same age group.
- In **Spain**, among women with caring responsibilities, 17.4% work part-time, compared to just 3.5% of men.

Economic Stability

- Reduced employment and unpaid care lead to financial vulnerability for women. Informal carers are often dependent on the financial support of their family or minimal government aid (Eurofound, 2020). Informal caregiving increases financial stress and reduces long-term financial independence (Koomson et al., 2024).
- **Gender pension gap in the EU: 26% →** Women receive, on average, about a quarter less in pensions than men (EIGE, 2024).
- The impact of retirement is stronger among women with caring responsibilities: the percentage drop in earnings after retirement being higher among retired women and more persistent over time. This leads to a higher risk of financial difficulties and poverty in later life (Maura & Profeta, 2024).
- Active women also earn less than men: on average, partnered women in the EU **earn 69% of their partner's earnings**, which may lead to lower influence in the decision-making process as well as increased financial dependency, limited autonomy, and higher vulnerability.
- 21% of partnered women in the EU between 18 and 64 years old were living in 2019 in household where their partner was the sole earner, compared to only 6% of men (EIGE, 2024).

Structural barriers

These disparities are not only the result of individual choices but are strongly shaped by structural barriers:

- Limited access to formal care services, with rigid labour markets that do not accommodate flexible working arrangements, and insufficient family-friendly policies (e.g. flexible leave, financial support for carers etc.) make it more difficult for women to remain in stable and well-paid jobs while providing care for family members.

- Lack of recognition of informal caregiving, most often seen as a female duty, leads to the absence of financial compensation for carers and to reduced visibility of their work.
- Lack of adequate training affects both the carers' wellbeing and the quality of care provided.

Economic value of informal care

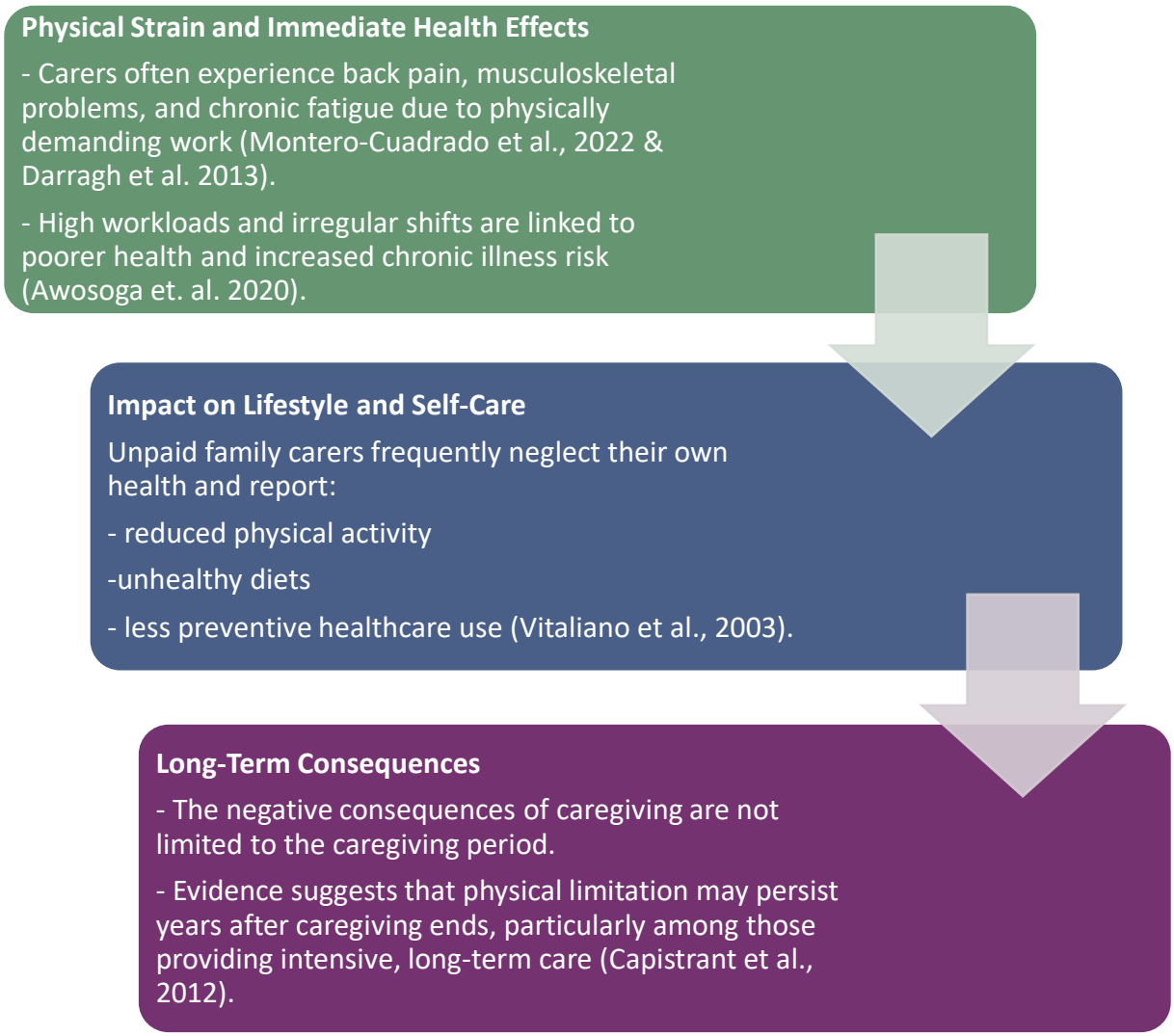
- Although often unrecognised, the work of informal carers has **significant economic value**, which is largely absent from official statistics and represents an overlooked contribution to national welfare and care systems.
- If informal care were compensated at market rates, it would account for between 2.4% and 2.7% of EU GDP.
- At the same time, reduced employment and early retirement among carers results in a loss of tax revenues of about 1% of GDP (Huis in 't Veld et al., 2022).
- In practice, people providing informal care are subsidizing public LTC systems with their unpaid labour.

There is an urgent need for financial compensation and investment in both formal and informal care systems, as well as the recognition of informal caregiving.

Key impacts on female caregivers

- In the long run, interruptions in employment and reduced working hours contribute to persistent gender gaps in income, career growth, and pension entitlements.
- Living in a state of increased financial dependence on a partner is associated with:
    - Negative effects on physical and mental health
    - Reduced opportunities to participate in education or paid employment
    - Higher risk of being a victim of domestic violence (EIGE, 2024).
- Employers and economies bear the costs of these gender disparities as well, through lost productivity and decreased labour force participation, particularly as care demands rise.

Physical Health



Emotional Wellbeing

Although caregiving can strengthen family bonds, it also places a considerable strain on carer's mental health (Schulz & Sherwod, 2008; Raffnson, Shankar &S Steptoe, 2015). The main challenges may take different forms, such as:

- Blurring of personal boundaries when carers must provide intimate support (e.g. hygiene or medical support).
- Conflicts and tensions within families when making decisions about daily routines or care arrangements.
- Constant stress and worry regarding the health and wellbeing of the dependent relative, which can be a heavy emotional burden.
- Social isolation as social engagement becomes difficult and limited due to care responsibilities.
- Increased risk of mental health problems such as anxiety, depression, and emotional exhaustion (Raffnson, Shankar &S Steptoel, 2015; Shulz & Sherwood, 2008)
- High likelihood of burnout, especially among long-term carers who lack access to respite centres or support networks. (Gérain & Zech, 2019)

- Low use of professional mental health services, as carers often neglect their own needs, lack time, and even prioritize the needs of the dependent relative over their own. (Awosoga, et al., 2020)

Possible solutions for **employers** and **public services** to protect the emotional wellbeing of **employed informal caregivers**

Solutions	**Employers**	**Public services**
Facilities and flexible work rights to reduce chronic stress and burn-out	- Create a confidential caregiver self-identification process - Provide predictable work schedules - Offer remote/hybrid options - Guarantee paid micro-breaks - Allow split shifts or compressed weeks - Enable temporary workload adjustments - Provide at least 3–5 paid days for caregiving, without career penalties.	- Provide guidance on caregiver-friendly accommodations - Develop and share model caregiver support policies for employees - Establish a dedicated hotline for workers and HR on caregiving issues
Co-funded respite with "recovery goals" to reduce emotional overload and isolation	- Offer stipends or vouchers for in-home/day respite services - Allow respite to be schedule during work hours - Integrate booking links in HR portals for direct access	- Expand day respite services (6–10 hours) to cover working hours - Provide residential respite (with accommodation for 2-3 nights) for caregivers - Ensure emergency respite for acute needs, hospitalizations, or caregiver exhaustion - Simplify eligibility criteria for respite access - Provide transport services where needed.
Peer support delivered where people work to improve coping skills	- Host monthly peer groups (on-site or virtual) co-facilitated by a psychologist - Offer micro-learning sessions on boundary setting and difficult family conversations.	- Assign a care navigator for employed carers to connect them to benefits, respite, and mental-health services.
Equip homes to reduce physical strain	- Offer stipends or vouchers for essential aids (hoists/slide sheets, transfer belts, adjustable beds/chairs) - Negotiate bulk-purchase discounts for care equipment	- Provide means-tested grants for essential care equipment - Create community equipment libraries (short-term loans)

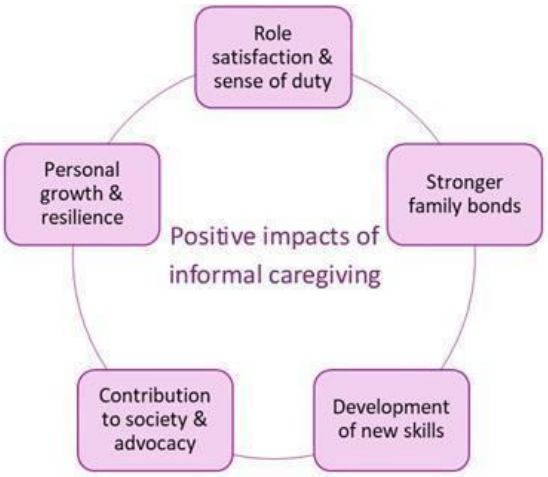
	- Provide paid time off for delivery/installation of equipment - Ensure access to a rapid physiotherapy/ occupational therapy (OT) hotline for setup guidance	- Fast-track OT home assessments (target: within 7 days from referral) - Apply VAT relief/ reimbursement for prescribed devices.
Smart tele-care and coordinated scheduling	- Co-fund fall sensors, medication dispensers with alerts, and bed-exit alarms - Provide licenses for shared calendar/care-coordination apps - Allow care-related notification exceptions during work - Include brief onboarding/ training for tele-care tools.	- Subsidize tele-care for high-need households - Integrate tele-care alerts with community nursing/GP triage systems - Set interoperability standards so devices feed into care plans - Provide basic digital skills training for carers and households.

While national systems may not explicitly discriminate against them, social norms and expectations place the care responsibilities disproportionately on women.

"Familistic" societies expect and normalize informal care to be undertaken by the family, and especially by women, putting stigma on institutionalization and increasing feelings of guilt and obligation among the younger generation.

Informal caregiving is not recognised as a role that deserves compensation, and is instead regarded as a family matter, leaving carers more exposed to economic insecurity and social inequality.

Positive Impact of Informal Caregiving



Although caregiving is often associated with burden, studies also show positive effects on caregivers, in areas such as family life, personal development, and contribution to society.

Role satisfaction and sense of duty

Caregiving is deeply embedded in cultural norms and moral expectations, particularly in societies where intergenerational solidarity remains strong (Broese Van Groenou & De Boer, 2016). For many, providing daily care to an older parent, spouse, or relative is not experienced solely as a burden, but as **a fulfilment of duty and reciprocity**.

- Caregivers often describe their role as an **act of returning** the care once received in childhood or throughout life, thereby **reinforcing continuity across generations**.
- This sense of moral obligation provides caregivers with **role satisfaction**, defined as the fulfilment derived from successfully performing a meaningful and socially valued role.
- From this perspective, caregiving satisfies not only instrumental needs but also the caregiver's desire for moral coherence and identity affirmation (Broese Van Groenou & De Boer, 2016).
- Research demonstrates that role satisfaction and the ability to identify positive aspects of caregiving are associated with **lower depressive symptoms** and **reduced burden** among caregivers, suggesting that these positive appraisals buffer the negative mental health consequences of caregiving. Studies show that positive aspects of caregiving, including feelings of competence and personal gain from fulfilling one's duty, help regulate caregiver burden and **mediate the relationship between life satisfaction and psychological distress**. (Fauziana et al., 2018; Van Droogenbroeck et al., 2025)

Stronger family bonds and emotional rewards

Caregiving is relational, affecting and reshaping the dynamics of the family.

- Shared caregiving responsibilities often foster **cooperation among siblings**, extended kin, and spouses, strengthening **intra-family solidarity**.
- The daily intimacy of caregiving - helping with meals, personal hygiene, or mobility - can **deepen emotional ties** between caregiver and recipient.
- These relational processes yield significant **emotional rewards**. Research show that prosocial behaviours such as caregiving enhance well-being by generating feelings of empathy, compassion, and gratitude. Caregivers often experience satisfaction when they see their loved one more comfortable or appreciative of their efforts. These affective exchanges create a feedback loop that reinforces both the caregiving relationship and the caregiver's emotional

resilience. Importantly, these emotional rewards can **buffer the stressors of care**, offering balance in otherwise demanding contexts (Lee & Li, 2022).

Development of new skills

Caregiving is also a powerful site of **skills acquisition and competency development**.

- Caregiving experiences can be understood as mastery experiences that increase individuals' belief in their ability to manage complex and uncertain situations.
- Caregivers frequently report improvements in:
    - Patience - cultivated through dealing with repetitive routines, slow recovery, or progressive decline,
    - Empathy, developed through daily engagement with vulnerability and dependence.
    - Time management -, as the caregivers must coordinate specific tasks, as healthcare visits, domestic tasks, and employment responsibilities (CEDEFOP, 2024).
- These competencies are highly transferable to other domains of life, including the workplace and civic engagement.
- European Commission funded projects such as Care4Skills[3] and Care4U[4] specifically address the training needs of the care workforce by facilitating knowledge exchange on daily practices and enhancing both digital and person-centerer care competencies across EU countries. Thus, caregiving functions as an **experiential learning process**, shaping the caregiver into a more adaptive, safety-conscious, and socially skilled individual with competencies that are increasingly recognized and valued within European health and social care frameworks.

Personal growth and resilience

Caregiving can foster resilience, defined as the ability to adapt positively to adversity.

- The daily unpredictability of caregiving - health crises, emotional strain, or bureaucratic challenges - requires flexibility, resourcefulness, and problem-solving skills.
- Over time, these coping strategies **strengthen psychological endurance**.
- Caregiving often contributes to **personal growth**. Frequently, caregivers report greater appreciation of life, stronger relationships, and an enhanced sense of purpose. In many cases, caregiving transforms self-concept: individuals see themselves as stronger, more patient, and more compassionate. This process illustrates that caregiving, while demanding, can be a profound catalyst for identity development and personal flourishing (Autio et al., 2024; Opsomer et al., 2022).

Contribution to society and advocacy for care rights

At the societal level, unpaid caregiving represents a significant form of **social capital.**

- In countries where LTC systems remain underdeveloped or fragmented, families provide the bulk of daily care, effectively substituting for professional services.
- The **economic value** of this unpaid labour is substantial, relieving public systems of costs they are unable or unwilling to bear. Thus, caregivers sustain not only their own families but also the resilience of welfare systems at large (EIGE, 2021, EIGE, 2023).
- Moreover, caregivers often evolve into advocates for care rights. Through direct experience of systemic shortcomings - limited services, financial strain, lack of training - they acquire

[3] https://care4skills.eu

[4] https://www.care4youproject.eu

unique insights into policy gaps. Many channel these experiences into collective forms of action: participating in caregiver associations, lobbying for better support policies, or raising awareness about the rights of care recipients and carers.

- Framed through civic engagement, caregiving thus extends beyond the private sphere into the public domain, contributing to policy change and the recognition of care as a fundamental social right. (EIGE, 2023).
- Women caregivers, in particular, become key agents of policy change and contribute to the recognition of care as a fundamental social right rather than merely a private, feminised responsibility (Alvariño, 2025).

Positive Highlights

Caregiving is often experienced as a fulfilment of duty and reciprocity, and not solely as a burden.

Shared caregiving responsibilities foster cooperation and strengthen solidarity among family members.

Caregiving allows carer to acquire or develop new skills such as time management, empathy, and patience.

Caregiving contributes to personal growth, fostering a greater appreciation of life and an enhanced sense of purpose.

Informal carers sustain welfare systems and increasingly advocate for care rights.

The Need for Employer and Organisational Support

Balancing work and care

Providing informal long-term care for relatives is a growing reality for many employees. It often comes with significant physical, emotional, and financial burdens.

- Balancing work responsibilities with caregiving tasks can lead to stress, fatigue, and reduced productivity.
- In some cases, employees with caring responsibilities may even be forced to leave the workforce altogether.
- Without adequate support, informal carers are at higher risk of burnout, poor health outcomes, and economic insecurity.
- These risks ultimately affect employers as well, through increased absenteeism, staff turnover, and lower performance (Eurofound, 2025).

Why should employers act?

Work-life balance is essential for employees in general, and so much more for those with caregiving responsibilities.

- By recognising the needs of employees with caregiving responsibilities, employers can reduce stress, retain staff and improve productivity (Hlebec et al., 2024)
- For those caregivers who are not employed, employers could implement targeted hiring practices aligned with the **Work-Life Balance Directive**:
    - Offering programs for career re-entry
    - Providing part-time or job-share arrangements
    - Explicitly stating flexible work options in job postings
    - Removing bias against employment gaps in screening processes.
    - Managers might also consider phased return-to-work schedules, remote work opportunities, and clear pathways for advancement that accommodate caregiving realities (European Commission, 2019a).

The role of employers and organisations

Employers and organisations therefore play a critical role in supporting employees who are carers.

- By implementing flexible working arrangements, offering access to information and counselling services, and fostering a culture of understanding, organisations can help employees manage their dual responsibilities more effectively.
- Such measures not only improve the wellbeing and resilience of carers, but also contribute to employee retention, loyalty, and long-term organisational stability (Hlebec et al., 2024).
- In addition, providing structured support for informal carers aligns with broader social responsibility objectives and contributes to a more inclusive and equitable workplace. As populations age and the demand for long-term care increases, forward-looking organisations that recognise and address the needs of working carers will be better positioned to respond

to demographic changes while maintaining a healthy and motivated workforce (Hlebec et al., 2024, Eurofound, 2015).

Employers can no longer treat caregiving as "someone else's problem." As a growing share of employees quietly shoulder an invisible second shift, proactive support has become a core workforce strategy - one that protects productivity, retains experienced staff, and advances inclusion.

- **The invisible second shift: why caregiving impacts the workplace**

A significant and growing portion of today's workforce is juggling a second, often invisible, full-time job: providing informal care for aging parents, sick spouses, or relatives with disabilities. This dual role of employee and caregiver creates immense physical and emotional strain, which inevitably impacts the workplace. The stress of managing appointments, finances, and daily care needs can lead to **presenteeism**, where employees are physically at work but mentally distracted and less productive. It also results in higher rates of **absenteeism** due to care-related emergencies. Without adequate support, organizations risk burning out and losing experienced employees who are forced to reduce their hours, turn down promotions, or leave the workforce entirely to manage their responsibilities at home (Das et al., 2024).

- **A strategic investment: the business case for support**

Implementing support for employee-caregivers is not simply a compassionate gesture; it is a critical business strategy with a clear return on investment. By offering flexible work arrangements, providing access to caregiver resources, and fostering an understanding management culture, employers can directly mitigate the negative impacts of care-related stress. (Hlebec et al., 2024). This support is proven to boost **staff retention**, as employees who feel valued and supported are far more likely to remain loyal. It also enhances **productivity and engagement**, as reducing an employee's outside stressors allows them to be more focused and effective in their role. Ultimately, this support is an investment in building a resilient, stable, and highly motivated workforce (Fuller, 2024).

- **Building an inclusive culture for the future**

Furthermore, providing robust caregiver support is a powerful and tangible way to advance **Diversity, Equity, and Inclusion (DEI)** goals. Statistically, caregiving responsibilities still disproportionately affect female employees, and a lack of support can become a major barrier to their career advancement (EIGE, 2021). By creating policies that acknowledge and accommodate these external responsibilities, organizations can better retain female talent and ensure a more equitable path to leadership. Fostering a caregiver-friendly environment sends a clear message that the organization values its employees as whole people, building a compassionate and human-centred culture that strengthens its reputation and makes it an employer of choice in a competitive market (EIGE, 2023).

Examples of carer-friendly practices

FLEXIBLE WORK ARRANGEMENTS

Family Working Manifesto (Italy – NHOA Energy, 2020) promotes remote work, flexible schedules, and the recognition of rights such as family time, wellness (physical and mental), and parental responsibilities.

LEAVE AND FINANCIAL SUPPORT

KPMG Romania *(2023):* within a pilot program, it provides an extra 5–7 paid days off for employees to support work–life balance, plus study leave. It recognises the importance of rest and personal time, especially for employees with caring responsibilities.

Initiative #RiParto *(Italy):* funds corporate welfare programmes offering psychological, physical and financial support, along with incentives for returning to work after childbirth or adoption.

Implementation across Italy varies regionally, with different strategies such as vouchers, nurseries, and parental leave schemes to improve work-life balance (Presidenza del Consiglio dei Ministri – Dipartimento per le politiche della famiglia, 2022).

EMPOWERMENT AND RECOGNITION

Emilia-Romagna Regional Law (Italy, 2014) is the first law in Europe to formally define the informal carer. It grants carers rights to information, training, psychological support, financial allowances, and representation. It also includes a "Caregiver Day."

Citizens: Empowering Women Caregivers (Spain), developed by the Women's Foundation in Spain, provides guidance, workshops, and participation spaces for women carers to reconcile care with personal and professional development.

Day Care Centres and Mobile Units for People with Dementia and Their Families (Greece), developed by the Greek Association of Alzheimer Disease and Related Disorders (Alzheimer Hellas). The programme combines clinical care with psychosocial services, reaching families across multiple regions. Caregivers benefit from counselling, education, and empowerment through innovative cultural programs such as *"Writing Our Couples' Life Book"* and *"Caregiver's Voice"*, which harness storytelling and theatre to build emotional resilience and raise public awareness. Recognised as a model of holistic dementia care and caregiver inclusion, it offers a replicable framework for other countries.

TRAINING AND SKILL DEVELOPMENT

School for Carers (Spain, "la Caixa" Foundation, 2018) offers online workshops for family caregivers on physical care, nutrition, emotional support, and self-care.

Entrena Empleo (Spain), developed by the Santa Maria la Real Foundation, supports women re-entering the labour market after periods of long-term unemployment spent providing unpaid care work. It focuses on the importance of caregivers' mental health and recognises the valuable skills acquired through caregiving.

Matia Eskola (Spain) is an online portal with courses, videos, and resources for carers, focusing on good treatment and accompaniment of older persons, awareness of ageing and the needs of this category.

Interactive Activities

Activity 1: A Day in Their Shoes - Empathy Mapping Roleplay

Aim:

- To build empathy and awareness about the challenges faced by informal carers in the workplace.

Materials and Resources

- Printed fictional role cards (one per group/or per participant if groups cannot be formed)
- Printed empathy map template (A3 for group work or A4 per individual)
- Pens, markers, sticky notes

- Trainer's Notes/ Model Solutions
- Background reading: Empathy mapping method https://www.nngroup.com/articles/empathy-mapping/

Steps

Step 1 Trainer introduces the activity, explaining the purpose and how empathy map works.

Step 2 Participants are divided into small groups (3-5 people). Each group receives one role card.

Step 3 Groups fill in the empathy map for their character - answering questions of the 4 quadrants: think & feel, see, say and do, hear.

- What does the person think and feel?
- What do they see in their environment?
- What do they say and do at work?
- What do they hear from colleagues, managers, family members?

Step 4 Groups identify support gaps in the workplace and propose one improvement

Step 5 Each group presents its empathy map and recommendation.

Instructions for trainers

- Print one card per group or per participant (in cases where group work is not possible)
- You may adapt demographic details to reflect your audience's context
- Encourage participants to think about both professional and personal challenges faced by each character.

Role cards

MARIA	
Age	40
Job	HR Officer in a medium-sized company, full-time
Care duties	Provides daily care for her father (72 years old) with Alzheimer. Approximately 25 hours of care per week (mornings and evenings)
Workplace challenges	Often requests flexible hours, find it difficult to attend late meetings, colleagues sometimes perceive her as less reliable
Personal goals	Wants to advance in her HR career

JUAN	
Age	35
Job	IT support specialist, full-time
Care duties	Provides evening and weekend care for his younger brother (22) with severe mobility impairment
Workplace challenges	High absenteeism during medical crises, cannot commit to overtime, sometimes receives negative feedback from his manager
Personal goals	Wants to maintain stable employment and avoid burnout

REBECA	
Age	50
Job	Teacher in a high school

Care duties	Provides daily care for her husband with mobility issues following a stroke. Also responsible for household chores.
Workplace challenges	Needs frequent short-term leave, emotional strain sometimes affects her concentration and teaching performance
Personal goals	Wants to teach until retirement

FRANCESCA	
Age	28
Job	Project assistant
Care duties	Share caregiving responsibilities of her grandmother (age 83) with her mother. Supports with shopping, meals, medical visits.
Workplace challenges	Employer is unaware of her caregiving role, feels anxious about asking for flexibility
Personal goals	Wants to develop a stable career and maintain work-life balance

ANA	
Age	32
Job	Assistant Manager in a private company
Care duties	Provides daily care for her son with autism (age 7)
Workplace challenges	Needs flexible hours to manage her son's therapy schedule, occasional absences due to emergencies, experience stress balancing deadlines at work with care responsibilities.
Personal goals	Wants to advance within the company

Empathy Map Template

(with guiding questions in each quadrant, provided as handout in A3 for group work or A4 for individual use)

Think/ Feel

See

What does the person think about their situation? *What feelings do they experience most often?*	*What does the person see in their environment?* *What challenges and opportunities does the person see?*
[Space for notes]	[Space for notes]

Say/Do

Hear

What does the person say at work? *How does the person act to manage both work and care responsibilities?*	*What does the person hear from colleagues, managers, family members?* *What do others expect from them?*
[Space for notes]	[Space for notes]
Identified Support Gaps:	
Proposed Improvement:	

Trainer's Notes/ Model Solutions

These notes are intended for the trainer only and should not be shared with participants during the exercise.

They provide examples of possible empathy maps entries and common support gaps or improvements. Use them as a reference to guide the discussion, highlight missing points after group work, and connect participants ideas to common patterns.

Model Solution – Role card 1 (Maria, HR officer, caring for father with Alzheimer)

Empathy Map Example

Think / Feel I want to do well at work, but I am constantly tired. Feels guilty for not being fully present either at work or with her father.	**See** I see my colleagues staying late, meetings are scheduled at inconvenient times**.** Company has no policies on carers.
Say/ Do I keep saying I am fine. I often request to leave early. Avoids volunteering for extra projects.	**Hear** Maria is not as reliable as before. – from colleagues. Family always comes first. – from relatives.
Identified Support Gap: Lack of formal flexibility policies	

Proposed Improvement: Introduce formal policies for carers and awareness-raising sessions to normalise caring responsibilities in the workplace.

Model Solution – Role Card 5 (Ana, Assistant manager, caring for her son with autism)
Empathy map example

Think / Feel	**See**
My son's needs always come first. Feels stressed, tired, and worried about being judged as less committed at work.	Long therapy schedules, tight project deadlines. Other employees without caring responsibilities are progressing faster.
Say/ Do	**Hear**
Requests emergency leave; sometimes misses deadlines. She shares her situation with close colleagues.	Encouragement from friends and close colleagues, frustration from her manager about missed deadlines or lack of concentration; advice from parents is similar situations.
Identified Support Gap: Lack of emergency leave arrangements or flexible work arrangements for carers.	
Proposed Improvement: Provide paid emergency leave and introduce flexible work arrangements for employees with care responsibilities.	

Generic Guidelines for Any Role Card
Empathy Map – Common Patterns

Think / Feel	**See**
Carers often experience stress, guilt, fear of burnout. They want to do well in both roles (employee and carer) and feel pulled in two directions.	Limited formal support in the workplace Colleagues without care duties advancing more easily Family expectations to provide constant care
Say/ Do	**Hear**
They often request flexible working arrangements, avoid extra tasks, appear distracted or tired. They often say "I can manage"	Mixed messaged: support from family/ friends; criticism from managers or colleagues about reliability and commitment
Typical Support Gaps Identified: ● Lack of formal carers' leave or policies ● Negative perceptions of carers at work ● Limited flexibility or emergency support	
Typical Improvements Proposed: ● Introduce or formalise carers' leave ● Training for managers to support employees with caring responsibilities ● Create awareness campaigns to reduce stigma	

- Offer peer networks to support carers

Activity 2: Workplace Audit - Carer-Friendly or Not?

Aim

- To assess how supportive a workplace is for employees with caring responsibilities, identifying strengths and weaknesses, and proposing solutions for improvement.

Materials and Resources

- Printed checklist (Carer-Friendly Workplace)
- Pens, markers, sticky notes
- Fictional company profile (optional; e.g. *Company W*, provided by trainer)

Steps

Step 1 Trainer introduces the concept of carer-friendly workplace and distributes the printed checklist.

Step 2 Participants work in pairs or small groups to complete the checklist. They can analyse:
- their own workplace or
- a fictional company profile provided by the trainer (e.g. Company W with 200 employees, flexible hours but no carers' leave, supportive managers but no formal policies)

Step 3 In pairs or small groups, participants complete the checklist. They review each practice and tick whether it is Present, Absent, or Needs Improvement in the workplace they are analysing.
- From the items ticked as Present, groups select two practices they consider strong points of the workplace (e.g. flexible working hours, supportive managers)
- From the items ticked as Absent or Needs Improvement, groups select two priority issues where change is most urgent.
- Groups write their 2 strengths and 2 weaknesses/ areas for improvement on a flipchart sheet (or in a worksheet provided by the trainer).

Step 4 Each group presents their results to the whole class.

Read the information below and complete the checklist

Fictional Company Profile: Company

Sector and size	Mid-size manufacturer with 200 employees
Work arrangements	The company provides some flexible working for administrative staff, but production workers follow fixed shifts
Remote work	Possible only for office roles.
Carers' leave	None - Employees rely on annual leave or unpaid leave when facing care responsibilities
HR policies	Do not explicitly recognise carers
Support programmes	The company does not provide training, peer networks or employee assistance programmes.
Managerial support	In general managers are supportive, but flexibility depends on individual goodwill rather than clear organisational policies

Carer-Friendly Workplace Checklist

Practice	Present	Absent	Needs Improvement
Flexible working-hours (start/finish times, part-time options)			
Remote work or hybrid arrangements			
Paid carers' leave			
Unpaid emergency leave			
Recognition of carers in HR policies			
Inclusion of carers in diversity and inclusion strategies (recognising carers as a specific group)			
Confidential discussion with manager about care responsibilities			
Training opportunities for carers			
Employee assistance programme (counselling, support groups)			
Carer peer networks within the organisation			
Awareness campaigns on carers' issues in the workplace			
Financial support or allowances (vouchers, subsidies for care services)			
Regular employee support regarding work-life balance			

Key Takeaways of Module 1

- Europe faces rapid population ageing, with the share of people 65+ expected to reach record levels by 2050.
- Long-term care (LTC) supports individuals who can no longer manage daily living independently, through health, social, and personal assistance.
- Formal care (paid, trained professionals in hospitals, residential facilities, or community services) is increasingly constrained by issues of availability, affordability, and quality. Waiting lists, high costs, and staff shortages leave many older adults without the support they require.
- Informal care (family members, friends, or neighbours) covers up to 80% of all care needs in Europe yet remains undervalued and invisible. it the true backbone of the system. Yet, this contribution is often invisible and undervalued.
- Informal care is strongly gendered: women, particularly daughters and daughters-in-law, shoulder most responsibilities.
- Informal care can bring personal fulfilment and skills development, but also carries heavy costs, including emotional strain, financial sacrifice, and negative effects on health and employment.
- Cultural traditions of intergenerational solidarity sustain informal care, but shrinking families make this model unsustainable without proper recognition and support.
- Without resources and respite, family carers face burnout and social isolation, undermining both their wellbeing and the resilience of the care system.

- Informal caregiving is critical for sustaining long-term care systems across Europe but has deep effects on carers' wellbeing.
- Employment impact: Women are far more likely than men to reduce working hours, work part-time, or exit the workforce prematurely to provide care. This creates persistent gender gaps in employment rates across Europe.
- Physical impact: Caregiving tasks such (lifting, bathing, mobility support) cause musculoskeletal problems, fatigue, and chronic health conditions.
- Emotional impact: Carers experience stress, blurred boundaries, family tensions/ conflicts, social isolation, burnout, and anxiety, and long-term psychological strain, though sometimes stronger family bonds.
- Recognition: Caregiving is frequently regarded as a private, family duty, rarely compensated or formally acknowledged. Lack of training or institutional support reduces the quality of care delivered and affects the wellbeing of carers.
- Financial impact: Unpaid care leads to long-term vulnerability, with many carers (especially women) relying on family resources or limited state aid.
- Cultural expectations: "familistic" norms frame care as women's duty and institutionalisation as shameful or inappropriate, reinforcing guilt and invisibility of informal caregiving in policy.

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