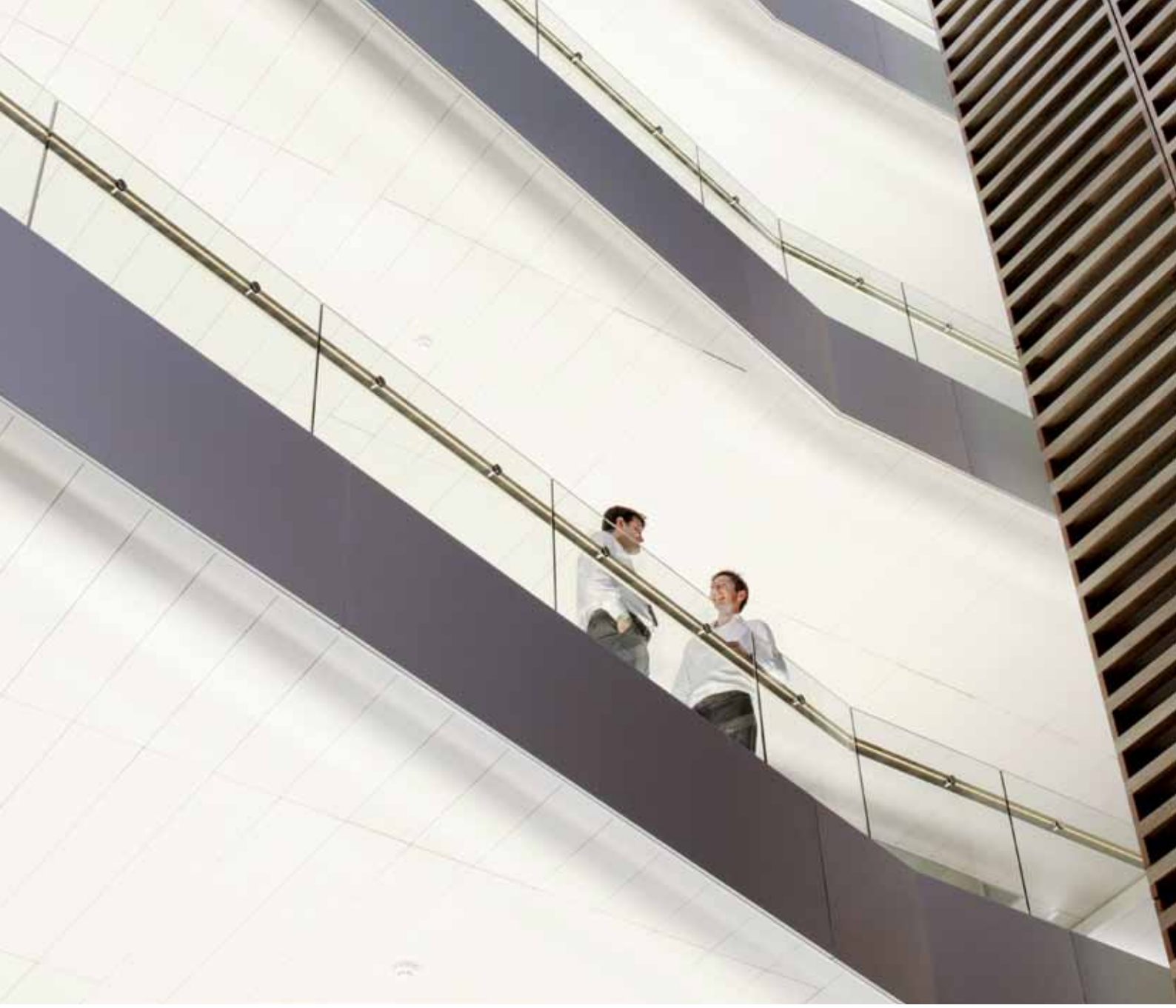

Practical Guide for Alzheimer's Professionals

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FUNDACIÓN REINA SOFÍA

La Suma de Todos

Content

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Capítulo 1
Introduction

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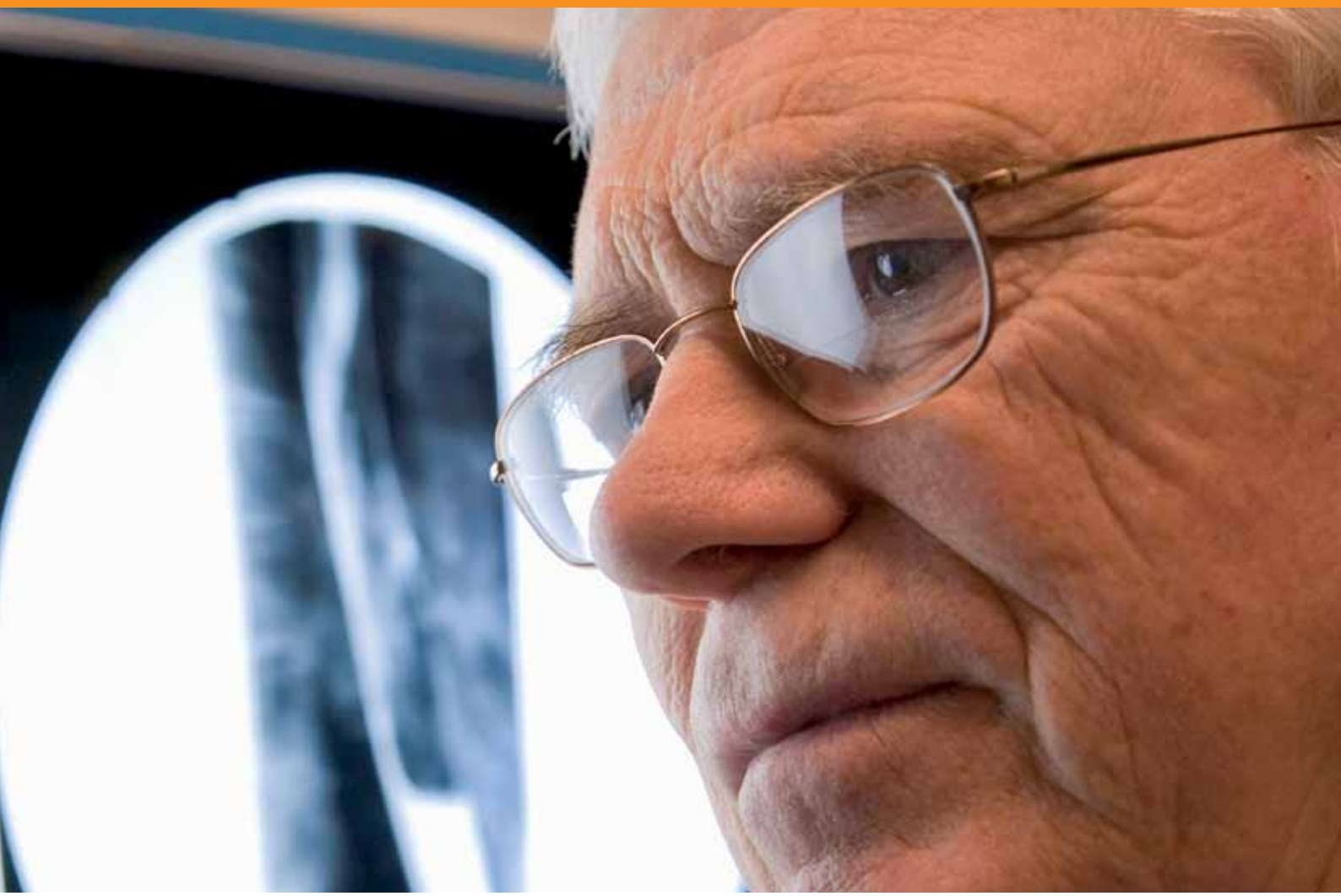
1.1. Background

The current phenomenon of population ageing is the result of factors such as the increase in life expectancy, sharp fall in the birth rate, new lifestyles, etc. In view of these factors, and according to a National Statistics Institute study on long-term Spanish population projections, entailing a statistical simulation of population structure over a 40-year period (2009-2049), the highest population growth is concentrated in the elderly. It also establishes that the above-64 age group will double in size to account for 31.9% of Spain's total population, as compared with 17.2% in 2011.

There is also a new demographic phenomenon referred to as the "ageing of the aged", or the increase in the population aged over 80. As a result, socioeconomic policies in general must be adapted, particularly gerontological policy, by creating new intervention strategies. New care resources are required and existing provisions must be adapted to a higher ratio of elderly and dependent persons.



At June 2012, 2,334,387 dependent persons have exercised their right to request the benefits provided by the "Law on Dependence" (IMSERSO data); a large proportion are elderly people.

The Law on Dependence defines this concept as *"the permanent state in which people that for reasons derived from age, illness and disability and linked to insufficient or lack of physical, mental, intellectual or sensorial autonomy find themselves, thus requiring the care of other person/s or significant assistance in order to perform the basic activities of daily living, or, in the case of persons with intellectual disability or mental illness, other support for their personal autonomy".*

As this process of ageing and growth in dependency results in increasing numbers of people that require specialised care, recourse to the institutionalisation of patients in specialised care centres is also growing.

Within this aged population structure in need of specialised professional care, we must refer to people with dementia and, more specifically, Alzheimer's patients, of which there are around 600,000 in Spain, based on current estimates.

This guide has been prepared by professionals working in the Care Unit at the Reina Sofia Foundation's Alzheimer Centre.

It is intended to provide help and reference material for all professionals who work with patients showing neurodegenerative dementia. Chapter by chapter, this guide describes the work methodology employed to provide comprehensive care. The techniques and methods are examples of ways in which professionals may work with this type of patients.

Finally, there is a description of the main lines of research currently in progress internationally and at the Alzheimer Centre's own Research Unit.

1.2. Description of the Centre

There follows a description of the Centre; although the professionals involved in the preparation of this guide will provide working guidelines for dementia patients in general, and more specifically Alzheimer's patients, it will be useful to be able to picture their daily work environment.

The Reina Sofia Foundation's Alzheimer Centre provides comprehensive, specialised care for people with Alzheimer's and other neurodegenerative dementia. The complex is divided into three areas: a Training Unit, a Care Unit and a Research Unit.

The project dates back to 2001, when the Reina Sofia Foundation began to study the possibility of creating a space in which to give specialised care to persons with this type of pathologies. Following a preparatory phase, the project was completed in March 2007 when the Centre was opened in the Vallecas district of Madrid, on land assigned by Madrid City Council.

Once completed, the Reina Sofia Foundation assigned the Training Unit and the Care Unit to the Madrid Regional Government's Department for Social Affairs, which is responsible for managing the Centre through the company Clece Servicios Sociales.

The Ministry of Economy and Competitiveness (formerly Ministry of Science and Technological Innovation), through Instituto de Salud Carlos III, is responsible for managing the Research Unit (Fundación CIEN), and the Madrid Regional Government manages the Care Unit and the Training Unit. Each of the institutions involved has signed a collaboration agreement and a common work project.

The Training Unit addresses specific matters relating to Alzheimer's and other dementias, as a benchmark centre for this kind of training. Courses target Alzheimer's patients' families and caregivers, professionals related to the sector, volunteers and students, i.e. anybody that is interested in and sensitive to these pathologies. The Unit has an annual schedule comprising courses, seminars, workshops, symposia, international congresses, etc. All its activities are continually evaluated by the Department for Social Affairs, which is responsible for monitoring.

The Care Unit, in which public places are allocated by the Madrid Regional Government, comprises a **Live-In Residence** (for 156 patients), a **Day Centre** (40 patients) and a **Weekend Centre** (20 patients).

The Day Centre provides the comprehensive care required by these patients, from Monday to Friday, supporting families and in some cases delaying permanent institutionalisation. We have the necessary professionals to cater for all our patients' needs and to stimulate them physically and cognitively, together with the necessary equipment and facilities. The same applies to the Weekend Centre.

The Live-In Residence includes beds for Alzheimer's patients and other neurodegenerative disorders, and for their companions; this allows the patient's healthy partner or elderly family member to live in the Centre, though not an Alzheimer's patient, where all their needs are covered and their receive full care.

The residence is divided into nine life units, based on the patient's degree of impairment. There are six type-I units (three for patients in the initial phase and three for patients in the moderate phase) and three type-II units (for severe Alzheimer's patients).

This distinction between life units allows the comprehensive care and therapies applied to be specific to the resident's Alzheimer's phase.

There are a maximum of 18 residents in each type-I unit and a maximum of 16 in each type-II unit, due to their increased physical, cognitive and behavioural needs.

This is a benchmark centre in terms of its design, which has a positive impact on both patients and professionals. Quality and welfare are apparent and merge with the functionality required for daily activities.

Division into small life units means that users find themselves in small spaces that are more familiar and cosy, favouring spatial orientation; professionals, direct care personnel and the interdisciplinary team deal with a group of people that, to the extent possible and bearing in mind the difficulty that this entails, are in the same phase of Alzheimer's.

The Centre's architecture is designed to be tailored to the needs of its users and professional team. Its luminous, low buildings occupy an extensive area. Each life unit has a garden area to ensure that patients are in permanent contact with the exterior, through a large central window, so as to facilitate their perception of time and the seasons.

We also have a large exterior garden with walking areas and therapeutic zones for activities such as horticulture, garden therapy, aromatherapy and mechanotherapy, which are so important for patients' motor, cognitive and functional capabilities. This garden is also a meeting point for family members and residents; it has a play area for children to ensure that their visits are dynamic and pleasant, allowing different generations to share their time together as if they were in a play area inside a park.

As indicated, the complex includes a care area, a training unit and a research centre. Work can therefore be performed combining these three viewpoints, thanks to the collaboration agreement between the institutions involved in the project. With this in mind, a Multidisciplinary Support Unit has been created (MSU).

The MSU is formed by specialists in neurology, psychiatry and sociology from the Research Unit and involves various specialists in geriatrics, neuropsychology, physiotherapy and occupational therapy from the Care Unit, who systematically evaluate the Care Unit patients so as to achieve a multidisciplinary assessment (clinical and sociodemographic) of the residents.

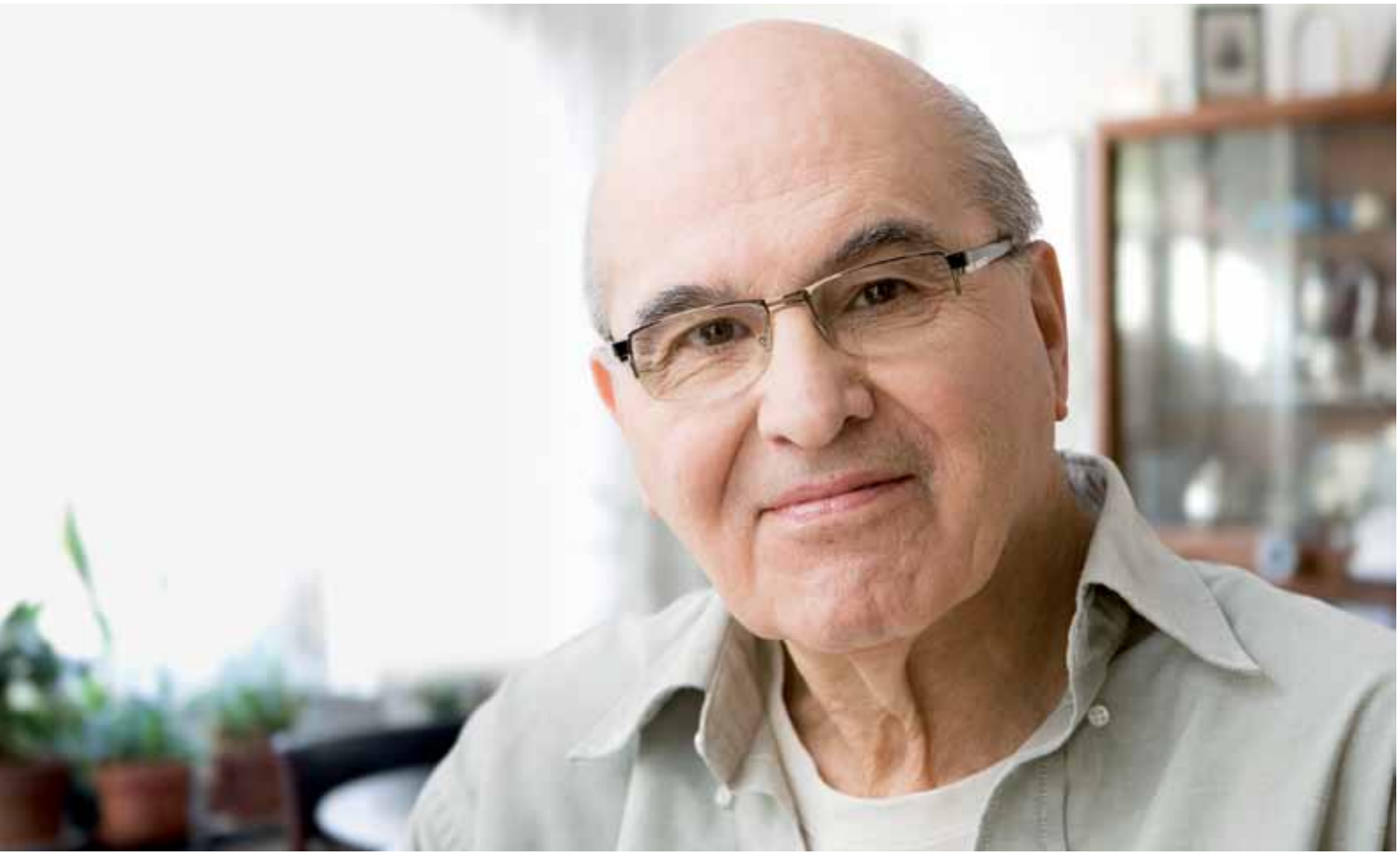
Through the MSU, the aim is to obtain a multidisciplinary profile for users; this entails the use of data such as their clinical history (evaluation on admission and subsequent evolution), co-morbidity, neuropsychological state, additional deficiencies, possible complications, aspects related to the caregiver and the environment, social and healthcare data, etc. The data are complied by the Centre's interdisciplinary team through its six-monthly evaluations, to ensure that data are not duplicated. Once compiled, the data are furnished to the MSU's researchers, which may in turn observe the residents and consult the care personnel in contact with them on a daily basis.

Moreover, the Care Unit cooperates with other areas of the Research Unit in the following ways:

a) Neuroimaging of residents.
b) Neuropathology area: samples of brain tissue are taken from deceased donors in order to conduct a postmortem study to arrive at a neuropathological diagnosis; the samples are preserved for future research.
c) Cellular biology laboratory: blood, urine and brain samples are taken from deceased donors for subsequent analysis.

(It should be noted that all evaluation, sampling and neuroimaging is authorised by the residents' family members; it is not a prerequisite to access the Centre.)

Chapter 6 of this guide provides detailed information on the research projects currently undertaken by Fundación CIEN.



1.3. Professional team

In addition to the general services team (maintenance, cleaning, laundry, gardening, catering and reception), we have an interdisciplinary team of professionals engaged in structured and synergic activities in order to provide comprehensive care.

At the Reina Sofia Foundation's Alzheimer Centre, this team is formed by the following professional categories and supervised and coordinated by the Centre's management team:
- Doctor.
- Nurse.
- Social worker.
- Neuropsychologist.
- Occupational therapist.
- Physiotherapist.

This team meets regularly to discuss incidents relating to residents and to establish and review individual care plans. These meetings result in the care plan for the Centre's users. All matters and guidelines addressed in the meetings are duly recorded in each resident's personal file.

In general terms, the members of this professional team perform the following functions:

Doctor

- Assess the resident's health on admission, defining care and treatment guidelines.
- Prepare and update his or her clinical record.
- Write prescriptions, if required by the healthcare centre (not all healthcare centres allow residence doctors to officially stamp prescriptions).
- Refer residents to a hospital when deemed necessary.
- Review incidents that have arisen during previous shifts and incidents that could be repeated during his or her shift; this entails:
  - Reading reports prepared by doctors, nurses and geriatric nursing assistants.
  - Visiting the units to clinically supervise all residents that are convalescent.
  - Asking the infirmary to measure vital signs and to apply simple diagnosis methods, if appropriate.
  - Changing treatments as applicable.
  - Informing the infirmary of changes to medication for immediate application.
  - Reflecting evolution in clinical history files.

Nurse

- Prepare the infirmary case file containing the admission evaluation.
- Prepare and administer medication to residents following the doctor's instructions; keep an administration record.
- Measure vital signs on a regular basis.
- Perform glucose tests on diabetic residents.
- Take blood for analysis, Sintrom tests, etc.
- Prepare cultures for subsequent analysis (urine, feces…).
- Apply treatments following the doctor's instructions.
- Monitor observance of diets ordered by doctors.
- Liaise between geriatric nursing assistants and the medical department.
- Attend to residents' needs, providing the doctor with the necessary cognitive data.
- Complete the relevant healthcare registers.

Social worker

- Arrange resident pre-admission, obtaining information to facilitate admission.

- Preparation and monitoring of the resident's social history.
- Liaise between the Public Administration and the Centre.
- Collaborate in the preparation of the Centre's activities programme.
- Encourage the integration of residents and their family members.
- Contact family members.
- Evaluate on a multidisciplinary basis.
- Communicate with public bodies.
- Interview family members.

Occupational therapist

- Training residents in basic daily activities that can be recovered.
- Maintain autonomy in basic activities of daily living (ADLs) that can still be performed independently.
- Adapt the resident's environment to encourage ADL independence.
- Maintain autonomy in instrumental activities of daily living that can still be performed independently.
- Stimulate cognitive capabilities to slow the progressive deterioration caused by the disease.
- Maintain cognitive capabilities that are preserved.
- Encourage upper limb mobility.
- Encourage social and leisure skills.
- Perform an initial evaluation of the resident's functional status (applying standard scales).
- Prepare the resident's treatment plan and assign adequate therapies.
- Encourage the resident's physical, cognitive and emotion autonomy.
- Collaborate with the other team members in the preparation of the Centre's activities programme.
- Oversee technical assistance required by patients.
- Encourage resident integration to prevent loneliness, through leisure activities and games.
- Collaborate with the psychology department in cognitive workshops.

Physiotherapist

- Perform an initial evaluation of the resident's physical-functional status (applying standard scales).
- Prepare the resident's treatment plan.
- Encourage patient independence, focusing basically on mobility issues.
- Collaborate with the occupational therapy department to select the most appropriate technical assistance for each resident.
- Train geriatric nursing assistants in techniques to mobilise residents.
- Review objectives with the other team members in order to enhance the treatment afforded to residents.
- Improve/maintain the resident's capacity to move in the most independent and functional way possible.
- Improve/maintain independence in movements.
- Improve/maintain joint mobility and muscle tone to avoid stiffness and atrophy.
- Improve/maintain the best possible posture.
- Reduce joint and muscle pain.
- Work to prevent falls.
- Contribute, through physical exercise, to an improvement in the resident's state of mind and sociability.

Neuropsychologist

- Perform a neuropsychological evaluation of the resident's cognitive, behavioural and emotional state (applying standard scales).
- Prepare and apply an individual or group treatment plan, proposing therapeutic objectives.
- Plan cognitive, behavioural and affective intervention strategies.
- Monitor interventions.
- Meet with families in the process of accepting the disease, evolution and grief.
- Lead mutual help groups.

In addition to this interdisciplinary technical team, the work of assistants caring directly for the patients is particularly relevant, as they carry out the most tasks with residents; we refer here to the geriatric nursing assistants,

who functions encompass the following activities:

- Assist residents with their personal hygiene and physiological needs and in the rest of the activities of daily living.
- Accompany residents from morning to night.
- Attend to residents who feel incapable of performing the basic activities (stimulating self-esteem, encouraging autonomy and maintaining residual skills); communicate and register anomalies detected.
- Encourage mobility and movement, subject to medical guidelines, to avoid stiffness, atrophy and the appearance of pressure ulcers.
- Help nurses to perform tests for medical analysis, diabetic programmes, hypertension, administration of medication, blood extraction for analysis and any other healthcare prescription ordered by the doctor.
- Receive and distribute meals, feeding assisted residents who cannot feed themselves and helping others when necessary.
- Support the technical team as instructed during scheduled exercises or rehabilitation plan activities, etc.
- Execute the resident's hygiene programme.
- Provide residents with suitable personal hygiene training.
- Collaborate in sociocultural entertainment and occupational therapy activities.
- Ensure that the equipment used by the personal care service is in a good state of repair at the end of each shift
- Carry out control and monitoring activities with each resident.
- Monitor food and drink intake, changes of clothing, incontinence and posture changes, in addition to control rounds.

1.4. Individual Care Plan

The Individual Care Plan (ICP) is the basis of the work carried out by the Centre's interdisciplinary team. Before defining the ICP, we must highlight the importance of an adequate evaluation of residents on all levels, i.e. an comprehensive, interdisciplinary evaluation. This determines their characteristics and circumstances, allowing insight into their needs and expectations, so as to provide the most personalised care possible.

Comprehensive evaluation: performed both on admission to the Centre and at least every six months, or whenever necessary due to a change in the resident's condition. Although an initial evaluation is carried out on admission, it is reviewed after one month in order to assess the user's adaptation. This evaluation addresses the following areas:

- Healthcare area (doctor and nurse): a comprehensive healthcare evaluation is performed, encompassing both chronic and acute processes. The evaluation takes into account data collected by the healthcare team itself and data provided by the family (pre-admission clinical data). The medical team requests all parameters necessary for the diagnosis and the treatment plan (six-monthly analyses, urine samples, tests by specialists...).

- Psychological area: the aim is to evaluate the resident's cognitive, affective, behavioural and social status. This entails direct observation, consultation of prior information provided by the family, and standard scales and tests.

- Occupational therapy area: data are compiled and the resident is observed in order to evaluate his or her functional status. Various standard scales and tests are used to determine the therapeutic application of work, leisure and self-care activities, seeking to increase or preserve (as applicable) the resident's autonomy. If necessary as a result of this evaluation, tasks and materials will be adapted to maximise functional independence.

- Physiotherapy area: evaluation of the resident's physical condition to provide personalised physiotherapy treatment.

- Social area: in order to evaluate social aspects, the social worker obtains all possible data on the resident's family and social situation. The resident is observed on admission and during subsequent adaptation and residence. Measures taken following this evaluation seek to maximise the resident's quality of life and well-being.

(In subsequent chapters, each professional will describe this evaluation process in detail, except for the medical department, in view of the diversity of diagnoses and treatments applied on a daily basis).

Individual Care Plan: this document is prepared by the interdisciplinary team, from the viewpoint of prevention and rehabilitation; it contains a full evaluation of each user's healthcare, social, physical, functional and psychological situation, at minimum. Standard evaluation tools are applied to determine objectives, the interdisciplinary work plan and each area's interventions, as well as an appraisal of results in terms of improvements in quality of life for the patient and his or her family.

The purpose of the ICP is to establish targets to be achieved with each

resident at the preventive and healthcare levels.

In addition to the prior evaluation referred to above, a full ICP requires the following actions:

- Ongoing identification of needs and potential.
- Proposals of specific objectives for each user.
- Programmes and activities to achieve the proposed objectives.
- Planning of specific activities/ therapies.
- Application of the therapies.
- Plan follow-up: revaluation, review of objectives and maintenance or definition of new guidelines.

Content

Chapter 2
Intervention from the neuropsychology area

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Neuropsychology is the discipline which, by studying the location of brain functions, has established a direct, causal relationship between the brain and behaviour. In clinical terms, the objectives are thus the evaluation, rehabilitation and/or minimisation of cognitive and psychological aftereffects caused by traumatism and by pathological processes.

More specifically, in connection with dementias, neuropsychologists play an important role in the evaluation and treatment of cognitive, affective and behavioural alterations caused by the demential syndrome.

A series of psychological tests and techniques are conducted to assess cognitive, affective and executive functions and to determine whether the central nervous system is functioning in a normal or pathological manner. All the information gathered is general contrasted and confirmed using neuroimaging tests performed by other professionals in this area. The most useful imaging test for neuropsychologists is functional magnetic resonance imaging, which shows working brain activation/deactivation. In other words, we can observe images of the brain while it executes certain motor, cognitive and

linguistic tasks, or when stimulated in a certain way. Findings from tests on healthy people and on people with dementia or some kind of cognitive impairment are used to prepare an etiological diagnosis of the clinical problems observed.

A practical distinction is made when applying neuropsychology in this field as regards the concept of intervention versus rehabilitation. Professionals working with dementia employ the term "intervention" rather than "rehabilitation" because our stimulation of cognitive processes is intended mainly to preserve the patient's remaining capabilities for as long as possible, and not to rehabilitate processes already lost. The purpose of our intervention is not therefore to restore their daily functions (personal, social and work) to pre-morbid levels but to boost functions and thus enhance quality of life and independence.

This chapter explains the neuropsychological profile of people with dementia (and, more specifically, with Alzheimer's), the appraisal and evaluation necessary to determine the degree of impairment and possible intervention strategies.

2.1. Neuropsychological profile of people with dementia

Dementia is a neurobehavioural syndrome that includes cognitive and psychological-behavioural symptoms which are sufficiently intense to alter a person's functionality.

In addition to memory loss, there must be at least one other cognitive symptom, such as time-space disorientation, aphasia, aprosexia, agnosia, apraxia or executive dysfunction; there must be a break with the prior level of functioning, which must occur in the absence of alterations in consciousness and must remain over time. The neuropsychological analysis of these cognitive changes is highly relevant; although dementia causes overall intellectual disorder, we may observe different patterns depending on the etiology of the neurodegenerative process.

The variety of symptoms for each type of dementia is a reflection of the different forms of brain damage evolution and its relationship with individual differences pre-existing in each individual.

Although there are pre-senile cases, the syndrome appears much more frequently in elderly persons; although there are many organic factors that can cause it (infectious disease, metabolic, vascular, cranioencephalic, etc.), neurodegenerative diseases (Alzheimer's, Parkinson's, Lewy Body, etc.) are the most common causes of dementia in elderly persons.

Within the broad spectrum of dementias in a care centre, one useful classification for intervention purposes is the distinction between cortical dementias, the main example being Alzheimer's disease (responsible for most of these dementias), and subcortical dementias, such as Parkinson's disease or Huntington's disease. In cortical dementias, we find a significant destructuring of higher functions (particularly memory and language) and abstract reasoning, while the main alterations in subcortical dementias are motor- and behaviour-related, together with a characteristic hyper-alert state.

In view of its greater prevalence, unless otherwise stated this guide refers in general to the characteristics of and interventions for Alzheimer's disease.

We begin by describing the specific characteristics of each cognitive deficit, followed by psychological-behavioural aspects and, in the physiotherapy section, motor alterations.

Memory alteration: the episodic memory relates to the information encoding and storage system for episodes that are dated in time and located in space, in a person's life. The deficit is characterised by amnesia affecting recent events, resulting in the incapacity to complete the new information registration or storage phase. In other words, it is more a deficit in the learning process than in the recovery of mnemic traces. The biological correlation to this alteration is damage to the medial temporal lobe, such as atrophy of the hippocampus and entorhinal cortex typical of Alzheimer-type dementia.

As the dementia advances, this difficulty extends to memories more distant in time, an involution process that is observed until the final phases of the disease. This loss of episodic memories is accompanied by a deficit in semantic

memory or in general knowledge of the world, caused by damage to the association cortex.

The implicit memory, which is responsible for motor skills, for example, remains unaffected for a longer period in cortical dementias.

Aprosexia: attention is another cognitive process that is damaged prematurely in people with dementia. The capacity to discriminate between a relevant stimulus and an accessory stimulus for selective attention is impaired and the attentional process declines more quickly with respect to maintained attention. During evaluation or intervention, we must always consider these attentional limitations, which can contaminate data obtained in the evaluation or complicate the cognitive stimulation process in activities proposed as part of the intervention programme. The effect of fatigue must always be considered.

Agnosia: the recognition of stimuli in different forms of sensory perception is another characteristic impairment. The difficulty or impossibility of interpreting what is perceived is a major issue in the patient's communication with the environment.

Language alterations: aphasia that typically accompanies dementia includes verbal fluency issues in the use of names, semantic processing and comprehension. Discourse becomes poor in meaning and is filled with set phrases, causing the message to appear empty. If the person emphasises something, this generally entails considerable paraphrasing and circumlocution which complicate the clear and concise transmission of information. Anomia, or difficulty in finding the desired words, is an early symptom of the appearance of the syndrome. The structure and complexity of sentences becomes gradually more simple.

In a more advanced phase, language may disappear completely or be reduced to single words, meaningless expressions or guttural sounds.

Writing is also altered as the disease progresses; from the initial phases it declines in length and syntactic complexity and, though coherence is initially maintained, semantic replacements and spelling mistakes begin to appear.

Executive dysfunction: executive functions relate to the more advanced cognitive processes that were therefore more recently developed in our species. They include capabilities related to self-control and behaviour regulation, judgement, decision-taking, planning, initiation and verification of behaviour, inhibition and the will to overcome inhibition. Deficits may appear in these functions in very early phases or even in the prodromic phase of Alzheimer's disease, preceding the decline of other cognitive processes such as language or attention.

Alteration of visuospatial skills: visuospatial impairment increases as the disease advances in activities that require the use of visuoconstructive or spatial orientation capabilities.

In addition to all the cognitive symptoms described, various psychological-behavioural symptoms may gradually appear, associated at times with these cognitive deficits (e.g. erratic wandering associated with disorientation), or separately, in which case these symptoms are themselves a product of cortical degeneration.

Mood alteration: the alteration of the morphology and functioning of the hippocampus and, therefore, of the limbic system causes a tendency to emotional lability which affects emotions associated with the situations experienced by a person with dementia.

In the initial phase, there may also be a certain tendency to low spirits, apathy and depression, as a reaction to the person's awareness of the loss of capabilities. The anxious-depressive syndrome may appear as a consequence of this. The most behavioural component of these mood alterations may be a tendency to apathy or lack of motivation in the person's areas of interest.

Motor agitation: anxiety, seen as the accumulation of energy that causes discomfort, may manifest itself in the appearance of repetitive conduct or stereotypes without purpose. Erratic wandering (and the resulting risk of flight), following the caregiver, repetition of movements associated with the person's professional experience and constant swaying are frequent forms of expression.

Appearance of psychotic symptoms: delirium or irrational thoughts on a variety of subjects (theft, damage, jealousy, grandeur, etc.) and hallucinations or objectless perceptions in any sensory sphere entail a break from reality and the creation of a parallel reality experienced by the patient.

Lack of inhibition or actions outside socially accepted limits: including aggressive conduct, uninhibited speech and inappropriate sexual conduct.

Sleep-wake cycle disorder: people with dementia frequently become agitated when the sun goes down. This is known as the "sundown syndrome" and is caused by time-space disorientation. When maintained over a period of time, sleep-wake cycles are altered and the patient tends to nap during the day and to be more active at night.

In general, the most predominant psychological and behavioural symptom depends on the phase of the disease. For example, depressive tendencies are more likely to arise in the initial phases, while symptoms of the psychotic kind are more common in the later phases.

In addition to all the symptoms and characteristics described in the neuropsychological profile, it should be noted that, because most people with dementia are elderly, there are commonly and probably other accompanying pathologies and disabilities (blindness, deafness, amputations, vascular problems, etc.) that will affect the course of the dementia.

2.2. Neuropsychological evaluation techniques

On admission into the care centre, the neuropsychologist conducts a standardised evaluation of the patient's cognitive-emotional-behavioural condition which, together with the medical and functions evaluations, will determine the status of the patient's disease. Evaluation instruments are also employed in periodic follow-up evaluations of users, which are recommendable every six months.

There follows a brief explanation of the cognitive and emotional-behavioural evaluation instruments most commonly used for dementias (for both patients and caregivers), particularly with Alzheimer's patients.

A) Cognitive evaluation

Title: **Global Deterioration Scale (GDS)**

Authors: *Reisberg, B.; Ferris, S. H.; De León M. J. y Crook, T.*

Category: multitask instrument with a staging system that permits the classification of users in seven based on cognitive and functional capabilities and deficits.

Estimated time: approx. 2 minutes.

Description: the GDS comprises detailed clinical descriptions of seven important stages that are clinically distinguished, from normal cognition to very severe dementia. Stages one 1 to 3 relate to pre-dementia; in stage 5, the patient cannot survive without assistance.

Title: **Mini Mental State Examination (MEC), 30- and 35-point version**

Authors: *Folstein, M. F.; Folstein, S. E y Mc Hugh, P. R.*

Category: cognitive, the purpose being to screen the cognitive deficit.

Estimated time: approx. 10 minutes.

Description: the Mini Mental State Examination (MMSE) developed by Folstein and colls. (1975) was translated and adapted into Spanish by Lobo and colls. (1979). The adaptation brought in certain changes to the original test, including the addition of two new items (reverse-order digits and similarities), thereby increasing the total score from 30 to 35. Subsequently, Lobo and colls. (1999) validated and standardised the MEC (first Spanish version of the MMSE).

This screening test detects the cognitive impairment and evaluates its gravity, as well as identifying cognitive changes over time so as to document the individual's response to treatment.

The following cognitive areas are explored:

- Time and spatial orientation.
- Immediate memory.
- Attention and calculation.
- Deferred memory.
- Language and praxis: naming, repetition, verbal order comprehension, reading, spontaneous writing and copy drawing.

It has proven to be sufficiently valid and reliable in psychiatric, neurological and geriatric populations in other clinical fields. The test is recommended by the American Geriatric Society as an instrument of choice for cognitive evaluation in geriatric populations. Of the two MEC versions, MEC 30 is recommended, since it allows comparisons with studies from other countries.

In both versions, the total score is the sum of the scores for each item; in both cases, the recommended cut-off point for a geriatric population (≥65 years of age)

is 23/24, such that scores ≤23 are deemed to indicate possible cognitive impairment and scores above ≥24 are considered to indicate normal cognitive functioning.

In special circumstances (illiteracy, blindness, hemiplegia, etc.), forcing the elimination of some items, scores must be recalculated based on the number of items applied.

Título: **SMMSE (*Severe Mini Mental State Examination*)**

Autores: *Harrell, L. E.; Marson, D.; Chatterjee, A. y Parrish, J. A.*

Category: cognitive.

Estimated time: 10 minutes.

Description: an instrument having a maximum score of 30 points and generating information on the cognitive state of patients showing the severest cognitive impairment. This test is very useful when the MEC results in a "floor effect" (scores for patients in severe states are so low that hardly any information is obtained on their cognitive state).

Buiza and colls. (2011) state, in their article on the preliminary findings of the Spanish version of this scale, that it broadens the MEC's lower measurement range, avoiding the "floor effect". On the basis of its results, the instrument may be considered valid and reliable, as well as fast and user friendly.

Title: **Clock Drawing Test (CDT)**

Authors: *Goodglass, H. y Kaplan, E.*

Category: a cognitive test to evaluate the user's overall functioning.

Estimated time: maximum of 5 minutes.

Description: the Clock Drawing Test is a simple, fast and user friendly screening test used both in clinical practice and research to evaluate a person's cognitive state. It assesses various mechanisms involved in task execution, basically visuoperceptive, visuomotor and visuoconstructive functions, attention and comprehension, motor planning and execution.

The patent is asked to draw a clock showing ten past eleven. The score ranges between 0 and 10 points, based on the following criteria: clock face (maximum of 2 points), hands (maximum of 4 points) and numbers (maximum of 4 points).

The recommended cut-off points are as follows:
0-6: cognitive deterioration.
7-10: normal cognitive functioning.

Title: **Pfeiffer Questionnaire (*Short Portable Mental Status Questionnaire*, SPMSQ).**

Author: Pfeiffer, E.

Category: cognitiva.

Estimated time: 5-10 minutes.

Description: a cognitive impairment screening instrument to determine the degree of impairment. It is useful with both institutionalised patients and the general population.

The following aspects are explored:
- Short- and long-term memory.
- Orientation.
- Information on daily facts.
- Calculation capacity.

Only incorrect replies are noted in this test.

Questions allowing several different replies are only accepted as correct if all aspects are correct.
From 0 to 2 errors: normal.
From 3 to 4 errors: mild impairment.
From 5 to 7 errors: moderate impairment.
From 8 to 10 errors: severe impairment.

One more error is allowed if the patient did not receive a primary school education and one less in the case of university graduates.

Title: **7 Minute Screen (7MT)**

Autores: *Solomon, P. R.; Hirschoff, A.; Kelly, B.; Relin, M.; Brush, M.; De Veaux, R. D. y Pendlebury, W. W.*

Category: cognitive test to early identify Alzheimer-type dementia.

Estimated time: 15-20 minutes.

Description: screening formed by four tests designed to detect specific aspects that fail exclusively in the event of dementia, particularly Alzheimer-type dementia, irrespective of the schooling level, anxiety or any other confusion factor.

The tests evaluate the following:
- Memory (assessing unstimulated and stimulated recall); a semantic code is used as a learning and memory technique.
- Orientation (assessing time orientation in relation to dates and times).
- Language (assessing verbal fluency by asking the patient to say the maximum possible number of animal names in one minute).
- Visio construction, calculation and praxis (assessed by means of the clock test)

Each of these four tests has a different relative significance in the total score; individual scores are transformed into points that are added together to arrive at the total score. A percentile of <20 is an indication of dementia.

The Spanish version of this test battery has been validated by the elderly population in Leganés thanks to Del Ser and colls. (2004), as quoted in (García-Portilla, M. P. and colls., 2011).

Title: ***Cognitive Alzheimer's Disease Assessment Scale (ADAS)***

Authors: *Mohs, R. C.; Rosen, W. G. y Davis, K. L.*

Category: cognitive-behavioural.

Estimated time: 45 minutes (full cognitive and non-cognitive test).

The cognitive ADAS comprises 11 items, evaluating the following cognitive functions:
- Memory: immediate word recall, word recognition and recall of memory test instructions.
- Language: linking of multiple orders, naming of objects and fingers, spoken language skills, spoken language comprehension and difficulty in finding the right words.
- Praxis: constructive and idea praxis.
- Orientation: time and spatial orientation.

Scores for cognitive ADAS items vary. In all cases, a higher score means greater impairment. The total score ranges between 0 and 69.

Reference scores are as follows:
Healthy elderly people: 0-10 points.
Mild-moderate Alzheimer not treated: 15-25 points.

The total score for the cognitive and behavioural subscales is calculated by adding together the scores for all items and ranges between 0 and 119 points; the higher the score, the greater the impairment.

Title: **CAM-COG (subtest of the CAMDEX-R Cambridge exploration test, reviewed for the evaluation of old age mental disorders)**

Authors: *Roth, M.; Huppert, F.; Mountjoy, C. y Tym, E.* Spanish adaptation: *López-Pousa, S.*

Category: cognitive. Subtest: CAMCOG.

Estimated time: approx. 45 minutes.

Description: brief neuropsychological battery test which, through a variety of items, evaluates the patient's capacity in different cognitive areas: time-spatial orientation, verbal and written language, praxis, calculation, abstract thinking, visual perception and passage of time, memory and recall, attention and concentration. It was designed specifically to assist in the diagnosis of dementia in an incipient stage.

The test takes approximately 45 minutes, depending on the user's state, attention level and collaboration.

This test is applied to individual users, provided the person has obtained a score of 25 points or more, out of 35, in the MEC (Lobo). It allows a more detailed and specific neuropsychological profile to be prepared on the patient's cognitive capabilities and is of assistance in the differential diagnosis of dementia types.

Title: **Hopkins Verbal Learning Test, (HVLT)**

Author: *Brandt, J.*

Category: cognitive.

Estimated application time: 5-10 minutes, excluding the 25-minute delay.

Description: the HVLT is a verbal memory test for elderly people with neurological disorders, since it involves fewer stimuli and less time than similar tests such as the CVLT or the TAVEC.

Different versions of this test are currently being validated and scaled for the Spanish population and the preliminary results show that it discriminates well between healthy subjects and persons with mild cognitive amnesic impairment (MCI) (mono and multidomain).

B) Behavioural evaluation

Title: **Neuropsychiatric Inventory (NPI)**

Authors: *Cummings and colls. (Spanish validation by Boada, M.).*

Category: behavioural.

Estimated time: 10-15 minutes.

Description: the NPI is a questionnaire applicable to the main caregiver of the person with Alzheimer's or other dementias, assessing 12 possible behavioural disorders:

1. Delirious ideas.
2. Hallucinations.
3. Agitation/Aggression.
4. Depression/Dysphoria.
5. Anxiety.
6. Euphoria/Jubilation.
7. Apathy/Indifference.
8. Disinhibition.
9. Irritability/Instability.
10. Abnormal motor behaviour.
11. Sleepiness.
12. Appetite and eating disorders.

For each symptom, three aspects or variables are addressed: gravity (1 to 3), frequency of appearance (0 to 4) and distress caused by that conduct in the caregiver (0 to 5). The questionnaire is applicable to people of practically all social levels, since the questions and examples are very specific, such as: "Do you believe that other people steal from you?" or "Does he/she take liberties, touch or hug other people in a way that does not match his/her character?" and other similar questions, thus facilitating application.

Scores range from 1 to 144.

Title: ***Non-cognitive Alzheimer's Disease Assessment Scale (ADAS)***

Authors: *Mohs, R. C; Rosen, W. G. y Davis, K. L.*

Category: behavioural.

Estimated time: 45 minutes (full cognitive and non-cognitive test).

Description: the non-cognitive part of the ADAS comprises a total of 10 items which evaluate the following behavioural alterations:

- Mood: crying, depression and appetite.
- Behaviour: concentration versus distraction, lack of cooperation during the evaluation, delirious ideas, hallucinations and psychomotor activity (erratic wandering, hyperactivity and trembling).

The score for each item varies between 0 and 5, the total score for the subscale being a figure between 0 and 50, which must then be increased by the score for the non-cognitive subscale.

C) Emotional evaluation

Title: **Geriatric Depression Scale (GDS)**

Authors: *Brinck, T. L.; Yesavage, J. A. y Lum, O.*

Category: affective.

Estimated time: 5-10 minutes.

Description: a self-applied scale that is only valid for people with mild cognitive impairment who can understand the statements included. The most extensive version comprises 30 items requiring dichotomic yes/no answers, although there is a shorter 15-item version (Sheikh and Yesavage, 1986) and even a five-item version (Hoyl and colls., 1999). It provides a total score that screens the absence of depression and possible depression. In the 30-item version, the cut-off point is 11 points.

In view of the intuitive nature of each item, we must take into account the social desirability factor when the person answers the questions.

Title: **Cornell Scale for Depression in Dementia**

Authors: *Alexopoulos, G. S.; Abrams, R. C.; Young, R. C. y Shamolan, C. A.*

Category: affective.

Estimated time: 5-10 minutes.

Description: a hetero-applied scale (which is not therefore limited due to the need for a preserved cognitive state, as in the case of the GDS described above) designed specifically to evaluate affective-behavioural aspects of people with Alzheimer's or other neurodegenerative dementia. In addition to a caregiver interview, the person with the dementia is interviewed and observed in order to corroborate and complete data.

It is divided into the following five dimensions, encompassing a total of 19 items:

- Mood-related signs: anxiety, sadness, absence of reaction to happy events and irritability.
- Behavioural disorders: agitation, slowness, complaints and loss of interest.
- Physical signs: loss of appetite, weight and energy.
- Cyclical functions: daytime mood changes, difficulty in getting to sleep, numerous awakenings or early awakening.
- Idea disorders: suicide, low self-esteem, pessimism and delirium.

D) Evaluation of other components

Título: **Alzheimer's Disease Related Quality of Life (ADRQL)**

Authors: *Rabins, P. V.; Kasper, J. D.; Kleinman, L.; Black, B. S. y Patrick, D. L.*

Category: quality of life.

Estimated time: 10-15 minutes.

Description: a scale designed to evaluate various aspects that family members and professionals involved with dementia consider to be important in connection with the quality of life of people with dementia. The aim is to avoid subjectiveness on the part of the person surveyed (family caregiver/professional) in a concept that is so intrinsically subjective such as the quality of life; the person is asked to identify behaviour recently observed (two weeks) and related to five dimensions of the life of the person with dementia:

1. Social interaction.
2. Awareness of themselves and of relevant persons.
3. Feelings and moods.
4. Enjoyment of daily activities.
5. Behaviour in the environment.

The items are dichotomic (agreement/disagreement) and the result has no specific cohort points; the higher the score, the better the quality of life.

Author: **Zarit Caregiver Burden Scale**Autor: *Zarit, S. H.; Reever, K. E. y Bach-Peterson, J.*

Category: caregiver stress.

Estimated time: 10 minutes.

Description: evaluates the negative repercussions of being responsible and caring for a dependent person and its influence on certain areas of the caregiver's life.

The frequency of appearance (from 1 to 5) of certain feelings or thoughts is measured in relation to:
- Physical health.
- Mental health.
- Social activities.
- Economic resources.

Table 1a. Summary of neuropsychological scales

GDS	Global Deterioration Scale	Global	Classify users in seven states based on their capabilities and cognitive and functional deficits.
MEC	Mini Mental State Examination	Cognitive	Screen cognitive deficits.
SMMSE	*Severe Mini Mental State Examination*	Cognitive	Obtain information on the cognitive state of subjects with a more severe cognitive impairment.
CDT	Clock Drawing Test	Cognitive	Evaluate the subject's cognitive state.
SPMSQ	Pfeiffer Questionnaire	Cognitive	Evaluate and determine the degree of cognitive impairment.
7MT	7-Minute Screen	Cognitive	Early identify Alzheimer-type dementia.
ADAS	*Alzheimer´s Disease Assessment Scale*	Cognitive, behavioural	Evaluate cognitive state and behavioural alterations.
CAM-COG	Subtest of the CAMDEX-R Cambridge exploration test, reviewed for the evaluation of old age mental disorders	Cognitive	Describe a more detailed and specific neuropsychological profile on the subject's cognitive capabilities and contribute towards the differential diagnosis of different types of dementia.
HVLT	Hopkins Verbal Learning Test	Cognitive	Evaluation verbal memory.
NPI	Neuropsychiatric Inventory	Behavioural	Evaluate behavioural disorders.
GDS	Geriatric Depression Scale	Emotional	Screen the absence of depression and possible depression.
-----	Cornell Scale for Depression in Dementia	Affective-behavioural	Evaluate the affective-behavioural state of people with Alzheimer or other neurodegenerative dementia.
ADRQL	Alzheimer's Disease Related Quality of Life	Quality of life	Evaluate various aspects that family members and professionals involved with dementia consider important in connection with the quality of life of people with dementia.
----	Zarit Caregiver Burden Scale	Caregiver stress	Evaluate the repercussions on the life of a dependent person's caregiver.

2.3. Intervention methodology

This section addresses practical aspects relating to first contacts with Alzheimer's patients entering an institution, definition of therapeutic objectives and preparation of a personalised treatment plan, which are necessary in order to implement a suitable care procedure for, in this case, a care centre resident.

Data compilation and first contact

For several days following the user's admission to the Centre, the neuropsychologist gathers relevant medical, psychological and social data needed to design a personalised treatment plan; the resident's medical history is consulted, conversations are conducted with family members and the patient, if possible, to obtain more detailed information on the resident's cognitive, affective-behavioural and social state, so as to be able to adequately monitor his or her adaptation to the Centre.

Information is obtained on the new resident by means of a quantitative and qualitative evaluation; the quantitative evaluation comprises structured, standard tests described in the section on evaluation techniques, while the qualitative evaluation entails chatting with the resident and observing his or her activities. This provides highly valuable data with which to obtain a first impression of the subject's overall state.

These data are gathered through:
- Direct observation.
- Informal, unstructured interview with the user, taking into account his or her state or evolution, i.e. questions are asked or contact is established, depending on the degree of impairment (e.g. reminiscence may be employed to determine biographical data, while closed questions are used for moderate states and sensory stimulation for severe states). The purpose is to obtain information on their capabilities and cognitive, sensory, physical and functional deficits and limitations.

The purpose of this data gathering is to design personalised objectives and to prepare a treatment plan tailored to the capabilities and deficits detected in the evaluation.

Individual Care Plan

On the basis of the information obtained from the standard evaluations, initial contacts with the resident (qualitative evaluation) and with his or her family, and the data furnished by the other professionals, the user's treatment is designed (Individual Care Plan, ICP) and specific objectives are proposed, the ultimate purpose being to make the resident as independent as possible, with an optimum quality of life in all areas. The objectives are proposed on an interdisciplinary (general objectives) and multidisciplinary (specific objectives for each professional area) basis.

The neuropsychologist informs the rest of the team of the specific objectives previously designed for the user. These objectives will be focused mainly on maintaining cognitive capabilities and on the optimal development of affective-behavioural and relational skills. Consequently, all the professionals will have overall knowledge of the resident once the information has been provided by each area.

In order for the information furnished to be available also to auxiliary staff and

geriatric nursing assistants (direct care personnel), who are in daily contact with residents, a register is prepared reflecting all the care afforded to the resident, guidelines for which have previously been provided by each professional forming the technical team (multidisciplinary care sheet). All these specific therapeutic instructions and orders are transmitted in order to be implemented. The psychology area, to which this section refers reports on the user's behavioural and mood characteristics (behavioural alteration, psychomotor agitation, anxiety, etc.) and specific guidelines are provided should such behaviour be exhibited.

Therapeutic intervention from the psychology area

In order the objectives proposed in the ICP, the psychology area performs therapeutic activities with family members and with users designed to improve quality of life in both cases.

Therapeutic intervention with residents is conducted in groups, individually or both, depending on the type of activity, the status of the disease and the objectives proposed. There follows a description of interventions at the cognitive, behavioural-affective and family levels that are conducted in a centre for Alzheimer's patients.

Cognitive stimulation is a therapeutic intervention designed to maintain the cognitive capabilities still preserved by the resident, so as to delay as long as possible the progress of the disease and associated cognitive deterioration. Quality of life is thus also improved, encouraging independence and functional autonomy.

Cognitive stimulation sessions are focused on basic and higher intellectual functions such as attention, perception, orientation, memory, calculation, language, reasoning, gnosis, praxis and executive functions. Depending on the degree of deterioration (mild-moderate-severe) and the objectives pursued, workshops and standard techniques that are suitable or necessary are selected for use with the resident.

The standard techniques shown in Table 1b below are commonly used in cognitive interventions and include the basis and higher cognitive functions:

a) ROT. Reality Orientation Therapy

This is a multimodel presentation technique (verbal, visual, written, gestural) to boost the patient's basic information: it focuses on cognitive processes such as vigilance, focused attention, fixation memory, episodic memory (knowledge of traditional festivities) and orientation in the three spheres (see Table 1b).

It is based on the idea that the repetition of basic information (greeting, what day it is, where we are, what time it is, what we are doing, etc.) can reduce disorientation and confusion and, at the same time, boost learning if a routine is established. According to Durante and Altimir (2004) and Sardinero (2010), this technique may be used in two ways. The first consists of 24-hour informal stimulation, i.e. transmission of current information on what is happening around the resident through comments and signs such as calendars and clocks on bulletin boards. The second takes the form of group or individual work sessions, depending on the resident's

Table 1b. Summary of neuropsychological scales

Memory	Orientation	Praxis	Attention
Concentration	Calculation	Body schema	Language
Reading-Writing	Perception	Gnosis	Reasoning

degree of impairment, consisting of more structured interventions so that users become aware of their situation in time and space.

In verbal and gestural communication questions are used, such as:
- Regarding time orientation (What day of the week is it today? What's today's date?, What season are we in?, What time of the day is it?, etc., reinforcing daily habits and routines).
- Regarding space orientation (Where are we?, What floor are we on?, What city are we in?, etc.).
- Regarding personal orientation (What's your name?, Are you married?, What's your wife's/husband's name?, Do you have any children, etc.).

The purpose of these questions is to orientate the patient in a time-space-person dimension and to reduce levels of anxiety, confusion and disconnection with the environment.

b) Reminiscence

This is a communication technique focused mainly on stimulating the user's episodic or autobiographic memory. It also involves processes such as focused attention, expressive and comprehensive language, orientation in the three spheres, semantic memory and gnosis. Materials used include photographs, music, recorded files, newspaper articles from the past, domestic objects, information conversations, etc. The aim is to preserve the subject's identity by reactivating their personal past and to provoke the recall of past situations (youth or infancy), activating the functioning and reminiscence of remote memory and highlighting emotional aspects of memory, such as historical and personal events that are important to the individual, feelings, smells or simple object recognition. This technique facilitates interpersonal relations and user communication, while increasing the feeling of well-being and self-esteem

Reality orientation and reminiscence techniques are appropriate therapeutic approaches for mild and moderate phases of Alzheimer's disease.

The following intervention and stimulation techniques are appropriate for all phases of the disease:

a) Neurosensory stimulation

This involves basic cognitive processes such as attention, perception and gnonis, entailing the presentation of basic sensory stimuli that are easy for the person with dementia to interpret (smells, tastes, sounds, tactile stimuli, etc.). This methodology is used continuously in severe phases of the disease to maintain the user's level of alertness and achieve the maximum possible connection with the environment.

b) Music therapy and psychomotor functions

These techniques are applied in association with the occupational therapy and physiotherapy areas and will be described in detail in the relevant chapters. The psychology's area's intervention in stimuli of this kind has specifically psychological objectives.

According to Mercadal and Martí (2008), music therapy is employed to favour and improve communication skills, expression of basic emotions and social behaviour (smiling, eye contact, physical conduct), to enhance self-esteem and to reduce behavioural-emotional disorders (mood and spirit changes, irritability, psychomotor agitation, aggressiveness, wandering) and apathy. It also stimulates cognitive processes such as focused attention, long-term memory, language and orientation.

As regards psychomotor functions, the neuropsychology area conducts exercises to maintain lateralisation and body schema to the maximum possible extent.

In addition to the interventions described, the area applies structured exercises to focus specifically on each cognitive function, i.e. exercises to stimulate attention, language, executive functions, perception, reading and writing, and calculation; these cognitive e exercises are generally executed using a pencil and paper. For example, a cancellation task is performed to stimulate attention, an action-ordering task using images is conducted to work on executive functions, a vocabulary task possibly including a written or verbal order from the professional is employed to stimulate language and semantic memory, etc.

c) Recreation therapy

This is also an interdisciplinary therapeutic intervention. Its purpose is to treat cognitive, physical and emotional aspects through informal, active and participative activities, while also addressing social or relational aspects. In planned and organised activities, the patient maintains his or her level of socialisation and enjoys free time in a group. Traditional popular games, ludotherapy, art therapy, garden therapy, etc. are examples of this kind of therapeutic intervention.

Finally, with respect to intervention at the cognitive level, the visual and hearing limitations that often affect the majority of users must be considered and we therefore need to know whether they need lenses or hearing aids so as to avoid potential frustration; types of intervention can be modified based on these individual differences.

Interventions related to affective-behavioural aspects are designed to monitor any disruptive behaviour and to reduce affective-behavioural disorders that affect users' daily activities.

Following a functional analysis of behaviour through direct and systematic observation, we prepare an action plan to control problematic behaviour. A problem arises when behaviour is harmful to the patients themselves or to their environment. Most of our behavioural interventions are thus focused on adaptation to an environment created specifically for people with dementia, eliminating potential hazards and elements that could disorientate or agitate the patient. In other words, it is more an environmental intervention than a programme to modify behaviour as such, due to the major cognitive limitations of a person with Alzheimer's, which complicate or even prevent any understanding of a behavioural programme.

It is also important to respect certain conduct that accompanies dementia, such as erratic wandering or certain forms of psychomotor agitation, provided they are not a hazard to the patient. We prepare areas in which people with significant cognitive impairment may wander safely and coexist, allowing them to express and display behaviour that would be strange in a different context but is common and entails no real difficulties in a centre specialised in dementia.

The psychological area also conducts interventions with users' family members; the most relevant general objectives pursued are as follows:

1. On admission

1.1. Role work: the user's admission into the Centre has a strong impact on a family system and each member must readapt individually or as a group, depending on the needs detected.

1.2. Release of guilt: the decision that must be taken prior to admission is a

tough process not without family and personal conflicts. Doubts, different viewpoints, anxiety issues and feelings of guilt, etc. Family psychological intervention seeks to recover the status quo lost by the patient's main support group.

1.3. Negative perceptions: the family's (and sometimes the user's) negative beliefs, ideas and expectations in relation to this type of care centre must be addressed to avoid interference or obstacles during the patient's adaptation process and life in the Centre. The aim is for decision-taking to be complete, adaptive and assimilated in an optimal and mature way by the family system, which will allow them to progress while accompanying and supporting the user, effectively and naturally, throughout the course of the disease.

1.4. Motivation: participation in the programmes and treatments prescribed for the user is encouraged, highlighting the importance of their involvement in leisure activities (excursions, parties, etc.) and other types of therapeutic activities that require their support.

2. Post-admission

2.1. Psychosocial orientation: periodic information on the user's status; guidelines to be followed in case of difficulties; professional advice for decision-taking, etc.

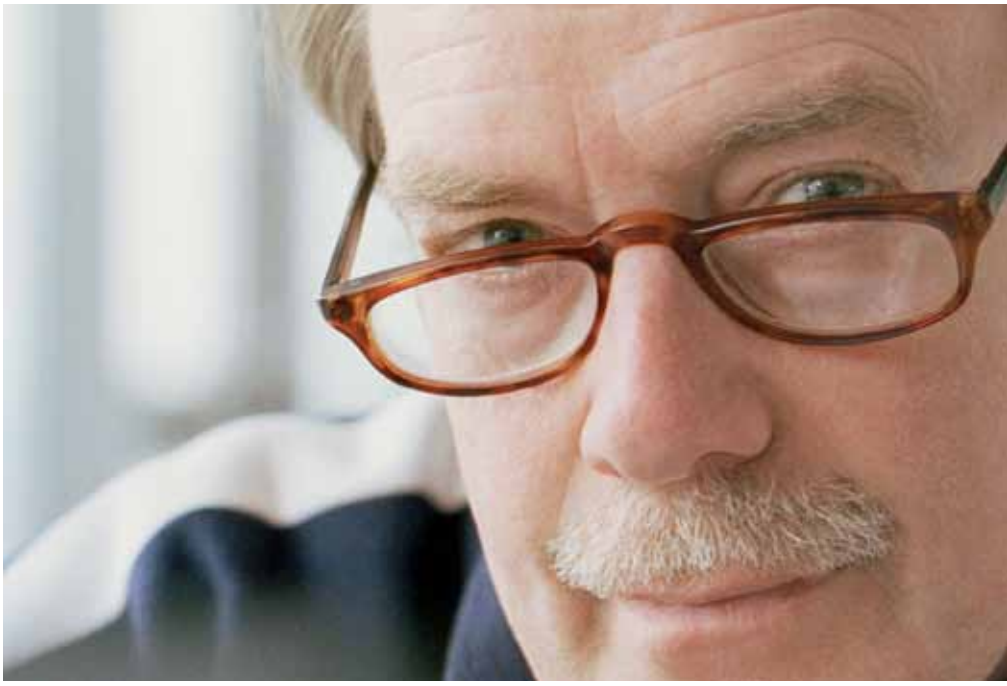
2.2. Family services: attention and advice for families that require our help in relation to specific issues.

2.3. Family therapy: intervention in conflicts, anxiety, channelling and expression of emotions, etc.

2.4. Training: courses, chats and conferences on different matters related to dementia; communication methods, decision-taking, handling of behavioural disorders, etc.

Additionally, the following joint interventions are conducted by the psychological care area, as described in detail in the social work chapter:

a) Terminal phase support: specific attention for families during the final phase of the disease, employing psychotherapy techniques such as



active listening and psychological support.

b) Grief accompaniment: following departure and medical certification of death, the family members are received in the Centre by the person in charge at the time, who will accompany them, if they wish, to the place in which their deceased relative lies.

From the moment the family members arrive until the deceased person has been prepared, psychological support is available to cover all physical and psychological needs that may arise.

Once with the user, the family is accompanied and receives psychological support at all times.

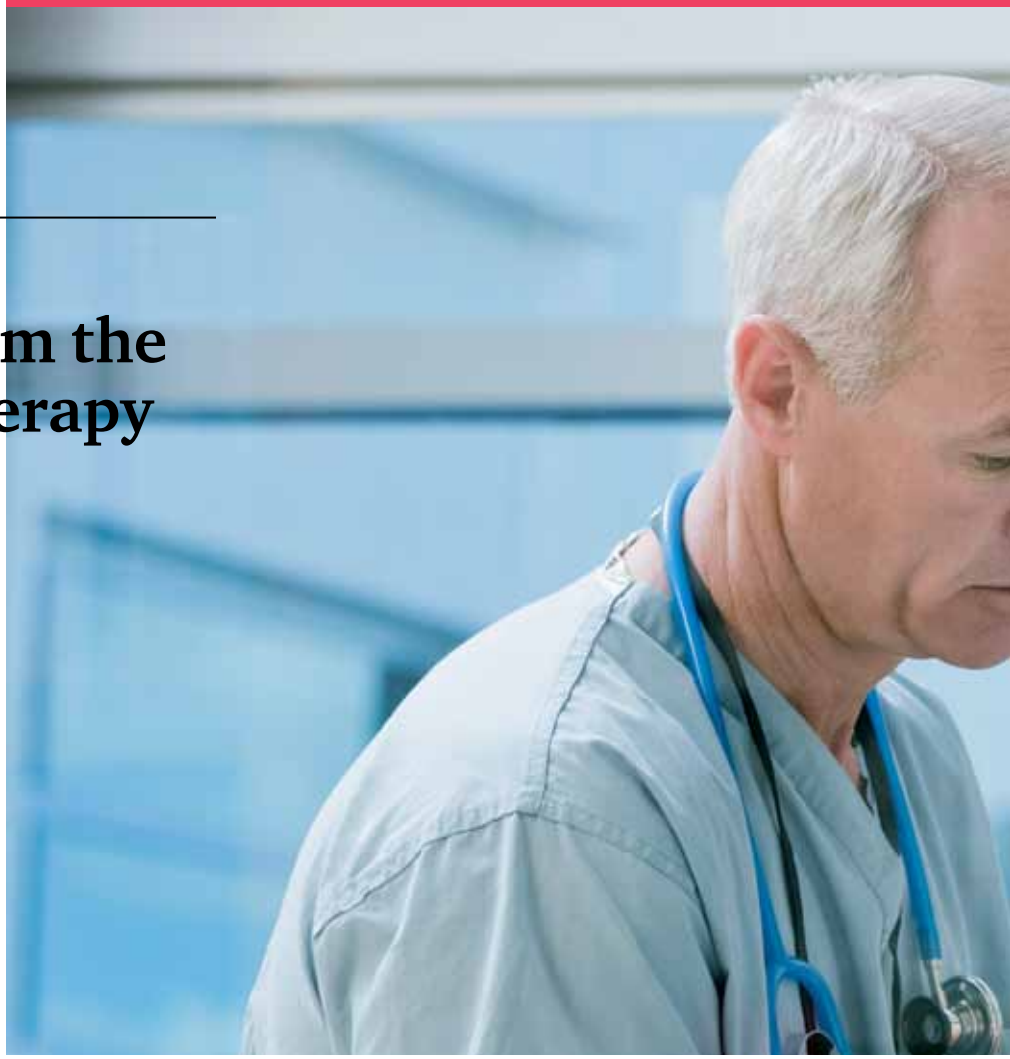
Where it is observed that the family's reaction in the grief preparation process is not entirely adaptive (possibility of a complicated grief process in the future), the emotional discharge is facilitated and specific information and advice are offered on the evolution and phases of grief preparation.

Once the initial moments in which emotional overload is highest have passed, they are offered the opportunity to remain accompanied by the professionals or to be alone for a prudent period of time with their relative.

Finally, the family members are informed that the deceased person will be transferred when they feel ready to do so. This grief accompaniment will be described in more detail in the social work chapter.

c) Mutual help groups: these are homogenous groups (e.g. group of husbands/children of residents) in terms of their relationship with the user. By interacting with people in the same situation, an atmosphere is created in which family members may share experiences, express doubts and release emotions.

Content



Chapter 3
Intervention from the occupational therapy area

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This chapter describes in detail an occupational therapist's intervention in dementia, particularly in connection with Alzheimer's disease. We focus on the work carried out by this area in a care centre, which is also valid for day centres, weekend centres, etc.

Occupational therapy may be defined as a socio-health discipline which, through the use of purposeful activities, seeks to achieve the maximum possible functionality, autonomy and quality of life in persons showing and/or at risk of limitations or some degree of dependence in the course of their daily activities.

The presence of occupational therapists is increasing in various socio-health areas; this professional has become particularly relevant in recent decades for elderly people and people with dementia, due to the high likelihood of dependence.

We know that, from the moment we reach optimum maturity, we progressively age throughout our life. This process accelerates in elderly people, whose organs and systems degenerate more rapidly. This is often combined with pluripathology and chronic illness, a sedentary lifestyle and consequences of traumatic actions, such

as a fall, etc., which weaken the body and the mind of elderly people and aggravate the risk of dependence.

In people with dementia, besides the ordinary ageing process, a series of signs may be observed that will progressively lead them into a situation of nearly total dependence.

Specifically, when working with dementia and with Alzheimer's disease, an occupational therapist performs a holistic analysis and then observes the relationship between physical-cognitive losses and functional losses, plus any environmental factors that may be affecting the process. Accordingly, through different types of activities described below, we seek to maintain the greatest possible autonomy and ensure that the subject's quality of life is enhanced in their daily environment, whether at home or in a residence.

One of the main objectives of non-pharmacological disciplines such as occupational therapy is to delay the dementia.

The activities conducted must pursue an objective and must be significant for the patient in order to enhance well-being and achieve the proposed goals. Where

possible, professionals must adapt to patients, not the other way around, respecting their rhythms, customs, beliefs and culture.

This chapter first provides a description of the functional profile of a person with dementia and how cognitive dysfunctions gradually affect their daily life; it goes on to describe in detail the occupational therapist's function in this area: evaluation, objective planning and treatment implementation.

3.1. Functional profile of people with dementia

From birth we progressively develop capabilities and skills, beginning with the basic activities of daily living (personal hygiene, dressing, toilet, etc.) before learning instrumental activities (household tasks, use of transport, handling money, etc.) and then the more advanced activities of daily living (work, play, social participation).

In people with dementia, the loss of these capabilities and skills occurs in reverse order.

The alteration of cognitive and psychological functions addressed in the neuropsychology section and the progressive loss of motor capacities result in the loss of autonomy. Subjects become increasingly less capable of carrying out functional activities and encounter difficulties in their habitual environment and activities, also losing the capacity to take care of themselves.

In the initial phases of the disease, the person is generally dependent or needs help to perform many of the advanced activities of daily living, but is still autonomous in basic activities and in nearly all instrumental activities.

Early time disorientation, which is characterised by confusion relating to the day of the week or the date, could cause the person to miss doctor's appointments, forget birthdays, not to attend meetings with friends, etc.

This deterioration is accompanied by a different type of disorientation: spatial. The person becomes disorientated in less familiar places, such as their children's district or large retail outlets.

Due to the initial language alterations (addressed in the psychology chapter), the person finds it difficult to name everyday objects, although this does not affect their independence in the activities of daily living, since they still recognise the objects and use them correctly. Despite this, we may observe difficulties in their relations with others, since they are afraid or ashamed of possible communication errors.

The initial phases of a dementia are characterised by the appearance of minor oversights that affect everyday activities, such as the use of transportation (forgetting the number of the bus, departure times…), shopping (forgetting to buy necessary items, leaving the purse at home or forgetting how much money is in it…), household tasks (leaving the oven on or the fire burning), etc. These situations are not sporadic but appear repeatedly in daily living.

These initial signs alter the performance of various activities, such

as work (the person will be forced to leave his or her work post due to the loss of executive functions), financial arrangements, leisure (people are incapable of organising free time or choosing an activity that motivates them) and personal relations. In the case of leisure and personal relations, deterioration may be more significant due to the subject's initial apathy and fear of being unable to do things or of acting incorrectly, as indicated previously.

As the disease advances, people become dependent in the activities of daily living and in nearly all instrumental activities (they generally maintain the capacity to perform routine and simple activities such as laying the table, washing the dishes or folding clothes). This is when they become dependent (to a greater or lesser extent) in basic activities of daily living; in some cases they may only require supervision or minimal assistance to perform a task correctly, while in other cases they will need full assistance.

In view of the increase in spatial disorientation, the person may get lost is closer and more familiar surroundings, such as their own district or house. Instrumental activities of daily living are thus altered, such as shopping, going to the health centre, caring for others (e.g. taking grandchildren to school), and some basic activities, such as sphincter control, because the patient can no longer find the bathroom.

Time orientation is totally affected, such that it may have a functional impact on the basic activities of daily living, such as dressing (wearing clothes that are not suitable for the season).

There is also a memory deficit that affect various activities. On many occasions, the patient does not remember whether or not he or she has eaten, taken medication or even fed or walked the dog.

The appearance of idea and ideomotor apraxia prevents a number of coordinated movements and the sequencing of complex actions. The most characteristic apraxia, with its own specific name, is dressing apraxia, where the person begins to have difficulty in buttoning clothes, fastening shoelaces, tying a scarf or a tie, or putting on clothes in the correct order.

During feeding, problems may be observed in the use of a knife and fork and, in some cases, the inability to use a fork, resulting in the use of a spoon to eat all kinds of food. Other activities that may initially be affected by the appearance of apraxia and agnosia are teeth brushing, hair combing, bathing (not all body parts are washed, suitable utensils are not used, hot and cold water cannot be regulated) or toilet use (the person still has the capacity to handle clothes, but cannot wash properly or uses inappropriate objects such as towels).

The progressive deterioration of cognitive and motor functions will later cause serious dependency in the basic activities of daily living and total dependency in instrumental activities. Despite this, a certain degree of cooperation might still be observed.

The person is now completely disorientated and needs constant support in his or her own surroundings, since they are no longer able to recognise the rooms in the house or there position in a room.

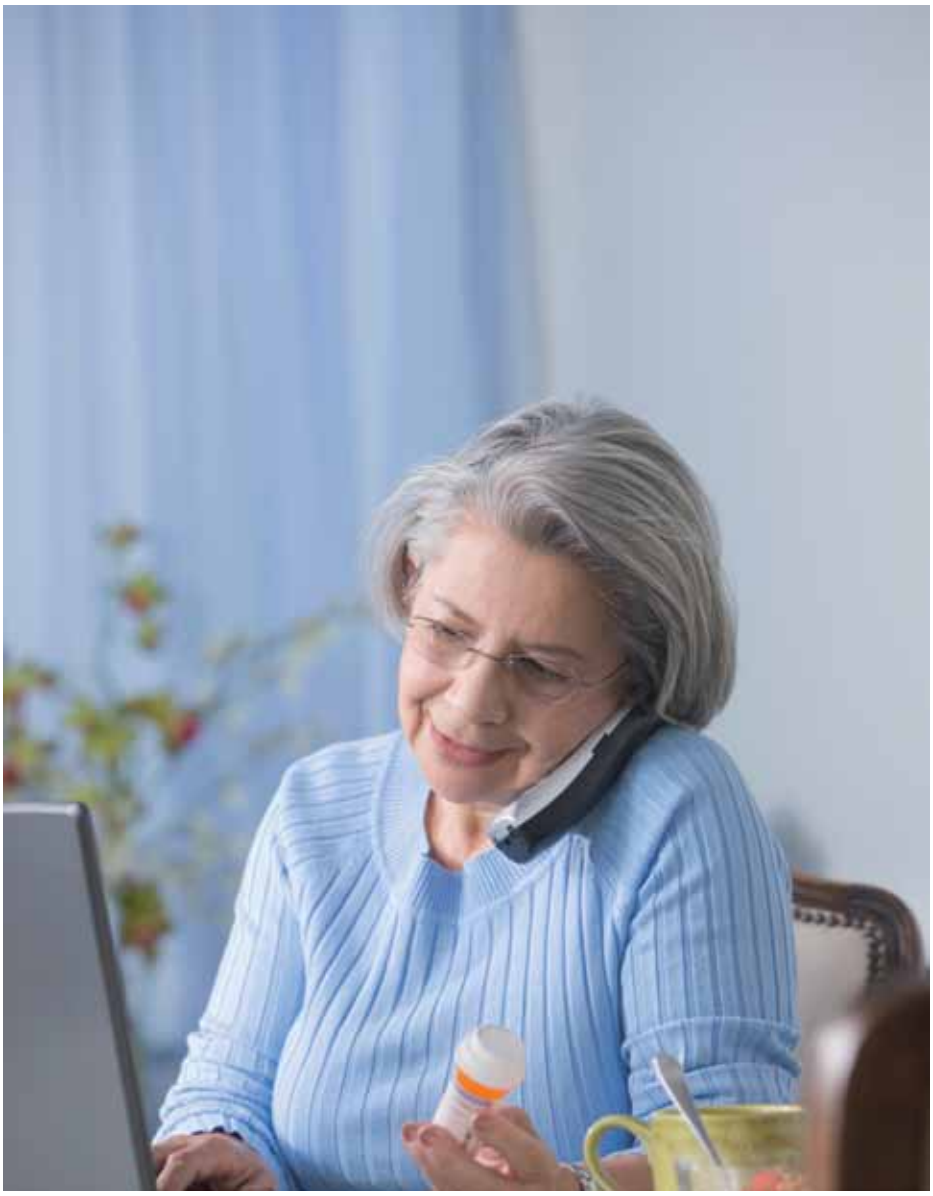
Assistance in dressing is generalised, although the patient might cooperate in some steps of the process (putting their arms in the jacket sleeves, standing up when asked, lifting a leg for a sock to be put on …). The same will occur during a shower, when minimum participation might be observed, lifting their arms when necessary or soaping some accessible areas while the caregiver washes their hair or back. They might cooperate by combing their own hair or drying their hands, if they are provided

with the necessary utensils or helped to start the movement.

At mealtimes, the subject is only able to use a spoon or begins to use his or her hands to put food in their mouth. They need continuous supervision due to the attention deficit.

In the final phase of the disease, total dependence is observed in all the activities of daily living, since the person scarcely responds to surrounding stimuli.

Having described the functional profile of a person with dementia, we must clarify that this is an overview of the disease based on theory, practical experience and applied evaluation. We should point out that the problems will not all appear in the stated order or in all cases. For example, there are people in advanced phases who are still able to put food in their mouth, while others with less severe cognitive impairment cannot do so and do not cooperate in any other activity of daily living.



3.2. Functional capacity evaluation techniques

The individual's functional capabilities must be assessed in order to recognise deficits and skills that are still preserved or preserved to a certain extent, so as to then propose treatment objectives.

When the person with dementia visits the occupational therapy service, it is important to gather the most relevant medical, psychological and social data, which are required in order to prepare a personalised treatment plan.

Therapists may use a combination of methods to identify the person's functional profile. The fundamental or basic methods are questions, tests and observation.

On first contact it is advisable to conduct an initial interview with the user in order to determine their cognitive, perceptive-sensory, physical and motor levels. This allows us to identify the limitations and potential that may subsequently affect their functional level in the performance of the activities of daily living.

At the cognitive level, we can begin by assessing whether they are orientated in personal, spatial and time terms, asking basic questions about their name, place of birth, where we are and today's date. We ask questions and propose activities to evaluate their immediate, short-term and long-term memory capacity.

Since language difficulties are common in this disease, it is important to ascertain levels of verbal and written expression and comprehension, as well as their spontaneous production capacity; in more severe cases, we observe whether the person still preserves automatic language. Attention levels are assessed through specific tests. During the interview, we observe whether they focus on tasks and are able to maintain concentration or are easily distracted by environmental stimuli.

Other cognitive functions that may be evaluated during the interview are calculation, body schema, gnosis, praxis…

At the perceptive-sensory level, different stimuli are used to assess their visual, hearing and proprioceptive capabilities, e.g. following an object with their eyes, recognising a body part that we have touched while their eyes were closed, responding to strong and weak hearing stimuli (hand clapping, whistling …), etc.

To finish, we may evaluate physical strength, range of movements and gross/fine motor functions.

All these data are subsequently completed with the evaluations performed by the other team professionals so as to compile more detailed information on the user.

Following this initial contact, a short interview should be held with the main caregiver or closest family member. This interview allow us to compare information requested from the patient during the evaluation and obtain information on their occupations and leisure activities currently and prior to the disease, etc. These data will also help us to propose intervention activities.

There follows a brief description of the standard evaluation methods that we consider to be most practical when

working with dementia, although we know that there are many other evaluation tools in occupational therapy, such as the Functional Independence Measurement (FIM), Routine Task Inventory (RTI), Assessment of Motor and Process Skills (AMPS) methods.

The most effective tools employed in our daily activities are summarised in table 2.

All these evaluation instruments can be applied directly to the user or to the main caregiver or family member.

Finally, we use direct observation as a complementary method of obtaining the information in cases in which caregivers or family members cannot provide all the necessary data. We ask the subject to perform the activities proposed in each index or scale and we take note of the scores.

Table 2: Evaluation tools

Evaluation tool	Description	Score
Barthel Index (modified) (Shah and colls., 1989) APPENDIX 1	Basic activities of daily living (bathing, dressing, personal hygiene, toilet use, moving around, transfers, use of stairs, urination, bowel movement and eating).	Ten basic activities are evaluated by degree of independence and need of assistance. Classification ranges are as follows: • 0-20: Total dependence. • 21-60: Severe dependence. • 61-90: Moderate dependence. • 91-99: Slight dependence. • 100: Independence.
Katz Index of Independence in ADLs (Katz and colls., 1963) APPENDIX 2	Basic activities of daily living (bathing, dressing, toilet use, mobility, continence and eating).	Each item is scored 1 or 0, depending on whether or not the activity evaluated is performed; the maximum score is 6. Classification ranges are as follows: - Independent in the six ADLs. - Independent for all the above functions except one. - Independent for all except bathing and one additional function. - Independent for all except bathing, dressing and one additional function. - Independent for all except bathing, dressing, toilet use and one additional function. - Independent for all except bathing, dressing, toilet use, mobility and one additional function. - Dependent in all six functions. - Dependent in at least two functions but not classifiable as C, D, E or F.
Lawton and Brody Index (Lawton and Brody, 1969) APPENDIX 3	Instruments activities of daily living (telephone, shopping, meal preparation, household chores, clothes washing, transportation, responsibility for medication and ability to use money). When the index is applied to a woman, all eight items are evaluated. However, when applied to a man, the items meal preparation, household chores and clothes washing are excluded.	The maximum score is 8 for women and 5 for men. Score ranges are as follows: • 5-8: Autonomous. • 4: Slight dependence. • 2-3: Moderate dependence. • 1: Severe dependence. • 0: Total dependence.
Red Cross Physical Disability Scale (Red Cross Central Hospital, Madrid, 1972) APPENDIX 4	A fast, simple evaluation of self-care capabilities is conducted to obtain an initial impression of the person's functional state.	Classification is performed by assigning the level that best matches the person's current state: • Level 0: Fully able to perform self-care activities; walks normally. • Level 1: Performs the activities of daily living adequately; walks with some difficulty; total continence. • Level 2: Some difficulty in activities of daily living, requiring help on occasions; walks with a stick or similar instrument; total contingence or rare incontinence. • Level 3: Serious difficulty in activities of daily living; walks with difficulty assisted by at least one person; occasional incontinence. • Level 4: Requires help in nearly all activities; walks with extreme difficulty helped by two people; regular incontinence. • Level 5: Confined to a bed or chair; total incontinence; needs permanent nursing.

3.3. *Intervention methodology*

Once the initial evaluation is complete and based on the data obtained, the occupational therapist must prepare a number of objectives that will guide the entire intervention process. In order to fulfil these objectives, the therapist will seek activities that are significant for the user, since we know that the best results are achieved when the subject participates actively in the treatment and enjoys the tasks.

3.3.1. Treatment objectives

Research has confirmed that non-pharmacological therapies such as occupational therapy, combined with pharmacological treatment, help to maintain and delay the progress of Alzheimer's disease and other dementias. Our main objective is therefore to preserve the greatest possible degree of autonomy, functionality and quality of life in the person with dementia. Quality of life is understood to mean the best state of health the person can achieve and the best environmental and personal conditions, offering opportunities for learning, personal recreation and participation in society. This is thus the fundamental pillar on which our treatment is based in order to implement specific objectives that will guide our intervention.

We should point out that, when working with dementia, such as Alzheimer's disease, which is not reversible, our objectives are designed to delay the disease, as mentioned previously. We do not therefore speak of rehabilitation or recovery, barring exceptional cases, and we employ the terms maintain, preserve, conserve, stimulate, favour, encourage, etc.

Pursuing the main objective defined, the occupational therapist seeks to maintain maximum independence in the performance of the person's basic and instrumental activities of daily living and, in the initial phases, in the advanced activities. Cognitive functions that are deteriorating and functions that are still preserved but we know will be gradually lost must be stimulated; movement and physical activities must also be encouraged in order to favour subsequent participation in the ADLs.

In Alzheimer's disease, apathy and mood changes are very frequent and we seek to improve these aspects in order to foment the performance of activities. It is also important for the subject to establish socio-emotional relationships and to continue to take part in social activities. We know that they progressively lose the capacity to perform routine activities and daily tasks, but we must continue to encourage them. The treatment that is to be proposed will seek to occupy the person and favour the appearance of feelings of usefulness, confidence in themselves and the feeling that life is still under control. We favour their autonomy so that, to the extent possible, the person makes choices and takes decisions necessary in daily living, from what type of clothing to put on to what kind of activity they prefer to perform.

These objectives, described here in general terms, are personalised for each individual, based on their current needs and physical, cognitive and emotional state. This is defined in the initial Individual Care Plan (ICP) prepared together with the multidisciplinary and interdisciplinary team, following a period of adaptation after the person's visit to the occupational therapy area.

3.3.2. Treatment plan

The occupational therapy area conducts a therapeutic intervention comprising various types of activities to achieve the

planned objectives. These activities are selected and adapted based on the user's impairment level.

Before the intervention begins, a number of factors must be considered that may favour the person's participation in the activities to be performed. The work environment must be tranquil and distracting stimuli must be reduced to a minimum.

We must guarantee that the user is in a state of optimal activation without agitation or nervousness, which would complicate the maintenance of attention during the intervention. If the level of alert is very low, we seek all kinds of stimuli (touch, sound…) to achieve a connection with the environment.

The occupational therapist uses a high tone to keep the user's attention but without irritating the user or speaking as if the person were a child. The therapist speaks clearly, vocalising, positioned in front of the person, if possible, so as to facilitate non-verbal language from the therapist. The person's name is used to reinforce their identity, even in the more severe phases. Instructions must be simple, consisting of short phrases and including reminders throughout the task.

As the disease advances and the person loses language expression and comprehension skills, we should speak using direct and closed questions. In order to avoid frustration, the person is allowed the necessary time to perform each step of the task and is not asked to perform more than one activity at the same time.

The work may be performed in groups or individually, depending on the users' physical and cognitive state and the requirements of each activity. Where a group activity is chosen, the number of participants should be limited to between eight and ten, and their degree of impairment should be as similar as possible.

In the initial phases of the disease it is advisable to hold group sessions; in addition to fulfilling cognitive and physical objectives, this will encourage relationships with other people and reduce apathy. As the disease advances and attention and participation capacities decline, better results are obtained in increasingly smaller groups or, ultimately, in individual sessions.

The activities proposed during the treatment must fulfil a number of conditions. They must be as functional as possible or be related to the future maintenance of capabilities that allow the resident to be autonomous. Activities must also be purposeful, designed to achieve an objective and significant for the person, as mentioned. The person receiving the treatment must be an active party and, to the extent possible, must take decisions relating to the process. In more advanced states, when decision-taking capacity is affected, we seek to adapt the treatment to the individual's tastes and interests. The occupational therapist must work with these variables and seek activities that fulfil all these conditions.

Sessions planned by this area comprise cognitive, physical and neurosensory stimulation, functional training, recreational therapy and other techniques such as psychomotor activities or music therapy.

- **Cognitive stimulation.** This is a significant part of occupational therapy treatment. Although it has already been explained in the neuropsychology chapter, we should point out that our objectives are different since, as occupational therapists, we seek to maintain cognitive functions at the optimal level in order to subsequently facilitate the activities of daily living. The functions summarised in the table provided by the neuropsychology area are stimulated, paying particular attention to gnosis, praxis, attention,

body schema and perception, which are all closely related to ADLs.

- The occupational therapy area always seeks to **activate and physically stimulate** the person to encourage them to work with their body and be aware of their body parts, despite the mobility limitations that progressively arise. We focus particularly on the upper limbs, emphasising fine and gross hand motor functions, which are essential to maintain maximum functionality. This stimulation may be performed actively by the user, if still possible in their current state, or passively by the professional through massages and mobilization. Physical stimulation by the therapist is fundamental when working with the elderly in general and people with dementia in particular. Besides physical activation and related functional implications, this process is vital because movements provide us with more information and environmental stimulation. This type of intervention always focuses on ADLs and bears relation to the environment; it is complemented by the physiotherapist's work.

- Another technique employed by therapists in this context is **neurosensory stimulation** to awaken the affected person's senses and thus activate their connections to the outside world.

  This technique is employed above all in the more advanced phases or when impairment is at the highest levels since, on many occasions, it is one of the few methods available for communication with users. We do not seek a specific response, such as in our work with gnosis, but to observe the way in which the subject responds or connects. The therapist must be alert to all gestures, movements or sounds generated by the person following the stimulation, allowing sufficient time for a reaction.

  Stimuli relate to all five senses. For example, touch can be stimulated using materials with different textures, shapes, temperatures or densities, and even vibrating objects, in order to establish contact with the body; our own hands can provide gentle stimulation by caressing the person's face, hands, etc., or more deeply by pressing lightly with our fingers on the person's extremities. Other senses may be stimulated using musical instruments, bright-coloured or shiny objects, etc.

  Snoezelen or multi-sensory rooms are spaces adapted to and prepared for this type of stimulation. They are widely used with people who have cerebral paralysis, learning difficulties or autism and are increasingly employed with positive effects in dementia treatment.

- **Psychomotor activities** provide an overview of an individual. This technique focuses on all dimensions and perspectives, taking into consideration cognitive, physical and emotional or socio-affective skills. Psychomotor activities allow us to work on the user's connection to their closest environment using their own body and cognitive capabilities. Psychomotor activities are an intrinsic part of human beings.

  The technique encompasses body, spatial and time schema:

  1. Body scheme relates to concepts such as lateralisation, recognition of body parts, their location and positioning, balance and coordination.

  2. Through spatial schema, we address the body's position in relation to the environment, stimulating concepts such as in front/behind, near/far, up/down, etc.

  3. Time schema includes duration, order, rhythm, frequency, etc.,

allowing us, for example, to organise daily activities or plan an activity. These three schema are affected by dementia and this techniques is very beneficial and useful, as the person may work on all three concepts at the same time. This experience may then be incorporated into daily occupations.

In a psychomotor session, various types of materials may be employed to stimulate or boost these skills, such as balls, sticks, hoops and string in different colours and sizes, music and other utensils such as photographs, numbers, stickers, etc., and even furniture.

The psychomotor technique is widely used by occupational therapists, since it allows us to work more extensively with residents, without focusing on one single process, making sessions more dynamic and appealing. Movements, games or leisure activities result in the assimilation of the three schema and appropriate cognitive stimulation. This technique is also used by physiotherapists, although their objectives are possibly more physical, while occupational therapists pursue a more cognitive, functional and relational objective. We seek to ensure that the person's capabilities are maintained so as to preserve the maximum possible degree of autonomy.

- As with psychomotor activities, **music therapy** allows occupational therapists to stimulate and work on different area: physical-motor, cognitive, socio-emotional and behavioural. At the physical-motor level, the main aim is to stimulate and maintain mobility, since increased physical activation permits interaction with a larger number of stimuli, as indicated previously. The therapeutic use of music also boosts all cognitive processes. We focus mainly on reminiscence (evocation of memories, personal and historical events, significant dates, etc.), which also stimulates functions such as language, attention, praxis, orientation… All musical activities have a major emotional and behavioural impact, since they enhance self-esteem, favour relaxation and reduce agitation. Moreover, music permits the recovery of emotions anchored in songs from the past. The person may not remember the exact moment in which he or she heard the song, but recalls the feeling it caused. In general, the feelings that appear are positive, since music is generally associated with leisure, games, activities with family and friends, etc. For this reason, and due to the feelings of usefulness generated, people with dementia are generally more willing to participate in this type of activities, reducing apathy and favouring social interaction. Such intervention may take place in practically all phases of the disease, since the capacity to sing, hum tunes or follow rhythms is preserved even in the severest states.

  Some activities that may be performed using music are repetition and following of rhythms, and completing the words of songs, gesticulation exercises, dancing, etc.

  The main work tools are musical instruments, our own body and our voice, since live music creation makes sessions much more appealing and dynamic than when a recording is used.

- Another equally important technique for working with dementia is **recreation therapy.** Manipulative, leisure or play activities are used to treat the symptoms and limitations caused by the dementia and to entertain the subject.

  The previous chapter referred to this therapy and its various subgroups (work therapy, ludotherapy, garden therapy, horticulture and art therapy,

among others). These activities always have an objective and a therapeutic basis.

Besides the physical and cognitive stimulation possible in these activities, leisure and personal recreation may be encouraged, stimulating an improvement in the person's mood. Despite the dementia, it is important to have the opportunity to continue to perform these activities, which is achieved through games, sewing, basketwork, growing plants, looking after and handling plants, painting or body expression, etc. This therapy allows users on different cognitive levels but sharing the same care level to be in contact with each other, since activities are adapted to each individual's capabilities.

- Functional intervention is the basis of occupational therapy, since all the objectives proposed in the previous interventions seek the greatest possible independence for the person with dementia in the performance of ADLs. Depending on the capabilities and limitations of the person, an occupational therapist may use different methods and techniques in functional training, such as supervision, verbal instructions, imitation and initiation of movements, and recommendation of technical assistance or adaptations to the environment and the necessary tools.

  Training will often take place while this activities is being performed at the relevant time of the day. Dressing time will be used to work on this activity so as to avoid making the subject undress at another time of the day, which could cause further disorientation. This approach is recommendable because people with dementia benefit from a structured timetable and routines. We favour their involvement in daily activities, even though the final result is not optimal. For example, we will let them lay the table, fold clothes, help to prepare lunch, dust or make the bed, even if they only participate in one step of the task.

  We have already indicated that it is not possible, a priori, in dementias and Alzheimer's disease recover lost functions and therefore, depending on the phase of the disease, it is likely to be more advisable to recommend adaptations to facilitate ADLs. Set out below are some examples and recommendations that may be of use in the functional training of a person with dementia (in this case, in both specialised centres and homes):

In addition to all these recommendations, we must consider that the performance of the activities of daily living are not only affected by the person's capabilities and limitations but also by environmental factors, such as an agitated environment, a change of caregiver, alterations to their routine, etc.

To conclude, we should point out that occupational therapy has a holistic vision of the person. Besides the cognitive and physical objective that will subsequently help to maintain functions, the therapies described have an emotional and behavioural impact. Through these activities we provide people with dementia, who are frequently inactive all day, with an occupation, thereby improving disorders caused by a lack of stimulation. Feelings of usefulness, cohesion and belonging to a group arise and there is a therapeutic effect while leisure activities are maintained as the disease advances.

Table 3: Challenges and solutions

Activity	Problems we may encounter	Recommendations
Shopping	Difficulty in reaching the shop due to disorientation. Forgets the products needed. Difficulty in planning the shopping list. Difficulty in handling money (spends too much, cannot identify the value of coins, forgets to take money, etc.).	Accompany the person to the shop and supervise the task. Always take a shopping list. In some cases, help the person to prepare the list. Calculate the approximate price of the purchase and give the person only the necessary money. Simplify the task and allow the person to continue participate in small purchases.
Household tasks	Difficulty in sequencing a task. Limited mobility complicates reaching objects or bending. Risk of falls due to bumping into furniture. Risk of intoxication due to difficulty in recognising cleaning products, medicines, etc. Difficulty in finding the necessary utensils to perform the task.	Guide the person verbally throughout the task. Simplify the task by dividing it into simpler steps. When the person is not capable of completing all household activities, they can be allowed to take part in simpler, more routine tasks such as dusting, laying the table or folding clothes. Adapt the environment so that all objects and utensils are at hand. Remove any obstacles, such as rugs, and illuminate the space adequately. Keep toxic products and medicines out of reach. Use posters and stickers for space recognition.
Meal preparation	Difficulty in task sequencing. Minor forgetfulness (leaves the gas on or forgets whether prior steps have been completed). Fails to recognise objects, utensils, food… Forgets the ingredients necessary to prepare a meal. Cannot foresee possible risks such as cuts or burns.	Supervise and/or verbally guide all steps of the task. Divide the task into simpler steps. Prepare in advance the food and tools required for the meal. The recipe may also be visible during the activity to recall each step. When the person no longer prepares the full meal or could be hurt in the process, he or she can be allowed to participate in the simple, routine tasks such as washing, sorting, cutting food, etc.
Eating	Confuses cutlery (eats soup with a fork). Incorrect use of utensils due to physical difficulty or the appearance of apraxia (unable to bring the spoon to his/her mouth or cannot coordinate a knife and fork). Distracted during the meal due to a lack of attention and apathy and do not start or continue the task. Eating is not adequate (stains clothes, spits food out, plays with food). Possible choking on food. Gobbles food. Rejects food or does not eat; food is not appealing.	Use only the piece of cutlery needed to eat each dish. Use cutlery, plates and glasses tailored to the person's needs; anatomic handles. Allow the person to eat with his/her hands if this guarantees independence. Simplify the task (cut the food before serving, in the event of difficulty in cutting with a knife and fork). Give verbal instructions or start the movement to stimulate the activity. Tolerate any bad manners. Maintain a good sitting position. Use small cutlery to avoid large amounts in the person's mouth and impulsive eating. Present the food in an attractive way and ensure that familiar food is prepared. Encourage decision-taking by providing two meal options. Monitor the state of dental prostheses and of gums to detect any sores that may make eating difficult.

Dressing	Difficulty in fastening buttons or shoelaces. Appearance of apraxia. He/she does not dress in the appropriate order and position (underwear on top of trousers) or cannot dress alone. Difficulty in choosing clothes. Aggressive replies when dressed by another person. Feels that privacy is invaded. Gets undressed continuously. Possible loss of balance or falls.	Give verbal instructions during the activity. Use clothing that is easier to put on (skirts and trousers without buttons, shoes without laces). Place clothing so that the person knows the order in which they are to be put on. Adapt clothes (replace buttons with zips, adhesive fastenings or elastic bands). Leave only seasonal clothing in the wardrobe. Use posters or labels to indicate where the clothes are in the wardrobe. If they need help, explain what we are going to do and verbalise each step. If the person gets undressed continuously, use clothing that is less accessible (opens at the back, stockings instead of socks, bodies, etc.). If the person is unstable when standing, most of the dressing activity may be performed in a sitting position.
Bathing and showering	Appearance of apraxia. Not able to use a comb, toothbrush, razor, wash hair, etc. Inadequate sequencing of the activity or repeats steps. Confuses or does not recognise the necessary utensils. Do not know how to regulate water temperature. Becomes aggressive when another person has to wash him/her, since it is a particularly private moment. Risk of falling in the shower. Difficulty in getting in and out of the bathtub.	Give verbal instructions to guide the activity. Adapt some utensils to facilitate their use, e.g. sponges or combs with long and anatomic handles. Replace the razor with a shaver. Use posters and labels to ensure objects can be recognised. Prepare water at a suitable temperature. If help is required, explain what we are going to do and verbalise each step. Change the bathtub for a shower, fit handles, non-slip surface, shower chair, etc.
Toilet use	Cannot find the bathroom, does not recognise the toilet and may therefore relieve himself/herself in inappropriate places. Does not clean himself/herself property. Difficulty dressing. Risk of a fall.	Use posters and labels to ensure the space can be recognised. Give verbal instructions to guide the activity. Fit accessories such as handles, a booster seat for the toilet… Respect privacy as far as possible (once help has been provided to sit on the toilet, we can leave the person unsupervised and allow sufficient time before returning).
Sphincter control	Progressive loss of control over urination and bowel movements	Plan a daily timetable for going to the bathroom. In between toilet visits, ask the person whether they need to go.

Appendices

Appendix 1
Barthel Index (modified) (IB-m)

Bathing

5 Independent. Does not need anybody to be present. Perhaps in the bathtub, shower or washing parts of the body, including their back.
4 Requires supervision to get into/out of the bathtub or safety supervision to test water temperature, etc.
3 Requires help to get into/out of the bathtub, wash or get dry.
1 Needs help in all phases of bathing.
0 Totally dependent.

Dressing

10 Includes fastening/unfastening clothes and tying/untying shoelaces.
8 Requires minimal assistance in the above activities.
5 Needs help putting on/taking off some garments (clothing or footwear).
2 The patient participates to some degree but is dependent in all aspects of dressing.
0 Dependent, does not participate in the activity.

Personal hygiene

5 Independent. Includes washing face and hands, combing hair, cleaning teeth and, for men, shaving (plugging in the shaver themselves, if electric).
4 The patient needs minimal assistance in some of the above processes but leads the entire process.
3 Needs help in one or more of the above-mentioned tasks.
1 Requires help in all steps involving in personal hygiene.
0 Dependent.

Toilet use

10 Enters/exits the bathroom alone, fastens/unfastens clothing, adopts the correct position, avoids staining clothes and uses paper without help. Can use a bedpan at night, but must be able to empty and clean it.
8 Requires safety supervision. Needs help to empty and clean the bedpan.
5 Requires help to fasten/unfasten clothing, get up, sit down or wash hands.
2 Requires help in all aspects.
0 Totally dependent.

Moving around

Without a wheelchair

15 Walks 50 metres without help or supervision. Can use all support accessories.
12 Walks alone, but not 50 metres without help or supervision, needs supervision in hazardous situations.
8 Requires help to reach or use walking accessories. Needs help from one person even in short distances.
3 Requires help from more than one person while walking.
0 Unable to walk. Confined to a wheelchair.

With a wheelchair

5 Able to propel the wheelchair alone, turn corners, turn around, manoeuvre and position the wheelchair next to the table, bed and toilet, and propel the wheelchair for at least 50 metres.
4 Able to propel the wheelchair alone. Needs minimal assistance turning tight corners.
3 Needs a person to position the wheelchair correctly next to the bed or chair, manoeuvre in the room, by tables, etc.
1 Able to propel the wheelchair alone only in short distances on a level surface.
0 Dependent.

Transfers (chair/bed)

15 Independent. In the case of a patient in a wheelchair, they can approach the bed, brake, raise the footrests, get onto the bed, lie down, sit up again on the edge of the bed, change the position of the wheelchair and sit on it again.
12 Security supervision.
8 Requires help from one person.
3 Although he/she participates, needs full assistance from one person.
0 Unable to participate. Two people are needed for the transfer.

Stairs

10 Goes up/down one flight of stairs without help and supervision. Can use a stick, banister or crutch and must be able to carry them.
8 Does not generally need help, although requires safety supervision at times, e.g. due to morning stiffness, dyspnoea, etc.
5 Requires some help or does it alone, but unable to carry the walking accessories normally used.
2 Requires help in all aspects.
0 Totally dependent.

Urination

10 Continent day and night; independent in the use of catheter, collection bag, etc.
8 Generally dry day and night, with occasional accidents; needs minimal assistance with a catheter or diaper.
5 Generally dry day but not night; needs help with the catheter or diaper.
2 Incontinent but helps and cooperates with the catheter or diaper.
0 Totally incontinent.

Bowel movements

10 Continent and independent in the use of suppositories or enemas.
8 Requires supervision with suppositories or enemas. Occasional accidents.
5 Unable to use suppositories or enemas alone and/or frequent accidents, but able to adopt the correct position. Requires help to put on the diaper.
2 The patient needs help to adopt the correct position for enemas and suppositories.
0 Totally incontinent.

Eating

10 Totally independent.
8 Independent if a tray is prepared, but needs help cutting meat, or opening a milk carton or a jar of jam. Otherwise, does not need another person to be present.
5 Eats without supervision; needs help in tasks such as adding sugar, salt or pepper, or spreading butter, for example.
2 Able to use some cutlery, usually a spoon, but needs active assistance during the meal.
0 Dependent in all aspects.

Observations

Total score

Appendix 2
Katz Index of Independence in ADLs

Bathing Bathing (sponge, shower or bathtub)

- Independent: needs help to wash one single body part (such as the back or a disabled limb) or bathes entirely without assistance.
- Dependent: needs help to wash more than one body part, get in/out of the bathtub or cannot bathe alone.

Dressing

- Independent: fetches clothes, puts them on , puts on jewellery and coats, and uses zips (shoelace tying is excluded).
- Dependent: does not dress alone or only partially.

Toilet use

- Independent: goes to, in and out of the bathroom, cleans himself/herself alone and fastens clothing (with or without mechanical accessories).
- Dependent: uses a bedpan or requires help to access or use the toilet.

Mobility

- Independent: gets in and out of bed, sits down in the chair and gets up (with or without mechanical accessories).
- Dependent: needs help to use the bed and/or chair; cannot complete one or more transfers.

Continence

- Independent: full control of urination and bowel movements.
- Dependent: partial or total urinary or bowel incontinence.

Alimentación

- Independent: moves the food from the plate or bowl to the mouth (meat cutting and butter spreading or similar are excluded).
- Dependent: needs help to eat or requires enteral or parenteral nutrition.

Appendix 3
Lawton and Brody Index

Telephone
Uses the telephone at own initiative, looks for and dials number 1
Can dial known numbers 1
Answers the phone but cannot dial 1
Does not use the phone at all 0

Compras
Shops independently covering all needs 1
Can only shop for small items 0
Must be accompanied while shopping 0
Entirely incapable of shopping 0

Meal preparation
Organises, prepares and serves all food independently ...1
Prepares food only if the ingredients are provided 0
Prepares, heats and serves food, but diet is not adequate .0
Needs meals to be prepared and served 0

Household chores
Performs household chores alone, only occasional help ...1
Performs light chores (dish washing, bed making...) 1
Performs light chores, but hygiene is insufficient 1
Needs help, but performs all household chores 0
Does not participate or perform any chores 0

Lavar la ropa
Washes all clothes alone 1
Only washes small items (socks, stockings, etc.) 1
Clothes must be washed by someone else 0

Transportation
Travels alone, uses public transport /drives a car 1
Can catch a taxi alone, does not use other public transport 1
Only uses public transport when accompanied 1
Travel limited to taxis or cars with help from other people (adapted) 0
Does not travel at all 0

Responsibility for medication
Able to take medication alone on the timely basis and in the correct dosage 1
Takes medicine only if prepared by someone else 0
Not able to take medicine alone 0

Ability to use money
Assumes responsibility for money matter alone 1
Makes daily purchases but needs help to go to the bank ..1
Unable to use money 0

Total:
Men: ***/ 5***
Women: ***/ 8***

Exhibit 4
Red Cross Physical Disability Scale

Degrees of physical disability

Level 0. Fully able-bodied, walks normally.

Level 1. Performs activities of daily living adequately. Walks with some difficulty. Total continence.

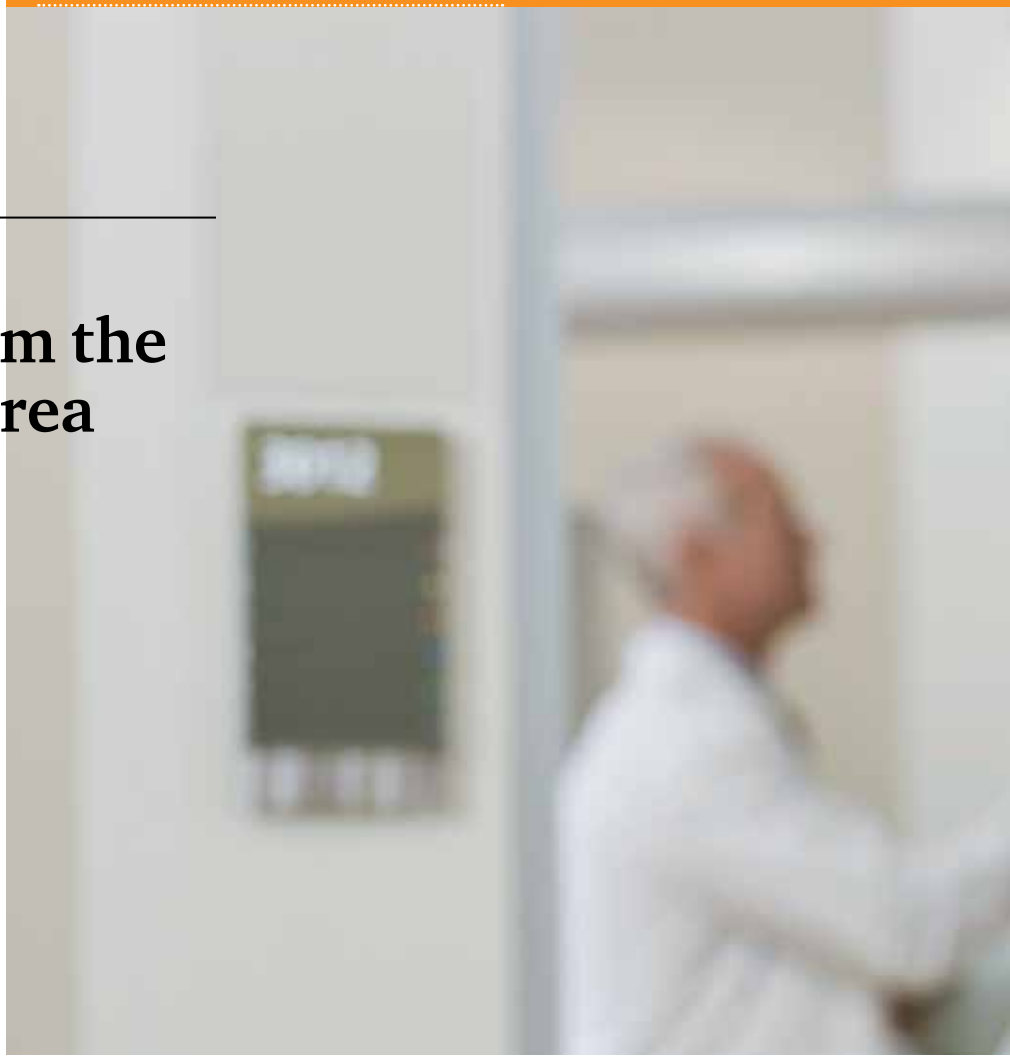
Level 2. Some difficulty in activities of daily living requiring help on occasions. Walks with a stick or similar instrument. Total contingence or rare incontinence.

Level 3. Serious difficulty in activities of daily living. Walks with difficulty assisted by at least one person. Occasional incontinence.

Level 4. Requires help in nearly all activities. Walks with extreme difficulty (two people). Regular incontinence.

Level 5. Confined to a bed or chair.

Content



Chapter 4
Intervention from the physiotherapy area

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4.1. Physical profile of people with dementia

The term dementia is employed to describe a syndrome characterised by a set of signs and symptoms that cause persistent deterioration of cognitive skills and affect functional capacity, in both social and work arenas, in people who show no alteration of consciousness. Although dementia is not strictly a pathology of the locomotor system, physiotherapy benefits locomotor aspects and slows mental deterioration.

There are different types of dementia, but here we will focus on Alzheimer's disease (AD). AD is clinically characterised by an insidious start and progressive cognitive, physical and functional deterioration, as well as by the appearance of mood changes and psychotic and behavioural alterations.

Three phases may be distinguished in the course of the disease: mild, moderate and severe.

Phase one: mild

This phase lasts between two and four years, approximately. The main characteristic is memory alteration. Personality changes, sharp mood changes, behavioural alterations and language use alterations may also appear, but the patient is still able to live life as normal.

There are not usually any physical alterations, but patients begin to become spatially disorientated, which may generate rejection or prevent them from going out, thus reducing physical and social activities.

Apathy, which is a characteristic of this disease, favours the absence of activity, causing physical deterioration.

During this phase, there are sometimes postural and gait disorders, e.g. reduction in arm movements, unusual stiffness, slowness…

Phase two: moderate

This phase spans between three and five years. The progressive intellectual deterioration is aggravated by a worsening of recent memory and the start of retrograde alterations; cortical

functions become impaired. Language becomes less rich and less fluent; judgement and abstract thinking are impaired. The patient does not understand some simple verbal orders relating to movement. They begin to lose independence in the activities of daily living, such as dressing, personal hygiene...

Physical alterations appear, such as the accentuation of parkinsonian signs, gait and postural alterations, lack of coordination and balance, muscular atrophy and weakness, stiffness and reduction in joint mobility, pain when movement is initiated, fatigue following effort and difficulty in independent transfers. Help or supervision may be required to walk and during transfers. The level of apathy increases. The patient becomes immobile (loss of initiative to walk due to the increased difficulty and fear of falling) and, therefore, pressure ulcers are more likely to develop.

During this phase, walking is characterised by the following:
- Slower rhythm.
- Shorter steps, dragging feet.
- Stopping between steps.
- Reduction or absence of arm movement.
- Marked swaying of the torso.
- Instability and lack of balance.
- Broadening of the support base.
- Postural alterations: lateralisation, bending or stretching of the torso, bending of the head and next (looking at the floor).

All this makes falls more likely.

Phase three: severe

This phase has a variable duration. Neurological signs become more prevalent and there is greater rigidity, spasticity and hyperreflexia. Primitive reflexes may also appear (rooting, sucking, Babinski's sign…) and pyramidal signs. In addition to parkinsonism, there may be myoclonus, dyskinesia and/or convulsive crises. Moods are unpredictable. Spatial-time disorientation is significant. Falls and fractures are common due above all to the gait disorder. Motor control becomes very unstable there are phases of locomotor agitation.

Postural (e.g. sliding and leaning while sitting) and gait disorders are accentuated, dependence in transfers increases, joint stiffness heightens, deformities appear and the patient tends to adopt a flexed posture, increasing the risk of pressure ulcers. Pain is felt during movements. Fatigue increases during efforts. The capacity to complete voluntary, spontaneous movements declines. The patient may lose the ability to walk or require considerable assistance (they forget how to walk). The risk of falls is greater during walking, transfers and sitting. They may need a lot of help in transfers (two people and even a crane). Fastening measures may be necessary (belt, overalls…). There may be circulatory alterations (such as swellings or edema), muscle spasms and pain at rest.

The end of this phase is characterised by the patient being bedridden, with irreversible pressure ulcers, major stiffness (fetal position), severe impairment of defence mechanisms, infections, significant weight loss causing frailty and weakness. The patient does not always reach this phase. This depends a great deal on the care and stimulation received, the person's other pathologies, age, the evolution of the disease…

4.2. Neurological signs

4.2.1. Parkinsonism: characterised by stiffness and bradycinesia, inexpressiveness, reduction in the speed of walking and in arm movement… There are neuroleptic drugs that can cause parkinsonism, but in this case the symptoms would be more intense. Parkinsonism intensifies as the disease advances.

4.2.2. Dyskinesia: a term employed, in a broad sense, to refer to the presence of involuntary movements or the inability to control voluntary movements. Mouth and face dyskinesia appears during moderate dementia, increases as the disease advances and may extend to other areas.

4.2.3. Myoclonus: appears in the late phase, generally six months into the disease. Most occurs while the patient is awake, but may appear during sleep.

4.2.4. Convulsive crises: appear on average seven years into the disease. Convulsive crises may be an evolutive marker, since they appear to be related to the late phase of the disease.

4.2.5. Gait impairment: a patient with moderate AD has falls and fractures related to a syndrome complex involving muscle weakness, Romberg's sign alteration, difficulty in walking alongside another person and other independent co-morbidity factors such as medication, cataracts, wandering, arthritis and admission into a residence. This gait alteration is characterised by indecision when walking, difficulty in keeping balance and avoiding obstacles, and the loss of an erect posture.

4.3. Physical/motor evaluation techniques

On admission into the centre, the physiotherapy area first compiles data (new case file) on various aspects of the person's physical and cognitive state, and other aspects, before defining objectives and a treatment plan. This is based on observation of the patient, previous physiotherapy reports, information provided by the family…

Prior to any treatment programme, a full evaluation and exploration must be performed, without forgetting that, in addition to dementia, there are other common pathologies in elderly people (osteomuscular, respiratory, diabetes, vascular, peripheral…). Due to the irreversible progression of the disease, periodic evaluations are required to bring the treatment up to date with the patient's current state and needs.

We first observe how the patient approaches us (walking independently, with help, in a wheelchair, lying down…).

We then conduct a physical examination to determine signs of:
- Pain: during the examination.
- State of joints and muscles: whether there are signs of degenerative osteoarthritis or arthritis, deformities or a tendency to develop them. Passive and active examination of joints, muscle strength and tone.
- Posture: standing, sitting and lying down.
- Movement disorders: whether there are restrictions, dyskinesia…
- Circulation and skin: whether there are edemas, varicose veins....
- Sensory deficits: mainly hearing and eyesight.

- Walking: we assess posture, length and duration of steps, type of assistance, associated arm movement and waist disassociation, going up/down stairs and ramps, balance while walking and standing.
- Coordination: for example, bending arms, alternating forearm movements, flexing hands and feet, lifting one foot and the opposite arm, etc.
- Body schema: verify the level of body part recognition.

Subsequently, a functional evaluation is performed of walking and balance using several types of standard, commonly used tests: Tinetti test, Timed Up & Go and Walking Scale. All users are tested at least twice a year.

- Tinetti test: comprises two sub-scales, one for balance and the other for walking. Various items are included relating to static posture control, posture changes, transfer and dynamic balance (see Appendix 1.)
- Walking Scale: consists of two sub-scales, one for functional capacity and the other for exploration. It also addresses supports and assistance in walking and an overall evaluation (see Appendix 2.)
- Timed Up & Go: consists of measuring the time the patient takes to stand up, walk three metres in a straight line and return to the initial position (see Appendix 3.)

The initial Individual Care Plan (initial ICP) includes all prior evaluations. The objectives are agreed with the rest of the professionals, the physiotherapist's initial evaluation findings are recorded and the treatment plan is prepared.

The physiotherapy applied to people with Alzheimer's disease is based on a series of physical and cognitive activities that seek to stimulate and train the patient so as to avoid impairment and loss.

4.4. Intervention methodology

Objectives

The physiotherapist's general objective is to enhance the resident's quality of life by encouraging the maximum possible level of autonomy and maintaining and/or improving their physical capabilities to minimise deterioration and immobility, promote health and well-being, and improved integration in the residence. A number of pre-planned physical and cognitive activities are employed, depending on the needs identified.

The following specific objectives are pursued through physical stimulation:

- Improve and/or maintain the capacity to walk as independently and functionally as possible.
- Improve and/or maintain independence in transfers.
- Improve and/or maintain joint mobility and muscle tone, avoiding rigidity and atrophy.
- Improve and/or maintain the best possible posture.
- Reduce joint and muscle pains.
- Avoid falls.
- Stimulate language and expression.
- Improve mood and encourage socialisation.

The physiotherapy intervention in Alzheimer's disease varies depending on various factors, the basic on being the phase in which we find the patient. Other factors are personality and related disorders, apathy level, mood, environment…

Activities follow a weekly plan to facilitate them for the patient. The therapeutic intervention consists of stimulating the person to perform the pre-planned activities.

4.4.1. General treatment plan

Individual activities

Kinesitherapy

A set of therapeutic procedures in which a series of movements are performed and applied (active, assisted, resisted or passive movements) to maintain or improve mobility muscle strength, or to treat a variety of pathologies, as well as to avoid the harmful effects of immobility.

Mechanotherapy is a kinesitherapy method in which movements may be assisted, directed or resisted by mechanical devices designed to cause and direct body movements while regulating strength, trajectory and range (peddler, pulleys, shoulder wheel, hand table, finger ladder).

Thermotherapy

A technique in which heat is applied to the body for therapeutic purposes using objects or radiation at a high temperature, above physiological levels (between 34 and 58 ºC). This stimulates peripheral circulation and has an analgesic and decontracting or relaxing effect. An infrared lamp is the tool most frequently employed.

Massage

A set of therapeutic manipulations that modify the state of tissues underlying the organic area treated. Massage techniques most commonly applied are: relaxing, decontracting, circulatory and manual lymphatic drainage.

a) Joint and muscle pains are relieved due to muscular and psychic relaxation, elimination of accretions and activation of peripheral circulation.
b) Movements are facilitated due to the reduction in stiffness.
c) Physical contact facilitates the relationship with the patient.

Cryotherapy
A technique in which cold is applied as a therapeutic agent having anti-inflammatory and calming effects. It is used mainly for inflamed joints.

Postural reeducation
A therapeutic technique designed to correct inadequate postures that can cause rigidity and pressure ulcers, and that interfere with the patient's functionality and body schema. It is applied while the patient is walking, standing, sitting or lying in bed.

Respiratory physiotherapy
This is a physiotherapy speciality intended to prevent, treat and stabilise respiratory dysfunctions or alterations; the general objective is to improve lung ventilation, gas exchange, respiratory muscle functions, dyspnoea, tolerance to exercise and quality of life.

The physiotherapist, depending on the clinical case and the user's capacity, will apply the following techniques:
- Reeducation of inhalation and exhalation, and teaching of abdominal/diaphragm breathing.
- Reeducation of coughing and expectoration.
- Clapping.
- Postural drainage.
- Reeducation of the coordination of breathing and physical activity (effort retraining).

Reeducation of walking and transfer training
Physiotherapy techniques are applied to walking, balance and transfers (from sitting to standing and vice versa, transfer to the bed). The necessary technical or human support is employed, depending on the patient's impairment and physical capacity. The aim is to achieve the greatest possible autonomy, encouraging independence and functionality; spatial orientation is therefore also favoured (e.g. going to the bathroom, to the bedroom …).

Where independent walking is not possible, walking is assisted, whether supervised or physically supported, by the physiotherapist or direct caregivers and/or with technical assistance (stock, walker, handrails); help may even be required from two people.

In order to enhance walking training, where physical condition allows it, ramps and stairs are used to strengthen lower limbs and favour independent walking. Walking is also trained over longer distances, at difference paces and on irregular terrain to encourage independence and work on balance so as to avoid falls, as well as to train progressive adaptation to effort. Conversely, where physical disability is significant, walking is trained over shorter distances with physical support, on parallel bars, a single bar… and standing. Where users have lost the capacity to walk and support themselves, we work on postural reeducation and passive, active or assisted mobilisation (kinesitherapy) of limbs, and on the correct completion of assisted transfers.

Hydrotherapy
A discipline that forms part of balneotherapy, physiotherapy and medicine, defined as the art and science of the prevention and treatment of disease and injuries using water as the therapeutic agent.

This method includes the following techniques:
- Contrast baths for hands and feet showing edema and rigidity (the hand or foot is submerged in hot and cold water alternately, to stimulate circulation and mobility).
- Hydrotherapy pool: the patient is submerged in hot water and the effects are leveraged to perform joint mobilisation techniques having diverse effects: relaxing, analgesic, anti-gravity.

Outdoor walks
This activity allows people able to walk to exercise outdoors and obtain the

benefits of sunlight, oxygen, absence of noises, interaction with vegetation, etc. It is generally recommendable and may even help to improve interpersonal relations.

Physical exercise in contact with nature brings numerous mental benefits, such as a greater feeling of revitalisation and energy, increased commitment to the activity and lower levels of tension, confusion and depression. It also offers greater satisfaction and enjoyment.

Physiotherapy activities performed by direct caregivers
Physiotherapists train the team of geriatric nursing assistants to perform daily controls of the patient's sitting posture so that people showing alterations or inadequate postures sit as correctly as possible. Cushions and footrests are used if necessary.

A number of daily walks or mobilisations (standing) are also performed with certain residents that need physical help, supervision and/or motivation to carry out this activity.

It is vital to perform transfers correctly with dependent patients, following an adequate, tailored method.

A gentle massage is also applied from the knee downwards when there are circulatory alterations and rigidity, or in hands showing rigidity. Caregivers are trained to perform these massages correctly and such massage is always very gentle, applied in one direction and very superficial, without using any special technique and only when prescribed.

Group activities

Kinesitherapy routine (see Appendix 4)
This is a simple exercise routine designed to mobilise the head, neck, torso, upper limbs and lower limbs, including different levels of difficulty based on the following factors:

a) Starting position: depends on the person's physical capabilities (balance, stability, resistance, pain…) and may be sitting, standing, or partly standing and partly sitting.
b) Complexity of the exercise: basic, simple movements or more complex, unfamiliar movements.
c) The number of repetitions are generally in the range of 5-10-15 or 20 in each exercise, at a faster or slower pace and with more or less recovery time between exercises.
d) Session duration: usually 20-30 minutes.
e) Longer or shorter explanation: the fewer the guidelines or explanations given, the more complicated the exercise may prove to be.
f) Use of materials: sticks, hoops, balls …

The patient is intended to learn the exercises as a result of repetition guided by the physiotherapist.

Participants form a circle with the physiotherapist in the middle. The residents perform the exercises in a sitting position with their backs straight, their arms touching their torsos and their feet resting on the floor, unless a different reference position is indicated, such as a standing position.

The exercises are explained and performed by the physiotherapist and then by the patients. Each exercise begins with a simple verbal explanation accompanying execution.

Psychomotor activities (see Appendix 5)
A therapeutic intervention combining physical and cognitive aspects in order to develop motor, expressive and creative possibilities in the body.

The cognitive and physical aspects addressed include attention, language, memory, lateralisation, body part recognition, form and colour recognition. This activities is also

performed in the occupational therapy area, though with different objectives.

In the case of physiotherapy, the main purpose is to generate spontaneous active movements, psycho-physical relaxation, improved moods and socialisation. A number of materials are used, such as balls, sticks, hoops, etc.

One of the most important psychomotor techniques is referred to as the "walking circuit", where various obstacles and marks are placed on the floor (circuit) for the user to avoid or follow, based on an established pattern. The physiotherapist first walks the circuit to demonstrate (once the user has learnt the circuit, this is no longer necessary) and then invites the patients to do so, one by one or even in small groups, providing assistance where necessary (supervision, verbal assistance or physical help). There are different levels of difficulty in accordance with each person's capabilities and needs.

In addition to the aspects mentioned above, this technique helps to reeducate walking and enhance balance.

Music therapy
A therapeutic activity that uses music and its characteristics (sound, rhythm, melody, harmony) to facilitate and promote communication, learning, mobility, expression, organisation and other therapeutic objectives, so as to address the patient's physical, social and cognitive needs. This activity is also performed by the occupational therapy department, but with different aims.

Physiotherapists seeks similar effects to those obtained in psychomotor sessions (appearance of spontaneous active movements, psycho-physical relaxation, improved moods and socialisation), although there is an additional aspect: the characteristics of music, which facilitate to a large degree the appearance of these therapeutic effects.

One of the most common activities in this therapy is dance, which fulfils all the objectives pursued and motivates the patient more effectively.

Relaxation
A psycho-physical technique that employs breathing, motor functions and cognitive aspects to achieve a state of calm and relaxation. It is generally used to complete other types of sessions, such as the gymnastic routine.

4.4.2. Treatment plan per phase

Physiotherapy intervention in the mild phase
In this phase, the main objectives of the treatment are to delay the patient's loss of physical capabilities and functional independence, since the progress of the disease cannot be prevented.

Treatments may be applied in groups or individually to address each patient's specific needs. This phase may include the following activities:

1. Individual activities
- Mechanotherapy: exercises with the finger ladder, hand table, shoulder wheel...
- Pain treatment: thermotherapy (infrared lamp), massage, cryotherapy…
- Postural reeducation: verbal orders are used to correct sitting, standing and walking postures, encouraging the person to adopt a straight posture.
- Respiratory physiotherapy: exercises to lengthen inhalation and improve control over breathing. Kypotic posture correction is also important if the respiratory system is to function properly.
- Hydrotherapy: when working on limbs, contrast baths are used, while a heated swimming pool is employed for more general work.
- Transfer training: the purpose is to make transfers as independent as possible without any risk of falls.

- Reeducation of walking and balance: there are several levels of difficult in this activity, employing irregular terrain, stairs, ramps, obstacles, flat surfaces… in accordance with the patient's physical state.
- Outdoor walks: this activity may be arranged individually or in groups during this phase of the disease.

2. Group activities
- Kinesitherapy routine: exercises are designed to develop and improve the corporate schema (see Appendix 3).
- Psychomotor activities: various materials are used, such as sticks, balls, hoops, string, walking circuit…
- Music therapy: this complements other activities (accompanying the kinesitherapy routine, a psychomotor session, etc.) and sets the walking rhythm, dancing…
- Relaxation: used mainly at the end of kinesitherapy routines, psychomotor sessions, during outdoor walks…
- Outdoor walks: this activity may be arranged individually or in groups during this phase of the disease.

The exercises must not cause fatigue and must be tailored to each patient's needs.

Physiotherapy intervention in the moderate phase

Cognitive and physical impairment is more significant in this phase. The user must be addressed slowly and clearly, with simple orders. Forgetfulness is frequent and important. Security measures must also be intensified to prevent accidents and falls. Sensory deficits, bradycinesia, time-space disorientation, functional impotence, demotivation and dependence on external help for most daily tasks all increase, while the capacity to respond to stimuli, respiratory capacity, voluntary activity and functional independence all decline.

1. Individual activities
- Active-assisted and passive kinesitherapy: the technique used depends on the patient's joint stiffness and cognitive capacity.
- Pain treatment: the same techniques as are applied to patients in the mild phase.
- Postural reeducation: exercises to correct deformities and control posture are intensified to enhance flexibility, elongate muscles and strengthen muscles in active, active-assisted and passive ways, depending on the level of mobility and patient cooperation. Cushions and wedges are used where necessary.
- Posture changes: in order to avoid the appearance of pressure ulcers, rigidity and deformities, and to correct anomalous postures. Sitting position: sitting up straight. In bed: at least every two hours (right side, left side and supine positions).
- Hydrotherapy: mental disorders and urinary/fecal incontinence are already significant, meaning that this technique is only applicable in exceptional cases.
- Transfer training: standing up and sitting down in a chair, lying on the bed and getting up.
- Reeducation of walking and balance: walking must continue in order to delay as long as possible the complications of immobility. Balance and coordination work helps to reduce the risk of falls. If possible, accessories may be used such as sticks and walkers… The user must wear suitable, comfortable shoes that balance and hold their feet.
- Outdoor walks: during this phase of the disease, outdoor walks may be individual or in groups.
- Fall prevention measures:
  - Adapt the environment: remove obstacles and rugs from walking areas, install antislip floors, adapt bathrooms correctly, take into account the width of doors…
  - Suitable footwear: preferably velcro fastenings, antislip sole and no heel.
  - Encourage mobility and autonomy as far as possible.

- Use technical aids, glasses or hearing aids as appropriate.
- Supervise and/or help during walking and transfers if necessary.
- Encourage self-confidence and security.
- Control bed height (medium height).
- Chairs with armrests and a good back.
- Good lighting and helpful signs.
- Medication control.
- Belt in the chair or bed, handrails, etc., as a last resort.

2. Group activities

- Kinesitherapy routine: due to the patient's cognitive impairment in this phase, the exercises are very simple and require more explanation. The patient starts in a sitting position. Few repetitions are performed, the pace is slow and the sessions last for approximately 10 to 15 minutes.
- Psychomotor activities: activities are more simple, using a variety of materials such as sticks, balls, hoops, string, walking circuit…
- Music therapy: same objectives and materials as with patients in the mild phase.
- Relaxation: mainly at the end of kinesitherapy routines, psychomotor sessions, during outdoor walks…
- Outdoor walks: depending on the patient's functional state and physical capacity, this activity may be performed individually or in groups.

Physiotherapy intervention in the severe phase

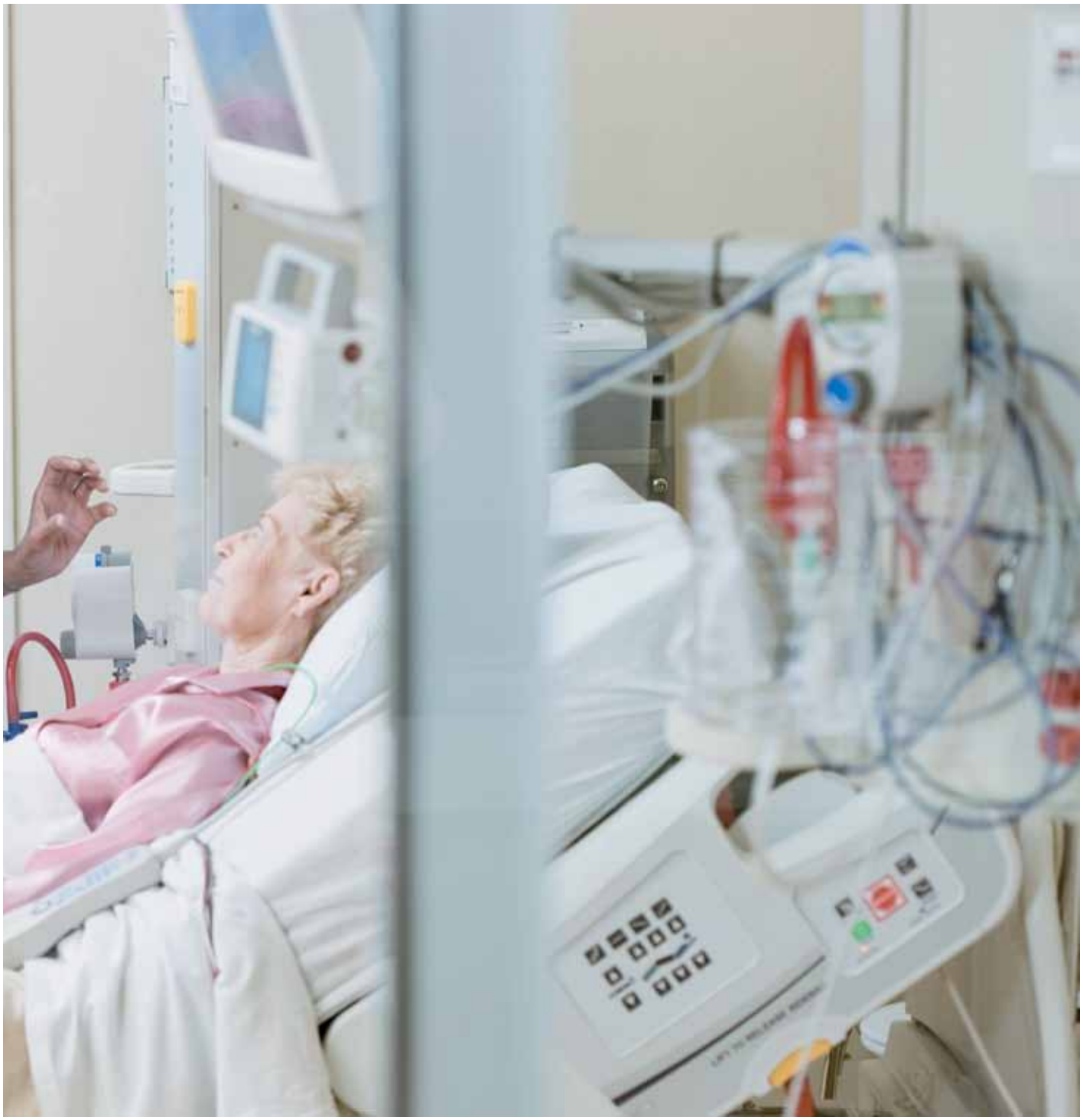
Cognitive deterioration is highly significant and it is very difficult to achieve collaboration and order execution from the resident. In this phase the patient becomes bedridden, although all possible efforts are made to delay this moment, since it causes major health complications. The main objective of physiotherapy in this phase is to prevent the side-effects of immobility.

1. Individual activities

- Passive kinesitherapy: on a daily basis, analytical and overall treatment, paying particular attention to the hands (opening hands).
- Pain treatment: circulatory massotherapy, thermotherapy and gentle mobilisations.
- Respiratory physiotherapy: in the event of respiratory pathology and the accumulation of secretions, bronchial cleaning techniques are applied (vibration, clapping, postural drainage).
- Posture control: exercises for flexibility and muscle elongation, depending on the patient's mobility level. Cushions and wedges are used.
- Posture changes: the fact that they are more frequent becomes particularly relevant during this phase.
- Walking and standing training: in this phase, patients may have lost the capacity to walk or may need help from two people. If walking is impossible, standing is encouraged.
- Outdoor walks: due to the patient's severe physical and cognitive impairment, the activity will generally be performed in a wheelchair.
- Direct caregivers are taught about posture hygiene and ergonomics.

2. Group activities

Group activities are not possible in this phase of the disease.



ANEXOS

Appendix 1
Tinetti Test

Part I: Balance
Instructions: the patient is sitting on a hard chair without armrests. The following manoeuvres are performed:

1. Seated balance
- Leans forward or slides in the chair 0
- Remains steady 1

2. Standing up
- Impossible without help 0
- Able, with help from their arms 1
- Able, without using arms 2

3. Intentos de levantarse
- Unable without help 0
- Able, but needs more than one attempt 1
- Able to stand up in a single attempt 2

4. Immediate standing balance
(First 5 seconds)
- Unstable (swaying, moving feet, marked swaying of the torso) 0
- Stable, but uses a walker, stock or other object while standing 1
- Stable without a stick or other support 2

5. Standing balance
- Unstable 0
- Stable due to increasing the support area (heels more than 10 cm apart) or uses a stick, walker or other support 1
- Narrow support base without support 2

6. Pushing
(The patient is standing, torso erect, feet together; the examiner gently pushes the patient's sternum with the palm of the hand three times)
- Tends to fall 0
- Sways, regains balance and does not fall 1
- Stable 2

7. Eyes closed (in the previous position)
- Unstable 0
- Stable 1

8. 360-degree turn
- Discontinuous steps 0
- Continuous steps 1
- Unstable (grabs hold or sways) 0
- Stable 1

9. Sitting down
- Insecure, calculates the distance badly, falls into the chair… 0
- Uses arms or movement is not smooth 1
- Secure, smooth movement 2

Balance score: / 16

Parte II: Walking

Instructions: the patient is standing next to the examiner, walks about eight metres at a normal pace and then returns at a fast but secure pace.

1. Initiative for walking

(immediately after telling the patient to walk)

- Hesitation or numerous attempts to begin 0
- No hesitation 1

2. Length and height of steps

a) Right foot movement

- Does not go past the left foot in the step 0
- Goes past the left foot 1
- Right foot does not fully separate from the floor in the step 0
- Right foot separates fully from the floor 1

b) Left foot movement

- Does not go past the right foot in the step 0
- Goes past the right foot 1
- Left foot does not fully separate from the floor in the step 0
- Left foot separates fully from the floor 1

3. Step symmetry

- Length of step with left and right foots is not the same 0
- Length appears to be the same 1

4. Step flow

- Stops between steps 0
- Steps appear to be continuous 1

5. Trajectory

(Observe the movement of one foot for about three metres)

- Serious deviation from the trajectory 0
- Slight/moderate deviation or use of support to maintain the trajectory 1
- No deviation or support 2

6. Torso

- Marked swaying or use of support 0
- No swaying, but bends knees or back, or separate arms while walking 1
- No swaying, no bending, no use of arms or other support 2

7. Walking posture

- Heels separated 0
- Heels almost touching 1

Walking score: / 12

Total Tinetti score: / 28

Appendix 2
Walking scale (Version 1.0-2008; Martínez Martín)

I. Functional capacity

1. Area in which walking takes place
0- Normal. Walks freely outdoors and indoors.
1- Walks freely indoors, but with precaution and/or companion outdoors, few limitations.
2- Requires some help or support indoors. Limited or no outdoor walking.
3- Inability or great difficulty walking indoors, even with help.

2. Walking autonomy
0- Normal.
1- Only shows limitations in more demanding activities (fast walking, long steps, getting over obstacles or very irregular terrain, etc.).
2- Requires some help or shows limitations in some basic activities involving simple routes (strolls, access to a method of transport, going to other rooms, washing and hygiene).
3- Fully dependent on others in all walking.

3. Getting up from a chair and bed
0- Normal.
1- Rather slow and/or with some difficulty, but totally independent.
2- Very slow and/or with many difficulties. May require supports or some help to complete the action.
3- Totally dependent. Unable to complete these actions.

4. Going up and down stairs
(Exclude other aspects unrelated to neurological alterations, such as "fatigue" caused by lung or heart disease, arthropathy, etc.)
0- Normal.
1- Rather slow and clumsy; could be normal in an elderly person. Does not require assistance.
2- Moderate difficulty, slowness and/or clumsiness. May need help.
3- Considerable help and difficulty, or unable to go up/down stairs.

5. Walking
0- Normal.
1- Slight difficulty and/or slowness.
2- Moderate difficulty and slowness. Requires help in some circumstances.
3- Considerable difficulty and slowness. Needs significant assistance to take a few steps or is totally unable to walk even when assisted.

6. Falls
(Assess in relation to what would occur if the patient were to walk unassisted, or with a stick or physical support [no human assistance])
0- Never or only accidentally.
1- Rarely (less than once a month).
2- Certain frequency (more than once a month but less than once a week).
3- Very frequently (more than once a week) or unable to walk.

II. Exploration

7. Lower limb stiffness
(Exploration performed with the patient sitting, in a natural position, with hips and knees flexed at about 90º and feet together. Hip resistance to passive mobility is assessed, reflected through thigh abduction-adduction [range of 25-30 cm], with the explorer's hands placed on the patient's knees, which are initially together. The movement is explained to the patient and maximum relaxation is encouraged to allow it. The explorer must be located to one side [not in front!] of the patient and must make several attempts until a reliable evaluation has been obtained)
0- Normal.
1- Slight or hardly detectable.
2- Moderate; full range of movement is achieved easily.
3- Intense; range of movement is achieved with difficulty or is not achieved.

8. Standing up from a chair/straightening up
(Patient is sitting on a chair about 45 cm from the floor with a straight back. Wrists are resting on the proximal portion of the thighs, semi-pronated, in a natural position)
0- Normal.
1- Stands up slowly but straightens up in a single movement.
2- Needs several attempts, swaying and/or support from arms. Does not need help.
3- Cannot stand up without help.

9. Beginning to walk
(Patient standing, stationary. Patient is asked to begin to walk immediately following the order)
0- Normal.
1- Slow start, a little longer than normal, but with scarce or no difficulty.
2- Very slow start. Start hesitation. Moderate difficulty.
3- Unable or scarcely able to begin walking; it is very difficult or impossible.

10. Freezing
0- None.
1- Occasional or rare and very brief (<2 seconds or < 5 "little steps"). Do not result in falls.
2- Frequent and longer (>2 seconds or >5 "little steps"). May cause a fall.
3- Constant; clearly prevent walking. Frequently cause falls or patient is unable to walk so this aspect cannot be evaluated.

11. Length of step
0- Normal.
1- Shortened, although each food clearly passes the other.
2- Moderate-severe shortening. One foot does not pass the other.
3- Walking "in tiny steps" (each foot moves a few centimetres) or walking not possible.

12. Arm swinging
0- Normal.
1- Reduction in swinging, on one side or both.
2- Absence of swinging, on one side or both. Arms in normal position.
3- Absence of swinging with arms flexed.

13. Turns
0- Normal.
1- Somewhat slow or cautious. Maximum of two phases.
2- Turning is difficult, requiring three or more phases. Moderately slow.
3- Turning is very slow and difficult, requiring help or support, or impossible.

14. Dynamic balance while walking
0- Normal.
1- Occasionally altered. Corrected alone or with minimal support.
2- Moderately altered. Requires support or help to walk (stick, companion). May fall due to this type of alteration.
3- Very altered. Difficult to walk or unable to walk, even with significant help, for this reason.

15. Posture
0- Normal.
1- Not totally erect; a slight stoop, but could be normal in an elderly person.
2- Moderate stoop (clearly abnormal). May lean slightly to one side and/or slightly flex limbs.
3- Marked stoop; may lean clearly to one side. Flexed posture.

16. Push test
(The patient is standing with his/her eyes open; the explorer is behind the patient. The patient's fees may be slightly apart [up to 30 cm]. The patient is told that he/she is to be pushed backwards from the shoulders and must do his/her best to keep or recover balance; i.e. they must not let themselves fall passively. The push must move the shoulders quite sharply, about 7-8 cm backwards)
0- Normal.
1- Retropulsion, but recovers after one or two steps.
2- Retropulsion without recovery. Must be supported to avoid a fall.
3- Very unstable. Tends to fall spontaneously or is incapable of preventing a fall without help.

17. Supports and assistance for walking
0- Not necessary.
1- Autonomous with instrumental support (stick, crutches).
2- Needs help from one person.
3- Needs help from two people or cannot walk.

Comprehensive walking evaluation

0. Normal; able to perform demanding activities.
1. Normal; not able to perform demanding activities.
2. Abnormal; no limitations in ADLs.
3. Abnormal; few limitations in ADLs.
4. Abnormal; quite a lot of limitations in ADLs.
5. Abnormal; not able to perform ADLs.

Appendix 3
Time Up & Go test

The patient is sitting in a chair with a height of 45-46 cm, with an armrest and a straight back. The patient is asked to stand up, walk three metres, return and sit down again. The path must be marked on the floor. If the patient normally walks with a stick, the stick may be used; in this case, the patient holds the stick before receiving the order. The test is conducted once without being timed (for "training" purposes) and is then timed. When the order "now" is given, a stopwatch or the second hand of a watch is used to time the activity.

* Time taken: ..... seconds

Appendix 4
Kinesitherapy routine

A session consists only of the exercises deemed most suitable based on the group's characteristics. The following exercises are ordered from less complex to more complex.

Next exercises
1. Move your head forwards and backwards (as when nodding).
2. Turn your head from side to side (as when shaking your head).
3. Move your head in order to try to touch your shoulder with your ear.
4. Make gentle, slow circles with your head one way and then the other.

Shoulder exercises
1. Raise both shoulders at the same time without moving your arms.
2. Raise one shoulder, lower it and then raise the other.
3. Make circles with your shoulders, first forwards and then backwards, without moving your arms.
4. Move your shoulders forwards and backwards (as if trying to bring them together and separate them).

Arm exercises
1. Raise and lower both arms at once, with your elbows extended.
2. Joint your hands and raise and lower both arms, with your elbows extended.
3. Raise both arms and clap your hands above your head.
4. Make circles with both arms forwards and then backwards.
5. Windmill forwards and then backwards.
6. Raise one arm and lower the other alternately, keeping your elbows extended.
7. Swim breaststroke.
8. Swim crawl.
9. Swim backstroke.
10. Place your hands on your shoulders and then separate them from your shoulders and then touch your shoulders (bending and extending the elbow).
11. Place your hands on your shoulders and then turn them forwards and then backwards.
12. Place your hands on your shoulders and try to touch your elbows together in front of you, then separate them.

Hand exercises
1. Open and close your hands vigorously.
2. Clap strongly.
3. Wave goodbye with your hands.
4. Count your fingers, separate and join your fingers, make claws with your fingers.
5. Close your fists and make circles, first towards one side then towards the other.
6. Hands in front with elbows extended, raise and lower your hands (wrists flexing and extending).
7. Join your hands together and turn your wrists towards one side then towards the other.
8. Pretend to play piano.

Torso exercises (preferably standing)
1. Place your hands on your waist and bend your torso right and left.
2. Lean your torso towards one side and at the same time raise the opposite arm; repeat towards the other side (sitting and standing).
3. Place your hands on your waist and flex and extend your torso (moving your torso forwards and backwards).
4. Place your hands on your legs and flex and extend your torso (sitting).
5. Arms raised and shoulders extended, try to touch your feet (sitting and standing).

6. Place your hands on your waist, turn your torso left and right.
7. Join your hands together in front of you, elbows extended; turn your torso right and left, accompanying it with your hands (sitting and standing).
8. With both hands, hold on to one of the chair armrests and then move both hands to the other armrest repeatedly (sitting).
9. Imagine you are holding the oars of a boat and row, moving your torso forwards and backwards (sitting).
10. Lean your torso to the right side to touch your right foot with your right hand; repeat to the left (sitting).
11. Place your hands on your waist and turn your torso and pelvis fully to the right and then to the left.

Leg exercises (preferably sitting)

1. Raise both legs at the same time, extending your knees, then lower them to the floor.
2. Raise first your right leg, extending your knee, lower it, then raise your left leg, alternating legs.
3. Raise your right leg with the knee bent and, after lowering it, raise your left leg.
4. With your feet resting on the floor, separate and join your legs, keeping your knees bent.
5. With your feet together, resting on the floor, move them forwards and backwards.
6. Extend your right leg and turn it with your knee extended, first outwards, then inwards. Repeat with your left leg.
7. Raise your legs in the extended position and cross one leg over the other; change legs.
8. Raise both extended legs at the same time and, once horizontal, quickly raise and lower your legs, alternating right and left.
9. Raise both extended legs and, once horizontal, open and close them.
10. With your feet resting on the floor, make circles, with both feet at the same time, outwards and inwards.
11. With your feet resting on the floor, move one foot forward and one foot backwards, simultaneously.
12. With your legs together, separate both feet from the floor at the same time, raising your flexed knees; then lower them.
13. Standing, with your hands on your waist and your feet as close together as possible, bend and extend your knees.
14. Standing on the spot, raise first one leg and then the other, bending your knee (as if taking steps).

Foot exercise (sitting)

1. Feet together, resting on the floor; raise your heels to leave toes resting and then raise your toes to leave heels resting.
2. Heels of your feet together, separate and join together the front ends of both feet.
3. Front ends of both feet together, separate and join the heels of both feet.
4. Raise both legs, knees extended, and move the front ends of both feet upwards and downwards.
5. Raise your right leg, knee extended, and turn your ankle first outwards and then inwards; do the same with your left leg.

Appendix 5
Example of a psychomotor session

Materials: chairs, hoops, balls, sticks, string, music …
Location: wide, open space.
Number of participants: approximately 10.
Duration: approximately 30 minutes.

Methodology

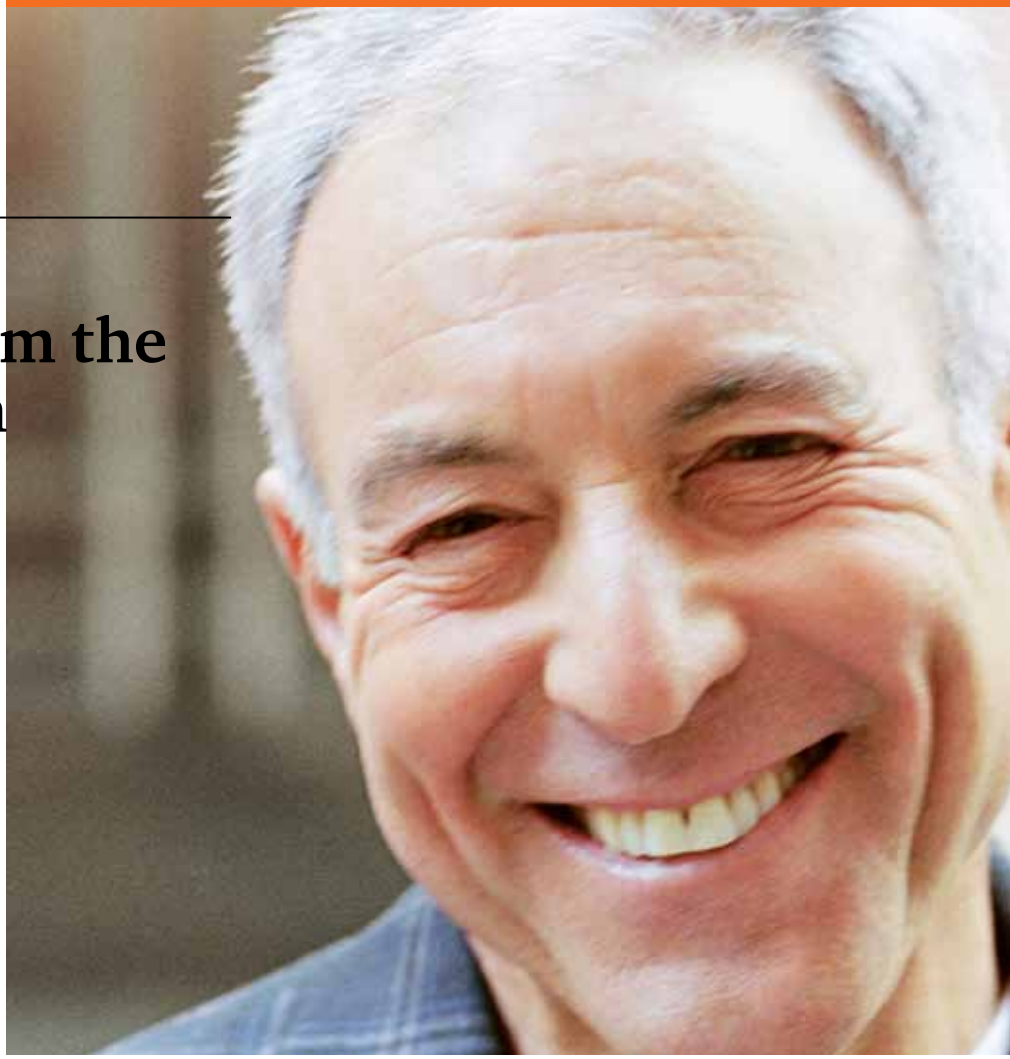
The participants form a circle with the physiotherapist in the middle. The first exercise consists of throwing hoops of different sizes over sticks of different lengths. Though a group activity, it is performed individually.

We then work with balls of different sizes, textures and weights. The physiotherapist throws the ball to the patient and the patient throws it back; the participants then pass the ball to each other using hands and/or feet.

In the final part of the session, the physiotherapist provides each patient with a ball or a stick to perform a number of exercises, such as raising, lowering, moving to one side, etc.

The psychomotor session is accompanied by appropriate, lively music to encourage users to perform the movements.

Content



Chapter 5
Intervention from the social work area

Raquel Díaz Rodríguez.
Social worker

5.1. Facing the disease: institutionalisation

Initially, when Alzheimer's disease is first diagnosed, families have different ways of facing the situation, since each person has a different relationship with the patient. Each person's role in a family unit evolves and changes in different phases; therefore, when faced with this situation, each person will react differently and change his or her strategy.

Without doubt, caregivers must take care of themselves and other people must take care of the caregivers.

The family members of people that are admitted into a socio-health centre are generally faced with quite a complex situation, since they have cared for their relative during a period of their life in which they may have undergone anxiety and depression, in which they may have been ill, and this situation may even have resulted in them consuming psychoactive drugs. Factors that may aggravate the caregiver's situation include isolation due to limited free time, prior family issues that merely

complicate the facing of the disease, and limited knowledge of the disease and its consequences.

The caregiver must therefore be advised, informed and supported to alleviate a situation that is already very difficult to accept and experience on a daily basis. It is thus important for the patient to be institutionalised when it is observed that the caregivers cannot or do not know how to face such a complex situation and are debilitated on a number of levels (physical, mental, economic, spatial, etc.).

Once the disease has been diagnosed, when considering institutionalisation, family members feel a significant burden of guilt, since their perception is distorted and they see it as "abandonment". This is one of the main tasks of a social worker from the initial moment, the process of accepting the institutionalisation of their relative.

The Centre will implement the best possible strategies to facilitate this process, both for the new residents and their families. The admission process is facilitated by meeting their implicit and explicit needs.

Steps for admission into a public socio-health centre
Firstly, an appointment with a social worker is requested at the local Social Services Centre, since the dependency evaluation procedure is conducted through the Social Services Network.

After requesting an appointment, an evaluation of the level of dependency must be requested so as to access various resources that require the recognition of the degree and level of dependency. This evaluation will determine what benefits may be obtained and at what level.

The following documentation is required: national ID number of the applicant or legal representative, if applicable, health report issued by an authorised doctor, registration certificate and completed application form. (This may vary depending on the Autonomous Region.)

Once the application has been submitted, we must wait until the applicant is contacted to arrange a home visit. A telephone call will be received indicating the day and time of the evaluation. The assessor will visit the person's home to perform the appropriate examination in the form of an interview and observation (the assessors are social workers, occupational therapists or nurses). A report will be prepared on the environment and the consultation will be completed. (It is advisable for a family member to be at home on the evaluation date.)

When the home evaluation has been completed, the body having competence for dependency will issue a decision recognising the degree and level of dependency that will give entitlement to the system's benefits and services.

The degree of dependency having been recognised, the final step is to request public admission into a residence, provided this is the most suitable recourse in the circumstances.

5.2. Social intervention

To quote Silverio Barriga, we understand social intervention to be a set of strategies designed to bring about changes in a community's social reality, requiring active participation from the community.

Social intervention may be regarded as a planned, technical change to tackle social problems or problematic situations, particularly for the underprivileged, to help them to face and resolve problems, improve quality of life and, therefore, human quality. In short, the purpose is to transform social reality and achieve changes in society.

A social worker's functions in a socio-health centre are structured based on a number of intervention levels.

Manuel Martín García highlights the functions attributed to social workers in a residential centre, which may be summarised by nature as follows:

- Preventive functions: seeking to facilitate residents' integration and foresee potential conflicts in various areas.
- Socio-educational function: planning and executing activities that favour social relations of both Centre residents and their family members.
- Care function: based on needs that may arise, providing information on resources available and implementing projects to favour and enhance internal dynamics.
- Planning function: facilitating the Centre's internal organisation at all

times and assuming project development, ensuring that execution periods and objectives are entirely realistic and acceptable; seeking to promote efficiency.

- Organisation and coordination function: forming part of the multidisciplinary team, we must favour actions undertaken by each work area, always endeavouring to encourage an overall, integrated vision so that issues may be addressed from different perspectives.

5.3. Social worker's functions

Although the first section of this guide contains a description of the social worker's general functions, this section defines them in relation to the Centre's daily activities, since they are applicable at both the individual and family levels, on a complementary basis, to foment integrated improvement for the resident.

- Provide information on the Centre and all matters that could be raised by the user and the family.
- Manage case files received from the body responsible for dependency.
- Conduct pre-admission and admission interviews.
- Receive and accompany residents and families on the admission day.
- Prepare the family's social report genogram.
- Explain the protocol to be followed following admission and protocols applicable in various situations such as outings, hospital admission, death, etc.
- Encourage the resident's integration in the Centre's activities and facilitate family collaboration in the activities.
- Receive the social demands of the resident and the family, providing them with the necessary information and advice on the resources available to them.
- Resolve incidents that may arise in an empathetic manner.
- Prepare projects requiring individual and collective actions, establishing follow-up guidelines and the evaluation process.
- Provide information on the incapacity procedure; if families are interested, offer advice and explanations of the steps to follow.
- Participate in Individual Care Plan (ICP) meetings.
- Conduct interviews with the resident's family members.
- Maintain or encourage the resident's relations with the family and the family's relations with the Centre.
- Encourage the family to prepare and participate in activities organised in the Centre.
- Provide the family with information on their relative's integrated evolution in the Centre.
- Favour smooth communication with the family, resolving any incidents that may arise.

5.4. Pre-admission and admission evaluation

Users admitted into the Reina Sofia Foundation's Alzheimer Centre must fulfil specific requirements.

The public body responsible for dependency will provide us with the prospective resident's contact details. Once the information is received, the social worker contacts the family to provide them with information on the Centre and on the evaluation process. In this initial contact, we must obtain important information for the subsequent evaluation, such as the patient's social and medical data.

Subsequently, we arrange an appointment with the family and the patient, on a specific date, requesting that they visit the Centre for an interview and preliminary evaluation; they will be asked to furnish any medical reports that are available.

The prospective resident's current situation will be evaluated on an interdisciplinary basis at a number of levels (physical, cognitive-behavioural and functional) prior to their possible admission. This evaluation will be performed by the geriatric doctor, neuropsychologist and occupational therapist. The aim is to determine whether or not the person may be diagnosed as having a neurodegenerative dementia and to evaluate their global deterioration (GDS) to check whether there is a room in an adequate life unit.

On arrival, the social worker will receive the prospective resident and family and will accompany them during the evaluation. Once the process is complete, any further issues that may be raised by the family will be resolved.

Following the evaluation and provided the profile is suitable for admission, the social worker will contact the family to inform them. An interview appointment will be made, followed by a tour around the Centre's facilities.

Pre-admission interview
The family members will be received by the social worker on the interview day and accompanied to the interview room, where we will explain the documentation required for the admission process and the personal items that must be prepared. They will be informed of the admission date and time.

During this interview, we will discuss the legal incapacity procedure and the formalities that must be undertaken, should it be necessary to request it. We also inform the family that we are obligated to notify the court of the admission of a person with Alzheimer's disease or a primary dementia in our Centre. This step is necessary to obtain the relevant court authorisation. We must also submit notice of the patient's registration details following admission into the Centre.

During the interview we may request further information on the family, family dynamics, each member's roles, how they reacted to the disease diagnosis from the first moment, what are the strengths and weaknesses in order to adapt the intervention and favour the achievement of our objectives, both with the user and the family.

Following the interview, we will visit the Centre and take a tour of the training area where courses and workshops on dementia are held. In this area we respond to the need referred to in this chapter for families and caregivers to be informed about the disease and to have adequate resources and techniques to

face their relative's daily reality in the best way possible.

As indicated previously, and taking into account the collaboration between the Care Centre and the research unit, the social work area must encourage involvement in this type of projects to facilitate research into different types of neurological diseases. On the admission day, family members meet with a research area member to receive detailed information relating to any doubts they may have.

Admission interview
The social worker again receives the family members, who will then go to the office to fill in forms and protocols in a relaxed atmosphere.

During the interview with the family, the social worker must give priority to the patient's emotional well-being.

All the information and documentation requested on the pre-admission day will be collected. The main documents to be furnished on admission are the national ID card, Social Security card, death insurance policy (if applicable), up-to-date medical reports, recent photograph (if applicable), information sheet containing the names, telephone numbers and addresses of contact persons in order of priority, incapacity ruling (if applicable) and photocopy of the Dependency Law ruling.

All the documents furnished by the user will be filed as appropriate in the psycho-social file, medical file…

The resident must sign a number of authorisations and documents on admission, which will be included in his or her social file. We refer to documents such as the internal regulations, Centre admission contract, sheet of permits and authorisations, etc. Bearing in mind that Centre users have a dementia, this functions is generally performed by the family members or persons with responsibility. However, each document will bear the new resident's fingerprint.

We must also prepare the social report, which is an essential tool for social workers. This will include the following data and may be extended if deemed necessary: full name, life unit, room, internal file number, file number of the relevant Autonomous Community, socio-family situation, expectations of both the resident and the family, etc.

Social workers are responsible for the following administrative formalities:
- Notifying the competent body of the admission into the Centre.
- Registering the new resident in the Centre's management software and also in the register of new/departed residents containing relevant data, such as their internal file number, full name, address and telephone number, etc.
- Informing the Court of the admission, since we are required to report this without 24 hours in order to begin the voluntary admission process. The Centre will subsequently be visited by the Judicial Committee and the social worker will accompany them to the life unit in which the resident is located.
- The Court will then send a notification containing the admission decision and authorisation for the person's voluntary admission. This is filed and entered in the management software. The social work area notifies the Court, every six months, that the resident continues to live in our Centre. The Court is also informed of the death of a resident.

Once this procedure is complete, we accompany them to the doctor's office, where the healthcare evaluation is performed and the clinical history is prepared, before moving on to the life unit, where the direct caregivers receive the patient and the family and all their belongings will be organised.

Finally, the family members have a personal meeting with a neurologist from the Research Unit, who will explain the new resident's possible participation in research projects; the family will sign consent forms, if necessary.

In short, the aim is to favour the resident's integration into a new space in which his or her daily activities will be conducted.

The social work area must provide a family care programme to respond to doubts and issues as they arise, performing an individual follow-up of each case. The social worker plans family care times during which incidents are resolved, questions are answered and proposals are noted.

Ongoing information and advice is offered on the social resources that are most adequate based on the user's needs. There is also an information and advice service for families not linked to the Centre that turn to us because they have a dependent relative. We then notify their local social worker.

5.5. Adaptation to the Centre

Many difficulties can arise following admission to the Centre, for both the patient and the family.

The patient will perceive the change in various areas: affective, because their relationship with family members and friends will change; material, due to the abandonment of their home and personal objects.

They must also adapt to a new routine of times and activities, a new environment and new companions. This period generally lasts for between one and three months, although this is illustrative, since some people become integrated in less time and others never fully adapt.

There are certain parameters that help us to observe the resident's degree of integration. On occasions the information may be verified by the user, but there are cases in which this is not possible, such as people with dementia. What aspects help us to observe the resident's level of integration? Their relations with companions, involvement in Centre activities, participation in outings organized, whether or not they cooperate in Centre tasks, their moods, etc. All these factors reflect the patient's well-being or unease following admission.

During the initial period, the family experiences a variety of emotions, such as sadness, guilt, fear, anger … The professionals must take this situation into account and work to change these emotions in the best possible way, creating a climate of confidence and affection that gives them security and tranquillity.

Finally, this adaptation period will not come to an end, since there may be difficulties, changes and situations requiring an adaptation process right through the patient's stay in the Centre. Follow-up and evolution are therefore an essential part of life at a socio-health centre.

5.6. Objectives proposed by the social work area

The data previously compiled by different professionals provides us with sufficient insight into users and their families; we are therefore in a position to establish the objectives deemed most fit to improve quality of life for the resident and the family members.

Objectives are defined by area and must be accompanied by a series of activities to allow us to achieve them.

The social work area may propose the following objectives (as an example):

- Favour residents' integration and participation in organised activities, providing support as needed.
- Develop smooth commun ication between the user, family and Centre.
- Provide users and families with information on resources available, handling formalities and ensuring that the families can take advantage of them.
- Foment coordination among team members to allow us to address issues and incidents in a comprehensive, integrated manner using multidisciplinary techniques and instruments.
- Foresee and mitigate any cohabitation issues that may arise in the Centre, favouring interpersonal relations.
- Encourage the user's relations with family members, group activities and community life.

Having defined the objectives that may be established by social workers in this type of institutions, there follows a table summarising the tasks to be performed. This does not include the evaluation process and is focused on three fundamental processes, defining social workers' intervention in each case.

Table 4: Tasks to be performed by the social worker

Pre-admission	Admission	Post-admission
Analysis of family's situation. Family structure. Issues. Dynamics of the admission interview.	Welcome and support programme. Contract signing. Social history. Review of belongings.	Family's involvement in Centre programmes and projects. Supervision of the adaptation process.
First contact with the Centre: - Tour of the Centre. - General information: timetables, programmes, personnel, requirements, rules.	Family information programme: - Physical location in the Centre. - Presentation of personnel. - Family-Centre information channels. - Basic functioning.	Family advice: - Training/Information. - Release of guilt. - Mitigation of fear. - Family-Centre coordination.
Setting of the admission date: - Arrange a day and time. - Request clinical reports. - List of necessary belongings.	Individual Care Plan: - Results of evolution. - How the patient came to the Centre. - Interventions to be applied.	Periodic evaluations and updates on intervention with families.
Family advice: - Guidelines during the adaptation period. - Release of guilt. - Favouring of realistic expectations. - Centre-family coordination. - Family involvement. - Transmit our professionalism: need for security.	Inform the Court: - Involuntary admission. - Registration in the competent body's computer system. - Registration in the Centre's computer software.	Planning and initiation of mutual help groups.

5.7. Keys to working with families

When we begin to work with family members of a person with dementia, we must consider that this situation will have a major impact on family dynamics and may even destructure the family. A number of aspects must therefore be taken into account when working with families in this situation.

We must start by defining and explaining Alzheimer's disease. A delicate approach is required when giving news and families must also be aware of the consequences of the disease in their lives, and particularly in relation to daily activities. Information transmitted to families must therefore be clear and broad so as to resolve all the doubts they may have, but without being excessive or full of technical language, which could have the opposite effect and cause the family to become overwhelmed.

Other resources must also be offered to facilitate their situation, such as participation in associations or specific training in matters relating to Alzheimer's disease.

Family members have often been the caregivers prior to admission, generating a situation of emotional overload; when dealing with them, we must take this into account. In certain situations they may feel more irritated and angry. Each family is unique and manages emotions differently; a flexible approach to work must therefore be adopted on a daily basis.

Family members' involvement in caring for the Alzheimer's patient must also be encouraged to avoid a single carer figure and reduce the excess burden of care.

When people with dementia are admitted into the Centre, family members suffer during the process and it is important to address with them the limitations created in their lives while caring for their relative: social, family, labour and affective limits. The family carer can now make new plans in life, recommencing activities that were abandoned or recovering old dreams that were prevented by care obligations. This will motivate family members to recall aspirations that became secondary.

What are the possible repercussions of a person with dementia on the family caregiver?

We will first refer to affective aspects, which include depression, anxiety, stress and/or low self-esteem. This is all caused by daily care-giving. The family area is also significant, since it is difficult to strike a balance between caring for a dementia patient and caring for a family. As regards work, a large number of caregivers stop working or reduce working hours to care for their relative. A considerable excess effort is required to return to employment once the relative has been institutionalised.

Finally, with respect to social aspects, while caring for the patient, the family caregiver may have been forced to neglect social relationships that they must now try to recover.

It should be noted that all of the areas mentioned are interconnected and objectives achieved in each area will also benefit the other areas.

Finally, we wish to provide guidelines for communicating with the resident that will be useful for professionals working in this area:

Table 5: Guidelines for professionals when communicating with Alzheimer's patients

Mild phase	Moderate phase	Severe phase
Memory problems and slight language deterioration. Difficulty finding the right words.	Further language and vocabulary impoverishment. Difficulty finding very common words.	Cognitive impairment is severe and communication is reduced to corporate expression through gestures.
Communication difficulties: - Difficult finding the right words. - No initiative when speaking. - Slower response time. - Following a conversation. - Less precise language. - Impoverishment of expression	Communication difficulties: - Language perseverance. - Impoverished expression more apparent. - Difficulty naming daily things or objects. - Language production more impaired in general. - Repetition of words in simple descriptions. - Certain incoherence in language content. - Changes in the use of words; same word used in various contexts.	Communications difficulties: - Has lost the ability to speak; communication consists basically of sounds. - Language does not prevail, silence, a certain separation from the environment.
Techniques to facilitate communication: - Include the patient in the conversation. - Try to avoid them feeling left out. - Try to speak as slowly and clearly as possible. - Address the patient directly and concisely, avoiding superfluous words. - Look the patient in the eyes when speaking.	Techniques to facilitate communication: - Be patient and understanding. - Be patient when the person speaks and allow time for expression. - Use imagination to understand the patient. - Speak in a low voice. - Try to use very simple, short sentences. - Non-verbal language is extremely important: caressing, smiling… - Look the person in the eyes with a smile or show of affection. - Use closed or simple questions, if the patient is able to reply yes or no.	Techniques to facilitate communication: - The patient cannot speak to us, but has feelings; communication takes place basically through eye contact and physical contact. - Through behaviour we may observe that something is occurring and we must therefore pay a lot of attention to gestures. - We must stimulate the patient to communicate in other ways, touching or pointing at objects we speak about. - Address them using their name so as to orientate and attraction their attention. - Personal objects and photographs can summon emotions and feelings from the past. - Use tactile therapies or physical contact to transmit affection, security, trust, company, tenderness, kindness. - Use music to relax them and perhaps create an emotional connection.
Try not to speak quickly. Be aware that the patient is there and avoid certain topics, even if we think they are not listening. Avoid noisy atmospheres when speaking to the patient. Try not to overprotect; let the patient speak. Objectives must be realistic and achievable; complex objectives can cause frustration, which has the opposite effect. Allow them moments to relax and rest to avoid exhaustion in complex, difficult exercises. Avoid authoritarian communication or treating the patient like a child. Avoid statements of the "you should" kind. Avoid frustrating the patient with difficult questions. Try to help them to remember, but without lengthy interrogation.		

5.8. Mutual help groups

As explained in Chapter 2, mutual help groups are formed in the psychosocial area as a collaboration between the psychologist and the social worker. They may have a general purpose, for caregivers of a relative or other person with dementia, or they may be more specific, for spouses or children. In any event, the aim is for group members to support each other in a context of communication and exchange of experiences. This space can allow emotions to be discharged while experiences are shared and enriched with other people in similar situations.

The main objective of these groups is to create a meeting point where they may be accompanied so as to face the evolution of the disease in a better position.

This department defines the members of the help group. We contact them and invite them to become involved, explaining the activities, times and frequency of group sessions.

Sessions are structured by the psychosocial department, which establishes a schedule and specifies subject matter and activities. We also take into account flexibility and requests from members, adapting sessions to needs as they arise.

A good climate of communication must be created for experiences and emotions to be expressed. A number of basic communication guidelines must therefore be defined from the outset and proposed to the group members so that a consensus may be reached.

The following is proposed as an example:

1. The information discussed in the group must be confidential.
2. Respect when other members are speaking is essential, as is listening to all members without judgement or criticism.
3. Each contribution and experience allows us to learn from other people.
4. Each person and each individual situation is different and everybody's opinion must therefore be respected.

5.9. Support during the terminal phase and grief process

The purpose of the social worker function is to favour situations that improve the patient's quality of life and reduce suffering, and to support grieving families.

These are generally situations in which residents have lost their autonomy, usually in the final phase of the disease. This causes considerable emotional and physical weakness in the main caregiver and the family in general.

Intervention in the terminal phase and in the grief process is performed jointly by the social worker and the psychologist; their combined objective is to support and facilitate formalities for the family during these tough, difficult moments.

What is the Centre's social workers' approach to grief?
We may summarise our approach following the resident's death. After death has been medically certified, the family members are received in the Centre by the person responsible at that moment, who accompanies them, if they wish, to the room in which their relative's corpse lies.

During the period from the family's arrival and the transfer of the resident's corpse, psychological support is provided, seeking to cover any needs that may arise. We must allow family members to cry, since this favour the release of emotions and suffering. A hug may have a therapeutic effect:

Once they are with their relative, they are accompanied and supported as necessary. Rational viewpoints do not always facilitate recovery during the grief process, but we must be aware that significant relationships based on affection help us to process grief more healthily.

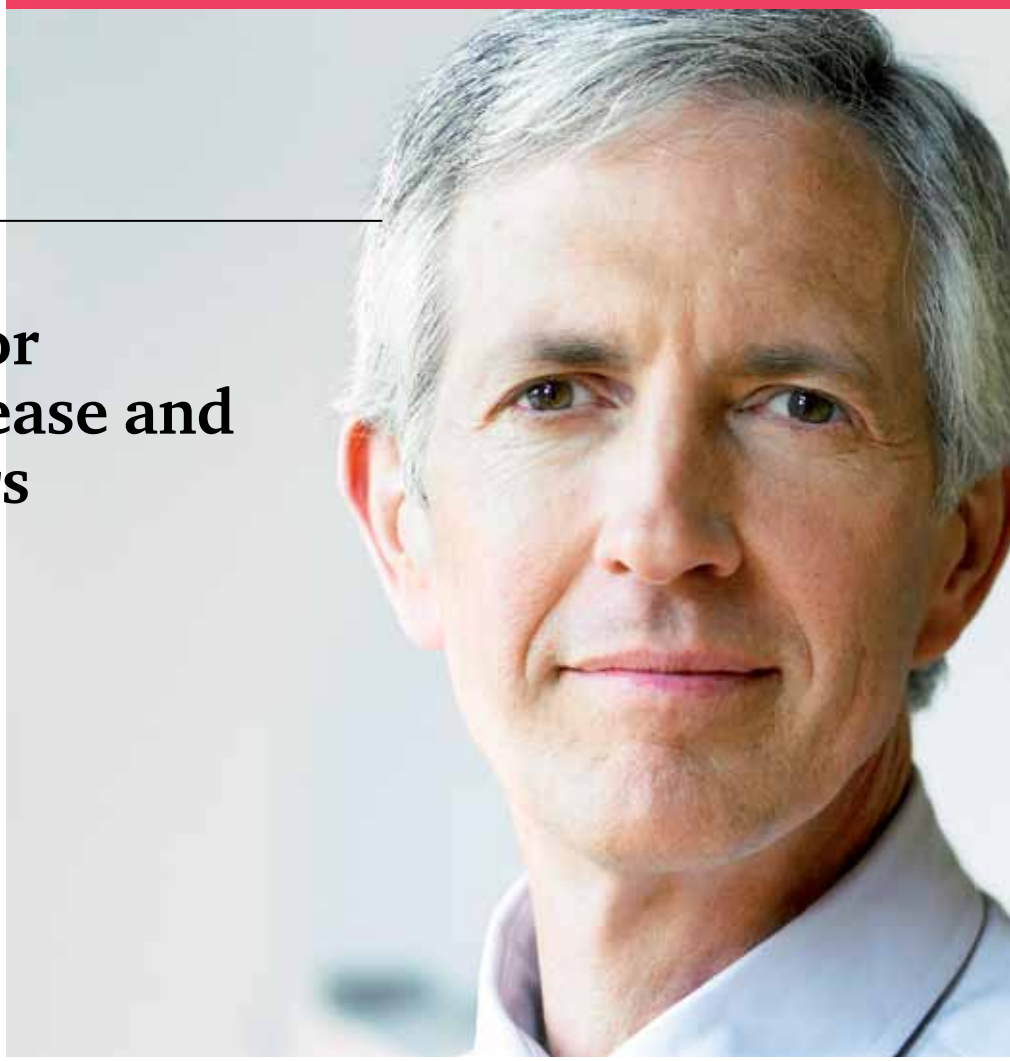
Following the initial moments when the emotional burden is heaviest, they are offered the possibility being alone with their relative, indicating that, when they are ready, the resident's corpse will be transferred.

When a person passes away, whether expected or otherwise, people tend to feel that what has occurred is not real. We must make the family members understand that this situation must be faced. When reactions in the grief preparation process are not entirely adaptive, the emotional discharge is facilitated and more specific information and advice are offered on grief period evolution and phases. A grief workshop could be organised in the mutual help group if necessary, in order to work on the grief process and help families to prepare for the emotions they will experience.

We may therefore apply a number of techniques to facilitate this process:

- Evocative language: we must be aware of the language we use with family members, since it is not the same to say "your father died" as "you lost your father". This type of language helps us to accept reality. It may also help to speak of the family member in the past tense.
- Use of symbols: they may bring photos of the deceased person, audiovisual recordings, clothing, objects…
- Write: have a place in which family members may express their thoughts and feelings in writing to help them to express things that that could not express at the time.
- Drawing: feelings and experiences may also be expressed in this way.
- Role playing: a way of helping people to develop skills.
- Cognitive restructuring: thoughts affect feelings. If the family member's thoughts are extracted and compared with reality, we may provide advice so that they become more objective.
- Book of memories: it is always useful to have a book narrating stories relating to the deceased person, photographs of trips, anecdotes, poems, fun situations during family parties...
- Guided imagination: the person may feel, imagine and talk to their loved one, i.e. talking to the person instead of speaking about the person.

Content



Capítulo 6
Research Unit for Alzheimer's disease and related disorders

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Ageing is a biological, psychological and social process resulting from the interaction of variables as different as heredity, environment and behaviour; it entails changes in physical and cognitive performance, particularly, in the latter case, a decline in the speed of information processing, memory deterioration (not long-term recognition) and impairment of some attentions tasks.

According to the World Health Organisation (WHO), the decrease in the birth rate, the reduction in mortality and the rise in life expectancy in developed countries will cause exponential growth in the number of people over 65 years of age and a parallel rise in age-related pathologies, including dementia.

Dementia is not a modern phenomenon, since it was know in the times of Hippocrates (400 BC), having been called different names (paranoia, idiocy, stupidity, senility….) throughout history.

The work dementia, as currently employed, derives from the Latin for "estranged" and "mind" (genitivo mentis), it is defined as the progressive loss of cognitive functions, i.e. memory,

attention, language, praxis, visuoconstructive skills and executive functions, such as problem resolution or response inhibition, among others. This cognitive loss entails a decline in autonomy to the detriment of social, labour and leisure activities of patients and their caregivers.

6.1. Current status

In general terms, dementia is estimated at between 5-10 cases per 1,000 people/year in the age group from 64 to 69, up to 40-60 cases per 1,000 people/year in the age group from 80 to 84 years of age. While prevalence is below 2% in the 65 to 69 age group, it doubles every five years to reach 10-17% in the 80-84 age group and 30% in the above-90 age group. In Spain, prevalence in people aged over 65 is between 5.5 and 16.3%, standing at 22% in men over 85 and 30% in women over 85.

Table 6. Prevalence of dementia by age group; cases per 1,000 people/year.

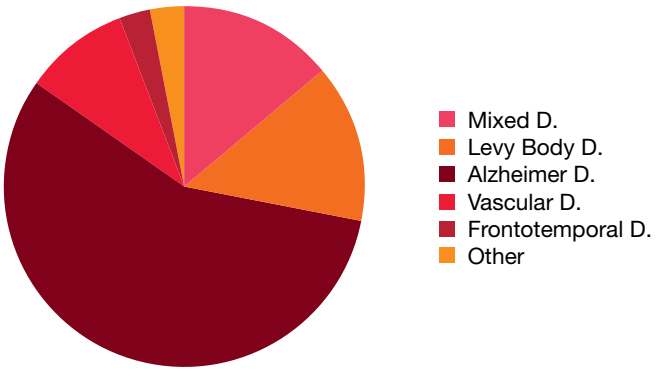
Age	Meta-analysis of nine European studies	Alterations of thinking in adults	MRC CFAS
65-69	9.1	5.4	9.3
70-74	17.6	9.7	14.1
75-79	33.3	13.5	23.7
80-84	59.9	38	43.3
85-89	104.1	58.6	91.3
90-94	179.8	89.4	-

MRC CFAS: *Medical Research Council Cognitive Function and Ageing Study* (estudio sobre función cognitiva y envejecimiento del Consejo de Investigación Médica).

As regards gender, women aged older than 55 have twice the risk of suffering dementia, due both to their life expectancy and the increased prevalence of dementia in the most elderly people.

If we consider the different causes of dementia, Alzheimer's disease (AD) is by far the most frequent (60-80% of cases), followed by dementia caused by a mix of vascular pathology and Alzheimer's, and then by vascular dementia (20-30% of the total); less prevalent dementia include Lewy Body and dementia associated with Parkinson's disease, frontotemporal dementia and secondary dementia. However, if we refer only to young patients (<65 years of age), frontotemporal dementia is more relevant; if we focus only on Parkinson's patients, dementia (after 10 years of evolution of the disease) may reach 75%.

Figure 1. Etiology of dementia.



Modified from *Green R. Diagnosis and Management of Alzheimer's Disease and other Dementias. Second Edition. Professional Communications, Inc. 2005.*

However, the progressive ageing of the population points to an increase in dementia worldwide. For example, in Spain it is estimated that by 2050 one in three people will be over 65 years of age and nearly one million people will have dementia. The WHO has already pointed out the possible consequences of this fact and has encouraged governments to take measures to reduce the socio-health impact of this devastating pathology.

Table 7. Population data for people aged over 65 and dementia patients.

	Total population	Aged over 65	Dementia patients
2001	41,116,842	6,796,936	407,816
2004	43,197,684	7,184,921	413,000
2030*	50,878,142	9,900,000	494,460
2050*	53,159,991	16,387,874	983,272

* Estimated for 2030 and 2050.
Source: INE (National Institute of Statistics).

By definition, dementia entails the deterioration of a person's functionality, resulting in a prolonged period of disability and dependency. According to the "Survey of Disability, Personal Autonomy and Dependency Situations" prepared in 2008, the rate of disability due to dementia stands at 90/1,000 inhabitants in Spain, which is in fifth place (more than 330,000 people) in terms of frequency of diagnosis following articular pathology, depression, cataracts and ischemic cardiopathy.

Beyond all other considerations (morbi-mortality, healthcare resources, provision of means), dementia is now one of the main causes of institutionalisation in comparable countries, affecting up to 90% of patients, as compared with 50% of the general population, entailing a 10.5% institutionalisation rate.

Figure 2. Relative risk (RR) of institutionalisation in dementia, as compared with controls.

Although dementia does not have direct consequences for the patient's working life, due to the age group affected, it does affect caregivers in this way. It is estimated that the productivity of 54.5% of caregivers (according to National Institute of Statistics data) is considerably reduced for this reason.

An Alzheimer's patient is estimated to need around 70 hours' care per week, including basic needs, medication control, hygiene and handling of symptoms and conflict situation; in most cases (80%), the caregivers are family members. In general, one family member takes on the most responsibility and devotes the most time to this task, a person that we refer to as the "main caregiver". As the disease advances, pressure on the caregiver increases and the so-called "caregiver overload" appears. Caring for dementia patients causes a higher level of stress than with other chronic diseases that generate disability and carer overload is estimated to affect over 75% of carers (83-84).

Table 8. Sociodemographic characteristics of the main caregiver (83).

Age	>=55 years of age >55 years of age	65% 33%
Gender	Women Man	67% 33%
Relationship	Spouse Child Other family member	47% 37% 16%
Cohabitation with the patient	Yes No	65% 35%

It is thus very important, and a social duty, to improve care for dementia patients so as to also enhance quality of life for them and their caregivers; support for caregivers is vital to prevent and treat social isolation and improve information on the disease and handling of patients.

As regards costs for society, AD is ranked third in developed countries, behind cancer and heart disease. The factors that most affect the huge expense caused by dementia are associated medical conditions (co-morbidity), neuropsychiatric issues and extra-pyramidal signs. But the variable that most affects cost is clearly the number of hours devoted to direct care or supervision of basic and instrumental activities of daily living. In over 80% of cases, AD patients are cared for by their families, which bear 87% of total expenditure (remaining 13% comes out of public funds); care costs account for 52% of total expenditure.

Tabla 9. Costes económicos.

Gastos directos	Gastos indirectos
Tratamientos.	Tiempo de cuidador informal. Salario de sustitución. Costes de oportunidad. Tiempo de ocio.
Consultas externas. Hospital y Urgencias. Centros de Día.	
Asistencia domiciliaria profesional.	
Aspectos técnicos: Remodelación del hogar.	
Convivencia con el enfermo.	

Improving information provided to the general public on the disease and building awareness in healthcare authorities of the benefits of early diagnosis are therefore priority tasks in order to ensure that general practitioners have better resources and training and specific dementia diagnosis and treatment units are created. A one-year delay in the appearance of AD due to preventive activities is calculated to reduce the number of patients worldwide by 12 million in 2050.

6.2. Clinical considerations

1. Definition

Dementia is a chronic clinical syndrome (though not necessarily irreversible) which causes disorders in cognitive functions and the alteration of the person's functional capabilities, interfering with social and labour activities (Figure 3).

Table 10. Dementia syndrome.

Cognitive alterations	Autonomy alterations	Behaviour alterations
Memory. Praxis. Language. Attention. Gnosis (recognition). Visuoconstructive functions. Executive functions.	Advanced activities of daily living. Instrumental activities of daily living. Basic activities of daily living.	Affective aspects. Thought. Perception. Behaviour. Personality.

Prior to the dementia, there is a phase of cognitive impairment detectable through neuropsychological tests which affects few cognitive domains (aspects) and does not alter the activities of daily living (no functional repercussions). This phase is referred to as "mild cognitive impairment" or "mild" (MCI) and is important because it allows the identification of individuals who do not yet have the dementia but have a high risk of developing it.

Due to its variety, a number of "mild cognitive impairment" sub-types have been proposed, based on the domains or areas affected:

- Amnestic: where memory impairment predominates.
- Multi-domain amnestic: in addition to memory alteration, there is evidence that other cognitive functions are affected such as attention, language, visuospatial skills and executive functions.
- Single-domain non-amnestic: any cognitive domain other than memory is affected.
- Multi-domain non-amnestic: more than one domain is affected but not memory.

It is currently difficult to precisely determine the limits between MCI and incipient dementia, but there are criteria; an example of this are the Mayo Clinic's criteria for amnestic MCI and the criteria employed by the Spanish Neurology Society.

2. Etiology

Many pathological processes are identifiable with dementia and there are numerous classifications, but perhaps the simplest and most commonly used is the classification of primary and secondary processes:

2.1. Primary degenerative dementia

- Alzheimer's disease.
- Lewy Body dementia.
- Frontotemporal dementia.
- Huntington's disease.
- Progressive supranuclear paralysis.
- Focal cerebral degeneration.
- Corticobasal degeneration.
- Parkinson's disease.

2.2. Secondary dementia

- Vascular dementia: ischemic, ischemic-hypoxic, hemorrhagic…
- Dementia related to neoplasia: primary brain tumours, metastatic brain tumours, paraneoplastic syndromes, meningeal carcinomatosis …
- Dementia with alteration of CSF: normal pressure hydrocephalus. Other chronic hydrocephalus.
- Dementia of infectious origin: tubercular meningoencephalitis, neurosyphilis, AIDS dementia complex, progressive multifocal leucoencephalopathy …
- Prion dementia: CJD.
- Dementia of endocrino-metabolic origin: chronic hypoglycemia, hiccups/ hyperthyroidism, Addison's disease, Cushing's syndrome, Wilson's disease, hepatic and uremic encephalopathy…
- Dementia related to innate metabolic errors: leucodystrophy, deposit diseases, mitochondrial encephalopathy…
- Dementia due to deficiencies: vitamin B12, folic acid, niacin, thiamin deficiencies…
- Dementia of toxic-medicinal origin: alcoholic dementia, heavy metal intoxication, lithium, methotrexate…
- Dementia due to vasculitis or collagen diseases.
- Dementia in psychiatric diseases.

2.3. Combined dementia

As with MCI, there are certain criteria for diagnosing dementia. The most commonly used criteria are contained in the WHO's International Classification of Diseases (ICD-10), in version four of the American Psychiatric Association's "Diagnostic and Statistical Manual" (DSM-IV), and the criteria employed by the Spanish Neurology Society.

A detailed analysis of these diagnostic criteria reveals three spheres: cognitive, behavioural and functions.

3. Diagnosis

A patient showing memory loss undergoes a systematic clinical evaluation comprising:

1. A quality **clinical history**; it is very important to contact a reliable source for the information. The clinical history must include the following data, *inter alia:*

- **Initial clinical manifestations**
  - Alteration of memory for recent events.
  - Inability to learn new tasks.
  - Personality changes.
  - Executive capacity difficulties.
- **Individual factors**
  - Cultural and educational level.
  - Socio-environmental and occupational circumstances.
  - Pre-morbid personality.
- **Family factors**
  - Family risk factors: vascular risk factors…
  - Genetic factors.
- **Temporal evolution**
  - Initial form: acute, sub-acute or gradual.
  - Evolution: see *Concurrent neurological or systematic diseases*.
  - Ischemic cerebrovascular accidents, crises, syncope…
  - Cardiopathy.
  - Endocrinopathy.
  - Sleep alteration.

2. A general physical exploration to detect alterations (causing, concomitant or aggravating) arising from the dementia, and a neurological exploration to rule out motor deficits, pathological reflexes, extra-pyramidal alterations or walking alterations. An adequate, thorough physical exploration provides reliable data that help in the syndromic and etiological diagnoses.

3. A correctly structured **neuropsychological evaluation** including the patient's level of attention and concentration, time-space orientation, spoken word recall memory, verbal fluency using a list of animals, fruit …, calculation, constructive praxis (copying a drawing), manual praxis (imitating manual movements), ideomotor praxis (performing simple tasks) and alternating motor and graphic sequences (frontal lobe evaluation).

The tests most widely used are Folstein's Mini Mental State Examination (MMSE) and Lobo's *Mini Examen Cognoscitivo* (MEC, Spanish adaptation of the MMSE), Pfeiffer's SPMSQ, the 7-Minute Screen, Buschke's Memory Impairment Screen (MIS) and the Clock Drawing Test. The patient's affective status must also be verified (in patient's over 55 years of age, Yesavage's Geriatric Depression Scale is useful), as must the presence or absence of behavioural alterations.

4. An **evaluation of functional capacity** to determine whether the patient's cognitive impairment affects the activities of daily living: handling their own money, taking medication, using public transport, administering bank accounts, using the telephone… (always based on knowledge of the patient's educational level and home environment). Scales used include the IQCODE or Informant Questionnaire, Pfeiffer's FAQ, the Lawton and Brody Index (instrumental activities of daily living), Barthel Index and Katz Index (basic activities of daily living).

Anamnesis and the neuropsychological exploration require a syndromic diagnosis and the set of complementary tests (laboratory and neuroimaging) require an etiological and differential diagnosis.

Alzheimer's disease

In developed countries, Alzheimer's disease (AD) is by far the most frequent cause of dementia (60-80% of cases), followed by dementia caused by a mix of vascular pathology and Alzheimer's, and then by vascular dementia (20-30% of the total); less prevalent dementia

include Lewy Body and dementia associated with Parkinson's disease, frontotemporal dementia and secondary dementia.

AD is a degenerative, progressive anatomoclinical entity. It is characterised clinically by causing dementia and morphologically by the presence of neurofibrillary degeneration or tangles and neuritic or senile plaques. Although it may be hereditary on occasions, due to gene mutation, in most cases it is sporadic, relating to various risk factors, particularly age.

There are different clinical phases:

- Asymptomatic pre-dementia phase, when only neuropathological alterations may be found.
- Symptomatic pre-dementia phase, reflected by memory loss without dementia. Many of these patients are included in the "mild cognitive impairment" diagnosis category.
- Dementia phase, which comprises three states: mild, moderate and severe; this entails cognitive and behavioural alterations, and loss of autonomy, to a greater or lesser extent.

The clinical evolution of AD is progressive and prolonged; death occurs due to systemic complications.

The in vivo diagnosis of AD is based on probability, except on rare occasions in which there is evidence of mutation in patients with hereditary forms. The sensitivity of clinical diagnostic criteria commonly used is relatively high (averaging around 80%), but specificity is low (around 70%). The most widespread diagnostic criteria are those of the National Institute of Neurological and Communicative Disorders and Stroke and the Alzheimer's Disease and Related Disorders Association [NINCDS-ADRA] (Dubois, B. and colls., 2007), the diagnostic criteria for Alzheimer-type dementia in version four of the American Psychiatric Association's "Diagnostic and Statistical Manual" (DSM-IV) and the new criteria of the National Institute on Aging/Alzheimer's Association [NIA/AA] (McKhann, G. M. and colls.,. 2011). However, certainty diagnosis is still based on evidence of characteristic neuropathological damage.

The therapeutic aims consist of improving the cognitive and functional aspects of the disease, although certain behavioural symptoms are possibly also changed; specific symptomatic drugs include acetylcholinesterase inhibitors (donepezil, rivastigmine and galantamine), which increase the altered cerebral cholinergic transmission, and non-competitive antagonists of the n-methyl-d-aspartate receptors (memantine), which increase following the blocking of the hyperactivity of the receptors that contribute to the appearance of symptoms and AD progression. Psychotropic drugs, sleep inducers, etc. are also necessary at times.

Family members or caregivers must also be informed of the nature of the disease, evolution, type of clinical manifestations that may be observed, positive and adverse effects of treatments, current legislation on dependency, support centres in their vicinity and/or guidelines to be followed in the final moments of the patient's life.

Table 11. Symptomatic therapy.

Preparation	Presentation	Guidelines
Donepezil.	Pills 5 and 10 mg.	Initial dosage 5 mg/24 h (night dosage). Maintenance dosage 10 mg/24 h.
Rivastigmine.	Pills 1.5; 3; 4.5 and 6 mg Oral solution 2mg/ml Transdermal patch 4.6 mg and 9.5 mg.	Oral therapy: initial dosage 1.5 mg/12 h. Increase by 1.5 mg every month. Maintenance dosage 4,5-6 mg. Transdermal therapy: initial dosage 4.6 mg. After one month, 9.5 mg.
Galantamine.	Delayed-release capsules 8, 16, 24 mg.	Initial dosage 8 mg/24 h (morning dosage). Maintenance dosage 16-24 mg/h.
Memantine.	Pills 20 mg Oral solution 1 mg/ml.	Initial dosage 5-10-15 mg/24 h (progression). Maintenance dosage 20 mg/24 h.

6.3. Current research into Alzheimer's disease and related diseases

Brief description	Bibliographic references
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Role of the TAU protein in neurodegeneration and synaptic dysfunction.	- Hoover, B. R. and colls.: *"TAU mislocalization to dendritic spines mediates synaptic dysfunction independently of neurodegeneration".* Neuron. 2010; 68: 1067- 1681. - Vossel, K. A. and colls.: *"TAU reduction prevents Abeta-induced defects in axonal transport"*. Science 2010; 330 (6001): 198.
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Clinical-pathological correlation of dementia in longitudinal studies. These are studies in which follow-up clinical and neuropsychological information on patients is available, as well as on postmortem neuropathological studies of the brain, providing epidemiological information on the prevalence of the pathologies observed so as to establish consensus criteria for clinical, neuropathological and neuroimaging diagnosis. This also allows the phenotypic variability of a disease such as Alzheimer's to be observed.	- Nelson, P. T. and colls.: *"Neuropathology and cognitive impairment in Alzheimer Disease: A complex but coherent relationship"*. J. Neuropathol. Exp. Neurol. 2009; 68: 1-14.
Neuropathological findings in the initial phases of neurodegenerative dementia. This is one of the main research lines addressed in longitudinal studies. It is highly important for the development of biomarkers applicable to the initial phases of diseases, including preclinical phases, and to obtain insight into the pathogen, i.e. processes that intervene in the first damage that may be observed in brain tissue.	- Sonnen, J. A. and colls.: *"Ecology of the Aging human brain"*. Arch. Neurol. 2011; 68: 1049- 1056.
Molecular basis of neurodegenerative diseases. In Alzheimer's, Parkinson's, Huntington's, etc. the core phenomenon observed in brain tissue is the deposit of anomalous proteins. Progress in knowledge of the pathological modifications of these proteins is a permanent source of new pathogen knowledge and of new therapeutic lines.	- Dickson, D. W.: *"Neuropathology of non-Alzheimer degenerative disorders"*. Int. J. Clin. Exp. Pathol. 2010; 3: 1-23. - Querfurth, H. W. and LaFerla, F. M.: *"Alzheimer's disease"*. New Eng. J. Med. 2010; 362: 329-44.

Genetic risk factors in degenerative dementia. The availability of biological samples (blood, brain tissue) and of a definitive diagnosis such as that provided by a brain bank, allow large cooperative studies to be undertaken to identify new genetic risk factors in the development of degenerative dementia.	- Rademakers, R. and Rovelet-Lecrux, A.: *"Recent insights into the molecular genetics of dementia"*. Trends. Neurosc. 2009; 32: 451-461.
Study on new phenotypes and new pathological entities associated with dementia. In recent year, huge progress have been made in the knowledge of degenerative dementia, the molecular basis of which was unknown, particularly in frontotemporal dementia. New pathologies and new proteins associated with these diseases are still being detected.	- Mackenzie, IRA. and colls.: *"Nomenclature for neuropathologic subtypes of frontotemporal lobar degeneration: consensus recommendations"*. Neuropathol. Doc. 2009; 117: 15-18.

6.4. Research Unit projects in progress at the Reina Sofia Foundation's Alzheimer Centre

Title	Brief explanation
Vallecas project on the early detection of Alzheimer's disease.	1,200 healthy people aged between 70 and 85 years of age will be studied. These volunteers will be subjected to a clinical, biochemical and neuroimaging protocol (cranial magnetic resonance), once a year over a five-year period. The objective is to find early markers or risk factor combinations for Alzheimer's disease.
Development of a clinical and social protocol for the evaluation of advanced dementia.	Selection and evaluation of measurements related to cognition, activities of daily living, affectivity, behaviour, motor skills ands quality of life. The aim is to determine biological and medical correlations for the manifestations of dementia, measure the effect of interventions and, if possible, harmonise measurements used by centres.
Correlations between structural neuroimaging and the functional and motor state of patients with advanced Alzheimer's.	Volumetric study using cranial magnetic resonance to determine which brain regions are involved in the loss of functional and motor skills in moderate or severe Alzheimer's.
Study of gait in cognitive deterioration and dementia.	Development and application of a scale to evaluate gait and mobility in cognitive deterioration and dementia. Analysis of clinical and structural correlations (using cranial magnetic resonance) of the loss of gait in Alzheimer's disease.
Apathy and dementia.	Development of a scale to evaluate apathy in all phases of dementia. Study of clinical and structural correlations (using cranial magnetic resonance) of apathy.

Robotherapy in dementia.	Controlled clinical trial applying two types of social robots in order to evaluate their potential benefits for behaviour and in other relevant clinical areas for people with dementia who visit the Day Centre or live in the residence. In association with the Universidad Rey Juan Carlos' Robotics Laboratory.
Quality of life and dementia.	Descriptive and comparative study of quality of life and correlations in different population groups (people in community, institutionalised people without dementia and institutionalised people with dementia, inter alia).
A controlled study of REAC to improve gait and mobility in advanced AD.	Clinical trial on the effect of the administration of weak radioelectric asymmetric conveyer (REAC) pulses on general mobility and gait in Alzheimer's patients.
Neuropsychiatric alterations in Parkinson's disease.	National study (fieldwork performed in 2010-2011) to develop and validate a scale for evaluating neuropsychiatric disorders in Parkinson's disease. During 2012, the exploitation of data and dissemination of results is continuing.
Non-Motor Symptoms Longitudinal International Study (NILS).	Long-term international longitudinal study led by Prof. K. Ray Chaudhuri (King's College Hospital and University, London UK) and the Science Director of the Centre's Research Unit, in its second year. The study is deemed to be relevant in England and currently forms part of the National Health System's official portfolio.
Analysis of buccal health, mastication and quality of the buccal cavity in patients with neurodegenerative diseases: Alzheimer' and Parkinson's.	Descriptive study of buccal health, mastication and buccal cavity quality by a mixed group of stomatologists from Salamanca University and UIPA researchers. Differences between subjects will be analysed and studies and controls will be conducted for future buccal healthcare activities.
Activation of the calpain/GSK-3/CDK-5 route in Alzheimer's disease.	The GSK3beta kinase has been involved in TAU protein hyperphosphorylation and the formation of neurofibrillary tangles, one of the fundamental features of Alzheimer's pathology. This project studies the regulation of GSK3 activity through processing by the calpain enzyme.
Genes related to TAU protein phosphorylation and their influence on the risk of sporadically developing Alzheimer's.	Various kinases and phosphatases contribute towards TAU protein phosphorylation balance. TAU hyperphosphorylation makes the protein lose its normal function as a microtubule stabiliser and acquire aberrant properties, forming neurofibrillary tangles characteristic of AD pathology. This study analyses different genes related to TAU protein phosphorylation and dephosphorylation as potential genetic risk markers.

Biomarker based diagnosis of rapid progressive dementias-optimisation of diagnostic protocols (DemTest).	This aim of this European project is to harmonise protocols for data collection, biological samples and analytical biomarker methods for the diagnosis of various rapid progressive dementia, including prion diseases in humans and atypical Alzheimer's cases.
Innovative solutions to accelerate identification and the development of drugs for Nervous System pathologies.	Development of new diagnosis methods and search for potential therapeutic targets, based on a study of altered routes in Parkinson's disease and amyotrophic lateral sclerosis through a combination of genetic markers, peptides and metabolites.
Identification of blood markers for the multiparametric diagnosis of Alzheimer's.	Development of diagnostic algorithms based on a combination of genetic markers, peptides and metabolites.
Study on common and differential genetic bases for different neurodegenerative processes.	Study on various genetic risk factors for Alzheimer's disease and other neurodegenerative diseases such as Creutzfeldt-Jakob, amyotrophic lateral sclerosis and Parkinson's.
VIBRA project for the identification of blood biomarkers through vibrational spectroscopy (Raman Laser and FTIR).	Analysis of the potential diagnostic value of infrared spectroscopy on peripheral lymphocytes and plasma in AD patients.
VIBRA project for the identification of blood biomarkers through vibrational spectroscopy (Raman Laser and FTIR).	Collaborative project to establish consistent protocols in different Spanish clinical centres for neuroimaging studies, sampling and analysis of biomarkers in Alzheimer's disease.
Vascular dysfunction associated with age in Alzheimer's disease.	The general objective of this project is to characterise the peripheral vascular dysfunction associated with senile Alzheimer's disease (AD) and study how this is modified as the disease progresses and its interaction with age, as follows: a) Determine plasmatic levels of vascular pathology markers, lipid metabolism and chronic inflammation to identify subgroups of patients with specific endophenotypes; and b) Characterise genetic risk associated with the disease and related to lipid metabolism and immune response.
Neuroimaging biomarkers in neurodegenerative diseases.	Study of quantitative biomarkers for neurodegenerative disease monitoring and early diagnosis.
Relationship between olfactory functioning, cognitive decline and neurological disease.	Study on the relationship between olfactory loss and neurodegenerative and neurological diseases.
Detection of iron deposits in the brain and their effect on neurodegenerative and neurological diseases.	Improvement of magnetic resonance acquisition techniques for the detection of iron deposits and observance of their effect on neuroimaging biomarkers and on the evolution of the pathology.

Relationship between essential tremor and neurodegenerative disease.	Some forms of tremor are associated with neurodegeneration processes. Possible motor involvement: study using functional MR while active and resting (Resting-State fMRI).
Hypoperfusion and neurodegeneration	Study on the relationship between perfusion deficits and dementia using the Arterial Spin Labeling (ASL) technique for the evaluation of perfusion without contrast.
Functional and structural cerebral connectivity in neurodegenerative and neurological diseases.	Development of MR techniques to evaluate functional and structural connectivity through diffusion tensor sequences and functional resting-state MR.
High-field neuroimaging study for the detection of the channels involved in tremor genesis as a pathogenic model for different neurodegenerative diseases.	Study using MEG and resting-state RMf to evaluate connectivity and see possible alterations in neurodegenerative diseases.
Study on the effect of various active ingredients in dairy products on cognitive health of elderly persons.	Forms part of a CENIT project. Possible DTI changes following the inclusion of active ingredients in enriched milk.
Dopamine-Dopaminergic modulation for the inclusion of rules in populations showing psychotic episodes or risk of developing bipolar disease or schizophrenia.	Possible relationship between imaging markers and cognitive processes in schizophrenic controls and patients.
Optimise. “Optimation of treatment and management of Zchizophrenia in Europe.”	This study has two objectives: optimise current treatments and explore new treatments for schizophrenia. The study is expected to provide information for the preparation of treatment guides based on evidence and the development of new therapeutic channels.
Wyeth trial: “Phase-3, multicentre, randomised, double-blind, placebo-controlled, parallel group trial on the effects and security of Bapineuzumab (AAB-001, ELN115727) in subjects with mild-to-moderate Alzheimer’s who are carriers of the EE apolipoprotein”.	Multicentre clinical trial.
Lilly trial: “Eli lilly H8A-MC-LZAN”. Effect of passive immunisation on the evolution of Alzheimer’s disease: LY2062430 vis-à-vis placebo.	Multicentre clinical trial.
Clozapine in the first outbreaks of schizophrenia as a possible preventive treatment for cerebral and clinical impairment.	Multicentre clinical trial.
Development of nanomagnetic markers for the early diagnosis and analysis of the progression of Alzheimer’s using magnetic resonance imaging techniques. Biomedical Technology Centre (CTB)/ETSIT-GBT.	Development of imaging markers related to the level of cognitive impairment.

Anatomical, functional and effective connectivity for the early diagnosis of Alzheimer's: contribution of the diffusion tensor in a multidisciplinary approach (PSI2009-14415-C03-03).	Study of subjects with MCI using MEG and DTI. Evaluation of connectivity changes to try to identify an early AD marker.
Cerebral dynamics of cognitive and affective processing in patients with fibromyalgia. Balearic Islands University.	Identification of imaging markers related to cognitive and affective changes detected through neuropsychological tests.
Compensation factors of cognitive ageing: The role of computer technology and physical activity - A behavioral and neuroimaging study of successful ageing.	Imaging study of factors related to cognitive reserve.
Frontoparietal network and change in cognitive performance.	Evaluation of structural and functional changes related to intensive training.
Neuropathological and molecular phenotype of sporadic and genetic tauopathies.	Continuation of the Project "Characterisation of TAU protein polymers in Alzheimer's disease: comparison with those found in other tauopathies. Characterisation of gene expression in the entorhinal cortex". Neuropathological and molecular characterisation (Western blot for TAU, isolation and ultrastructural study of PHF fibres) is performed on all cases of tauopathy (sporadic or genetic) studied in Fundación CIEN (BT-CIEN)'s Tissue Bank. In association with Prof. Jesús Ávila (CBM, CSIC, CIBERNED)'s group.
Hippocampal sclerosis: neuropathological characteristics and associated pathogenic factors.	Based on the work presented at the Alzheimer's Symposium 2011 ("Morphological patterns in hippocampal sclerosis"), a number of cases are being studied of neurodegenerative dementia with hippocampal sclerosis in order to characterise the damage, bilaterally, in terms of neuronal populations involved and specific neuropathological changes.
Neuropathology of dementia in very old patients ("oldestold"): estudio 85+CIEN.	A retrospective review of brains donated to the Tissue Bank (including the BTIN's historical file, located at H. U. Fundación Alcorcón), aged over >85 years on death, to systematically analyse neuropathological findings associated with the various pathologies (Alzheimer, vascular, Lewy, etc.), in comparison with younger age groups.
Clinical-pathological correlation of vascular pathology in dementia cases at the Reina Sofia Foundation's Alzheimer Centre (CAFRS).	Systematic evaluation of vascular pathology in brain tissue donated to the CAFRS, in accordance with a system recently published by an international consortium, in order to evaluate this pathology's contribution to patients' clinical state.

Advanced microscopy using nanoaggregate in Alzheimer's disease.	International project (involving German, French and Spanish groups) requested from the ERANET-NEURON project, short-listed in the first evaluation phase. The objective is to apply the most advanced microscopy techniques to Alzheimer disease samples (tissue, CSF, etc.) in order to detect nanoaggregates, for pathogenic and diagnostic research purposes.
SUR-8/Shoc2 expression in normal brain tissue and in Alzheimer's disease.	Collaboration in the project on SUR-8 expression in transgenic models and in human tissue. The protein plays an important role in neurogenesis signalling. Preliminary studies have already been performed on the hippocampus, with promising results.
Choroid plexus in Alzheimer's disease.	Collaboration in a project the main purpose of which is to explore the neuroprotective potential of the epithelial cells of choroid plexus as a regenerative therapy for Alzheimer's disease.
Search for a natural animal model for brain ageing and associated neuropathology.	Collaboration with Zaragoza University's Veterinary Department, Instituto Cajal, CSIC, Madrid Zoo and Faunia to create an animal brain tissue archive for various long-living species. The purpose is to perform a comparative study of pathologies associated with brain ageing, mainly tauopathies and Alzheimer-type pathology in different species.

Content

Capítulo 7
Conclusions

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After having reviewed professional intervention in a care centre for people with neurodegenerative dementia, there are certain matters that we feel should be addressed because they also directly or indirectly affect intervention.

7.1. Follow-up of treatment

Once the initial ICP has been prepared and personalised treatment has commenced, objectives are reviewed periodically. This entails repeating each of the evaluations applied at the start in order to identify improvement, decline or stability in the patient's cognitive, physical, social , mood and functional state. In this way, we know which objectives have been fulfilled and which must be reformulated.

As explained previously, the ICP review should be conducted approximately every six months and all the team should meet to obtain an overview of the

user's evolution, so that all members may participate actively in decision-taking. During the period between ICP reviews, informal meetings may be held to address incidents as they arise. Communication between members of the interdisciplinary team will be required, as will active contacts with the patient's family and direct caregivers to allow them to transmit any issues and difficulties that may arise in daily activities.

7.2. Importance of active training

In addition to training related to families of residents and users, a care centre for people with dementia must include among its functions refresher courses and new training for personnel, particularly direct caregivers.

Due to intense development in neurosciences and progress in knowledge of related pathologies, guidelines for activities and patient care are expanding continuously. It is therefore essential for a dementia

professional to gain up-to-date, documented theoretical and practical knowledge.

Access to specialised training is generally simpler for technical team members than for direct caregivers such as geriatric nursing assistants or auxiliary staff. Team members must therefore transmit the information and knowledge to other team members; training courses may be developed to enhance skills based on new specific Alzheimer care models. Aspects such as handling all behavioural symptoms, understanding cognitive deficits and their relationship with patient communication, and new non-pharmacological treatments and therapies are matters on which the technical team members may advice the rest of the team and which may be useful in the direct caregivers' daily activities.

As indicated in Chapter 5, "Intervention from the social work area", training and guidance for family members of people with dementia is extremely important.

Two main types of training may be identified based on the needs and availability of family members. Some people require shorter training because they have less time available, while others request more comprehensive, precise theoretical and practical training, which is provided by the different work areas (social, cognitive, functional and physical). Requests may be made by family members or a need may be identified by the professionals.

Training may also be individual and more personalised, provided the professionals consider this to be the best alternative. Group training brings the added benefits of peer work (families, in this case) in mutual help groups.

Finally, quality training and information for family members is important, since it will ensure improved handling of situations from all possible viewpoints.

7.3. Benefits of non-pharmacological therapies

As reflected in the systematic review performed by J. Olazarán and colleagues (2010), it has been demonstrated that non-pharmacological therapies, used in combination with drugs and other care, are effective when treating dementia. Some of the benefits that may be achieved applying the therapies described in this guide are the maintenance of the patient's cognitive, physical and functional state, the delay in the progress of the disease and a reduction in the level of apathy. It would be ideal to begin stimulation in the mild phase of the disease, or even before the initial symptoms appear, when scientific advances permit it. The benefits would be even greater. Finally, this type of intervention allows us to work comprehensively with some demential symptoms without recurring to drugs, which can also reduce treatment costs.

7.4. Bioethics in caring for people with dementia

Bioethics is the discipline that studies problems and issues which arise when there are conflicts between values in healthcare, in life care, in resource distribution and in biomedical research.

On occasions, when dealing with dementia, certain ethical conflicts raised are difficult to resolve, such as the use or non-use of belts or straps in certain cases; how to respect the patient's intimacy; restriction by a worker of the patient's decision-taking capacity; whether or not the decision must be taken to use nasogastric catheters; taking a person to hospital against their will or where the person is in a very serious state or is very old; etc.

Nearly all ethical theories and systems include principles for decision-taking and moral deliberation. These principles are action guidelines or illustrative criteria for good personal conduct and correct professional practice.

Bioethics comprises four fundamental principles that must be observed:

1. Principle of nonmaleficence: respect the physical and psychological integrity of human life and not do anything to harm the patient. Intentional harm, mistreatment, inadequate food, malpractice in care giving, failing to avoid harm caused by others, etc. are practices that clearly contravene this principle.

2. Principle of beneficence: encompasses all people whose work or profession involves caring for the elderly. The codes of ethics of these professions establish their raison d'être: do good to others through their profession. It is not sufficient to be a good person or to have good will; they must be adequately trained in attitudes and abilities for listening, empathy, non-verbal communication, etc. This is linked to the principle of autonomy, since we may wish to impose our own idea of good on the other person, without their consent, obliging them. It is thus necessary to consider what patients consider good for themselves, based on their values and wishes.

3. Principle of autonomy: professionals are required to respect the personal values and options of each individual in basic decisions affecting that individual. Issues are raised in relation to elderly people with some degree of cognitive impairment that makes it difficult for them to exercise the right to understand and decide, but it is important to maintain the presumption that, in principle, all elderly people are perfectly capable of taking their own decisions. This is relates to respect for the resident's intimacy and living will, among other matters.

4. Principle of justice: all people must be treated equally, without discrimination on the basis of social factors, age, sex, disease, etc. We are also subject to the duty of distributing resources and access to them equally, protecting the most needy.

These principles affect all issues raised and it may be difficult to take a decision that fulfils all four principles.

Should we need to choose between the principles of nonmaleficence and justice or observe the principles of autonomy and beneficence, the principles of nonmaleficence and justice will prevail, although the first two principles relate to the so-called minimal ethics, while the other two relate to maximal ethics.

All the recommendations made in the preceding chapters are basic, general guidelines for professionals working in care centres. In this case, we have explained in depth the characteristics, evolution and intervention at the cognitive, functional, physical, affective-behavioural and social levels for people with Alzheimer's disease. But we wish to point out that the intervention and follow-up models can be adapted to the specific context of the place in which we work. They may be modified based on the characteristics and the resources available; as dementia professionals, we must be flexible in terms of resources and work methods, without ever forgetting that our objective is to improve and maintain quality of life for our users.

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