Project "Ring – TransferRING Supports for Caregivers"
(LLP-LDV-TOI-09-IT-0446)
www.comune.torino.it/pass/ring

Promotor: City of Turin – Social Services and Relations with Health Authorities Division (Italy).
Partners: University of Turin – Department of Education and Training Science (Italy); Local Health Authority TO1 - Elderlies Long Care Department and Medical Area Department (Italy); Local Health Authority TO2 Torino Nord - Elderly Health Department (Italy); Catholic University of the Sacred Hearth, Faculty of Medicine – Rome (Italy); Sospiro Hospital Institute Foundation – Cremona (Italy); Maderna Centre Coop. Soc – Stresa (Italy); Ingema Foundation – San Sebastian (Spain); Transilvania University – Brasov (Romania); Istanbul Metropolitan Municipality (Turkey).

Fundacìon INGEMA
Instituto Gerontológico Matía

GAM: PSYCHO-EDUCATIONAL PROGRAMME TARGETING EMOTIONAL IMPROVEMENT IN CARERS OF PATIENTS WITH ALZHEIMER'S DISEASE

Therapist's handbook

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1. HANDBOOK STRUCTURE

The programme consists, in its original version, of 10 sessions organised into weekly sessions of 1½ hours in length. Within the Ring Project 6 sessions have been extrapolated from the original full training path. Its aims are: to improve the emotional state of carers of patients with Alzheimer's disease by providing them with information, help on how to handle care related situations and skills for dealing with the emotional aspect. Each section is therefore organised within the manual as follows:.

1. Objectives: Goals to be met by the therapist at each session.
2. Tasks for the therapist: Description of the explanations, techniques and exercises to be carried out by the therapist during the different sessions in order to achieve the objectives set.
3. Homework: Exercises proposed by the therapist towards the end of each session in order that the carer may, during the week, practice the skills and strategies explained and/or practiced during the session.
4. Record sheets: Back-up and appendices for use by the therapist, additional to section 2: "Tasks for the therapist".

The record sheets indicating "for the carer" should be given to the carers, although the therapist will still have access to them in the manual. The therapist will use these sheets where required as an aid to his or her explanations. The sheets are numbered by session and sheet number. For example, *sheet 1.2 (for the carer) will be the second record sheet of session 1 and the therapist should distribute them to the carers even if used to back his or her explanations by adding information, giving examples, etc.*

More than simple sessions, the teachings featuring herein are structured to continue throughout the intervention. Using information, exercises and corrections, the therapist will therefore seek to ensure the development of skills and strategies stretching beyond the limits of the different sessions. Thus, for example, while the relaxation techniques will be taught early on in the sessions, they will be revised and controlled throughout. Similarly, the cognitive restructuring of dysfunctional thoughts may occur prior to explaining the Beck and Ellis techniques, the ultimate objective of which is emotional self-control.

2. PROGRAMME ORGANISATION AND DEVELOPMENT

Session	Revision of tasks and solving of doubts	During the session	At home, carers should be asked to
1			• Read the information
2	Readings	Breathing practice	• Practice deep breathing once a day
3	Revision of deep-breathing	Breathing practice Relaxation practice	• Practice breathing once a day • Practice relaxation once a day • Read the material
4	Revision of the following techniques: • Breathing • Relaxation Revision of material read	Identification and rating of emotions Combined breathing/ relaxation practice	• Read the information • Practice combined breathing/relaxation
5	Revision of material read Revision of breathing and relaxation techniques	Identification and recording by the participant of cognitive errors	• Identify and write down irrational ideas • Practice combined breathing/relaxation • Practice the relaxation technique in non-stressful natural situations
6	Revision of the participants' records of: • Relaxation • Irrational ideas • Relaxation in natural situations.	Exercises on how to identify and modify disruptive behaviour	• Record by the carer of disruptive behaviour and of their attempts to modify this behaviour

2.1 FIRST SESSION. Introduction to the course and its participants

2.1.1 Objectives

- Introduce the participants to one another and get to know the group.
- Ensure that the participants attend the sessions and take an active part in them.
- Give the participants a general idea of the course structure and the work involved.
- Give a simple explanation permitting participants to understand the programme.

2.1.2 Session tasks

Task 1: Introduction *(sheet 1.1).* The therapist will introduce him or herself and give a brief description of the programme. He or she will then introduce the different members of the group, indicating their names, the person they care for and how they describe their situations at the present time. It must be clearly stipulated that the programme focuses on the carer and his or her problematic situation. The idea is to make the carers want to participate in the course by underlining the importance of their attendance and, above all, the advantages it offers to both carer and patient in the long term thanks to improved health, humour, care, shared experiences, etc.

Task 2: Rules. The therapist will inform participants of the basic group rules:

- Each participant must be listened to when speaking.
- They must respect the different opinions given.
- They must respect confidentiality, i.e. statements made during the sessions must not be repeated outside.

Task 3: Theory *(sheets 1.2, 1.3 and 1.4).* This task will involve providing a simple theoretical basis explaining the subjects to be dealt with in the programme. The therapist will therefore start by briefly explaining Alzheimer's disease. In order to learn the extent of the participants' knowledge of the subject, the group will be invited to contribute their ideas until achieving a definition of Alzheimer's disease and its symptoms. It is important that the carers understand the consequences of caring for a person with dementia at both mental and physical levels.

2.1.3 At home

The participants should be informed that they will be given tasks to do at home. On this occasion, the work will involve reading the material on Alzheimer's (*sheets 1.2, 1.3 and 1.4)* and writing down any doubts they may have on the subject.

SHEET 1.1 (for the therapist)

CONTENT OF THE INTERVENTION

This intervention focuses on the carer and the thoughts, feelings and reactions he or she experiences as a result of caring for a loved one. Caring for a person with Alzheimer's Disease is an enormous responsibility and carers may sometimes need help. This programme will focus on improving the wellbeing of carers by teaching them how to handle stressful situations arising from the providing of this care.

The programme will therefore serve to:

- Teach carers different ways of handling the problems arising from the behaviour of their relative.
- Teach carers techniques for improving their wellbeing. These include relaxation strategies and manners of increasing gratifying activities.
- Numerous research studies have shown that this kind of approach can be particularly useful in long-term situations such as caring for a person with Alzheimer's Disease. It is important to note that it takes time and practice to learn these new techniques, but that they are perfectly feasible with a little perseverance.

SHEET 1.2 (for the carer)

ALZHEIMER'S DISEASE

WHAT IS IT?

- Alzheimer's is a disease of as yet unknown origin which has a progressively degenerative effect on the brain cells (neurons). People suffering from the disease experience a variety of neuro-psychological alterations affecting cognitive functions such as the memory, the visual recognition of objects, the ability to make voluntary movements and logical reasoning.
- Alzheimer's also causes deterioration in the patients' quality of life and in that of their families, entailing serious difficulties when it comes to living under the same roof. It is one of the most widespread and best known forms of dementia.
- The most common form of dementia is Alzheimer's Disease, which affects around 10% of people over the age of 65.
- There are other kinds of dementia such as, for example, vascular dementia and Parkinson's Disease, although the ailment is less common in the latter.
- Dementia must not be considered as a normal part of aging. It is the result of a degenerative illness.

SHEET 1.3 (for the carer)

ALZHEIMER'S DISEASE

WHAT ARE ITS SYMPTOMS?

Dementia has a great many symptoms and signs. It is enormously difficult to briefly and concisely specify the necessary, suggestive and appropriate aspects determining the concept of dementia. However, the basic sign is the existence of persistent deterioration in a series of mental functions preventing the person from functioning in the social/working environment.

The functions affected cause some of the following symptoms:

1. **Memory loss**. Difficult to detect in its early stages. Patients forget what they've done with everyday objects (keys, purse, glasses, etc.) and repeatedly ask questions like: *what time is it, what date is it today, etc.* Memory loss is generally the first symptom.
2. **Trouble naming objects.** This may be difficult to establish. Patients' relatives refer to them not remembering the name of things and using descriptions to name them. For example, instead of "pen", they say: *that thing you use to write with.*
3. **Problem with words.** This can be both written and spoken. Peculiarities in this area may vary widely:

– Mixing up the syllables in a word. For example, *"congradulations"* instead of *"congratulations."*

– Inventing new words.

– Widespread use of onomatopoeic sounds.

– Poor quality of language with a reduction in the number of words used.

– Patients at a very advanced stage of the disease may stop talking altogether.

4. **Lack of personal care.** Patients start neglecting themselves: *they don't shower or bathe, they no longer go to the hairdresser's, etc.* This, logically, is one aspect that families do tend to notice.
5. **Arithmetic operations progressively worsen.** Patients are baffled by money:

SHEET 1.3 (for the carer) **(Cont'd)**

they don't recognise the coins and make mistakes when adding and subtracting. This may lead them to abandon all activities of a financial nature

6. **Confusion and hallucinations.** These symptoms have several and, sometimes, dangerous effects. Patients get lost in more unfamiliar places and, in the more advanced stages, even get lost in their own homes. Wandering, lost patients and accidents are potentially fatal situations and their origins lie in losing track of time and space. Trouble understanding visual images or spatial relationships cause hallucinations and illusions, the consequences of which are aggressiveness in situations of fear and towards people or carers.
7. **Impaired ability to move and understand by using the senses (apraxia/agnosia).** Apraxia consists of difficulty in performing motor activities: *problems getting dressed due to putting clothes on in the wrong order, forgetting how to do up buttons, loss of the ability to use cutlery, etc.* Agnosia is the impaired ability to recognise sensory information, for example: *being unable to identify sounds or recognise objects by touch, smell, etc.*
8. **Personality and/or behavioural disorders.** Generally speaking, patients experience changes in personality. They start behaving strangely, inconsistently, and even quite the opposite from usual. Often they become irritable and may even act aggressively towards others, lose control or behave anti-socially, demonstrate a loss of sexual inhibitions, etc. These disorders worry their families and are generally the main reason for going to the doctor.
9. **Disorder in the sleep-wake cycle.** Patients, particularly in the advanced stages, tend to suffer from sleep-wake cycle disorders. They are often more irritable and aggressive at night, tending to fall asleep during the day. This anomaly is generally a source of great frustration and concern among the patient's relatives and often ends in them being put into a home.

SHEET 1.4 (for the carer)

STAGES OF THE DISEASE

STAGE 1

The disease shows its first symptoms. Most of the patients' faculties remain unchanged. The main symptoms are memory loss and confusion with time and space. The affected person not only loses full awareness of his or her surroundings, but also, and this is more of a problem, of what is happening around him or her.

In fact, the worst problem at this stage is the personality change experienced by the patients as they realise what is happening to them. They tend to become melancholy, depressive, irritable, worried, anxious, etc. Both they and the members of their families suffer deeply at this stage.

STAGE 2

The symptoms of the disease have become much worse and have spread to many areas of the intelligence (memory, sense of time and place, judgment, language, motor activities, etc.). Behavioural disorders are becoming a problem, although they're not yet at their most serious.

Although it comes and goes, patients largely maintain a level of conscience permitting them to maintain contact with their surroundings and with themselves. Affective symptoms decrease as their behavioural disorders increase.

STAGE 3

The main characteristic at this stage is loss of the ability to recognise their surroundings and even themselves. They withdraw into a state of total autism caused both by the destruction of their memory and by the loss of the ability to understand and communicate. They live in their own worlds, for themselves, and only react to highly primary stimulus.

2.2 SECOND SESSION. Anxiety I.
A description of anxiety and how it affects emotions

2.2.1 Objectives

- To succeed in teaching carers how to recognise and moderate their response to anxiety.
- To succeed in making carers more relaxed on leaving the session than when they arrived.

2.1.2 Session tasks

Task 1: Revision of the information on Alzheimer's and solution of any doubts arising from its reading.

Task 2: Explanation of how to grade response to anxiety (*sheet 2.1*). It is important that carers understand the physical and mental consequences of caring for a person with dementia. An explanation will be given of the importance of the stress scale and how to measure stress from 0 to 10. Once the explanation has been given, carers will be asked to measure their anxiety and write it down for later comparison to a second measurement following the relaxation exercise based on the deep breathing technique.

Task 3: Explain anxiety, environment, cognition, physiological and motor response mechanisms (*sheet 2.2*). It is important to try and remove apprehension from the carers' minds regarding the possibility of contracting the "anxiety disease" and get the concept into perspective. We all suffer from anxiety at one stage or another and it can be controlled.

Task 4: Explanation of the deep breathing technique (*sheet 2.3*). Emphasis must be placed on the fact that relaxation (whether respiratory or muscular) is incompatible with anxiety. That's why learning to relax is so important.

Task 5: Practice breathing during the session. The therapist will explain the process. Emphasis must be placed on the fact that the point of the exercise is not actually to become relaxed, but to learn and understand how breathing functions so that, as

they practice and learn, participants may gain expertise with the technique and use it in stressful situations either at home or otherwise in their everyday lives.

2.2.3 At home

Breathing practice once a day; carers should note (on *sheet 2.4*) their anxiety levels before and after the exercise.

SHEET 2.1 (for the carer)

STRESS IDENTIFICATION

Carers tend to experience similar feelings and reactions. Some of these may be: sadness, confusion, anger, pity, desperation, guilt, ambivalence, frustration, tiredness, etc.

Although these feelings and reactions are normal, they may increase stress and reduce wellbeing. Learning to cope with stress means that carers learn to take care of both themselves and of their loved ones.

This programme will help carers to learn how to cope with the difficult moments of caring so that they will feel more in control of their everyday lives.

Stress

Exercise 1: Rate your stress

a) When you think of yourself as a carer, how would you rate your stress level on this scale?

1	2	3	4	5	6	7	8	9
No stress				Average stress				High stress

b) How did it feel to put a figure to your stress level?

Exercise 2: Think of a recent stressful experience in your role as a carer and ask yourself the following questions:

a) How do you feel when you're stressed?

b) How do you know when you're stressed?

c) What positive strategies do you use when you're stressed?

d) What negative strategies do you use when you're stressed?

SHEET 2.2

ANXIETY MECHANISMS

The first thing you have to remember is that anxiety is neither an illness nor a pathological disease: it's normal to feel anxious in certain situations and at certain times. Anxiety is a mechanism of adaptation, i.e. a physical and physiological response to certain situations which has permitted us to survive as a species and as individuals.

Fear, stress, nerves are different names for anxiety and we've all felt them at some stage in our lives. The problem when we don't know how to deal with this anxiety is that it adopts a chronic aspect unadvisable for the health (it affects the immunological system, blood pressure, etc.) and creates an unpleasant feeling which could become difficult to shake off if we're unable to cope with it.

Anxiety inter-relates with the factors normally involved in a relationship according to how each person behaves as a result of their past experience. Certain things trigger automatic anxious responses. For example, a loud noise behind us often sends our hearts racing (pumping more blood to the brain and the muscles), dilating the pupils (to increase the field of view), etc. In general, getting us ready for action, no matter who we are.

Apart from a series of situations likely to trigger these anxious reactions as an automatic reaction in almost everybody, people differ from one another as a result of their learning backgrounds. Not everyone is afraid of the same thing or in the same way; some people may react anxiously to a poodle but stoically and without batting an eyelid cope with a serious situation at which you would expect them to balk and vice-versa. That's why **some ways of coping with anxiety can be "learned"** in that we can use them to handle certain situations and condition our reaction to that situation (avoidance and escape from it or facing up to it).

We all respond in many different ways to anxiety. One of the most accepted models in any anxiety study consists of the so-called <u>triple response system</u>: <u>cognitive, physiological and motor</u>.

- **Cognitive:** the things going through our minds at that time, normally in the shape of images and words.

- **Physiological:** according to DSM IV, physiological responses to anxiety may include:
    1. Palpitations, a jumping of the heart or quickening of the heart beat
    2. Sweating
    3. Shaking or trembling
    4. Suffocating sensation or lack of breath
    5. Choking feeling
    6. Tightening of the chest or unease
    7. Nausea or abdominal discomfort
    8. Instability, dizziness or fainting
    9. Derealization/depersonalisation(feeling of unreality/separated from oneself)
    10. Paresthesia (numb feeling or pins and needles)
    11. Shivering
    12. Hot flushes
- **Motor:** anything muscular and observable. For example: running, grinding the teeth, tensing of the muscles, etc.

We all react differently to and experience anxiety in different ways. This said, the three response systems are linked in such a way that some of their components generally go hand-in-hand. Although each situation is different, anxiety typically develops as follows:

1. ***Situation:*** something has changed. For example: we come home to find a window open.
2. **Cognitive response:** we think “burglars!”
3. **Physiological response:** we feel a knot in the stomach, we start to shake and our heart starts beating faster.
4. **Motor response:** we run back out of the house, call the police, shout for help, etc.

Here we can see how the different responses are related. What would happen if, instead of the cognitive response: “burglars!”, we were to think: “I always forget to close the window?” This would probably mean that the chain of responses would fail to follow their course.

SHEET 2.3 (for the carer)

BREATHING EXERCISE

This technique only involves **breathing deeply**. Start by taking a deep breath and holding it in for 2 or 3 seconds. Breathe out slowly, over double the amount of time, while repeating to yourself: *"relax", "let it all out", "it's alright"*. As you let out your breath you will notice your shoulders and arms loosening and relaxing.

Example:

inhale for 4 seconds → hold your breath for 2 seconds → exhale for 4 seconds

Let's try it again. Take a deep breath and hold it in for a few seconds. Breathe out slowly while repeating to yourself *"relax", "let it all out", "it's alright".* As you let the air out, you will notice your shoulders and arms loosening and relaxing.

Let's repeat the exercise, but this time **clenching the muscles of your shoulders and hands while breathing in and holding your breath**. On breathing out, get rid of all of your stress and repeat the above words or any other words of your choice . Once again take a deep breath and hold it in for 2 or 3 seconds while clenching your muscles. Breathe out slowly, repeating the words of your choice and allowing your body to relax.

Exercise 1: Rate your stress after the exercise

a) How would you rate your stress level at this moment, after doing the relaxation exercise?

1	2	3	4	5	6	7	8	9
No stress				Moderate stress				High stress

SHEET 2.4 (for the carer)

Exercise: rate your stress before and after the exercise

Day 1

How would you rate your stress level at this moment, before doing the relaxation exercise? And after doing it? Please mark your answer on the scale.

1 2 3 4 5 6 7 8 9

No stress Moderate stress High stress

Day 2

How would you rate your stress level at this moment, before doing the relaxation exercise? And after doing it? Please mark your answer on the scale.

1 2 3 4 5 6 7 8 9

No stress Moderate stress High stress

Day 3

How would you rate your stress level at this moment, before doing the relaxation exercise? And after doing it? Please mark your answer on the scale.

1 2 3 4 5 6 7 8 9

No stress Moderate stress High stress

Day 4

How would you rate your stress level at this moment, before doing the relaxation exercise? And after doing it? Please mark your answer on the scale.

1 2 3 4 5 6 7 8 9

No stress Moderate stress High stress

Day 5

How would you rate your stress level at this moment, before doing the relaxation exercise? And after doing it? Please mark your answer on the scale.

1 2 3 4 5 6 7 8 9

No stress Moderate stress High stress

SHEET 2.4 (for the carer) **(Cont'd)**

Day 6

How would you rate your stress level at this moment, before doing the relaxation exercise? And after doing it? Please mark your answer on the scale.

1 2 3 4 5 6 7 8 9

No stress Moderate stress High stress

Day 7

How would you rate your stress level at this moment, before doing the relaxation exercise? And after doing it? Please mark your answer on the scale.

1 2 3 4 5 6 7 8 9

No stress Moderate stress High stress

Day 8

How would you rate your stress level at this moment, before doing the relaxation exercise? And after doing it? Please mark your answer on the scale.

1 2 3 4 5 6 7 8 9

No stress Moderate stress High stress

Day 9

How would you rate your stress level at this moment, before doing the relaxation exercise? And after doing it? Please mark your answer on the scale.

1 2 3 4 5 6 7 8 9

No stress Moderate stress High stress

Day 10

How would you rate your stress level at this moment, before doing the relaxation exercise? And after doing it? Please mark your answer on the scale.

1 2 3 4 5 6 7 8 9

No stress Moderate stress High stress

2.3 THIRD SESSION. Anxiety II. How to cope with anxiety

2.3.1 Objectives

- To teach carers how to practice relaxation techniques during the session (Jacobson's breathing and relaxation technique). The long-term objective is that carers will be able to go about these techniques on their own and apply them in their everyday lives.

2.3.2 Session tasks

Task 1: Revision of tasks and solving of problems experienced while practicing breathing during the week.

Task 2: Gauging of carers' anxiety. The carers will be asked to indicate their anxiety rate at this moment in time (following the layout of *sheet 2.3*) on a scale of 1-10. On completion of Task 4 they will be asked to repeat the indication and compare their anxiety rate before and after the exercise.

Task 3: Explanation of how relaxation can affect their emotional states: rage, anger, nerves, fear, etc. (*sheet 3.1*). The therapist must clearly explain that incompatible behaviours exist and that these can be brought to the forefront in situations normally generating emotions of any kind. One example of this is that it is impossible to be stressed and relaxed, or happy and sad at the same time. The aim of this training is that carers learn to apply this relaxation to create an emotion incompatible with anxiety, anger, stress, etc.

Task 4: Consolidation of the aspects learned in the previous session *(sheets 3.2, 3.3* and *2.3):*

- Explanation of differential relaxation and practicing of the complete relaxation exercise during the session *(sheet 3.3).*
- Explanation of breathing *(sheet 2.3)* and practicing of the complete breathing exercise during the session.

2.3.3 At home

Continued practice of the exercises studied at the session during the week:

- 1 relaxation and breathing exercise each day. The therapist will distribute sheets on which the carers should indicate their relaxation *(sheet 3.4)* and breathing *(sheet 3.5)* rates. The anxiety rate should be registered before and after the exercise. The therapist should explain how to fill in the sheet and give an example during the session.
- Read material *(sheet 3.3).*

SHEET 3.1 (for the carer)

THE CONSEQUENCES OF STRESS

Stress has different consequences. Let's analyse some of them:

A. Physical consequences of stress

When a person is tense, his or her body secretes a stress-related hormone called cortisol. This hormone is enormously important because it activates the body system (heart, lungs, circulation, metabolism, immunological system and skin) permitting us to deal with stressful situations.

The problem arises when stress is prolonged, i.e. when it lasts for a long period of time. In this case it can have an important effect on the body and cause any amounts of health problems. The situation of caring for a sick person could cause such prolonged tension or stress and therefore potentially lead to the following health problems:

- Arterial hypertension
- Heart problems
- High probability of catching colds and flu

B. Psychological consequences of stress

When stress is constant it can be come chronic and cause problems including: depression, loss of appetite, anxiety, insomnia, anger, lack of energy, irritability, desperation, etc. These reactions may have an adverse effect on the carer's quality of life and therefore negatively affect his or her ability to enjoy things.

C. Social changes experienced by carers

Very often a carer's friendships and social relations can suffer greatly as a result of their care work. However, striving to maintain this social network can help to reduce stress by giving carers the opportunity to talk about their feelings and thoughts. It is common for carers to feel that nobody understands what they're going through.

Carers should work at increasing their social network by contacting friends and family, even if they only need a moment's rest. Caring for an Alzheimer's patient is too exhausting a job for a single person.

SHEET 3.2 (for the carer)

BREATHING AND RELAXATION

Understanding the importance of relaxation.

As we have seen, people caught up in stress-producing situations may experience a variety of reactions. For instance, they may feel increased body stress or behave irritably. These signs help us to recognise when others are stressed before they themselves have realised it.

To help reduce this stress, we will explain various short relaxation techniques that carers can use when they feel themselves becoming tense. Relaxation techniques are not the only way to relax; some people succeed in relaxing by listening to music or even reading a book. The aim of this session is to learn simple, short relaxation exercises that can help carers to relax.

The technique taught during the session must be practiced at home so that carers can get better at it and therefore reduce their stress levels.

Before starting the exercise, carers will be asked to indicate their present stress level. The therapist will indicate that 1 means very relaxed and 9 extremely stressed.

1	2	3	4	5	6	7	8	9
No stress				Moderate stress				High stress

SHEET 3.3 (for the therapist)

DIFFERENTIAL RELAXATION EXERCISE

When we are distressed or nervous, certain muscles in our body become tense. If we could learn to identify these muscles, we could relax them and experience quite the opposite feeling to stress, we would feel relaxed because these muscles were relaxed. If we learn to relax as indicated and practice the techniques as instructed, after a while we will be able to relax in any situation causing anxiety.

You will be able to use relaxation as a self-control technique for the rest of your life, *before* a situation causing you to suffer anxiety, *during* the situation while you are anxious, and *after* an anxiogenic situation if the anxiety persists.

Relaxing twice a day, or whenever necessary, will help you to maintain a low level of anxiety, to shake off the fear of new things and also to rid yourself of the fear of certain situations.

The relaxation position

Sit in a chair, as comfortably as possible. Keep your head straight above your shoulders, don't bend forward or backwards. Your back must be touching the back of the chair. Place your legs in the correct position, without crossing them and with your feet completely touching the ground. Place your hands on your thighs. You are now in the relaxation position and can start the exercise.

Tensing and relaxing groups of muscles

Once comfortable, start tensing and relaxing groups of muscles. When you tense a muscle, try to note in which particular area you can feel the tension. It is very important to achieve as much tension as possible in each group of muscles. Now concentrate on what you feel when the muscles are relaxed. The sequence is therefore as follows: (1) tense your muscles as much as you can, (2) feel the tension in all muscles, (3) relax and (4) enjoy the pleasant feeling of being relaxed.

SHEET 3.3 (for the therapist) **(Cont'd)**

DIFFERENTIAL RELAXATION EXERCISE

Below is a description of how to tense and relax the different groups of muscles. Remember that you have to maintain the tension in each part of your body for around 5 seconds and that, afterwards, you should concentrate on enjoying the feeling of relaxation for a minimum of 10 seconds.

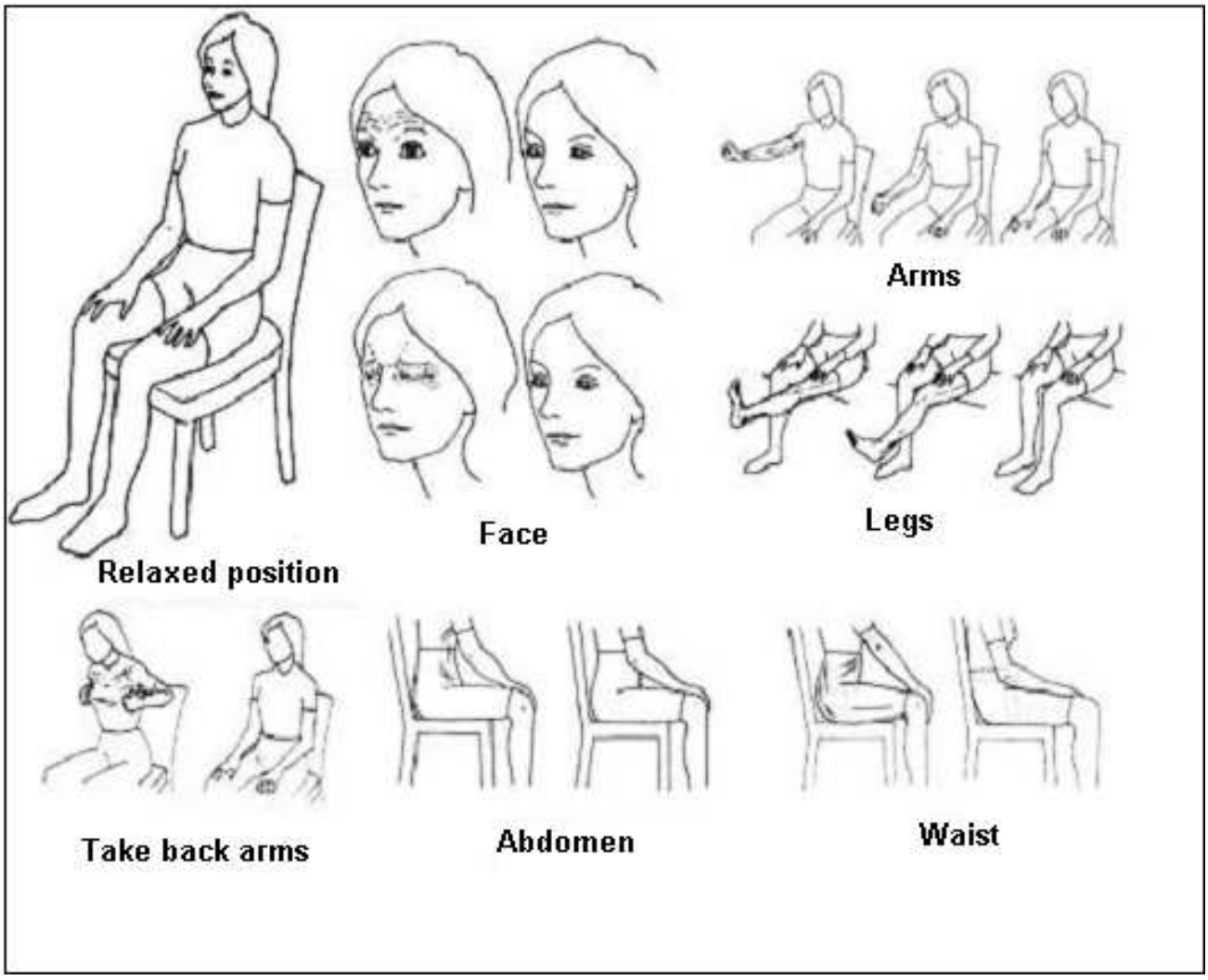
- **FOREHEAD:** Raise your eyebrows to wrinkle your forehead. Note the area in which you particularly feel the tension (on the bridge of the nose, around each eyebrow). Now relax very slowly, placing particular emphasis in the areas of greatest tension. Take a few seconds to enjoy the pleasure of feeling no tension in these muscles.
- **EYES:** Screw your eyes tight shut. You should feel tension in the entire area around the eyes, in each eyelid and on the lower and upper borders of each eye.
- **NOSE:** Wrinkle your nose. The bridge and holes of your nose must be particularly tense.
- **SMILE:** Fashion your expression and mouth into a forced smile. The upper and lower lips and both cheeks must be tense and rigid. Your lips should be tightly flattened against your teeth. Gradually relax the muscles on each side of your cheeks and face.
- **TONGUE:** Press your tongue hard against the roof of your mouth. Concentrate on the places in which you feel tension (inside the mouth, in your tongue or in the muscles beneath the jaw).
- **JAW:** Clench your teeth (the muscles tensed in this case are the ones running down either side of your face and at the temples).
- **LIPS:** Strongly purse your lips. Not the tension in the upper and lower lips and in the entire area around them.
- **NECK:** Tighten and tense your neck. Feel the tension (in your Adam's apple, at either side of your neck and at back of your neck). Another way of doing this is to bend your head forwards until touching your chest with your chin and then bend it backwards; or to tilt your head from right towards your shoulder and then to the left.

SHEET 3.3 (for the therapist) **(Cont'd)**

DIFFERENTIAL RELAXATION EXERCISE

- **ARMS:** Stretch your right arm out and, with your hand in a fist, make it is a rigid as possible. Make your whole arm as tense as possible, from hand to shoulder. Feel how muscular tension increases in your biceps, forearm, around the wrist and in your fingers. Repeat the exercise with your left hand.
- **LEGS:** Raise your right leg horizontally, arching your right foot backwards, towards the knee. Make it as tense as possible. Feel the tension (buttocks, shin, thigh, knee and foot). Repeat the exercise with your left leg.
- **BACK:** Bend your body forwards in the chair. Raise your arms, moving your elbows backwards and upwards towards your back while arching your back forwards. Note the areas in which you feel particular tension (shoulders and a little below the bottom half of your back).
- **CHEST:** Tense your chest, making it rigid. Try to press it inwards as though you were trying to crush your lungs. Note the areas in which you feel particular tension (somewhere around the middle of your chest and at the top and bottom parts of each side of the chest).
- **STOMACH:** Strongly tense the stomach muscles until they are hard as a board. Note where you feel most tension (in the naval and around it, in a circle of around 10 centimetres in diameter).
- **BELOW THE WAIST:** Tense all muscles below the waist, including your buttocks and thighs. You should feel is though you are rising off the chair. Your legs will also tense a little. Note where you feel most tension (buttocks, thighs and all muscles in contact with the chair).

DIFFERENTIAL RELAXATION: POSINGS



SHEET 3.3 (for the therapist) **(Cont'd)**

DIFFERENTIAL RELAXATION EXERCISE

The practical sessions must consist of tensing each area, noting the parts which are most tense, gradually relaxing the area and noting the relaxed feeling in the muscles of that area. Once you have done this, relax your whole body once again, but this time, instead of tensing the muscles, concentrate on relaxing each part of your body. Follow this with 10 or more deep breathing exercises while saying the word "R-E-L-A-X." At first this will take you around 15-20 minutes each day. With time, you will become able to *relax without tensing your muscles.* Complete each deep breathing exercise with the word "R-E-L-A-X."

Record your stress level over a period of two weeks until you gain command of the procedure. This daily record has two major advantages: (1) experience has shown us that individuals are more willing to practice if they keep a note of their behaviour; (2) the record constitutes a valuable indication of your progress with the programme.

Once you have learned to relax without first of all having to tense your muscles, you should practice relaxing in other positions: *standing, walking, lying down, etc.*

Lastly, we must stress that you can relax *before* a situation you think is likely to cause anxiety, *during* the situation and *after* it, doing the breathing exercises and relaxing all of the muscles in your body. If you are extremely anxious, although you won't always be able to completely eliminate the anxiety, you will be able to reduce it to bearable levels if you keep practicing.

SHEET 3.4 (for the carer)

Record of relaxation exercises for completion by the carer

Date	Time From/to	Situation in which you carry out the relaxation exercise	Anxiety before (1-9)	Anxiety after (1-9)	Notes, problems, remarks

SHEET 3.5 (for the carer)

Record of breathing exercises for completion by the carer

Date	Time From/to	Situation in which you carry out the relaxation exercise	Anxiety before (1-9)	Anxiety after (1-9)	Notes, problems, remarks

2.4 FOURTH SESSION. Emotions I.
A description of emotions and how to control them

2.4.1 Objectives

- To teach participants about emotions, how they function and how they can be adapted.
- To achieve a reduction in negative emotion by the end of the session.

2.4.2 Session tasks

Task 1: Revision of the previous session's tasks and solving of doubts.

Task 2: The therapist will propose that participants practice the combined breathing and relaxation exercises during the session. The aim is that each time they exhale, the carers relax their muscles and learn how to associate exhaling with muscular relaxation (*sheet 4.1*).

Task 3: What are emotions? The therapist will ask the carers what they understand by emotions and ask them to express their emotions during the care process: sadness, guilt, anger, fury, resentment, concern, fear, self-pity etc. The entire group will be asked to participate so that, in the next task, the therapist can explain the psychological aspect of emotions.

Task 4: The therapist will suggest taking a look at emotions from the way they are generally understood to the psychological model where emotions are considered to be natural factors that can be controlled by applying a series of actions (*sheets 4.2* and *4.3).* Learning how the emotions function. The emotional sequence will be explained alongside the part played by the different potential responses (cognitive, physiological and motor) and how they relate to one another.

Task 5: Learning to identify and gauge emotions (*sheet* 4.4). Explanation of the fact that it is natural to feel negative emotions in situations such as theirs and that it is normal to have unpleasant thoughts and feel bad, but that action can always be taken to reduce negative emotions.

2.4.3 At home

- Read the attached information *(sheets 4.2* and *4.3)*.
- Continue practicing the relaxation and breathing exercises, but trying to combine them and record anxiety levels before and after. The relaxation record sheet will once again be distributed to participants for completion (*sheet 3.4*).
- Record emotional incidents (*sheet 4.5).*

SHEET 4.1 (for the carer)

COMBINED RELAXATION AND BREATHING

Carers will be taught differential relaxation and how to place stress on relaxing their muscles each time they exhale with a view to combining the positive properties of both techniques.

SHEET 4.2 (for the carer)

HOW EMOTIONS FUNCTION

Emotions are a way of responding to certain circumstances which may be external (in our surroundings) or internal (within ourselves). These are manners of response involving different parts of our behaviour. According to the triple response system mentioned above, we can respond in cognitive, physiological and motor forms. Certain forms of generally shared response are known and form a part of our common vocabulary: happiness, sadness, anger, pride, etc. Some of them are essentially the same in one of the systems while they change in others. For example: fear and happiness resemble one another in that both cause the heart to race, the pupils to dilate and the ability to run in one or another direction, while they differ in what we think and in a number of other physical sensations; fury and anger are similar emotions at cognitive level, while at physiological level one is more intense than the other, etc.

Correct reaction to the context and to ourselves will mean that it is us who will control our emotions rather than them controlling us.

SHEET 4.3 (for the carer)

DYSFUNCTIONAL THOUGHTS

It is a good idea to pay attention to what we're thinking when we're stressed. Generally, feelings are related to thoughts. What we think affects the way we feel. Our thoughts are often associated to pleasant or unpleasant feelings. A stressed person doesn't concentrate on his or her thoughts. These thoughts are generally automatic, irrational and contribute to fuelling unpleasant feelings.

The first step in improving wellbeing is to stop and concentrate on these thoughts. The next time you feel stressed, take a moment to concentrate on your thoughts and feelings.

For example: Lydia cares for her husband David, who has Alzheimer's Disease. Although David can still go about his basic needs, he is unable to do any of the things Lydia tells him to do. In this situation, Lydia's thoughts are:

SHEET 4.4 (for the carer)

IDENTIFICATION AND RATING OF EMOTIONS

Mood diary

Exercise 1: On the emotion record sheet (*sheet 4.5*), please rate your mood each day on this 9-point scale. If you felt extremely well, mark a high level (9 for example). If you just felt okay, mark an average level (5 for example). And if you felt bad or sad, mark a low level (1 for example).

1	2	3	4	5	6	7	8	9
Very sad				Normal				Very happy
Very angry				Normal				Very happy
Very stressed				Normal				Very happy

SHEET 4.5 (for the carer)

Record of emotions for completion by the carer

Date/ time	**Situation** Describe events before you had an unpleasant feeling	**Thoughts** What am I thinking? What am I saying to myself?	**Feelings** How do you feel (sad, stressed, anxious, angry, etc.)	**Level (1-9)**

2.5 FIFTH SESSION. Emotions II.
Irrational ideas and their relation to emotions.

2.5.1 Objectives

- Learning how to identify emotions and cognitive errors/biases.
- Learning how to modify emotions.

2.5.2 Session tasks

Task 1: Revise the participants' homework, taking care to solve doubts and any problems found in order to ensure that the exercises are being carried out correctly and that participants know what they're doing. The emotion record sheet (*sheet 4.5*) should be used throughout the week to identify the irrational ideas appearing in Task 4.

Task 2: Influence of language on emotions *(sheet 5.1).* The session will focus on explaining the relationship between atmosphere, thoughts and emotions. The therapist will explain how, according to Beck's Model, thoughts can be classed as irrational, giving rise to unpleasant, misplaced emotions.

Task 3: Cognitive errors *(sheet 5.2).* Proceed to read sheet 5.2. The therapist will explain the different kinds of cognitive errors (selective abstraction, polarisation, generalisation, etc.), giving examples of the most common thoughts so that the carers can understand them and why they are irrational *(sheet 5.4).*

Task 4: In the next stage, the carers must try to identify the type of errors of thought on the record of emotions they have completed over the previous week (*on sheet 4.5*). The carers will then have to give examples of cognitive errors and explain why or to what they correspond. For example, the therapist says a kind of thought and the carers have to classify it. It is also important that they pay attention to their feelings while thinking of that irrational sentence or idea.

Task 5: Emotional modification. During the session, the therapist will try to refute (cognitive restructuring) some of the irrational ideas noted by the carers, placing stress on whether they correspond to reality, if they were truly as painful or terrible as they would have us believe and, lastly, suggesting ways of helping them to reflect

and “mull over” the subject, proposing that each participant try to refute his or her own ideas, not with the intention of convincing them, but of prompting them start to using the skill.

2.5.3 At home

- Identify and enter (on *sheet 5.3)* irrational ideas occurring during the week. The therapist will take participants through the steps of completing the sheet to make sure that they have understood the exercise.
- Continue to practice breathing and relaxation when not at the session. The therapist will distribute relaxation record sheets (*sheet 3.4*) with instructions to continue filling them in as they have been doing until now.
- Use the relaxation technique in natural, non-stressful situations (going to the shops, taking a stroll, etc.).

SHEET 5.1 (for the carer)

RELATIONSHIP BETWEEN THOUGHT, LANGUAGE AND EMOTION

There is normally a relationship between thought and emotions. While it is generally believed that it is events that make us feel one way or another, this is not exactly true. Two people can interpret the same situation in different ways. For example: *if a car shoots past you dangerously or you're shunned by a potential partner you may react in quite a different way to somebody else.* Some may get angry: *"he shot past me, what an idiot!"* or feel saddened by a negative attitude *"she rejected me, it's awful, I'll never meet another woman like her,"* while others may react differently: *"a madman at the wheel, let him go, he's better out of my way"* or even find their amorous rejections amusing: *"well, she said no, but there are plenty other fish in the sea."* The question is therefore "is it the situation that makes us feel good or bad?" Not necessarily. Very often it's how we think that makes us react in the way we do. **Rational, logic thoughts closer to reality bring us more balanced emotions and feelings** and therefore a fuller, more satisfactory existence.

The language we use to catalogue and define reality, these situations occurring in our everyday lives, is associated to sensations, emotions and feelings. Seeing the glass half full, half empty, or seeing it as horribly half empty without the possibility of being able to fill it are three different things while the glass is full to exactly the same level in all three cases.

SHEET 5.1 (for the carer) **(Cont'd)**

RATIONAL IDEAS AND IRRATIONAL IDEAS

It is therefore important to develop a rational manner of thinking, which is something we are not generally taught. Rational thought:

- Is based on things that can be demonstrated and does not involve exaggeration.
- Corresponds to reality.
- Is not absolutist.
- Does not predict and read the mind.

SHEET 5.2 (for the carer)

COGNITIVE ERRORS

1-SELECTIVE FILTERING/ABSTRACTION *("I can't stand it," "it's awful")*

A. What happened on other occasions? Was it really so bad?

B. Can something be done if it happens again?

2-POLARISATION *("good-bad," "black-white," "always-never," "everything-nothing")*

A. Can intermediate points exist between these two extremes?

B. To what extent or percentage is this the case?

C. What criteria or rules are you using to measure this?

3-OVERGENERALISATION *("Everything, nothing, always, never...")*

A. How many times did it really happen?

B. On what proof do you base your thoughts?

C. What proof do you have that things will always be the same?

SHEET 5.2 (for the carer) **(Cont'd)**

4-ARBITRARY INFERENCE OR INTERPRETATION OF THOUGHTS *("I think")*

A. On what proof do you base your thoughts?

B. Can we prove if it's true or not?

5-CATASTROPHIC VISION *("And what if.....happened?)*

A. You've thought it other times, and what really happened?

B. What are the actual chances of it happening?

6-PERSONALISATION *("They're referring to me", "comparing yourself with others")*

A. What are the consequences of comparing yourself when you're on the losing end? Does it help you in any way?

B. On what proof do you base your thoughts?

C. What criteria are you using? Are they reasonable?

D. Can we prove whether it's true or not?

7-CONTROL FALLACY *("I can't do anything about this," "I'm entirely responsible")*

A. On what proof do you base your thoughts?

B. Could other factors have influenced them?

8-FAIRNESS FALLACY *("It's not fair")*

A. On what proof do you base your thoughts?

B. Has that person the right to a point of view other than yours?

C. Isn't it really the case that you'd simply like things to be otherwise?

9-CHANGE FALLACY *("If that person or situation would only change, then I could…")*

A. What proof do you have that change depends on this?

B. Even if there was no change, could something be done?

10-EMOTIONAL REASONING *("If I feel bad it means I'm neurotic")*

A. What did you think to feel this way? Could you have felt this way as the result of an erroneous interpretation?

SHEET 5.2 (for the carer) **(Cont'd)**

B. How does feeling like this prove that you're an X?

11-LABELLING *("I'm/he/she's an X, and nothing but an X")*

A. Does this qualification completely prove what you are or what that person is?

B. Are you using this label to qualify a kind of behaviour? Does a kind of behaviour totally describe a person?

C. Could this person have other aspects or behaviours that can't be qualified with this label?

12-GUILT *("It's my fault," "it's his or her fault")*

A. What proof do you have of this?

B. Could other factors have intervened in this occurrence?

C. Does feeling and believing yourself to be guilty change matters?

13-YOU SHOULD *("I must, mustn't, he/she/they must…")*

A. What proof do you have that this must necessarily be the case?

B. Is it really such a problem if that isn't as it should be? Can we prove it?

C. Are you perhaps getting your wishes mixed up with your demands? What kind of harm are these demands causing you?

14-REASON FALLACY *("I'm right and they won't admit it")*

A. Tell me what, for you, does being right mean? And is that reasonable?

B. Could the other person have different points of view? Are you listening to them?

15-FALLACY OF DIVINE RECOMPENSE *("I may be suffering today, but tomorrow it will all be solved and I'll get my just rewards")*

A. What proof do you have that the situation can't be modified right now? What could be done now?

B. Does thinking this help or is it only passing consolation?

SHEET 5.3 (for the carer)

Record of cognitive errors for completion by the carer

Date/time	**Situation** Describe events before you had an unpleasant feeling	**Thoughts** What am I thinking? What am I saying to myself?	**Feelings** How do you feel? (sad, stressed, anxious, etc.)	**Irrational ideas** What kind of cognitive error could you be committing	**Level** **(1-9)**

2.6 SIXTH SESSION. How to handle problematic behaviour

2.6.1 Objectives

- To equip carers with skills in handling problematic behaviour

2.6.2 Session tasks

Task 1: Revision of tasks.

Task 2: Some things that Alzheimer ‘s patients do may be highly irritating, but these can often be changed. The therapist will explain why this behaviour may occur and why the care recipient continues to do so (*sheet 6.1*). The therapist will give a few examples of this behaviours to help caregivers to understand what he or she means. Ask the carers to try and identify this kind of behaviour in their patients.

Task 3: Having identified examples of this unpleasant behaviour, ask the carers to describe them according to the causal analysis cause-effect method (*sheet 6.2*). In the first place, give a written example of problematic behaviour and the carer’s reaction or response to it (*sheet 6.3*). The therapist should explain the example and invite the carers to propose different solutions to the problem. They will then be asked to do exercise 1, in which they must apply the theory learned in the example (*sheet 6.3*).

Task 4: Handling problematic behaviour. An explanation will be given of the principles of the technique and how it can be used to modify problematic behaviour with a view to achieving something more suitable. In this sheet (*sheet 6.4*) we propose, based on an example, that carers act creatively in their endeavours to change regularly occurring problematic behaviour in Alzheimer’s patients. Carers will be asked to throw out any ideas occurring to them that could help to solve this problem. The therapist will encourage the carers to give creative answers even if they don’t find them appropriate.

Task 5: This sheet (*sheet 6.4*) explains what happens when we reward a behaviour we don’t want to see repeated, and what happens when we reward a behaviour we do want to see repeated. That is, we will use simple sentences to explain how the

behaviour reward (encouragement) and extinction (withdrawal of the encouragement) mechanism functions.

2.6.3 At home

- Continue practicing the relaxation technique.
- Distribute a record sheet (*sheet 6.3*) in order that the carers may record their patients' disruptive behaviour and the strategies they use to change this behaviour.

SHEET 6.1 (for the carer)

PROBLEMATIC BEHAVIOUR

Why does problematic behaviour occur?

By problematic behaviour we understand all behavioural alterations likely to occur while caring for a patient and which, for some reason or another, cause a problem, risk or danger both for the person receiving the care and for their carers, or for third persons involved in providing the care. This category includes unsocial behaviour.

Examples of problematic behaviour:

- Hindering or aggressive reactions (pushing, insulting, resistance) to attention from the carer when going about an everyday action (bathing, getting dressed, going to bed, etc.).
- Looking sad or seeming to be “flat”.
- Trouble retaining urine.
- Repeating the same question or remarks, etc. time and again.
- Seeming lost, aimless, continuously walking from one place to another
- Exaggerated reaction (nervous, irritable, etc.) to certain relatively unimportant occurrences.
- Serious sleeping difficulties.
- Acting aggressively towards others in certain everyday circumstances.

Common causes of problematic behaviuor:

- Sickness or pain and sensorial problems (poor sight or hearing).
- Medication (side-effects).
- Psychopathological problems (anxiety, depression).
- Sensation of annoyance or frustration.
- Atmosphere (under- or over-stimulation).
- Social factors: speaking to people as though they were children, deaf, incapacitated, etc.
- Inability to express feelings and needs which they are unable to verbalise appropriately.
- Excessive incapacity.

SHEET 6.2 (for the carer)

READING. WHAT HAPPENS BEFORE AND AFTER THE BEHAVIOUR?

The first step in identifying the reason for the behaviour is to focus on what happens before and after it occurs. Something always happens before and afterwards. What happens before is what causes it and what happens afterwards is the response (it may be the way the carer feels or what the carer or the patient does).

A. DESCRIBE THE BEHAVIOUR

- What does the patient do?
- Where does it happen?
- How long does it last for?
- How intense is it?
- For whom is it a problem?

B. DESCRIBE "BEFORE"

- What was happening?
- Who was there?
- What may have happened to the patient?
- What was he or she doing?
- Has something changed recently?

C. DESCRIBE "AFTER"

- How did the patient respond?
- What did the person do afterwards?
- How did the others respond?
- What did the patient get out of this situation?

SHEET 6.3 (for the carer)

Example:

It's 10 a.m. on Monday morning and Carmen is sitting in her favourite chair, when her daughter, Juana, comes over to her and says: *"It's time to go to the doctor's."* Carmen says: *"I'm not going to the doctor's."* When Juana asks Carmen to get up, Carmen starts shouting. Juana cancels the doctor's appointment and leaves Carmen in her chair. Carmen stops shouting.

Juana fills in the following behaviour diary:

Date/ day of the week	Time	Person present	CAUSE: What sets it off →	PROBLEMATIC BEHAVIOUR →	EFFECT: Response
Monday	10:00	Juana (daughter)	• Mum is sitting peacefully in her chair. • I tell her it's time to go to the doctor's.	• Mum starts shouting.	• I leave her where she is and cancel the doctor's appointment.

SHEET 6.3 (for the carer) **(Cont'd)**

EXERCISE 1

Based on the above model, let's try and concentrate on some kind of problematic behaviour in our loved one and complete the following diary*:

Date/day of the week	Time	Person present	CAUSE: What sets it off →	PROBLEMATIC BEHAVIOUR →	EFFECT: Response

- You can use carer's sheet *(sheet 6.2)* to complete the table.

SHEET 6.4 (for the carer)

CHANGE BEHAVIOURS CHANGING RESPONSES

There are two ways to respond to behaviours:

A. Reward behaviours when we want their repetition: **REINFORCEMENT**
It is normal focusing only on the problematic behaviours of patient. However, it is very important taking in account their positive behaviours to reward them and favour their repetition.
For example, if your patient or family member shouts every day at 15.00, it would be a good idea to reward them the day in which they do not shout.
Example of rewards:

- Give him/her something he/she likes: food, object, smile, gush over.
- Tell him/her a good thing.
- Make a beautiful thing, take care, hug him/her, kiss him/her.

Rules to reward positive behaviours:

- Giving immediately a reward.
- Giving a reward every time that reflect badly upon the expected behaviour.
- Ensure that the reward is personal and has meaning for your patient.
- Do not give a reward unless you experience the expected behaviour.

B. Do not reward problematic behaviours: **EXTINCTION**
When problematic behaviour of your patients occurs, it's important not to reward the behaviour, even if you could be lured to make it.

An example of this is that you pay attention to your care when he/she cries. The best way to avoid this behaviuor is to pay attention to the causes. If the aim is to draw attention with the cries you should not pay attention when he/she cries. The alternative answers are:

- Ignore the problematic behaviour
- Reduce the attention paid to the situation

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This project has been funded with support from the European Commission. This publication [communication] reflects the views only of the author, and the Commission cannot be held responsible for any use which may be made of the iformation contained therein.

Il presente progetto è finanziato con il sostegno della Commissione europea. L'autore è il solo responsabile di questa pubblicazione (comunicazione) e la Commissione declina ogni responsabilità sull'uso che potrà essere fatto delle informazioni in essa contenute.

El presente proyecto ha sido financiado con el apoyo de la Comisión Europea. Esta publicación (comunicación) es responsabilidad exclusiva de su autor. La Comisión no es responsable del uso que pueda hacerse de la información aquí difundida.

Education and Culture DG