Co-funded by the European Union

Training Manual

for professional Caregivers assisting people with ALS

Indice

(IT) Finanziato dall'Unione europea. Le opinioni espresse appartengono tuttavia al solo o ai soli autori e non riflettono necessariamente le opinioni dell'Unione europea o di INAPP. Né l'Unione europea né l'amministrazione erogatrice possono esserne ritenute responsabili.
(EN)*Funded by the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or the INAPP. Neither the European Union nor the granting authority can be held responsible for them.*

(IT) Finanziato dall'Unione europea. Le opinioni espresse appartengono tuttavia al solo o ai soli autori e non riflettono necessariamente le opinioni dell'Unione europea o di INAPP. Né l'Unione europea né l'amministrazione erogatrice possono esserne ritenute responsabili.
(EN)*Funded by the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or the INAPP. Neither the European Union nor the granting authority can be held responsible for them.*

(IT) Finanziato dall'Unione europea. Le opinioni espresse appartengono tuttavia al solo o ai soli autori e non riflettono necessariamente le opinioni dell'Unione europea o di INAPP. Né l'Unione europea né l'amministrazione erogatrice possono esserne ritenute responsabili.
(EN)*Funded by the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or the INAPP. Neither the European Union nor the granting authority can be held responsible for them.*

(IT) Finanziato dall'Unione europea. Le opinioni espresse appartengono tuttavia al solo o ai soli autori e non riflettono necessariamente le opinioni dell'Unione europea o di INAPP. Né l'Unione europea né l'amministrazione erogatrice possono esserne ritenute responsabili.
(EN)*Funded by the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or the INAPP. Neither the European Union nor the granting authority can be held responsible for them.*

General introduction

Overview of ALS

Amyotrophic lateral sclerosis (ALS) is a progressive neurodegenerative disease that affects motor neurons, which are responsible for controlling voluntary muscle function. Located in the brain and spinal cord, these neurons undergo progressive deterioration, leading to a loss of essential abilities such as walking, talking, eating and breathing.

In Europe, ALS affects approximately 50,000 people, posing a wide-ranging clinical challenge and social and emotional problem. This neurodegenerative disease involves patients, families and healthcare professionals, requiring a multidisciplinary approach to address its complexities.

The relentless and incurable progression of the disease weighs heavily not only on the patient, but also on families and caregivers who provide daily support. This makes it crucial to adopt a care approach that puts the patient's well-being at the centre.

The disease subjects the family to continuously increasing psychological, economic and social stress, bringing those involved to a critical point, sometimes fatal to maintaining everyone's pre-existing living conditions in every respect. If the person affected does not have a family/social network around them, ALS also puts even the most advanced social welfare systems to the test, exposing the sick person to marginal and largely inadequate living conditions.

Despite the absence of a definitive cure, personalised care strategies and a holistic approach to the disease can make a difference. Integrated home care allows the complex needs of the disease to be addressed more effectively, significantly improving the quality of life of both the patient and their family members and carers. The ultimate goal is to alleviate the physical, emotional and social burden imposed by ALS, promoting dignity and autonomy.

To support patients in the advanced stages of the disease, it is essential to develop specific protocols for the management of dysphagia and respiratory impairment, as well as other consequences of the disease. These protocols must also include the active involvement of caregivers, with detailed instructions for dealing with practical difficulties and reducing emotional stress. In addition, training on early signs of deterioration can help prevent serious complications.

(IT) Finanziato dall'Unione europea. Le opinioni espresse appartengono tuttavia al solo o ai soli autori e non riflettono necessariamente le opinioni dell'Unione europea o di INAPP. Né l'Unione europea né l'amministrazione erogatrice possono esserne ritenute responsabili.
(EN)*Funded by the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or the INAPP. Neither the European Union nor the granting authority can be held responsible for them.*

Objectives of the Handbook

This manual was developed as part of the European RECROSS project (Reshaping ALS Home Assistance: Improving Skills of Homecare Operators), funded by the Erasmus+ programme (KA210-VET).

The aim is to provide an operational and training reference to improve the skills of home care workers, ensuring high-quality care for ALS patients.

RECROSS aims to revolutionise home care for ALS patients by adopting an innovative approach and promoting transnational collaboration between Italy and Turkey.

The project is not limited to enhancing the technical skills of operators, but aims to train a dedicated professional figure: the ALS Home Assistant. This figure is designed to provide qualified and humanised support within the home environment. The project also aims to share good practices that can be implemented in different cultural and geographical contexts.

The main objectives of the manual include:

1. Provide practical tools and specialist knowledge to address the daily needs of ALS patients, with a focus on hygiene, mobility, nutrition and communication;
2. Support the training of competent professionals who are able to work with sensitivity and precision, ensuring high-quality care;
3. Promote inclusivity and well-being by responding to the complex needs of patients with personalised and targeted approaches;
4. Disseminate international best practices developed through collaboration between RECROSS project partners, making the results replicable in other contexts.

In summary, the manual is a practical and cultural tool, designed to respond to the real challenges of ALS through an innovative and shared perspective.

Target audience of the manual

The manual is aimed at a wide range of readers, with a particular focus on those who face the daily challenges of caring for patients with ALS. Each section is designed to offer practical tools and knowledge that can be adapted to different operational needs.

(IT) Finanziato dall'Unione europea. Le opinioni espresse appartengono tuttavia al solo o ai soli autori e non riflettono necessariamente le opinioni dell'Unione europea o di INAPP. Né l'Unione europea né l'amministrazione erogatrice possono esserne ritenute responsabili.
(EN)*Funded by the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or the INAPP. Neither the European Union nor the granting authority can be held responsible for them.*

The main objective is to provide experienced carers with specialised training in the field of ALS, in order to enhance their skills and broaden their professional prospects.

The RECROSS Context

The RECROSS project represents an innovative model of international collaboration to address the challenges of ALS. Its strength lies in a holistic approach that combines practical training, experience sharing and the development of operational tools.

The main organisations involved include:

• ASSISLA APS (Italy): an Italian association specialising in assisting ALS patients, with the aim of integrating health and social services to provide continuity of care.

• ILKSENOL (Turkey): a Turkish organisation engaged in social assistance and volunteering, with a focus on inclusive and personalised programmes.

The main activities of the project include:

1. Development of a transnational protocol for home care, taking into account the specificities of the two countries involved.

2. Implementation of a training course, divided into theoretical and practical modules, for caregivers and home care workers. The programme includes simulations with real patients to offer concrete and formative experiences.

3. Creation of multilingual operational tools, including a manual and a practical toolkit, designed to be used in other cultural and geographical contexts.

Expected results:

- The training of 30 specialised home care workers and 10 carers through practical and theoretical courses.
- A significant improvement in the skills of carers and families, promoting greater independence and quality of life.

(IT) Finanziato dall'Unione europea. Le opinioni espresse appartengono tuttavia al solo o ai soli autori e non riflettono necessariamente le opinioni dell'Unione europea o di INAPP. Né l'Unione europea né l'amministrazione erogatrice possono esserne ritenute responsabili.
(EN)*Funded by the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or the INAPP. Neither the European Union nor the granting authority can be held responsible for them.*

- The dissemination of a replicable care model that integrates different cultural and methodological approaches.

Ultimately, the RECROSS project does not merely respond to the immediate needs of ALS patients, but lays the foundations for a new care paradigm centred on collaboration, inclusiveness and innovation.

Chapter 1. Hygiene

1.1 Introduction

Taking care of the personal hygiene of a patient with ALS is much more than a daily routine: it is an act of care that profoundly affects their physical and emotional well-being. Hygiene not only ensures cleanliness and comfort, but also prevents complications such as infections and bedsores. At the same time, respect for dignity and empathy during these activities help to preserve the patient's quality of life even in the most advanced stages of the disease.

As ALS progresses, patients gradually lose their independence, becoming increasingly dependent on their carers for basic activities such as washing, changing and skin care. The sensitivity with which these activities are performed can make all the difference, transforming a moment of need into a reassuring and dignified experience.

1.2 Hygiene Routine: Creating Care Habits

Establishing a clear and predictable hygiene routine is essential for both the patient and the carer. A well-structured routine allows you to anticipate the patient's needs and better manage every aspect of personal hygiene, while maintaining the flexibility necessary to adapt to their daily needs.

As a general rule, it is important to dry each area thoroughly and gently, but carefully, after washing with liquids, especially in areas with skin folds (armpits, groin, under the breasts, mucous folds on the hips and abdomen of obese people, perineal area and between the buttocks), to prevent opportunistic fungal infections.

Among the good and recurring hygiene habits, we also recommend eye care, which is of fundamental importance in ALS patients, both because the eyes take on an increasingly important role in communication with the outside world over time (optically controlled devices) and because of the patient's reduced ability to close their eyelids completely or move their eyes. This can cause dryness or irritation. Therefore, useful elements to consider could be:

- Regular cleaning with moistened gauze or cotton pads and the use of artificial tears to prevent dry eyes.

(IT) Finanziato dall'Unione europea. Le opinioni espresse appartengono tuttavia al solo o ai soli autori e non riflettono necessariamente le opinioni dell'Unione europea o di INAPP. Né l'Unione europea né l'amministrazione erogatrice possono esserne ritenute responsabili.
(EN)*Funded by the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or the INAPP. Neither the European Union nor the granting authority can be held responsible for them.*

- Protection of the eyes from dust or bright light.

1.2.1 Morning hygiene

Waking up is the ideal time to start the day feeling fresh and tidy. During this phase, tasks such as washing the face and hands can be carried out, helping the patient feel reinvigorated. For example, using a soft cloth dampened with warm water is often sufficient to gently cleanse the face. Choosing products suitable for sensitive skin is essential to avoid irritation.

Oral hygiene is equally important, both to prevent dental problems and to improve overall comfort. In patients with dysphagia, specific tools such as oral sponges soaked in antiseptic solutions or suction devices can be used to remove debris without causing discomfort. Where possible, using a rotating/oscillating electric toothbrush, without toothpaste or foaming agents, helps to maintain better oral health and can be easily managed by the carer. Lips should also be kept soft and moisturised using special lip balms or emollient creams.

1.2.2 Full or partial bath

Bathing is a crucial moment for the patient's general cleanliness and relaxation. However, this activity must be adapted to their physical condition. When the patient can be moved to the bathroom, the use of shower chairs or waterproof stretchers is a practical and safe solution. Alternatively, in cases of complete immobility, bed bathing can be performed by washing one section of the body at a time. This approach avoids exposing the patient to the cold and allows the carer to focus on each area carefully.

1.2.3 Intimate hygiene

Intimate hygiene requires special care, especially in patients who use nappies or catheters. It is important to clean these areas several times a day, using hypoallergenic wipes and mild cleansers that respect the sensitivity of the skin. For this purpose, specific foaming products for intimate washing without rinsing can be used. The regular application of creams specifically designed to prevent redness and bedsores to the most sensitive areas is also a good habit that should not be overlooked. In addition, regularly monitoring the intimate area for signs of irritation or infection allows for prompt intervention.

(IT) Finanziato dall'Unione europea. Le opinioni espresse appartengono tuttavia al solo o ai soli autori e non riflettono necessariamente le opinioni dell'Unione europea o di INAPP. Né l'Unione europea né l'amministrazione erogatrice possono esserne ritenute responsabili.
(EN)*Funded by the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or the INAPP. Neither the European Union nor the granting authority can be held responsible for them.*

1.2.4 Skin care

The skin of patients with ALS is particularly vulnerable to problems such as dryness and pressure sores. Applying moisturising or protective creams daily helps to keep the skin soft and resilient. Areas most prone to pressure, such as elbows, heels and the coccyx, require special attention. Light pressure with massage during the application of creams can also stimulate circulation, reducing the risk of sores. In addition to moisturising the skin, it is important to take regular care of the fingernails and toenails, keeping them short and clean to avoid discomfort, infection or injury, especially in the case of ingrown or brittle nails. The caregiver should check them during the hygiene routine to ensure the patient's comfort.

1.2.5 Evening hygiene and night-time preparation

Before going to sleep, gentle cleaning helps the patient relax and prepare for rest. Cleaning the face and hands, applying moisturiser and placing the patient in a comfortable position are all actions that contribute to peaceful sleep.

During the evening preparations, it is essential that the carer carefully checks that the patient's body is correctly aligned: legs, feet, arms and hands with fingers extended, head well positioned and free from hair or other elements that could cause discomfort or itching, as the patient may not be able to express their discomfort. In addition, it is necessary to ensure that the patient has easy access to alarm devices and communication systems to request assistance in case of need.

1.3 Essential Hygiene Tools

To make hygiene activities easier and safer, it is essential to have the appropriate tools. Wet wipes and disposable gloves, for example, are indispensable for ensuring quick and hygienic cleaning, especially in intimate areas. Similarly, shower chairs or stretchers, together with anti-decubitus mattresses, help prevent complications such as bedsores. There are inflatable rubber aids that allow bedridden individuals to have their hair washed.

The choice of tools must always take into account the specific conditions of the patient, and their placement in an easily accessible location facilitates daily management.

1.4 Practical Hygiene Techniques

The hygiene of ALS patients requires delicacy and attention to detail. For example, when bathing a patient in bed, it is important to prepare everything you need before you start, such as basins with warm water, mild

(IT) Finanziato dall'Unione europea. Le opinioni espresse appartengono tuttavia al solo o ai soli autori e non riflettono necessariamente le opinioni dell'Unione europea o di INAPP. Né l'Unione europea né l'amministrazione erogatrice possono esserne ritenute responsabili.
(EN)*Funded by the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or the INAPP. Neither the European Union nor the granting authority can be held responsible for them.*

soaps and towels. Washing one section of the body at a time allows you to keep the patient warm and focus on each area without rushing. Drying the skin and skin folds (as mentioned above) is important to prevent the onset of opportunistic fungal infections.

For oral hygiene, the use of soft toothbrushes, including electric ones (rotating/oscillating toothbrushes) and/or sponges soaked in disinfectant solutions, ensures a clean and healthy mouth. In patients with dysphagia, it is essential to carefully remove residues to prevent respiratory complications. The removal of bacterial plaque from teeth and tongue helps prevent bronchopulmonary infections.

Skin care also requires precision. Applying moisturisers with circular movements stimulates circulation, while regularly changing the patient's position helps prevent bedsores.

1.5 Hygiene as a Moment of Relational Care

In addition to its practical aspect, hygiene offers an opportunity to establish a relationship of trust and respect with the patient. Explaining each action before performing it and involving the patient, when possible, helps to reduce anxiety and create an atmosphere of collaboration. Small gestures, such as a smile or a gentle tone of voice, can make a big difference in making hygiene less stressful and more humane.

1.6 Conclusion

Hygiene in patients with ALS is a central element of care, requiring skill, sensitivity and respect. Every action, if performed with attention and care, can significantly improve the patient's quality of life, transforming a necessary activity into a moment of human connection and physical relief.

Chapter 2: Respiratory Management

2.1 Introduction

Respiratory management is one of the most critical aspects of caring for patients with ALS. Progressive weakness of the respiratory muscles compromises ventilation capacity, increasing the risk of secretion build-up and pulmonary complications. These problems not only worsen quality of life, but can also pose a significant risk to patient survival.

(IT) Finanziato dall'Unione europea. Le opinioni espresse appartengono tuttavia al solo o ai soli autori e non riflettono necessariamente le opinioni dell'Unione europea o di INAPP. Né l'Unione europea né l'amministrazione erogatrice possono esserne ritenute responsabili.
(EN)*Funded by the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or the INAPP. Neither the European Union nor the granting authority can be held responsible for them.*

Personalised respiratory management, integrating specific techniques and the use of appropriate devices, is essential to:

- Prevent complications such as infections and respiratory failure
- Improve well-being and sleep quality
- Reduce "respiratory anxiety" in both the patient and the carer

This chapter provides practical guidance on recognising risks, using support devices and applying drainage techniques, with a particular focus on the importance of caregiver training.

2.2 Risks Associated with Respiratory Impairment

ALS progressively affects voluntary muscles, including those involved in breathing. This deterioration causes a number of respiratory complications, including:

- Hypoventilation: The inability to maintain effective breathing leads to the accumulation of carbon dioxide (CO_2) and reduced oxygenation.
- Accumulation of secretions: Difficulty expelling mucus increases the risk of airway obstruction and infection.
- Sleep apnoea: Episodes of interrupted breathing during sleep cause chronic fatigue, daytime sleepiness, cognitive deficits, and can significantly increase the risk of heart attack and stroke.
- Recurrent lung infections: The stagnation of secretions promotes the proliferation of bacteria, increasing the risk of pneumonia.

Warning signs:

- Shortness of breath, especially during rest.
- Weak or ineffective cough.
- Thick secretions that are difficult to expel.
- Bluish-purple discolouration of the lips and nails (cyanosis).
- Persistent fatigue and daytime sleepiness.

The ability to recognise these signs early allows for rapid intervention, preventing serious complications.

(IT) Finanziato dall'Unione europea. Le opinioni espresse appartengono tuttavia al solo o ai soli autori e non riflettono necessariamente le opinioni dell'Unione europea o di INAPP. Né l'Unione europea né l'amministrazione erogatrice possono esserne ritenute responsabili.
(EN)*Funded by the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or the INAPP. Neither the European Union nor the granting authority can be held responsible for them.*

The Role of Coughing in ALS

Coughing is a fundamental mechanism for clearing the airways, but in patients with ALS, this process can be significantly compromised due to weakness of the respiratory muscles. The inability to generate adequate intrathoracic pressure limits the airflow necessary to expel secretions and debris, increasing the risk of lung infections. Strategies such as accelerating expiratory flow (Free Aspire), using assisted coughing devices such as cough-assist or cough machines, and abdominal compression techniques can help overcome this limitation. These techniques must be integrated into a personalised respiratory care plan and regularly monitored by the pulmonologist and respiratory physiotherapist of the ALS team to assess their effectiveness.

2.3 Respiratory Support Devices

Medical devices are essential to support breathing in ALS patients, adapting to their condition and level of impairment. Among the most commonly used devices are non-invasive ventilation (NIV), secretion aspirators and secretion management devices, each with specific functions to improve respiratory well-being.

The choice of device depends on the patient's condition and the severity of respiratory impairment.

2.3.1 Non-Invasive Ventilation (NIV):

- Function: Provides pressurised airflow through a nasal or face mask, supporting and supplementing breathing.
- Indications: Used in cases of daytime hypoventilation and/or sleep-disordered breathing.
- Benefits:
    - Improves oxygenation and sleep quality.
    - Reduces respiratory load.
    - Prevents further cognitive damage.
    - Decreases cardiovascular and cerebrovascular risk.
    - Delays the need for invasive ventilation.

(IT) Finanziato dall'Unione europea. Le opinioni espresse appartengono tuttavia al solo o ai soli autori e non riflettono necessariamente le opinioni dell'Unione europea o di INAPP. Né l'Unione europea né l'amministrazione erogatrice possono esserne ritenute responsabili.
(EN)*Funded by the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or the INAPP. Neither the European Union nor the granting authority can be held responsible for them.*

Another important tool for daily use in managing breathing control is the pulse oximeter, which is recommended for constant monitoring of respiratory flow and blood oxygenation and during assisted coughing and suctioning of the patient to provide greater safety and peace of mind during these operations for both the patient and the carer.

It is recommended that respiratory support devices be kept clean and that instruments used on a daily basis, such as aspirators, ventilation masks or feeding tubes, be cared for and cleaned, which is essential in preventing infections and complications in patients.

2.3.2 Secretion Suction Device:

- Function: Mechanically removes mucus from the upper airways.
- Precautions:
  - Clean the device thoroughly before and after each use.
  - Limit suction to 10–15-second intervals to avoid irritation.

2.3.3 Secretion management devices such as expiratory flow accelerators (Free Aspire) and cough machines (cough-assist):

- Description: These create resistance during exhalation, keeping the airways open.
- Advantages: They facilitate expectoration and reduce the accumulation of secretions.

2.3.4 Oxygen therapy:

- Indications: Only in the presence of documented hypoxaemia, always associated with adequate ventilation to prevent CO_2 accumulation.

2.3.5 Tracheotomy and Invasive Ventilation

Tracheotomy is an option for patients who cannot tolerate non-invasive ventilation or require continuous ventilatory support. Although it offers relatively higher survival rates, this procedure has significant implications, such as the risk of infection, the need for constant monitoring and careful management of

(IT) Finanziato dall'Unione europea. Le opinioni espresse appartengono tuttavia al solo o ai soli autori e non riflettono necessariamente le opinioni dell'Unione europea o di INAPP. Né l'Unione europea né l'amministrazione erogatrice possono esserne ritenute responsabili.
(EN)*Funded by the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or the INAPP. Neither the European Union nor the granting authority can be held responsible for them.*

complications, including obstructions and tracheal decubitus. Invasive ventilation does not slow down or alter the progression of the disease in any way.

The choice between invasive and non-invasive ventilation must be thoroughly discussed and decided as early as possible (in consultation with the psychological team), taking into account the patient's clinical condition, their desire for quality of life, and the ethical implications.

The guidelines on the type of therapy chosen by the affected person must be collected by the specialist medical team and shared among all operators, so that any emergencies/urgent situations involving them can be managed appropriately.

2.4 Drainage and Expectoration Techniques

Proper drainage of secretions is crucial for keeping the airways clear and preventing infections. In general, it may be helpful to monitor blood oxygen saturation with a finger pulse oximeter while performing these techniques. Techniques include:

2.4.1 Respiratory Physiotherapy:

- Chest percussion and vibration: Light tapping and vibration to mobilise mucus.
- Postural drainage: Positioning the patient with their head slightly lowered to promote drainage of secretions.

2.4.2 Assisted coughing:

- Description: The caregiver applies pressure to the abdomen or chest during exhalation to help the patient cough.

2.4.3 Mechanical Cough Devices:

- Function: These simulate a cycle of forced inhalation and exhalation to mobilise secretions and can be used in both non-invasive and invasive modes. When using the assisted cough device, it may be necessary for the caregiver to use gauze manually in addition to a suction device to remove thick secretions from the palate.

(IT) Finanziato dall'Unione europea. Le opinioni espresse appartengono tuttavia al solo o ai soli autori e non riflettono necessariamente le opinioni dell'Unione europea o di INAPP. Né l'Unione europea né l'amministrazione erogatrice possono esserne ritenute responsabili.
(EN)*Funded by the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or the INAPP. Neither the European Union nor the granting authority can be held responsible for them.*

- Benefits: They are non-invasive and particularly effective in patients with weak coughs.

2.4.4 Hydration and Aerosol Therapy:

- Hydration: Drink enough fluids to thin secretions.
- Aerosol: Saline solutions to humidify the airways and reduce irritation.

Manual removal of thick mucus deposits with the aid of 5x5 sterile gauze pads. Remove any accumulations of thick mucus from the patient's palate from time to time.

2.5 Respiratory Emergencies

In emergency situations, such as acute respiratory failure caused by airway obstruction, it is essential to remain calm and act quickly. Tracheobronchial suction techniques, removal of any mucus plugs and administration of oxygen using appropriate devices can mean the difference between life and death for the patient. Regular training of caregivers and preparation of an emergency kit are key elements in dealing with these situations.

2.6 Caregiver Education and Support

Respiratory management requires specific skills, which the caregiver must acquire through appropriate training.

Essential skills:

- Safe and correct use of medical devices.
- Timely recognition of signs of respiratory deterioration.
- Performing emergency techniques, such as removing upper airway obstructions

Caregivers must be trained not only in the use of medical devices, but also in the emotional management of respiratory emergencies. Relaxation techniques and strategies for reducing anxiety can improve their ability to intervene calmly in critical situations. In addition, it is useful to provide detailed guidance on the safe use of assisted coughing devices, emphasising the need for regular maintenance checks.

(IT) Finanziato dall'Unione europea. Le opinioni espresse appartengono tuttavia al solo o ai soli autori e non riflettono necessariamente le opinioni dell'Unione europea o di INAPP. Né l'Unione europea né l'amministrazione erogatrice possono esserne ritenute responsabili.
(EN)*Funded by the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or the INAPP. Neither the European Union nor the granting authority can be held responsible for them.*

2.7 Monitoring and Management of Secretions

The build-up of secretions is one of the main causes of lung infections in ALS patients. In addition to clearance techniques, regular monitoring of the colour and consistency of sputum is essential for the early detection of infections. Humidification systems, such as active or passive humidifiers, can be used to prevent the airways from drying out and to promote mucus liquefaction.

Emotional support:

- Caregivers should be supported by a multidisciplinary team to manage emotional stress and prevent burnout.
- Participating in training courses or support groups can increase confidence in one's abilities.

2.8 Conclusion

Respiratory management is an essential component of ALS patient care, significantly affecting their quality of life and disease progression. The implementation of specific techniques, such as postural drainage, assisted coughing and the use of mechanical coughing devices, offers practical and effective tools for preventing complications and improving ventilation. Similarly, the appropriate use of respiratory support such as non-invasive ventilation, secretion management devices and secretion aspirators can reduce the respiratory load and ensure better oxygenation.

Particular attention should be paid to the training of caregivers, who play a crucial role in the daily application of these techniques and in the management of any emergencies. The ability to recognise early signs of respiratory deterioration and to intervene promptly with the appropriate tools and skills can make all the difference to patient safety and well-being.

In summary, personalised, multidisciplinary respiratory management not only prevents complications but also provides an opportunity to improve patient comfort and dignity, while providing essential support to caregivers.

Chapter 3: Nutritional Support

3.1 Introduction

(IT) Finanziato dall'Unione europea. Le opinioni espresse appartengono tuttavia al solo o ai soli autori e non riflettono necessariamente le opinioni dell'Unione europea o di INAPP. Né l'Unione europea né l'amministrazione erogatrice possono esserne ritenute responsabili.
(EN)*Funded by the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or the INAPP. Neither the European Union nor the granting authority can be held responsible for them.*

Nutritional support is a fundamental aspect of caring for patients with ALS, as proper nutrition significantly affects quality of life and survival.

As the disease progresses, the muscles responsible for chewing and swallowing weaken, leading to dysphagia and increasing the risk of food aspiration into the respiratory system, dehydration and malnutrition. The latter, found in a significant percentage of ALS patients, increases the risk of death by 7.7 times. Therefore, effective nutritional management not only prevents medical complications such as dehydration, weight loss and infections, but also helps to maintain the patient's dignity and autonomy, significantly improving their quality of life. The supplementation of antioxidants, such as vitamins E and C, can also play a protective role against the oxidative damage associated with the progression of the disease.

3.2 Assisted Feeding

When patients lose the ability to feed themselves, caregivers play a crucial role in ensuring that feeding remains a safe and peaceful experience. In the early stages of the disease, it is essential to assess dysphagia early on in order to implement a modified diet that includes high-calorie foods and nutritional supplements.

This approach helps prevent significant weight loss by improving the patient's energy balance.

The approach to mealtimes requires particular attention:

- Prepare a quiet environment: reduce distractions such as television or background noise, creating a calm and welcoming atmosphere;
- Correct positioning: the patient should be sitting upright, with the head slightly tilted forward, to facilitate swallowing and prevent the risk of aspiration;
- Administer small bites and sips: Use specific utensils, such as small teaspoons, and respect the patient's schedule. When the patient is still self-feeding, ergonomic cutlery with non-slip handles is recommended; plates with raised edges or suction cups at the bottom can facilitate partial self-feeding and increase the patient's sense of autonomy.
- Prevent the risk of aspiration: Avoid giving food or fluids if the patient experiences cough or discomfort. Monitor for signs such as voice changes, shortness of breath, or coughing while feeding;

(IT) Finanziato dall'Unione europea. Le opinioni espresse appartengono tuttavia al solo o ai soli autori e non riflettono necessariamente le opinioni dell'Unione europea o di INAPP. Né l'Unione europea né l'amministrazione erogatrice possono esserne ritenute responsabili.
(EN)*Funded by the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or the INAPP. Neither the European Union nor the granting authority can be held responsible for them.*

• Choice of mineral water: The choice of mineral water is important to ensure adequate hydration of the ALS patient, at any stage of the disease regardless of how it is administered to the patient. It is recommended to use oligomineral waters with a low fixed residue and a neutral or slightly alkaline pH, as they are gentler on the stomach and useful for counteracting acidity. In some cases, water with a specific level of mineral salts (for example, richer in sodium or magnesium) may be indicated to support the nutritional and metabolic needs of the patient. The choice must be personalized according to the indications of the doctor or nutritionist as each patient may have different needs.

3.3 Suitable consistencies

Adapting food and beverage textures is essential to ensure safe swallowing and prevent accidental inhalation. Food must also be balanced in relation to the increased energy requirements typical of ALS.

Recommended foods:

• Foods that are properly blended, homogenized, or creamy, such as mashed vegetables, soups, yogurt, cream soups, baby flours, and puddings, which do not require chewing but guarantee a complete supply of nutrients;

• Food thickeners, such as nectarine, honey, or pudding, to transform liquids into semi-solid consistencies, allowing for more controlled swallowing.

Supplementation with specific nutrients, such as high-quality proteins and antioxidants, is equally important to counteract the risk of malnutrition and improve patient endurance.

Foods and drinks to avoid:

• Crumbly or granular foods that can fragment easily (e.g. dry biscuits, rice...);

• Fluids that are too fluid and can be accidentally inhaled (e.g. water, tea);

• Sticky or stringy foods, such as string cheeses or gummy candies, are difficult for patients to manage;

• Dried, stringy meats, fish with bones even when pureed;

• Double-textured foods that may crumble or change texture in the mouth;

• Vegetables and fruit not blended and/or with the presence of peel, seeds and filaments.

(IT) Finanziato dall'Unione europea. Le opinioni espresse appartengono tuttavia al solo o ai soli autori e non riflettono necessariamente le opinioni dell'Unione europea o di INAPP. Né l'Unione europea né l'amministrazione erogatrice possono esserne ritenute responsabili.
(EN)*Funded by the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or the INAPP. Neither the European Union nor the granting authority can be held responsible for them.*

3.4 Nutritional Monitoring

Regular monitoring of the patient's nutritional status allows for early identification of any problems and timely intervention.

Nutritional status assessment:

- Body weight: Regularly monitor for involuntary weight loss, a sign of possible malnutrition. Regular body weight monitoring is essential to prevent both overweight and weight loss, ensuring a balance appropriate to the patient's condition. In addition to the scales used during specialist check-ups in the hospital, in the advanced stages of the disease in case of difficulty moving or bedding the patient, weight control can be carried out at home using suspended scales integrated or added to the lifts. These tools allow for precise measurement without causing stress to the patient, improving the management of nutritional support;
- Daily caloric intake: record the dietary intake that the patient receives an adequate amount of calories and nutrients;
- Skin and muscle conditions: Dry skin, the presence of bedsores, or reduced muscle mass may indicate nutritional deficiencies.

Personalized Interventions:

- Work with a nutritionist or dietitian to develop a meal plan that meets the patient's specific needs;
- Supplement your diet with liquid nutritional supplements or protein powders, if necessary;
- Ensure adequate fluid intake, even using thickened solutions in case of dysphagia.

Enteral Nutrition: When oral feeding is no longer sufficient or safe, enteral nutrition may be necessary, through:

Nasogastric tube: Temporary solution for limited periods.

Endoscopic percutaneous gastrostomy (PEG): Allows long-term nutritional intake, reducing the risk of aspiration and improving quality of life.

(IT) Finanziato dall'Unione europea. Le opinioni espresse appartengono tuttavia al solo o ai soli autori e non riflettono necessariamente le opinioni dell'Unione europea o di INAPP. Né l'Unione europea né l'amministrazione erogatrice possono esserne ritenute responsabili.
(EN)*Funded by the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or the INAPP. Neither the European Union nor the granting authority can be held responsible for them.*

3.5 Artificial Nutrition: PEG and Nose-Gastric Tube

The progression of the disease at a certain point inevitably leads to the progressive suppression of the glottic reflex, therefore, oral feeding is no longer possible due to the very serious risk of inhalation of the food bolus. In these cases, Artificial Nutrition (NA) is used, divided into:

- **Parenteral Nutrition (PN):** Administration of nutrients directly into the bloodstream via a venous catheter;

- **Enteral Nutrition (NE):** Introduction of nutrient mixtures into the digestive tract through tubes or stomas. In this case too, as with ventilation, it is best for the medical team caring for the patient to share with them the future need for this type of therapy, in order to make the patient understand the need to operate early. Waiting until dysphagia is complete to install an NA can have a significant biological cost, in terms of both weight loss and muscle loss, so it is often advisable to insert an NA before dysphagia becomes complete, so as to maintain muscle trophism for as long as possible. The fact that the patient can feed in both ways will also allow for better acceptance of the artificial way. Here too, the patient's decisions regarding this therapeutic act must be collected in writing and shared with the entire medical staff.

La Gastrostomia Endoscopica Percutanea (PEG) è la tecnica più utilizzata per l'alimentazione enterale a lungo termine.

- **Cos'è la PEG:** consiste nell'inserimento chirurgico di una sonda che collega lo stomaco all'esterno, consentendo un apporto nutrizionale sicuro e duraturo.
- **Indicazioni:** La PEG è indicata in pazienti con disfagia grave o impossibilità di alimentarsi per via orale per periodi prolungati. È preferita rispetto al sondino nasogastrico (SNG) per il comfort del paziente e la minore incidenza di complicanze.
- **Gestione della PEG:** È importante mantenere una corretta igiene del sito di inserzione e monitorare regolarmente la pervietà della sonda per evitare ostruzioni.

Per una corretta gestione della PEG è fondamentale:

- pulire il sito di inserzione almeno due volte al giorno con soluzione fisiologica e garze sterili;

(IT) Finanziato dall'Unione europea. Le opinioni espresse appartengono tuttavia al solo o ai soli autori e non riflettono necessariamente le opinioni dell'Unione europea o di INAPP. Né l'Unione europea né l'amministrazione erogatrice possono esserne ritenute responsabili.
(EN)*Funded by the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or the INAPP. Neither the European Union nor the granting authority can be held responsible for them.*

- controllare regolarmente che non vi siano segni di infezione, come arrossamento, gonfiore o secrezioni purulente;
- consultare un professionista in caso di anomalie, come dolore persistente o ostruzione della sonda.

Complicanze della PEG:

- **Precoci:** Emorragie, infezioni, peritoniti.
- **Tardive:** Infezioni peristomali, migrazione della sonda, erosione cutanea.
  La gestione attenta e il monitoraggio costante riducono significativamente il rischio di queste complicanze.

Il Sondino Naso-Gastrico (SNG) è una soluzione temporanea, utilizzata in genere per brevi periodi.

- **Indicazioni:** È preferito in situazioni in cui si prevede un recupero a breve termine della capacità di alimentarsi per via orale.
- **Svantaggi:** Il SNG può essere meno tollerato dal paziente e comporta un rischio maggiore di polmonite da aspirazione.

3.6 Modes of Administration

Nutrient mixtures can be administered in several ways:

1.Single-bolus: Allows the patient to consume nutrients in a single solution, but may cause abdominal distension or regurgitation.

2.Intermittent infusion: Simulates a physiological diet, dividing administrations into 3-6 portions per day.

3.Continuous infusion: Ensures gradual nutrient intake using an infusion pump. It is particularly indicated in patients with poor gastric emptying.

3.7 Conclusion

Nutritional support in ALS patients is a complex process that requires expertise, sensitivity, and a multidisciplinary approach. Artificial nutrition, through devices such as PEG or SNG, represents a

(IT) Finanziato dall'Unione europea. Le opinioni espresse appartengono tuttavia al solo o ai soli autori e non riflettono necessariamente le opinioni dell'Unione europea o di INAPP. Né l'Unione europea né l'amministrazione erogatrice possono esserne ritenute responsabili.
(EN)*Funded by the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or the INAPP. Neither the European Union nor the granting authority can be held responsible for them.*

fundamental resource for ensuring the patient's well-being in the most advanced stages of the disease. Proper management and continuous monitoring help reduce complications, improve quality of life, and preserve patient dignity.

Providing caregivers with practical tools and up-to-date knowledge is essential to addressing nutrition challenges safely and effectively, turning every meal into a time of care and respect.

Tracheostomy and PEG are invasive procedures for which the patient must give his consent so that intervention can be carried out even in emergency conditions. For a conscious and ethically respectful choice of the patient's wishes, it would be useful to address the topic in a preventive manner, if possible with the patient himself or otherwise with family members, in order to plan interventions in a timely manner, avoiding acting in extreme emergency situations and in conditions already severely compromised.

Chapter 4: Safe Handling

4.1 Introduction

Safe handling is an essential component in the care of ALS patients, who progressively lose the ability to move independently. This condition leads to an increasing dependence on the caregiver for transfers and daily activities, increasing the risk of accidents for the patient and physical fatigue or injuries for the caregiver.

Ensuring effective handling management requires expertise, attention and the use of appropriate tools. It's not just about preventing falls or injuries, but about preserving patient comfort and dignity, as well as protecting caregiver health. This chapter explores safe transfer techniques, appropriate use of lifts, and strategies for comfortable and risk-free dressing.

4.2 Transfer and Positioning Techniques

Transferring a patient safely is an operation that requires preparation and sensitivity. Before starting, it is essential to assess the patient's condition, organize the space, and ensure clear communication.

4.2.1 Preparation for transfer

(IT) Finanziato dall'Unione europea. Le opinioni espresse appartengono tuttavia al solo o ai soli autori e non riflettono necessariamente le opinioni dell'Unione europea o di INAPP. Né l'Unione europea né l'amministrazione erogatrice possono esserne ritenute responsabili.
(EN)*Funded by the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or the INAPP. Neither the European Union nor the granting authority can be held responsible for them.*

Safety begins with an analysis of the patient's physical condition: how much residual strength does he possess? Is he able to cooperate? These factors influence the approach to be taken. The environment must also be properly organized, removing any obstacles and checking that the floor is free of risk conditions or such as carpets, obstacles on the floor (doorstop tinsel, stools, bags, pots, uninsured electrical wires or pipes, etc), use of waxes for polishing. Check that the space for passage is always adequate (especially for the use of walking aids). Finally, communicating each step to the patient helps reduce anxiety and fosters collaboration, improving the experience for both parties.

4.2.2 Practical transfer and positioning techniques

In patients able to provide a minimum of cooperation, the caregiver may opt for light care. In these cases, the patient is placed on the edge of the bed with his feet firmly on the ground. By using a transfer belt, the caregiver can provide safe support when transitioning to a standing or chair position.

In more complex situations, when the patient is unable to cooperate, it is necessary to resort to support tools such as lifts. These devices allow the patient to be lifted and transferred without the risk of falls and without excessive physical effort for the caregiver.

4.2.3 Guardians and Supports

To address muscle weakness in the limbs, specific devices can be used. These aids help prevent falls and improve patient mobility, and in later stages of the disease they can relieve the patient's wheelchair or bedridden posture in terms of comfort and prevention of deciliter injuries:

For patients with weakness, using specific supports can improve mobility and prevent falls.

For example:

- The Codevilla spring is useful for compensating for foot drop, making walking easier;
- Knee braces offer stability and reduce the risk of sagging during transfers;
- Palm supports can help patients with hand weakness maintain a more secure grip while using walkers or other aids
- Lower limb braces for bedridden patients (such as post-operative ferulas) that prevent retroversion of the hips and are for anti-decubitus protection;
- Upper limb braces for wheelchair or bedridden patients so that the muscles of the hands and fingers are stretched and aligned and placed in the correct position to reduce muscle and joint pain;
- Padded headrests for patients in wheelchairs to which soft straps can be applied with Velcro to provide stability to the movements and oscillations of the garment and ensure it to the headrest;

(IT) Finanziato dall'Unione europea. Le opinioni espresse appartengono tuttavia al solo o ai soli autori e non riflettono necessariamente le opinioni dell'Unione europea o di INAPP. Né l'Unione europea né l'amministrazione erogatrice possono esserne ritenute responsabili.
(EN)*Funded by the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or the INAPP. Neither the European Union nor the granting authority can be held responsible for them.*

- Padded safety straps that can ensure the patient's torso adheres to the back of the chair or wheelchair to prevent them from leaning forward.

These devices must be chosen and adapted according to the individual needs of the patient, under the supervision of a physiotherapist or an orthopedic technician.

4.2.4 Caregiver precautions

Adopting correct posture during transfers is crucial to avoid musculoskeletal injuries. It is important to bend your knees, keep your back straight, and avoid sudden twisting or sudden movements. Furthermore, when the patient is completely dependent, it is essential to use appropriate aids to reduce the physical load.

4.3 Use of Lifts

Lifters are an indispensable tool for ensuring patient safety and reducing the physical burden on the caregiver. These devices are designed to gently and controlledly lift the patient, facilitating transfers between the bed, wheelchair, or bathroom.

Types of lifters

There are different types of lifts, each with specific characteristics:

- Manuals: require minimal physical intervention from the caregiver, but are ideal for simple transfers;
- Electric: Equipped with motors, they allow for effortless lifting, particularly useful for fully dependent patients;
- Track-based: Installed on the ceiling or on moving tracks, they are suitable for frequent transfers to different areas of the house.

Correct use of lifters

Before use, it is essential to check that the device is in perfect condition. In the case of electric lifts, the battery must be fully charged. Placing the harness correctly under the patient is essential to ensure stability and comfort. Once the lift is operated, the movement should be slow and controlled, ensuring that the patient feels comfortable throughout the operation.

Benefits of lifters

(IT) Finanziato dall'Unione europea. Le opinioni espresse appartengono tuttavia al solo o ai soli autori e non riflettono necessariamente le opinioni dell'Unione europea o di INAPP. Né l'Unione europea né l'amministrazione erogatrice possono esserne ritenute responsabili.
(EN)*Funded by the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or the INAPP. Neither the European Union nor the granting authority can be held responsible for them.*

Using lifts significantly reduces the risk of accidents and physical fatigue. These tools are particularly useful in confined spaces or in the presence of architectural barriers, offering a practical solution for caregivers managing patients with reduced mobility.

4.4 Dressing

Dressing an ALS patient may seem like a simple activity, but in the advanced stages of the disease it can become a real challenge. A careful and patient approach is essential to ensure comfort and safety.

Preparation for dressing

Choosing suitable clothing is the first step to making dressing easier. Soft, breathable, and easy-to-handle fabrics, such as side-zipped garments or hook-and-loop fasteners, instead of buttons or zippers, are particularly useful as they require less movement and therefore facilitate the management of the patient's dressing with reduced limb strength. Additionally soft, hypoallergenic tissues can prevent skin irritation. The environment also plays an important role: the room must be well heated to prevent the patient from cooling during the operation.

Dressing techniques

For the upper body, it is advisable to gently lift one arm at a time, sliding the sleeve of the garment and carefully pulling it over the head. For the lower part, pants and underwear may be slid down to the knees before helping the patient lift slightly to complete the operation.

Shoes, preferably with Velcro closures, are easier to manage than traditional lace-up styles. It is important to avoid sudden or forced movements, always supporting the patient to prevent imbalances or falls.

4.5 ALS Patient Physical Well-Being: Passive Massages and Soft Physiotherapy Exercises

Often in ALS patients, chronic pain and musculoskeletal discomfort represent a topic to be addressed and managed during the course of the disease. Taking care of this aspect could include:

- Non-pharmacological strategies, such as light massages, localized heat, or compresses;
- Referral to the doctor for pharmacological management in case of persistent pain.

(IT) Finanziato dall'Unione europea. Le opinioni espresse appartengono tuttavia al solo o ai soli autori e non riflettono necessariamente le opinioni dell'Unione europea o di INAPP. Né l'Unione europea né l'amministrazione erogatrice possono esserne ritenute responsabili.
(EN)*Funded by the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or the INAPP. Neither the European Union nor the granting authority can be held responsible for them.*

Passive massage and targeted physiotherapy exercises, such as passive movements, gentle stretching, and soft passive gymnastics, are essential to improving the physical well-being of ALS patients throughout the entire course of the disease.

Main objectives:

- Prevent or limit muscle and joint pain;
- Reduce muscle stiffness, cramps, tingling (paresthesia), muscle fibrillation, and other uncomfortable sensations related to prolonged immobility;
- Improve general circulation, promoting tissue oxygenation and lymphatic drainage;
- Promote relaxation and reduce muscle tension, improving the patient's quality of life.

Recommended practices:

- Passive movements of the upper and lower limbs: The caregiver or physiotherapist gently moves the patient's joints and muscles to maintain mobility and reduce stiffness;
- Passive stretching: Slight stretching of muscles to improve flexibility and prevent muscle retractions with particular reference to the lower limbs and feet and upper limbs and hands;
- Passive massages: Circular or linear movements performed with light pressure to relax muscles, stimulate blood circulation and reduce tension points, including reducing the perception of muscle fibrillations;
- Soft passive gymnastics: Exercises performed with the assistance of a caregiver or physiotherapist, aimed at stimulating the patient's muscles without active effort.

Additional benefits: These activities not only improve physical condition, but also offer an important moment of relational connection between caregiver and patient, promoting psychological relaxation.

Please note: All activities must be customized to the patient's specific condition and performed with the support of a qualified physiotherapist. Abrupt movements or excessive pressure should be avoided so as not to cause further discomfort.

Recommended tools:

- Moisturizing oils or lotions for massage;
- Supports for correct positioning of the limbs during activities;
- Anti-decubitus mattresses to promote a comfortable environment during sessions.
-

4.6 Safety and Environmental Adaptation

(IT) Finanziato dall'Unione europea. Le opinioni espresse appartengono tuttavia al solo o ai soli autori e non riflettono necessariamente le opinioni dell'Unione europea o di INAPP. Né l'Unione europea né l'amministrazione erogatrice possono esserne ritenute responsabili.
(EN)*Funded by the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or the INAPP. Neither the European Union nor the granting authority can be held responsible for them.*

The issue of environmental safety in the patient's home has been very important since the onset of the disease, with the first discomforts and difficulties in dealing with daily life habits. Some initial aspects will need to be evaluated including:

- Elimination of slippery carpets or obstacles;
- Installation of support handles in bathrooms or along hallways;
- Adequate lighting, to avoid accidents.

As the disease progresses, but at an appropriate and timely pace with respect to its evolution, it is advisable to request a technical inspection and an assessment by a specialized CAD (Home Adaptation Centers) technical center to evaluate and ensure environmental safety in the patient's home. Technicians conduct an in-depth analysis of the home environment, identify any risks, and propose specific interventions to adapt the home to the patient's new needs, improving accessibility, safety, and comfort.

4.7 Conclusion

Safe handling is a key component in ALS patient care, requiring technical expertise and human sensitivity. Through the application of appropriate transfer techniques, the use of lifts, and a careful approach to dressing, it is possible to significantly improve the patient's quality of life while ensuring the caregiver's safety and well-being. Continuous training and the adoption of appropriate tools are the basis for effective and humanized management of daily care.

Chapter 5: First Aid

5.1 Introduction

Managing medical emergencies in ALS patients represents one of the most complex challenges for caregivers. The progressive nature of the disease, with the involvement of respiratory muscles and motor functions, makes these patients particularly vulnerable to critical situations. Common emergencies include breathing difficulties, airway obstructions, falls, and seizures, all of which require rapid, targeted interventions.

Being prepared means not only knowing what to do in theory, but also being able to stay calm and act confidently. This chapter provides detailed guidance for competently addressing frequent emergencies, ensuring greater patient safety and greater caregiver peace of mind.

(IT) Finanziato dall'Unione europea. Le opinioni espresse appartengono tuttavia al solo o ai soli autori e non riflettono necessariamente le opinioni dell'Unione europea o di INAPP. Né l'Unione europea né l'amministrazione erogatrice possono esserne ritenute responsabili.
(EN)*Funded by the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or the INAPP. Neither the European Union nor the granting authority can be held responsible for them.*

5.2 Management of Respiratory Difficulties

Respiratory difficulties are among the most common emergencies in ALS patients, due to progressive weakness of the respiratory muscles and the accumulation of secretions. Recognizing signs early is essential to avoid serious consequences.

How to recognize a breathing difficulty

Signs of emergence include labored or shallow breathing, cyanosis (bluish-purple discoloration of the lips and skin), inability to expel mucus, and changes in mental status, such as confusion or loss of consciousness. These signs indicate that the patient is not receiving an adequate supply of oxygen.

Practical interventions

To assist breathing, it is helpful to place the patient in a semi-sitting position, promoting airflow. If secretions block the airways, an aspirator can be used to remove them, taking care not to cause irritation. In patients using noninvasive ventilation (NIV), it is essential to check that the mask is well positioned and functioning. In case of severe respiratory distress, do not hesitate to call emergency services.

In case of respiratory emergencies, it is useful to have an emergency kit available containing:

- Portable aspirator with sterile cannulas;
- Humidifiers to facilitate breathing;
- Portable oxygen tank, if authorized by your doctor.

Placing the patient in a semi-sitting position can promote airflow and reduce the feeling of suffocation. While waiting for medical help, the caregiver can monitor the level of consciousness and respiratory rate, noting any changes to report them to healthcare providers.

5.3 Obstructions of the Airways

Airway obstruction can occur suddenly, often due to food debris or secretions, and is one of the most dangerous situations for ALS patients.

Recognizing an obstruction

(IT) Finanziato dall'Unione europea. Le opinioni espresse appartengono tuttavia al solo o ai soli autori e non riflettono necessariamente le opinioni dell'Unione europea o di INAPP. Né l'Unione europea né l'amministrazione erogatrice possono esserne ritenute responsabili.
(EN)*Funded by the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or the INAPP. Neither the European Union nor the granting authority can be held responsible for them.*

If the patient coughs weakly, cannot speak or breathe, or puts his hands to his throat, these are obvious signs of choking. In severe cases, cyanosis or loss of consciousness may appear.

How to intervene

If the patient can still cough, it is important to encourage them to continue, as coughing is the most natural way to clear the airways. Otherwise, a modified version of the Heimlich maneuver can be performed, applying pressure to the abdomen, or assisted coughing devices can be used to remove the obstruction. If attempts fail, contact emergency services immediately.

5.4 Fall Management

Falls are a common occurrence in ALS patients, especially when muscle weakness compromises stability. A fall can cause not only pain and injury, but also a strong emotional impact, both on the patient and the caregiver.

Assessing the situation after a fall

Before moving the patient, it is important to assess whether there are signs of trauma, such as pain, swelling, or visible injuries. Additionally, more subtle symptoms, such as dizziness or confusion, should be monitored, which may indicate more serious complications.

How to help the patient get up

You should never lift the patient hastily or without adequate tools. Using a lift or involving another person can make the operation safer. In case of suspected fracture or head trauma, it is essential to contact a doctor. 5.5 Convulsive seizures

Although rare, seizures can occur in ALS patients, often as a consequence of neurological complications or the use of certain medications.

Signs of a seizure

During a seizure, the patient may experience involuntary movements, loss of consciousness, and irregular breathing. These episodes can be scary, but it's important to stay calm.

What to do

The priority is to protect the patient from injury. Remove dangerous objects and do not try to block movement or open the patient's mouth. If the seizure lasts more than 5 minutes or repeats within a short time, call for help immediately. After the seizure, place the patient on his side to promote breathing.

(IT) Finanziato dall'Unione europea. Le opinioni espresse appartengono tuttavia al solo o ai soli autori e non riflettono necessariamente le opinioni dell'Unione europea o di INAPP. Né l'Unione europea né l'amministrazione erogatrice possono esserne ritenute responsabili.
(EN)*Funded by the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or the INAPP. Neither the European Union nor the granting authority can be held responsible for them.*

5.6 General Emergency Procedures

In all emergencies, communication with relief is critical. Providing clear information about the patient's status and the medical devices used can speed up the intervention.

Emergency kit

A well-stocked kit is essential for dealing with critical situations. Essential tools include disposable gloves, a discharge aspirator, disinfectants, gauze, and an emergency contact list.

5.7 Caregiver Training

Caregiver preparation is a crucial aspect of managing emergencies safely and effectively. Knowing techniques such as cardiopulmonary resuscitation (CPR) and the use of medical devices can make a difference in critical situations. Attending specific courses helps build the confidence to deal with even the most stressful events. For this reason, caregivers can benefit from specific first aid courses designed for home care of ALS patients.

Such courses should include:

- Cardiopulmonary resuscitation (CPR) techniques adapted to patients with tracheostomy or assisted ventilation;
- Practical management of choking episodes or respiratory crises;
- Simulations of emergency situations to develop safety and response readiness.

5.8 Conclusion

First aid in ALS patients requires a combination of alertness, technical expertise, and empathy. Intervening promptly in emergency situations not only saves lives, but also improves the overall quality of care. This chapter aims to provide caregivers with the practical tools and knowledge needed to confidently and humanely address the daily challenges of illness.

Chapter 6: Psychological support

6.1 Introducing psychological tools and frameworks for understanding emotional needs of ALS patients and their families

(IT) Finanziato dall'Unione europea. Le opinioni espresse appartengono tuttavia al solo o ai soli autori e non riflettono necessariamente le opinioni dell'Unione europea o di INAPP. Né l'Unione europea né l'amministrazione erogatrice possono esserne ritenute responsabili.
(EN)*Funded by the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or the INAPP. Neither the European Union nor the granting authority can be held responsible for them.*

La Amyotrophic Lateral Sclerosis (ALS) presents complex psychological challenges that necessitate comprehensive understanding and support within the clinical framework. This progressive neurodegenerative condition manifests multifaceted impacts that extend beyond individual patient experiences, creating significant reverberations throughout the family system. The intricate nature of these challenges demands a sophisticated approach to psychological intervention and support mechanisms.

The psychological dimensions of ALS care encompass several critical domains: anticipatory grief processes that affect both patients and family members; continuous adaptation requirements in response to evolving physical capabilities; identity reconstruction challenges as patients navigate role transitions; and systemic family impacts, including role reorganization, caregiver burden, and dynamic familial adjustments. These domains are underpinned by established theoretical frameworks, including Family Systems Theory, the Stress-Coping Model, and Attachment Theory, Personality Psychodynamic Theories and Phenomenological Approaches which provide crucial insights into the interconnected nature of patient and family experiences.

Assessment and intervention strategies in ALS care necessitate a comprehensive toolkit that includes specialized Quality of Life Assessments, regular Depression and Anxiety Screening protocols, and Family Functioning Scales. These empirically-validated instruments facilitate the systematic evaluation of psychological well-being and family adaptation processes. Other tools are empathetic conversation, the work of narration and meaning construction and methods of managing emotional involvement. The integration of these assessment tools with theoretical understanding enables the development of targeted interventions that address both individual and systemic needs within the ALS care context.

6.2 Exploring strategies for effective communication, empathy, rapport and relationship building with patients.

The theoretical underpinnings of effective clinical communication are grounded in multiple psychological frameworks that elucidate the mechanisms through which practitioners establish and maintain therapeutic relationships. These foundational theories encompass, among others, Person-Centered Theory, which emphasizes Rogers' fundamental conditions of therapeutic interaction; Social Learning Theory, which illuminates the behavioral modeling aspects of patient-practitioner dynamics, the Emotional Intelligence Framework, which provides insights into the affective dimensions of clinical communication. and bereavement theories.

(IT) Finanziato dall'Unione europea. Le opinioni espresse appartengono tuttavia al solo o ai soli autori e non riflettono necessariamente le opinioni dell'Unione europea o di INAPP. Né l'Unione europea né l'amministrazione erogatrice possono esserne ritenute responsabili.
(EN)*Funded by the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or the INAPP. Neither the European Union nor the granting authority can be held responsible for them.*

The operationalization of these theoretical frameworks manifests through several key psychological components. Active listening serves as a primary mechanism, incorporating sophisticated elements such as non-verbal cue recognition, reflective listening techniques, and systematic validation of patient experiences. Furthermore, the development of empathic competencies encompasses both cognitive and emotional dimensions, facilitating comprehensive understanding of patient perspectives and emotional states, ultimately culminating in the formulation of compassionate therapeutic responses.

The establishment and maintenance of therapeutic rapport constitutes another critical domain, comprising multiple interconnected elements. These include systematic trust development processes, cultural competency enhancement, and the implementation of appropriate professional boundaries. The integration of these psychological foundations enables practitioners to develop and implement empirically-supported communication strategies that facilitate authentic therapeutic alliances with patients and families, thereby optimizing clinical outcomes.

6.3 Addressing caregiver burnout prevention techniques

The comprehension of psychological mechanisms underlying caregiver burnout represents a critical foundation for developing efficacious prevention strategies. This understanding is derived from a sophisticated integration of psychological theories and empirical research, encompassing stress responses, adaptive coping mechanisms, and resilience factors. The theoretical framework encompasses several pivotal models, including the Stress-Diathesis Model, which elucidates the interaction between individual vulnerabilities and environmental stressors; the Conservation of Resources Theory, which explicates the dynamics of resource depletion and replenishment, psychoanalytic theory that studies the role of frustration in adaptation to the disease, the phenomenological theories that study the ways of processing and overcoming the critical situations and the Self-Determination Theory, which emphasizes the fundamental psychological needs essential for maintaining optimal functioning. It is also useful to delle depor into the tools of narration and reconstruction of meaning of ALS experience sia del paziente sia della famiglia.

The psychological architecture of caregiver burnout comprises multiple interconnected components. Cognitive factors encompass automatic thought patterns, perfectionist tendencies, and self-efficacy beliefs, which collectively influence the individual's psychological adaptation to caregiving demands. Emotional elements incorporate emotional regulation capacity, compassion fatigue dynamics, and manifestations of

(IT) Finanziato dall'Unione europea. Le opinioni espresse appartengono tuttavia al solo o ai soli autori e non riflettono necessariamente le opinioni dell'Unione europea o di INAPP. Né l'Unione europea né l'amministrazione erogatrice possono esserne ritenute responsabili.
(EN)*Funded by the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or the INAPP. Neither the European Union nor the granting authority can be held responsible for them.*

guilt and anxiety responses, representing crucial determinants of psychological well-being in caregiving contexts.

Behavioral manifestations constitute the third fundamental domain, incorporating self-care practices, help-seeking behaviors, and boundary-setting mechanisms. The comprehensive understanding of these psychological elements facilitates the development of targeted interventions that address the foundational causes of caregiver burnout, rather than merely ameliorating symptomatic presentations. This nuanced approach enables the implementation of more effective prevention strategies and support mechanisms within the caregiving context.

6.4 Applied Psychology: delving deeper into psychological principles relevant to caregiving, including Bereavement (Grief, loss, mourning) and coping mechanisms

The implementation of psychological principles within caregiving contexts necessitates a comprehensive understanding of multifaceted psychological processes and their empirical implications for both care providers and recipients. This intricate domain encompasses various theoretical frameworks and practical applications that facilitate effective caregiving practices while maintaining optimal psychological well-being for all parties involved.

The core psychological processes integral to caregiving encompass three primary domains: bereavement (grief, loss and mourning processing), coping mechanism development, psychological resilience, dealing with sense loss and crisis elaboration and overcoming.

bereavement involves the systematic recognition of grief dimensions according with bereavement theories, management of anticipatory grief, and identification of complicated grief patterns. Coping mechanism development incorporates both problem-focused and emotion-focused strategies within the particular cultural context, while psychological resilience emphasizes the identification of protective factors, resource mobilization capabilities, the cultivation of growth mindset paradigms.

The theoretical foundations underlying these processes are substantiated by several established frameworks. The bereavement theories, as the literature tells us, illustrate the grieving process from different points of view, for example the Dual Process Model of Grief elucidates the dynamic oscillation between loss-oriented and restoration-oriented coping mechanisms. Stress and Adaptation Theory provides insights into the temporal aspects of caregiving adjustment, while the Positive Psychology Framework emphasizes

(IT) Finanziato dall'Unione europea. Le opinioni espresse appartengono tuttavia al solo o ai soli autori e non riflettono necessariamente le opinioni dell'Unione europea o di INAPP. Né l'Unione europea né l'amministrazione erogatrice possono esserne ritenute responsabili.
(EN)*Funded by the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or the INAPP. Neither the European Union nor the granting authority can be held responsible for them.*

strength-based approaches to addressing caregiving challenges. These theoretical underpinnings collectively contribute to a sophisticated understanding of the emotional and cognitive processes inherent in caregiving, thereby facilitating the development of more efficacious support interventions.

6.5 Role-playing scenarios as an example to practice communication skills, conflict resolution, and emotional support techniques

Role-playing serves as a sophisticated pedagogical and therapeutic instrument, fundamentally rooted in established psychological theories and learning paradigms. Its efficacy in clinical skill development is substantiated by multiple theoretical frameworks, including Social Learning Theory, Experiential Learning Theory, and the Cognitive-Behavioral Framework. These theoretical underpinnings provide a comprehensive foundation for understanding the mechanisms through which role-playing facilitates professional development.

The psychological architecture of role-playing encompasses several critical dimensions. The cognitive domain involves the formation and refinement of clinical schemas, the development of sophisticated mental models, and the enhancement of decision-making capabilities. Simultaneously, the emotional dimension addresses the cultivation of empathic understanding, the refinement of emotional regulation competencies, and the management of clinical anxiety. These components interact synergistically to create a comprehensive learning experience.

The implementation of role-playing scenarios is systematically structured to optimize learning outcomes through various methodological approaches. These include observational learning mechanisms, behavioral modeling principles, and opportunities for concrete experimentation in controlled environments. The integration of feedback processes and behavioral rehearsal further enhances the educational value, ultimately facilitating the development of robust clinical competencies within a secure and supportive learning environment.

Chapter 7: Integrated, Psychophysical and Social Well-being of ALS Patients

(IT) Finanziato dall'Unione europea. Le opinioni espresse appartengono tuttavia al solo o ai soli autori e non riflettono necessariamente le opinioni dell'Unione europea o di INAPP. Né l'Unione europea né l'amministrazione erogatrice possono esserne ritenute responsabili.
(EN)*Funded by the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or the INAPP. Neither the European Union nor the granting authority can be held responsible for them.*

Particular attention should be paid to the integrated well-being of the ALS patient, understood as the overall well-being of the person, which includes mind, body, social relationships and spiritual dimension. Even when addressing areas that appear distinct from each other, the common goal of this approach is to improve the quality of life of the patient and their families. A comprehensive assessment of these aspects involves all the person's profiles (physical, mental, emotional, social, spiritual) and considers them as closely interconnected, capable of promoting the patient's internal psychological well-being.

7.1 Cognitive stimulation to cultivate a full and active mind

Techniques, exercises, and activities to promote memory, learning, and creativity and maintain a clear and trained mind.

7.2 Leisure management, play activities, music therapy and pet therapy as nourishing tools for personal well-being.

The role of play and recreational activities for relaxation and improving mood and socialization may be important, as many of these are compatible with the patient's residual abilities even in the most advanced stages of the disease, such as music and audiobooks.

It is possible to organize outdoor activities for the ALS patient such as trips to the countryside or the sea, at specially designated and specialized facilities. These experiences, whether individual or shared with the family, are supported by appropriate means of transportation, designed to ensure maximum comfort and safety for patients, promoting psychophysical well-being and socialization in natural environments.

Pet therapy also represents a valuable therapeutic support, promoting patients' emotional and relational well-being through interaction with their pets or during specially organized outings, in facilities that offer guided tours and opportunities for such touching and meaningful experiences for many patients. This activity stimulates communication, reduces stress and promotes a feeling of calm and safety in the patient.

7.3 Spiritual Support: Cultivating Innerity

For patients who want and request it, spiritual support, a listening and comfort space designed and dedicated to those who feel the need to cultivate their inner dimension, may be provided. With full respect for all faiths and cultures and based on the needs of each individual, with respect to their professed worship, the patient can be followed on a path of reflection and spiritual and intimate support that can help foster their balance and serenity throughout the course of their illness.

(IT) Finanziato dall'Unione europea. Le opinioni espresse appartengono tuttavia al solo o ai soli autori e non riflettono necessariamente le opinioni dell'Unione europea o di INAPP. Né l'Unione europea né l'amministrazione erogatrice possono esserne ritenute responsabili.
(EN)*Funded by the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or the INAPP. Neither the European Union nor the granting authority can be held responsible for them.*

7.4 The role of the caregiver in the integrated well-being of the ALS patient

In the context of the integrated well-being of the ALS patient, the caregiver plays a key role, of social relevance, which requires multidisciplinary preparation. It must be able to support activities such as cognitive stimulation, leisure management, pet therapy, reading, music therapy and spiritual support, adapting them to the patient's needs. With adequate technical skills, preparation, and empathy, the caregiver contributes to improving the quality of life, promoting the overall well-being of the ALS patient and his or her family.

Chapter 8: Communication and Relational Interaction in ALS Patients

8.1 Introduction - Dysarthria and other communication difficulties

Communication plays a fundamental role in the quality of life of ALS patients, their families, and caregivers. Dysarthria, a difficulty articulating words caused by muscle weakness with progressive loss of voice, is a common problem in ALS patients and, in addition to significantly limiting their ability to communicate, has a significant impact on the patient's psyche, with negative consequences and effects on their well-being. The gradual worsening of this problem, combined with the inability to use the upper limbs for writing or typing due to the weakening of the body's muscles, has a direct and severe impact on the quality of life of the patient and his family and on all his interpersonal relationships.

8.2 Communication and Interaction Strategies

To address this challenge, it is essential to adopt targeted strategies:

- **Speech therapy:** The involvement of the speech therapist is essential to enhance the patient's residual abilities. Buccal breathing and motor exercises, customized for each stage of the disease, can improve word articulation.

8.3 LOW-TECH tools in ALS patient communication.

(IT) Finanziato dall'Unione europea. Le opinioni espresse appartengono tuttavia al solo o ai soli autori e non riflettono necessariamente le opinioni dell'Unione europea o di INAPP. Né l'Unione europea né l'amministrazione erogatrice possono esserne ritenute responsabili.
(EN)*Funded by the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or the INAPP. Neither the European Union nor the granting authority can be held responsible for them.*

Low-tech devices represent simple and cost-effective solutions to facilitate communication in ALS patients, especially in the early stages or when access to advanced technologies is limited. These tools, which lack electronic components, offer immediate and intuitive support for daily interactions but require constant assistance and presence from family members and caregivers. These low-tech tools for the early and advanced stages of the disease are:

8.3.1 Alphabet tablets: Simple instruments with the alphabet written on a surface, which the patient can point to with the finger or with the gaze to compose words.

8.3.2 Signs with pictures or symbols: They represent common needs (e.g. food, water, pain) and facilitate quick communication in case of verbal difficulties.

8.3.3 Erasable whiteboards: Useful for writing short messages quickly and easily.

8.3.4 ETRAN boards: Tools that allow the patient to select letters or words with eye movement.

8.3.5 Personalized notebooks or notebooks: These contain useful phrases or words written in advance to facilitate communication.

These tools are easy to use, inexpensive, and require no advanced technology, making them ideal for all stages of the disease.

8.4 Digital Tools, Advanced Assistive Technologies, Augmentative and Alternative Communication (AAC), and AI for Communication in ALS Patients.

Augmentative communication tools, technological devices, such as assisted technologies, and text-to-speech software (communicator/pointer) are increasingly a valuable tool for maintaining effective interaction. Assistive digital technologies based on advanced software and AI are becoming increasingly relevant in the management of ALS.

Artificial Intelligence (AI)-based technologies are revolutionizing the field of assistive communication, offering advanced tools to support ALS patients at different stages of the disease. Some examples include:

- Advanced text-to-speech devices: These tools can analyze and personalize the patient's voice, offering more natural and immediate communication;
- Predictive systems: Software that learns the patient's language habits to speed up typing or word selection on alphabetic tablets or touch screens;
- Personalized virtual assistants: AI applications that include voice or gesture commands, simplifying daily interactions and improving patient autonomy;

(IT) Finanziato dall'Unione europea. Le opinioni espresse appartengono tuttavia al solo o ai soli autori e non riflettono necessariamente le opinioni dell'Unione europea o di INAPP. Né l'Unione europea né l'amministrazione erogatrice possono esserne ritenute responsabili.
(EN)*Funded by the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or the INAPP. Neither the European Union nor the granting authority can be held responsible for them.*

These tools, although not yet widespread in all contexts, represent a promising future for improving patients' quality of life and reducing caregiver burden. In this area, too, the caregiver's role is important from both an operational and training perspective not only to coordinate and supervise the communication activity by the patient but also to solve the small critical issues related to the daily use of advanced technological systems.

8.5 Environmental adaptations

Creating a calm, relaxed environment and encouraging slow, patient communication from the caregiver while avoiding distractions or tension can reduce the patient's sense of frustration.

8.6 Role of the Caregiver in Communication

The caregiver plays a central role in communication and interaction with ALS patients and their families, often representing the main bridge between the patient and the outside world. Adequate training in this area is essential to ensure effective, empathetic, and respectful communication, thus improving not only the patient's quality of life but also the emotional and relational well-being of the entire family unit.

Practical tips for interacting with the patient in an empathetic and clear way and behavioral approaches to facilitate daily communication:

- **Listen carefully:** show patience and interest, avoiding interrupting or completing the patient's sentences;
- **Speak slowly and clearly:** use a calm and reassuring tone, maintaining eye contact;
- **Ask simple questions:** Use short, direct sentences, giving the patient time to answer.
- **Adapt your environment:** Reduce distractions, such as background noise or multiple conversations;
- **Respect nonverbal cues:** I observed gestures, gaze, or other expressions to better understand the patient's needs;
- **Use communication tools:** Provide the patient with alphabetic tablets, voice devices, or other assistive technologies, if necessary;
- **Involve the patient in decisions:** always ask for his opinion and respect his preferences;
- **Show empathy:** Offer emotional support, acknowledging the patient's difficulties and showing understanding for their needs.

These measures help create a climate of trust and serenity, improving the quality of daily interactions.

8.7 Conclusion

(IT) Finanziato dall'Unione europea. Le opinioni espresse appartengono tuttavia al solo o ai soli autori e non riflettono necessariamente le opinioni dell'Unione europea o di INAPP. Né l'Unione europea né l'amministrazione erogatrice possono esserne ritenute responsabili.
(EN)*Funded by the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or the INAPP. Neither the European Union nor the granting authority can be held responsible for them.*

These interventions not only improve the patient's quality of life, but also facilitate communication throughout all phases of daily care management and care, as well as crucial moments, such as assisted feeding and respiratory management.

In summary, communication tools and strategies help maintain dignity and improve the patient's mental and physical condition and general well-being as much as possible throughout the period of his illness.

(IT) Finanziato dall'Unione europea. Le opinioni espresse appartengono tuttavia al solo o ai soli autori e non riflettono necessariamente le opinioni dell'Unione europea o di INAPP. Né l'Unione europea né l'amministrazione erogatrice possono esserne ritenute responsabili.
(EN)*Funded by the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or the INAPP. Neither the European Union nor the granting authority can be held responsible for them.*