

Appendices

Appendix A - Psycho-educational program details: “Pour mieux vivre avec la maladie d’Alzheimer”

1. Generalities

The psycho-educational program « Pour mieux vivre avec la maladie d’Alzheimer» is a multidisciplinary project organized in Brussels by the hospital Erasme, Aremis (home care service) and Alzheimer Belgium (association for patients and family caregivers).

It was addressed to caregivers who wish to develop their abilities and knowledge in order to better help their loved ones live at home.

This psycho-educational program was composed of 12 sessions of 2 hours each, spread over 6 months, with 8 to 12 people. They took place in the nursing home «Les Jardins de la Mémoire», located near the Erasme Hospital. These were led by a neuro-psychologist, in the presence of an external observer (psychologist or occupational therapist with experience in the field of dementia) in order to then be able to discuss the content and course of the sessions and improve them.

A symbolic financial contribution was requested in order to ensure the maximum cohesion of the group. This training focused on the behavioral and cognitive aspects of the disease.

2. Content and course of session

It included many role plays, several discussions, active and interactive family intervention. The topics covered during the sessions involved a theoretical introduction to dementia and Alzheimer’s disease. 5 sessions were dedicated to cognitive disorders and 5 to behavioral disorders. The last session provided an opportunity to conclude the session and discuss the supports and resources available for the caregiver.

This psycho-educational program provided detailed information about the disease, as well as a description and explanation of symptoms. This information process was structured, as complete as possible, progressive and spread out over time. It was therefore a contribution of clear and up-to-date information, scientifically supported data.

Psycho-education taught caregivers to detect deficits, disorders and their ‘warning signs’. She taught specific strategies for behavioral change and how to modify their interactions with the patient.

After each session, participants received a written support summarizing this information.

An art-therapy workshop allowed optimal occupation of patients in parallel to allow close caregivers to participate in psycho-education sessions.

The program also included monthly home visits by referral nurses and/or occupational therapists for 8 months to provide a multidisciplinary and personalized response to patients and their caregivers (listening, support and advice from experts in the living environment).

3. Aim

The aim of psycho-education was to accompany the caregiver in the recognition, acceptance and management of the disease. In details, the main objectives of psycho-education were to:

- Inform/ bring more knowledge about Alzheimer's disease and others dementia syndrome
- Bring to a better understanding of the sick person, of his or her experience.
- Give practical advices
- Promote the exchange of experiences between the members of the group
- Help caregivers to find the right way to deal with the patient and practical problems frequently encountered ; and to better control and manage their stress
- Develop personal strategies to cope with the care of their loved ones
- Improve well-being, quality of life and relieving the emotional burden
- Help caregivers better control and manage their stress
- Assist caregivers in their difficulties (exchanges with the group and the professional)
- Put into practice what caregivers have learned during group sessions

4. Funding

The psycho-educational program was funded by Erasme Hospital, King Baudouin Foundation (Geert Noel Award) and National Lottery, Alzheimer Belgium, Novartis®, Lundbeck® and Janssens-Cilag®.

Appendix B – NCPI Questionnaire

A. Memory Disorders

Does the patient have memory problems? Does he/she frequently forget information? We are not talking about a simple occasional forgetting but rather about knowing, it is if the patient has frequent, important and unusual forgetting.

NO (Go to the next question) / **YES** (Check the appropriate proposals below)

1. The patient forgets information or events that occurred a few hours/days before.
2. The patient forgets information or events of the past.
3. The patient is helped by clues.
4. The patient has difficulty learning new information.
5. The patient frequently forgets to take his or her medication.
6. The patient should note more so as not to forget.
7. The patient modified his/her behavior to compensate for his or her memory difficulties.
8. The patient tries to hide his or her memory difficulties.
9. The patient asks the same questions repeatedly.
10. Sometimes he/she does a second time something he/she has already done because he/she has forgotten it.
11. The patient has difficulty remembering where he/she has stored things. He/she often loses his/her belongings.
12. The patient is disturbed by the changes.
13. Sometimes he/she does not remember the people he/she knows, does not know who they are.
14. There are other memory changes.

Determine the frequency and severity of these memory disorders.

> Frequency

- Rarely: less than once a week
- Sometimes: about once a week
- Often: several times a week but not every day
- Very often: almost all the time

> Severity

- Mild: memory disorders are perceptible but have little impact on daily activities. The difference is slight compared to the patient's usual behavior and does not disturb the patient.
- Moderate: memory disorders are significant and disruptive to the patient and hinder daily activities; they can be limited through the use of tools, compensatory means or through the adaptation of activities.
- Severe: memory disorders are glaring and disturbing to the patient. Most of the time, no help or strategy can limit their effects on daily activities.

> Distressing character for the caregiver: How emotionally have these troubles been distressing for you?

- Not at all
- Slightly
- Suite
- Moderately
- Rather
- Very

> Managing the disorder: I was able to cope, manage the situation or end the behavior.
Yes/No.

B. Spatio-temporal Orientation Disorders

Does the patient have difficulty navigating in space or time? Does he/she frequently get lost? Not knowing the date? We are not talking about an occasional error, but rather about whether the patient has frequent, significant and unusual difficulties that seem to be abnormal to be in time and/or space
NO (Go to the next question) / **YES** (Check the appropriate proposals below)

1. The patient is no longer able to orient himself with a plan.
2. The patient has difficulty in navigating, getting lost in little known places.
3. The patient is mistaken on familiar, usual journeys.
4. The patient is regularly lost in familiar places.
5. Sometimes the patient does not know where the patient is in a well-known location.
6. The patient does not know today's date.
7. The patient does not know what the day is today.
8. The patient does not know what the month is.
9. The patient does not know what year it is.
10. The patient does not know what the season is.
11. There are other changes in spatio-temporal orientation.

Determine the frequency and severity of this spatio-temporal disorientation

> Frequency

- Rarely: less than once a week
- Sometimes: about once a week
- Often: several times a week but not every day
- Very often: almost all the time

> Severity

- Mild: spatio-temporal disturbances are perceptible but have little impact on daily activities. The difference is slight compared to the patient's usual behavior and does not disturb the patient.
- Moderate: spatio-temporal disturbances are significant and disruptive to the patient and hinder daily activities; they may be limited through the use of tools, compensatory means or through the adaptation of activities.
- Severe: spatio-temporal disturbances are glaring and disruptive to the patient. Most of the time, no help or strategy can limit their effects on daily activities.

> Distressing character for the caregiver: How emotionally have these troubles been distressing for you?

- Not at all
- Slightly
- Quite
- Moderately
- Rather
- Very

> Managing the disorder: I was able to cope, manage the situation or end the behavior.
Yes/No.

C. Communication/Speaking Disorders

Does the patient have difficulty expressing or understanding what is being said to him/her? Does he/she frequently not find a word? Making mistakes in vocabulary or grammar? We are not talking about an occasional error but rather about whether the patient has frequent, significant and unusual difficulties that seem to you to communicate, understand, express themselves.

NO (Go to the next question) / **YES** (Check the appropriate proposals below)

1. The patient has difficulty understanding long and complex messages.
2. The patient does not understand implied messages (e.g., irony, expressions, intentions)
3. The patient has a misunderstanding disorder that prevents him/her from following a simple conversation.
4. The expression of the patient is impoverished: his speech is little elaborated, little content, his sentences shorter, simpler.
5. The patient's speech is inconsistent.
6. The patient seeks his or her words.
7. The patient's vocabulary is poor, less rich.
8. The patient forgets words, uses them in an inappropriate context.
9. Patient does not complete or repeat sentences (or certain words).
10. The patient is increasingly using non-verbal communication.
11. The patient becomes talkative, speaking for pleasure to anyone.
12. The patient speaks little, his or her circle of exchange is reduced.
13. The patient is unable to write properly.
14. The patient can read but does not understand what he/she is reading.
15. There are other changes to the communication.

Determine the frequency and severity of these communication disorders

> **Frequency**

- Rarely: less than once a week
- Sometimes: about once a week
- Often: several times a week but not every day
- Very often: almost all the time

> **Severity**

- Mild: communication disorders are perceptible but have little impact on daily activities. The difference is slight compared to the patient's usual behavior and does not disturb the patient.
- Moderate: communication disorders are important and disruptive to the patient and hinder daily activities; they can be limited through the use of tools, compensatory means or through the adaptation of activities.
- Severe: communication disorders are glaring and disruptive to the patient. Most of the time, no help or strategy can limit their effects on daily activities.

> **Distressing character for the caregiver:** How emotionally have these troubles been distressing for you?

- Not at all
- Slightly
- Suite
- Moderately
- Rather
- Very

> **Managing the disorder:** I was able to cope, manage the situation or end the behavior.

Yes/No.

D. Apraxias

Does the patient have difficulty performing certain gestures, movements on a voluntary basis (when he/she has no motor or sensitive impairment)? Does he ever forget how to handle certain objects properly? Not being able to organize correctly (in the right order) the different movements to reach a goal? We are not talking about an occasional error but rather about whether the patient has

frequent, significant and unusual difficulties, abnormal to perform voluntary or on-demand movements.

NO (Go to the next question) / **YES** (Check the appropriate proposals below)

1. The patient encounters difficulties to perform complex gestures: driving, using the washing machine, writing, etc.
2. It is difficult for the patient to organize the movement sequences in the correct order to achieve his or her goal.
3. The patient has difficulty performing simple gestures and handling common objects properly: dressing, lighting a lamp, styling, etc.
4. The patient is no longer able to perform automatic movements, even when they are helped to initiate the movement (using the fork to eat).
5. The patient produces inconsistent gestures, inconsistent with what he/she verbally expresses.
6. The patient has difficulty dressing.
7. There are other changes in gestures, voluntary movements.

Determine the frequency and severity of these praxic disorders

> Frequency

- Rarely: less than once a week
- Sometimes: about once a week
- Often: several times a week but not every day
- Very often: almost all the time

> Severity

- Mild: praxic disorders are perceptible but have little impact on daily activities. The difference is slight compared to the patient's usual behavior and does not disturb the patient.
- Moderate: praxic disorders are significant and disruptive to the patient and hinder daily activities; they can be limited through the use of tools, compensatory means or through the adaptation of activities.
- Severe: praxic disorders are glaring and disruptive to the patient. Most of the time, no help or strategy can limit their effects on daily activities.

> Distressing character for the caregiver: How emotionally have these troubles been distressing for you?

- Not at all
- Slightly
- Suite
- Moderately
- Rather
- Very

> Managing the disorder: I was able to cope, manage the situation or end the behavior. Yes/No.

E. Agnosias

Does the patient have difficulty recognizing certain objects, certain people (when he/she has no perceptual problems)? Does it happen that it can no longer identify an object? No longer know how to use it properly, what is it for? Not recognizing people anymore? We are not talking about an occasional error but rather about whether the patient has frequent, significant and unusual difficulties, abnormal to recognize elements/people in his environment.

NO (Go to the next question) / **YES** (Check the appropriate proposals below)

1. The patient no longer recognizes certain objects when he/she sees them.
2. The patient no longer knows the function, the use of certain objects.
3. The patient is assisted when the object is in hand.
4. The patient no longer recognizes certain objects, even when they are in his or her hand.
5. The patient no longer recognizes some friends, neighbors, ...
6. The patient no longer recognizes some of his or her loved ones.

7. The patient no longer recognizes some familiar sounds or music.
8. There are other changes to recognition.

Determine the frequency and severity of these gnostic disorders

> Frequency

- Rarely: less than once a week
- Sometimes: about once a week
- Often: several times a week but not every day
- Very often: almost all the time

> Severity

- Mild: Gnostic disorders are perceptible but have little impact on daily activities. The difference is slight compared to the patient's usual behavior and does not disturb the patient.
- Moderate: Gnostic disorders are important and disruptive to the patient and hinder daily activities; they can be limited through the use of tools, compensatory means or through the adaptation of activities.
- Severe: Gnostic disorders are glaring and disruptive to the patient. Most of the time, no help or strategy can limit their effects on daily activities.

> Distressing character for the caregiver: How emotionally have these troubles been distressing for you?

- Not at all
- Slightly
- Quite
- Moderately
- Rather
- Very

> Managing the disorder: I was able to cope, manage the situation or end the behavior.
Yes/No.

F. Thinking Difficulties

Does the patient have difficulty thinking, thinking logically, taking into account different information, making inferences, assumptions? We are not talking about occasional difficulties but rather about whether the patient has frequent, important and unusual difficulties, abnormal to reason with.

NO (Go to the next question) / **YES** (Check the appropriate proposals below)

1. The patient is no longer able to make complex inferences and reasoning (based on assumptions, taking into account different factors, etc.)
2. The patient has difficulty mentally performing a complex operation (e.g., calculation).
3. The patient is no longer able to make simple inferences and reasoning.
4. The patient has difficulty performing a simple operation (e.g., calculation) mentally.
5. The patient has difficulty constructing or maintaining a logical argument.
6. The patient has difficulty understanding an argument.
7. The patient has difficulty making decisions, making choices based on different elements/variables.
8. The patient is no longer able to be critical.
9. There are other changes in the reasoning.

Determine the frequency and severity of these thinking difficulties.

> Frequency

- Rarely: less than once a week
- Sometimes: about once a week
- Often: several times a week but not every day
- Very often: almost all the time

> Severity

- Mild: reasoning disorders are perceptible but have little impact on daily activities. The difference is slight compared to the patient's usual behavior and does not disturb the patient.
- Moderate: reasoning disorders are important and disruptive to the patient and hinder daily activities; they can be limited through the use of tools, compensatory means or through the adaptation of activities.
- Severe: reasoning disorders are glaring and disruptive to the patient. Most of the time, no help or strategy can limit their effects on daily activities.

> **Distressing character for the caregiver:** How emotionally have these troubles been distressing for you?

- Not at all
- Slightly
- Suite
- Moderately
- Rather
- Very

> **Managing the disorder:** I was able to cope, manage the situation or end the behavior.
Yes/No.

G. Attentional Disorders

Does the patient have difficulty concentrating, keeping his/her attention on a task? Is he/she easily distracted? We are not talking about an occasional error but rather about whether the patient has frequent, significant and unusual attentional difficulties.

1. Patient has difficulty staying focused on an activity/task for more than 20 minutes.
2. Patient has difficulty staying focused on an activity/task for more than 5 minutes.
3. The patient is easily distracted by environmental noise.
4. The patient is unable to concentrate if other people are speaking in the room.
5. The patient appears to be distracted for no discernible reason (noise, etc.) or by internal thoughts.
6. The patient has difficulty managing two activities/tasks at the same time.
7. It is difficult for the patient to move flexibly from one task to another.
8. The patient has difficulty following a conversation with multiple interlocutors.
9. The patient appears to be not paying attention, awake to what is happening around him.
10. There are other changes in attentional skills.

Determine the frequency and severity of these attentional disorders.

> **Frequency**

- Rarely: less than once a week
- Sometimes: about once a week
- Often: several times a week but not every day
- Very often: almost all the time

> **Severity**

- Mild: attentional disorders are perceptible but have little impact on daily activities. The difference is slight compared to the patient's usual behavior and does not disturb the patient.
- Moderate: attentional disorders are significant and disruptive to the patient and hinder daily activities; they can be limited through the use of tools, compensatory means or through the adaptation of activities.
- Severe: attentional disorders are glaring and disruptive to the patient. Most of the time, no help or strategy can limit their effects on daily activities.

> **Distressing character for the caregiver:** How emotionally have these troubles been distressing for you?

- Not at all
- Slightly

- Suite
- Moderately
- Rather
- Very

> **Managing the disorder:** I was able to cope, manage the situation or end the behavior.
Yes/No.