



Enabling Technologies for People with Dementia

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Report on User Requirements-

when designing and introducing technical devices

for people with dementia

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Summary

User requirements were initially defined in a pr-deliverable early in the project, and formed a baseline for how the devices were developed and chosen for user trials. They were based on former experience in earlier projects as well as experience amongst the researchers, as well as a literature review and Universal Design Principles from University of North Carolina.

Through focus groups and throughout the user assessments in the project, the user requirements were assessed and revised, and the result is presented in this final deliverable.

The ENABLE devices are described, and the reasons for why they were chosen.

The specific requirements related to technology that aims at being used by people with dementia are described in a general way, and specific to each device.

The 7 Universal Design Principles are quoted, and the specific needs and requirements of people with dementia are defined.

Finally, the design process is described, and what makes it special when designing for people with dementia.

The project partners in ENABLE hope that this report can help designers, suppliers and prescribers of assistive technology, as well as mainstream products, to make devices that help promote the wellbeing and independence of people with dementia and their carers.

1 Introduction

1.1 The content of the report

The overall objective of the ENABLE project was to investigate whether it is possible to facilitate independent living of people with dementia and to promote their well-being through access to enabling technological devices. One part of the project is the development of these user requirements.

This report is edited by Sidsel Bjørneby, with inputs from most of the co-researchers in the ENABLE project. At the beginning of the project, user requirements were defined and formed the basis for choosing and adapting the devices, as well as the methodology for the user trials. After the user trials, the requirements have been adjusted, according to the experience in the user trials.

The contents of the report builds on:

- Previous work in the EC projects Technology, Ethics and Dementia (TED)¹ ², and in A Social and Technological Response to meeting the needs of Individuals with Dementia and their carers (ASTRID)³
- Knowledge and previous experience as family carers as well as professionals amongst the partners
- A literature review
- Input from focus groups on the ENABLE products early in the project in the partner countries. The national focus groups were held with family caregivers, people with dementia and professional carers and occupational therapists, presenting them with the products and discussing user aspects with them.
- User needs analysis and user trials throughout the ENABLE project in five countries with altogether 155 users and 127 carers
- Experience and analysis by the researchers in all five countries
- Universal design principles from the University of North Carolina, US

The selection of products to be developed in ENABLE was based on:

- Focus group meetings where engineers and designers at Bath Institute of Medical Engineering discussed with family carers and health professionals. This led to the product concept of a gas cooker monitor, an automatic night lamp and a bath water level and temperature control;
- A professional social worker who experienced interest in sing-a-long activities among day care clients and her work with PC applications of this (Picture gramophone);
- A family carer's experience of needs of a family member with memory problems (automatic night and day calendar, remote day planner, locator for lost objects)

¹ Project Technology, Ethics and Dementia (TED), EC concerted action under BIOMED II, 1999

² Holthe, Hagen and Bjoerneby, Evaluation of an electronic calendar as helping aid for persons suffering from memory problems or cognitive impairments, part of TED project, 1999

³ Project A Social and Technological Response to Individuals with Dementia (ASTRID), EC FP 4 project under TIDE, 2000

1.2 Why user requirements

The objective of these user requirements is to help produce devices that are of benefit for people with dementia, despite the symptoms of dementia illness and age related changes.

Hopefully the report can raise awareness of how assistive devices should be designed in order to be beneficial for people with dementia.

The target audience of this report consists of designers, producers and suppliers of assistive technology, as well as standard products, and users with early dementia, their family carers and professionals that are in charge of recommending and prescribing devices for people with dementia.

People with dementia represent a user group that is rarely the target of technology designers and producers of assistive technology. However, previous projects TED and ASTRID indicate that technology, if well designed and adapted, may be of benefit to this user group and their carers, but that there is little awareness of these potentials.

An electronic calendar to support time orientation developed by a family carer was selected for trial in the TED Project. The calendar was found to be of help for many people with memory problems. Important prerequisites for positive outcomes are:

- The products quality – how it meets the users' requirements
- Users' attitudes, needs and abilities
- How the product is introduced, where it is placed, etc
- Support and guidance from family members and carers ⁴

1.3 User needs analysis

Individual user needs analysis is always the basis for choosing products and solutions. User needs analysis is often done by an occupational therapist or other care professional. Here it is important to remember that people with dementia often have difficulties to express their needs clearly, and carers may need to be involved in the needs analysis.

Quite often a person with early dementia will not admit to problems while asked by the doctor, but when back home, is just as distressed and confused. Only by actually seeing and experiencing the day to day problems and activities is it possible to decide the impact of the disease, and how products can influence in a positive or negative manner.

Failure to understand user needs can result in distress and negative reactions. In the ENABLE project, inclusion and exclusion criteria were also defined before choosing respondents to the assessment study where devices were tried and assessed with users in five countries. User needs were considered at the recruitment stage, and in order to try to ensure that the devices were in compliance with the user group's as well as individual user's needs.

⁴ Holthe, Hagen and Bjoerneby (1999), What Day is it Today? Using an automatic calendar, in Journal of Dementia Care, July/August 1999

2 Who is the user

2.1 People with dementia

The person with dementia is the primary user or subject in relation to the user requirements in this report. One way of defining the user is that he/she is somebody who uses the product independently. But he/she is also a user if he/she is not able to operate the product, as is the case with automatic products or if support is needed for the use. Therefore we define the user as the person whose situation is aimed to become better (more enjoyable, safe, interactive, social) with than without the device.

In relation to the use of technology, some symptoms and manifestations commonly experienced by people with dementia and their carers are:

- Deterioration of cognitive abilities
- Low concentration ability
- Limited short term memory
- Irritability and other behavioural problems or challenging behaviour
- Deterioration of the use of hands, apraxia, poor co-ordination
- Depression
- Agnosia, or the inability to perceive or recognise objects even though the senses are functioning.⁵

Because of deteriorating social and cognitive abilities the persons with dementia experience numerous difficulties in everyday life. One aim of ENABLE was to identify existing devices and to develop new products that could support independence and give some feelings of self-integrity and success, despite the effects of the dementia.

To design for people with dementia, we need to be very well aware of the complexity of the dementia process. The solutions need to be adapted to the very special needs.

In the early stages, the person with dementia can be tormented by a fear of being stigmatised, and therefore deny products that may be looked at as stigmatising. This speaks for using new products that “others” also use, like the mobile phone or the PC. However, in later stages, new phenomena and technology of recent years have often been erased from their memories.

The person with dementia gradually loses more and more abilities to perform in a way that is acceptable to people around him. There is a need for technology to compensate for deterioration and maintain personal capabilities longer. If the technology is introduced at an early stage of the dementia process, there is a better chance for the person to get used to and benefit from the product. It is a common problem that people wait too long before asking for help or technical aids. Good publicity and information around the disease and the products could help avoid this.

⁵ Bjoerneby et al, TED Handbook: A guidebook on how to apply technology in dementia care. Norwegian Centre for Dementia Research, 1999.

2.2 Normal age related changes

Most people with dementia are 65 years and above. Therefore it is necessary to consider and respect normal age related changes that most people experience, as well as the changes related to the development of the dementia. Some of the normal age related changes that are not particularly related to dementia but are necessary to consider for older people with dementia:

Reduced physical strength, mobility, and co-ordination

- Poor balance
- Reduced ability to handle small controls and objects

Visual changes

- From 55 to 75 years of age the field of vision is reduced by 50%
- Ability to distinguish differences in contrast and light is generally reduced
- Ability to focus is reduced
- A person of 89 years needs many times more light than a younger person
- Reduced ability to discriminate colours, especially between green and blue
- The eye is more vulnerable to glare, because it takes longer for the pupil to contract

Changes in hearing ability

These changes are both in relation to strength and frequency of sounds.

- Reduced ability to hear high frequency sounds is quite common (cannot hear birds any more). But the largest consequences are when the ability to hear frequencies between 300 and 3000 Hz is reduced, because this is where the human voice lies.
- It is more difficult to distinguish where the sound comes from.

Slower reaction time

This happens to most people with age.

- Increased time to make decisions
- Longer response time on signals
- The combination of quick movements and dexterity increases reaction time

Changes in memory and learning ability

- Learning and perceiving new information takes longer
- It takes longer to recall memory
- It takes longer to recall names on persons and things

2.3 Carers

Even though the person with dementia is the main target for the user requirements in this report, other user groups are also important to consider. Family carers are always involved in user issues, and feel the problems if the devices do not function as expected. Their interest, response and acceptance of technology are crucial for the success or failure of devices. Some devices can be of use and support for them, and through this, be of benefit to the persons with dementia. Because of this, the family carers' opinions and attitudes were recorded in the project, and are included in the user requirements in this report. Another group is professional carers working in day care or residential care. In ENABLE we focus on people living at home, but who may be users of day care facilities. Professional carers' opinions and attitudes towards technology in general are most important as is their previous experience

User Requirements

about use of technology in their work. When any new devices or systems are implemented, training of this group is crucial.

A third group consists of the supporters, for example care or rehabilitation professionals that are responsible for procuring, implementing, setting up and maintaining the devices. If they are not aware of potentials of assistive technology, or have negative attitudes to technology, the user situation can be affected in undesirable ways.

3 The ENABLE devices and why they were chosen

3.1 The enabling quality of the devices

Current social policy aims to provide support so that persons with dementia can live in their own home as long as possible, and many affected people want to live at home and manage daily tasks themselves. However, their ability to maintain relationships or to handle different tasks and activities deteriorates progressively and reduces their quality of life. Even people with mild to moderate dementia experience frequent failures. The complexity of the technology around them plays a role in the loss of abilities, and carers emphasise the disabling role of contemporary technology. Together, this can lead to worries and depression, and in turn to poorer functioning than otherwise could be possible. Thus, many of the challenges for people with dementia and their family carers are of a very practical nature.

Different technological systems and devices require different end user involvement:

- Devices that are operated by the person (e.g. radio, TV)
- Systems and devices that others have installed and maintain, but which the user use (e.g. electricity, water supply system, air condition)
- Monitoring and surveillance systems and devices which are
 - activated by the user (e.g. safety alarms)
 - activated automatically when an incident occurs (e.g. fire alarm, fall alarm)
 - monitoring continuously or when the operator decides (e.g. cameras installed at public places, tagging devices)

The user requirements will to some extent be dependent on which category the product fits. Also, the ethical dilemmas will be somewhat different depending on category.

3.2 Time orientation

Confusion about day and date is a common problem for people with dementia. Not knowing what day it is may have severe consequences for a person since it is a basis for structuring one's life, and making plans for the days to come. Disorientation of time has been rated as a big and burdening problem by formal as well as family carers⁶. Many people with dementia ask what day it is over and over again, some times at very short intervals. This was also shown in the ENABLE interviews of people with dementia and their carers. Carers are often stressed by frequent questions, and these can create irritation and thus affect the relations between the person with dementia and the carer in a negative way. Different assistive devices are available to facilitate time orientation. Case reports have shown that some persons increase their time orientation as a result of using an assistive device, and that their feeling of coping was supported^{7 8}. Also, the carers experienced fewer questions, since the person with dementia was able to find out day and date him/herself.

Case reports in the paper by Johansson and Nygård illustrate how problems with time orientation are manifested in daily life for different people. The interviewees living alone and who otherwise were able to manage daily tasks felt that time orientation was a big problem for them. The authors emphasise the importance of identifying the problems as early as possible and to offer appropriate assistive aids. They expect that a person with mild dementia can get used to the device and be able to

⁶ Sweep, M. 1998, Technology for people with dementia: User requirements. Eindhoven IGT/98.319, part of the TED Project.

⁷ Holthe et al. 1999

⁸ Johansson and Nygård, The experience and management of temporality in five cases of dementia, 1999

make use of it for a longer period. Johansson and Nygård also emphasise that the use and acceptance of the assistive device seem to be dependent upon the individual; his/her (premorbid) personality, insight into own situation as well as motivation and ability to try something new. The study of Holthe et al. concluded that the individual's personality seemed to be important for the person's acceptance of the assistive aid provided.

Results of ENABLE field trials in five countries confirmed all these previous findings and emphasised the importance of motivation of the user if time orientation is to be supported with memory aids.

Daytime/nighttime confusion

Whether it is daytime or night is a problem for some people with dementia. Examples of unintended consequences of this are:

- Waking up family carers at night by telephone calls
- Going out of the house at night, for instance at 5 a.m., instead of 5 p.m. to wait for the taxi to pick them up to the family dinner. The persons may feel embarrassed and be depressed by not being able to cope. There are also many examples of incidents and accidents if they are not able to find their way back home.
- Digital watches which differentiate between day-time and night-time are difficult to use for people with dementia, since they are not able to interpret the information, e.g. "19.45" to "a quarter to eight".

Falling

Falls at night is a well-known incident when old people get up at night, e.g. to go to the toilet.

Turning on the light may reduce the number of falls. In a care home for 8 people with dementia, no falls were registered during a 2-year period after installation of an automatic bedroom lamp that was activated when the person got out of bed⁹. In a care home of similar size, 4-5 falls were registered during one year, and in a care home for 12 people, 10 falls were registered during one year. No falls were registered in a care home where the light was kept on during the whole night. (Bjørneby 1996)

3.2.1 Memory support

To forget to turn off the cooker may cause burning of food and pans, and in some cases, fire. Cooker alarms which turns off the electricity in case of over-heating, are commercially available for electric, but not for gas cookers. Damage due to forgotten cookers is a big problem. Smoke, burning or fire damage constituted 15% of all insurance costs in Norway in 1995, and people > 67 years were particularly vulnerable (Bjørneby, 1996). Bjørneby's study demonstrates that cooker alarms may prevent damage since no fires occurred in a care home for people with dementia equipped with cooker alarms. The care home was equipped with smart house installations, which also included smoke detectors, door alarms and other safety sensors. The cooker alarm was released most frequently of all the alarms. However, fires were prevented since the incident was detected quickly, and actions were taken immediately.

Many people with dementia experience frustration when they cannot find for example handbag, purse, walking stick or other objects that they have misplaced. A locator was developed in the ENABLE project and tried out.

Forgetting to take medications can have serious effects, and is often a problem for people with early dementia, their family and care services. Therefore, it was decided to try a medicine reminder that is commercially available in Norway.

⁹ Bjoerneby: Evaluering av BESTA Installasjon i Toensberg, 1996

3.2.2 Support communication

It is a common problem that people with dementia do not use the telephone to make phone calls. They do not feel comfortable with modern telephones or have problems handling long numbers. They are therefore dependent on somebody else to call them, which can lead to a feeling of being forgotten or not being able to communicate. Social interaction is just as important to people with dementia as to everybody else, and the telephone is the most common means of communicating with friends and relatives outside the home. It is also a common way of getting in touch with somebody when problems occur. For the family carer it is also important to know that the person with dementia is still able to call independently if needed.¹⁰ A commercially available picture phone was chosen for the ENABLE trials.

3.2.3 Pleasure

When considering the needs of people with dementia, safety and security are the first aims of interventions. Rarely do we remember that they have the same needs for participating in activities that produces pleasure and entertainment and fun. In ENABLE it was decided to include a product that could provide pleasure and entertainment in the trials.

The Picture Gramophone (PG) multimedia program was developed in Finland in the 1990s by Outi Mäki to be used by people with dementia, to stimulate them and give pleasure. People with dementia choose songs on a touch screen and sing along like a karaoke activity. The original PG included only one part that was for playing a ready made multimedia product. The picture gramophone has proven to be very successful as a means to give entertainment and pleasure, but the findings suggested that more flexibility towards individual needs of users is required¹¹. In ENABLE the PG was further developed: an Editor was added for creating individual PGs to be used by the original PG player. The Editor is used by professionals or family carers to create the PGs, and the PG Player is used by people with dementia.

3.3 The ENABLE products

In the ENABLE project, new assistive technological products have been developed for people with dementia, who tried and used them to find out whether these products could further enable them in their daily tasks. All the products address well-known needs of people with dementia and have been developed in collaboration with users, carers and experts. The design and functionality have been based on the specific user requirements developed as an early part of the project. The products in the ENABLE project aim at improving enabling, stimulation and self-confidence:

Item	Usage	Expected effect
Automatic Night and day-calendar (Forget-me-not TM adaptation)	As a calendar. Day and date is always correctly displayed, together with time of the day (Morning, Afternoon, Evening or Night)	Facilitate time orientation, prevent people from going out and make phone calls at night
Locator for lost objects	Pressing picture button causes a tag on the lost item to beep. Stops when the object is picked up	Finding frequently lost items, such as keys and purse. Reduce worries and time spent for seeking lost objects

¹⁰ Topo et al: Can telephone using abilities of people with dementia be promoted? An evaluation of a simple to use telephone. *Technology and Disability*, 14, 2002

¹¹ Maki and Topo: Use of multimedia for stimulation of people with dementia, 2002

User Requirements

Automatic bedroom lamp	Turns on the light when the person gets out of bed, turns it off when person is back in bed	Prevent falls at night, reduce anxiety
Gas cooker monitor	A cooker which the user can operate as usual, but which is fitted with sensors which detect pan overheating. The cooker is turned off in a manner which enables the user to subsequently carry on using the cooker without outside help being necessary.	Prevent fire or food being burnt due to overheating because the user has forgotten to turn off the cooker. Reduce worries.
Do-it-yourself picture gramophone PG	Choose songs on touch screen and sing along lyric text and music. The edited PGs are similar to karaoke. When PGs are used, the user can select from a list of artists or groups of, two to six themes or types of music they would like to listen to.	Provide entertainment and pleasure



Two different versions of Night- and Day Calendar, both were assessed.

User Requirements



Locator for lost objects



Automatic bedroom light



Gas cooker monitor



Picture gramophone

In addition to devices designed and developed as part of the project, some existing, commercially available devices were chosen as part of the user trials, because they could support needs for enabling products.

Item	Usage	Expected effect
Picture telephone	Nine photos or nametags replace buttons, in addition to the normal numbers. To telephone familiar persons	Facilitate making phone calls independently
Medicine reminder Careousel	Battery operated, automatically opens compartment with medicine and sounds a beep when time to take them	Memory support for independent taking of medicines at the right time



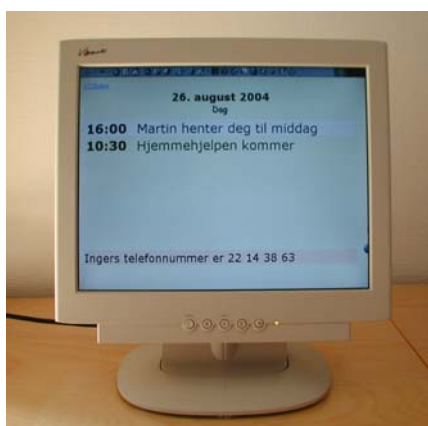
Picture telephone



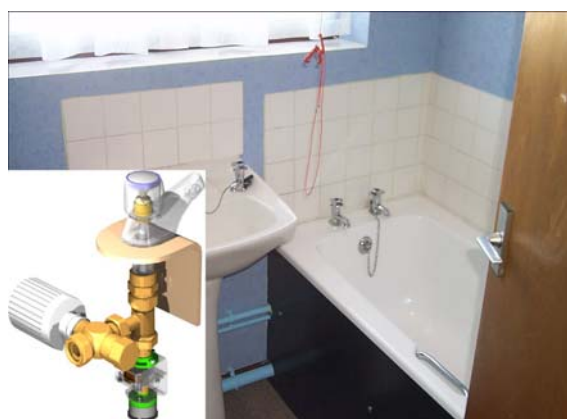
Careousel

Two products were developed in the ENABLE project, but were not chosen as part of the user trials. These two products are:

Item	Usage	Expected effect
Remote day planner (chosen by Norway, but not tested)	Carers write a limited number of activities to remind the user on each particular day	Support carers who have the responsibility of reminding a person with dementia
Bath water monitor	The water will turn itself off automatically when it has reached a certain level	Prevent flooding



Remote day planner



Bath water monitor

User Requirements

In the table below the products are sorted in terms of what it supports and if activity is required by the person with dementia in order to use the product. This kind of thinking is useful when considering if a device is suitable for a person with dementia.

A. Product supports memory and active use by pwd	B. Product supports memory, requires attention	C. Product is activated automatically, supports safety
Locator	Night and day calendar	Automatic night light
Picture telephone	Medicine reminder	Gas cooker monitor
Picture gramophone	Remote day planner	Bath water monitor

4 ENABLE product specific requirements

The products in ENABLE were chosen with the aim of enabling people with dementia to keep themselves occupied with activities that give pleasure, support memory and facilitate communication.

The product specific requirements in this part were made initially as part of the design process and have been adapted as a result of the user trials and assessments in the project.

4.1 Night and day calendar

Specific requirements	Suitable stage of dementia
Display large enough that letters can be read from distance to the table Easily programmable for different time zones and summer/winter time Easy to decide when is the relevant change for morning, day, evening and night “Fiddleproof” More important with large letters and good contrast than a picture Avoid reflections in glass Text not in capital letters, but not block letters	Mild to moderate

4.2 Locator for lost objects

Specific requirements	Suitable stage of dementia
In relation to hearing problems, alternative sounds Loudness of sound from tags must be sufficient in final product Tag should be smaller in final product Padded tag (to put on walking stick) Size, visibility and indicator of picture of lost object Put picture on button to avoid confusion of what to press Provide a click to indicate that button is activated	Mild to moderate Supports carers Useful for other user groups with memory problems

4.3 Automatic bedroom light

Specific requirements	Suitable stage of dementia
The light turns on when person leaves the bed at night The light fades off when back in bed “Fiddleproof” Optional manual operation Weight sensor suitable for several bed types and easy to set Look as normal as possible Possible to not use in summer in Northern countries when nights are light	All

4.4 Gas cooker monitor

Specific requirements	Suitable stage of dementia
Safe and dependable functioning is crucial for this product	All
Secure for gas leakage	
Different gas cookers require different solutions	
Turns off knob as well as gas supply	
Good hand size on knob	

4.5 Do-it-yourself picture gramophone

This device is different from the other devices and was tried out by groups of people with dementia in day centres as well as in private homes. The requirements described here also apply to other products that aim at providing pleasure and entertainment.

When new tools are developed for activities in dementia care, the main part of any balanced cord is that the content is so attractive that the technology does not get too much attention. For example in the original PG popular songs from the war time and high quality photographs showing famous film stars and vocalists and musicians were used. The actions taken by the person with dementia should be based on their earliest skills, i.e. skills learnt in early childhood. In PG the user's skill to point out something interesting is utilised.

From the research we know that often one's ability to read is maintained despite the dementia progress. The research has also confirmed the everyday experience that even if a person with dementia has great difficulties in talking she/he may still be able to sing the lyrics. These facts were utilised in the design by Outi Mäki: the lyrics are shown and the played melody and the recorded singing stimulates the users to sing along.

If a product is designed for pleasure and entertainment a person with dementia needs to be perceived as an active and able subject. When using PG the user makes decisions about what she/he prefers and takes actions. The material used includes (mainly) music written for adults. Despite help needed, the feeling after using PG can still be "I did it. Did you see?" A person with dementia is not responsible for using the product correctly: the product should be designed so that the user's possibilities to make mistakes is minimised. In the PG photographs and the titles are placed in large keys that cover most of the screen: When you touch the screen you always touch one of the activated parts of it. The use is made as simple as possible.

Taking into account decrease in the users sensory capabilities as well as functional and cognitive abilities: In PG the font size used is as large as possible and maximum of six lines of the lyrics are shown at one time and the touch screen can be used even if hands are shaking if the keys on the screen are large enough. The activity should be easily and quickly accessible: In PG everything needed is in the PC and in the CD- ROMs. When you create an individual PG it takes quite a lot of time to find the music, lyrics and photographs but once it is done it can be used countless times.

Because flexibility should be added into the products so that they can be individually tailored according to individual preferences and changes in cognitive abilities. The new part developed in ENABLE called PG Editor made it possible to create PG multimedia products which were based on each user's music preferences and their personal photographs.¹²

¹² Maki and Topo: Designing products for entertainment and pleasure: Do-it-yourself Picture Gramophone, 2004

User Requirements

Specific requirements	Suitable stage of dementia
Must be easy to program, requires interested staff or carer Large display, good contrast, large letters on lyrics Not too many verses at a time Pictures relevant to songs Good loudspeaker Individual or group activity best? Appropriate price / cost	All

4.6 Picture telephone

Specific requirements	Suitable stage of dementia
Age appropriate design, looks like a telephone Sufficiently large photos, or written names Adjustable sound in receiver and for ringing One touch dial Easy to program for carers Can be used as normal telephone (numbers) Letters on number buttons are confusing to some users	Mild to moderate

4.7 Careousel medicine reminder

Specific requirements	Suitable stage of dementia
Easy to program by carer Blink as well as beep to alert user to take medicine Blink or sound when time to change battery Easy to change battery Re-chargeable battery Adjustable sound Portable in handbag when travelling Easy to learn to empty out pills (turn upside down) Easy to clean Easy to change time and to switch to summer/winter time Simple user guide in relevant language Possibility to connect to community alarm system Possibility to connect to mains electricity	Mild to moderate

5 Requirements related to people with dementia

The requirements in this report relate to aesthetic, humanistic and technological aspects of products for people with dementia. Products and applications are appropriate for people with dementia if they have the following characteristics:

- They give a feeling of independence to the person
- They support the person in making choices
- They have a positive impact in her/his life
- They support the skills maintained and do not emphasise lost skills
- They do not treat the user as a person with disabilities, but supports the self image of being a person with abilities
- They remind of solutions that existed before
- The use of the products is possible by the information visible/available at all times ¹³

Product requirements developed for an automatic calendar in the TED Project were:

- Text showing day and date appears automatically
- No particular abilities required
- No need to change habits or behaviour
- No need to set the calendar
- Minimal risk of false setting by accidentally turning of knobs or switches
- Appearance should be similar to a familiar calendar type
- It should look nice – something one would like to have at home ¹⁴

A product that is designed for people with dementia is good for most people; it is easy to use and the functions can be easily understood by all.

5.1 Design guidelines developed in the ENABLE project

Several useful design guidelines were developed during the ENABLE project. They are the result of close co-operation with and inputs from the partners in the project, focus groups with professionals, carers and people with dementia, and from the process of and discussions during the assessment study. Like all guidelines these are generalisations, and there are probably many exceptions. Nevertheless it is felt useful to list some of the more important ones that were experienced and defined by Bath Institute of Medical Engineering.

- No learning should be needed on the part of the user. Devices such as the locator that do require some limited learning were useful for people in the early stages of dementia and for carers, but could not be easily used by people in the later stages of dementia.

¹³ Outi Mäki, The TED Guidebook.

¹⁴ Holthe et al, Journal of Dementia Care. July/August 1999

- Support equipment should seem familiar. For people with dementia a new device has to operate and feel just like similar equipment they have always been used to. The supportive features need to be incorporated in an invisible way. The cooker monitor for example used the same cooker that the user had always been using but just added replacement knobs that had the ability to turn themselves off in the event of danger. The taps explored within ENABLE looked and felt like “normal” taps but had the facility built in for turning themselves off in the event of a flood.
- Control should not be taken away from the user. The cooker monitor didn’t just shut down the gas to the cooker and leave the user confused about what had happened. It turned off the knobs in a similar manner to a carer faced with the same situation, and the user could just carry on using the cooker subsequently without having to rely on someone to come in and reset everything.
- The user should be reassured by the device. Support technology should not be threatening or alarming. The automatic nightlight for example doesn’t just suddenly turn on when the user gets out of bed at night, it gently fades up in a reassuring manner.
- Devices that make judgements about user behaviour must deal with errors. Equipment like the cooker monitor has to make judgements about user behaviour. Such judgements are by definition probabilistic and will inevitably on occasion be in error. Any errors should be false positives, ie the cooker turns off when it doesn’t need to, rather than stay on when it should not.
- For devices that are providing backup and support to ensure safety it is preferable that the user should not have to interact directly with the device. In these cases the best support device is one that can detect when it has to support the user and do so automatically without their intervention.
- Safety critical devices must have a backup that can call for help. If the cooker monitor sensed danger that persisted after it had acted, it would shut off the main gas supply to the cooker and call for help via carer’s mobile phones.¹⁵

5.2 Usability, usefulness and acceptance

These three dimensions of how user aspects are experienced are all important and always interact in each user situation. They may be of different importance, also in relation to the needs of a particular user. When designing and trying products for people with dementia, these three aspects of the product must be assessed and respected.

5.2.1 Defining Usability

Usability of a product defines if a person is able to use the product and what the user quality of the product is.

A literature review carried out by Petrina Duff within the ENABLE project shows that some of the definitions found focus on usability and are applicable to the devices being developed within ENABLE. But they are missing two central elements of the ENABLE technologies, that is, the assistive and enabling functions of the devices. Because of this it has been necessary to develop user requirements that encompass all the elements of usability applicable to the project purposes.

The reviewed literature clearly indicates that mainstream industry has been focussing on design-for-all or universal design for many years and as a result a lot has been written on the topic of usability. Much of the literature that exists on the concept tends to come from an industrial perspective. Working definitions of usability coming from the technological perspective are mainly related to computers, their interfaces and components.

¹⁵ Orpwood, Roger, Bath Institute of Medical Engineering

The following table (Table 1) summarises the main elements found in the search of both mainstream and dementia-specific literature referring to usability.

Table 1. Summary of the main elements of usability found in the literature search ¹⁶

Concept	Scope	Measures
Usability	<ul style="list-style-type: none"> • Focuses on the design of the device • Usually comprises a checklist of information about how well the product or device was designed for use by a particular target user group. • Can be examined on a scale from ease to difficulty/complexity of use of the technologies • Technically, usability relates information about how well the interface/user combination is adapted to perform the task. • One problem in usability evaluation is the very large number of components that may need to be considered when measuring usability. 	<ul style="list-style-type: none"> • Measure of operability <ul style="list-style-type: none"> • setting-up the technology • operating the technology • Measures for design & functionality including... <ul style="list-style-type: none"> • display • knobs • dials • lights • alarm sounds • labels • instructions • menus • etc. • Measures of portability • Measures of dependability <ul style="list-style-type: none"> • any false alarms • etc.

5.2.2 Defining usefulness

It is possible to define the usefulness of a product by observing if the product is being used and how the users express their opinion of whether they use and need the product or not. A product can have a high usability, i.e. is easy to use, but still the user does not find that the product is useful, i.e. they do not need it in their life. In the ENABLE field trials, the actual use of the devices was recorded, and is reported in the Cross National Analysis Report.

5.2.3 Defining acceptability

The product can be both usable and useful, but the user may not accept it for different reasons. The price of procuring and using the device may be prohibitive, and there may not be a public system for paying for the device. Another reason why a product is not acceptable for the user is the aesthetic and design aspects of the product. It may be stigmatising, or it may not look like something that a person with dementia would feel familiar with. Older people are often more sceptical to technology, therefore familiar design is important. The products must also be acceptable to family members and to a certain degree to care services.

Product failures lead to disillusion and have negative effects on the persons with dementia, as well as carers. This was very evident in the assessment studies in the project, when dropout reasons were analysed.

¹⁶ Duff, Petrina, Work Research Centre, Dublin

User Requirements

The user requirements in this report are related to the usability, usefulness and acceptability of the products and the design process. But in the project, several factors in the research method also influenced how successful the results of the user trials were.

- Factors related to the person with dementia include the stage of the disease, cognitive functioning, nature, duration and degree of the problems, ethnicity, personality/attitudes, social life and previous interests, economic situation and activity level.
- 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 and general health issues.
- Environmental factors comprise services from the social or health care system as well as the home environment of the user.
- Factors related to the devices include design, function and reliability, as well as usability, usefulness and acceptability issues of the device.
- In an assessment study, the attitudes and motivation of researchers influence the outcome of a study.

6 User requirements within a universal design context

In this part the specific needs and requirements of people with dementia are defined within the framework of the principles for universal design (<http://www.design.ncsu.edu/cud/>) . Universal design is the design of products and environments to be usable by all people, to the greatest extent possible, without the need for specialised design. The intent of the universal design concept is to simplify life for everyone by making products, communications and the built environment more usable by more people at little or no extra cost. The universal design concept targets all people of all ages, sizes and abilities.¹⁷ Therefore they are also applicable to people with dementia.

But even though the principles of universal design aim at making all products usable by all users, special needs apply in how technology can be of benefit to people with dementia, and these have been defined in ENABLE.

Each Universal Design Principle is quoted from the guidelines from North Caroline State University, and is written in italic.

In the frame below each quote are the extra needs of people with dementia and the requirements that apply to these needs, described.

6.1 Principle 1. EQUITABLE USE

The design is useful and marketable to any group of users.

Guidelines:

- *Provide the same means of use for all users: identical when possible; equivalent when not*
- *Avoid segregating or stigmatising any users.*
- *Provision for privacy, security and safety should be equally available to all users.*
- *Make the design appealing to all users*

Needs	Requirements
Prevent stigmatisation Maintain social contact Safety Ethical considerations Age relevance and familiarity Enough time to carry out tasks Support empowering and reassurance Low cost or available financing	High quality products for adults If using pictograms, make sure they are logical and self-explanatory to this age group Emphasise interactive aspects Intrinsic safety Consent procedures in case of monitoring Familiar and attractive design, the way they are used to. Adapting a product they are used to Aesthetically pleasing Avoid childishness, use familiar concepts, avoid “funny”, special and decorative fonts for information

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User Requirements

Needs	Requirements
	Design to fit in with environment Sufficient reaction time before timeout Cost issues to be dealt with

6.2 Principle 2. FLEXIBILITY IN USE

The design accommodates a wide range of individual preferences and abilities.

Guidelines:

- *Provide choice in methods of use*
- *Accommodate right- and left-handed access and use*
- *Facilitate the user's accuracy and precision*
- *Provide adaptability to user's pace*

Needs	Requirements
Adaptability to individual needs and changing conditions "Happy helpers", not annoy the carers Right- as well as left-handed mode of use Adaptability to pace and co-ordination problems	Pre-programmable choices, (not visible to pwd) User friendliness for the carers, no extra work, integrate product in daily activities Preferably not for one OR the other Ensure enough time to carry out an activity and enough time between activities. Individual settings if possible

6.3 Principle 3. SIMPLE AND INTUITIVE USE

Use of the design is easy to understand, regardless of the user's knowledge, experience, language skills or current concentration level.

Guidelines:

- *Eliminate unnecessary complexity*
- *Be consistent with user expectations and intuition*
- *Accommodate a wide range of literacy and language skills*
- *Arrange information consistent with its importance*
- *Provide effective prompting and feedback during and after task completion*

Needs	Requirements
Solve common problems easily, increase independence Minimal need for learning	Link with long term memory Intrinsic logic Few functions, operations and choices in one product

User Requirements

Needs	Requirements
Experience of success	Recognisable product / function
Avoid stress, produce stimulation	Avoid too much information at one time
Avoid confusion	Remove irrelevant and confusing information and decoration
Maintaining of familiar situations	Restrict number of actions necessary
Using long term memory	If several steps; logical, visual and clear
Pleasurable to use products, aesthetics, touch, dignity	Product and control must be close together
Not to have to reason	Preferably no remote control (except TV)
Feeling of enabling	Switch should give traditional feedback, by feeling the turn or a click
Feeling of security	Easy to see it
	Pushbutton controls with click provide good tactile cues
No need to search for product, easy to find	Do not mix different types of operation, like turning, pushing, pulling
Feeling of familiarity and a natural solution to a problem	Automatic functions must not be confusing
Assistance in time orientation	Add aids to already existing and used technology, e.g. place an automatic calendar next to a clock or an aid that shows what time of day
Respect for normal age related changes	

6.4 Principle 4. PERCEIVABLE INFORMATION

The design communicates necessary information effectively to the user, regardless of ambient conditions or the user's sensory abilities.

Guidelines:

- *Use different modes (pictorial, verbal, tactile) for redundant presentation of essential information.*
- *Provide adequate contrast between essential information and its surroundings*
- *Maximise "legibility" of essential information in all sensory modalities.*
- *Differentiate elements in ways that can be described (i.e. make it easy to give instructions or directions)*
- *Provide compatibility with a variety of techniques or devices used by people with sensory limitations*

Needs	Requirements
Meet the needs associated with normal ageing changes in vision	No glare or reflexes, provide large letters and numbers and good contrast between text and background
	Sufficient lighting
	Consistent colour coding

Needs	Requirements
<p>Meet the needs associated with common age related cognitive problems</p>	<p>Put the most important information in the middle of the visual field.</p> <p>Make certain that text has the size and dimensions in relation to reading distance and light</p> <p>Good fonts are Helvetica, Arial and Verdana</p> <p>Information must be clearly visible, in simple, plain words, in understandable language</p> <p>Isolate individual messages</p> <p>Reduce speed of spoken messages</p> <p>More functions in one product can be confusing</p> <p>Form, colour and materials must support the recognisability and/or function of the product</p> <p>Put the product in a logical place</p> <p>Avoid unnecessary decoration (for example background decoration)</p> <p>Give analogue instead of digital numbers, for example for a clock</p> <p>Use letters rather than symbols /pictograms</p> <p>If using graphical illustration (pictograms) for information, make sure it is logical and familiar, and combine with text</p> <p>Use more signals to attract the attention to the same function, e.g. image, sound and colour</p>
<p>Meet the needs associated with normal age related hearing changes</p>	<p>Do not rely on auditory cues or warnings only</p> <p>Make volume control logical and easy to operate</p> <p>Keep auditory messages in the range between 500 and 1 500 Hz</p> <p>Reduce or remove confusing background noise</p> <p>If auditory message is given, use a sound first to get the attention</p> <p>Sound pitch. Choose intermittent or continuous</p>

6.5 Principle 5. TOLERANCE FOR ERROR

The design minimises hazards and the adverse consequences of accidental or unintended actions.

Guidelines:

- *Arrange elements to minimise hazards and errors: most used elements most accessible; hazardous elements eliminated, isolated or shielded.*

User Requirements

- *Provide warnings about hazards or errors.*
- *Provide fail safe features.*
- *Discourage unconscious action in tasks that require attentiveness/vigilance.*

Needs	Requirements
<p>Reliable products, these users have lower tolerance for errors</p> <p>Experience of failure is distressing to people with dementia, and lead to not wanting to use the product</p> <p>Feeling of safety and security is depending on stable functionality</p> <p>Supporting safe taking of medication</p>	<p>The product must work immediately, no waiting time, because of short concentration span</p> <p>Prototypes must be fail safe to be tried with this user group</p> <p>Fail safe backup</p> <p>No possibility to injure oneself</p> <p>Spoken messages of danger must be clearly distinguishable from background noise</p> <p>Emphasise good diction and pronunciation in spoken messages. Some consonants are difficult to distinguish from each others in auditory messages: s, f, sh</p> <p>Fireproof</p> <p>No loose parts</p> <p>Safe to put in the mouth, not contain hazardous materials or colours.</p> <p>As few plugs or electric flexes as possible</p> <p>Domestic appliances must switch off automatically if failure</p> <p>Give clear messages of what is wrong if errors</p> <p>Not expect reasoning in error corrections</p> <p>Not breakable, stable, solid, good quality products</p> <p>In signalling, red is danger, green is safe</p> <p>Alerting the person of dangers is not enough, it is often necessary to alert the carer also</p>

6.6 Principle 6. LOW PHYSICAL EFFORT

The design can be used efficiently and comfortably and with a minimum of fatigue.

Guidelines:

- *Allow user to maintain neutral body position.*
- *Use reasonable operating forces.*
- *Minimise repetitive actions.*
- *Minimise sustained physical effort*

User Requirements

Needs	Requirements
Meet the needs associated with lower physical strength, poorer fine co-ordination	Large controls, suitable to the hand's optimal, functional position Avoid fine manipulation As few manual operations and little hand strength as possible Sometimes it is easier to control a product with both hands

6.7 Principle 7. SIZE AND SPACE FOR APPROACH AND USE

Appropriate size and space is provided for approach, reach, manipulation and use, regardless of the user's body size, posture or mobility.

Guidelines:

- *Provide a clear line of sight to important elements for any seated or standing user.*
- *Make reach to all components comfortable for any seated or standing user.*
- *Accommodate variations in hand and grip size.*
- *Provide adequate space for the use of assistive devices or personal assistance.*

Needs	Requirements
Relevant in relation to where product is positioned	Not require unfamiliar movements or locations Place all controls within comfortable reach of where the user normally is for each activity Use mechanical principles to ease movements

7 The design process

7.1 User involvement

In addition to methods in the research and the defined user requirements, the design process is of importance. There is a general consensus about appropriate methodologies for designing assistive technology that has been evolved by practitioners over many years¹⁸. A key feature of this process is the need to deal with the complications that arise from the user-interface aspects of such designs. Involving people with dementia in a methodical manner in the design, development and trials forms an iterative process that helps to design user friendly, useful and acceptable products.

User-needs analysis requires a close working relationship with the user to get an accurate assessment of the problems they face. The same issues arise when trying to design new equipment. The designer has to involve potential users of the new design to ensure the complex needs of someone with a disability are effectively dealt with using the new design. This user involvement is not only crucial in determining the aims of the device at the start of the process, but is also crucial during the development work to try out and comment on designs, and to guide any changes that are highlighted by the testing. Such processes are at the core of most design methodologies for assistive technology and the assumption has been that they must constitute the most effective way of designing for people with dementia. In ENABLE, people with dementia were involved in focus group discussions.

7.2 Ethical issues in the design process

However trying to apply user-led design methodologies to devices for people with dementia uncovers a number of ethical problems. Implicit in the methodology discussed above is a need to expose people with dementia to devices that are at an early prototype stage where the functioning of the device is probably at a poor level, and where they are very likely to go wrong. It is quite unethical to put people with dementia through such experiences. They are very likely to become anxious and upset by any failures, and the experience can further reinforce their own sense of inadequacy and failure. It is also very likely that they would be unwilling to test out modified devices once the design has been improved.

A number of techniques have resulted from the ENABLE project that are felt to be very helpful in circumventing these ethical problems. The basic idea behind most of them is to try and get a prototype device to a fairly mature stage before someone with dementia is exposed to them. Hopefully by this stage if any further changes are needed they will be minor and the person with dementia will not be trying out a device that will cause them difficulties. The design methodology still requires a close guidance of the evolving prototype, but this guidance can be done by relying on the understanding of personal carers. A carer will acquire a very intimate understanding of how the person they are caring for is likely to react in different situations and this understanding can be used to provide a kind of proxy judgement of the effectiveness of a new and evolving design. Indeed within the ENABLE project a lot of success was achieved with devices actually developed by creative personal and professional carers. The Night and Day calendar was developed by Inger Hagen following her experiences as a personal carer. The Picture Gramophone was developed by Outi Maki through her close professional involvement with people with dementia.

¹⁸ Orpwood, 1990; Poulson, Ashby & Richardson, 1996

7.3 Input from others

For designers without this close personal understanding, other techniques are needed to involve personal carers to guide the development process.¹⁹ The engineering designers within ENABLE used contacts through local Social Services in the UK and through the Alzheimer's Society to arrange discussion groups to explore ideas for new designs. These discussions tended to follow an iterative process whereby carers could relate problems they dealt with, the designers could make suggestions for items of assistive technology that might help, and carers could comment, reject or modify these ideas. Such discussions have been found to be very effective in homing in on ideas that would appear to have much potential. A useful rule of thumb which came from these meetings was to look at designs which emulated the strategies that carers found to be effective. These carer strategies would be based on a great deal of experience, and a device which could emulate that strategy should be quite close to something effective.

The same kinds of meetings were set up to test prototypes and review designs. Carers were very good at imagining how the person they cared for might react to a new device, and could make comments and suggestions about how they could be improved. Within ENABLE this process was taken further by using focus groups involving a wide variety of people, including carers, therapists and social workers, to comment on designs and enable the designers to fine-tune the technology they were evolving.

7.4 Age relevant users

Some aspects of a design that need testing relate more to the age group of the user rather than dementia as such. These aspects can be tested with age-matched people. For example with the locator device, which enabled lost objects to be found by activating a noisy tag attached to the object, the volume of sound needed to be decided. Too loud and the battery would not last long. Too quiet and most users would not be able to hear it. Tests with a group of elderly users who did not have dementia enabled a good understanding to be gained of an appropriate sound volume threshold.

7.5 Strain on users

In design processes the users and their carers have to cope with some products that require improvements, and this puts strain on those involved, including researchers and design staff. This experience in ENABLE would lead us to recommend ensuring all initial testing with people with dementia used very small-scale tests initially (1 or 2 users) until any remaining problems are completely resolved.

New designs do need to be tested by people with dementia, and inevitably some issues will normally need to be improved following feedback. It is very important that when users are exposed to new designs for the first time they are given as much support as possible, and for initial tests to be very short and certainly terminated as soon as any problems occur or are predicted. The ENABLE project highlighted very much the difficulties that can arise when new devices are tested and where design problems remain. The project involved the construction and evaluation of quite large test series (up to 50 for some devices) and it was not easy to make improvements once evaluations were underway. A lot of very valuable data has been collected and hopefully some very useful items of new technology are going to be available as a result.

¹⁹ Orpwood, Faulkner, Gibbs & Adlam, 2003

8 Conclusions

To support designers and producers in creating devices and products that are suitable for people with dementia and their carers, it is necessary to use a combination of

- Knowledge about user needs
- Consideration of dementia specific requirements
- Consideration of age related requirements
- User involvement in the design process

The researchers in the ENABLE project hope that this report can help to develop and choose devices that are of benefit for people with dementia, despite the symptoms of dementia.

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