



## **Enabling Technologies for People with Dementia**

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### **Report of Assessment Study in Finland**

#### **WP 4.4.1 Assessment study Finland**

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## 1. Introduction

Enable is an exploratory and descriptive study, with the overall aim being to determine whether it is possible to facilitate independent living of people with dementia, and to promote their well being by facilitating access to enabling technological systems and devices. Between March 2001 and June 2004, the Enable methodology was guided by the ethical considerations and the needs of people with dementia in research from five European countries – *England, Lithuania, Ireland, Finland, and Norway*, with the overall objective for the study being to:

1. Define the feasibility of the devices
2. To assess the effects of providing assistive devices to people with dementia
3. Provide a cross-country analysis of the devices tested by European countries.

A methodological approach was developed by Enable to assess the benefits of enabling technology, and to ascertain the socio – economic costs associated with using assistive devices to facilitate independent living for people with dementia.

The protocol was developed and defined for use with research for people with dementia in their homes. The protocol submitted for ethical approval was guided by adhering to the sensitive ethical conditions required within a study in which people with dementia provide informed consent.

To date, very few studies have sought to include people with dementia in their research. However, in the last five years, researchers have increasingly appreciated the value of obtaining user led information through the use of data collection tools, which are designed for use with people with dementia. Part of the dilemma of defining the assessment tools for Enable was to meet the need of the person with dementia sensitively and appropriately to that of the tools available. The multi disciplined nature of the team revealed the complexity of issues that can prevail - including concerns about hearing the voice of the person with dementia. The majority of partners asserted that it was vital for the person to be heard to provide a meaningful insight into technology and its use in the home of a person experiencing dementia.

### 1.1. Introduction to Finnish assessment studies

One main task in the ENABLE project for STAKES was to organise national assessment study on the ENABLE products. This is the report of the main national findings. The starting point in the whole project and in the assessment study was that technology assessment should be tied in the WHO model on functioning and disability. The framework in this model is to assess functioning and disability in a social and physical context. In ENABLE assessment study this meant that plenty of information need to be collected on so called background variables and in the analysis these should be used not only as a background characteristics but as information on a dynamic socio-physical context in which the intervention is carried out. (WHO, International classification of functioning, disability and health, ICF 2001)

Another aspect stressed in the ENABLE is the potential interaction between quality of life and use of enabling technologies. In ENABLE this interaction is studied firstly from the point of view of the person with dementia and secondly from the person who takes the main responsibility of the daily care. When this topic has been investigated in ENABLE the perspective has been overall quality of life of a person with dementia as assessed by himself but when quality of life of a carer has been investigated the perspective has been on the impact of care stress in the quality of life.

An important methodological issues in ENABLE has been to find ways in collecting information from the persons with dementia throughout the study. This methodological question is further discussed at the end of this report. The whole framework of ENABLE project is described elsewhere (Hagen et al. 2002). Here we concentrate on the national data collection and results.

In a national level we also had some national research interests. We were interested in finding out how motivated people with dementia and their carers were to try and to use stand alone products which could support their every day life, and whether the motivation and usefulness were associated to the aim of the design of the product. Both national (for example Jylhä et al. 1996) and international (Sweep 1998) studies have shown the complexity of problems people with dementia and their carers face in their everyday life. It was obvious that ENABLE products could give help in some of the problems but not all. From the point of view of motivation this kind of situation was very interesting.

In Finland STAKES carried out the assessment study together with three subcontractors: two Alzheimer's associations, one in Helsinki and one in Tampere and the Finnish Society for Dementia Care and Treatment. The national plan for the assessment study was done together and modified according to the ENABLE protocol. The Alzheimer's associations role was in recruitment and they participated the data collection as well. The Finnish Society for Dementia Care and Treatment participated the data collection and did most MMSE tests which were used to define severity of dementia. The subcontractors checked the Finnish translations of all the questionnaires which were done by STAKES. The assessment studies were carried out in the capital area of Finland and in city of Tampere.

The whole national ENABLE team agreed that in Finland we should focus on participants who do not live alone. This was not underlined by other ENABLE partners but in the project meeting it was accepted that in Finland this kind of inclusion criteria can be used. This aspect was emphasised also by the Ethical Committee of STAKES when it assessed the national plan in the beginning of 2002. The ethical committee underlined the question of reliability of the assessment data and reduction of possible risks associated to technology for the participants with dementia.

During the study it became obvious that recruiting people was even more demanding than expected and because of this we included five people who lived alone but had daily visitor or at least daily contact with their primary carer. We followed up their situation very carefully.

## 2. Devices assessed

Products aiming to support memory, facilitate communication, or to provide pleasure and comfort had been identified prior to the start of the project. Prototypes and test series of seven new products was developed during the first year of the project. In Finland day and night calendars, locators of lost items, easy-to-use telephones and night lights were assessed. The goal was to assess maximum of

- 10 electronic Day and Night calendars to support time orientation
- 10 locators for lost objects to help in finding lost objects
- 4 pre-programmable telephones to support social contacts
- 10 automatic night lamps to give enough lightning in night time when waking up

In addition, a multimedia product for entertainment called Do-it-yourself Picture Gramophone was assessed in two day care centres and in one private home but the results of this assessment study are reported in another Enable deliverable.

Other products which were assessed in some other ENABLE countries were

- A gas cooker monitor to prevent incidents due to forgotten pans
- A bath water level control to prevent flooding (prototype)
- A remote day planner to remind appointments and events (birthdays etc.)
- A medicine reminder, which gives a sound when it is time for medication

### DAY AND NIGHT CALENDAR

Disorientation for time is common among people with dementia. Also, some people mistake night for day and vice versa. The aim of the Day and Night calendar is to:

- Enable people with dementia to find out whether it is day or night, what date it is and which day of the week it is.
- Reduce the risk that the people with dementia go out in the middle of the night and get lost.
- Avoid that people with dementia call family members or others in the middle of the night and wake them up - unless they need help.
- Help people with dementia with time orientation.

The Day and Night calendar consists of an LCD display which shows day, date and “Morning”, “Afternoon”, “Evening” or “Night”, as appropriate. At midnight, day and date shifts automatically, and similarly, the time of the day shifts from Night to Morning at 7 a.m., to Afternoon at 12 noon, to Evening at 6 p.m. and to Night at 11 p.m. It is connected to the mains. The text will disappear in case of power failure, but will reappear when the current is turned on.

Development of the Day and Night calendar is based on the software of the Forget-me-not™ calendar which has been on the market since 1998. A new microprocessor (PIC16 627) has been used, and the software modified according to the new functions specified. A revised circuit card has been designed. Day, date and time of the day (Morning, Afternoon, Evening and Night) are shown in the respective language on a LCD display of 4x20 characters, according to the specifications given by the leaders of the WP4.1- 4.4. The Day and Night calendar prototypes were fit into a commercially available picture frame, except for the use of a specially constructed encapsulation on the back side. It can be placed on the wall, on a table etc. where it easily attracts the user’s attention. A picture, personal or other can be put into the frame.

### LOCATOR

The locator device is aimed at enabling people who have mislaid objects in their homes to locate them. It also enables carers to locate objects that have been mislaid by the person they are caring for. The device has a series of touch buttons on the front onto which can be stuck pictures of objects to be located. When the user touches the picture they initiate a noise from tag attached to the lost object so that it can be found. The device is not yet commercially available.

The device can be placed on a horizontal surface or be wall-mounted, and requires plugging into the mains. It has space for five objects to be pictured on the front panel together with a cancel button. The touch panels simply need to be touched by the user to initiate a search, and a light appears within the panel to indicate that it is signalling. Each object to be found has a tag connected to it or inserted in it. The tag detects that it is being called by the panel unit and initiates the sound. If it is picked up it will stop. Users can cancel the sound on the panel if they wish by touching the cancel sign, and it will stop anyway after 5 minutes. The unit generates a coded radio signal that is picked up by the tags. The tags check every two seconds to see if they are being called but go into sleep mode in between to conserve their batteries. The unit has a range that is suitable for a domestic dwelling. Battery life is about 5 months. The tags can be mounted on keyrings, pension books etc. or put inside purses, glasses cases etc. The sound has been developed to be two-toned. A pure tone is provided at the resonant frequency of the sounder to maximise output. In addition a brief burst of pseudo white noise is provided as this has been shown by other workers to be easier to locate.

## **NIGHT LIGHT**

The night light is aimed at providing light, particularly in a bed room, when the user gets up at night. A sensor under a bed leg detects bed occupancy and an ambient light sensor detects whether it is dark or not. If it is dark and the user gets out of bed the bedside light is faded on. If they leave the light on when they get back to bed it will fade the light off again. The device is not yet commercially available.

The bedside light comes with all the electronics packaged within the lamp base, and two cables attached, one with a mains plug on the end and the other with a small plug on the end. To set it up the lamp needs to be placed in a convenient position and plugged into the mains. The bed-leg sensor needs to be placed under a leg and the other cable from the lamp plugged into it. It only operates when it is dark and will automatically fade on if someone gets out of bed after they have been in it. It will automatically fade off again about 5 minutes after the user has returned to bed. The lamp can be turned on and off through the normal switch at any time. To demonstrate it in daylight the small ambient light sensor that is fitted on the very top of the lamp base needs to be covered up to simulate darkness. The sensor unit comes with a series of ringed inserts. The inserts allow the sensor to be configured to the size of the bed leg. The lamp will automatically adjust itself according to the weight of the user. It generates a running average of the load that the sensor is seeing and looks for any changes from this that indicate that someone has got out of bed. So it should not be sensitive to someone turning over in bed for example. It is recommended that the sensor is put under a bed leg at the head end of the bed. If two people share the bed it is best to put the sensor under the leg on the side used by the person with dementia. If the other person gets up the light may sometimes come on as well. The sensor unit is quite insensitive to water being spilled on it and will function properly again once it has been dried out. The light level achieved after it has faded up can be adjusted by means of a small adjuster under the base of the lamp.

### 3. Methodology

#### 3.1. Outcome Measures

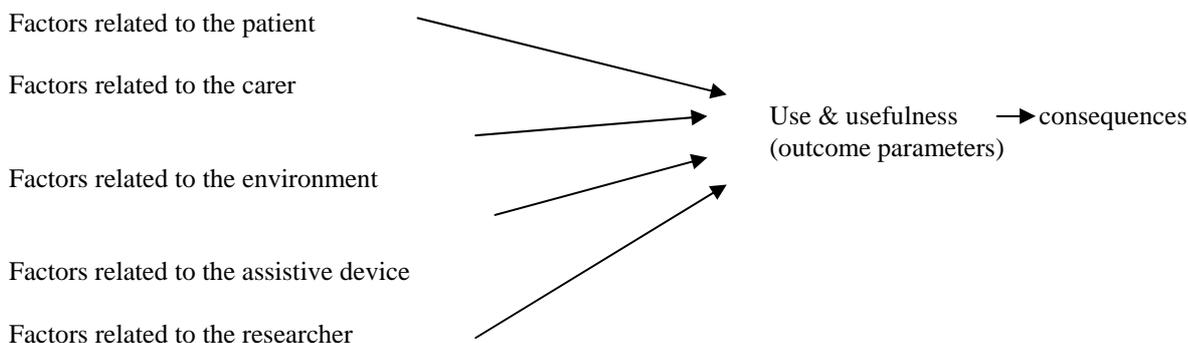
A methodology for the assessment of effects, including cost-benefit analysis has been developed (theoretically) as part of the ENABLE project. The methodology will be tested out in practice in a pilot study among users in Ireland, England, Norway and Finland. The ICF model (International Classification of Functioning, disability and health) has been used as the general framework for the methodology development. ICF was developed by WHO to classify the functions and disability associated with various health conditions (WHO, 2000). The ICF model encompasses different aspects, as follows

- The individuals health condition: dementia comprises different diseases which affect the brain in different ways and which may give rise to symptoms of different character and progression rate. Co-existing medical conditions can also be important.
- The individuals body function and structure: dementia diseases are progressive and effects are often dependent on the phase of the disease.
- Personal factors: each person is unique and effects may be dependent on factors such as gender, personality, attitudes, education and profession.

Environmental factors: these include home environment, availability of family and professional care services etc., which may promote or reduce the impact of enabling products.

#### 3.1.2 Primary and secondary outcome measures

Our hypothesis is that whether the person with dementia uses the product or not can be explained by factors related to the person with dementia, the carer, the environment, the product or the researcher, as illustrated below.



Factors related to the patient include the stage of the disease, cognitive functioning, nature of and degree of the problems, duration, ethnicity, personality/attitudes, social life;

- Factors related to the carer include family relation to the patient, co-habiting or not, frequency and character of caring, working status, attitudes towards the person with dementia, feeling of burden/general health;
- Environmental factors comprise both services from the social or health care system as well as the patient's home environment;
- Factors related to the devices include the design, function and reliability;
- Factors related to the researcher include motivation and attitudes to the project, the devices, the patients and the carers.

Use & usefulness are the primary outcome measures. Use of the devices may have further consequences for the patient, the carer and the community. These will depend on the character of the problem (falls at night, forget to turn off cooker, time orientation), the importance of the problem for the patient, the carer and the society and how it affects them, respectively. These are secondary outcome parameters. Outcome parameters marked with \* are used as outcome parameter categories also for the primary carer.

Categories of secondary outcome measures (consequences) are:

- Support independence
- Support feeling of coping
- \*Create pleasure, activity
- \*Reduce general emotional burden due to worries, anxiety, stress or irritation
- \*Prevent unwanted incidents or accidents
- Support memory
- \*Prevent situations creating unwanted negative feelings between the patient and the carer due to stress in connection with e.g. not finding lost objects, repeated questions, passivity

An approach to cost-benefit analysis will be made both on micro and macro level.

## 4. Recruitment of participants and data collection process

### 4.1. Recruitment

The ethical approval for the field study was received from Ethical Committee of STAKES in March 2002. The recruitment was started immediately after that. People were recruited first in two towns, Helsinki and Tampere and later on also in Vantaa. The local Alzheimer's associations in Helsinki and Tampere co-operate in ENABLE as subcontractors for STAKES. They recruited people and did the basic assessments on severity of dementia and device specific needs. In Vantaa dementia care counsellor who worked for local Alzheimer's association Vantaa recruited some participants.

**The inclusion criteria were:**

- People who live in their own home with a diagnosis of mild or moderate dementia according to ICD-10, preferably Alzheimer's disease, vascular dementia or mixed Alzheimer's/vascular types. Patients with sub-cortical dementia may be included, but must be described carefully.
- Age > 50
- MMSE score > 12
- Reasonably good nutritional status and general health; i.e. able to move on their own both within the house and outside

- A primary caregiver who is able and willing to participate. A primary caregiver is defined as that persons or persons who have responsibility for the day to day care needs of a cognitively impaired person. The definition does not exclude carers living apart from their dependent, or those who have additional care/work responsibilities (Stone et al 1987)
- The primary caregiver can either live with the person with dementia or have frequent contact with him/her. Frequent contact means telephone call or visit at least once a week.
- Informed consent given

**The exclusion criteria were:**

- People participating in other intervention studies
- Any major psychiatric disorder
- Active malignancy
- People with fronto-temporal dementia
- Patients without a reliable caregiver
- Nursing home patients
- People on a waiting list for nursing home

Recruitment started in March 2002 in Tampere and in April 2002 in Helsinki. Recruitment was found to be time consuming because of rapidly changing situations in the families and because of changes in participants health conditions. Not all the products had arrived to STAKES from the other ENABLE partners when the recruitment was started in Finland. As the subcontractors were involved in the recruitment it was important to follow up the original time schedule in recruitment. This caused a situation when several families were recruited but they needed to wait for the devices. Some of these families decided not to participate when the products arrived and they were contacted again. For the subcontractors the situation was not easy: they tried to motivate people to participate even if it was not sure when the products will arrive. In addition, recruitment in summer time was problematic due common use of summer houses in country side and this fact caused some delay in the recruitment.

Technical problems in the night lights and the locators have caused drop outs of four families which wanted to cease soon after the beginning. These problems have also caused extra work for the recruitment and for the data collection. Another problem which may be dementia specific was quite low motivation of the persons with dementia and their carers to participate such a trial even if they could agree to have such a problem in their everyday life which might be mitigated by ENABLE solutions.

In Finland altogether 27 participants passed T0 interview but at least as many families were contacted and asked about their willingness to participate. Out of the 27 participants

- 10 tested the day and night calendars
- 11 tested the locators
- 3 tested the telephones
- 3 tested the night lights

All the families which started with the night light wanted to stop participation due technical problems of the lights. No new participants for testing of the lamp were found even if advertisements were published in the local Alzheimer's association's newsletter "Synapsi" and a nation-wide magazine "Muisti". The problem was also unsuitable timing: after the night light was modified to be technically more reliable and to fit better in Finnish circumstances it was summertime when you don't need any light even in night time for some months. Thus, motivation was very low for testing the lamp.

Recruiting people for the use of telephone with photos was difficult because of the very common use of mobile telephones in the country but finally four participants were found. One telephone got broken in the very beginning of the testing and the family decided before the T0 interview not to participate the assessment.

Because of several problems in recruiting enough participants it was decided that also those persons with very mild dementia who lived alone could be recruited if there is a daily contact with a primary carer. This change in inclusion criteria was in accordance with the ENABLE inclusion criteria. The Mini Mental Status examination test gave score from 20 to 24 to the participants who lived alone which means that their cognitive skills were still high.

Altogether 13 persons have participated the assessment of the multimedia product Do-It-Yourself Picture Gramophone. They have been recruited via the day care centres and the person who assessed the device at home was recruited via local Alzheimer's association. These results are reported in another ENABLE deliverable report.

## 4.2. Data collection process

The assessment studies last 12 months and all those who were involved three months were classified as completers. Thus, the main data include experiences during the first three months and the main focus in this report is in that time period.

The international ENABLE project team developed the questionnaires for all the data collection points (T0-T5). These questionnaires were transferred to national studies. Before the data collection was started all the questionnaires were translated in Finnish including Brod Scale for the assessment of the quality of life of the participants with dementia and Relative Stress Scale for assessing the quality of life of family carers. Neither of these scales had been used in Finland before. These two scales were translated by an official translator. When the T0, T1, T2 and part of T3 questionnaires were available in Finnish one day training session was organised for the interviewers. Altogether six persons shared the interviews, two of them took the main responsibility for interviewing in Tampere and four shared interviews in Helsinki and Vantaa. Trained persons carried out all the MMSE tests needed. In T0, T2 and T3 interviews two interviewers were used to make it easier for the family to organise separate interviews for the person with dementia and the family carer. A senior researcher from STAKES did the first T0 interviews with another researcher to ensure that the questionnaire was working well. Altogether 110 interviews were done and the number is actually much higher because both the family carer and the person with dementia were interviewed both together and separately in T0, T2, and T3.

A series of questionnaires comprised to form the final interview schedule. Questions pertaining to quality of life for the carer and the person with dementia, use and usefulness of devices and the socio economic benefits were incorporated to enable analysis of the primary and secondary outcomes defined below:

Scales	T0 Baseline	T1 Post 1 week	T2 Post 3 weeks	T3 Post 3 months	T4 Post 6 months	T5 Post 12 months
Socio-demographic data on patient	X		X	X	X	
Form I A (on product)	X					
Form I B (on outcomes on product)				X		
Form II problem/need analysis interview	X					
Form II.i Willingness to pay			X	X	X	
RUD Interview with carer A1.1, A1.2, A1.3	X					
RUD Follow up questionnaire B1.1, B1.2			X	X	X	

Relative's Stress Scale (Greene)	X		X	X		
Experiences on the product			X	X	X	
Telephone-call Is everything OK?		X				
Telephone-call Is product still in use?						X

**B: Interviewing person with dementia (time 1 –11/2 hours maximum)**

Scales	T0 Baseline	T1 Post 1 week	T2 Post 3 weeks	T3 Post 3 months	T4 Post 6 months	T5 Post 12 months
MMSE (if notavailable from the memory clinic)	(X)					
Socio-demographic data (if possible)	(X)					
Quality of life (Brod)	X		X	X		
Experience with product/overall impression			X	X	X	

After the interviews one researcher transferred the data in the English questionnaires and sent it to Norway for scanning. Later when it was found out that the scanning did not succeed all the Finnish data was put in the computer in STAKES according to the code book developed by the Norwegian Centre for Dementia Research, Work Research Centre and STAKES.

Informed consent was asked from persons with dementia and their carers before the product was implemented. Their willingness to participate was confirmed in T1 interview and in T2,T3, and T4 interviews. Informed consent was asked separately from the person with dementia and the carer and a leaflet about the project was given with the name and contact information of the responsible researcher in STAKES. They were informed tha the participation can be stopped any time.

## 5. Drop outs

Out of 27 participants nine wanted to stop the assessment during the first three months. Two stopped soon after T0 (405, 421), four after one week (408, 411, 432, 437) and three after three weeks (406, 407, 409) (see Figure 1). The main reason for dropping out was technical problems of the devices and another main reason was low motivation of the person with dementia (see Table 1). Two persons need to stop because they moved to institutionalised care, one because of rapid change in his health condition and another because her spouse - and her family carer- died.

**Figure 1 Participation in ENABLE field trial in Finland**

	T0 (N=27)	T1 (N=25)	T2 (N=21)	T3 (N=18)	T4 (N=12)	T5 (N=9)
Calendar FIN401						
Calendar FIN404						
Calendar FIN406						
Calendar FIN422						
Calendar FIN423						
Calendar FIN425						
Calendar FIN426						
Calendar FIN427						
Calendar FIN429						
Calendar FIN435						
Locator FIN402						
Locator FIN403						
Locator FIN405						
Locator FIN409						
Locator FIN410						
Locator FIN411						
Locator FIN424						
Locator FIN428						
Locator FIN431						
Locator FIN432						
Locator FIN437						
Telephone FIN433						
Telephone FIN434						
Telephone FIN436						
Night Light FIN407						
Night Light FIN408						
Night Light FIN421						

**Table 1** Drop out reasons and times in Finland

<b>Participant</b>	<b>Drop out reason</b>	<b>Drop out time*</b>
FIN405	The carer passed away and the PWD moved to the institutional care.	<b>T0</b>
FIN406	PWD moved to the institutional care. Only the carer interviewed in T2 and T3. Calendar	<b>T2</b>
FIN407	All the night lights were sent to Bath, and the family was not willing to continue the testing.	<b>T2</b>
FIN408	The adapted sensor did not function at the bed-room as expected. Night light.	<b>T1</b>
FIN409	The family ceased the participation because Locator did not function.	<b>T2</b>
FIN411	The PWD was not willing to use Locator	<b>T1</b>
FIN421	The night light went on when the PWD was moving in the bed. The PWD wanted to stop the use.	<b>T0</b>
FIN432	The PWD was not willing to use Locator	<b>T1</b>
FIN437	The PWD was too restless to use Locator and did not want to use the device.	<b>T1</b>

\*The timepoint of the last completed interview

## **6. Data analysis**

### **6.1. Quantitative**

All the questionnaire data was put in SPSS file according to the code book and analysed by SPSS. Because of the small number of the participants the analysis is mainly descriptive and based on frequencies and statistical parameters. In cross tabulations we have used only 2x2 tables and analysed statistical significance by Fisher exact test. In the analyses both cross sectional data sets (T0, T2, T3 and T4) and longitudinal data set (T0-T3) has been used.

#### **6.1.1. Cross sectional**

T0 data set has been analysed to find about the starting point of the assessments and T2 and T3 data sets to investigate the outcome of the assessments.

#### **6.1.2. Longitudinal**

The data collected between T0 and T5 have been pooled in one data set to be able to analyse longitudinal outcome of the assessments. Analyses have been done by SPSS.

### **6.2. Qualitative**

All the qualitative data in open ended questions has been transferred in MS-Office documents. The analyses have been done by using Excel files and in further analyses colour coding was used to classify the responses. Because the main value of the qualitative data is in individual case studies the data has been organised in Excel files so that all the qualitative data concerning each individual is in one sheet. Some qualitative data is in the journals kept by some participants. It had been analysed by content analysis.

#### **6.2.1. Cross sectional**

In the Excel files the qualitative data is organised so that cross sectional analyses were possible to made in T0-T5. This data has been used to find out about reasons for dropping out and to understand the context of the main outcome.

#### **6.2.2. Longitudinal**

The longitudinal data is available in the Excel file. It has been analysed by the colour coding and by formulating case studies.

## 7. Results

### ***7.1. Characteristics of the participants with dementia***

During the recruitment approximately 45-50 families were contacted to answer if they were interested in participating the project. Out of them 27 persons were recruited and they all finished T0 baseline interview.

In the beginning of the assessment study all lived in their own home but during the first three weeks one person moved to institutionalised care because his spouse died and another one because her health condition deteriorated. Most of the participants lived with spouse and/or someone else (child or co-habitant). Those who lived alone had someone who took the main responsibility of the daily care. It was either an adult child or a grandchild living next door or in the same town or a combination of paid home help and family care. (Table 2) The gross income of the household varied very much (Table 4) and ten respondents either refused or could not answer the question. Even if nine participants ceased the testing there was no other trend seen in dropping out except the more frequent dropping out of participants whose socio-economic status was blue collar compared to other groups. One person was included and later his diagnosis was confirmed to be frontal dementia but at that point it was agreed in the national team that the person should continue because he willing to continue and he had found the product useful.

**Table 2 Characteristics of the participants in the beginning of the assessment (T0), after three weeks (T2) and after three months (T3)**

	T0 (N=27)	T2 (N=21)	T3 (N=18)	(Drop outs, N=9) <sup>3</sup>
<b>Age in years</b>				
min - max	57 - 86	57 - 86	57 - 86	68 - 81
mean	71	70	70	73
median	70	69	68	71
<b>Gender</b>				
Male	14	11	9	5
Female	13	10	9	4
<b>Socio economic status<sup>1</sup></b>				
white collar	13	13	12	0
blue collar	11	5	3	9
other (housewife, enterpriser)	3	3	3	0
<b>Housing</b>				
living with someone else	22	17	14	8
living alone	5	4	4	1
<b>Diagnosis</b>				
Alzheimer's disease	16	11	10	6
Vascular dementia	2	2	1	1
Lewy Body disease	5	4	3	2
Other <sup>2</sup>	4	4	4	0
<b>MMSE Score,</b>				
min - max	6 - 28	6 - 28	6 - 28	15 - 27
mean	20	20	20	19
median	20	20	20,5	17
No info	1	0	0	1
<b>Severity of dementia</b>				
Mild (MMSE 18-30)	18	15	14	4
Moderate (MMSE 12-17)	7	5	3	4
Severe (MMSE 0-11)	1	1	1	0
No info	1	0	0	1
<b>Medication for dementing illness</b>				
Yes	24	18	16	8
No	3	3	2	1
<b>Goes out alone</b>				
Yes	17	13	12	5
No	10	8	6	4

<sup>1</sup> Classification made according to [http://www.stat.fi/tk/tt/luokitukset/lk\\_en/sosioekon\\_asema\\_89.html](http://www.stat.fi/tk/tt/luokitukset/lk_en/sosioekon_asema_89.html)<sup>2</sup> Alzheimer's disease + frontotemporal degenerative dementia, frontal dementia, hydrogefalus, syndroma psychoorganica<sup>3</sup> Includes only those who dropped out before T3

We had a wide variety in age among the participants: the youngest participants with dementia was born in 1945 and he was 57 when the assessment was started. The oldest participant with dementia was 86. Ten participants did not need help in PALD or needed only very little help but two needed help in most PALD activities. In IADL all the participants needed some help and 10 help in all IADLs. Most of this help was received from family members.

The Brod Scale was used to get information about the subjective quality of life of the participants with dementia. The results show that in the beginning of the assessment studies only two persons rate their overall quality of life as fair and seven rate it to be very good or excellent. The sum score of the different aspects of the quality of life showed similar results after three weeks and three months. (Table 3)

**Table 3 Quality of life of the participants with dementia according to Brod Scale in the beginning of the assessment (T0), after three weeks (T2) and after three months (T3)**

Sum scores	Minimum and maximum of the score	T0 (N=21)	T2 (N=15)	T3 (N=14)
<b>Self-esteem</b>				
Mean		14	14	14
Min	4	7	9	6
Max	20	19	19	20
<b>Feeling of belonging</b>				
Mean		10	11	12
Min	3	6	6	7
Max	15	14	15	15
<b>Sense of aesthetics</b>				
Mean		19	20	19
Min	5	10	13	14
Max	25	25	25	23
<b>Positive affect</b>				
Mean		22	22	23
Min	6	16	15	17
Max	30	28	29	29
<b>Negative affect</b>				
Mean		28	27	27
Min	11	17	17	18
Max	55	36	34	38

Table 3b Overall quality of life of persons with dementia in T0, T2 and T3

Overall quality of life	T0 (N=27)	T2 (N=21)	T3 (N=18)
Bad	0	0	0
Fair	2 (7 %)	1 (5 %)	0
Good	17 (63 %)	12 (57 %)	12 (67 %)
Very good	6 (22 %)	3 (14 %)	3 (17 %)
Excellent	1 (4 %)	3 (14 %)	2 (11 %)
Not answered	1 (4 %)	2 (10 %)	1 (6 %)
Mean	Good (3)	Good (3)	Good (3)
Median	Good (3)	Good (3)	Good (3)

## 7.2. Description of the family carer characteristics

The oldest family carer was 72 years of age and the youngest 28. Because of this very wide age range family carers had very different situations: some had retired years ago while others combined paid work, child care and care of a person with dementia. Two thirds of the carers were women and three out of four were spouses or cohabiting with the person with dementia. (Table 4) Time spend in caring the person with dementia varied very much: one fifth cared the person all the time while most respondents said that caring does not take much time. Several respondents found it difficult to estimate time spent in care because many of them would spend

that time with the person anyway. On the other hand some respondents did not recognise themselves as carers and it was not easy for some persons to accept that their husband or wife is getting more dependent of them.

Most of the respondents were not working and those having a job were working part time except one person with full time employment. Every second carer received a care allowance. Most carers lived in the same household or in very near by: 22 lived in a same household, two in a distance less than 3 kilometres and three in a distance over 10 kilometres. Table 4 shows that most participants who stopped testing before three months lived with the person with dementia.

**Table 4 Characteristics of the family carers**

	<b>T0, N=27, (%)</b>	<b>T2, N=21, (%)</b>	<b>T3, N=18, (%)</b>
<b>Age in years</b>			
min - max	28 - 82	28 - 76	28 - 76
mean	61	60	59
median	64	61	60
<b>Gender</b>			
Male	8 (30)	6 (29)	5 (28)
Female	19 (70)	15 (71)	13 (72)
<b>Relationship</b>			
spouse	18 (67)	14 (67)	11 (61)
cohabitant	2 (7)	1 (5)	1 (6)
child	5 (19)	4 (19)	4 (22)
other	2 (7)	2 (10)	2 (11)
<b>Currently taking medication</b>			
Yes	15 (56)	9 (43)	9 (50)
No	12 (44)	11 (52)	8 (44)
No answer	0	1	1 (6)
<b>Currently working for pay</b>			
Yes, full time	1		
Yes, part time	6		
No	20		
No answer			
<b>Receive care allowance</b>			
Yes	13 (48)		
No	14 (52)		
<b>Gross income of the household, €<sup>1</sup></b>			
<14 999	2 (7)	2 (10)	1 (6)
15000 - 24999	5 (19)	5 (24)	3 (17)
25000 - 29 999	6 (22)	6 (29)	6 (33)
30 000 - 34 999	3 (11)	3 (14)	3 (17)
35 000 - 39 999	1 (4)	1 (5)	1 (6)
No answer	10 (37)	4 (19)	4 (22)
<b>Distance from the patient, km<sup>1</sup></b>			
0	23	18	14
1,1-9,9	1	1	1
10-30	2	1	1
31 -	1	1	1

<sup>1</sup> Question was asked only in T0 and information gathered in T0 is used also in T2 and T3

Relative's Stress Scale was used to investigate the quality of life and a burden of care of a family carer. The results can be seen in Table 5 and it shows that carer's with poorer quality of life were involved in the beginning but by time the quality of life of those involved did not change much. By time those with higher stress score more likely dropped out of the study.

**Table 5 Carers experienced stress due care responsibilities according to Relative's Stress Scale**

<b>Sum Score</b>	<b>T0 (N=27)</b>	<b>T2 (N=21)</b>	<b>T3 (N=18)</b>
<b>0-10</b>	2 (7 %)	3 (14 %)	3 (17 %)
<b>11-20</b>	5 (19 %)	4 (19 %)	4 (22 %)
<b>21-30</b>	7 (26 %)	6 (29 %)	5 (28 %)
<b>31-40</b>	9 (33 %)	6 (29 %)	3 (17 %)
<b>41-50</b>	2 (7 %)	0	1 (6 %)
<b>51-60</b>	0	0	0
<b>Missing</b>	2 (7 %)	2 (10 %)	2 (11 %)
	<b>T0 (N=25)</b>	<b>T2 (N=19)</b>	<b>T3 (N=18)</b>
<b>Mean</b>	27	23	22
<b>Median</b>	28	23	22
<b>Min</b>	5	5	6
<b>Max</b>	46	37	41

### 7.3 Description of care provision

In the beginning of the assessment study five participants received home help services and three persons received meals-on-wheels services. Public health nurse visited three participants. Nine participants visited regularly day care centres for people with dementia and five mentioned that they visit groups in Alzheimer's association. One person received private cleaning services and another one shopping services. (Table 6)

Family members were the most important care providers: all of them gave at least some help in IADLs and two thirds in PADLs and nearly half supervised the person. Approximately two thirds of the participants received some help from their family every day. Half of the respondents received care only from the family carer. (Table 7)

**Table 6 Home help or meals on wheels or community nurse received at home as reported in T0**

	<b>T0 (N=27)</b>	<b>T2 (N=21)</b>	<b>T3 (N=18)</b>
<b>Yes</b>	8 (29,6 %)	4 (19,0 %)	4 ( 22,2 %)

**Table 7 Who else is taking care of the person with dementia besides the primary carer as reported in T0**

(The respondent may have chosen more than one alternative)

	<b>T0 (N=27)</b>	<b>T2 (N=21)</b>	<b>T3 (N=18)</b>
	<b>N (%)</b>	<b>N (%)</b>	<b>N (%)</b>
<b>Family members</b>	10 (37)	7 (33)	6 (33)
<b>Relatives</b>	6 (22)	5 (24)	6 (33)
<b>Neighbours</b>	1 (4)	1 (5)	1 (6)
<b>Friends</b>	2 (7)	2 (10)	2 (11)
<b>No other help</b>	13 (48)	10 (48)	8 (44)

## 7.4. Expectations and motivation

Before the T0 interview all the participants have been discussed with to find out their daily problems and to understand which device could meet their specific needs. Only one ENABLE device was used by each person. When the T0 interview was carried out several questions were asked about motivation and expectations. The answers on these questions are shown in Table 8.

Half of the persons with dementia recognised the problem which was the target of the intervention as either important or very important and carers rated it even more important. In the beginning of the intervention the carers and participants with dementia were asked what they expect about the usefulness of the device. They expected the device be mainly very useful or useful for the person with dementia but the expectations were not so high on the usefulness for the carers.

The crucial question on the motivation was if the person with dementia is motivated to use the device without any costs. Two persons with dementia were not able to answer but all the rest answered yes. All the carers thought that the persons with dementia were motivated to use the product.

**Table 8** Expectations and motivation of the participants in the beginning of the study (T0)

	Not important	Somewhat important	Important	Very important	Missing
<b>How important is the problem which is tried to be solved by the device for the person with dementia (own report)</b>	1 (4 %)	12 (44 %)	10 (37 %)	3 (11 %)	1 (4 %)
<b>How important is the problem which is tried to be solved by the device for the carer</b>	1 (4 %)	10 (37 %)	12 (44 %)	4 (15 %)	0
	Not useful	Somewhat useful	Useful	Very useful	Missing
<b>How useful the device is expected to be for the person with dementia (own report)</b>	0	6 (22 %)	16 (59 %)	4 (15 %)	1 (4 %)
<b>How useful the device is expected to be for the carer</b>	1 (4 %)	6 (22 %)	14 (52 %)	6 (22 %)	
	Yes	No	Missing		
<b>Is person with dementia motivated to try the product, own opinion</b>	25 (93 %)	0	2 (7 %)		
<b>Is person with dementia motivated to try the product, carer's opinion</b>	27 (100 %)	0	0		

Table 9 shows that most participants had several positive expectations for the product in the beginning of the assessments. The expectations were given in a ready-made list with an alternative "other". Because the products were quite different the list of expectations was not the same and in fact not even the same number of ready-made alternatives were given in all the products. In Table 10 the number of expectations is analysed by the participation in the study up to three months.

**Table 9** The number of positive expectations the participants had for the product in the beginning of the assessment, T0 (N=27)

<b>T0</b>	
<b>Positive expectations for the person with dementia</b>	
	<b>N (%)</b>
0	0
1	8 (30)
2	10 (37)
3-	9 (33)
<b>Positive expectations for the family</b>	
	<b>N (%)</b>
0	1 (4)
1	20 (74)
2	4 (15)
3-	1 (4)
No answer	1 (4)
<b>Positive expectations at the community level</b>	
	<b>N (%)</b>
0	2 (7)
1	17 (63)
2	4 (15)
3-	0
No answer	4 (15)

**Table 10** Expectations for the person with dementia on the product in the beginning and participation in the study, data collected in T0

	<b>T0 ( N=27)</b>	<b>T2 (N=21)</b>	<b>T3 (N=18)</b>
<b>Positive expectations for the person with dementia</b>			
	<b>N (%)</b>	<b>N (%)</b>	<b>N (%)</b>
0	0	0	0
1-2	18 (67)	14 (67)	12 (67)
At least three	9 (33)	7 (33)	6 (33)

### **7.5. Installation of the devices and maintenance before T3**

Most of the devices were installed at the end of T0. Many participants were visited several times because the devices were not working as expected. This happened with all the other devices except the calendars. Two out of the four telephones had technical problems and one was replaced by a new telephone. All the locators had some technical problems most of them were caused by the broken tags. These problems started already during the first week. All the night lights had some technical problems but some of them were caused by missing grounding in the bedrooms and requirement of double insulation for the lamps. One family ended up in assessing the calendar but it was obvious that they had more central need for night light. All the visits to the families were done by the researchers. Technical problems were the main reason for ceasing the participation in the study but it was not the only one reason.

## 7.6. Use of the products

When the families were contacted after one week since the installation of the product most of them had used the product (Table 11). If it was not used that was due technical problems (N=2) or because it was not needed (N=2). The question about the use of the product is not easy to answer either "yes" or "no" because for example the locator of lost objects is used only when something is lost but it is ready for use all the time.

During the first three weeks all persons except two had used the product and according their own reporting most of them had used the devices very often. (Table 12) Carer's response on these questions was very similar. Most carers had used the products themselves which shows the type of the devices: calendar, night light and the phone can be used by anyone and the locator was used by both the person with dementia and the carer.

After three months the situation was very similar according to the responses of the persons with dementia: most of them used the products. (Table 11) More radical change had occurred in the frequency of the use: the products were not so frequently used any more. (Table 12) Again the problem in defining whether the product has been in use or not was complex, thus some "non-user" had had the product ready to be used but there had not been need for using it. Carer's own use of the product had stayed common during the last two months.

**Table 11** Use of the products in T1-T3

<b>Pwd has used reported by himself:</b>	<b>T1 (N=27)</b>	<b>T2 (N=21)</b>	<b>T3 (N=18)</b>
Yes	-	18 (86 %)	15 (83 %)
No	-	2 (10 %)	3 (17 %)
No answer	-	1 (5 %)	-
<b>Pwd has used reported by carer:</b>	<b>T1 (N=27)</b>	<b>T2 (N=21)</b>	<b>T3 (N=18)</b>
Yes	23 (85 %)	18 (86 %)	14 (78 %)
No	4 (15 %)	3 (14 %)	3 (17 %)
No answer	-	-	1 (6 %)
<b>Carer has used:</b>	<b>T1 (N=27)</b>	<b>T2 (N=21)</b>	<b>T3 (N=18)</b>
Yes	-	16 (76 %)	12 (67 %)
No	-	5 (24 %)	6 (33 %)
No answer	-	-	-

**Table 12** How often the product had been used by the person with dementia?

<b>Own reporting</b>	<b>T2 (N=21)</b>		<b>T3 (N=18)</b>	
	<b>N</b>	<b>%</b>	<b>N</b>	<b>%</b>
every day/night	13	62	7	39
once a week	3	14	2	11
more seldom than once a week	2	10	1	6
otherways (every other day)	1	5	4	22
no answer <sup>1</sup>	2	10	4	22
<b>Carer's reporting</b>	<b>T2 (N=21)</b>		<b>T3 (N=18)</b>	
	<b>N</b>	<b>%</b>	<b>N</b>	<b>%</b>
every day/night	11	52	5	28
once a week	3	14	2	11
more seldom than once a week	2	10	1	6
otherways (every other day)	1	5	3	17
no answer <sup>1</sup>	4	19	7	39

<sup>1</sup> Includes also respondent who had not used the product

## 7.7 Usefulness of the products

The usefulness of the product was already asked in a phone call for the carer after a week: "What positive experiences you have had with the product or has the product been beneficial for you as a carer or for the person with dementia?" Most respondents reported that it takes time to get used to the product and that they had been trying it. Some reported benefits already. (Table 13)

Interestingly the number of those who reported that the product had been useful did not increase during the next two weeks but the number of those did not find it useful decreased much. This shows that if the participant found the product not useful they very likely stopped participation. After three months since the device was implemented the carers assessed them to be useful for the half of the participants, not useful for every third and no response was received from two carers. The person's with dementia assessed the usefulness of the products in a similar way. (Table 13)

**Table 13** Has the product been useful for the person with dementia?

Own reporting	T1 (N=27)		T2 (N=21)		T3 (N=18)	
	N	%	N	%	N	%
Useful	-	-	12	57	12	67
Not useful	-	-	4	19	3	17
No answer/Missing/Not applicable	-	-	5	24	3	17
Carer's reporting	T1 (N=27)		T2 (N=21)		T3 (N=18)	
	N	%	N	%	N	%
Useful	12	44	13	62	10	56
Not useful	15	56	4	19	6	33
No answer/Missing/Not applicable	-	-	4	19	2	11

The participants with dementia and their family carers were interviewed together about the outcome of the use of the products and the results are shown in Table 14. After three months of use of the products most frequently were reported positive experiences were those experienced by the person with dementia. Positive experiences were reported for family members as well. Several respondents said that it was difficult to estimate the outcome on a community level. The results concerning outcome of the product use are reported in detail in product specific results.

**Table 14** Experienced positive outcomes of the product according to answers by the participants with dementia and their carers after three months (T3)

Number of positive outcomes for the person with dementia T3, N=18	
	N (%)
0	8 (44)
1	4 (22)
2	5 (28)
3-	1 (6)
Number of positive outcomes for the family T3, N=18	
	N (%)
0	7 (39)
1	9 (50)
No answer	2 (11)
Number of positive outcomes at the community level T3, N=18	
	N (%)
0	8 (44)
1	2 (11)
No answer	8 (44)

## **7.8. Improvements of the products suggested by the participants**

Both persons with dementia and the carers were asked about how they would like to improve the products. These are listed below. Because this part of the interview was done together and suggestions were often a conclusion of a discussion the proposals are reported here together without specifying who mentioned them. The text below is a summary of all the answers in T2, T3 and T4 interviews.

What could be improved with the Locator of lost objects? (N gives the number of families)

- tags should be smaller (N=7)
- should be able to use outside (N1)
- should work properly, better reliability (N=4)
- clear buttons in the panel (N=1)
- sometimes you need to press the panel hard, sometimes not, need to be changed (N=1)
- sound should be louder (N=1)
- the plug should be better attached (n=1)
- the panel should be portable (N=2)
- tags should be cushioned or padded to be able to use with walking stick (N=1)

What could be improved with the Day and Night calendar?

- add clock in it (N=3)
- add notice board (N=2)
- bigger text (N=7)
- should be more silent (N=1)
- reflections in the surface of the calendar, should be changed (N=3)
- add year (N=2)
- day and night should change earlier (N=2)
- the contrast should be better (N=2)
- the name of the day is too high up (N=3)
- the calendar should be bigger (N=1)

What could be improved in the Night Light?

- it should work properly
- it should switch off automatically
- the switch off/on button should be found easier

What could be improved in the Easy-to-use telephone?

- could show numbers of the coming call (N=1)
- the handset should have different colour (N=2)
- key switch get caught sometimes (N=2)
- answering machine included would be helpful (N=1)
- keys should be larger (N=1)

## 8. Product specific results (T0-T3 and T4-T5)

### 8.1. Results of the assessment of Automatic Day and Night calendars

Automatic Day and Night calendar (called calendar here) was assessed by 10 participants. The oldest participant was 83 and the youngest 57 years of age (Table 15) and six were men and four women. They had either Alzheimer's disease, vascular dementia, Lewy body disease, frontal dementia and one person's diagnosis was syndroma psycho-organica. MMSE of the participants varied between 28 and 6. The person with the lowest MMSE had quite severe aphasia and thus, it can be expected that MMSE test gives lower score because of symptoms caused by aphasia. This is why he was included in the study but will be excluded from the cross-national analyses. All the participants except one lived with someone and the person lived alone was visited everyday either by a home helper or her grandchild. She also visited a day care centre and the staff was informed about the assessment study and they also followed up if she had any problems with the calendar.

**Table 15** Participants of the Day and Night calendar assessment

CODE	GENDER	YEAR OF BIRTH	LIVING	MMSE	DIAGNOSIS	PARTICIPATION
FIN401	Male	1925	Together	21	Vascular dementia	T0-T5
FIN404	Male	1937	Together	19	Lewy Body disease	T0-T5
FIN406	Male	1931	Together	18	Vascular dementia	T0-T2
FIN422	Male	1945	Together	6	Alzheimer's disease	T0-T3
FIN423	Female	1936	Together	28	Syndroma Psycho organica (levis)	T0-T3
FIN425	Male	1932	Together	22	Frontal dementia	T0-T3
FIN426	Male	1942	Together	26	Alzheimer's disease and frontotemporal degenerative dementia	T0-T5
FIN427	Female	1931	Together	17	Lewy Body disease	T0-T3
FIN429	Female	1934	Alone	20	Lewy Body disease	T0-T5
FIN435	Female	1920	Together	16	Alzheimer's disease	T0-T3

In the T0 interview in the beginning of the assessment of the calendar nine out of ten participants listed at least one incident the calendar has been supposed to help with. Table 16 lists all the incidents mentioned in the interviews. These incidents had caused stress for some of the carers and all the carers expected that the calendar will support memory of the person with dementia. They also expected it to support independence (N=4), prevent negative events which create negative feelings (N=2), to stimulate and comfort. All except one carer expected the calendar to benefit the family but one respondent expected only "minor benefits". In the level of community most respondents said that it is difficult to answer the question but those who gave an answer mentioned "increased independent living", "beneficial for all people with cognitive problems", "makes life easier", "keeps people stimulated and activated".

**Table 16** Incidents mentioned by carers the calendar has been designed to provide help with (T0, N=10)

<u>Incidents</u>	<u>yes</u>
Wander at night	2
Confuse day and night	3
Actions at wrong times	2
Anxiety due time confusion	1
Confuse date and days of week	5
Confuse day and night medication	1
Difficulties in keeping appointments	1
Repeated questions on date	1
Repeated questions on day of week	1
Stays awake at night	1

According to carers' opinions the problems associated to time orientation was very important for one person with dementia, important for four participants with dementia and somewhat important for three. One carer defined the problems not important and one did not answer. One carer agreed that time orientation of the person with dementia was very important for her as a family carer, four mentioned it as important and another four somewhat important, one did not answer and one said the problem was not important.

All the respondents except one who did not answer the question expected the calendar to be at least somewhat useful (N=2) for the person with dementia (useful N=6, very useful N=1). Two carers expected it to be at least somewhat useful for themselves, four useful and three very useful.

The families expected that the calendar would support memory (N=9), help in day and night confusion or help in date and weekday confusion (N=9), to prevent negative events in relationship (N=2) and to support independence (N=4). In addition, one carer expected the calendar to stimulate.

For the family they expected less negative situations because of day and night or other time confusion. On the community level the carers expected the use of such product can increase confidence of persons with cognitive problems and that it could support the work of community service providers.

The calendars were implemented at the end of the T0 interview and the families were called after a week (T1). The calendar had been in use in nine families and five families reported some benefits of the use already. No one reported technical problems with the product.

After three weeks since the product was implemented (T2) eight persons with dementia reported that they had used the calendar and carers reporting confirmed this result. One participant had severe aphasia and he was not able to answer about frequency of the use but all the others told that they had used it every day and/or every night. According to carers two persons with dementia had not used the calendar but if it has been used the use had been daily. Six carers had remind about the calendar but two spouses reported that they had not followed up the use at all. Five participants with dementia had found the calendar useful, one not useful and four did not answer. The carers opinion was more positive: six had found it useful for the person with dementia. Two carers reported that there had been day and night confusion during the last three weeks. Most carers had used the calendar too (N=6).

When reasons for the usefulness or not usefulness of the calendar were asked people with dementia responded (T2):

- I can't see the text without glasses which are always lost.
- I don't not know.
- I do not necessarily need this calendar even though there is a room in my table. I consider it as a nice toy.
- I use to watch the calendar several times a day.

- If I get worried about which day it is.
- One knows which day it is.
- The calendar shows all day long what day it is. "I don't know about past or future, but today it's Friday".

The carers' response was very similar and it is summarised below:

- He can not read the text without glasses. If the letters were bigger the calendar could be useful.
- Not very useful for the wife. The husband has not followed up how often the wife has used the calendar.
- One knows what day is going on.
- The calendar has calmed down the pwd. It has been easier to follow night and day.
- The pwd does not ask frequently what day it is when the pwd is in his room. The calendar is in pwd's room and the smaller one in the kitchen.
- The pwd uses the calendar only short times because she visits in a day care centre every day.
- The small size of the text has limited the use of the calendar. The pwd has been in the cataract operation and her sight is not perfect yet.
- You know for sure what day it is going on.

Three respondents told that they worry about time of the day and seven had looked the calendar in day time and four if they had woken up in night time. Four had problems with seeing the text and two with contrast. The list of improvements seven respondent recommended is given in chapter 6.8.

At this point of time (T2) six participants with dementia would like to recommend the calendar for a friend and seven said that they were satisfied with it. Eight carers were ready to recommend it for other carers.

When participants with dementia were asked about any positive experiences about the use of the calendar 5 answered the question:

- Days are in order.
- I don't remember any situations but the calendar has been used.
- If I alone at home I can see the day and date from the calendar. I use an almanac with it.
- It's important to know what day it is going on, especially in the summer-cottage where we don't get any newspapers.
- When I'm alone the device gives me some feeling of security.

The only negative issue mentioned was that one person had put too many stickers on the calendar to remind herself about appointments but it did not help her.

Carers response on the same questions is summarised below. It can be seen that some carers had been disappointed because the person with dementia had not been motivated or had not been able to understand the function of the calendar.

- "More like negative experiences". My husband can't be bothered to get up from his rocking chair to look at the calendar. Instead he asks me to tell what day it is.
- Difficult to say.
- It gives some kind of support.
- It has calmed the person with dementia for example reading that it's Sunday has decreased the restlessness.
- No need to ask what day and what time it is, you can look at the calendar.
- He does not shout from his room asking the day from the carer. This has set the carer's mind at rest.
- You can see when it is time to take the medication in the morning and evening.

Only one carer reported negative experience: the light of the calendar had disturbed the person with dementia in night. Six carers were satisfied with the product and dissatisfaction was associated to the performance of the person with dementia

*"She checks the date from the newspaper or asks me."* (FIN)

*"He need to be reminded every time."* (FIN)

At this point (T2) the families were ready to pay for such a calendar 10 €(N=2), 20 €(N=2), 30 €(N=1), 40 €(N=1) or 50 €(N=1). One family wanted to stop using the calendar because the person with dementia moved to institutionalised care (FIN406).

Nine persons continued the trial up to three months (T3). As can be seen in a Table below most had used the calendar. The person who did not use it had low motivation already in the beginning even if the carer was highly motivated. One spouse was not able to report whether her husband had used the calendar because she had not followed this issue. The calendar was replaced in her husband's bedroom. Most carers had also used the product.

**Table 17 Has person with dementia used the product, reported in T3, N=18**

Product	yes	no	Total
Calendar	8	1	9
Locator	4	2	6
Telephone	3	-	3
Total	15	3	18

**Table 18 Has person with dementia used the product, reported by the carer (N=17)\*, T3**

Product	yes	no	Total
Calendar	7	1	8
Locator	4	2	6
Telephone	3		3
Total	14	3	17

\* No information N=1

**Table 19 Has the carer used the product (N=18), T3**

Product	yes	no	Total
Calendar	6	3	9
Locator	4	2	6
Telephone	2	1	3
Total	12	6	18

Most of the users of the calendar had benefited the use. Benefits were very much the same as in T2.

**Table 20 Is the product useful or not, according to person with dementia, T3 (N=15)\***

Product	Useful	Not useful	Total
Calendar	6	1	7
Locator	3	2	5
Telephone	3		3
Total	12	3	15

\* No information N=3

**Table 21 Is the product useful or not, reported by the carer (N=16)\*, T3**

<b>Product</b>	<b>Useful</b>	<b>Not useful</b>	<b>Total</b>
Calendar	4	3	7
Locator	3	3	6
Telephone	3		3
<b>Total</b>	<b>10</b>	<b>6</b>	<b>16</b>

\*No information N=2

Below we present two successful case stories of the calendar:

### **Case story 1**

*A man around 60 years of age who had frontotemporal dementia and Alzheimer's disease and mild dementia (MMSE 24). He lived with his wife and children in a flat and was physically very active. He had several problems with time orientation and the most difficult problem for the family was his tendency to wake up in night time and start washing up, cleaning, walking around etc. Sometimes his activities woke up the whole family. His wife was retired and had pains because her musculus sceletal disease. Children went to school or to work early in the mornings. (FIN)*

*One calendar was implemented at the end of the first interview and after a week another calendar was implemented because the wife reported need to be able to use the calendar in day time in their living room or kitchen and in night time in his bedroom. After the calendar was implemented next to his bed he still woke up but came back to the bed after going to toilet. The small light in the calendar made it possible to see text "night" in the calendar when he woke up. Especially the wife was very pleased about the changed situation but the husband was also aware about the problems his symptoms are causing for the whole family and he was also very satisfied with the calendar. The family used the calendar 12 months and wanted to keep it after the trial. (FIN)*

### **Case story 2**

*A woman with a Lewy body disease who lived alone. She had mild dementia (MMSE 20). Her primary carer was a grand daughter who lived in the same town. In addition she received private home help several times a week and she was regular visitor in a day care centre. She was socially very active. She had problems with time orientation and it had caused difficulties for her in following which day it is and what date it is. She was still very independent and the problem with time orientation was causing harm in every day life. (FIN)*

*One calendar was implemented at the end of the first interview. She used it together with the note book and a pocket calendar. In the pocket calendar she marked all the appointments independently or with some help and from the electronic calendar she check which day and date it was. She hardly had any problems with night and day confusion yet. She was satisfied with the calendar and used it 12 months. She kept it after the trial. (FIN)*

The case 3 describe non-successful case:

*(FIN435)Over 80 year old woman who lived with her daughter. She had Alzheimer's disease and MMSE score 16. She stressed in every interview that she find hardly any problems with her memory and that everything is fine with her because her daughter is always helping her. She aske about data and time of day from her daughter as well. Her daughter had different view: mother had problems in most daily activities and needed constantly help. The daughter said that she is very tired about caring her mother (Score in the Burden of scale test in T0 37/60 and in T3 41/60). The daughter was very positive about the calendar and was wishing it to bring positive change in their situation. The mother was not motivated to try the calendar in the beginning but after a short discussion she said that it can be left for them to try if they like it. It was put in the room where her bed was and she said several time that she does not really need one but it can stay there. Her daughter tried to encourage her in using the calendar but it did not help. In the night time the mother did find the light of the calendar disturbing and turned it around. In addition, she was suspicious about the fact that the use of the calendar did not cost anything. Their ceased the participation after three months.*

Four participants (FIN401, FIN404, FIN426, FIN429) were willing to continue the assessment of the calendar after three months (T3). When interviewed after six months (T4) two persons with dementia had used the calendar everyday, one had used every second day and only one said that he had not used the calendar anymore or at least very seldom. Most of them (N=3) considered the calendar useful, one did not know if it is useful or not. Following reasons for usefulness were mentioned by persons with dementia:

- Before I had to ask the date from my wife. (FIN426)
- Especially the calendar has been useful in our summer cottage, because it has been the only thing to check the date. In the morning when I wake up I look at the calendar to find out what day and date it is. (FIN404)
- If I wake up I can check the date and the time. (FIN429)

These four families were willing to continue the testing after T4. When the carers were interviewed in phone after 12 months (T5) three of them said that the calendar is in use at the moment. According to the one carer the pwd has ceased the use of the calendar about couple of months ago. He does not watch the calendar but instead asks about the time from the carer who is tired to always encourage him to look the calendar. There had not been any technical problems with the calendar in any family during this time period. Three families wanted to keep the device.

## 8.2. Results of the assessment of the Locators of lost items

Eleven persons started assessment of the Locators of lost items (called locator here) and six continued up to three months. The youngest participant was 61 years of age and the oldest 86 years of age, five were women and six men. One person had Lewy body disease and all the rest Alzheimer's disease. The lowest MMSE score was 12 and the highest 24. Two participants lived alone and all the others with someone. One woman who lived alone was living next door to her daughter in a block of flats. Another woman who lived alone lived in a same town as her daughter. Both these women were visited everyday by their daughters or another relative.

**Table 22** Locator participants

CODE	GENDER	YEAR OF BIRTH	LIVING	MMSE	DIAGNOSIS	PARTICIPATION
FIN402	Male	1935	Together	20	Alzheimer's disease	T0-T4
FIN403	Female	1920	Together	23	Alzheimer's disease	T0-T5
FIN405	Female	1922	Together	24	Alzheimer's disease	T0
FIN409	Male	1931	Together	16	Lewy Body disease	T0-T2
FIN410	Male	1935	Together	20	Alzheimer's disease	T0-T3
FIN411	Female	1928	Alone	24	Alzheimer's disease	T0-T1
FIN424	Male	1935	Together	24	Alzheimer's disease	T0-T5
FIN428	Female	1916	Alone	22	Alzheimer's disease	T0-T4
FIN431	Female	1941	Together	12	Alzheimer's disease	T0-T5
FIN432	Male	1933	Together	15	Alzheimer's disease	T0-T1
FIN437	Male	1932	Together	?	Alzheimer's disease	T0-T1

All the participants had problems with finding lost items such as eye glasses, keys, wallet, walking stick. In addition, many other things were lost everyday. One person and his carer have many problems in finding clothes. All families reported that they would like to have some help in finding lost objects (N=11), help with stress and anxiety because of searching lost objects so frequently (N=4) and help in need for assistance (N=4). Three families reported increased irritation and two negative relations because of frequent loose of objects. All the carers reported that more time is needed for searching than before.

The families expected the use of locators to support independence of the person with dementia (N=2), support coping (N=7) and to support memory (N=5) and to reduce general worry (N=1). The carers expected the use of the product to prevent stressful situations (N=8) and to reduce time spent on searching. On the level of community the respondents expected that the use of the product could reduce general burden (N=1), negative feelings (N=3) and one carer though that it could increase length of living at home independently.

Family carers defined the problems of losing objects as somewhat important (N=7) or important (N=4) for the person with dementia, and for themselves either somewhat important (N=4) or important (N=7). Thus, the problems was seen more important for the carers but altogether participants had high expectations for the use of the locator. This is seen also in responses about what they expected about the usefulness of the

product: the carers expected it to be either somewhat useful (N=4) or useful (N=7) for the person with dementia and the results were exactly the same when the assessed it from their own point of view.

One family (FIN405) stopped the participation soon after T0 because of the carer of the participant died and she needed to move to institutionalised care.

When the families were called one week after the installation (T1) of the locator four families reported that the product had been used and three that they had found keys quicker. One participant with dementia did not want to use the tags and one family carer told that one of the tags did not work. Three families (FIN 411, 432, 437) wanted to stop participation because two persons with dementia refused to use the locator and also the third person did not want to use the product and he was also very restless (FIN437).

Seven families continued the use of the locators at least three weeks (T2). Six persons with dementia had used the locator and one had not used it because she had not lost any of the keys with the tags. According to the responses of the persons with dementia and their carers one family had used the product every day, three once a week, two more seldom than once a week and one did not answer the question. It had been used for finding keys (N=2), walking stick (N=1) and wallet (N=1). All the persons with dementia who answered the question had found the use easy (N=6). But most of them had been helped by pressing the panel (N=1) or the product had been used together (N=1) or it had been used by the carer (N=1). Only one person with dementia reported that it was difficult to hear the sound of the tags and another that he gets frustrated when the locator is not functioning. Three persons with dementia had found the locator useful for them, three not useful, one did not answer and one found it difficult to say because it had not been in use. The carers response was very similar.

Five participants and five carers were ready to recommend the locator for a friend or for other carers but two found the tags too big for use. Only 3 persons with dementia said that they were satisfied with the product, three were dissatisfied and 2 did not answer. Three carers reported positive events when the locator was used. It had decreased their stress because walking stick, wallet or keys had been found quicker. One carer reported that the person with dementia was able to find keys independently. Only one carer did not report negative experiences. Those mentioned were:

- A couple of times in the night-time the tag has beeped by itself.
- Only the size of the tags is a disadvantage.
- Tags don't always beep even the button has been pressed. On the other hand the beeping sound does not stop even if the tag is picked up, it has to be shaken heavily. Sometimes a tag starts to beep without pressing the button.
- The tag is so big that my husband has difficulties to put the wallet to his pocket. Nowadays he often puts his wallet to my handbag.
- The tag moves back and forth in the walking stick. There should be a way to attach it better. The pwd tries to prevent the walking stick to fall down so that the tag would not get broken.
- When the locator does not operate we find lost objects by looking for them.

Even if carers reported so many negative experiences four were ready to pay for the product between 60-150 € Only one family wanted to stop participation at this point because the locator had not been working (FIN409).

Six families tested the locator three months (T3) and two had found it to support memory and coping. *"you don't get so anxious when you loose something"* (FIN)

From the point of view of the family two respondents told that it had prevented situations with negative feelings. At the community level they had not experienced any benefits. Four families had used the locator but two had not been able to use because it had not been working properly. This had irritated and frustrated the carers and the persons with dementia. In one family the items with the tags had not been lost. (See Tables 17 to 21)

Even if the experiences had not been very positive five out of six families were willing to pay for the product if it worked properly. The price was between 84 to 200 € Five persons with dementia would recommend the product for a friend if it worked well and five carers for other carers. This is very positive result because only three families (pwd and carer) had found the product useful. They had searched keys, walking stick and wallet. These three families had used the product successfully; the items had been found. All the respondents with dementia who could answer the question on whether they found the use of locator easy answered "yes" (N=4) but one said that it was difficult to hear the sound of the tags. One carer reported that pwd had problems with the use of the locator. Only three persons with dementia said that they were satisfied with the products (See Tables 19-21).

*"It should work better."* (FIN)

Three families reported positive experience with the use of the locator. One family had been going out when the carer did not find his wife's keys. The keys were found quickly because of the locator. Two families just reported that less time is used for searching. The negative events reported by four families show the technical failure of the product.

- No other harm but the tags have stopped working.
- No other negative things than not being able to use it (properly).
- The fact that the locator has not worked has caused frustration.
- The tags are inconvenient.

Even if only three families were satisfied with the product altogether five wanted to continue with the product.

Below we present two successful trials:

#### **Case story 1**

*Around 70 year old man who lived with his wife. He had Alzheimer's disease and mild dementia (MMSE 24). He was physically very fit and stayed with his wife in their summer house long periods of time. The family did not have a car anymore and they used public transportation. The man's habit to put things in very unexpected places cause troubles in everyday life. The lost objects were searched together with his wife but the situations were sometimes unhappy because the husband got angry for himself.*

*The locator was implemented at the end of the first interview. The tags were put to a wallet and keys. The keys were kept in a small leather pocket and the tag was too big for the pocket. Even if the family complained about the too big size of the tags they were willing to use the product. By time they reported situations when the product had been helpful in finding the keys and the wallet. Because they spend quite a lot of time in searching clothes for example the product could not solve all these problem. Even if the family was not satisfied with the design of the product and felt that the design limited the usefulness they still wanted to continue the use up to 12 months and were willing to keep the product after the trial. (FIN)*

#### **Case story 2**

*A woman aged 82 who lived with her daughter. She had Alzheimer's disease and mild dementia (MMSE 23). They lived in a big house and the woman used walking stick and had problems with walking and balance. The walking aid was lost very often and that caused problems in every day life because of the big size of the house and because of her increased risk of falling. The locator was implemented at the end of the first interview. Tags were put in keys and the walking stick. During the first days the walking stick felt down and the tag broke. Another tag was added but the same problem was faced again. One tag was modified so that some padding was added around the tag. The sound of the tag was still heard. The locator was used mainly for searching the stick and the family had found it very helpful in that. They were also satisfied with it because it was working in a big house with thick walls. They used the locator 12 months and were willing to keep it after the trial. (FIN)*

Five families continued the assessment of the locator up to six months. They were FIN402, FIN403, FIN424, FIN428, FIN431

Only two persons with dementia had used the locator since the interview three months ago and they had used it only seldom. These two found it useful because it had been easier to find keys, wallet and walking stick. These two also found the use easy and they had used it together with the carer. One person had not lost any items with the tags and she said that she cannot answer any questions but that the locator had made any harm either. In the beginning when the locator was shown to her she asked "What is that?" (FIN)

Three persons with dementia would recommend locator for a friend even if only one was satisfied with it as it was. In addition, three out of five carers would recommend it to other carers even if only one was satisfied with it. Three families said that they would be ready to pay for such a product between 50 to 200 € if it work properly.

The three families which had benefited the use of the locator continued participation in the field trial up to 12 months. In the telephone interview they reported the following issues:

- The locator has not been in use for months. All the tags except one has got broken. (FIN403)
- Even though the size of the tags has limited the benefits (e.g. recently the glasses have been often lost) the device has still been useful. (FIN424)

The pwd and the carer have not used the device because they have felt the big tag uncomfortable. The use of the device has ended already after T3 but at that time they wanted to continue the testing. (FIN431)

### 8.3. Results of the assessment of Easy-to-use telephone

Assessment of Easy-to-use telephone (called telephone here) was assessed by three persons aged 72, 69 and 65. (Table 18) Their MMSE score showed that all of them had mild dementia. Two participants lived alone but both were in a daily contact with their relatives or home help workers. Two had Alzheimer's disease and one diagnosis hydrocephalus.

**Table 23** Easy-to-use telephone participants

CODE	GENDER	YEAR OF BIRTH	LIVING	MMSE	DIAGNOSIS	PARTICIPATION
FIN433	Male	1937	Together	20	Alzheimer's disease	T0-T5
FIN434	Female	1933	Alone	22-24	Alzheimer's disease	T0-T5
FIN436	Female	1930	Alone	23	Hydrocephalus	T0-T4

The participants expected the phone to help with social isolation, make it easier to get help and to make phone calls in general. They also expected it to support feeling of coping and independence. In addition, one carer stressed that they expected it to bring joy and activate social life. For the family they expected it to decrease time spent on checking that everything is ok. A daughter of one participant expected that the new phone would make it easier for her mother to call her. On the level of community one family expected it to reduce general emotional burden and to support social bonds.

One carer found the problems related to ability to use phone as somewhat important and two very important for the person with dementia. One found it somewhat important for himself and two very important. They expected that the telephone will be useful for one person with dementia and very useful for two and that it will be useful for one carer and very useful for the two other carers.

When the families were interviewed three weeks after implementing the telephone (T2) all the participants with dementia had used the telephone frequently. All had found it useful because of the keys with programmed numbers. One participant had been able to call a taxi for himself independently.

Two persons with dementia were satisfied on the design of the telephone but one person had problems with perceiving. All said that the space for a name or text in the keys was large enough and that they had no problems in seeing them. All had had positive experiences with the use of the telephone and one reported some criticism:

- Key switch has got caught and phone was changed to another one.
- The same participant would also have liked to have photos instead of the names.

Altogether all were satisfied with the telephone because

- *"It is clearly better than my earlier phone. I don't have to search telephone numbers from notes or address book."* (FIN)
- *"I don't have to press many keys with numbers."* (FIN)

Two persons with dementia were ready to recommend the telephone to a friend and one did not answer the question.

The carers also reported that all the pwds had used the telephone and so had they. In addition, carers told that the telephone has been in use daily or in every other day by participant with dementia and that all of them had benefited from it.

*"It has made it easier for him to call. The names are clear."* (FIN433)

*"...He has discussed with relatives in the phone."* (FIN)

According to carers the use of the telephone has been easy for two persons and one did not know. The design has been good from the point of view of the pwd according to 2 carers. One person had problems in recognition and the white colour of the telephone had caused problems for him. Two carers recommended improvements and they are in paragraph 6.8.

All the carers mentioned positive experiences:

- The pwd has called by himself to his relatives and friends. He had not called anymore with the old phone. The pwd answers the phone as he has done before with the old phone.
- The pwd makes a call right away if she has some problem.

Carers did not report any negative experiences in T2 but one carer said that

*"Nothing has changed between the communication with phone with me and my mother".* (FIN 434)

The respondents were ready to pay something for the telephone but only one said any price which was much higher than the price paid (100 €).

All the families continued the telephone use and they were interviewed again after three months of the installation. At that point of time (T3) they had experienced that communication with friends and relatives has been easier and that the new telephone had supported feeling of coping. (Tables 17-21)

Two had experienced benefits for the family and one benefits on the level of community.

At this point of time (T3) all the carers were willing to pay for such a telephone either 35, 50 or 100 €. The carer who lived in the same household had used the telephone themselves as well and the use had been daily or nearly daily. Two participants with dementia had used the telephone either daily or every other day and one did not answer. According to pwds the telephone was still useful and easy to use for all of them because

*"I can only press one key..."* (FIN)

*"Really useful because it is so easy to use."* (FIN)

Only one of them was not satisfied with the size of the keys and she had problems with seeing the text. They all were ready to recommend it for a friend. All of pwds had had positive experiences and no negative experiences were reported. Overall everyone was satisfied with the phone.

At this point it became evident that if a person with dementia did not live with someone it was impossible to get reliable information about the phone use:

*"I don't know which way my mother uses the speed dialling buttons."* (Carer FIN 343)

The same carer said that it's impossible to really say if her mother was benefited from the new telephone because she is not calling more frequently to the daughter than before.

All the carers mentioned positive experiences (T3):

- I can trust that my sister (the person with dementia) can get on to me.
- My husband can make a call by himself. He calls a taxi to the local Alzheimer group by himself. (Although the carer says that usually she have to invite him to make a call.)
- There are not so much good, simple phones in the market these days

Two carers mentioned negative experiences in T3:

- In one day the phone did not worked.
- My mother (pwd) has picked up the phone and answered as she has done before (but not called).

Below we present two successful case stories, but in fact all participants could have been presented here as such.

#### **Case 1**

*A woman who lived alone and had hydrocephalus and mild dementia (MMSE 23). She had great problems in moving and needed much help in her every day activities. She received home help every day at least two times and her sister and some other people called her every day. She was also visited during the weekends. She had four phones at home, one of them was a mobile phone and another one a phone in which she could program numbers. The keys in these two phones were getting too small for her and she had problems with dialling. The phone was very necessary for her and she was very motivated to try an easy-to-use telephone. She lived in a rural area. The telephone was implemented at the end of the first interview and it was used in her bedroom. After some weeks the telephone did not work any more because one of the keys was stuck. The telephone was replaced by a new one and the trial continued. She has been satisfied with the telephone and it is the main phone she uses. The telephone has been in use by so far seven months and the trial is continuing. (FIN)*

#### **Case 2**

*A man over sixty years of age who had Alzheimer's disease and a mild dementia (MMSE 20). He lived with his wife in a flat and some services were quite far away from home. He had some problems in talking but his main problems were in recognition, moving and time orientation. He was able to go to a day care centre independently by a taxi. His wife found it problematic to leave him at home alone when she needed to go shopping etc. She had bought a mobile phone for herself to help keeping contact with him when she was out. The husband did not call anymore independently and not always answered the phone. He had dialled wrong number several times and it had caused harm for himself. The new telephone was implemented at the end of the interview and it was the only one phone they used. Some numbers were programmed and a colourful tape was taped in the handset to help recognition of it. (FIN)*

*The man was able to use the telephone independently and he for example called a taxi for himself one day. The wife found that she was more able to contact the husband when she was out. The family was very satisfied with the telephone and used it 12 months. They have kept it after the trial.*

All the three families continued the use of the phones up to 12 months and all of them wanted to keep the phones afterwards. When interviewed after six months (T4) two of the pwds and two of the carers said that the person with dementia has used the telephone daily. In one family the pwd has used the phone more seldom than once a week. All the carers and pwds considered the product useful.

*"Of course. This is so practical"* (person with dementia, FIN436)

*"The persons I usually call to are programmed to the keys so I don't have to look for their phone numbers"* (person with dementia, FIN343)

The carers were willing to pay 50 € at maximum for this kind of telephone .

At the moment two participants has tested the phone 12 months and both of them has wanted to keep the phone. One testing is still going on.

#### 8.4. Results of the assessment of Automatic Night Light

Because of several technical problems and difficulty to find participants for assessing the automatic night light (called night light here) only three persons passed T0 interview (Figure 1). All the night lights were sent to Bath, UK for changing the insulation system but no family was willing to continue after that. The night lights had other technical problems as well and the families wanted to cease the testing because of that. Other problems were: one night light was twinkling when it was dark, another one went on when the spouse moved in a double bed. In addition, several families were interested on the assessment but the sensor did not fit in their beds. The sensor was designed for beds with round legs and it was found out that most candidates had very different bed legs. One family used the night light till it was sent back to Bath and their experiences are reported below as a case study.

**Table 24** Automatic night light participants

CODE	GENDER	YEAR OF BIRTH	LIVING	MMSE	DIAGNOSIS	PARTICIPATION
FIN407	Female	1930	Together	15	Alzheimer's disease	T0-T2
FIN408	Female	1921	Together	16	Alzheimer's disease	T0-T1
FIN421	Male	1934	Together	27	Lewy Body disease	T0

Because all the trials needed to be stopped because of technical problems we report only the base line information of the participants as case stories:

##### Case 1

*The participant FIN407 was 72 years of age and lived with her husband. She had Alzheimer's disease and his MMSE was 15. The family did not receive any home help and the husband spend approximately 3.5 hours per day in helping his wife and they daughter helped them weekly half an hour. According to the family carer they had not had any problems in the night time yet and because it was spring and night were getting lighter they expected the night light to benefit them later in the autumn. They were willing to test the night light because the wife wakes up and goes to toilet in night time. They expected the night light to help in finding back to bed and increasing safety because you could see better. The husband expected the night light to decrease stress for himself because he did not need to wake up and worry about how his wife can cope.*

##### Case 2

*The participant FIN408 was 81 year old woman who lived with her husband. She did not go out alone and according to her husband "She forgets everything new". Her diagnosis was Alzheimer's disease and her MMSE score was 16. They lived in a block of flats and get home help only one and half hour per month and the husband did all the caring. The wife managed with all the PADLs but needed help in shopping, cooking, cleaning etc. The husband found it difficult to estimate how much time this type of support takes from him but said "I do it all the time". The wife had problems with heart and difficulties in walking. She confused day and night and had once left their apartment in a night and her husband woke up when she rang the doorbell. She is often active in night time. They expected the Night light to help in finding back to bed and in giving enough lightning. The husband had problems in hearing and he expected to wake up when the light goes on. They both agreed that the problems in night time are important for them and expected much benefit from the night light. The sensor was modified in UK to fit in their bed leg and this caused some delay for the starting of the evaluation after T0 interview.*

## 9. Discussion

### 9.1. Recruitment

The recruitment was more difficult than expected: motivation of people with dementia and even the family carers towards trying a new product was often found to be low. It was also found that many family carers were not motivated either if they had severe difficulties in coping with their care responsibilities. Luckily some people were ready to try the products but there were several families who reverse their participation before the first interview. The fact that the products arrived to STAKES later than expected cause more difficulties for the recruitment: it was difficult to motivate the subcontractors to recruit when it was unclear when the products will arrive. When the products arrived many locators and night lights did not work as expected. This caused more delay but the more important impact of this was confusion of the subcontractors who had worked hard to find the participants. Unreliability of the products which was seen also later in the trials made it difficult for the subcontractors to recommend the products for their customers. They also expressed their worry about their reputation if the trial will cause harm for the participants because of failures of the technology. This worry was realistic for example because in one family they woke up several times per night because the night light was going on and off if they moved in their bed.

In addition, the night lights arrived so late in spring to STAKES that nights were already very light in Finland. This delay was partly caused by the fact that a double insulation was added to the lights. After the lights were changed to have double insulation it was found out that hardly any older flat or house have a wall socket for that kind of plugs in bedrooms. The recruitment did not success mainly because of the time of the year but another reason was the shape of the sensor (detector): it did not fit into beds of several families. This is an example of cultural differences which are not easy to figure out beforehand.

Because of these several difficulties we changed the recruitment method to be able to find more participants. Enough participants were finally found to be able to carry out the assessment tasks. In addition, the variety of the participants was large and could give us a good overview of this user group.

### 9.2. Methods used

The questionnaires included many areas of life and the interviews were long. For some people with dementia they were too long: when the Brod Scale was asked at the end of the interview many were too tired to concentrate on the questions. Some questions were also difficult to answer for the carers, especially the those about time spent in different actions. Some questions were found peculiar, for example the question about household income and repetition of the nearly the same questions in about expectations, usefulness and benefits.

Even if the questionnaires were long some questions would have been helpful especially when trying to estimate whether people had benefited the use of the products. For example specific questions about how much time is used in finding lost items before the Locator and after starting to use the Locator or a getting a detailed picture about problems in using an ordinary telephone and what specific problems were solved with the new phone. This would have required more standardised set of questions for each stage and it may have turned the questionnaires too long. One aim of ENABLE was to investigate if quality of life of people with dementia and their carers could be increased by the use of enabling products. The methods used can partly answer the questions but a more further conceptualisation about what is meant by quality of life in these contexts would had been helpful in answering the question.

The most positive aspect about the methods used was the involvement of the person with dementia in decision making and in providing information. This data gave us very original information about the

perspective of the person with dementia on this kind of interventions but also on their quality of life and coping with every day life. This data should be carefully analysed and published.

In the beginning of the trial the follow up period was one week, then two weeks, then two months and a week, then six months and again six months. We found the follow up period good in the beginning and too long when it was more than two weeks. More frequent telephone calls would have been very useful in understanding the changing situations of the families. This would of course cause far more work and it may have required cut of numbers of the participants.

### **9.3. Results**

The results show that at their best enabling products can have very positive impact on lives of people with dementia but at the same time they show that if the product fails it can cause stress and harm for the family. Results also describe the process of having an illness causing dementia symptoms. In mild dementia many people understand their situation and are very anxious about it but by time their understanding about having such an illness may gradually disappear. According to our results enabling products may be most useful for those people who still are able to recognise their cognitive problems. The results also suggest that the motivation of the person with dementia is most important: if it lacks not even a high motivation of the carer can help (see also Nygård, L. & Johansson, M. 2001).

According to the results the implementation phase was much longer than expected. This is mainly because of several technical problems but it is in accordance with previous studies (Leikas et al. 1996; Harinen 2002). The usefulness of the products did vary very much and a further analysis would be helpful in understanding impact of the use of the technically more reliable products on the quality of life. The calendar was technically very reliable and the results of the trial showed that if the needs of the person are carefully assessed and if the person is motivated to try the calendar it can be useful in reducing the problems of time orientation.

The carers were sometimes very frustrated with the technical failures of the products. This is very important to remember when further analyses are planned on the quality of life and the use of the products. It is also a clear sign that not only the person with dementia may suffer from failing trials but also the carer can have negative feelings. When the quality of life and use of the products are analysed it may be necessary to focus on those products which did not have so many technical problems. The qualitative results show that some participants benefited so clearly that it had an impact on their quality of life but whether this is shown in general quality of life scale such Brod Scale is unlikely. In our sample the Brod scale showed that those persons with the lowest quality of life score most likely stopped participation in the trial. Similarly carers with lowest quality of life score according to Relative Stress scale more likely stopped participation than the others. Thus, quality of life information is very valuable in understanding reasons behind success or failure of the trial participation.

### **Product specific results**

#### **Discussion of the Calendar**

- It would have been important to define requirements for seeing in the list of inclusion criteria.
- Some people clearly benefited either the day and night function or the date and week day functions
- Some people with a clear problem in time orientation refused the use of it. This underlines the need to understand the right timing for introducing this kind of a product. The persons who refused seem not to understand their inability in time orientation and thus they did not recognise any need for such a product.
- If the person with dementia was used to ask day and date from a carer and if he did not recognise this as any problem it was not easy to change but in one case it worked successfully.

- The motivation of the person with dementia was crucial for the successful use, the motivation of the carer was not so important.
- Reflections of the glass and small size font and/or poor contrast caused severe problems for some participants in seeing the texts.
- One calendar was not always found to be enough as there was a need to see it both in day time and in night time.

### Discussion of the Locator

- The locator seem to work well even in a big house but as it was not possible to use it in a garden this was found not motivating (keys were quite often lost outside, in garage etc.).
- The product was not technically ready for field testing. This caused harm for the participants and made it nearly impossible to figure out benefits of such a product in several families.
- The need for such a product is obvious: the participants were highly motivated in the beginning.
- Because of technical failures not even all highly motivated participants were able to benefit.
- Some families got over the technical problems and had a product which was working clearly and they benefited from it
- only in one family low motivation of the person with dementia to use such a product was pointed out but even here it was related to technical failure of the product not the main function of it.
- The product can obviously work as a design for all product: it can be used by anyone

### Discussion of the Telephone

- The results were most positive of all but the number of users was very low.
- The phone is not a new device: It is only slightly different from the others and it is used for the same purpose than ordinary phones that may partly explain the very positive results and no problem in motivation.
- There were some technical problems but they did not cause any drop outs.
- By minor changes in the design it can be easier to use for persons who have problems in recognition.

### Discussion of the Night Light

- So many technical problems that there are no results of the assessment study.
- The baseline information show that there is a need for such a product.
- The recruitment fail because of the time of the year when no lights are needed in Finland and because of the shape of the sensor (detector) which did not fit in beds in Finland.
- Further development of such a product need more information about cultural differences.

## 9.4. Emerging themes

Several people expressed they worry about their illness. Those respondents who did not feel that they had any dementia did not express any special worry, but discussed about very concrete issues. Several respondents were happy about their family members taking care of them and loving them. For many respondents nature, being in summer cottage etc. was very positive.

Some carers expressed how tired they are about being always available for the user. They mainly worried how long they will be able to continue to care for their family member. Some carers were also trying to get more information about different alternatives (respite care, rehabilitation, technology). It became obvious that there is a lack of knowledge about the basic services available.

Being involved in a trial was mainly mentioned to be positive. For example one person who lived alone called the interview "You are like a sunlight for me. Welcome again". The carers were in most cases very positive about having a visitor and coffee was nicely served in many families. Even when the product did not function humor was used to get over disappointment. Some persons also expressed that they find it important to be able to help in developing products for the younger generations. This aspect should also taken into account when designing the future studies: personal contacts are much valued and aims of the trial need to be clearly expressed.

How to motivate a user to try a device was sometimes not a question at all but in some families it required a lot of discussion. A need for a specific solution was recognised before the family was met for the first time but even so the main question which raise was how to get the situation relaxed and a person with dementia to feel that there is nothing hidden from him. However this was not always associated with the usefulness of the device but the whole situation and the symptoms of the person with dementia and his/her personality. Need for right timing and right expressions in introducing the product were clearly seen in the study.

In one family the carer was not motivated at all and in other family the carer was ignoring his wife's illness. In these families the carers did not support the use of the device but this was not associated with the usefulness of the device. If the carer was tired and the researcher knew that the device planned for this family was not very reliable (locators and night lights) it was not very easy to leave the device. This combination was later shown to be one of the main reasons for drop out even if the families were encouraged to contact and tell if there are any problems. If the carer and the person with dementia got well together then the whole process was much easier to go through.

Problems with the products were the main reason for drop outs. As the products did not work as they should have done in the beginning (locators were broken, lights went on when a person turned in the bed, calendars felt down, keys of one telephone did not always work) this had an impact on researchers motivation and on the motivation of the subcontractors in recruiting the families.

We had several people involved in interviewing but we did not find any systematic difference between the results. It was agreed that the task of the researchers is to listen to the participants and not to give their opinion about the products etc. The products were introduced as prototypes (except the telephone) and the families were encouraged to contact the researcher if they had any problem. Understanding about symptoms of dementia and sensitivity about the topic seem to be most important for getting the interviews successfully completed. The group involved had a good knowledge in dementia and skills helping them in discussing some sensitive issues.

The results in Finland will be distributed in several scientific articles and posters in Finnish in 2004 (Manuscript "First Finnish experiences of Brod Scale"; manuscript "When can a time aid help a person with dementia who lives at home?" are under progress and will be presented in spring 2004). A further national analyses will be carried out and presented there.

## 9.5 Ethical concerns

- Main ethical concern was the failure of the products.
- One concern was the extensive length of the questionnaire and concern that not all the information may not be used.
- One concern was those people who lived alone: what if they have problems with the product? How reliable is the information gathered from them and their carers? The previous three national studies had risen up the risks of technological interventions when people with mild to moderate dementia are involved. In one study (Leikas et al. 1996) features of the technological surveillance systems caused stress for people with dementia when they were alone at home or if they lived alone. The technology used included several detectors and telephones with loud speakers. The telephone line could be opened after any alarm was received. In some cases one even could ask whether the technological intervention caused more harm than benefits. Another study by Harinen 2002 showed similar results: the technological intervention was stressful for the persons with dementia who lived alone even if the intervention carried out was part of their regular home care services and they were not expected to actively use the products. The technological system used was based on different detectors following up stove, smoke, problems with balance, going out and restlessness of the person. Finally our own previous study on easy-to-use telephone (Topo et al. 2002) similar problems were faced. Even if only people who lived with someone were included one person got stressed and got hallucinations associated to photographs in the phone and another person was not able to place the handset properly after the phone call and thus, the line stayed busy.
- The fact that the families were able to keep the products solved one ethical concern (see Rauhala & Topo 2003).
- Use of the telephone caused costs but this issue was not discussed in the project: should they be covered? The use of the calendar and the night light used electricity and some persons were concerned about it. The new telephone aim to support one's abilities to call but in fact it cannot solve problems associated to short term memory and this may had caused rise in phone bills because of repeated calls (see Topo et al 2002). If the costs would have been (partly) covered these problems may had been avoided.

## 9.6. Conclusions

Enabling products have potential in supporting people with dementia who live at home but this requires high quality products and good skills of professional in finding out when the person could benefit a product. In addition, a follow up is needed in figuring out the situation and possible problems of the product. Enabling products cannot solve all the problems people with dementia have in their every day life but at their best they can mitigate some of them.

## 9.7. Recommendations for the cross national analysis

The following issues are important to investigate

- quality of life of person with dementia and the carer need to be emphasised.
- include only product which did not have several technical problems in analysis of the compliters vs. drop outs
- analyse quality of life of those who clearly benefited the products between T0-T3/T4

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