



**Project “Ring – TransferRING Supports for Caregivers”**

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***Kit Ring***  
***User Manual***

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## 1 Introduction

The KIT RING can be used to structure training programmes on the assistance relationship, directed at formal and informal caregivers involved in caring for the **elderly with dementia**.

The entire training package can also be used in other contexts, more specifically for whoever renders assistance to the **disabled, mentally infirm or persons with chronic illnesses**.

The KIT allows for the training to be structured over **six sessions each lasting for two-three hours**. The instruments that make up the KIT can however easily be used to formulate training programmes on care and assistance relationships, which are structured over a different number of hours and sessions.

The Kit Ring consists of the following training instruments:

- a **“Guidelines for caregivers”** namely an information guide for caregivers on the different forms of dementia, the course of the illness, practical indications regarding care and support at the end of the patient's life, drawn up by the "Fondazione Istituto Ospedaliero di Sospiro" (Cremona);
- a **“Psycho-educational programme targeting emotional improvement in carers of patients with Alzheimer's Disease”** prepared by the "Ingema Foundation" of San Sebastian" (Spain);
- a **DVD, “Caregiving: flashes of truth from the world of cinema”**, containing film clips on the subject of care-giving, used as teaching supports in training, prepared by the "Centro Maderna" (Stresa);

**The three instruments correspond to three different requirements:**

- The first provides information on the course of dementia (especially Alzheimer's), simple and practical indications on how to approach patients and the management of everyday problems in caring for them, as well as useful points and observations for whoever will be supporting patients during the last stages of their lives.
- The second intends providing operators with an instrument to acquire knowledge regarding their anxieties and tension, so as to manage these better. The rational observation of the behaviour displayed by the person being cared for helps to approach this behaviour in an appropriate manner.

- Finally, the DVD naturally complements the first two instruments as it consolidates the content that corresponds with the messages in the first two, and at the same time provides a stimulus for reflection on the subjects being dealt with in the project.

The combination of the three instruments into a single product provides a training programme in the context of assistance relationships, offering flexible support and is aimed at improving the caregiver's psychological-physical position.

## **2 Guidelines for caregivers**

The Guide sets out the course of the illness, providing assistance and advice to whoever is called to assist a patient while living alongside them. The Guide also seeks to provide essential information so as to understand the symptoms produced by the illness and the decisions that have to be taken up until the advanced stages, where the patient relies completely on the care of whoever is assisting them. Even at the most advanced stages of an illness, where death seems imminent or has become inevitable, it is still possible to put in place a series of actions that will guarantee a dignified end for everyone, including the Alzheimer's patient.

### **2.1 Guidelines Index**

#### **FIRST PART**

##### WHAT IS DEMENTIA?

1. Definition
2. Diagnosis and symptoms
3. Pharmacological treatment

##### PRACTICAL ADVICE

1. What is always best to do
2. What is always best to avoid
3. The peculiarities of the disease
4. The caregiver

#### **SECOND PART**

1. The final stage of the disease
2. End of life decisions
3. Symptoms control
4. The very last moments
5. Care beyond the end

### 3 Psycho-educational programme targeting emotional improvement in carers of patients with Alzheimer's Disease - GAM

The purpose of the programme is to **improve the emotional condition of caregivers** to patients affected by Alzheimer's Disease by providing them with information and assistance regarding the **management of situations associated with treatment and the ability to cope with the emotional aspects.**

#### 3.1 Programme organisation and development

The sessions offered by the programme are:

1. Introduction to the course and its participants.
2. Anxiety I. A description of anxiety and how it affects emotions.
3. Anxiety II. How to cope with anxiety.
4. Emotions I. A description of emotions and how to control them.
5. Emotions II. Irrational ideas and their relation to emotions.
6. How to handle problematic behaviour.

Session	Revision of tasks and solving of doubts	During the session	At home, carers should be asked to
1			<ul style="list-style-type: none"> <li>• Read the material</li> </ul>
2	Readings	Breathing practice	<ul style="list-style-type: none"> <li>• Practice deep breathing once a day</li> </ul>
3	Revision of deep-breathing	Breathing practice  Relaxation practice	<ul style="list-style-type: none"> <li>• Practice breathing once a day</li> <li>• Practice relaxation once a day</li> <li>• Read the material</li> </ul>

4	Revision of the following techniques: <ul style="list-style-type: none"> <li>• Breathing</li> <li>• Relaxation</li> </ul> Revision of material read	Identification and rating of emotions  Combined breathing/relaxation practice	<ul style="list-style-type: none"> <li>• Read the information</li> <li>• Practice combined breathing/relaxation</li> </ul>
5	Revision of material read  Revision of breathing and relaxation techniques	Identification and recording by the participant of cognitive errors	<ul style="list-style-type: none"> <li>• Identify and write down irrational ideas</li> <li>• Practice combined breathing/relaxation</li> <li>• Practice the relaxation technique in non-stressful natural situations</li> </ul>
6	Revision of the participants' records of: <ul style="list-style-type: none"> <li>• Relaxation</li> <li>• Irrational ideas</li> <li>• Relaxation in natural situations.</li> </ul>	Exercises on how to identify and modify disruptive behaviour	<ul style="list-style-type: none"> <li>• Record by the carer of disruptive behaviour and of their attempts to modify this behaviour</li> </ul>

### 3.2 Handbook structure

Each session in the manual is organised as follows:

- **Objectives:** outcomes to be achieved in each session by the trainer.
- **Trainer's responsibility:** description of explanations, techniques and exercises provided during the various sessions so as to achieve the objectives that have been set.
- **Homework:** exercises provided by the trainer at the end of each session, so that during the week the caregiver can practice the skills and strategies explained and/or tried during the sessions.
- **Support material:** back-up and appendices for the trainer's use.

The material labelled “for the caregiver” must be distributed to participants; the trainer will be able to access this material in the manual. The trainer will use this material when required as support for his explanations. The support material is numbered in progressive order and subdivided according to session: for example, sheet 1.2 (for the caregiver) will be the second record sheet in session 1 and trainers must distribute these to the caregivers so as to provide support to their explanations with the addition of information, providing of examples, etc.

More than just simple sessions, the teaching provided here is structured in such a way that it continues through the entire training process. By using information, exercises and corrections, the trainer will try to ensure the development of skills and strategies beyond the limits of each single session. So for example, the relaxation techniques will be introduced during the initial sessions, but will be reviewed and consolidated over the entire period.

## 4 Caregiving: flashes of truth from the world of cinema - DVD

The DVD proposes using films as a stimulus for reflection, a way to simplify communication, and as an emotional go-between in the training process. It includes clips of film, entire sequences or single clips to provide ideas, provocation and support in the training process of caregivers.

Individual sequences provide support to the training process, even when they come from films that do not specifically deal with the subject of "caregiving". They have been lifted from different films and selected not so much for the message they convey, but rather for the opportunities they provide in the classroom for dealing with a specific subject.

### 4.1 List of films

- A. **AWAY FROM HER.** Canada 2008, directed by Sarah Polley, with Julie Christie, Gordon Pinsent, Olympia Dukakis.
- B. **THE SAVAGES.** USA 2007, directed by Tamara Jenkins, with Laura Linney, Philip Seymour Hoffman, Philip Bosco.
- C. **THE DIVING BELL AND THE BUTTERFLY** ("Le scaphandre et le papillon") France 2007, directed by Julian Schnabel, with Mathieu Amalric, Emmanuelle Seigner, Marie-Josée Croze, Anne Consigny.
- D. **PATCH ADAMS.** USA 1999, directed by Tom Shadyac, with Robin Williams, Daniel London, Monica Potter.
- E. **CARAMEL** ("Sukkar banat") France, Lebanon 2007, directed by Nadine Labaki, with Nadine Labaki, Yasmine Al Masri, Joanna Moukarzel, Gisèle Aouad, Adel Karam.
- F. **THE GIRL BY THE LAKE** ("La ragazza del lago") Italy 2007, directed by Andrea Molaioli, with Toni Servillo, Nello Mascia, Marco Baliani, Giulia Michelini, Fausto Sciarappa.
- G. **FRIED GREEN TOMATOES.** USA 1991, directed by Jon Avnet, with Kathy Bates, Mary Stuart Masterson, Mary-Louise Parker, Jessica Tandy, Cicely Tyson.
- H. **DOLORES CLAIBORNE.** USA 1995, directed by Taylor Hackford, with Kathy Bates, Jennifer Jason Leigh, Judy Parfitt, Christopher Plummer, David Strathairn.

## 4.2 Short plots of films

As for the two movies opening the review, the protagonists have a need in common: taking care of an old family member who is becoming more and more confused, due to dementia. In the first case, “**Away from her**” a woman has to put in institutional care; the movie stimulates in the spectators an emotional involvement and a sharing of the husband’s pains, due to the separation from his wife who has been hospitalized.

In the second movie “**The Savages**”, two brothers decide to look after their father because of their sense of duty towards the parent who had been irascible and violent.

More painful is the issue of “**The diving bell and the butterfly**”. A journalist, completely paralysed by a stroke, can communicate only by the eyelid of the single and healthy eye. His message is: “I’ve decided not to have pity on myself again”. It’s a real story. He will manage to hold out. Thanks to his caregivers too.

By “**Patch Adams**” we find out as reality may seem unlikely. A young man feels his route is taking care of others, after a tempted suicide; he will do this studying medicine. He will heal illness by talking and listening to his patients, even making himself up as a clown to administer cheerfulness as a drug. It’s a real story.

“**Caramel**” brings us to Beirut, in Lebanon, where we follow histories lived by some women among which Rose, who sacrificed her best years and her happiness to take care of her sister Lili.

In “**The girl by the lake**”, a young woman drowned in a lake in a province of Friuli, is found naked along the shore. Her death is investigated by Commissario Giovanni Sanzio, rough and introverted man who has to cope with difficulties pertaining to his wife’s dementia who recognises neither him nor her daughter Francesca.

The movie “**Fried green tomatoes**” brings us to a rest home where old Mrs. Ninny revives Evelyn’s will to live, an overweight housewife frustrated by the indifference of her husband, by telling an old story in episodes. The emotional states of the old lady will be able to enter Evelyn’s life who will come back to life, will rediscover the pleasure of feeling alive will be able by adjusting what in her life is not going as she’d like.

The housemaid Dolores in “**Dolores Claiborne**” was accused of killing her landlady: in the flashbacks we can see the development of their deep and adversarial care relationship.

### 4.3 List of clips

CLIP	FILM	SESSION	DIRECTED AT	MINUTES
I am going out of my mind, and am aware of it	A	1	T	03:51
Now I'll quickly show you round the institution	A	1	F – I	07:16
Isn't this just the way he is?	A	1	T	03:14
What we suffer now as old people doesn't count for much	A	4 – 5	F	02:56
Don't make me out to be the bad one who wants to get rid of dad	B	2 – 3	I	02:03
It's a facility for old people, they used to be called old-age homes	B	2 – 3	I	03:39
We are horrifying	B	2 – 3	T	04:27
You come here to die	B	2 – 3	T	04:20
I am not a domestic servant, I am a nurse	B	4 – 5	T	02:35
Is this life?	C	4 – 5	D	08:56
I've decided never to feel sorry for myself again	C	4 – 5	D	04:51
I want to die	C	6	T	02:28
Don't act as if he's not here	C	6	T	01:41
I will help my neighbour	D	6	T	13:26
Do you want to help me?	D	6	T	01:21
This is not a game	D	6	T	02:08
You have a gift	D	6	T	01:38
If one person is cured I guarantee you we are winning	D	6	T	05:47
Lily is alone and I can't relax	E	4 – 5	I – P	03:03

Sooner or later I will kill him/her	E	4 – 5	I – P	02:05
I want to get my hair done	E	4 – 5	I – P	01:03
Aaaah look how beautiful we are looking! What are you doing, going out?	E	4 – 5	I – P	01:07
I am tired of living this life	E	4 – 5	I – P	02:35
Is it someone I should know?	F	1	T	02:59
Did you see? He smiled at you.	F	4 – 5	I	02:02
You don't get better with the thing that mum has	F	4 – 5	I	04:17
Not even a daughter could be so kind	G	6	T	03:30
She was my friend, I loved her	G	6	F	01:44
She died peacefully in her sleep	G	6	F	02:25
If this is what they palm off as life	H	6	T	04:27

Directed to	Key
Formal caregivers	<b>F</b>
Informal caregivers	<b>I</b>
Caregivers working with the DISABLED	<b>D</b>
Caregivers working with PSYCHIATRIC PATIENTS	<b>P</b>
All types of caregivers	<b>T</b>

## **5 Integrated use of instruments making up the Kit Ring**

The KIT RING was designed to support training programmes on the assistance relationship, directed at formal and informal caregivers; the choice to use the instruments that it contains must therefore be made with the sole objective of promoting the success of these programmes, by mainly taking into account the characteristics of the participants and their requirements.

In order to facilitate the use of the Kit Ring's content, and solely by way of example, an indication has been made in the paragraphs that follow regarding the parts/sections of the three instruments that could be used for each of the six sessions.

If we were to think of the Kit's components as wheels forming part of the same mechanism, the parts relating to the "Guide on the people being cared for" have been identified with a yellow wheel, the parts relating to the GAM Psychological-Educational programme with a red wheel, and the parts taken from the DVD have been marked with a green wheel.

The KIT allows for the training to be structured over six sessions each lasting for two-three hours. The manual does not however dictate the sequence of use, or the time that should be spent on each single activity, because it was considered better to leave these choices to the trainer or trainers of the course.

It is advisable however to introduce the day by illustrating the objectives for the day, and to subsequently suggest the viewing of one or two film clips so as to make it easier for participants to express their state of mind. Starting off from what emerges, the trainer should go on to explain the theoretical content taken from the "Guide on the people being cared for", and then move on to the indications for the session contained in the "GAM Psycho-Educational Programme", using the support material provided. It is possible to close off a meeting by viewing another film clip.

## 5.1 SESSION 1 - Introduction on the course and its participants

### Objectives:

- Introduce each of the participants to the others and get to know the group.
- Ensure that all participants attend the sessions and take an active part.
- Provide participants with a general idea on how the course is structured and the work to come.
- Provide a simple explanation that will allow participants to understand the programme.



### FIRST PART

#### WHAT IS DEMENTIA?

1. Definition
2. Diagnosis and symptoms
3. Pharmacological treatment



1.1	Content of the intervention	Descriptive sheet
1.2	Alzheimer's disease	Descriptive sheet
1.3	Alzheimer's disease	Descriptive sheet
1.4	Stages of the disease	Descriptive sheet



CLIP	FILM	SESSION	DIRECTED TO	MINUTES
I am going out of my mind, and am aware of it	A	1	T	03:51
Now I'll quickly show you round the institution	A	1	F – I	07:16
Isn't this just the way he is?	A	1	T	03:14
Is it someone I should know?	F	1	T	02:59

## 5.2 SESSION 2 - Anxiety 1. A description of anxiety and how it affects emotions.

### Objectives:

- Succeed in teaching caregivers how to recognise and moderate their response to anxiety.
- Ensure that the caregivers leave the session more relaxed than when they arrived.



### FIRST PART

#### PRACTICAL ADVICE

#### 3. The peculiarities of the disease



2.1	Stress identification	Exercise
2.2	Anxiety mechanisms	Descriptive sheet
2.3	Breathing exercise	Technical sheet: breathing
2.4	Exercise: rate your stress before and after the exercise	Exercise



CLIP	FILM	SESSION	DIRECTED TO	MINUTES
Don't make me out to be the bad one who wants to get rid of dad	B	2 – 3	I	02:03
It's a facility for old people, they used to be called old-age homes	B	2 – 3	I	03:39
We are horrifying	B	2 – 3	T	04:27
You come here to die	B	2 – 3	T	04:20

### 5.3 SESSION 3 - Anxiety II. How to cope with anxiety.

#### Objectives:

- Teach caregivers how to practise relaxation techniques during the session (Jacobson breathing and relaxation techniques). The long term goal is for caregivers to be able to independently apply these techniques in their everyday lives.



#### FIRST PART

#### PRACTICAL ADVICE

1. What is always best to do



3.1	The consequences of stress	Descriptive sheet
3.2	Breathing and relaxation	Exercise
3.3	Differential relaxation exercise	Exercise
3.4	Record of <b>relaxation</b> exercises for completion by the carer	Exercise
3.5	Record of <b>breathing</b> exercises for completion by the carer	Exercise



CLIP	FILM	SESSION	DIRECTED TO	MINUTES
Don't make me out to be the bad one who wants to get rid of dad	B	2 – 3	I	02:03
It's a facility for old people, they used to be called old-age homes	B	2 – 3	I	03:39
We are horrifying	B	2 – 3	T	04:27
You come here to die	B	2 – 3	T	04:20

## 5.4 SESSION 4 - Emotions I. A description of emotions and how to control them.

### Objectives:

- Teach participants how emotions function and how to intervene to adjust them.
- Achieve a drop in negative emotions by the end of the session.



### FIRST PART

#### PRACTICAL ADVICE

2. What is always best to avoid



4.1	Combined relaxation and breathing	Descriptive sheet
4.2	How emotions function	Descriptive sheet
4.3	Dysfunctional thoughts	Descriptive sheet
4.4	Identification and rating of emotions.	Exercise
4.5	Recordi of emotions for completion by the carer	Exercise



CLIP	FILM	SESSION	DIRECTED TO	MINUTES
What we suffer now as old people doesn't count for much	A	4 – 5	F	02:56
Did you see? He smiled at you.	F	4 – 5	I	02:02
I am not a domestic servant, I am a nurse	B	4 – 5	T	02:35
Is this life?	C	4 – 5	D	08:56
I've decided never to feel sorry for myself again	C	4 – 5	D	04:51
Lily is alone and I can't relax	E	4 – 5	I – P	03:03
Sooner or later I will kill him/her	E	4 – 5	I – P	02:05
I want to get my hair done	E	4 – 5	I – P	01:03
Aaaah look how beautiful we are looking! What are you doing, going out?	E	4 – 5	I – P	01:07
I am tired of living this life	E	4 – 5	I – P	02:35
You don't get better with the thing that mum has	F	4 – 5	I	04:17

## 5.5 SESSION 5 - Emotions II. Irrational ideas and their relation to emotions.

### Objectives:

- Learn to identify emotions and cognitive errors.
- Learn how to adjust emotions.



### FIRST PART

#### PRACTICAL ADVICE

4. The caregiver

### SECOND PART

2. End of life decisions (*only for family members*)

4. The very last moments

5. Care beyond the end



5.1	Relationship between thoughts, language and emotions	Descriptive sheet
5.2	Cognitive errors	Descriptive sheet
5.3	Record of cognitive errors for completion by the carer	Exercise



CLIP	FILM	SESSION	DIRECTED TO	MINUTES
What we suffer now as old people doesn't count for much	A	4 – 5	F	02:56
Did you see? He smiled at you.	F	4 – 5	I	02:02
I am not a domestic servant, I am a nurse	B	4 – 5	T	02:35
Is this life?	C	4 – 5	D	08:56
I've decided never to feel sorry for myself again	C	4 – 5	D	04:51
Lily is alone and I can't relax	E	4 – 5	I – P	03:03
Sooner or later I will kill him/her	E	4 – 5	I – P	02:05
I want to get my hair done	E	4 – 5	I – P	01:03
Aaaah look how beautiful we are looking! What are you doing, going out?	E	4 – 5	I – P	01:07
I am tired of living this life	E	4 – 5	I – P	02:35
You don't get better with the thing that mum has	F	4 – 5	I	04:17

## 5.6 SESSION 6 - How to handle problematic behaviour.

### Objectives:

- Equip caregivers with useful skills for managing problematic behaviour.



### FIRST PART

#### PRACTICAL ADVICE

1. What is always best to do
2. What is always best to avoid



6.1	Problematic behaviour	Descriptive sheet
6.2	What happens before and after the behaviour?	Technical sheet: observation
6.3	Behaviour diary (cause - effect)	Exercise



CLIP	FILM	SESSION	DIRECTED TO	MINUTES
I want to die	C	6	T	02:28
Don't act as if he's not here	C	6	T	01:41
I will help my neighbour	D	6	T	13:26
Do you want to help me?	D	6	T	01:21
This is not a game	D	6	T	02:08
You have a gift	D	6	T	01:38
If one person is cured I guarantee you we are winning	D	6	T	05:47
Not even a daughter could be so kind	G	6	T	03:30
She was my friend, I loved her	G	6	F	01:44
She died peacefully in her sleep	G	6	F	02:25
If this is what they palm off as life	H	6	T	04:27

## **6 APPENDIX – Integration to the User Manual for caregivers of disabled people**

The Guide is directed at social workers, volunteers and family members that are involved with people with physical motor disabilities.

This often involves disabilities caused by trauma, progressive neuro-muscular pathologies and spinal cord lesions or strokes, which suddenly impact on the lives of people and their families.

In these cases the caregiver takes on a dual role: that of “prosthetic assistance” in the sense that they serve as a total or partial replacement of the disabled person in carrying out all the functions of everyday life, but also inevitably constitute a key point of relational reference.

In certain respects, the context of caring relationships in the case of the caregiver involved with disabled people is no different from the context that involves the caregiver dealing with the care of old people affected by dementia. In both cases, the caregiver often experiences feelings of debasement and alleviation in their relationship role, with consequences that are often hurtful to their image as an adequate and competent person.

However, while old people progressively lose their ability to take care of themselves and to attend to satisfying their everyday needs with self-determination, disabled people progressively or suddenly lose their independence, but not their ability for self-determination.

In the case of people with neuro-muscular conditions, significant and unforeseen deterioration can take place that is similar to what is generally seen in illnesses with an inauspicious prognosis (terminal stage illnesses).

But very rarely do these neuro-muscular conditions ever impact the ability for self-determination, which remains intact and effective.

Caregivers in these cases have to confront situations that are similar to the terminal stages experienced by old people, but which cannot be defined as terminal because prospects for life still exist.

In these cases, caregivers see their function of interpreting the needs for assistance reduced, while the executive side of their duties increase, cognisant of the person with disabilities.

The relationship context therefore takes on fundamental importance in the quality of the relationship that is created between caregivers and the person with disabilities they are assisting, because on the one hand it is necessary to reduce the risk of progressively depersonalising the assistance activities directed mainly at prosthetic actions, but on the other hand there is also the risk of excessive emotional involvement that needs adequate support and processing.

## **7 APPENDIX – Integration to the User Manual for caregivers of people affected by mental illness**

Psychiatric illnesses can lead to the deterioration of skills that have been "learnt" and result in a world of loneliness that hinders the acquiring of new and alternative skills: this is referred to as existential disability, and the caregiver is the person that takes care of the person, supporting and rehabilitating them.

Both formal and informal caregivers of psychiatric patients are exposed to a series of stressful factors, referred to as high "loads" accelerating burn-out, which is considered a syndrome where there has been a process of ineffective adjustment to excessive individual stress.

According to research on the subject, the objective and subjective loads appear to be connected not so much to being the caregiver of a mental patient, but rather to "being in a relationship with a mental patient".

Furthermore, the seriousness of the patient's symptoms is not the determining factor in influencing the caregiver's stress, anxiety and insomnia. Other factors are more important, like the caregiver's quality of life, the extent of the involvement and upheaval in their life and the residual abilities of the patient.

Caregiver and patient make up a dyad, where the "well-being" of the one and the "health" of the other mutually influence each other.

The complete implementation of the **"Psycho-educational programme targeting emotional improvement in carers of patients with Alzheimer's Disease"** would therefore prove useful, combined with the clips highlighted in the DVD **"Caregiving: flashes of truth from the world of cinema"**.

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