



Night and Day calendar case stories

From the assessment trials carried out in the ENABLE¹ project in Norway
Ireland, Finland, England, and Lithuania

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Table of content

Table of content	2
Summary.....	2
ENABLE Assessment trial.....	2
Night and Day calendar case stories	3
Cases from the assessment trial in Norway.....	3
Case 304: Useful, but should have got the calendar earlier?	3
Case 305: Not useful, did not understand what the calendar was.....	4
Case 306: Useful now and then, dependent on the user’s wellbeing.....	4
Case 311: “...feel safer...”	5
Case 314: “It is a good help for me”	5
Case 317: The user could live in own home for longer	6
Case 319: “If the calendar shows Night I turn my head and sleeps”	7
Case 322: Useful?	7
Case 326: One calendar in the sitting-room and one by the bed-side.....	8
Case.calendar: No calls nor visits at night.....	8
Reasons why an assistive device is useful or not.....	9
Factors of importance for the outcome	10
References.....	11

Summary

The ENABLE project concluded that assistive technologies can facilitate independent living of people with dementia and promote their wellbeing. Thirty-seven case stories recorded by the researchers in the five participating countries illustrate the different situations and circumstances one needs to take into account when doing a user needs analysis. By analysis of the case stories factors that one needs to consider have been identified. The ENABLE project recommended that guidelines for user needs analysis should be based on the factors identified as important for the outcome. It was further recommended that assistive devices for people with dementia should be implemented as early as possible. Systems to secure this should be addressed by decision-makers at national as well as local level.

ENABLE Assessment trial

The aim of the ENABLE project was to examine whether it was possible to facilitate independent living of people with dementia and to promote their wellbeing through access to enabling technological systems and products. People with dementia living in their own home tried one device aimed to solve or reduce a problem they had in their daily life.

People with dementia and their family caregivers were recruited to the study from memory clinics, the Alzheimer’s Societies in the respective countries and through health service professionals and other service providers. People with dementia and their family

caregiver were interviewed before implementation of the assistive device and after 3 weeks, 3 months and 6 months. Case stories were written both from successful and unsuccessful experiences with the product.

Night and Day calendar case stories

Many people with dementia cannot keep track of the day and the time. Some people mistake night-time and day-time and may go out or phone relatives in the middle of the night. This may be embarrassing or even dangerous for the person with dementia and worrying and stressful for their carers. Carers are also often stressed by frequent questions as to what day or time it is. This can be very irritating and lead a negative effect on the relationship between the carer and the person with dementia.

As the Lithuanian study points out,

...this may have severe consequences for a person since it is the basis for structuring one's life.

The Night and Day calendar aims to support the person by showing day, date and whether it is “Morning”, “Afternoon”, “Evening” or “Night” on a display. The day, date and time is set correctly by the manufacturer and a back-up battery secures that the correct information is shown on the display when the calendar is connected to the mains in the user's home. Case stories demonstrating positive, neutral and negative outcome with the Night and Day calendar are from the assessment trial in Norway, lead by occupational therapist Torhild Holthe, Norwegian Centre for Dementia Research.

Cases from the assessment trial in Norway

Case 304: Useful, but should have got the calendar earlier?

Background Widow, 88 years old, MMSE 23, Alzheimer's disease, lives alone in a flat.
Problem Forgets about appointments, doesn't remember day or date, asks frequently about this. Calls family carer (son) early in the morning about day and date. Has twice (to her son's knowledge) been confused about time of day. Does often mislay wallet and keys. It is often dark in her apartment because she disconnects the plugs and she isn't able to reconnect them. (Probably in order to save electric energy).
Product Night and day calendar
Implementation She wanted the calendar to hang on the wall by her dining table, where she often sits. The calendar was hung on a certain spot to avoid/minimize glare/reflection in the screen.
Result The calendar was perceived as useful to her. She felt it supported her self-esteem. Sometimes she forgets to look at it. Family carer said she should have had the calendar one year earlier. The patient ended participation in the study after 3 months participation (between T3 and T4) because she moved to a nursing home.
Conclusion The calendar was found useful these three months. Son wished she had had it earlier.

They suggested better letters and numbers (better contrast) and a screen without reflection as improvements of the product.

Case 305: Not useful, did not understand what the calendar was

Background
Woman, 76 years old, MMSE 16, Alzheimer's disease, married, lives with husband in a flat.
Problem
Forgets about day or date, asks frequently about this. Calls family members at wrong times of day. She is worried about how the disease may deteriorate. Husband is doing "everything" in the house.
Product
Night and day calendar
Implementation
She was shown the calendar, while sitting in the lounge, and then she was able to read the text on the screen. The calendar was first put on a drawer in the sitting room, but she paid little or no attention to it. The husband moved the calendar into the bedroom after a few days and put it by her bedside as she may benefit from the information at night, instead of waking him up.
Result
When the woman woke up at night, she did not recognize the calendar, and she was worried about the "green light" in the display. She woke her husband to ask what it was. She was not able to read the text from other angles. (she could only read it when it was right in front of her)
Conclusion
The calendar was found not useful and dropped out of the study after 10 days time.

Case 306: Useful now and then, dependent on the user's wellbeing

Background
Man, 82 years old, MMSE 22, mixed dementia, widowed, lives alone in a flat. Daughter is family carer
Problem
Forgets about day and date, problems in knowing what day and date it is and night-time from day-time. Impaired vision and hearing.
Product
Night and day calendar
Implementation
The calendar was placed on a table close by his chair in the sitting room.
Result
The man found the calendar useful to him. The daughter was more in doubt. She was not sure that her father used it without being reminded to do so. She also feels that the calendar is difficult for him to read because of low contrast.
Conclusion

The calendar was found useful to some extent. Possibly the use and benefit of the calendar varied with how the man felt from day to day. The man found the calendar useful, the daughter was not sure. They wanted to keep the calendar.

Case 311: “....feel safer...”

Background

Woman, 82 years old, MMSE 19, Alzheimer’s disease, lives alone in a flat. Frail person, uses a walking cane with wheels in order to walk. Only relative (family carer) lives 4 hours drive away. Visits from social worker make her happy. Attends a day centre 4 days a week. She has a note on her door telling which days to go the centre, and that she should not leave the flat unless the driver has called at the doorway. Receives help from home nurses every day.

Problem

Forgets about day and date, and time of day. Has been waiting for the bus to take her to the day-centre in the evening. Has called family carer 5 in the morning. Sleeps with her clothes on. *“I am getting blunt – is it really this day today?”* Doesn’t know when /which day to go the daycentre.

Product

Night and day calendar

Implementation

The calendar was placed in the bedroom, on a table by her bedside.

Result

The calendar was useful. She can orient herself about time of day in peace and quiet. She talks about the calendar in a way that shows that she is aware of it and that it means support for her. She doesn’t call family carer at night/early mornings any longer. *“First of all it make me feel more secure – earlier, I felt that I was dangling in the air..”*

Conclusion

The calendar was found useful to her. It provides security. The letters are modern and can be difficult to read, should have been in block letters (capitals) and bigger. Both patient and carer is content with the calendar. The woman moved to a nursing home and brought the calendar.

“ I am now getting used to the modern letters...”

Case 314: “It is a good help for me”

Background

Woman, 89 years old, MMSE 12, vascular dementia, widowed, lives alone in a house at the countryside. She is frail. Poor balance. She tells me she is tired most of the day, and takes a nap every now and then. Becomes tired after dressing. Spends much time alone. Likes to watch TV. Likes her house and feel safe here. Happy that her daughter lives nearby and comes to see to her a couple of times every day. Daughter is family carer and lives in neighbourhood. (couple of minutes walk). Daughter works part time and is quite burdened by the care.

Problem

Forgets about day, date and time of day, problems in knowing names of relatives and friends, forgets appointments at the GP. Impaired hearing. Asks frequently about day and time of day, and the daughter is tired of these questions.

Product

Night and day calendar
<p>Implementation</p> <p>The calendar was placed on a table in the sitting room. She could easily see it from her best chair, from where she used to watch TV and read the paper.</p>
<p>Result</p> <p>The woman found the calendar useful. The daughter: <i>“Mum hasn’t asked which day it is since she got the calendar. In that way it is a relief for me too!”</i> Once, she visited her mother late at night. Mother was sitting in the dark and watching TV. She said: <i>“Look – I am sitting here and watching the calendar – and it doesn’t say night yet!”</i></p> <p>At T2, the woman told that she found the calendar useful: <i>“It helps me a lot – It was unpleasant to sit here, not knowing whether it was Sunday or Monday...”</i></p> <p>The woman said she would like to have one calendar by her bedside as well, and she was provided with one. The daughter told that mother never had mistaken night and day since she got the calendar. But she might have problems reading all the letters. i.e. V could be interpreted as U, and the daughter suggests better contrast of the display as an improvement.</p>
<p>Conclusion</p> <p>The calendar was found useful. Once, the calendar showed odd squares instead of letters and numbers, - the daughter unplugged it and re-plugged it, and then it worked as it should. When the patient was offered a room in a care facility, she would probably still benefit from the calendars, however, the daughter insisted they were no longer needed as the care facility had staffs that could remind her mother of days and time of day. The woman dropped out of the study shortly before T3 (3 months after implementation).</p>

Case 317: The user could live in own home for longer

<p>Background</p> <p>Woman, 87 years old, MMSE 18, unspecified dementia, widowed, had recently moved into a flat in a seniors’ centre. Impaired hearing and uses a hearing aid. Uses a rollator.</p>
<p>Problem</p> <p>Forgets about day, date and time of day. Asks frequently about day and time of day, and sometimes she calls her children at night or several times a day to know day and time of day. The son is tired of these calls, because he needs to collect strengths for his working day. The night staff at the centre said that the woman did not fit in, and rather should be transferred to a nursing home, because she walked in the corridors at night and wanted to visit other residents. The night staff was afraid she would wake up the residents by her behaviour.</p>
<p>Product</p> <p>Night and day calendar</p>
<p>Implementation</p> <p>The calendar was placed beside the telephone on a drawer in the bedroom. Her son said in a serious voice that she was not allowed to dial when the calendar showed night.</p>
<p>Result</p> <p>The woman found the calendar useful. She did not call her son or daughter after having the calendar. She can read it, even though the reflection sometimes can be disturbing. Neither had she left her flat at night to visit other residents, after having the calendar. Night staff is happy with that.</p>
<p>Conclusion</p>

The calendar was found useful by the woman and by her family carers and staff at the centre. Placement of calendar must be paid attention to avoid reflection in the screen. Son suggests better contrast (red letters on black background) as improvement.

Case 319: “If the calendar shows Night I turn my head and sleeps”

Background

Woman, 91 years old, MMSE 25, unspecified dementia, widowed, had recently moved into a flat in a seniors’ centre. Uses a wheelchair. Attends a day-centre 4 times a week. Feel bored during the weekends. Loves car riding, and to look at the scenery and surrounding changing after time of year.

Problem

Forgets about day, date and time of day. Asks frequently about day and time of day, and sometimes she calls her children at night or several times a day to know day and time of day. Her daughter is tired of these calls, and says they are burdening and stressful, because she often has to drive to see that everything is OK with the mother.

Product

Night and day calendar

Implementation

The calendar was placed beside the telephone on a small table in the sitting room. The cord was hidden behind the sofa in order to not being unplugged. She also asked for one in her bedroom, which was installed a few weeks after T0.

Result

The woman found the calendar useful. She did not call her daughter that often after having the calendar. The woman shows the calendar to all visitors and several of the staff was very enthusiastic about it. She said: *“If I am in bed, and wake up, I can look at the calendar and if it says NIGHT, I turn my head and sleep on...”* The daughter said that *“the calendar is very useful for mum, she can easily update herself on day and time of day, and it gives her the feeling of being able to cope I think. The calls from mum have decreased – now she dials only twice a week or something...”*

Conclusion

The calendar was found useful by the woman and by her daughter and staff at the centre. Particularly the one she had by her bedside. *“I think it was a good thing for me to have that calendar – it’s company for me...I love it”*

Case 322: Useful?

Background

Man, widower. Lives in a flat in his daughter’s house

Problem

Forget what day and date it is and appointments. After a rest, he is uncertain whether it is night-time or day-day-time.

Implementation

Night-and Day-calender

Result

The person says he uses the calendar and that it is useful to him. The family carer knows that he used it in the beginning but she is uncertain whether he is still using it. She is also uncertain whether it is useful after 6 months (T4).

Conclusion (project worker’s assessment):

The user tells that he uses the calendar and finds it useful. It would have been helpful for me to know where the calendar was placed and when he used it. His daughter informed that the home nurse visits him in the morning and that he therefore may not use the calendar. I wonder whether the calendar was placed on his night table, and should he also have had one in the sitting-room?

Case 326: One calendar in the sitting-room and one by the bed-side

Background

Man, living alone in a 2-room flat. Good contact with his two sons. One of them calls him several times a week.

Problem

Day-time and night-time disorientation, in particular during the dark winter season. Passivity, reduced initiative. Problems to remember who is who of his sons and grandchildren when talking to the ENABLE researcher.

Implementation

Positive to the calendar. Thinks it may be useful to him because he wakes up during the night and does not know whether it is day-time or night-time. One calendar is placed on his night table. After 3 weeks he got one calendar that was placed in his sitting-room.

Result

The person uses the calendars and reads the text easily. It is useful to him.

Case.calendar: No calls nor visits at night

Background

Widow, age76. Moved to a flat for the elderly 3 weeks ago, but not got used to live there. Night staff think she is should move since she leaves her flat at night. She is often awake at night and calls her children to ask what time it is. Her children are frustrated since the calls wake them up one or more times at night. The woman uses hearing aid and glasses.

Problem

Some times she leaves her flat at night to visit the neighbors. Home nurse thinks she should move to another home.

Product

Night and Day calendar

Implementation

The calendar was demonstrated for the woman and her family. Decision about where to place it was agreed. The family meant it should be placed on the drawer by her bedside, close to her telephone.

Result

The woman looked at the calendar when she woke up at night. She remembered the instruction not to call her family when the calendar displayed Night and has since not called her family at night. The night staff has neither observed that she has left her flat at night nor disturbed her neighbors at night. The woman take a look at the calendar several times both at day-time and night-time. In particular, it is useful for her after she has taken a nap.

Conclusion

Useable and useful.

Reasons why an assistive device is useful or not

One of the research questions addressed in the ENABLE project was to identify reasons why an assistive device would be useful for some people and not for others. The hypothesis developed was based on the thought that the reasons could be explained by:

- Characteristics of the person with dementia (such as degree of dementia, motivation for trying the device etc),
- Characteristics of the family carer (motivation or ability to support, relation to the person with dementia),
- The environment (suitability for implementation of the device, type of support from home help etc.)
- The assistive device (functions and design, usability etc.)
- The researcher (person who did the interviews prior to implementation of the device and the follow-up interviews afterwards)

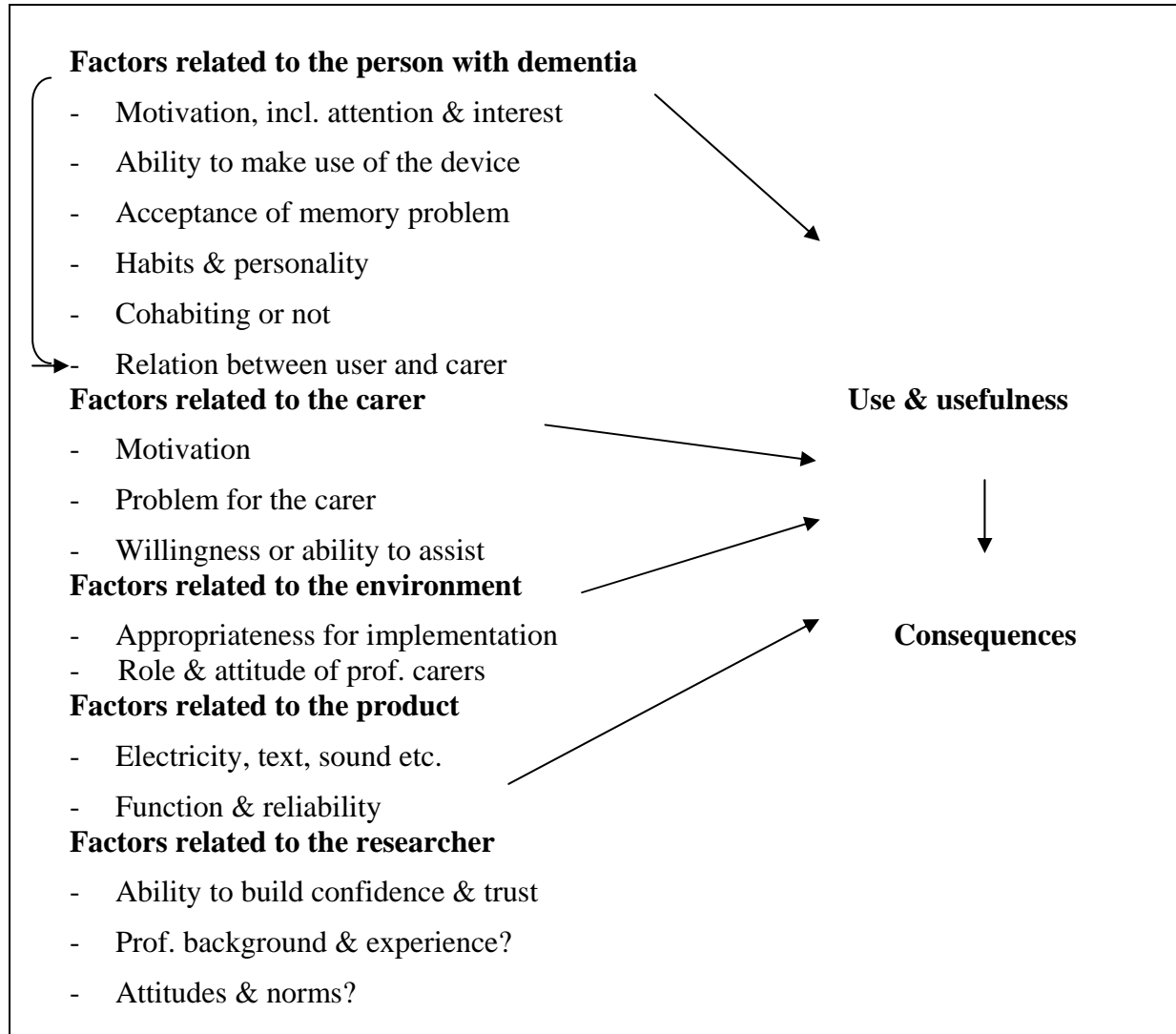
It was also thought that a useful device could have further consequences for the person with dementia and their family carer. The sort of consequences would depend upon the device implemented. For instance, installing a picture telephone might enable a person to make telephone calls and thereby support his/her social contact and self esteem.

Analysis of 37 case stories from experience with 6 different assistive devices provided knowledge about causal factors which facilitate and promote positive, neutral or negative effects. Examples of reasons for success were that the persons with dementia perceived and accepted their memory problem, and that they were motivated and able to use the device. Some people would need time to get used to the new device and to accept it. The device was often found useful if both the person with dementia and the carer were motivated, either because it reduced or solved a problem for both of them, or the carer wanted and was able to support and help the person being cared for. A good relationship between the person with dementia and the carer was adding to this. In some cases, living with someone was essential for the usefulness of the device. Examples were reported with a medicine reminder, where the person with dementia could hear the bleep, but did not understand what it was. Her husband's hearing was impaired, but when his wife told she heard the bleeping he would know it was time for her to take her medicines. Similar team work was reported with a locator for lost object.

Reasons for dropping out included technical problems with the device, personality/attitude of the person with dementia or the person with dementia was unable to use the device, such as reading the text shown at the Night and Day calendar at night. For one person a pre programmable picture telephone had too few buttons to meet her needs and the contrast on the number buttons was insufficient. Another reason was progress of the dementia itself, for instance a person could after some time no longer remember the Night and Day calendar and time orientation was no longer a problem.

Drop-out was often caused by a mixture of factors. These could be that the carer was more motivated than the person with dementia and prompted to use the device and thereby reminded the person being cared for about his/her memory problem. An already stressed relationship between them could worsen the situation. The hypothesis and the factors to consider are illustrated below.

Factors of importance for the outcome



A user needs analysis would need to consider the factors identified. In addition, one must keep in mind that the devices address different needs and require different competence and actions from the person with dementia. Some devices are fully automatic, whereas others require attention, initiative and ability to read a message or hear a bleep, whereas others require some new habits or learning. The role of a family carer for successful use must also be taken into account.

References

- 1) Reports at ENABLE web site www.enableproject.org
- 2) Dementia. The international journal of social research and practice vol. 3 (3) 2004