

# **Online self-management support for informal caregivers for managing behavioral changes in their relative with dementia**

## **INTERVENTION PROTOCOL**

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## 1. For whom is this intervention protocol intended?

This intervention protocol has been written for nursing staff who will be in e-mail contact with informal caregivers during online self-management support.

These nurses must be specialized in guidance of people living at home with dementia and their informal caregivers. They could for instance be nursing staff whose daily practice involves working as a case manager. This requires extensive knowledge about providing assistance for informal caregivers when there are behavioral changes in their relatives.

## 2. To whom is online self-management support offered?

The intervention is intended for informal caregivers who meet the following criteria:

- they are a family member of a person diagnosed with dementia (all subtypes are possible)
- and they are in contact with the relative with dementia at least once a week
- they are aged 18 or over
- they have access to the Internet and are able to use the Internet and e-mail themselves

## 3. What are the objectives of online self-management support?

Online self-management support will give informal caregivers options for dealing effectively with behavioral changes in their relatives. The ultimate objectives are that the informal caregiver will feel better capable of coping with the changed behavior, that it will help improve the relationship between the informal caregiver and the person with dementia, and that behavioral changes will be reduced.

## 4. What are the elements of the online self-management support?

The online self-management support intervention consists of three parts: offering personal e-mail contact with the nurse, online videos, and e-bulletins. Each of those elements is explained below:

- a. Offering an opportunity for **personal e-mail contact** with a nurse, spread over a period of 12 weeks. Please refer to the paragraph “What do the e-mail contacts involve?” The nurse will instigate a total of at most three e-mail contacts within a period of twelve weeks overall. E-mail contacts are only made after the videos and e-bulletins have been offered (see b and c).
- b. Offering **online videos** about dealing with behavioral changes in dementia. A total of six videos (approximately 15 minutes) are available about dependent behavior, aggressive behavior, suspicious behavior, apathetic behavior, restlessness at night, and masking behavior respectively. In each of the videos, an informal caregiver speaks about the changing behavior of their relative with dementia. Examples are also given. There is an explanation of what causes the behavior and what exactly it comprises, as well as tips focusing on what the informal caregiver can do to deal with that specific behavior. Finally, the informal caregiver is asked to examine what the possible causes could be of their relative’s behavior and what potential ways the informal caregiver can think up that might improve the situation.

In the context of the study, an informal caregiver is predominantly offered one specific video. This is the video that, according to the informal caregiver, fits best with the behavioral change that the

informal caregiver is experiencing the most problems with. This has been stated by the informal caregiver in the questionnaire. The other five videos are then shown below it with less emphasis. The informal caregiver can watch these as well.

- c. Mail messages with an **e-bulletin** about dealing with behavioral changes in dementia. This e-bulletin provides practically oriented information about the various behavioral changes in dementia and how the informal caregiver can cope with them. The behavioral changes are the same as in the videos (dependent, aggressive, suspicious, apathetic, restless at night, and masking behavior). The e-bulletin is a summary of the points addressed in the video.

## 5. What do the e-mail contacts involve?

### 5.1 Practical aspects of the e-mail contacts

The nurse:

- answers e-mails from the informal caregiver using the 'Reply' functionality. This means that all the e-mails will be grouped together.
- always responds within two working days to an e-mail from an informal caregiver.

These are personal e-mail messages from the informal caregiver that the nurse will not share with third parties. For the purposes of the study, the nurse does however record a number of data items during the research period, such as:

- the number of contacts that there have been for each informal caregiver;
- whether the informal caregiver has filled in their response to the video. If the informal caregiver does not do this, the nurse will not receive an e-mail from the informal caregiver. For that reason, the nurse sends a standard e-mail to the informal caregiver if no response has been received after one week.

### 5.2 First personal e-mail from the nurse

*Situation:* The informal caregiver has received one of the six videos about changed behavior in their relative with dementia. The informal caregiver is then asked to answer four questions:

- Would you please describe your informal caregiving situation briefly?
- What kind of <type> behavior have you noticed in your relative?
- What could be causing this?
- How do you deal with this behavior?

The nurse receives an e-mail with the answers that the informal caregiver supplies to these questions.

*Content and focus:*

In the e-mail, the nurse:

- introduces themselves to the informal caregiver, if the informal caregiver has not received a standard e-mail);
- responds to the informal caregiver's answers and attempt to use them to give a list of experiences and requirements;

- provides information about contacting the nurse by e-mail.

The first mail from the nurse emphasizes ‘Assessing’ and ‘Advising,’ i.e. the first two steps of the 5A model for self-management support<sup>1</sup>.

Assessing: Make an inventory of and then explore the experiences of the informal caregiver with behavioral changes in their relative with dementia, including their knowledge, expectations, and convictions, and how they cope with the illness and its consequences.

Advising: Respond to and explain the informal caregiver’s findings, providing tailored information that fits in with the information that came to the fore during the Assessing stage.

### 5.3 Second personal e-mail from the nurse

#### *Situation*

The informal caregiver has provided a response to the first e-mail contact from the specialist nurse.

#### *Content and focus:*

The nurse:

- gives individual feedback (a compliment, tip, or additional information) about the actions that the informal caregiver initiated and how they progressed;
- gives an answer/feedback to exactly what the informal caregiver has said they want to know, with references to other sources of assistance if needed;
- reiterates what the informal caregiver says that they would like to achieve;
- asks the informal caregiver what they think is most important;
- gives feedback to assist the informal caregiver in choosing realistic and feasible objectives. (It is important to be able to achieve successes, no matter how small they may seem. The goals must answer questions such as: What do you want to achieve? And why is that important for you? The goals must also provide motivation for the informal caregiver, as well as something to hold on to when the going gets tough. Formulate specific actions in terms of behavior: “What exactly are you going to do?”)
- creates a picture of potential obstacles and thinks up problem-solving techniques and strategies that the informal caregiver may be able to use;

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<sup>1</sup> The 5A model provides caregivers with a structure for self-management support, based on what the care user themselves (in this case the informal caregiver) believes to be important and required. The steps in the 5A model are

A	Assessing the state of behavior, beliefs, and motivation;
A	Advising based upon personal health risks;
A	Agreeing on a realistic set of goals;
A	Assisting in anticipating barriers and developing a specific action plan;
A	Arranging follow-up.

The 5A model is explained further in the national module for self-management (CBO, 2014).

- If the intended goals are not achieved, or not achieved in full, it is important to discuss any negative feelings the patient may have (particularly about guilt and failure), to reinforce positive actions, and to get the patient to commit to the objectives once again.

This e-mail contact focuses on the third and fourth A's of the 5A model: Agreeing and Arranging. Agreeing should be seen in the sense of clarifying the personal objectives and support requirements of the informal caregiver. Arranging should be seen in the sense of discussing and recording the goals.

## 5.4 Third personal e-mail from the nurse

### *Situation*

This is the final e-mail contact. The informal caregiver has provided a response to the second e-mail contact from the specialist nurse.

### *Content and focus:*

The final e-mail contact will above all emphasize the final two A's of the 5A model, Assisting and Arranging (see also the second e-mail, Section 5.3). However, depending on the informal caregiver's responses, attention can also be paid to the other A's, Assessing, Advising, and Agreeing.

The nurse:

- gives individual feedback about the actions that the informal caregiver initiated and how they progressed;
- records the 'agreements' by listing the points that have been discussed in the previous e-mail contacts;
- formulates the goals and activities (allowing the informal caregiver to see if they have achieved the objectives);
- gives further ideas for if it does not work. Is a one-time recommendation enough? Or is more extensive advice, a number of follow-up appointments, specialist help, or intensive guidance required? Is a referral therefore needed?
- emphasizes that it is important that the informal caregiver saves the e-mail conversations somewhere themselves, so that the information is visible to the informal caregiver and can be retrieved easily;
- makes clear that this is the concluding e-mail.

## 5.5 What does the nurse have to do if an informal caregiver does not respond?

### Before the start of the e-mail contacts

After an informal caregiver has been registered for the e-mail contacts, the idea is that the nurse should receive a response by e-mail from the informal caregiver within a week. If the nurse does not receive a response, the nurse sends a reminder e-mail to the informal caregiver. If the informal caregiver does not respond to this either, the nurse does not have to do anything further.

#### After the first/second e-mail contact

It is also possible that there will be no response from the informal caregiver after a personal e-mail from the nurse (the first or second e-mail). In that case, the nurse should do the following:

- The nurse sends an e-mail reminder to the informal caregiver. If the informal caregiver responds to this, the e-mail contacts can be continued.
- If the informal caregiver does not respond to the reminder, the nurse does not have to do anything further. If the informal caregiver makes contact a long time after the reminder, the contacts can be continued again.