ICWE

Informal Carers Well-Being Enhanced

ICWE Working with Informal Carers

Training Program

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Contents

Introduction

This training program addresses the needs of adult educators and care professionals in their work with informal carers. Specifically, it aims to improve the professionals' competencies in effectively communicating with informal carers and provide them with useful, needs-based information for their role as caretakers.

Module 1: General Information on Caretaking

Introduction

This module introduces informal caregiving (IC) by defining its scope and distinguishing it from formal caregiving. It examines the various responsibilities informal caregivers undertake, including emotional, psychological, physical and logistical challenges, and highlights the global prevalence of informal caregiving. By understanding these demands, stakeholders can better recognize the essential role of informal caregivers and advocate for improved resources and services to support them.

Learning Objectives

- Define informal caregiving and differentiate it from formal caregiving.
- Understand the types of support informal caregivers provide, including physical, emotional and medical care.
- Identify the emotional, psychological, physical and logistical challenges faced by informal caregivers.
- Recognize the importance of holistically assessing and addressing the needs of care recipients, including physical, emotional and social well-being.
- Explore the long-term physical and mental health impacts of caregiving on informal caregivers.
- Understand national legal protections and rights relevant to informal caregivers.

Introduction to Formal Caregiving

Definition and scope of informal caregiving

Caregiving, as a general concept, refers to the assistance, or care, provided by a person to another person. Etymologically, 'care' originates from the term "wicim", an Old English term twitch means "mental suffering, mourning, sorrow, or trouble", while "give" to "bestow gratuitously" (Charalambous, 2023; Hermanns & Mastel-Smith B, 2012). Combined "caregiving is the action/process of helping those who are suffering" (Hermanns & Mastel-Smith B, 2012).

> *'There are only four kinds of people in the world: those who have been caregivers, those who are currently caregivers, those who will be caregivers, and those who will need caregivers. '*
>
> *Rosalyn Carter*

Informal caregiving (IC), as opposed to formal caregiving, is assistance provided to someone by another person belonging to their social network, typically family members or friends who are not trained professionals. The financial nature also differs; it is unpaid assistance. (WHO, 2019). The table below further illustrates the differences between formal and informal care.

Table 1: Basic characteristics of formal and informal care (Džakula, Banadinović, Lončarek & Vočanec, 2023)

Feature	**Formal**	**Informal**
Provider	Trainer professionals	Family members, friends, or neighbors
Payment	Paid services	Unpaid services
Setting	Structured setting (nursing home, assisted living facility, home health agency)	Home Based or community-based
Regulation	Regulated by government agencies or professional organizations	Unregulated
Focus	Specific tasks and services	Personalized care and support
Flexibility	Schedules and services may be more rigid	Schedules and services may be more flexible
Emotional Connection	May have less emotional connection with the recipient	May have a strong emotional connection with the recipient

In defining IC, three essential characteristics describe informal caregivers:

> One, someone who systematically (at least twice a week) provides care and, two, that someone has long-term needs either by a chronic illness, disability or other. Three, they are unpaid and not a part of any professional framework (Charalambous, 2023; Henwood, Larkin & Milne, 2017).

The prevalence of IC globally is vast; often referred to as the "invisible workforce", informal caregivers provide care for their family members or other individuals in the millions. A report by Alzheimer's Disease International found that the average care by informal workers for people living with dementia was approximately 6 hours a day and completed by around 40 million full-time workers in 2015 with the figure estimated to increase to 65 million by 2030 (Wimo et al., 2018). In the EU specifically, it is estimated that informal caregiving approximates 60% of all long-term care and informal caregivers make up 10- 25% of the European population depending on how IC is measured (Triantafllou et al., 2010). The financial value of IC cannot be understated; the economic value in countries like the United States is estimated to be in the billions annually (Chari et al., 2015).

Different Types of Care

Informal caregivers provide different types of assistance to the people they care for, typically depending on their respective needs. Similar to formal caregiving, unpaid caregiving varies in duration. Short-term IC could include care following hospitalization and long-term IC could be due to a disability or chronic illness (National Alliance for Caregiving & AARP, 2020). Often, IC also extends beyond the medical and physical needs and often encompasses emotional and social support and is typically provided in private households (Grigorovich et al., 2021). The table below outlines four types of care typically found in IC.

Routine activities of daily living (ADLs) Physical care: e.g., bathing, eating, bathroom	**Instrumental activities of daily living (IADLs)** Transportation, Finances, Housework, Shopping
Companionship and emotional support Comfort and company, coping with stress/depression	**Medical and Nursing** Administering medication, wound care, medical device care

(Reinhad et al. 2012)

Informal caregivers, in contrast with formal caregivers may live with recipients of care in the same household, frequently blurring the lines and challenging the boundaries between personal life and caregiving (Evercare Study, 2006).

Gender & Culture

Most informal carers are between the ages of 50 and 75 and they are typically taking care of parents, parents-in-law or partners (Verbakel et al., 2014). Women are overwhelmingly taking on caregiving roles on a global scale. More specifically, older women are more likely to be informal carers; 21% of women aged 50-64 as compared with 11% of men of comparable age provided IC every day or several days a week in 2016. Younger generations (25-49) provide care in reduced numbers; 13% for women and 9% for men (European Institute for Gender Equality, 2019).

There are multiple explanations as to why this phenomenon occurs. One explanation is the patriarchal expectations for women to perform traditional gender roles as ‘natural caregivers’ and the intersection between cultural, ethnic and religious beliefs. IC practices are often influenced by different cultural expectations, mainly who should provide care, what kind of care is provided and how the care is perceived by the greater family and community (Dilworth-Anderson et al., 2005).

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Roles and Responsibilities of Informal Carers

Common duties and tasks

Informal caregivers perform a variety of different tasks for the individuals they care for. Formal caregivers typically focus on specific tasks related to their professional training, like clinical and medical tasks alongside physical assistance. Informal caregivers, however, due to the nature of their relationship with the person they care for and the blurring of lines between their relationship with the carer as family member and as care receiver, take on a broader set of responsibilities. These include nursing care, pharmaceutical management, coordination of care, financial management, as well as providing psychosocial support. Informal caregivers report that psychosocial support, social engagement, and physical assistance are the most common types of care they provide. The table below outlines various types of care and a list of duties commonly observed among ICs.
Source: (Boyle, 2023 p.38)

Table 4 - Multidimensional components of care mastery expected of informal cancer caregivers

Care coordination	Informational
Schedule medical care appointments Accompany and navigate the healthcare system: parking, waiting, accessing wheelchair Understand varied roles of providers (i.e., who to ask for what) Coordinate visitation Shop for and order supplies, medications, equipment Mobilize resources	Prepare questions relative to appropriate care provider Chronicle progress to providers Liaison with professional network to determine next steps Manage information exchange Participate in problem-solving and decision-making

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Determine delegation of tasks (i.e., which and to who) Anticipate and troubleshoot gaps in care Plan transition to new care sites	Provide medical updates about patient status to social and employment network Liaison with family network to inform nature of patient status Explain rationale for treatment decisions to family members
Psychosocial	**Functional**
Respond to negative emotions Provide encouragement to patient Offer reassurance to family Plan opportunities for socializing Manage personal emotions Manage frustration related to system fragmentation Contain anxiety about the unknown Assume responsibility for self-care	Assist with ADLs, IADLs Assume responsibilities for doing or delegating domestic tasks (i.e., meal shopping and preparation, cleaning, home upkeep) Assist with adherence to care recommendations (i.e., exercise) Troubleshoot medical equipment malfunction Arrange or provide for transportation
Nursing care	**Pharmaceutical**
Assist with toileting, mobility Monitor weight loss, sleep, pain, mood, fatigue, and other symptoms Assess intensity and pattern of toxicity Manage symptom distress	Oversee drug utilization Organize, supervise, request refill orders Ensure dose/schedule accuracy Fill pill reminder devices

Advocate for medication titration Describe the nature of potentially emergent symptoms and scenarios Modify patient care based on condition changes Perform drain, port, wound care, and dressing changes Determine environmental safety Advocate on patient's behalf Assess nature of patient and family coping Make referrals when indicated Ensure advance care planning paperwork is available	Monitor level of adherence Consider strategies to improve adherence Monitor symptoms associated with new medication Respond to and/or research suggestions advocating use of complementary substances Financial Maintain/file of medical paperwork Oversee bill payment Lobby with insurers Track paperwork documenting discrepancies or problems Establish location of will

Research on Parkinson's disease conducted in the United Kingdom indicated that approximately 80% of informal caregivers (ICs) assist with domestic tasks such as cooking and cleaning, as well as social engagement activities like relationship building and providing companionship. Other tasks that were commonly reported by caregivers were dressing (63%), feeding (49%), bathing (41%) and toileting (37%) (Hand et al., 2019).

Balancing caregiving with other responsibilities

In the European Union, it is estimated that 50-60% of informal caregivers are working either full-time or part-time jobs simultaneously as they are providing care. (UNECE, 2019).

Given the fact that women are disproportionately taking on long-term caregiving roles, it is evident that the impact of caregiving has significant consequences for their careers and their financial stability. To perform their caregiving roles, women are more likely to work fewer hours, have to interrupt their careers, decline offers for promotions, or even leave the workforce entirely. Additionally, they face long-term consequences; diminished earning potential, limited career growth, reduced retirement savings and lower overall lifetime earnings (Pavalko & Woodbury, 2000). This burden of responsibilities creates an effect of further amplifying gender inequalities in employment as well as economic security.

Men are less likely to reduce work hours or need to leave the workforce to accommodate their caregiving; research shows that they are more likely to complement their caregiving with outside assistance, such as hiring formal caregivers. Additionally, the tasks and duties they typically perform are more practical and task-oriented rather than psychosocial. When men do decide to reduce working hours or step back from their careers, they often encounter societal pushback; they face societal pressure related to traditional ideas of masculinity which in turn positions them to experience role conflict and ultimately emotional strain (Pavalko & Woodbury, 2000; Thompson et al., 2012).

‘Sandwich Generation’
“Individuals or couples within the age group 45 to 65 who, in addition to their work activities, also take care of their own (young or growing up) children together with the care of their ageing parents.” (Bronselaer, 2016).
Impact ● Financial stress: Reduced working hours→ reduced financial stability ● Emotional toll: High levels of stress, depression, physical exhaustion and burnout ● Reduced social life: Reduced time for activities and nurturing of social relationships → isolation ● Family conflicts: Disagreement on the assignment of tasks and duties→ Stress and reduced family cohesion
European Institute for Gender Equality. 2017; Pierret, 2006.

Beyond gendered expectations, cultural upbringing, norms and beliefs can impact the conception and application of caregiving. In many societies caregiving, especially towards family members, is viewed as an obligation or duty rather than an individual choice, despite the availability of professional caregiving services or institutional care. In multigenerational households especially, there is a heavy stigma associated with outsourcing the caregiving of a family member, especially the placement of an elder in a nursing or community home. (Kao et al., 2016; Schulz & Eden, 2016).

Identifying the Needs of Care Recipients

Assessing physical, emotional, and social needs

Evaluating the needs of people receiving care is important for providing tailored support. This involves checking their physical, emotional and social needs to ensure they are well taken care of. The table below outlines assessment protocols for care recipients categorized in physical, emotional and social needs.

Physical Needs Assessment	
Activities of Daily Living (ADLs): ● Conduct regular assessments of the care recipient’s ability to perform ADLs to identify areas where assistance is needed.	Instrumental Activities of Daily Living (IADLs): ● Assess IADLs, such as managing finances, meal preparation, transportation and medication management, to determine the level of support required.
Health Monitoring: ● Monitor health conditions, track symptoms, and ensure proper management of chronic illnesses through appropriate medical interventions.	Home Environment Assessment: ● Evaluate the care recipient’s home for safety and accessibility, identifying potential hazards and necessary modifications to support independence.
Regular Updates: ● Regularly update care plans based on changing physical needs to ensure responsive and personalized care.	

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Emotional and Psychological Needs Assessment	
Identification of Emotional Needs: - Identify emotional and psychological needs, particularly for those dealing with conditions such as depression, anxiety or social isolation.	Decision-Making Participation: - Assess how well the care recipient can participate in decision-making about their care, which can change over time, especially in cases of cognitive decline.
Access to Mental Health Resources: 1. Ensure that assessments include access to mental health services for both care recipients and caregivers, as mental health plays a crucial role in overall well-being.	
Social Needs Assessment	
Facilitating Social Interaction: - Facilitate social interaction and community engagement to ensure the care recipient maintains relationships and participates in activities.	Evaluation of Social Support Networks: - Assess the presence and effectiveness of the care recipient's social support networks, including family, friends and community resources.
Cultural and Environmental Considerations	
Understanding Cultural Context: - Recognize how cultural beliefs and values affect the care recipient's needs, preferences and willingness to engage in certain activities or care plans.	Environmental Needs Assessment: 1. Assess the physical environment of the care recipient's home for safety and accessibility to enhance independence and comfort.
Bangerter et al. (2019); Barker & Fink (2019); Casado et al. (2021); Cohen & Wills (1985); Gitlin et al. (2010); Lawton & Brody (1969); Pinquart & Sörensen (2011); Schulz & Eden (2016).	

Personalized care planning

Personalized care planning is an approach to healthcare in which individual custom care plans are created that fit the unique needs of each individual. The plans are actively and collaboratively created between patients and healthcare providers and should include each patient's goals, and preferences and accurately reflect their values (NHS., 2024). This approach, unlike traditional routes, prioritizes the patient and takes into account their health as well as their emotional well-being and social support. Research on individuals with chronic conditions shows that personalized care planning can have multiple positive impacts such as improved health patient outcomes, enhanced patient satisfaction and higher adherence to medical protocols (Coulter et al., 2015). There are however many challenges in its implementation; Healthcare providers are insufficiently trained, lack of resources and challenges in the coordination between settings and healthcare professionals.

Common Care Cases

Understanding Alzheimer's Symptoms and Dementia

> "Alzheimer's disease is a type of brain disease, just as coronary artery disease is a type of heart disease. It is caused by damage to nerve cells (neurons) in the brain. The brain's neurons are essential to all human activity, including thinking, talking and walking."
>
> (Alzheimer's Association, 2024 p. 5)

Alzheimer's disease is a progressive neurodegenerative disorder characterized by a gradual decline in cognitive function, memory and overall daily functioning. In simple terms, the disease slowly and over time causes brain changes; the brain shrinks and then the brain cells eventually die. Approximately 6.5 million people in the U.S. live with Alzheimer's (Alzheimer's Association, 2022).

Dementia is an umbrella term for a group of symptoms. Symptoms characteristic of dementia typically entail memory, language, problem-solving and thinking skills. Alzheimer's is one cause of dementia. Specifically, the changes the brain experiences with Alzheimer's are the most common contributor to dementia. (Alzheimer's Association, 2024). Dementia caused by Alzheimer's is called 'Alzheimer's Dementia'. The progression of the disease is a gradual decline in memory, language, problem-solving and thinking skills ultimately affecting the ability to function.

Globally, more than 55 million people have dementia; In the European Union alone, 8 million people are affected by dementia. Alzheimer's dementia is the most common form and estimates suggest it makes up for about 60-70% of cases (World Health Organization, 2024). Dementia is the leading cause of disability and dependency in older adults (Alzheimer Europe, 2024).

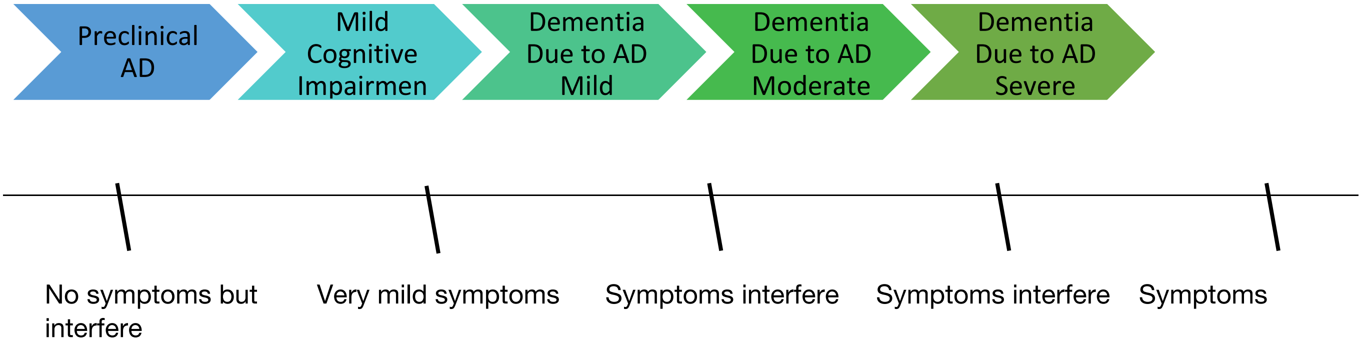
Signs of Alzheimer's Dementia (Adapted)	
Memory Loss that disrupts daily life	Forgetting learned information, asking the same question over and over, relying on memory aids
Challenges in planning or solving problems:	Changes in ability to follow or work with numbers, follow a familiar recipe, keep track of bills, difficulty concentrating
Difficulty completing familial tasks	Trouble driving to a familiar location, organizing a grocery list, remembering the rules of a game
Confusion with time or place	Lose track of dates, seasons and passage of time. Forget where they are or how they got there
Trouble understanding visual images and spatial relationships	Vision problems, trouble judging distance, determining color and contrast, issues with driving
New problems with words in speaking or writing	Trouble joining or following a conversation, repairing themselves, struggling with vocabulary, trouble naming familiar objects, and naming objects incorrectly
Misplacing things and losing their ability to retrace steps	Placing objects in unusual places, losing things, may accusing others of stealing

Decreased or poor judgment	Changes in judgment or decision-making, paying less attention to grooming and keeping themselves clean
Withdrawal from work or social activities	Changes in holding or following conversations →hobby withdrawal, trouble keeping up with sports teams or activities
Changes in mood, personality, and behavior	Can become confused, suspicious, depressed, fearful or anxious, easily upset at home, work, friends or when out of their comfort zones
Source: Alzheimer’s Association. (2024) Alzheimer’s Disease Facts and Figures. Alzheimers Dement 2024;20(5).	

The Alzheimer's disease continuum describes the gradual progression from unnoticed brain changes to memory and thinking problems, eventually leading to physical disability and is divided into three main stages: preclinical Alzheimer’s, mild cognitive impairment (MCI) and Alzheimer’s dementia, with the dementia phase further classified into mild, moderate and severe stages. The time individuals spend in each stage varies based on factors such as age, genetics and other influences. (Alzheimer's Association, 2024, p. 10).

Figure 1

Alzheimer’s Disease (AD) Continuum*



possible biological changes in the brain	that may not interfere with everyday activities	with some everyday activities	with many everyday activities	with most everyday activities

*Although these arrows are of equal size, the components of the AD continuum are not equal in duration.

Recognizing Mental Illness Symptoms and Personality Changes in Care Recipients

Informal caregivers typically will begin to regularly care for someone following a diagnosis and a decline in abilities. It is however imperative that symptoms and signs are identified early and addressed on time. This applies especially to mental health symptoms.

Many patients with dementia can exhibit changes in personality and behavior, such as agitation, withdrawal and mood swings; these can mistakenly be attributed to natural aging or an expected progression of the disease. Such behavioral changes, however, require timely intervention as they may indicate mental health issues, especially personality changes like aggression, emotional flatness or irritability. The intertwined nature of dementia and mental illness can complicate the process of diagnosis and symptoms as symptoms can overlap. Delayed intervention for symptoms like anxiety and depression can also worsen cognitive impairment (WHO, 2019). It is therefore vital that caregivers are on the lookout for any onset of mental health issues and intervene as soon as such symptoms are present (Natural Institute of Aging, 2019).

Changes in personality and behavior (Mayo Clinic, 2024)		
• Depression • Loss of interest in activities • Social withdrawal	• Mood swings • Distrust in others • Anger or aggression • Changes in sleeping habits	• Wandering • Loss of inhibitions • Delusions, such as believing something has been stolen

As aforementioned, it is vital to complete comprehensive assessments and screenings for cognitive and mental health (American Academy of Neurology., 2016; WHO, 2019). One way this can be applied is for caregivers themselves to actively monitor care recipients' abilities to perform Activities of Daily Living (ADLs) and Instrumental activities of daily living (IADLs) (Alzheimer's Society, 2020). This all-encompassing approach can ensure that interventions are targeted and personalised so the quality of life can be enhanced for both care recipients and caregivers. Additionally, caregivers should work on maintaining an open line of communication with care recipients; they should attempt to actively engage in conversations, listen to care recipients' feelings and experiences, and be on the lookout for emotional distress. This approach can help enhance emotional connections and lead to better identification of any mental health issues (Roth et al., 2019). Caregivers also should be aware of available resources near them as early identification and intervention can significantly impact the quality of life.

Finally, most of the duties and responsibilities fall to the caregiver; it's vital that the caregivers themselves also ensure to take care of their well-being as research shows that stress and burnout can impact their ability to effectively care for the care recipients; they may fail to recognize changes in behavior and mental health (Australian Government, 2015).

Challenges Faced by Informal Carers

Informal carers face many challenges. As informal carers are often juggling both individual and immediate family needs, as well as caring for someone else they can become overstrained and overburdened. One in four informal caregivers report feeling stressed out (De Klerk et al, 2017). The setup often leads to adverse effects on both psychological and physical aspects.

Caregiver burden: 'a multidimensional response to the negative appraisal and perceived stress resulting from taking care of an ill individual' (p. 846) (Kim et al., 2012).

Emotional and Psychological Challenges

The table below outlines research findings on the emotional and psychological challenges informal caregivers face.

Challenge	Description
Psychological distress	50% of caregivers report high levels of stress and psychological strain, which worsens with the severity of the care recipient's condition.
Stress and emotional exhaustion	Long-term caregiving can lead to guilt, frustration, anxiety and emotional exhaustion.
Decline in health	Especially for carers managing severe mental illness or Alzheimer's.
Isolation and lack of support	Lack of professional support by healthcare systems can lead to feelings of emotional strain and helplessness.
Inadequacy and stress from lack of training	Lack of training leads to feelings of inadequacy, increasing stress for caregivers.
Mental health risks	Long-term caregiving is associated with risks of developing anxiety, depression and PTSD, particularly in cases of terminal illness.
Guilt and frustration	Caregivers often feel guilty about perceived inadequacies in care and frustrated from balancing personal needs with caregiving responsibilities.
Gendered challenges	Women face societal pressures to take on caregiving roles, while male caregivers may experience isolation and a lack of support.
Burnout	Lack of formal support means caregivers must constantly adapt, leading to emotional and physical burnout.

Sources: Adelman et al. (2014); Hagglund et al. (2019); Khasne et al. (2020);Müller et al. (2022);Papastavrou et al. (2011);Pavalko & Woodbury (2000); Pinquart & Sörensen (2003); Roth et al. (2016); Schulz et al. (2020); Sung et al. (2022); Thompson et al. (2012).

Physical and Logistical Challenges

The table below outlines research findings on the physical and logistical challenges informal caregivers face.

Challenge	Description
Financial strain	Caregivers often face financial challenges, such as out-of-pocket expenses for medical care, transportation and supplies.
Time constraints and overwhelm	Caregiving requires significant time, leading caregivers to feel overwhelmed as they balance caregiving with personal and professional responsibilities.
Physical health issues	Caregivers frequently experience physical ailments such as back pain, fatigue, and chronic illness due to the demanding nature of caregiving tasks. Caregivers who are stretched out too thin use more healthcare services as well as get more prescribed medication.
Coordinating care and healthcare systems	Navigating complex healthcare systems and coordinating care among multiple providers often leads to frustration.
Lifting and moving care recipients	The physical demands of lifting and moving care recipients contribute to health issues such as musculoskeletal strain.

Reduced work hours or job loss	Caregivers often reduce their work hours or leave their jobs entirely, which exacerbates financial strain.
Lack of access to community resources	Many caregivers struggle with insufficient access to community resources.
Grief and post-caregiving challenges	After the care recipient’s death or institutionalization, caregivers may experience grief and difficulty reintegrating into work and social life.
Sources: Fredman et al. (2010); Hagglund et al. (2019); Khasne et al. (2020); Müller et al. (2022); National Alliance for Caregiving (2020); Serrano-Aguilar, (2006); Schulz & Eden (2016); Schulz et al. (2016); Sung et al. (2022).	

Support for Young Carers and Caregivers of Children

Young carers are children or adolescents who provide significant care to family members, often without adequate recognition or support. These young individuals may assist with physical tasks like bathing or lifting, manage household responsibilities or offer emotional support to parents or siblings facing illness or disability. The caregiving role, although noble, places a substantial burden on their emotional, academic/work and social development. Studies show that young carers are more likely to miss school, experience anxiety or depression and face social isolation compared to their peers. They may struggle to balance educational demands with caregiving responsibilities, often sacrificing personal development and future opportunities.

For caregivers of children with chronic illnesses or disabilities, the challenges are different but equally complex. These caregivers, often parents or guardians, must navigate medical systems, manage treatments or therapies and adapt their parenting style to meet the child’s evolving developmental and emotional needs. The pressure to be constantly vigilant, coupled with sleep deprivation and financial strain, can lead to caregiver burnout.

To support both groups effectively, systems should provide targeted resources such as peer support groups, educational accommodations, counseling services and respite care. Schools and community organizations play a critical role in identifying young carers and ensuring their needs do not go unnoticed. Public awareness campaigns and caregiver education programs are also essential to destigmatize caregiving at a young age and promote resilience.

Exercises/ Activities

Scenario:

Mrs. Maria Evans is a 75-year-old woman who was diagnosed with Alzheimer’s disease two years ago. She lives at home with her daughter, Anna, who is her primary caregiver. Anna, 42 years old, also works part-time as a data analyst. Over the past year, Mrs. Evans’ condition has worsened, and she now requires assistance with almost all daily tasks. In addition to cognitive decline, Mrs. Evans struggles with arthritis, making mobility difficult. Her memory loss has worsened and she often forgets familiar faces, including Anna’s. She experiences frequent mood swings, sometimes becoming agitated or withdrawn. Anna, as the sole caregiver, is feeling overwhelmed by her caregiving responsibilities and balancing her work life. She reports feeling physically exhausted and emotionally drained, with limited time for self-care or social interactions.

Instructions:

1. Read the Case Study
2. Identify the Needs of the Care Recipient: After reading, participants will list the physical, emotional and social needs of the care recipient. These could include help with mobility, emotional reassurance or social engagement. Refer to section 3.3 for further details on needs assessment.
3. Analyze the Informal Caregivers Roles and Responsibilities: Participants will outline the various roles the caregiver plays, such as assisting with medical care, managing daily tasks and providing companionship. Refer to section 3.2 for a full list of roles and responsibilities.
4. Discuss the Challenges: Participants will identify specific challenges they infer from the case study. If there is time, participants can discuss possible strategies to address these challenges.
5. Present Findings

Expected Outcomes and Learning Points:

- Understanding Caregiver Roles and Responsibilities: Participants will gain a deeper understanding of the diverse roles informal caregivers play, from providing emotional support to managing medical care.
- Identifying Care Recipient Needs: Participants will learn to holistically assess the needs of care recipients, including physical, emotional and social aspects.

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- Recognizing Challenges and Solutions: Participants will identify common challenges faced by informal caregivers, such as emotional burnout or lack of support and discuss potential strategies to overcome these barriers.

Dealing with violence and aggression in the care environment

In informal caregiving environments, especially ones that are handling care recipients with Alzheimer's or dementia, aggression and violence can be common. Such behaviors can be exhibited physically, verbally or emotionally. They are typically influenced by the medical condition (e.g., Alzheimer's), environmental factors and any disruptions that create confusion to familiar routines (Duxbury & Whittington, 2005; Cohen-Mansfield, 2001).

Informal caregivers need to be well-informed and prepared to recognize and act on the early warning signs of aggression. A preventative approach is vital to any intervention strategy and especially important in dealing with aggression in dementia patients. As a general rule, calm and structured environments have been shown to minimize stress by creating a sense of safety and predictability ultimately reducing aggression (Duxbury & Whittington 2005). Research indicates that creating and sticking to risk assessment protocols and safety plans can help reduce incidents. More specifically, the plans can include environmental modifications, communication strategies and alert systems (Fricke et al, 2023).

Strategies for Managing aggression and violence in patients	
Identify Triggers	Observe and identify changes in body language or verbal cues to prevent escalation
De-Escalation	Maintaining calm tones, Maintaining non-threatening body language, Redirecting focus
Interventions	Non-pharmacological interventions like music therapy, sensory stimulation or physical activity

Safety Planning	Creating a personalized safety plan like preparing safety exits and having emergency contacts
Support Systems	Access to peer groups, counseling and other professional resources can help provide emotional and psychological relief to the caregiver
Professional Support	● Creating a network of professional support including social workers, therapists or doctors for help with additional strategies and monitoring ● Hiring emergency temporary care to allow caregivers to rest and to help them recharge for the ongoing needs of care ● Training caregivers on safe physical intervention methods
Sources: Alzheimer's Society, 2024; Cohen-Mansfield, 2001; Duxbury & Whittington, 2005; Fricke et al., 2023 ; Lachs & Pillemer, 2015	

Quiz

1) **What is the main distinction between formal and informal caregiving?**

a) Informal caregiving is paid and formal caregiving is unpaid.

b) Formal caregiving is provided by trained professionals, while informal caregiving is provided by non-professionals such as family members.

c) Informal caregiving only occurs in institutional settings.

Reflective Question: How does the emotional and psychological stress of caregiving affect an informal caregiver's ability to provide care?

2) **Which of the following is a common task performed by informal caregivers that formal caregivers may not typically engage in?**

a) Administering medications.

b) Providing emotional support and companionship.

c) Performing surgery.

Reflective Question: What logistical challenges do informal caregivers often face when balancing caregiving with other responsibilities?

3) **Why is it important to regularly assess both the physical and emotional needs of care recipients?**

a) To ensure care is personalized and responsive to changing needs.

b) To reduce the caregiver's workload.

c) To increase the duration of care provided.

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Module 2: Legal, Financial, and Other Useful Resources to Provide for Informal Carers

Introduction

Informal carers - relatives, friends, or neighbors who provide unpaid care to individuals in need - form the foundation of long-term care across Europe. Despite their essential contribution, their role is often under-recognized in public policy and under-supported by formal care systems. According to the European Commission, approximately 52 million Europeans provide informal long-term care on a regular basis, yet many do so without adequate legal protection, financial compensation, or access to training and support services.

Carers often face a complex range of responsibilities: from assisting with daily activities and administering medications, to providing emotional support and coordinating medical appointments. In doing so, they not only help their loved ones maintain dignity and independence, but also relieve pressure on formal healthcare and social systems. However,

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the weight of these duties can come at a cost to carers' own physical and mental health, employment prospects, and financial stability.

Recognising these challenges, the European Union has taken important steps to strengthen carers' rights and improve their access to services. Initiatives like the European Care Strategy (2022), the Work-Life Balance Directive (2019/1158), and Principle 18 of the European Pillar of Social Rights aim to increase formal recognition of caregiving and promote supportive conditions for carers in every Member State.

"Informal carers continue to provide the largest bulk of care in the EU." - **European Commission Staff Working Document (2022)**

This training module was developed to address the real and pressing needs of informal carers across Europe. It offers practical guidance on how to navigate legal frameworks, access financial support, and connect with networks and healthcare systems. It also provides insight into the growing recognition of young carers and those supporting children, and encourages carers to reflect on their rights, responsibilities, and the tools available to them. By the end of this module, participants will be able to:

- Identify key European legal instruments that protect the rights of informal carers, including their right to leave and flexible working arrangements.

- Understand the financial support and social benefits that may be available to carers at both EU and national levels.

- Discover and engage with community networks and digital platforms designed to provide practical support, training, and advocacy.

- Learn how to navigate different European healthcare systems and understand carers' rights to cross-border care.

- Explore targeted resources and good practices related to caregivers of children and young carers.

  This module does not aim to provide legal advice or exhaustive country-specific information, but rather a broad overview and gateway to further learning. Where possible, links and references to national authorities and organisations are included to support learners in taking the next steps suited to their personal situation.

"Supporting informal carers, who are often women and relatives of care receivers, through training, counselling, psychological and financial support, is a key priority." - European Commission, European Care Strategy (2022)

ADDITIONAL RESOURCES: You can listen to this podcast at this link:

https://podcasts.apple.com/gb/podcast/the-informal-carer/id1591933851?i=1000541324159

And this: https://shows.acast.com/conversations-with-carers/episodes/the-informal-carer

1. European Legal Frameworks for Caregiving

Across the European Union, informal carers benefit from a growing body of legislation that recognises their unique challenges and aims to create more inclusive, supportive environments. While the provision of care remains primarily a national responsibility, the EU has taken meaningful steps to improve the rights of carers - especially those balancing care with paid employment.

1.1 The Work-Life Balance Directive (2019/1158)

This directive, adopted in 2019, is a cornerstone of EU action for carers. It introduces minimum rights for workers with caregiving responsibilities and aims to address work-life balance through several key measures:

Carers' leave: the directive grants all workers the right to five working days of carers' leave per year. This is a legal entitlement and does not depend on the employer's goodwill.

Flexible working arrangements: carers have the right to request flexible working hours or remote work options to help them better manage their dual role.

Gender equality: a key objective of the directive is to promote a more equal sharing of care responsibilities between men and women by encouraging fathers and male relatives to take an active role in unpaid care.

It is up to each Member State to define the terms and conditions under which this leave is granted, including whether or not it is paid, but the legal right to time off is now guaranteed EU-wide.

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1.2 The European pillar of Social Rights

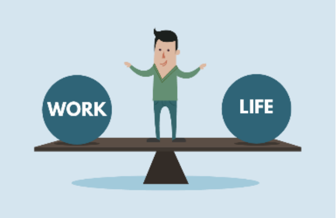
- Proclaimed in 2017, this political commitment serves as the EU's social policy compass. It includes 20 principles, two of which are directly relevant to informal carers: **Principle 9 – Work-life balance**: All workers have the right to suitable leave, flexible working arrangements, and access to care services.

- **Principle 18 – Long-term care**: Everyone has the right to affordable long-term care services of good quality, particularly home and community-based care.

These principles reinforce the EU's broader commitment to social justice and inclusion, and they underpin policies like the European Care Strategy and funding allocations under social programmes.

1.3 The Working Time Directive (2003/88/EC)

Although not specific to carers, this directive establishes rights that benefit them indirectly. It sets limits on weekly working hours and ensures minimum rest periods and paid annual leave. For informal carers who also work, these protections are essential in preventing burnout and safeguarding their health.



1.4 Anti-Discrimination and Equal Treatment Directives

Carers may also benefit from broader EU laws that protect workers from unfair treatment:

- **Directive 2000/78/EC (Employment Equality Directive)** prohibits discrimination in the workplace based on disability, religion, age, or sexual orientation. While caregiving is not explicitly mentioned, carers of people with disabilities may benefit indirectly.

- **Directive 2006/54/EC** on the implementation of the principle of equal opportunities and equal treatment of men and women in matters of employment and occupation also helps protect carers, especially women, from career penalties.

Together, these directives support carers' inclusion in the labour market and aim to eliminate systemic inequalities faced by those with care responsibilities.

2. Financial Support and Benefits in Europe

Caring for a loved one often brings with it significant personal and emotional rewards—but it can also carry serious financial consequences. Many informal carers reduce their working hours, leave their jobs, or incur out-of-pocket expenses for medical care, equipment, transport, and home adaptations. For this reason, access to financial and social protection is a key pillar of support for carers across Europe.

While support schemes vary widely from one country to another, the European Union has encouraged Member States to recognise and alleviate the financial burden carried by carers. These efforts are channelled both through funding programmes and through coordination of national social security systems.

2.1 EU-Level funding and programmes

Although the EU does not directly provide benefits to individual carers, several funding programmes indirectly support carers by financing projects in which they can participate or benefit from. These programmes are often implemented by local authorities, NGOs, or training providers, and can be highly valuable for carers seeking opportunities for education, inclusion, or community-based services.

- **European Social Fund Plus (ESF+)**
  This is the EU's main financial instrument for social inclusion, education, and employment. ESF+ funds can support:
    - Training courses and upskilling opportunities for carers wishing to re-enter the labour market
    - Support services such as respite care and psychological support
    - Local projects promoting gender equality in care
- **Erasmus+ (Adult Education and Lifelong Learning)**
  Though commonly associated with students, Erasmus+ also funds educational mobility for adults, including carers. Through this programme, carers may participate in exchange programmes, community learning experiences, or transnational training.
- **Horizon Europe**
  As the EU's main research and innovation programme, Horizon Europe funds projects exploring:
    - New models of long-term care and informal care integration
    - Technological tools to support home-based care

  - Digital and e-health solutions for carers and dependents

These opportunities are typically project-based, and carers should seek participation through local NGOs or community organisations engaged in EU-funded initiatives.

2.2 National Social Security Systems

The bulk of financial support for informal carers comes from national welfare systems. While policies differ across countries, common forms of support include health coverage, pension credits, allowances, and unemployment support.

- **Health Insurance Access**
  In most Member States, informal carers are entitled to basic health insurance, either through their own employment status or by being recognised as dependents of the care recipient. Some countries automatically include registered carers, while others require formal application. Health coverage is essential to ensure carers can look after both their dependents and themselves.

- **Pension Contributions and Credits**
  Several EU countries recognise caregiving periods as contributory for pension purposes.

  - For example, in **Germany**, carers providing more than 14 hours per week receive pension contributions from the long-term care insurance scheme.

  - In **France** and **Sweden**, similar pension credits are offered for recognised carers.

Carer's Allowances and Cash Benefits
Many countries provide monthly stipends to carers who meet certain eligibility criteria:

- **"Pflegegeld" in Germany** is a non-taxable allowance for people providing home-based care to relatives.

- The **UK's Carer's Allowance** provides weekly cash support for individuals caring for someone at least 35 hours per week.

- In **Italy**, financial support is usually regional and linked to levels of dependency of the care recipient.

These allowances help offset the costs of care, though the amounts often remain modest.

- **Unemployment and Income Protection**
  In some countries, carers who reduce or leave paid work due to caregiving responsibilities may be eligible for partial unemployment benefits.

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For instance, in **France** or the **Netherlands**, specific provisions exist to allow part-time carers to access income support during periods of care-related absence.

- **Tax Relief and Deductions**
  In addition to direct benefits, carers may be entitled to tax credits or deductions for disability-related expenses, home modifications, or transportation costs. These benefits require careful documentation and may vary depending on the household's income and care level.

  Carers are encouraged to contact their local social security or tax office to understand eligibility, application procedures, and supporting documentation required.

2.3 Navigating Funding and Support Opportunities

Accessing these benefits is not always straightforward. Barriers include bureaucratic complexity, lack of awareness, and inconsistent terminology across Member States. Carers often need guidance to:

- Identify the relevant national institutions (e.g., social welfare offices, municipalities, insurance bodies)
- Understand eligibility rules, which may depend on income, hours of care, or the level of dependency
- Collect necessary documentation (e.g., medical certificates, care assessments)

Support organisations like Eurocarers or national carer associations can provide guidance and help navigate these systems.

· See the EU Social Security Coordination portal for country-by-country guidance.

3. Accessing European Community Resources

In addition to legal and financial support, informal carers greatly benefit from being part of a community—especially when that community offers guidance, recognition, and opportunities to learn from others. In Europe, the key reference network for carers is Eurocarers, which brings together organisations, researchers, and policymakers from across the continent.

3.1 Eurocarers – The European Network for Informal Carers

Eurocarers is the leading European network dedicated to the needs and rights of informal carers. It represents carers' organisations and research institutions from more than 20 countries and works closely with the European Commission to promote care-related policies and improve support structures across the EU. Through its activities, Eurocarers provides:

- Up-to-date information on EU policies affecting carers
- Research publications and policy briefs
- Online training materials and guides
- A dedicated programme for young carers (Eurocarers Youth)
- Resources on mental health, gender equality, and work-life balance

Eurocarers also coordinates European Carers Day (6 October), raising awareness and visibility of carers' contributions. Their platform is an excellent starting point for carers looking to connect with national organisations, find practical tools, or explore EU-funded initiatives that promote wellbeing and inclusion.

4. Navigating European Healthcare Systems

One of the major responsibilities of informal carers is to help their care recipients access healthcare services. Whether it involves managing appointments, understanding treatment plans, or dealing with insurance paperwork, carers often serve as the primary link between vulnerable individuals and health systems. But navigating healthcare can be especially complex in Europe, where each country has its own structure, policies, and entitlements.

This section helps carers understand the different models of healthcare in Europe and outlines the rights related to accessing care both within and across borders.

4.1 Healthcare Systems Across Europe

In the European Union, healthcare is organised and financed differently from one Member State to another. However, most systems are based on one of three models:

- **The Beveridge Model**
  Funded primarily through general taxation and typically free at the point of use. Countries like the United Kingdom (before Brexit), Spain, and the Nordic states use this model. Services are often publicly provided and centrally managed.
- **The Bismarck Model**
  Based on social insurance systems funded jointly by employers and employees. It’s used in Germany, France, Austria, and several other countries. Individuals are insured through “sickness funds,” and both public and private providers may deliver services.

- **The National Health Insurance Model**

Found in countries like Italy, Portugal, and Greece, this model combines aspects of both the Beveridge and Bismarck systems. The government acts as a single payer, and care is delivered through a mix of public and private entities.
Although each country organises its system differently, all EU Member States are bound by common principles: universal access, solidarity, and quality care. For carers, this means that—despite national variations—they can expect access to a core set of healthcare services and should be informed of how to assist care recipients within their country's system.

· National ministries of health or local health authorities are often the best first contact for understanding the structure of services and referral procedures.

4.2 The European Health Insurance Card (EHIC)

The **European Health Insurance Card (EHIC)** is an important tool for informal carers who travel or temporarily relocate with their care recipient.
This free card allows EU citizens (as well as citizens of EEA countries and Switzerland) to access medically necessary public healthcare during short stays in another participating country. The card ensures that care is provided under the same conditions—and at the same cost (sometimes free)—as for local residents.

Important notes about the EHIC:

- It covers only *medically necessary* treatments during a temporary stay.
- It does **not** replace travel insurance and does not cover private healthcare.
- It is issued free of charge by the national health authority in the country of residence.

For informal carers, especially those travelling with people in need of ongoing medical care (e.g., dialysis, oxygen therapy), the EHIC can be a vital safeguard—though advance planning is always recommended.

4.3 Cross-Border Healthcare Rights (Directive 2011/24/EU)

Beyond emergency or unplanned care, EU citizens also have the right to seek **planned medical treatment** in another EU country under **Directive 2011/24/EU**.
This directive allows a patient to receive healthcare services in another Member State and claim reimbursement from their home system—usually up to the amount that the same treatment would cost at home.
For carers, this can be especially relevant in cases where:

- A treatment is not available or has long waiting times in the home country
- The care recipient is already temporarily staying in another EU country
- Specialist services are needed that are better provided abroad

Steps carers should take before planning cross-border care:

- Check if prior authorisation is required (for hospital stays or high-cost treatments)
- Confirm which costs are covered and what documents are needed
- Contact the national contact point for cross-border healthcare in their country

· Each Member State has a National Contact Point (NCP) for cross-border care. These offices provide guidance on patient rights, covered services, and reimbursement procedures.

5. Supporting Carers of Children and Young Carers

Not all informal carers support older adults. Across Europe, many carers are responsible for the care of children, adolescents, or other younger individuals living with chronic illness, disability, or psychological vulnerability. These carers face specific challenges that require tailored support—whether they are adults caring for children, or children themselves providing care.

This section explores both perspectives: adults who care for children, and **young carers**, a population that remains largely under-recognised despite their growing visibility in EU policy debates.

5.1 Caring for Children and Adolescents with Support Needs

Caring for a child with complex physical, cognitive, or emotional needs often involves navigating a web of services: schools, hospitals, social workers, therapists, and specialists. Unlike care for older adults, child-focused care must also consider educational development, emotional wellbeing, and family dynamics.

Carers in this context often report:

- High emotional stress and time pressure
- Limited access to respite services adapted to children
- Challenges coordinating between health, education, and social care providers
- Financial strain due to reduced work hours or additional medical costs

Across Europe, the level of support varies. Some Member States provide targeted allowances for carers of children with disabilities, while others offer tax benefits, priority access to social housing, or early intervention services. However, many families struggle to access inclusive schooling or face long waiting lists for therapy or specialist care.

Improving care for children also means supporting the family as a unit—including offering counselling, peer groups for parents, and integrated case management. Community organisations play a key role in bridging formal services with the daily needs of families.

5.2 Young Carers: Recognising an Invisible Group

Young carers are children, teenagers, or young adults (typically under 25) who provide significant care to a family member with a disability, illness, addiction, or other dependency. Their care may include household tasks, physical assistance, emotional support, interpreting, or managing appointments and medication.

This group faces unique challenges:

- Higher rates of anxiety, depression, and social isolation
- Difficulty concentrating or attending school regularly
- Lack of recognition by teachers, peers, or professionals
- Reduced access to leisure, friendships, or future opportunities

Because young carers often go unnoticed by professionals, they may not receive the support they need. In recent years, however, several EU countries have begun to develop policies and programs that explicitly target this group.

Examples include:

- **Sweden**: National strategies promote school-based support and early identification.
- **Austria and the Netherlands**: Municipal programmes offer youth clubs and mental health counselling for young carers.

At EU level, organisations such as **Eurocarers Youth** advocate for the inclusion of young carers in policy, research, and project development. Supporting young carers means investing in their wellbeing, educational attainment, and long-term life chances.

· “Young carers are still too often invisible, and their rights to education, participation and rest must be protected.” – Eurocarers Youth

6. Learning outcomes

These learning outcomes are designed to equip informal carers with the essential knowledge and skills to navigate the legal, financial, and community resources available across Europe effectively.

1. **Understanding National Healthcare Systems:** Carers will learn about different European healthcare systems, including the Beveridge, Bismarck, and National Health Insurance models. They will understand key features such as gatekeeping, patient co-payments, and reimbursement mechanisms.

2. **Navigating National Healthcare Systems:** Practical strategies for engaging with healthcare providers will be emphasized. Carers will learn to research, prepare for appointments, and build relationships, along with how to find and evaluate healthcare services using local resources.

3. **Patient Rights and Healthcare Regulations:** Participants will gain knowledge of patient rights, including consent and privacy, as well as how to navigate insurance and payment systems.

4. **Enhancing Caregiver Skills and Knowledge:** The significance of continuous learning will be highlighted. Carers will explore opportunities such as local workshops, online resources, and support groups to improve their skills and confidence.

5. **Addressing Challenges and Solutions:** Common challenges, such as complex administrative processes and language barriers, will be identified. Strategies for overcoming these issues, including advocacy and seeking professional guidance, will be discussed.

6. **European Legal Frameworks for Caregiving:** Participants will examine EU regulations impacting informal caregiving, including employment rights and social security benefits, helping them understand their legal protections.

7. **Financial Support and Benefits in Europe:** An overview of EU-level financial aid programs and country-specific benefits will be provided to inform carers of available financial resources.

8. **Accessing European Community Resources:** Carers will learn how to identify and connect with pan-European support networks and navigate EU-wide platforms for caregiving resources.

9. **Collaborating with European NGOs and Community Groups:** Effective strategies for collaboration with NGOs and community groups will be explored, highlighting the potential benefits of partnerships for caregivers.

7. Exercises/ Activities

Activity 1: Role-play

Description: Participants will engage in a role-play in which they will play various roles, such as caregivers, NGO representatives, and social service officials, to explore the dynamics of access to community resources and support from organisations.

Instructions:

- Distribute specific roles to participants with details of their goals and needs.
- Participants should interact with each other, discussing what resources or supports would be available, how to request them, and challenges that may arise.
- After the role-play, hold a reflective discussion on what they have learnt and what solutions could improve access to resources.

Expected outcomes and learning points: Participants will develop empathy and understanding for the difficulties caregivers face in accessing resources and services; they will also improve negotiation and problem-solving skills.

*****Role profile**

1. Family Caregiver: Maria, 45 years old

Role description: Maria takes care of her elderly father, who suffers from Alzheimer's disease. She works part-time and finds it difficult to reconcile work and caregiving needs. She needs financial support to cover the costs of caregiving and seeks training opportunities to improve her skills.

Objectives:

- Obtain information on possible financial benefits and public support.
- Find a training course to learn how to better manage the care of a person with Alzheimer's disease.
- Find out if there are psychological support services or support groups for caregivers.

Challenges:

- She has little free time and has difficulty navigating the bureaucratic system to apply for help.
- She feels emotionally overburdened and needs psychological support, but does not know where to turn.

2. Professional Caregiver: Luca, 30 years old

Role description: Luca works as a home carer for people with disabilities. He would like to expand his skills and obtain certifications recognised at European level to improve his career prospects. He is also interested in discovering resources that could help his clients.

Objectives:

- To find information on EU-funded or supported training courses for professional certification.
- To seek EU resources and assistance to improve the welfare of his clients.
- To find out if there are funding programmes that could help his clients to access additional services.

Challenges:

- He needs a recognised certification, but is not sure which courses are valid at European level.
- He wants to improve the quality of life of his clients, but often encounters bureaucratic obstacles.

3. NGO Representative: Giulia, 50 years old

Role description: Giulia works for an NGO that provides support to informal carers. Her organisation offers free legal advice and organises training courses, but has limited resources. She is looking for collaboration opportunities to expand the NGO's impact.

Objectives:

- To gather information on the needs of caregivers in order to develop new support programmes.
- Promote the services offered by the NGO, such as support groups and legal advice.
- Establish partnerships with other local authorities to optimise resources and expand available services.

Challenges:

- Limited financial resources preventing the expansion of NGO services.
- Difficulties in reaching new caregivers, especially those who may not be familiar with the services offered.

4. Social Services Officer: Paolo, 55 years old

Role description: Paolo is a social services officer responsible for caregiver support programmes in his community. His office can provide assistance in accessing financial contributions, but is often limited by strict regulations and insufficient budgets.

Objectives: To provide information on the criteria for accessing financial benefits and support services.

- Identify the main difficulties carers face in accessing services and assess how to improve application processes.
- To establish contact with the NGO represented by Giulia to explore possibilities for collaboration.

Challenges:

- Has to work with limited resources and has little flexibility to change the criteria for accessing funds.
- She is aware that the application process is complex but has little power to simplify it.

Activity 2: Interactive Storytelling: Sharing Caregiving Experiences

Description: Participants, in small groups, tell short stories or anecdotes related to their caregiving experience or the challenges faced by caregivers they know.
Instructions:

- Each participant shares a story or anecdote about how they handled a difficult situation as a caregiver.
- Other listeners can ask questions or offer suggestions on how they would have dealt with the situation.
- Conclude with a group discussion on what supports or resources might be useful in similar situations.

Learning points: Through storytelling, participants learn from the experiences of others, develop empathy and improve their understanding of the needs of carers.

Quiz

1. Which of the following statements best reflects the purpose of the Work-Life Balance Directive (EU) 2019/1158?

a) To regulate working hours across Europe uniformly

b) To guarantee access to public healthcare for informal carers

c) To promote flexible working and carers' leave to support work-care reconciliation

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2. According to the European Pillar of Social Rights, which two principles are most directly relevant to informal carers?

a) Principle 2 (Education) and Principle 11 (Housing assistance)

b) Principle 9 (Work-life balance) and Principle 18 (Long-term care)

c) Principle 5 (Secure employment) and Principle 13 (Unemployment benefits)

3. What is a key distinction of the Bismarck healthcare model compared to the Beveridge model?

a) It relies on employer-employee contributions to sickness funds It is tax-funded and publicly administered

b) It is tax-funded and publicly administered

c) It provides universal healthcare only to pensioners and carers

4. Under Directive 2011/24/EU, what must a citizen generally do before receiving planned medical care abroad?

a) Contact the embassy of the host country

b) Register with the foreign healthcare system

c) Obtain prior authorisation if required and clarify reimbursement terms

5. Why is the EHIC (European Health Insurance Card) not a substitute for travel insurance?

a) Because it doesn’t cover planned treatment or private services

b) Because it only applies to emergencies in non-EU countries

c) Because it is no longer valid post-Brexit

6. What role does Eurocarers play at the European level?

a) Provides direct financial assistance to caregivers

b) Coordinates long-term care insurance funds in Member States

c) Advocates for informal carers’ rights and disseminates resources and policy updates

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7. Which of the following is a potential disadvantage faced by young carers?

a) Increased risk of social isolation and academic underachievement

b) High visibility in national education policies

c) Early access to vocational programmes

8. What type of support is most commonly provided at national level to informal carers in the EU?

a) Personal assistance from EU civil servants

b) Direct cash benefits, pension credits, and access to health insurance

c) Fully funded private respite services for all registered carers

9. How can the European Social Fund Plus (ESF+) support carers indirectly?

a) By subsidising their personal income

b) By funding projects that provide training, community care, and reintegration into employment

c) By providing universal healthcare access across all EU states

10. What is one of the key challenges informal carers face when accessing financial or community support?

a) Navigating fragmented systems with limited guidance and unclear eligibility rules

b) Lack of public sympathy for carers' situations

c) Excessive taxation on caregiving benefits

Resources

32003L0088. EUR. (n.d.-a). https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX%3A32003L0088

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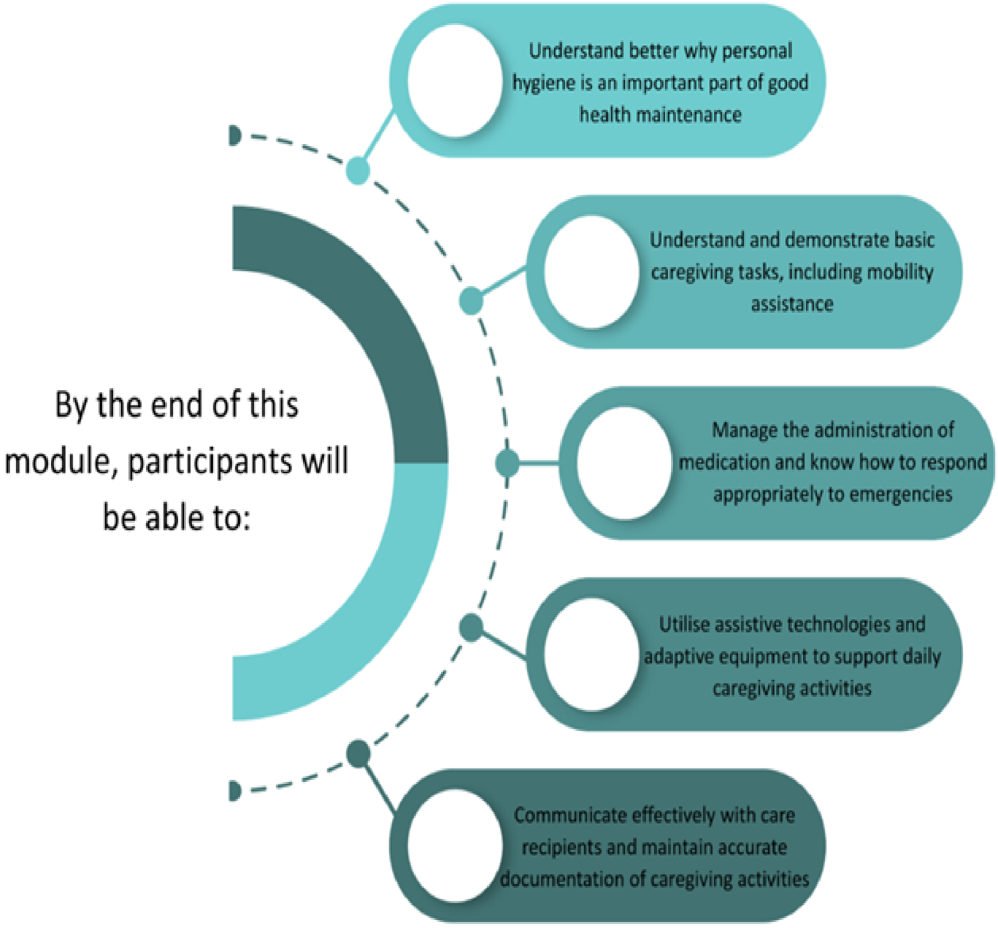
Module 3: Skills and Competences for Informal Carers

Introduction

Caregiving often seems to place significant emotional and physical demands on informal carers, many of whom are untrained. Module 3 focuses on equipping educators and care professionals with skills and competences needed to train and/or support informal carers. Participants will learn about central caregiving techniques, such as personal hygiene assistance, mobility support, medical management, and communication skills. They will gain both theoretical knowledge and practical experience in caregiving techniques, ensuring they are prepared to assist informal carers in developing essential caregiving skills.

Learning Outcomes



By the end of this module, participants will be able to:

- Understand better why personal hygiene is an important part of good health maintenance
- Understand and demonstrate basic caregiving tasks, including mobility assistance
- Manage the administration of medication and know how to respond appropriately to emergencies
- Utilise assistive technologies and adaptive equipment to support daily caregiving activities
- Communicate effectively with care recipients and maintain accurate documentation of caregiving activities

3.1 Basic Caregiving Skills

The learning objective of the first part is to understand personal hygiene and grooming techniques for care recipients and learn about safe mobility and transfer techniques to prevent injuries.

Personal Hygiene and Grooming

Personal hygiene and grooming are fundamental aspects of caregiving that not only maintain the physical health of care recipients but also contribute to their emotional well-being. Informal carers must understand the importance of maintaining a clean and well-groomed appearance for those in their care. Assisting with personal hygiene is crucial to maintain good health and prevent the spread of germs, reduce the risk of infection, and promote the dignity and self-esteem of the care recipient. However, these tasks can be deeply personal and sensitive. Caregivers must be respectful, supportive, and mindful of the individual's preferences, promoting an environment of trust and dignity.

Care needs for *hygiene* are tasks that help with health and infection prevention. It's about keeping germs from building up on the skin and other areas of the body. This includes washing the body in a shower, washing dirt from the hair, washing hands to stop the spread of disease, and cleaning up after using the toilet. Putting on appropriate clothing that is clean is part of a daily hygiene routine. Changing bed sheets at least every two weeks is a hygienic task. As sheets build up bacteria and insects like dust mites, changing and laundering sheets is important. This is why families need to discuss *housekeeping services* in addition to personal care services. Brushing and flossing teeth are part of a daily hygiene routine. Taking care of her bridges or dentures is part of hygiene. Hygiene also includes making sure the skin isn't dry and cracked or showing signs of infections or irritation and applying lotions and creams that treat those issues.

Grooming is an aspect of hygiene, but it's not as strongly tied to infection and disease control. It's more about how an individual looks. For example, trimming your nails is a grooming task. Trimming a mustache, beard, or shaving facial hair is grooming. Grooming tasks also include adding cologne after getting dressed, applying deodorant to prevent body odor, and styling the hair. Applying lip balm or facial moisturizer is part of grooming.

Personal cleaning and grooming activities, such as washing hair, nail care, shaving, or dressing, should be done in a way that respects the individual's choices and privacy and ensures comfort for care recipients. For example, some individuals might prefer to bathe at night, while others prefer to shower in the morning.

Personal hygiene and grooming should not only focus on physical hygiene but also support the emotional and psychological well-being of care recipients, ensuring that they feel respected, confident and valued. Therefore, it is also important to support individuals to be more independent. Some individuals may be able to bathe, shave, dress, and otherwise take care of themselves with no support. Others may need assistance or support to complete their personal care activities.

Maintaining good health also includes nutrition, leisure opportunities, sleep, and exercise. As you can see, there are many factors that contribute to feeling and looking good. Feeling and looking good are important to everyone's emotional and physical wellbeing. In the following section, personal care guidelines will be listed, which were collected through online desk research and compiled from various sources and handbooks (see references). They aim to provide an overview of the main personal hygiene and grooming skills.

Hair Grooming

Having well-groomed hair is important to everyone and is no less so for the individual you support. Individuals like different kinds of shampoo or conditioner and may have a preferred style. These choices should be respected and supported. Supplies that should be prepared beforehand are a *comb*, *brush*, *mirror*, and *personal hair products*.

- Remember, hairstyle is an individual choice. Ask the individual how he or she prefers his or her hair style today.
- Use only the individual's personal comb and brush and clean them regularly.
- Use a comb and brush with a gentle touch. Pulling on tangled hair can cause damage to the hair. If their hair is long, divide it into sections before combing or brushing.
- Gently combing or brushing from the scalp to the ends of the hair stimulates circulation. If the hair is curly, start at the ends of the hair to assure that all tangles are removed before brushing from the scalp to the ends.
- Combs with sharp teeth can injure sensitive scalps.
- Encourage the individual to do as much as he or she can for him/herself.
- Teach and assist with drying wet hair with the hair dryer and apply chose gels, hair spray, and other hair products.
- Encourage the individual to look in a mirror when finished styling. Having hair clean and groomed looks great, increases self-esteem, and you can't have a "bad hair day".

Check the video for more tips on how to wash the hair of the care recipient in bed: https://www.youtube.com/watch?v=rYiSQdqGwQs

Fingernail and Toenail Care

Cleaned and trimmed fingernails and toenails are important for overall health. Germs often collect underneath the nails. Frequent and thorough hand washing, and foot care is an effective way to prevent germ or fungus buildup. Nails that become too long and/or are rough and torn can scratch and cut an individual's skin and may result in a local infection. Athlete's foot, a fungus that causes inflammation, cracking, and peeling of the skin between the toes and can also infect the toenails, is of particular concern and must be treated as soon as it is noted.

Individuals with diabetes require *professional assistance* with nail care (see below). Trimming the nail too short may cause ingrown nails that can be painful and cause infection. Individuals often like to have nail colour applied and may need assistance. Encourage individuals to do as much as they can for themselves.

Supplies that should be prepared beforehand are *personal nail clippers or nail scissors, personal cuticle or orange stick, bathtub or bowl, clean water, soap, personal towel, personal emery board or nail file.*

- Teach and assist the individual how to soak his or her hands or feet in warm water for at least 5 minutes and then wash hands or feet with soap. This will soften the nails and make them easier to trim. Do not rinse in soapy water (it can have many germs from the nails).
- Teach and assist how to gently push nail cuticle back (from fingers or toes) with cuticle or orange sticks to prevent hangnails. A clean washcloth can be used for this step. You can demonstrate these steps on your own nails.
- Teach and assist the individual to clean under the nails (fingers or toes) with an orange stick or tool on nail clipper for this purpose.

IMPORTANT! *Individuals with diabetes need professional assistance for nail care*. Improper care of foot or cutting of toenails, especially in diabetes patients, is a significant factor that could result in the amputation of toe finger and foot in the future. For more information see here: https://www.gatesheadhealth.nhs.uk/wp-content/uploads/2023/09/Diabetes-Nail-Care-Advice.pdf

Shaving

Shaving one's legs, underarms, or face is a very personal matter. Cultural differences may be a key to whether an individual shaves or does not shave. For example, in some cultures, women do not shave their legs or underarms. In some cultures, men do not shave their facial hair. It is important to assist and support the individual to shave safely and to avoid nicks and cuts that can lead to infection. Some individuals may learn to use an electric razor. Other individuals may be assisted and supported in using a blade razor.

Supplies that should be prepared beforehand are *a personal electric or other style razor, shaving* *cream and aftershave lotion, personal towel, sink or other clean water source, a mirror.*

- IMPORTANT! *Electric razors should not be used around water*, since this can cause injury or death. Always ensure the razor is turned on safely and away from water.
- Check all types of razors for chips or rust on the blades and always dispose used razor blades, if necessary.
- Use only an individual's personal razor and clean blades as needed (razor off and unplugged) to ensure a smooth shave.
- Supervise the use of razors closely for safe and correct handling before individual shaves independently.
- Use gentle, even pressure while shaving, and check for missed hair using a hand or mirror.
- Apply aftershave or lotion if desired.
- Encourage the individual to do as much for him or herself as possible.

For more information on how to shave with non-electric and electric razors, consult this guide: https://www.cmhcm.org/provider/centrain/Training_Units/Personal_Care_Hygiene_Grooming.pdf

Bathing and Perineal Care

Bathing means cleaning one's body from head to toe. Perineal care means the bathing of the genital and anal (rectum) area, or "private parts." Providing assistance and support for bathing can be a very sensitive personal care activity for an individual and a IC. Individuals can be more comfortable of this activity is completed by female caretakers for women and girls and by males for men and boys. The IC needs to know what bathing skills an individual has before beginning to provide support for bathing. It is important that the IC provides whatever assistance is needed to ensure individuals are clean.

Supplies that should be prepared beforehand are *a clean basin, bathtub, or shower stall, robe or clean clothes, soap (preferably mild) or personal toiletries (shampoo, conditioner, deodorant), personal towel and washcloth, disposable gloves for perineal care, non-skid bathmat, shower chair of shower cap if necessary and a blanket to cover the person using the shower chair, clean clothes.*

When assisting with bathing or showering:

- Find out how much assistance, teaching and supervision is required for bathing or showering. The person should complete as much of the routine as possible.
- Assure that personal choice is honored: does the person prefer a bath or a shower, does the person prefer to bathe/shower in the morning or the evening, what type of shampoo and soap does the person prefer, etc. Prepare the person by explaining what is going to take place.

- Always test the temperature with your elbow or a bath thermometer before bathing someone. It should be warm, not hot (ideally between 37-38°C).
- To prevent injury, more than one person may be needed when transferring an individual from chair to tub and back to chair.
- Provide privacy for the individual and talk about things of interest to the individual.
- Encourage the individual to do as much as he or she can for him/herself.
- IMPORTANT! If complete assistance is needed, begin by cleaning the eye area, then apply soap to the washcloth. Finish washing the face and then proceed down toward the feet. Wash the genital area last.

IMPORTANT! Dry the skin completely. Moisture in the skin folds can result in cracking and the breakdown (infection) of skin. Moisture between the toes can result in cracking and infection. Give particular attention to skin where two surfaces meet (under the breasts, between the toes, between the thighs).

Check the video for more tips on how to wash the care recipients' body in bed: https://www.youtube.com/watch?v=6lFjcMLtXtY

For more information about bathing and showering procedures and **perineal care for men and women**, consult the following guide: https://www.cmhcm.org/provider/centrain/Training_Units/Personal_Care_Hygiene_Grooming.pdf

Mobility and transfer techniques

Safe mobility and transfer techniques are important for both caregivers and care recipients to prevent injuries and maintain the comfort of the individual being cared for. Here you find an overview of key aspects related to lifting, transferring, and positioning, as well as the right use of transfer devices and methods for preventing falls and injuries.

Safe Lifting, Transferring, and Positioning Techniques

These techniques involve moving a care recipient safely from one position or location to another, such as from a bed to a wheelchair or from a chair to a toilet. It's important for caregivers to use correct techniques to avoid injuries to themselves and the care recipient.

Lifting:

- Always bend at the knees, not the waist, to use your legs rather than your back to lift the care recipient.
- Keep the care recipient close to your body to require less effort to move.

- Maintain a wide stance for better balance and stability while lifting someone.
- Make sure the person’s legs are on the floor before trying to stand up.
- If someone is in bed, first roll the person to the side of the bed and help him/her to a sitting position with feet flat on the ground.
- Place your arms around the person’s waist. Do not have the person put his/her arms around your neck, as that can cause you to lose your balance. If the person feels a need to hold on to something, have him/her put arms around your waist/shoulders.
- IMPORTANT! Know your limitations and save your back. If you feel a strain, get help; don’t do it alone. This is for your safety and for the safety of the person you are trying to move. If you hurt your back, you aren’t going to be able to care for someone else.

Positioning:

- Reposition bedridden care recipients regularly (every 2-4 hours) to prevent bedsores (pressure ulcers). Use pillows and cushions to support limbs and maintain body alignment.

Transferring:

- Consider the patient’s weight. This will heavily impact your ability to transfer them.
- Ensure the care recipient is involved as much as possible in the transfer. For instance, ask them to push with their arms or legs if they can.
- Use smooth, controlled movements rather than sudden jerks, which could cause injury.
- Pivot your feet rather than twisting your back during the transfer.
- Watch this video from the for helpful instructions to transfer a loved one (Family Caregiver Alliance): https://www.youtube.com/watch?v=oB0uPouIcXo

Proper Use of Transfer Devices

Transfer devices can assist with safe and efficient movement of care recipients who have limited mobility. These devices reduce the physical strain on caregivers and minimize the risk of injury for both parties.

Hoists/Hoyer Lift (Mechanical Lifts)
:

- Used for transferring care recipients who are unable to assist in their own movement.
- Always check the equipment for safety before use and ensure the hoist sling is positioned correctly under the care recipient.

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- Learn more about the Hoyer Lift here: https://www.youtube.com/watch?v=jLetizMjNHg

Transfer Boards:

- Used for transferring between surfaces, such as from a wheelchair to a bed or toilet.
- Place the board securely under the care recipient's buttocks, ensuring a firm grip.
- Help guide the care recipient as they slide across the board, keeping their hands and fingers clear of the edges to prevent pinching or injury.
- Learn here how the transfer board works: https://www.youtube.com/watch?v=TZ6xeS_GjSk

Gait Belts:

- These are worn around the care recipient's waist to assist with standing and transferring.

- Secure the belt snugly, but not too tight, and use it to support the care recipient during movement without pulling or lifting by the arms.
- Learn here how to use the Gait Belt: https://www.youtube.com/watch?v=MODz8uRSVjM

Draw Sheet:

- A draw sheet is a small sheet placed under a care recipient that helps caregivers reposition or transfer them in bed without causing discomfort or injury. It reduces friction and strain for both the caregiver and care recipient.

Preventing fall and Injuries

Assess the Environment

Ensure that the area is free of hazards, such as loose rugs, clutter, or slippery floors. Keep the transfer area tidy, and make sure any equipment is in a stable and locked position.

Prepare the Care Recipient

Ensure the care recipient is physically ready to be transferred (e.g., fully awake, cooperative, and not in pain). Encourage them to wear non-slip footwearor or use foot grips during transfers.

Communicate

Always explain the transfer process to the care recipient. Ask him/her to help you when able. Use clear instructions, such as "I will count to three, and then we'll stand together."

Body Mechanics

Keep your spine straight, lift with your legs, and avoid twisting your torso while transferring. Consider using a second person if the care recipient is particularly heavy or uncooperative.

3.2 Medical and Medication Management

According to the Royal College of Nursing, Medication management is defined by the UK's Medicines and Healthcare Products Regulatory Agency (MHRA) as: "The clinical, cost-effective and safe use of medicines to ensure patients get the maximum benefit from the medicines they need, while at the same time minimising potential harm." Medical support is any support that enables a person to manage their medicines. In practical terms, this covers: prompting or reminding people to take their medicines, helping people remove medicines from packaging, or administering a person's medicines. Always assess what medicines support a person’s needs as part of their general assessment. Home care workers must have the necessary knowledge and skills. These should be updated regularly, and they should undergo competency assessments, which include being observed. In which areas a person needs support with their medicines, it should always be recorded the following details in their care plan:

- the person's needs and preferences
- how you will seek consent
- details of who to contact about their medicines - this can be the person needing support or a contact they choose
- what support they need for each medicine
- how the medicines support will be given
- who provides medicines support, especially when more than one caregiver is involved
- when the medicines support will be reviewed - for example, after a few weeks.
- staff who assess people's medicines support need to be trained and competent to do so
- only take responsibility for people's medicines where the assessment indicates there is a need.

Review the storage place for medicine at intervals appropriate for the person. This is particularly important where a person has declining or fluctuating mental capacity. If you store medicines, your processes should cover safe and appropriate access. You could consider:

- who has access to medicines
- how to store them safely or securely.
- Where a person stores medicines in their own home, they do not need a separate medicines fridge. You need to check that any fridge used to store medicines is in working order and check the temperature regularly.

Administering medication

Regarding correct procedures for administering both oral and topical medications, the following abstract will provide some instruction overview to promote safe and effective care. Participants will be introduced to methods for administering oral and topical medications and how to monitor medication schedules. Medication can be introduced into the body by several routes. Each route has specific purposes, advantages, and disadvantages.

These routes may be:

- Taken by mouth.
- Given by injection into a vein, into a muscle, into the space around the spinal cord, or beneath the skin.
- Placed under the tongue or between the gums and cheek.

- Inserted in the rectum or vagina.
- Placed in the eye or the ear.
- Sprayed into the nose and absorbed through the nasal membranes.
- Breathed into the lungs, usually through the mouth or mouth and nose.
- Applied to the skin for a local or bodywide effect.
- Delivered through the skin by a patch for a systemic effect.

The following abstract will focus on the most common forms for informal caregivers to administer medication (orally; applied to the skin for a local or systemic effect).

Administer Oral Medications

Regarding correct procedures for administering both oral and topical medications, the following abstract will provide some instruction overview to promote safe and effective care. Medication can be introduced into the body by several routes. Each route has specific purposes, advantages, and disadvantages. These routes may be:

- Taken by mouth.
- Given by injection into a vein, into a muscle, into the space around the spinal cord, or beneath the skin.
- Placed under the tongue or between the gums and cheek.
- Inserted in the rectum or vagina.
- Placed in the eye or the ear.
- Sprayed into the nose and absorbed through the nasal membranes.
- Breathed into the lungs, usually through the mouth or mouth and nose.
- Applied to the skin for a local or bodywide effect.
- Delivered through the skin by a patch for a systemic effect.

Administer Oral Medications

Many medications can be administered orally, through the mouth, as liquids, capsules, tablets, or chewable tablets. Because this route is the most convenient and usually the safest and least expensive, it is the one most often used. However, it has some limitations because of the way a drug typically moves through the digestive tract. For drugs administered orally, absorption may begin in the mouth and stomach. However, most drugs are usually absorbed from the small intestine. When a drug is taken orally, food and other drugs in the digestive tract may affect how much of and how fast the drug is absorbed. IMPORTANT! Therefore, some drugs should be taken on an empty stomach, others should be taken with food, others should not be taken with certain other drugs, and still others cannot be taken orally at all.

Some orally administered medication irritates the digestive system. For example, aspirin and most other nonsteroidal anti-inflammatory drugs can harm the lining of the stomach and small intestine to potentially cause or aggravate preexisting ulcers. Other drugs are absorbed poorly or erratically in the digestive tract or are destroyed by the acid and digestive enzymes in the stomach.

Other routes of administration are required when the oral route cannot be used, for example:

- When a person cannot take anything by mouth;
- When a drug must be administered rapidly or in a precise or very high dose;
- When a drug is poorly or erratically absorbed from the digestive tract.

Frequency in prescriptions is indicated by how many times a day the medication is to be administered or how often it is to be administered in hours or minutes. Examples of frequency include verbiage such as once daily, twice daily, three times daily, four times daily, every 30 minutes, every hour, every four hours, or every eight hours (Ernstmeyer et al., 2021).

- Make sure to verify the expiration date of the medication. Ensure this is the right medication, right dosage, right route, and right time.
- Is the person exhibiting the right response to the medication?
- Listen to the person if they verbalize any concerns about medications.
- If a pill falls on the floor, it is contaminated and should not be administered. Dispose them.
- If you notice a patient coughs immediately after swallowing water or has a “gurgling” sound to their voice, do not administer any medications, food, or fluid until you have reported your concerns to the health care provider.
- IMPORTANT! It is essential to verify if a tablet may be crushed. For example, medications such as enteric-coated tablets, capsules, and sustained-release or long-acting medication should never be crushed because doing so will affect the intended action of the medication.
- Position the person receiving oral medication in an upright position to decrease the risk of aspiration. They should remain in this position for 30 minutes after medication administration, if possible. If the person is unable to sit, assist them into a side-lying position.

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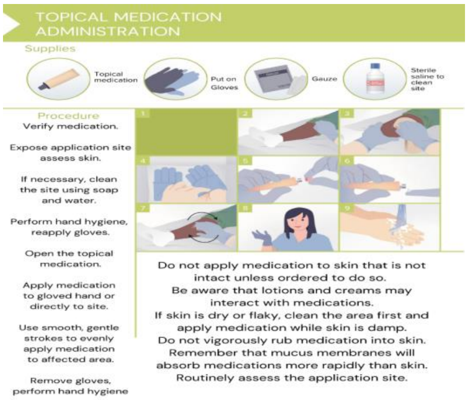
- Remain with the patient until all medication has been swallowed before documenting to verify the medication has been administered.
- If medication is given sublingual (under the tongue) or buccal between the cheek and gum the mouth should be moist. Offering the patient a drink of water before giving the medication can help with absorption (Ernstmeyer et al., 2021).

Apply Topical Medications

Medication applied to the skin is usually used for local effects and thus are mostly used to treat skin disorders, such as psoriasis, eczema, skin infections (viral, bacterial, fungal), itching, and dry skin. The medication is mixed with inactive substances (MSD Manual). The active ingredient in a topical preparation is mixed with an inactive ingredient (vehicle). The vehicle determines the consistency of the skin product (e.g. thick and greasy or light and watery) and whether the active ingredient remains on the surface or penetrates the skin. Depending on the vehicle used and, on the consistency, the same medication can be placed in: Ointments, Creams, Lotions, Baths and soaks, Foams, Solutions, Powders and Gels.

In addition, many preparations are available in different strengths (concentrations). Choice of vehicle depends on where the medication will be applied, how it will look, and how convenient it is to apply and leave on. For example, ointments are greasy and contain very little water. They are best for adding moisture to the skin and are more effective than creams at delivering medicine into the skin. Ointments are also less irritating than creams, gels, lotions, and solutions, especially on open wounds like ulcers. They work best when applied after a bath on damp skin.



Verify medication.
Expose application site assess skin.
If necessary, clean the site using soap and water.
Perform hand hygiene, reapply gloves.
Open the topical medication.
Apply medication to gloved hand or directly to site.
Use smooth, gentle strokes to evenly apply medication to affected area.
Remove gloves, perform hand hygiene

Do not apply medication to skin that is not intact unless ordered to do so.
Be aware that lotions and creams may interact with medications.
If skin is dry or flaky, clean the area first and apply medication while skin is damp.
Do not vigorously rub medication into skin.
Remember that mucus membranes will absorb medications more rapidly than skin.
Routinely assess the application site.

Creams, which are very common, are made mostly of water with some oil mixed in. Creams are easy to rub in and disappear into the skin. They usually don't cause much irritation.

Lotions are like creams but contain more water. They are less effective than ointments, creams, and gels at delivering medicine and are less potent. However, lotions are good for hairy areas and are useful for cooling or drying inflamed skin, such as in conditions like contact dermatitis, athlete's foot, or jock itch.

Baths and soaks are used to treat large areas of the body. This is often done with sitz baths to treat mild skin problems like haemorrhoids. Baths are rarely used for strong prescription medications because it's hard to control how much medicine is absorbed.

Foams are made with a liquid stored under pressure. When sprayed, they absorb quickly into the skin and are useful for hairy areas. Solutions are liquids in which a medication is dissolved. Solutions are easy to apply, especially on the scalp, but they tend to dry out the skin, which can help with wet, oozing conditions. Depending on the vehicle used, solutions can be irritating to the skin, particularly when those containing alcohol and propylene glycol are applied to open wounds.

Powders are used to keep skin dry and prevent rubbing, like between the toes, in the armpits, or under the breasts. They can also be mixed with medication, such as antifungals, to treat infections. Gels are water- or alcohol-based and contain no oil or fat. They don't absorb into the skin as well as ointments but are useful for slow absorption, like in acne or scalp conditions. Gels tend to be quite irritating on open wounds and diseased skin.

Transdermal Patches

Some medications are delivered through a patch on the skin. The medication, mixed with a substance like alcohol to help it pass through the skin, enters the bloodstream without an injection. These patches provide a steady release of medication over hours or days, keeping the drug level in the blood stable. Patches are good for medications that would need to be taken frequently in other forms. However, they can sometimes irritate the skin and are only suitable for drugs that are needed in small daily doses, like nicotine or pain relievers.

Monitor Medication Schedules

Managing medications can be complicated, particularly if individuals are taking several prescription drugs that treat different conditions. It is important to follow prescribed medication schedules and to track medication times, prevent missed doses, and adjust for care recipients' daily routines, while also maintaining accurate records to ensure compliance with the care plan. After administering medication, immediately *document the administration* to avoid potential errors from an unintended repeat dose.

- Understand the medication routine and confirm the exact *dose* and *timing* of each medication. Follow the schedule exactly, and administer the exact dose prescribed. Check which medications need to be taken on an empty stomach or with food.

- Always double check the information, if you are not sure.

- Write down the medication schedule and track changes. Place the daily medication routine on a calendar or chart. Printable medication schedule templates are available

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online to make it easier. Update the schedule each time the medicine changes.

- ➢ Keep the schedule in an obvious place and put it in a place easy to see, like the door of the refrigerator or of a kitchen cabinet.
- ➢ Make the medication process part of the daily routine. Try setting a timer on your phone, watch or alarm clock or time the administering medication always after e.g. brushing the teeth or before eating breakfast.
- ➢ Caregivers can set up a schedule, use medication boxes organized by day and time or automatic pill dispensers with an alarm system.

Time sensitive medicines are those that need to be given or taken at a specific time. A delay in receiving the dose or omission of the dose may lead to serious patient harm.

Common examples include insulin injections, medicines for Parkinson’s disease, medicines that contain paracetamol, medicines that need to be given before or after food and antibiotics.

Preventing Medication Errors

Medication errors can happen at different stages, from prescribing to administering. Errors are most common when doctors prescribe the wrong medication, dose, route, or frequency. By following some practical recommendations, informal caregivers can help ensure the safe administration of medications to keep their loved ones safe.

- Create a *detailed schedule* that lists all medications, including the name, dose, and time they need to be taken.
- Always *double-check* the medication label before giving any dose.
- *Avoid distractions* like TV or conversations when preparing or giving medication.
- Be aware of *medications with similar names* or packaging.
- Use a *pill organizer* to prepare daily or weekly doses.
- Set *alarms on your phone or use a medication reminder app*.
- Maintain a *written record of when each medication is given*.
- *Ask Questions*! Do not hesitate to ask a pharmacist or doctor for clarification if anything about the medication or its instructions is unclear.
- Pay extra attention to *high-risk medications* like insulin, anticoagulants, or opioids.

- Keep *all medications in one place*, stored properly (some may require refrigeration) and clearly labelled.

Recognizing and Responding to Medical Emergencies

Medical emergencies can happen unexpectedly and are unpredictable, especially when caring for an older individual or disabled loved one. Being prepared helps reduce panic and ensures quick and appropriate action when emergencies occur.

- *Keep Important Information Accessible*: Have essential documents, such as ID, insurance cards, and medical directives, in a waterproof, portable container. Maintain an updated list of medications, doctors' contacts, and emergency phone numbers. Keep both physical and digital copies but always have paper copies available for quick access.

- *A List of Emergency Numbers*: make sure you keep a list of emergency numbers.
- *Pack a Hospital Overnight Bag*: Prepare a bag with clothing, toiletries, medications, and items for both your loved one and yourself, in case of a hospital stay. The bag should be prepared to use for at least two to three days.
- *Learn Emergency Response Skills*: Take first aid and CPR classes. Keep a first aid kit at home and in your vehicle.
- *Share Caregiving Responsibilities*: Caregiving can be overwhelming, so it’s important to alternate duties with family, friends, or neighbors. Take time for self-care and consider joining support groups to manage caregiver stress.
- *Consider Medical Alert Systems*: Medical alert devices can be lifesaving, allowing your loved one to easily call for help. Options include bracelets or necklaces that connect to emergency services. Choose a system that fits your loved one's needs, whether it's for in-home use or mobile with GPS tracking.

What Should I Have in My First Aid Kit?

A first aid kit should be a small, easy-to-access box or bag that is clearly labelled. Keep it out of reach of children, and ensure it’s regularly checked and restocked as needed. It’s also important that all family members know where it is and how to use the items inside. Make sure to check expiration dates regularly and know how to properly use each item in case of minor injuries.

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Here's what your basic first aid kit should include:

- Gauze or dressings (various sizes)
- Wound plasters and bandages (various sizes)
- Elastic bandages
- Microporous (medical) tape
- Scissors
- Tweezers
- Burn gels
- Wound cleansers (wipes or pads)
- Triangular bandage
- Gloves
- Over-the-counter medications like aspirin, paracetamol and ibuprofen
- Emergency blanket
- Thermometer
- Emergency First Aid instructions.

3.3. Assistive Technologies and Devices

The learning objective of this chapter is to equip participants with knowledge about available assistive technologies and adaptive devices to enhance the safety, independence, and quality of life of care recipients. Participants will gain some new ideas how to incorporate modern technologies like medication reminders and home safety systems into daily caregiving routines.

Using Mobility Aids and Adaptive Equipment

It exists a range of mobility aids and adaptive equipment to enhance the safety and independence of care recipients at home. By utilizing these, informal caregivers can create a safer and more supportive environment for their loved ones and enhance their independence and quality of life.

Mobility and Transfer Aids

Canes provide support and stability for individuals who have difficulty walking. They come in various styles, including single-point and quad canes.

Walkers offer more support than canes and are suitable for those with greater mobility challenges. They can have wheels (rolling walkers) or be stationary.

Manual or electric wheelchairs help individuals with limited mobility move around. Manual chairs require someone to push them, while electric chairs can be operated by the user.

Electric mobility scooters are great for individuals who can't walk long distances but still want to maintain their independence.

Patient lifts assist in lifting and transferring individuals safely from one place to another, reducing the risk of injury for both the caregiver and the

Adaptive Equipment

Grab Bars installed in bathrooms and other areas provide support when getting up or sitting down. They are especially helpful near toilets and in showers or bathtubs.

Raised toilet seats make it easier for individuals to sit down and get up from the toilet, reducing strain on the legs and hips.

Shower chairs allow individuals to sit safely while bathing.

Bathing aids like long-handled sponges or brushes to help with personal hygiene without straining.

Reaching tools like grabbers or reachers help individuals pick up items from the floor or high shelves without bending or stretching.

Adaptive cutlery and kitchen tools can help individuals with limited hand strength or dexterity eat and prepare food more easily.

Dressing sticks, sock aids, long handled shoehorns, button hooks, or elastic shoelaces can help for dressing.

Weighted or ergonomic handles can be added to tools like scissors or gardening tools to make them easier to grip.

Communication aids like speech-generating devices or apps can assist individuals with speech difficulties.

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Communication aids like speech-generating devices or apps can assist individuals with speech difficulties.

Home Modifications

Ramps can be installed to make it easier for individuals in wheelchairs or with mobility aids to enter and exit the home.

Non-slip mats placed in bathrooms and other areas to prevent slips and falls.

Motion-activated lights or night lights can improve visibility and safety at home, especially at night.

Technology to Support Daily Care

Modern assistive technologies can simplify daily caregiving tasks, improve the quality of care, and reduce the physical and emotional strain of caregiving.

- *Telehealth platforms* allow for virtual medical consultations, making it easier for caregivers to access healthcare providers without needing to travel.
- *Medication management apps* help track medication schedules, set reminders for doses, and provide information about medications.
- *Smartwatches and fitness trackers* that monitor vital signs, activity levels, and sleep patterns.
- *Smart cameras and sensors* that allow caregivers to monitor the safety and well-being of their loved ones remotely.
- *Voice-activated assistant devices* like Amazon Echo or Google Home can assist with reminders, setting alarms, and providing information, allowing individuals to stay more independent.
- *Smart home devices* such as automated lighting, temperature control, and security systems enhance safety and comfort for individuals with mobility challenges.
- *Emergency response systems as wearable devices* that allow individuals to call for help with the press of a button, providing peace of mind for both the individual and the caregiver.
- *Communication aids, devices and apps* designed to assist those with speech difficulties.

- *Sensors* that track daily activities and routines, alerting caregivers if there are significant changes or deviations.
- *Smart pill dispensers* remind users when it's time to take their medication and dispense the correct dosage.
- *Meal delivery services* that provide healthy meal options for individuals who may have difficulty cooking or grocery shopping.
- *Virtual reality (VR) therapy* is used for physical therapy and rehabilitation, helping individuals engage in exercises or activities in a controlled environment.
- *Electronic health records (EHR) systems and online platforms* that consolidate medical information, making it easier for caregivers to access and manage health records.

- *Electronic health records (EHR) systems and online platforms* that consolidate medical information, making it easier for caregivers to access and manage health records

3.4. Documentation and Record-keeping

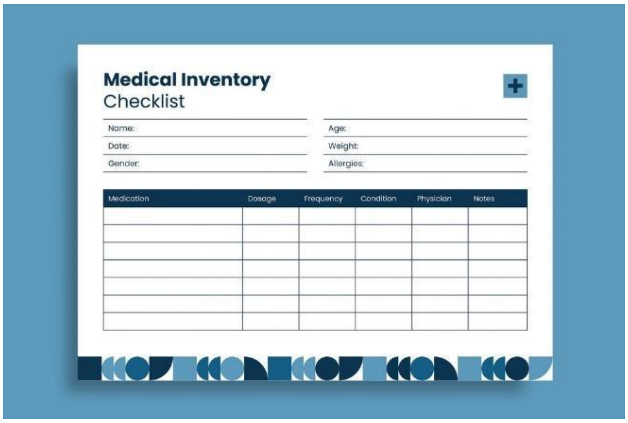
Proper documentation and record-keeping are important parts of the caregiving process to ensure the continuity of safe care and legal protection. By maintaining accurate records, caregivers can track essential caregiving activities, such as medication administration, daily routines, and any changes in the care recipient's health. This practice not only supports the well-being of the person being cared for, but also helps caregivers stay organised and ensures they meet legal and medical standards.

- Keep a detailed *medication log* of all medications administered, including the medication name, dosage, time of administration, and any observed effects or side effects. Always note any changes in the medication regimen and communicate these to the doctor, if necessary.
- *Document daily activities* such as meals, physical activity, sleep patterns, and personal care tasks (e.g., bathing, dressing). This log helps identify any changes in behaviour or condition and allows healthcare professionals to monitor the individual's well-being over time.
- Agree with the person you are caring for on *how medicines will be disposed* of and record this decision in the care plan.

- For *medications that require special handling*, such as controlled substances or injectable medications, ensure a clear procedure for disposal is in place and that it is documented.
- Maintaining accurate records is not just about organization. It is important for *legal and medical purposes*. Well-documented logs provide evidence of care provided, which can be important in the event of legal or medical questions. It also helps avoid potential liability by ensuring that medications and procedures are being followed properly.

A *caregiver resource* is a collection of essential tools, templates, and information designed to help family caregivers manage all aspects of care. Whether you’re caring for a neurodivergent child, a family member with disabilities, or someone with complex medical needs, a well-organised caregiver resource ensures that key information, from daily routines to emergency protocols, is easily accessible and up to date.

A caregiver resource can be as simple as a digital dashboard or a physical binder containing critical documents like medical records, contact lists, and care routines. The goal is to make caregiving more manageable, especially in stressful situations or emergencies. This resource system helps centralize essential information, making it easier for any caregiver to step in and follow the caregiving plan without confusion or delays. It also reduces stress for family caregivers, as they can quickly access what they need, ensuring continuity of care even if a new caregiver temporarily takes over. Ultimately, a well-organized caregiver resource saves time, reduces anxiety, and promotes a more efficient and consistent caregiving experience.



Medical Inventory
Checklist

Name:
Date:
Gender:
Age:
Weight:
Allergies:

Medication	Dosage	Frequency	Condition	Physician	Notes

3.5. Supporting Specific Groups: Carers of Younger Individuals and Young Carers

While much informal caregiving guidance focuses on older adults, many caregivers also support *children* and *young people with disabilities*, *chronic illnesses*, or *developmental needs*. Additionally, a growing number of young people themselves act as informal carers, often taking on adult responsibilities without formal support.

Informal Carers of Children and Young Adults with Disabilities

Caring for a child or young adult with a disability or long-term health condition requires a different set of skills, often combining medical, educational, emotional, and developmental support. These caregiving responsibilities are usually long-term and may evolve as the child grows, requiring ongoing adaptation and learning.

- **Hygiene Support**: Children with physical or sensory impairments may need support with toileting, bathing, and oral hygiene. Use *child-sized bathing aids*, such as adjustable bath seats, non-slip mats, and long-handled sponges. For incontinence, carers may need to manage catheters, continence pads, and skin protection routines to prevent irritation and infection.
- **Feeding and Nutrition**: Children with conditions such as *cerebral palsy* or *Down syndrome* may require adaptive cutlery, non-spill cups, or feeding tubes. A dietician may help establish routines that support both nutrition and developmental goals.
- **Mobility and Positioning**: Use age-appropriate transfer boards, slings, or pediatric hoists when needed. Postural support cushions and wheelchairs with positioning aids help children remain safely seated.
- **Assistive Technologies**: For children with communication challenges, devices such as speech-generating devices (SGDs) or apps like Proloquo2Go can support expressive language. Switch-accessible toys, tablet stands, and adaptive keyboards help encourage interaction and learning.

- **Education and Resources**: Carers often coordinate with schools, therapists, and healthcare professionals. It’s helpful to maintain a care notebook or digital app (e.g. Birdie, Jointly) that tracks symptoms, routines, and appointments.
- **Medication**: It can be difficult to get *children* to take medications. Liquid or chewable forms are often easier for them. For infants or very young children, droppers can be used to place the medication between the gum and cheek to avoid choking. Mixing medicine with soft foods can help, but it’s better not to mix it with a favorite food to prevent the child from refusing that food later. Giving the child something cold, like a popsicle or frozen fruit bar, before the medicine can numb their tongue and make the medicine taste less strong.
- **Resources** like Early Intervention Centres, Special Education Needs and Disability support services, or parent-led support networks (e.g. *Contact* in the UK, *Associação Pais 21* in Portugal) offer practical advice and emotional support.

Young Carers

Young carers who care for a family member due to illness, disability, mental health issues, or substance dependency often face a hidden and under-recognised burden. Their caregiving duties can range from helping with mobility and household chores to providing emotional support or managing siblings in the absence of adult supervision.

Supporting young carers begins with recognition, many do not self-identify as carers and may not ask for help. It is important to ensure they have access to counselling services, school-based support programmes, and information that is age-appropriate and empowering. Educational professionals and healthcare providers should be trained to identify young carers and to refer them to suitable services. Creating safe spaces for peer interaction, such as support groups or mentoring programmes, can help young carers feel understood, less isolated, and more confident in managing their responsibilities.

- Young carers benefit from **simple, clear guidance on basic tasks** such as administering medication, helping with hygiene, or lifting safely. Training materials should be adapted to their literacy level, and tasks should always be explained in the context of personal safety and emotional wellbeing.
- Many young carers experience **chronic stress or anxiety** due to their caregiving role. Schools and community services should be proactive in identifying and supporting young carers. Referral to youth counselling, peer support groups, or support programmes.
- **Apps or journals** that help track care tasks and appointments can empower young carers to organise their time and communicate with professionals. **Posters or cheat sheets** in the home can also support medication routines, emergency contacts, or hygiene steps in an easy-to-follow way.
- It's important to help young carers understand that they do not need to manage everything alone. Emphasising **safe boundaries**, encouraging communication with trusted adults, and offering respite support through social services can help avoid burnout or educational disruption.

Exercises and Activities

Activity 1: Skills Demonstration - Personal Care Tasks and Assistive Devices

Objective: To practice personal care tasks and the use of assistive devices, ensuring correct techniques, safety, and effective communication with the care recipient.

Preparation: Set up several stations, each focusing on a different personal care or mobility task. Participants should be divided into pairs to complete the activities. These could include the following.

Station 1: Assisting with mobility (e.g., transferring from bed to chair, using wheelchair). Use simple materials such as a chair, wheelchair, or a sturdy surface to simulate a safe transfer. If available, use a transfer belt (or an improvised sturdy belt) to assist in practicing the technique. Begin by explaining the importance of proper body mechanics in transferring a person to avoid injury to both the caregiver and the care recipient. Show the proper way to assist a person from sitting to standing and then into the wheelchair. [see module 3.1 & 3.3]

Station 2: Administering medications (e.g., using an oral syringe, giving medication safely). [see module 3.2]

Station 3: Using assistive devices (e.g., walkers, canes, grab bars, or communication aids).

Ensure that each station has necessary equipment, such as mobility aids, medication charts, and documentation templates. Have trainers observe participants' techniques and communication at each station. [see module 3.1 & 3.3]

Implementation: Participants rotate through each station, practicing the tasks. At each station, participants will perform the required task (e.g., safely assist someone from a wheelchair to a standing position) while incorporating safety measures such as proper body mechanics and maintaining clear communication with the care recipient. Trainers will observe participants' execution of tasks, focusing on the correctness of the technique, ensuring the comfort and safety of the care recipient throughout the task, and communication skills, particularly how well the participant speaks to the care recipient, ensuring they are informed and reassured during the task.

Feedback and Reflection: After each station, participants receive constructive feedback on their performance. This includes tips on how to improve their technique, and how to better communicate with care recipients during the tasks.

After the rotation, gather participants for a discussion on the challenges they faced at each station. Ask for feedback from the group on ways to improve communication and safety measures during personal care tasks.

Activity 2: Role-Playing Scenarios

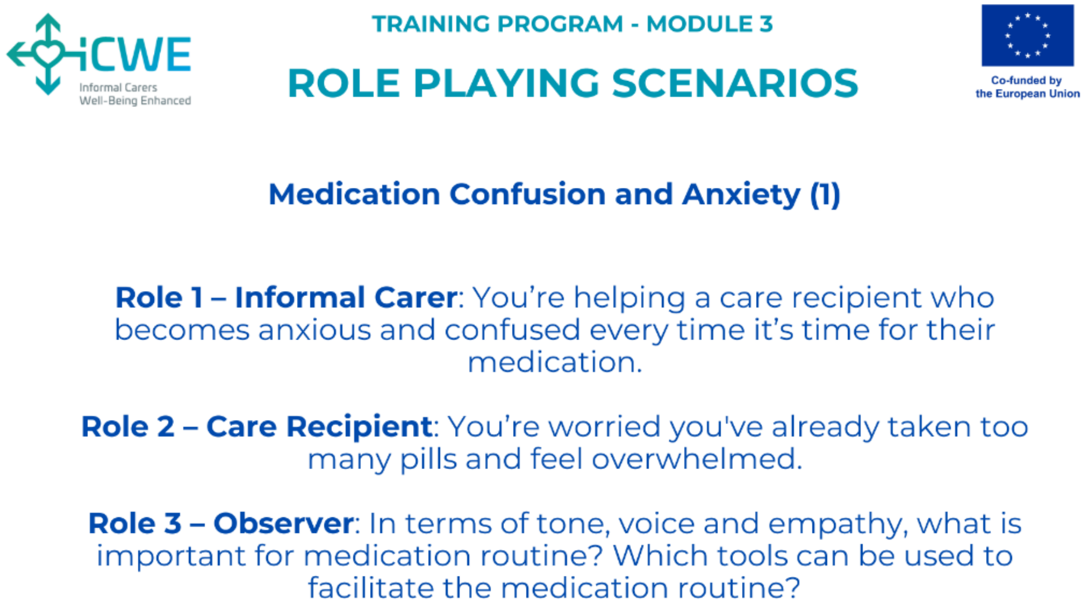
Objective: To practice communication techniques and documentation skills through role-playing scenarios, focusing on common caregiving challenges.

Preparation and Implementation: Print the following scenario cards for role-playing. The exercise will propose different scenarios, you can also choose another one within the context which you find relevant.

During role-playing, trainers observe the following:

- Effective communication skills, especially in challenging situations.
- Correct handling of emergency scenarios and clear, calm documentation.
- Precision and clarity in documenting daily activities, reflecting on the care provided.

After each role-playing scenario, participants will share their experiences and challenges. Trainers will offer feedback on how to improve responses in real-life caregiving situations and emphasize the importance of both effective communication and accurate documentation. One of the following feedback charts can be used to collect feedback.



TRAINING PROGRAM - MODULE 3

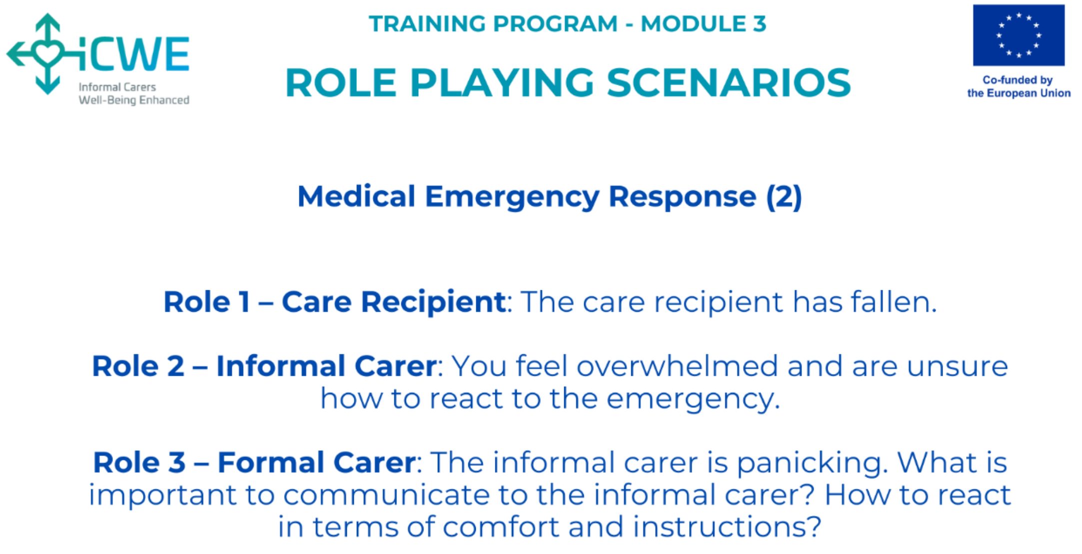
ROLE PLAYING SCENARIOS

Medication Confusion and Anxiety (1)

Role 1 – Informal Carer: You're helping a care recipient who becomes anxious and confused every time it's time for their medication.

Role 2 – Care Recipient: You're worried you've already taken too many pills and feel overwhelmed.

Role 3 – Observer: In terms of tone, voice and empathy, what is important for medication routine? Which tools can be used to facilitate the medication routine?



TRAINING PROGRAM - MODULE 3

ROLE PLAYING SCENARIOS

Medical Emergency Response (2)

Role 1 – Care Recipient: The care recipient has fallen.

Role 2 – Informal Carer: You feel overwhelmed and are unsure how to react to the emergency.

Role 3 – Formal Carer: The informal carer is panicking. What is important to communicate to the informal carer? How to react in terms of comfort and instructions?

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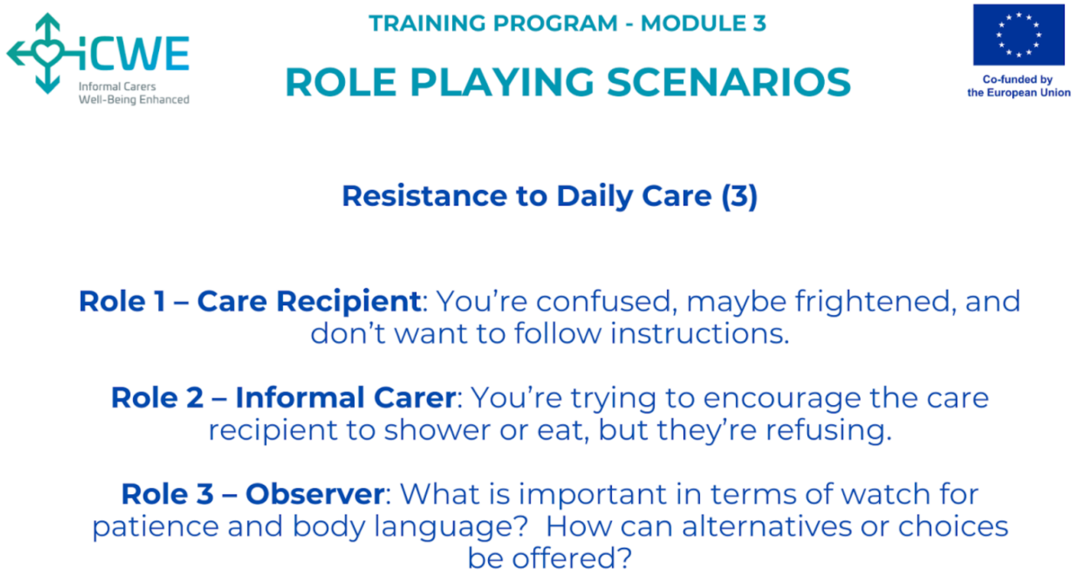


TRAINING PROGRAM - MODULE 3

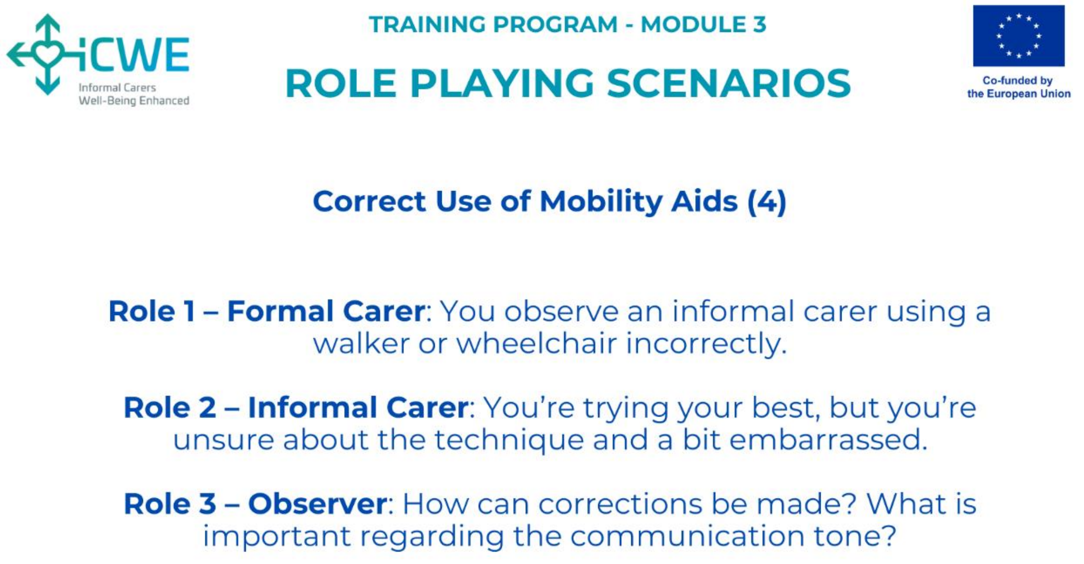
ROLE PLAYING SCENARIOS

Resistance to Daily Care (3)

Role 1 – Care Recipient: You're confused, maybe frightened, and don't want to follow instructions.

Role 2 – Informal Carer: You're trying to encourage the care recipient to shower or eat, but they're refusing.

Role 3 – Observer: What is important in terms of watch for patience and body language? How can alternatives or choices be offered?



TRAINING PROGRAM - MODULE 3

ROLE PLAYING SCENARIOS

Correct Use of Mobility Aids (4)

Role 1 – Formal Carer: You observe an informal carer using a walker or wheelchair incorrectly.

Role 2 – Informal Carer: You're trying your best, but you're unsure about the technique and a bit embarrassed.

Role 3 – Observer: How can corrections be made? What is important regarding the communication tone?

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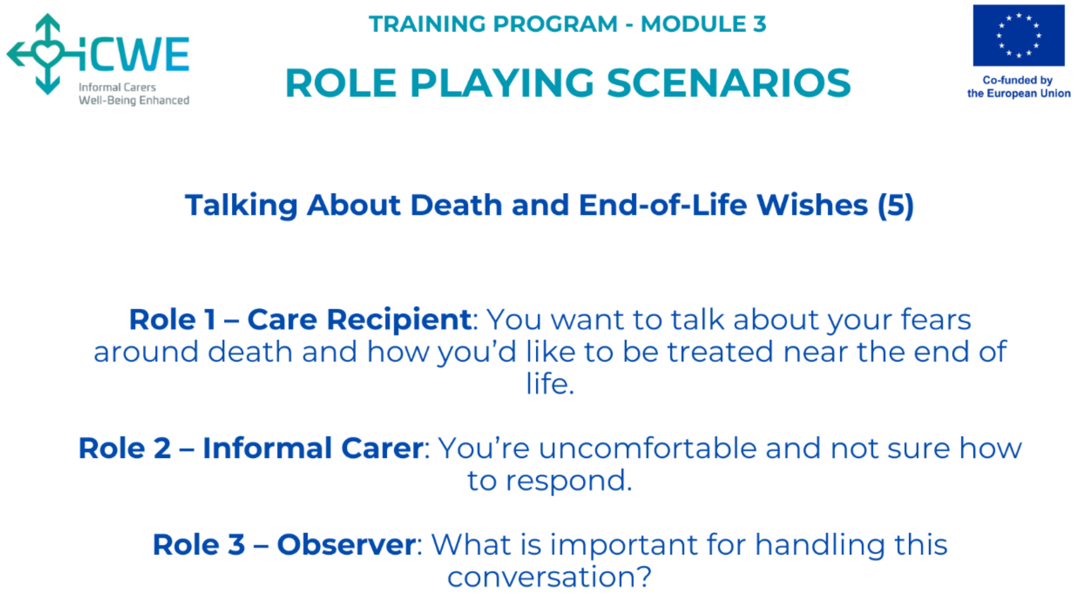


TRAINING PROGRAM - MODULE 3

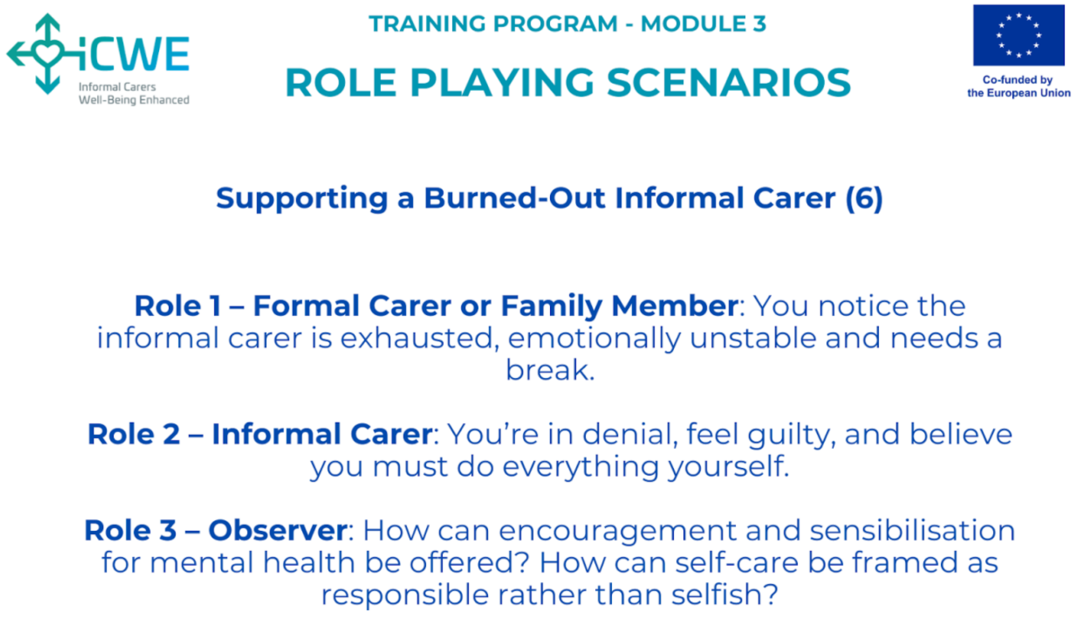
ROLE PLAYING SCENARIOS

Talking About Death and End-of-Life Wishes (5)

Role 1 – Care Recipient: You want to talk about your fears around death and how you'd like to be treated near the end of life.

Role 2 – Informal Carer: You're uncomfortable and not sure how to respond.

Role 3 – Observer: What is important for handling this conversation?



TRAINING PROGRAM - MODULE 3

ROLE PLAYING SCENARIOS

Supporting a Burned-Out Informal Carer (6)

Role 1 – Formal Carer or Family Member: You notice the informal carer is exhausted, emotionally unstable and needs a break.

Role 2 – Informal Carer: You're in denial, feel guilty, and believe you must do everything yourself.

Role 3 – Observer: How can encouragement and sensibilisation for mental health be offered? How can self-care be framed as responsible rather than selfish?

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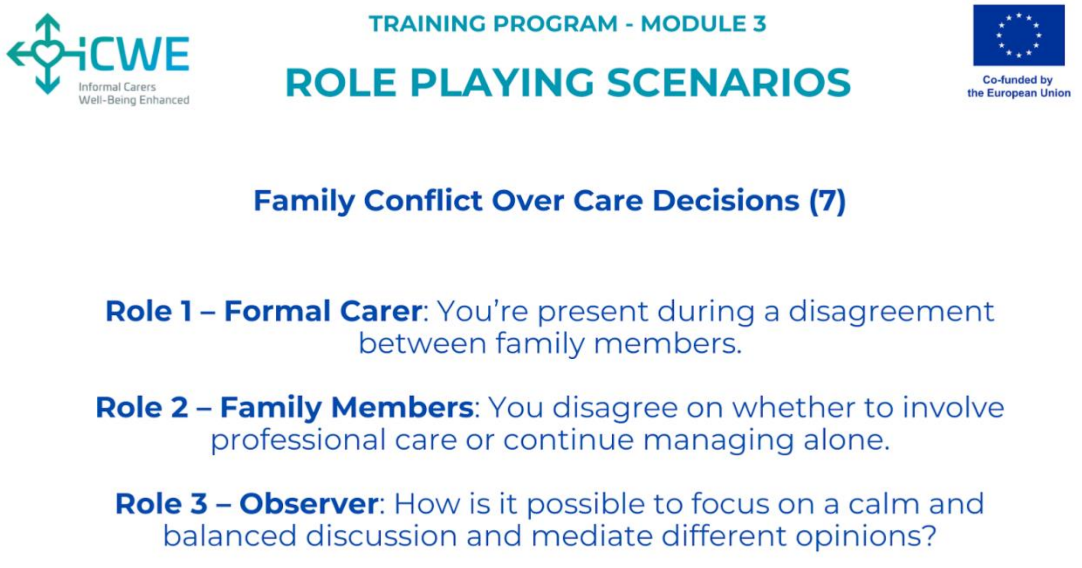


iCWE Informal Carers Well-Being Enhanced

TRAINING PROGRAM - MODULE 3

ROLE PLAYING SCENARIOS

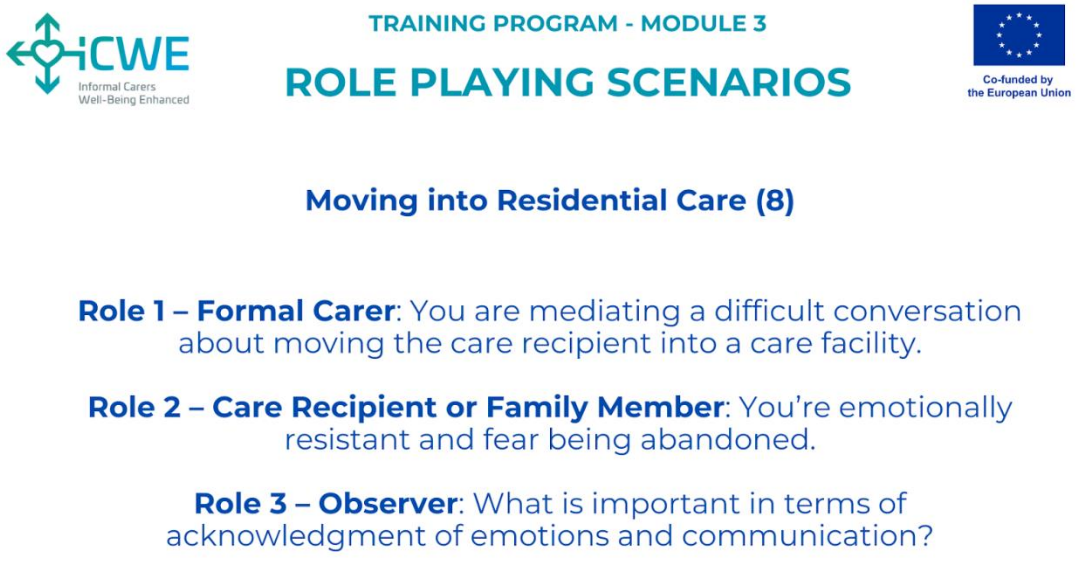
Co-funded by the European Union

Family Conflict Over Care Decisions (7)

Role 1 – Formal Carer: You're present during a disagreement between family members.

Role 2 – Family Members: You disagree on whether to involve professional care or continue managing alone.

Role 3 – Observer: How is it possible to focus on a calm and balanced discussion and mediate different opinions?



iCWE Informal Carers Well-Being Enhanced

TRAINING PROGRAM - MODULE 3

ROLE PLAYING SCENARIOS

Co-funded by the European Union

Moving into Residential Care (8)

Role 1 – Formal Carer: You are mediating a difficult conversation about moving the care recipient into a care facility.

Role 2 – Care Recipient or Family Member: You're emotionally resistant and fear being abandoned.

Role 3 – Observer: What is important in terms of acknowledgment of emotions and communication?

Role-Plays Module 3 – Observer Feedback Sheets

Scenario 1: ____

1. Tone and Communication Style

Was the communication calm, clear and respectful?

☐ Excellent ☐ Good ☐ Needs Improvement: ________________________

Comments: ____

____

2. Understanding of the Situation

Did participants understand the needs or emotions of the other person?

☐ Excellent ☐ Good ☐ Needs Improvement: ________________________

Comments: ____

____

3. Listening and Emotional Awareness

Did the participant practice active listening and validate the person's emotions?

☐ Excellent ☐ Good ☐ Needs Improvement: ________________________

Comments: ____

____

4. Problem-Solving and Guidance

Was the situation handled with practical solutions / suggestions?

☐ Excellent ☐ Good ☐ Needs Improvement: ________________________

Comments: ____

____

I especially liked: ____

____

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	Tone & Communication Was the communication style calm, clear and respectful?	Needs & Understanding Did participants understand the needs of the other person?	Listening & Awareness Did they practice active listening and validate the person's emotions?	Problem-Solving Was the situation handled with practical solutions and suggestions?	I especially liked:
Scenario:					
Scenario:					
Scenario:					

Quiz

What is the primary reason for assisting a care recipient with personal hygiene?

A) To promote relaxation.
B) To reduce the risk of infection and maintain skin health.
C) To save time in their daily routine.

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D) To support dignity and prevent complications related to hygiene.

What is the safest way to help a care recipient stand up from a seated position?

A) Pulling them up by their hands
B) Positioning their feet flat on the floor and assisting from the waist
C) Lifting them under the arms
D) Supporting their shoulders while pulling them forward

Which of the following best demonstrates active listening when a care recipient is sharing their feelings?

A) Nodding occasionally, maintaining eye contact, and summarising their main points to show understanding.
B) Offering immediate advice or sharing a personal experience to relate to their story.
C) Reassuring them quickly and changing the subject to lighten the mood.
D) Asking multiple follow-up questions before they finish speaking

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Module 4: Communication and Relationship Building

Introduction

Formal caregivers are professionals who provide paid care services, such as nurses or home health aides, while informal caregivers are often unpaid individuals, often family members or friends, who provide care out of personal relationships or obligation The goal of Module 4 is to strengthen the communication skills of formal and informal caregivers by educating them how to use communication as a tool to simplify certain processes. Communication can open many doors and can also decrease misunderstanding with patients, formal carers whom they have to work with and also authorities.

The module aims to:

- Educate participants in the fundamentals of effective communication, such as verbal & non-verbal communication skills and active listening & empathy
- Build positive relationships with care recipients and their families as well as professional boundaries and ethics
- Identify sources and conflicts and techniques for managing and resolving conflicts
- Create an understanding of cultural differences and communication with cultural sensitivity

Learning objectives

- **Use verbal and non-verbal communication effectively** for clear and persuasive interactions.
- **Apply active listening and empathy** to connect better with others and strengthen relationships.
- **Build trust and positive relationships** with care recipients and their families.
- **Understand and uphold professional boundaries** and ethical standards.
- **Identify sources of conflict** and apply effective conflict resolution strategies.
- **Understand cultural differences** and respond with sensitivity.
- **Communicate with cultural awareness** to avoid misunderstandings and show respect.

1.Fundamentals of Effective Communication

What is verbal Communication

Verbal communication is the use of spoken or written language to convey information, ideas, thoughts, and feelings between people. It involves the use of words to express meaning and can occur in various forms, including face-to-face conversations, phone calls, speeches, video calls, emails, and text messages.

Effective verbal communication not only depends on the words used but also on clarity, tone, volume, and speed of speech. In contexts like healthcare, where clear understanding is essential, verbal communication is crucial for explaining medical conditions, discussing treatment options, and ensuring patients understand instructions.

What is nonverbal Communication

Non-verbal communication is the use of signals and cues to express feelings, intentions and also information. It is as powerful as verbal communication because its usage can underline or even stress certain information. It often helps also in situations where the person who is speaking and the person who is listening have trouble understanding each other verbally.

Types of non-verbal communication include:

1. **Body Language**: Our stance, movements, facial expressions, and eye contact reveal valuable insights about our emotions, attitudes, and intentions.
2. **Tone of Voice**: How we deliver our words, through pitch, inflection, and rhythm, can greatly shape the message's impact. For instance, a simple phrase can come across as enthusiastic, sarcastic, or indifferent, depending on how it's spoken.
3. **Facial Expressions**: Our faces convey a wide range of emotions, such as joy, surprise, anger, or sadness, and these expressions are often universal, crossing language boundaries.
4. **Eye Contact:** The duration and nature of eye contact can indicate interest, attentiveness, confidence, or unease, and help in establishing rapport and trust.
5. **Posture and Gestures:** The way we carry ourselves and move our hands and bodies provides additional context to our words. For example, crossed arms might suggest defensiveness, whereas an open, relaxed stance can signal receptiveness.

Verbal vs. Nonverbal Communication

Verbal and non-verbal communication is both essential components of effective human interaction, each with unique strengths that complement and, at times, even contradict each other. Verbal communication relies on words—spoken or written—to convey specific information, ideas, and feelings. It allows for clarity, precision, and the ability to convey complex ideas directly, making it indispensable in contexts like education, business, and medicine. However, the power of verbal communication can be undermined or misinterpreted if the accompanying non-verbal cues don't align with the message.

Active listening and empathy

Active listening is more than simply hearing words or nodding along—it's about fully engaging with the thoughts and emotions behind those words. Unlike passive listening, which might involve merely paraphrasing back what was said, active listening is a two-way exchange that requires both empathy and focus.

Steps to Practice Active Listening

To be an effective listener, we need to go beyond just “hearing” and consciously choose how we listen in each conversation. Here are practical steps to improve active listening:

1. Identify Your Default Listening Style:

There are various styles of listening: task-oriented (focused on information transfer), analytical (neutral problem-solving), relational (emotion-focused), and critical (judgment-focused). Recognizing your default style can help you adjust based on what the conversation requires.

2. Make an Intentional Choice to Listen: ´

Consider the goal of the conversation and the other person’s needs. Are they seeking support, connection, or advice? Tailor your listening style accordingly, staying mindful not to hijack the conversation with personal stories or judgments.

3. Stay Focused and Avoid Pre-emptive Responses:

Resist the urge to plan your response mid-conversation. Instead, stay present, process the speaker’s words fully, and ask questions to deepen understanding rather than jumping in with solutions.

4. Continuously Refocus Attention:

If you notice your attention slipping, gently redirect it back to the speaker. If you missed something, don’t pretend otherwise; ask them to repeat it.

5. Ask Questions to Uncover Hidden Concerns:

Listening isn’t just about absorbing; it’s about engaging. Asking open-ended questions can encourage the speaker to share underlying concerns, adding depth to the conversation and demonstrating that you’re listening with intent.

For caregivers, active listening is an invaluable skill that can enhance their relationships with clients, families, and colleagues. In a caregiving role, truly listening to understand rather than just hearing words can build trust, provide emotional comfort, and create a safe, supportive environment. Here’s how active listening can directly benefit those in caregiving roles.
Video recommendation: “Learn how to talk to patients!”
https://www.youtube.com/watch?v=PGKs8qOU1to

2. Building Trust and Rapport

- Building positive relationships with care recipients and their families
- Professional Boundaries and Ethics

Building positive relationship with care recipients and their families

Building a positive patient-caregiver relationship is foundational for enhancing both the caregiver's effectiveness and the patient's overall well-being. Whether caregiving for a loved one or relying on a professional, several key practices foster a strong, trust-based relationship that can significantly improve daily experiences and long-term care outcomes.

Taking Time to Get to Know Patients

Building rapport takes time, as it does in any relationship. Professional caregivers often undergo training to establish connections with patients, focusing on empathy and understanding. It's essential for caregivers to approach patients with patience, recognizing that needing help can feel challenging and vulnerable. Taking time to learn about a patient's history, preferences, and unique needs enables caregivers to provide personalized support that enhances comfort and trust over time.

Effective and Respectful Communication

Communication is at the heart of quality caregiving. Open, honest conversations about care needs, routines, and expectations create clarity for both parties, fostering a mutual understanding. Caregivers should actively listen, ask questions, and observe non-verbal cues to adjust their approach if something isn't working. This attentiveness not only enhances trust but also helps caregivers respond to changes in a patient's physical or emotional state, which is especially important in managing conditions or adjusting care strategies as needs evolve.

Respecting Privacy and Independence

Respecting a patient's privacy empowers them and helps maintain their dignity and sense of control, which is vital for their mental and emotional well-being. Caregivers should avoid taking privacy requests personally, instead recognizing these as important elements of a patient's autonomy. Respecting privacy also includes safeguarding personal information, which strengthens the trust essential for a healthy caregiver-patient relationship.

Setting and Honouring Boundaries

Boundaries ensure a professional and respectful caregiving relationship. Clear boundaries allow caregivers to provide consistent care without overstepping into areas that might make patients or their families uncomfortable. These boundaries also help caregivers manage their own mental well-being, which can prevent burnout. By discussing boundaries openly with patients and their families, caregivers can create a balanced and comfortable care environment for everyone involved.

Regular Check-ups with Family Members

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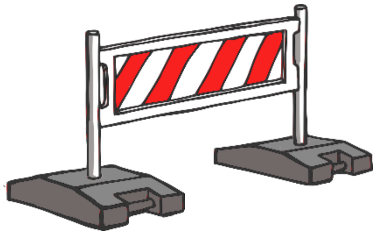
Frequent communication with family members is crucial in caregiving, as it allows for the quick resolution of any issues that arise. Family members often have insights into the patient's preferences or behaviours that can aid in delivering personalized care. Through ongoing conversations, caregivers can adjust their approach to better meet the patient's needs and ensure everyone involved feels heard and supported. This collaborative approach not only strengthens the caregiver-family relationship but also contributes to a consistent, high-quality care experience for the patient.

Professional Boundaries and Ethics

As a caregiver, maintaining professional boundaries is essential to providing respectful, compassionate, and responsible care. Boundaries define the caregiver-client relationship, ensuring a safe environment for both parties and establishing a clear, professional tone. Here are some practical guidelines for navigating and upholding these boundaries:

Key Characteristics of Professional Boundaries



Boundaries are the limits within which the caregiving relationship occurs. They establish professionalism and safety, creating a framework for consistent, respectful care. These boundaries include scheduled visit times, limits on personal disclosure, respecting client privacy, and maintaining professionalism in language and behaviour. Boundaries also help separate your personal life from your caregiving role, which helps you remain focused on your client's needs.

Who Manages Boundaries?

As a caregiver, you are responsible for setting and maintaining boundaries, as clients often rely on your expertise and may find it challenging to express their own needs regarding boundaries. Caregivers hold a position of trust, and it's essential to protect that trust by always prioritizing the client's best interests. Although clients may occasionally ask for help outside your caregiving duties, it's crucial to kindly but firmly maintain professional boundaries to prevent misunderstandings and ensure quality care.

Common Areas Where Boundaries May Blur

Certain situations can make it challenging to maintain boundaries. Here are a few examples and guidelines for each:

1. Self-Disclosure:

Sharing personal information can sometimes help build rapport, but keep it minimal and ensure it serves the client's needs, not your own. Too much self-disclosure may shift the focus from the client and blur the line between professional and personal relationships.

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2. Gifts:

It’s generally best to avoid exchanging gifts, as this can shift the caregiver-client dynamic. If a client offers a small token gift, consider the intent and impact carefully before accepting. Politely declining can often help reinforce boundaries and prevent any sense of obligation.

3. Dual Relationships:

Avoid dual roles with clients, such as also being a family friend, supervisor, or employer, as these relationships can complicate your caregiving role and make it difficult to act impartially.

4. Power Imbalances:

Recognize the inherent power imbalance in the caregiver-client relationship. Avoid asking clients for personal favours, such as assistance with tasks or business ventures, as this can compromise the professional nature of your relationship.

5. Friendships and Socializing:

While it’s natural to develop a friendly rapport with clients, it’s best to keep the relationship professional. Refrain from socializing or forming friendships outside the caregiving setting, as this can make it difficult to maintain professional detachment and objective care.

6. Physical Contact:

Touch can be a form of support, but it’s essential to use caution and sensitivity. Always be aware of cultural and personal boundaries regarding touch, and when in doubt, ask permission or keep physical contact minimal. With children or in specific therapeutic practices requiring touch, explain its purpose clearly and obtain consent to avoid misunderstandings.

7. Humour and Informal Communication:

Using humour or informal language can ease tensions but should always remain professional. Avoid any language that could be misinterpreted, such as personal compliments or jokes of a sensitive nature. Maintaining a respectful tone reinforces the boundaries of a caregiving relationship.

Final Tips for Caregivers

- **Communicate Regularly and Transparently:**

Good communication is the foundation of a successful caregiving relationship. Set clear expectations with clients and their families, and consult with them if any boundary concerns arise.

- **Reflect on Each Situation:**

Each caregiving scenario may present unique challenges, so use your professional judgment to assess how best to uphold boundaries based on the client's needs and your caregiving responsibilities.

- **Seek Support When Needed:**

If you're unsure about a boundary issue, consult with colleagues or supervisors. Talking through these challenges can help reinforce your approach and ensure that both you and your clients feel supported.

By prioritizing these boundaries, you can build strong, trust-based relationships that respect the needs of clients while preserving the professionalism essential to quality caregiving.

3. Conflict Resolution

- Identifying sources of conflict
- Techniques for managing and resolving conflicts

Key Types of Conflict in Health and Social Care

Health and social care environments are complex, with multiple potential sources of conflict. Understanding these different types can aid in anticipating and managing disputes before they escalate.

1. Information Conflicts

Information conflicts occur when there is a lack of clear, consistent, or relevant information. In health and social care, this might include incomplete medical records, errors in prescriptions, or inadequate communication during shift handovers. These situations can jeopardize the quality of care, lead to staff frustration, and diminish trust among team members.

2. Value Conflicts

Value conflicts arise from differences in personal beliefs, priorities, or standards. For example, a healthcare professional may have high expectations for patient care but find themselves limited by time constraints or lack of resources. Such conflicts may strain the relationship between staff and management, as staff may feel that their values are being compromised, leading to resentment or burnout.

3. Interest Conflicts

Interest conflicts stem from competition over resources such as time, space, or attention. In a busy ward, a family may feel their relative is not receiving enough attention, which can create friction with other families or with staff. These situations require a sensitive approach to communicate priorities and establish a balanced care routine.

4. Relationship Conflicts

Relationship conflicts are rooted in interpersonal issues, often fuelled by miscommunication, assumptions, or emotional stress. High-pressure environments make it easy for minor misunderstandings to escalate into larger disputes. Negative emotions like frustration, distrust, or anger can lead to strained interactions between staff, service users, or families, creating a hostile environment.

5. Structural Conflicts

Structural conflicts are driven by organizational challenges, including staffing shortages, rigid hierarchies, or unequal workloads. In health and social care, these conflicts are common due to high turnover, limited advancement opportunities, and a sometimes-hierarchical work environment. When staff feel unsupported or undervalued, morale suffers, and conflicts can arise as a result of these systemic issues.

Techniques for managing and resolving conflicts

Preventing and managing conflict in health and social care requires proactive strategies, clear communication, and structured support systems. Here are some best practices for conflict resolution:

1. Encourage Open Communication:

Create an environment where staff, patients, and families feel comfortable expressing concerns. Active listening and empathy are essential in resolving misunderstandings before they escalate.

2. Implement Mediation Techniques:

In cases of interpersonal or relationship conflict, mediation by a neutral party can help bridge differences and find common ground. In health settings, mediators can facilitate discussions, helping parties to express concerns and collaboratively identify solutions.

3. Provide Training in Conflict Resolution:

Offering regular training in communication, conflict resolution, and de-escalation techniques equips staff to handle conflicts calmly and professionally. Training programs should also cover cultural competence to handle value conflicts that may stem from differing beliefs or practices.

4. Develop Clear Protocols for Conflict Management:

Establishing clear protocols for handling conflicts, including reporting mechanisms and guidelines for addressing specific scenarios, provides staff with a roadmap for resolution.

5. Focus on Supportive Leadership:

Leaders in health and social care settings should actively promote a positive, inclusive culture, demonstrating empathy and responsiveness to staff concerns. This includes addressing structural issues like workload imbalance and ensuring fair access to resources.

Effective conflict resolution not only improves the workplace environment but also enhances the quality of care, reduces stress for all involved, and builds trust between caregivers and service users. By acknowledging the complex dynamics of health and social care settings and proactively addressing conflict, we can foster a supportive, compassionate, and high-performing care environment.

Managing Confrontations with Family Members or Service Users

Addressing conflict with family members of patients or service users requires a similar approach to working with colleagues, but with added sensitivity. Family members may be under significant stress, making it essential to prevent or de-escalate conflict to maintain a stable environment. When resolving conflicts about care or treatment, consider these additional points:

- Stay calm, patient, and empathetic.
- Actively listen to understand their concerns fully.
- Adopt a patient-centered approach and remain mindful of patients' rights and family input.
- Work collaboratively toward a solution, which may involve multiple healthcare professionals.
- Communicate clearly and transparently to ease any concerns.
- Consider providing educational materials if they need more information to feel reassured.
- Strive to reach a solution that aligns with the needs and preferences of all parties involved.

Positive Confrontation Techniques to Implement

Health and social care professionals can benefit greatly from learning positive confrontation techniques. Here are several key strategies to keep in mind:

1. Stay Solution-Focused, Not Combative

Rather than focusing on who is right or wrong, aim to resolve the issue. Avoid adopting a defensive or combative stance, as this only escalates the conflict.

2. Acknowledge the Other Person’s Perspective

Validating the other party’s viewpoint or acknowledging any oversight on your part can often be the first step toward resolution and mutual understanding.

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3. Be Emotionally Aware

Recognize that emotions can amplify conflicts. Show empathy where appropriate, and be mindful that emotional reactions can make issues seem larger than they are.

4. Focus on the Problem, Not the Person

Direct your attention to the issue at hand rather than personalizing the conflict. This keeps the discussion productive and prevents the other person from feeling attacked.

5. Maintain a Calm, Neutral Tone

Avoid shouting or using aggressive language. A calm, measured voice helps keep interactions non-threatening and signals that you are focused on resolution.

6. Practice Active Listening

Allow the other person to express their concerns fully before responding. This is particularly helpful in high-stress situations, where people may simply need a chance to release frustrations before moving toward a solution.

7. Use First-Person Language

Using “I” statements instead of “you” helps express your viewpoint without making the other person feel blamed or defensive. For example, “I feel concerned about...” instead of “You did this…”

4. Cultural Competence and Sensitivity

In caregiving, especially for those working in foreign cultural environments, cultural sensitivity is a foundational skill. Cultural sensitivity involves recognizing and respecting diverse backgrounds, beliefs, and practices while adapting caregiving to honour these differences. This sensitivity enables caregivers to foster mutual respect, build trust, and improve client outcomes by aligning care practices with clients’ cultural contexts.

Caregiving is inherently a cross-cultural experience, especially for migrant caregivers. Cultural sensitivity requires both an understanding of cultural customs and a commitment to respectful communication. This means going beyond language proficiency to include an awareness of cultural nuances, avoiding potentially offensive language, and building an environment of trust. As caregivers interact with clients from various backgrounds, they often act as bridges between cultures, facilitating understanding and avoiding miscommunication through culturally appropriate practices.

Understanding cultural sensitivity entails awareness and adaptation of one’s behaviour, communication, and caregiving approach to accommodate cultural differences respectfully. This includes recognizing that different cultures influence health beliefs, treatment preferences, communication styles, and perceptions of wellness.

The importance of cultural sensitivity in caregiving is multifaceted

1. Respect for Diversity: Acknowledging and honouring cultural diversity allows caregivers to tailor their approaches to meet individual needs, which is critical for providing effective, person-centered care.

2. Effective Communication: Cultural sensitivity enhances communication by adapting both verbal and non-verbal elements. For example, caregivers can adjust language and gestures to match the client's cultural expectations, which helps build trust and clarity.

3. Higher Quality of Care: Sensitivity to cultural norms fosters collaboration and trust, leading to better engagement, adherence to treatment, and overall client satisfaction.

4. Addressing Health Disparities: By providing culturally appropriate care, caregivers contribute to reducing health disparities, ensuring that clients from diverse backgrounds receive equitable and effective healthcare.

Caregivers can apply cultural sensitivity through several strategies

- **Educate Yourself:** Learning about your clients' cultural backgrounds, beliefs, and values can help you understand their needs and preferences more deeply. This could involve cultural competency training or cross-cultural learning.
- **Listen Actively and Show Empathy:** Empathy and active listening are essential. By listening without judgment and considering the client's perspective, caregivers create a supportive environment that fosters mutual understanding.
- **Respect Cultural Differences and Avoid Judgments**: Approach cultural differences with respect and curiosity. Avoid assumptions, and be open to learning from each client's unique perspective, adapting care accordingly.
- **Adjust Care Practices:** Tailor caregiving to respect cultural norms, such as dietary preferences or specific healthcare rituals. This may also mean accommodating different communication styles and respecting cultural expectations around touch, eye contact, and other non-verbal cues.
- **Consider Language Barriers:** In cases where there are language differences, work with professional interpreters or translators to ensure accurate, culturally sensitive communication. This not only fosters trust but also upholds confidentiality and privacy.
- **Adaptability to Taboos and Sensitive Topics:** Different cultures have unique values and taboos, particularly regarding sensitive topics like religion or gender roles. Being mindful of these boundaries shows respect for the client's beliefs and promotes an inclusive atmosphere.

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- **Promote Inclusive Communication:** Active listening, empathy, adaptability, and seeking clarification when uncertain all contribute to an inclusive caregiving environment where clients feel valued and understood.

Video recommendation: "What is culturally competent healthcare?"
https://www.youtube.com/watch?v=E4k8YWqkjqo

5. Tips for Informal Carers Supporting Children and Teens

Caring for young people—especially those facing health issues, trauma, or big life changes—can be challenging and emotional. Here are some helpful ways to connect, support, and communicate with kindness and confidence:

1. Listen More Than You Talk

- Let them speak freely without jumping in with advice right away.
- Use open-ended questions like:
  "How are you feeling today?" or *"What's been on your mind lately?"*
- Try to stay calm, even if they say something upsetting or frustrating.

2. Be Honest, but Age-Appropriate

- Kids and teens can often tell when something's being hidden.
- If there's bad news, explain things simply and truthfully.
- It's okay to say, *"I don't know right now, but I'll find out,"* if you're unsure.

3. Respect Their Feelings and Opinions

- Even if you don't agree with them, acknowledge their emotions.
- Say things like, *"That sounds really hard,"* or *"I understand why you feel that way."*
- Never dismiss their struggles with things like, *"You'll be fine"* or *"It's not that bad."*

4. Be Consistent and Keep Promises

- Trust means everything—especially to young people who feel vulnerable.
- If you promise to show up, call, or bring something—do it.
- Routine and stability help them feel safe.

5. Stay Calm and Patient

- They might push boundaries or act out—it's often fear or frustration talking.

- Take a breath before reacting. Try saying, *"Let's take a minute and come back to this."*

6. Give Them Some Control

- Offer choices whenever possible:
  "Do you want to talk now or later?" or *"Would you rather do this or that?"*
- Teens especially need to feel like they have a say.

7. Show Love in Small Ways

- A kind note, a favorite snack, a gentle touch on the shoulder—small things go a long way.
- For teens who don't want hugs, show care by asking about their interests or offering practical help.

8. Keep Things Confidential (Unless Safety Is at Risk)

- If they open up, treat it with care. Let them know you'll only share if they're in danger.
- This builds trust—and they're more likely to keep talking to you.

9. When Things Get Tough…

- **Stay close**, even if they push you away.
- **Seek professional help**—talk to a doctor, counselor, or support line.
- **Don't take it personally**—sometimes they act out because they trust you.

Video recommendation: "What's it like to be a young carer?"
https://www.youtube.com/watch?v=DwgXqvC8LeI

Exercises/Activities

Role-Play Scenario: "Shift Handover and Patient Briefing"

Objective of the Role-Play: To enhance communication and teamwork through clear and understandable handover and empathetic interaction.

Scenario:

A caregiver, after a busy shift, is handing over patient information to the team coming on shift. During this process, misunderstandings or ambiguities could arise, providing an opportunity to practice clear communication and active listening.

Roles:

1. Caregiver 1 (Night Shift):

This caregiver is tired after a long shift and wants to finish the handover quickly. They have important details to relay about a patient, but the information is communicated somewhat quickly and unclearly.

2. Caregiver 2 (Morning Shift)

Has a few questions and isn't entirely sure they've understood everything. They try to ask clarifying questions and want to ensure they have all details needed for the patient's care.

3. Moderator (Optional Observer):

Observes the role-play and gives feedback at the end, noting areas of miscommunication and offering suggestions for improvement.

Role-Play Steps:

1. First Phase – Handover (Approx. 5-7 Minutes):

Caregiver 1 gives Caregiver 2 the essential information for the shift handover, particularly for a patient who has a complex wound. However, the information sometimes lacks structure and may be incomplete.

Moderator's Observational Questions:

- Is the information presented clearly and logically?
- Can Caregiver 2 easily follow the instructions?
- Are there misunderstandings or areas of ambiguity?

2. Second Phase – Clarifying Questions (Approx. 5 Minutes):

Caregiver 2 asks specific questions about unclear points. They try to improve communication by summarizing and confirming the information they receive. Caregiver 1 responds to the questions and clarifies any misunderstandings.

Moderator's Observational Questions:

- Are the questions from Caregiver 2 clear and specific?
- Does Caregiver 1 repeat or explain the information clearly to resolve confusion?
- What communication improvements could be suggested?

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3. Third Phase – Reflection (Approx. 5-10 Minutes):

The moderator provides feedback on the communication strategies used, and both caregivers reflect on what went well and where there is room for improvement. Suggestions might include:

- Speaking slowly and emphasizing key points.
- Offering summaries or encouraging questions.
- Giving important details, like medications or wound care steps, in clear, structured sequences.

Key Skills Practiced:

- Active Listening: Caregiver 2 practices summarizing and confirming understanding.
- Structured Information Sharing: Caregiver 1 practices presenting information in a logical, concise way.
- Empathy and Patience: Both caregivers work on being patient and validating each other's concerns.

Follow-Up:

The caregivers, together with the moderator, discuss how to continue improving communication skills and what lessons they can carry forward into daily work.

Quiz

Question 1:

In verbal communication, what elements are important besides the words used to ensure effective communication, especially in fields like healthcare?

A. Clarity, tone, volume, and speed of speech

B. Facial expressions, gestures, and posture

C. The use of complex vocabulary

D. Avoiding all forms of nonverbal communication

Question 2:

What is a key benefit of setting and maintaining professional boundaries in a caregiving relationship?

A. It allows caregivers to become friends with clients and their families.

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B. It helps caregivers focus on clients' needs while maintaining their own well-being.

C. It creates an informal environment for caregivers and clients.

D. It minimizes the need for regular communication with family members.

Question 3:

Why is regular communication with family members essential in caregiving?

A. It enables family members to take over certain caregiving tasks.

B. It allows caregivers to learn and incorporate specific patient preferences, enhancing personalized care.

C. It reduces the need for professional boundaries.

D. It lets family members manage all aspects of the patient's care independently.

Question 4:

What is a common cause of conflict in health and social care settings that arises from incomplete medical records or inadequate shift handovers?

A. Value Conflict

B. Relationship Conflict

C. Information Conflict

D. Structural Conflict

Question 5:

Which type of conflict in health and social care typically stems from competition over resources like time or attention?

A. Structural Conflict

B. Interest Conflict

C. Value Conflict

D. Information Conflict

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Question 6:

Why is it important for healthcare professionals to use “I” statements during confrontations?

A. It allows professionals to share their opinions without the need for feedback.

B. It personalizes the conflict, making it more intense.

C. It prevents the other person from feeling blamed or defensive.

D. It enables professionals to avoid focusing on the problem.

Question 7:

What strategy can help healthcare workers prevent misunderstandings before they escalate?

A. Rely on a strict, formal tone in all communications.

B. Maintain a solution-focused approach and avoid blaming others.

C. Avoid listening to others' concerns in high-stress situations.

D. Increase competition for resources to promote productivity.

Question 8:

In a busy ward scenario, a healthcare assistant feels frustrated when asked to respond to a call bell while two nurses are socializing. This scenario is an example of which type of conflict?

A. Value Conflict

B. Structural Conflict

C. Information Conflict

D. Interest Conflict

Question 9:

Why is cultural awareness considered essential in health and social care environments?

A. It allows caregivers to enforce their own cultural beliefs.

B. It prevents misunderstandings and promotes respectful interactions.

C. It helps caregivers avoid having to adapt to different patient needs.

D. It ensures all caregivers follow the same cultural practices.

Question 10:

What is one effective approach caregivers can take to overcome language barriers with patients from different cultural backgrounds?

A. Avoid using translation tools as they may create confusion.

B. Only communicate in simple English, assuming basic understanding.

C. Use professional interpreters or visual aids when possible.

D. Require family members to translate medical information.

Resources

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Module 5: Well-being and Coping with Informal Care- supporting careers to stay well

Introduction

The primary purpose of this module is to raise awareness of the importance of self-care or self-management as it is sometimes called. The module will look at some key areas and offer ideas and examples of exercises that can be done with informal carers and key resources that can be used by informal carers and the people they care for may find helpful.

Living with health conditions and disabilities and caring for people with support needs requires a wide range of skills. To feel empowered in these areas we need to feel confident, we need the right knowledge, and we need the skills.
This module will introduce some key areas and a starting point for more in-depth exploration through a range of exercises you can do with informal carers and those they care for.

Throughout this module we will talk about a personalized approach- an approach that is based upon what matters most to the person being cared for and the informal carers so that people’s hopes and values are considered.

How to use this module- complete the exercises your self – this will help you see the situation for a carer perspective. Similar exercises will be in the carers tool kit- work through them with people you are supporting to identify beneficial ways of improving the lives of carers and their support. These exercises are applicable to everyone regardless of role or age.

Learning objectives

By the end of this module, participants will be able to:

- Be familiar with the concept of self-care
- Able to support informal cares in developing self-care strategies and set goals
- Recognise early signs of stress and be aware of key coping strategies

- Be aware of a rage of strategies for maintaining life balance
- Be able to support informal cares to develop a self-care plan

Self-care Practices

Importance of self-care for carers

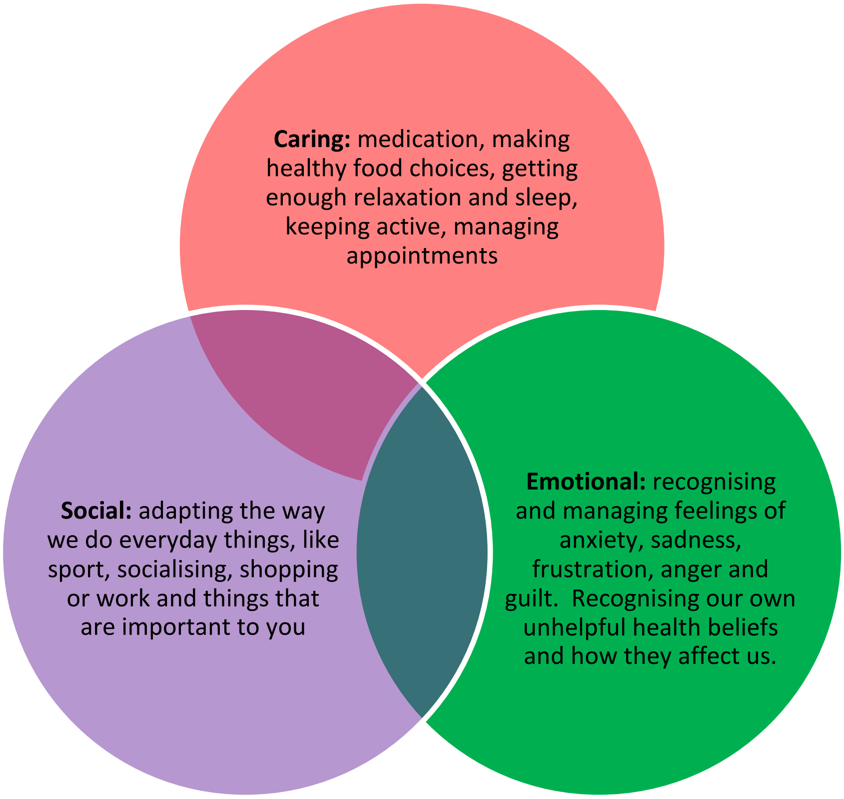
The idea of self-care or self-management might seem new to you. We all self-care every day, whether we call it that or not. We take decisions about what we eat, how much we exercise and rest and whether to take any medication, go to work. We have choices in how we manage life as a carer. A key area is the need to make changes that are brought about by the situation, make helpful adaptations in the way we live and enable family, friends, health professionals and colleagues to support us. In this way we remain in control.

This sense of being in control is what self-management or self-care is about. Through the various tools available you will find out how to accept and make changes. We have all found things that did and did not work for us.

Activity

Take some time to reflect on what self-care means to you-
You may wish to make some notes emotional and social aspects

Self-care is more than managing your wellbeing and caring responsibilities; it is about managing the impact caring has on your life **and** managing the on your own wellbeing. While it is important to take care of the various aspects of caring, we also have to take care of the emotional and social aspects.



Caring: medication, making healthy food choices, getting enough relaxation and sleep, keeping active, managing appointments

Social: adapting the way we do everyday things, like sport, socialising, shopping or work and things that are important to you

Emotional: recognising and managing feelings of anxiety, sadness, frustration, anger and guilt. Recognising our own unhelpful health beliefs and how they affect us.

We optimally self-care when we:-

1. Have a good understanding of care needs, how it affects us and the steps we can take to look after ourselves within this. This might include things like taking medicine, doing exercises and making healthy food choices.

2. Recognise and acknowledge that our caring responsibilities has an effect on our emotions and how we feel. For many of us our emotions can also affect our levels of energy and tolerance, so it works both ways. If we are aware of this connection we can work at reducing this impact.

3. Acknowledge and accept that we may need to make changes in the daily activities we carry out or are involved in. This might include our work, our social life or even just how we shop or mow the lawn.

On top of all of this there are the everyday things in life that we don't have control over – they just happen.

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The 3 circles overlap and interact. Self-care is about considering all 3 circles at the same time and how they fit with our everyday life. Whilst we are managing the impact our caring responsibilities has on our lives, we also need to carry on with the day-to-day things like looking after our house, our families and work. Achieving optimal self-care is about ensuring we look after all 3 areas of our wellbeing and carry on with our everyday lives too.

Optimal self-care happens when we are looking after all 3 circles at the same time and carrying on with everyday life. There will be happy times and times which can be challenging and frustrating – self-care is about having a holistic approach to living with our caring responsibilities.

Managing life as a carer can feel like hard work at times and overwhelming - it takes time and practice.

Worksheet 1

Complete this work sheet by considering what affects you and the things you may need to manage in each area.

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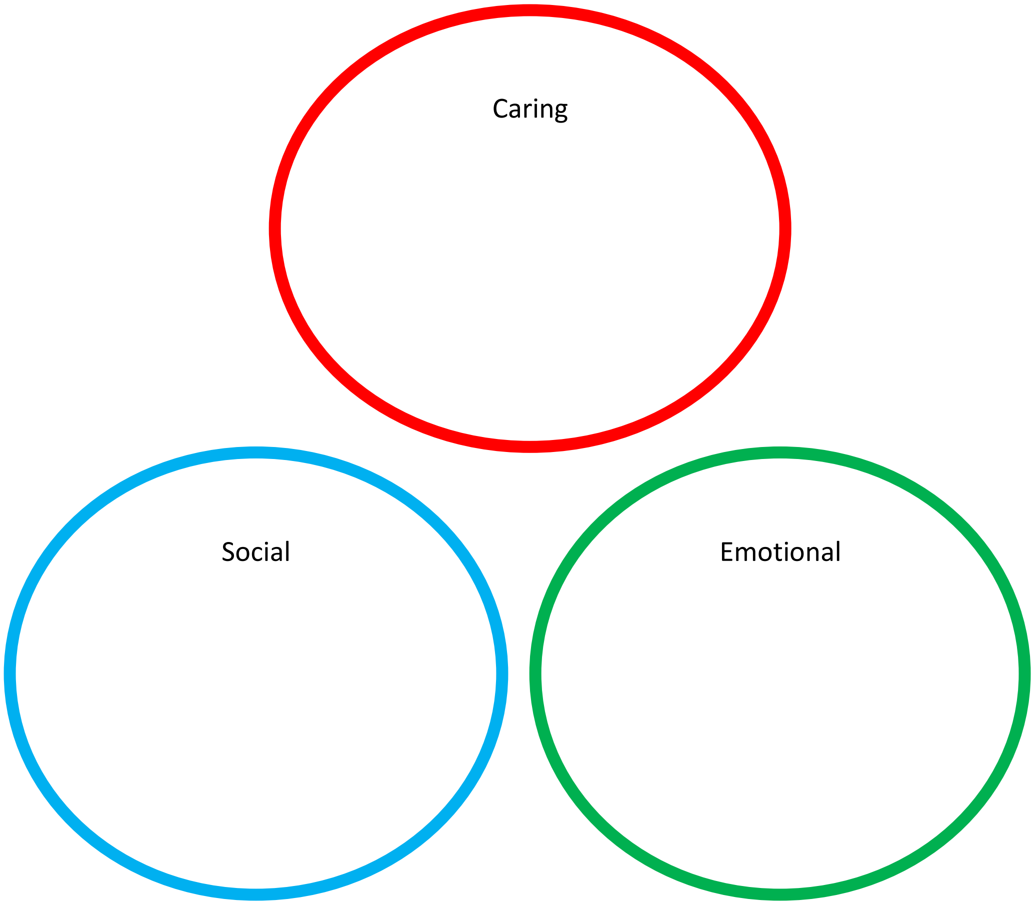
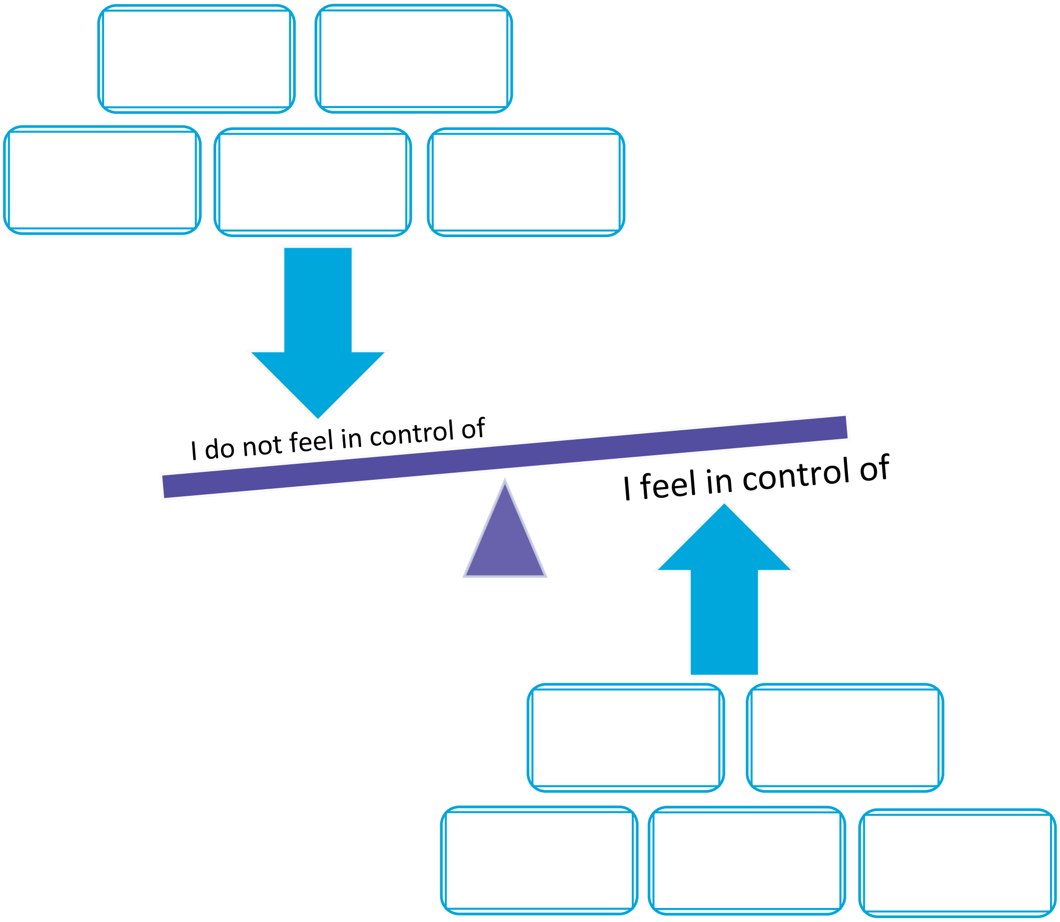


On the next exercise put these things into the boxes according to whether you feel in control of them or not.

Some of the things we wrote in the circles we may feal we have complete control over. Other areas may be dictated by things outside of our control. This applies equally to informal carers and if you are in a paid role.

Put these things into the boxes according to whether you feel in control of them or not-



Reflect- are any of the things I'm not in control of changeable? How much do I worry about the things I can't control? Those areas I am in control of- what is it that allows me to feel in control?

Developing self-care routines

We can feel more in control by increasing our knowledge and understanding of our situation. We can do this by reading about our situation, talking with other people who share the same circumstances, and asking our care team questions. We should also feel that we can challenge the things decided about care

It is important to know not only what we want, but also to know how to reach our goals.

We feel more in control of our own life, including our caring role when we become more motivated to change some of the things that we do and think that aren't helping our situation.

To feel more in control we need to think about our motivation to change and the things that can help us. We gain confidence when we discover and celebrate our own strengths

We can also feel in control when we can recognise the things that get in our way and that hold us back, including your own resistance to making change. And we should also recognise that there are some things that we can't change.

Thinking about the positive results if you are successful can help you feel more motivated. This helps you to become more active in your self-care and taking care of yourself helps you get the highest possible quality of life.

Worksheet 2: Changing the things that matter to you

In this exercise use the boxes to help identify where you want to make changes. This process can help you move from not feeling in control to being in control.

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What do I need to change?

What are the things? that can help me?

How much do I want to change?

What are the things that get in my way

How can I manage the things that are in my way

What would Success be?

Setting a goal to support change or develop a new routine

One of the most important tools in supporting us to self-care, when we have caring responsibilities, is goal setting.

Making changes is difficult- goal setting is a technique that helps up make changes and make adjustments as we go.

Goals focus our attention on something we want. If that something is important to us, we are more likely to put our efforts into achieving it. If it is something we have chosen, not something someone tells us we have to do, we are even more likely to succeed.
Achieving a goal we have chosen, which we feel is important and worthwhile to us, demonstrates to ourselves and to other people, that we are able to overcome problems and obstacles and be successful. Setting goals which we choose is a key self-management tool
A goal which is slightly challenging but which is achievable if we are willing to put in the effort is likely to bring the most benefit, both in what we achieve and in how we feel about ourselves when we succeed.

Goals help us to:

- Identify what we want
- Make a plan to get there
- Move to action
- Keep going until the goal is reached or a better one identified

Research has shown that people are most likely to stick to a plan if they have identified and chosen their own goals. A goal may be a short, medium or long-term aim.

Collaboratively setting goals with family and those close to us or our care team helps to ensure that the goals we set are relevant and important to us and allows them to help by supporting us.

Setting and reaching goals allows us to gain more control over the changes that living with a long term condition brings; it also enhances our self-esteem and self-confidence. There are three steps towards identifying and setting a goal;

- **Set a reasonable goal** – the goal should relate to a positive change and should make sense to us within our own life.
- **Break the goal into smaller steps, ‘do-able’ chunks** – this is the **plan**
- **Carry out the plan** – taking it one step at a time, learning from setbacks

Goals can relate to any area of life. Some goals we might choose to work on may be around the medical side of the condition – for example managing our medication well- but they can be for any aspect of our lives where we wish to make changes or achieve something.

A goal could be to do something differently rather than something completely new. An example of this might be:

“Instead of worrying about my next meeting with the consultant, I am going to spend ten minutes writing down the things I want to talk about in the meeting.”

Once we have chosen our goal we need to write it down and plan how we will achieve it.

Use the space below to identify some of your goals.

My Goals

…………………………

………………………………………………………………………

………………………………………………………………………

………………………………………………………………………

…………………………………………

………………………

……………………………………………

…………………………

………………………………………………………………………

………………………………………………………………………

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Plan Goal

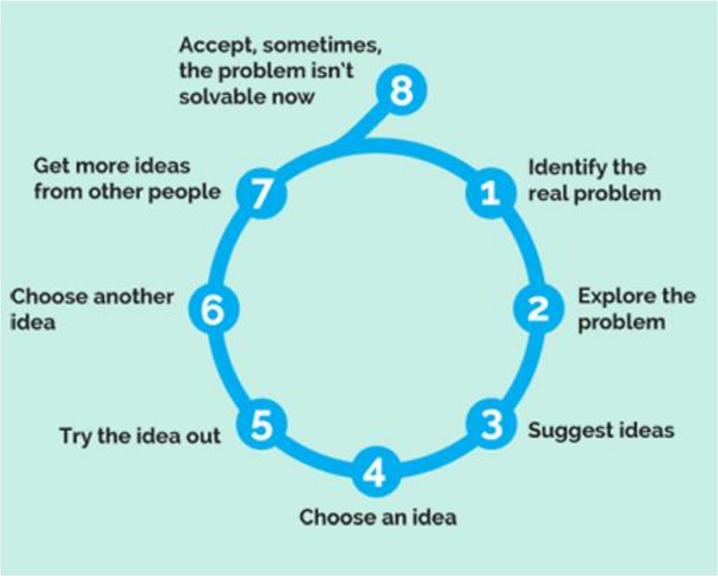
This is the process of breaking the goal down into smaller, more do-able steps. It is the plan for how a goal will be reached. Our plans are more likely to succeed if they are **SMART Plans.**

Specific	What will I do?	Phrase this in a positive way. It is about what action you will take, not what the outcome will be, eg to go swimming, not to get fitter.
Measurable	How much? How often?	It can help to aim for small successes here, it is better to achieve a small step rather than not achieve a big step
Appropriate	Is this important to me? And what makes it important?	Using a scale of 0-10 can help here: 0 - you couldn't really care less 10 – it feels like the most important thing in the world right now Consider the reasons why this goal is important to YOU. What difference will achieving this goal make to you?
Realistic	How confident am I that I can complete this?	Using a scale of 0-10 can help here: 0 - you have no hope of success 10 -you have no doubt you will be successful If your confidence level is 7 or more, you have a good chance of success. If less than 7, you might want to consider what stops you from being confident, and whether there are things you can do to improve your chances of success
Time-based	When will be the best time for me to complete this?	Try to imagine yourself carrying this out. When are you likely to have the best chance of success?

Based on the SMART framework, your plan should specify:

- What will I do?
- How much? How often?
- How important is this to me?
- When will I do it?
- How confident am I that I can achieve it?

Checking out our feelings about importance and confidence can help us to identify problems that may be blocking us from reaching a goal. When a problem is identified, it can be helpful to use a structured approach to tackling the problem. We can use the Problem-solving process.



Source Health Foundation Cocreating health

Something else which can be helpful to us, is to identify support we can get from other people around achieving our goals, this could be from family, friends, a clinician you work with regularly or another member of this group. Your first Goal plan could be around identifying people who would best be able to support you.

Goal setting

What is my goal?

………

My plan: What will I do to achieve this?

………

How important is achieving it, to me? ***Mark on scale***

1 2 3 4 5 6 7 8 9 10

0 = not at all important , 10 = extremely important

What makes is my goal important to me?

………

How much, (many, often), will I do?
(e.g. 15 mins, 7 times, twice a week)

………

When will I do it? (e.g. before lunch)

………

If I visualise myself doing this bit of my Goal, this week/month
how confident am I? *Mark on scale*

1 2 3 4 5 6 7 8 9 10

0=not at all confident 10 = absolutely confident

If less than 7 you may choose to look at the barriers

which may be preventing you from feeling confident.

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Weekly Goal-setting

What is my Goal?

………………………………………………………………………………………………………
…………………………………………………………………………

How important is achieving it, to me? 0-10

What makes it important?

……………………………………………………………………………
……………………………………………………………………

My plan: What will I do to achieve this?

……………………………………………………………………………
……………………………………………………………………………………

Which bits will I do this week?

How much? How often? When?

……………………………………………………………………………
……………………………………………………………………………………

If I visualise myself completing this bit of my Goal,

how confident am I? 0-10

……………………………………………………………………………
……………..

Mental Health Support

- Recognizing signs of burnout and depression
- Accessing mental health resources and support

Not all stress is bad, sometimes stress can be a good thing. Stress is normally a healthy reaction and is only a problem when it interferes with your everyday life. Stress does not mean the same to everyone and we all react in different ways when we are stressed. Some people get angry and some people take themselves away from situations and become really quiet. What may seem very stressful to one person may be very exciting and highly motivating for another.

Some stress is useful as the hormones that go around our body when we are stressed can give us energy that can help to keep us motivated to do the things we need to as well as the things that we enjoy. And sometimes stress can be harmful to us and cause physical symptoms as well as making us feel bad. This stress reaction helps us to stay and confront difficult situations or to run away from situations we think may be dangerous or threatening. This is called the ‘fight or flight’ response.

When we feel threatened in some way we feel stressed. When this happens the cells in our body start to produce substances called hormones. We cannot prevent this happening as it is our body’s way of coping. The two main hormones produced by the cells are called adrenaline and nor-adrenaline which affect our body in a physical way.

If the stress goes on for a long time, another hormone called cortisol is released and the constant presence of these hormones can often leave us feeling ill. When we feel ill our mood changes and this can affect the way we behave and feel. If we do not recognise an increase in our stress levels, we cannot do anything about it. Too much stress and worry leaves us feeling anxious, and can also cause health conditions such as heart disease, stroke, headache, migraine, asthma, skin rash, psoriasis, eczema, stomach ulcers, diabetes, irritable bowel syndrome and colitis.

Everyone experiences stress in their lives, sometimes life becomes more stressful, this stress will only be short term and things will calm down and return to normal within a few days. Sometimes the feelings of stress may last for much longer and then the impact of stress may become more severe and difficult to cope with. Stress can have an affect on your existing health conditions as well as causing new symptoms of stress. The key is to know how stress affects us, so that we can see the signs and quickly do something about it.

How does stress feel to me?

Activity

This activity below is to help you to recognise the signs and symptoms of stress and will give you tips on how you can cope better with stressful situations. As you start to feel more in control, you will find that the symptoms and the health problems which may be caused by stress will reduce.

Think about how you feel when you are stressed, this is about how you feel physically, emotionally and how you behave. This will help you to be able to recognise when you are feeling stressed.

My body

- My heart beats faster
- I feel hot and flushed
- I can feel my heart beating faster
- My mouth is dry
- I sweat more
- I get pins and needles
- My stomach gets upset
- I get butterflies
- My body aches
- I feel tired
- I get headache

My emotions

- I feel more weepy
- I am grumpier
- I am more moody
- I feel sadder than is normal
- I feel frustrated
- I feel like I am on my own
- I feel nervous
- I am snappy with people
- I feel like I cant think properly
- I feel angry
- I feel lonely

My behaviour

- I eat more
- I eat less
- I eat more unhealthy foods
- I can't be bothered doing things
- I don't want to go out
- I smoke more
- I drink more
- I sleep less
- I become quieter and withdrawn
- I can't concentrate
- I have negative thoughts

Worksheet 4 How stressed and anxious am I?

The activity below can help you to think about how stressed and anxious you are. This can help you to understand your own stress levels and if the stress you feel is helpful or unhelpful to your health.

I feel tense or wound up
- All of the time ☐
- Most of the time ☐
- Sometimes ☐
- Never ☐

I think worrying thoughts
- All of the time ☐
- Most of the time ☐
- Sometimes ☐
- Never ☐

I feel scared and have butterflies
- All of the time ☐
- Most of the time ☐
- Sometimes ☐
- Never ☐

I feel restless and have to eb on the go
- All of the time ☐
- Most of the time ☐
- Sometimes ☐
- Never ☐

I get the feeling somethi bad is about to happen
- All of the time ☐
- Most of the time ☐
- Sometimes ☐
- Never ☐

I can relax and sit at ease
- All of the time ☐
- Most of the time ☐
- Sometimes ☐
- Never ☐

I get sudden feelings of panic
- All of the time ☐
- Most of the time ☐
- Sometimes ☐
- Never ☐

Reference: adapted from Snaith RP & Zigmond AS (1974) The Hospital Anxiety and Depression Scale Manual. NFER Nelson.

Score 1 for never, 2 for sometimes, 3, most of the time, 4 all of the time

If you have scored 7 you are the most laid back person going! The higher your score the more stress you are carrying. If we are very stressed from long periods of time its important we do something about it. This may need medical help as well as self care

Indirect

Making use of the stress adrenaline as a way getting things done and avoiding the causes

Direct

Identify the problem and work out how to solve it or manage it

Thinking about the ways you we deal with stress can help us to manage our stress in different ways in the future.

Think of three things that you do to deal with stress, what kind of coping mechanism is it? Does it help or harm you? Does it help you to solve the problem?

Tips on handling stress

Doctors have traditionally prescribed medicines to treat stress but research has shown that there are many other effective ways of taking care of yourself when you are stressed. The more you understand about stress, the better you can take care of it. Here are a few tips:

Try to live a normal lifestyle
Try to live a healthy lifestyle and eat a balanced healthy diet. Try to avoid ways of coping which may make you feel worse such as emotional eating, drugs, smoking or alcohol. These may lead to f health problems such as obesity, heart disease, addiction, cancer and liver disease. Instead try to use healthier ways of coping such as relaxation and exercise.

Try to say how you feel
Many people who are stressed bottle up their feelings and this may make you feel worse. To try to stop this happening find someone you can trust to talk to. Try telling them how you feel. If you think you need professional help, talk with your GP, or arrange to see a counsellor. Ring a helpline to gain support.

Try to think positively
When we are low we tend to see things in a negative or bad way and this may make it difficult to get motivated. Try to avoid making excuses for why you can’t do things. Think of ways you can take care of the problems you have, e.g. by setting small and achievable solutions and goals. Once you have achieved some of your small goals you will soon start to feel better.

Relax!
Learn relaxation techniques and try other things to relax, such as listening to music and having a hot bath. Try to increase your level of exercise because this helps reduce physical symptoms of stress. Studies show that exercise is just as good as taking anti-depressant tablets.

Build up your confidence
Try to build up your confidence skills and stand up for yourself more, so that you feel better about yourself. Set some time for yourself and try doing things you have always wanted to. Don’t be put off by what others say.

Manage your stress
Try to think about what is making you feel stressed and the things that are making the situation worse. Make an action plan of things you can do to reduce your stress.
Try to get a balance between work and play.

Grief and Loss and the care role

Grief and loss aren't only due to bereavement. Major life changes can also cause these feelings, such as:

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- Losing a person gradually through dementia, leading to multiple losses as the disease progresses.
- Young carers grieving over lost teenage years spent caring for a sibling or parent.
- The sense of losing a future together when a partner needs care, altering future plans.
- Grieving a career cut short by family caregiving responsibilities.

Many people talk about stages of grief. A common frame work is the five stages of grief first proposed by Elisabeth Kübler-Ross. Grief is not a linear process- you may experience all the emotions in an day or only some.

Stage	**Description**
Denial	Feeling numb is common in the early stages. Denial of the situation is common
Anger	Anger is a completely natural emotion, it may be directed at people around us who are not experiencing the same thing or at the cause of our grief and loss
Bargaining	When we are in pain, it’s sometimes hard to accept that there’s nothing we can do to change things.
Depression	Sadness and longing are what we think of most often when we think about grief. This pain can be very intense and come in waves.
Acceptance	Grief comes in waves and it can feel like nothing will ever be right again. But gradually it eases though may never go away fully

It is important to acknowledge and accept these feelings of grief and loss. Talking to someone you trust, whether it is a friend, family member, or professional, can help you process your emotions. Joining a support group with others who are experiencing similar situations can also provide comfort and understanding.

Additionally, engaging in self-care activities and finding new hobbies or interests can be beneficial in managing grief and maintaining your well-being. Make sure to take time for yourself, and be patient with your healing process. Everyone's journey is unique, and it

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is essential to give yourself the space and time needed to navigate through these changes.

Accessing resources and support

Every country, district and town will have different resources. Often resources provided by the government can be over stretched. We have to become resourceful if we are to get the support we need.

Many peoples first place to look is the internet and social media. If we use these resources we need to be confident we are getting accurate information and ideas.

What do we need to l look for?

1. Is the resource provided by a government agency?
2. Has the resource been recommended by a care professional?
3. Is it provided by a well known not for profit/charity?
4. Is it trying to sell you a service or product? If yes it may be biased or want to charge you money
5. Is it asking you to do something different from advice of a professional?

Use these questions to make an informed choice about where you get support- ideally talk to a professional, start on government agency websites

Use this box to write down sources of support in your area

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Life Balance

Strategies for balancing caregiving with personal life
Time management techniques

Setting a self-care plan

Setting goals and developing a plan is an important aspect of self-care. Most of us have found it a helpful experience to have a plan clearly set out in any aspect of our lives. This is even more important to allow us to manage the complex job of living well with our caring responsibilities and managing our own health and personal life.

Organisations and the professionals supporting informal carers can play an important role in developing care plans

In some areas people are being offered the opportunity to work in partnership with a member of their medical or care team to plan the management of care to produce a Care-Plan.

A care-planning meeting is a little different because we can find out more about how to self-manage our situation. We can share some of our experiences of life as a ceres and the person cared for, and we can think about and make shared decisions about future care management. Someone once described it as the doctor or other member of the medical team “looking with, rather than looking at, the patient”.

Perhaps you have already been given the opportunity to do this. If so, how did you find it? Was it a helpful experience?

A member of the care team might have more knowledge and be an expert in the care aspects of the situation, but carers are the experts in their own lives.

With care-planning we can have a meeting to discuss the management of care. At this meeting we can look at what support we may need, do we need respite care? Support to take a break. We can also look at the impact the situation has on our lives and whether there are actions either we or the care team can take to lessen this impact. If we feel that other support would be useful to help us to manage, we can also agree and arrange this.

If we don’t have access to this type of support its still important we st out plans. This helps us maintain a life balance and identify areas we may need to change or get support with.

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You can use some of the previous activities to develop you own care plan to help achieve a balance between care responsibilities and your own needs

However well we plan events often overtake us and you may feel you always run out of time. This often means you don't do the things that are important for you self-care.

Time management

For caregivers, time management plays a key role in managing life balance.
With a wide range of tasks to be completed every day it can all feel overwhelming. Effective time management can mean you can take control of the pressure of caregiving, avoiding burnout in the long term.

What is time management?
Time management refers to the process of organising one's time efficiently to maximise productivity and achieve specific goals. Effective time management skills have been demonstrated to reduce stress and enhance overall life satisfaction. Although managing time can be particularly challenging in caregiving situations, it is a skill that can be cultivated and refined, ultimately ensuring the maintenance of a balanced life.

Tips	**Description**
Understand you starting point Create a time audit	track daily activities, identify working behaviour patterns
Planning and goal setting	Minimise stress and wasted time, plan for the big picture, break down into smaller goals
Write a daily to-do list	Start with a 'to-do' list, check things off the list, maintain a clear focus
Focus on one task	Multitasking makes things worse, focusing on one task at a time is better
Block out distractions	Don't always have your phone with you- put it where it becomes a conscious choice to check it
Setting time limits for tasks	Set a time limit, use a timer if need be.
Find time for yourself	Make time for own well-being, schedule breaks, say no!
Learn when to say no	Understand when to say no, reflect on existing commitments before answering
Break down big tasks into portions	Break down big tasks, delegate tasks to team members or find help

Final word

However much we plan, manage our time and self-care life throws things at us that can make it hard to cope. Self-care can help us get back on track Remember – you don't have to be perfect!

Quiz

1. Name four symptoms of stress
2. Name three parts of an action plan
3. Name two ways of managing stress
4. Name three ways to manage time

Resources

All materials are adapted from The Centre for Empowering patients and communities self management and self care resources [Patient Resources | CEmPaC]

Quizzes Answers

Module 1 - Correct answers

1b, 2b, 3a

Module 2- Correct answers

1B, 2B, 3C, 4B, 5B, 6A, 7B, 8A, 9B, 10B

Module 3 – Correct Answers

1B, 2B, 3A

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Module 4– Correct Answers

1A,2B, 3B, 4C, 5B, 6C, 7B, 8B, 9B, 10C

Module 5 – Correct Answers

Question 1- Possible answers

- feeling tense or wound up
- Worrying thoughts all the time
- I feel scared and have butterflies in stomach
- Often restless
- Feeling something bad is about to happen
- Sudden feeling of panic

Question 2

- Identify what you want to do
- When will you do it?
- How much/how long?
- How confident are you?
- How important is it?

Question 3

- palliative
- indirect
- direct

Question 4

- time audit
- Planning and goal setting
- write a to do list
- focus on one task
- learn when to say no
- break down big tasks into smaller ones

About ICWE

ICWE aims to develop an easy to use and accessible website with resources and information regarding informal care, while delivering efforts towards the advancement of a training program for care professionals working with ICs and a toolkit for ICs, designed at covering their common faced needs when caring for other people. Looking at data for Long-Term Care (LTC) (European Commission, 2021), there are growing trends in aging population, life expectancy, and number of potential dependents in the household, that contribute to the increase of LTC needs in Europe, which, as evidence shows, is mainly done by ICs. Even though there is an expected growth in access for institutionalized assistance for LTC, the fact remains that the estimates for the raise in informal care far outweighs other forms of care availability. Informal care is currently the main form of care provided by people across Europe (Hoffman & Rodrigues, 2010). The project looks to address these barriers and ICs needs by developing an initial website where informal carers and care workers, as well as any relevant stakeholder, can get information on local/national/international policies and organisations working in LTC and informal care, as well as get concrete, up-to-date information on issues of informal care, common questions, and practical tools and considerations to help them in their role of caretakers. Additionally, it will develop training materials and a toolkit for adult educators (specifically those working in care professions) and for informal carers respectively, so that we can bridge the knowledge and skills gap identified, by capacitating adult educators so they can work with ICs efficiently, addressing their own needs, and by providing ICs with a practical, easy-to-use tool that they can utilize in their own contexts as caretakers, focusing not only on concrete issues of informal care, but also on aspects of well-being. The ICWE project is an Erasmus+ funded project, under the Key-Action 2, from December 2023 until December 2025. The ICWE consortium consists of six partners from six different countries: Germany, Portugal, Italy, Ireland, Greece and Cyprus.

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