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Chapter 3

State of the Art in Electronic Assistive Technologies for People with Dementia

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Abstract It is estimated by 2050 that one-third of Europe's population will be over 60. Life expectancy has on average already risen by 2.5 years per decade and the number of old people aged 80+ is expected to grow by 180%. Nowadays, there are 5.5 million cases of Alzheimer-afflicted people in Europe and more new cases being added every year. In fact Alzheimer's disease has been called the "plague of the twenty-first century". There is currently no cure for this disease; however, prevention and early diagnosis may play a huge role in delaying the onset of the worst effects of this severe disease. Modern technologies could have an important role to satisfy main needs of people with dementia. Nonetheless, despite recent advancements in information and communication technologies and growing sales numbers, industry has been rather reluctant to standardise access technologies and to implement them in a "Design for All approach". Because of this, in last years, there have been launched in Europe a great number of initiatives, both public and private, which try to improve the situation of those persons who suffer this ailment and that will be detailed in this chapter.

Abbreviations

AAL	Ambient Assisting Living
EMA	Electronic Memory Aid
FP5	Fifth Framework Programme
GPRS	General Packet Radio Service
GPS	Global Positioning System
GSM	Global System for Mobile communications
ICT	Information and Communication Technology
IR	Infra Red
IST	Information Society Technology
PDA	Personal Digital Assistant

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3.1 Introduction

There is a vast range of associations and companies along the EU (European Alzheimer's Associations 2009) that are offering some kind of support for persons with dementia and their carers. Most of them are informational websites that offer helpful information for carers, but seem less attuned to the persons with dementia and furthermore they do not offer personalised content. Information and Communication Technology (ICT) solutions, aimed at compensating for deficiencies such as memory problems and inconsistent daily activities, demonstrate that people with mild to moderate dementia are capable of handling simple electronic equipment and can benefit from it in terms of acquiring more confidence and feeling more positive (Reinersmann et al. 2007). Major ICT support for coping with behavioural and psychological changes in dementia is relatively disregarded as yet, while support for social contact can be effectively realised through the new technologies that are appearing on the market every day.

Some of the needs, that people with dementia and their informal carers currently perceive as insufficiently met by regular care and support services, can be alleviated, or even be met, using modern Information and Communication Technology.

However, most often, the design and the implementation of appliances, mobile phones and remote controls are driven by the ambition to satisfy users that are already engaged in modern technologies. Thus many people with disabilities, in particular persons with cognitive disabilities and older persons, are excluded from using modern technologies, at home and in the public. I2Home (2009) and MORE (2009), two projects involved in making life easier for persons with any disability, have considered these aspects and have focused their work in developing accessible and easy to use home appliances and devices for elderly and disabled people. Their main objective is that these persons are not severely impeded any longer in participating in our society, in living an independent life and in realising their full potential.

However, despite all these new initiatives, support for carers continues being urgently needed and governments have a key role to play in raising awareness and improving outcomes for sufferers of dementia and those around them. Significant resources will be required to address the clinical and social aspects of Alzheimer's disease as well as new models of care that span across health and social services are needed (Fig. 3.1).

Based on those unmet needs that were most frequently mentioned by a group of people with dementia and their carers that participated in a field research (Reinersmann et al. 2007), we can pick out four main strands: the need for support with regard to symptoms of dementia (the most frequent one being the loss of memory), the need for social contact and company, the need of supporting daily life activities and the need for health monitoring and perceived safety.

The need for general and personalised information mentioned by persons with dementia refers to information on the diagnosis, condition, available support services and care (including information on support for memory problems). Informal carers want information on diagnosis, prognosis, treatment, care structures, day care

Fig. 3.1 Person with dementia and her carer

facilities and other services including legal and financial issues. The mentioned need for support with regard to symptoms of dementia refers to all types of instrumental support in a person's daily life activities, including support to enhance participation and supervision/guidance.

The need for social contact and company refers specifically to ways of staying connected with family, friends and the social environment and also to feeling useful. Reported needs for health monitoring and perceived safety refer to the wish to be cared for and to feel safe when the disease progresses and disabilities increase.

3.2 Support for Memory

To help Persons with dementia undertake specific types of time-linked tasks (e.g. taking medication, keeping appointments or following a daily schedule) various possibilities of automatic reminders via Electronic Memory Aids (EMAs) are explored, such as NeuroPage (2009) and MemoJog (2009) solutions. The first one is the most common and simple since it only uses an ordinary pager and that can be an advantage because of its easy use. The second one makes use of the new generation of mobile phones and palmtop computing technologies to provide memory jogging messages to the user about upcoming activities for the day. In this respect, COGKNOW (2009) also offers several memory services that not only help Alzheimer's patients in their daily life activities but also provides them enjoyment and comfort as well as ways to support their independence and communication with other people (Fig. 3.2).

Fig. 3.2 Electronic memory aid

Most researchers recognise the importance of involving informal carers in the implementation of EMAs, since carers motivate the person with dementia to use the EMA but also benefit themselves, as use of an EMA by a person with dementia reduces feelings of worry in the informal carer. An EMA informing the person verbally, using vocal recordings, of specific appointments or tasks, also has positive effects on Alzheimer patients.

Besides training the dementia patients' brain and stimulating their memory with solutions as Smartbrain (2009) system, which not only stimulates but also develops the main cognitive capacities of adult people by training their memory, language, calculation and orientation, several services present in the market also consider relaxation and enjoyment as other important activities in the daily life of Alzheimer-afflicted people. COGKNOW has taken these aspects into account and not only centres on memory assistance or help for daily activities such as eating, but has implemented functions that focus on enriching the life of persons with dementia. One of these implemented functions is a music library that can be played by patients whenever they want to. This service stimulates them and improves their feelings of comfort and happiness since in many studies researches suggest that music can have a strong effect on mental stability of people with dementia (Yasuda et al. 2006).

3.3 Support for Daily Life Activities

Most of the people with dementia live in the community and are supported by both family and friends and professional carers and services. A minority lives in institutions such as homes for the elderly, sheltered housing projects and nursing homes. Caring for a relative with Alzheimer's disease has been described as "life changing, exhausting and stressful". To help people in this matter, several initiatives, such as Proyecto Alzheimer (2009) or Enabling Smart Houses (2009), have been carried out in the EU. The first one consists of a social and healthy approach that tries to face the consequences that Alzheimer's disease provokes in both sufferers and relatives. The project focuses on a residence for Alzheimer's sufferers coupled with an investigation and provision of training about the disease making this centre stand out among the several other centres that have been built.

Designing and developing smart home technologies that could assist dementia sufferers within their own living environment is another important aspect that both patients and carers point out as essential to carry a normal life. Enabling Smart Houses has considered this and the house itself monitors the occupant's behaviour and, through automatic equipment and verbal prompts and reminders, also reacts to any issues that arise. Other projects and initiatives available on the market, such as Easy Line Plus (2009), not only consider these aspects in making easier and more comfortable the normal life of Alzheimer patients, but also take into account the need for compatibility and development of devices close to market. Good ICT design is highly important and can add value to the offered product/s (Fig. 3.3).

Fig. 3.3 Persons with dementia daily life activities

People are more and more concerned about losing their independence at some point in their lives, be it through growing older, becoming ill or disabled. Organisations that support people living at home need to provide a safe environment and be certain that the right services are provided at the right time. Fortunately, nowadays there are many different technologies and appliances specially designed and adapted to those needs. Patients can also buy many of these devices independently. Companies such as Tunstall (2009) or Alares (2009) have on offer different services or products especially developed to enhance a person's independence, health and feeling of well-being. People who need some kind of support can buy devices that will help them avoid emergency situations inside and outside home, but before doing so, they should contact their local social services authority or similar support departments.

Unfortunately, specialised support is not growing at the same high rate as the elder population numbers and this makes necessary the development of technological systems, such as COGKNOW, to give sufficient assistance. This highlights the situation that there are not enough products and services oriented to health-care and life improvement of patients who suffer from Alzheimer. Nonetheless, although not specifically designed for dementia patients, there are European projects and systems developed to improve the life of persons with disabilities. In this way we find projects such as ALADIN (2009), INHOME (2009), MonAMI (2009), OLDES (2009) or SHARE-it (2009) which correspond to the European Information Society Technology (IST) Thematic Priority in the framework of Ambient Assisting Living (AAL) for the Ageing Society. They mainly focus on elderly people and the improvement of their quality of life. Intelligent home environments, assistive systems and the development of generic technologies for managing the domestic environment are some of the facilities that projects mentioned above offer to elderly. These could be also used by Alzheimer's sufferers since some of their needs are similar to the elderly people's ones: support for memory, daily life activities assistance and enhancing feelings of safety inside and outside home.

ENABLE (2009), "Enabling technologies for persons with dementia", was one of the first European longitudinal studies inside the Fifth Framework Programme for Research and Innovation (FP5) which investigated whether it is possible to facilitate independent living and promote well-being of persons with dementia living in their own home through access to products which allow them to carry out their daily life activities. Spanning across five countries, (Norway, Finland, Ireland, the UK and Lithuania), a total of 140 families with dementia sufferers were recruited to the study, which involved the testing out of assistive technologies in their homes. The products introduced into people's homes included an automatic night-and-day calendar, a gas cooker monitor, an automatic night lamp, a picture button telephone and an item locator. From all of these products, only two (the night-and-day calendar and the picture telephone) are now available commercially and are supplied by providers in Sweden and Norway.

COGKNOW also considers all these services and helps Alzheimer's patients in their daily life activities providing them contentment and comfort, ways to support their memory and to enhance communication with other people. However, although

COGKNOW does not consider all services in the same way like ENABLE the final result is similar – providing the same utilities and help services. Likewise, another system called PEAT (2009) provides queuing and scheduling assistance for individuals with memory, attention and cognitive disorders. With this system, persons suffering from this impairment can feel safe and calm, an important aspect that a lot of experts highlight as essential, since it also provides a virtual caregiver presence 24 h a day via cellular phones.

3.4 Support for Social Contacts

Continuing in the same vein and as we have already mentioned, people with dementia have many needs during the progression of their disease, varying from memory support in mild dementia, to support in almost all aspects of daily functioning in severe dementia. Family carers, neighbours and friends meet some of these needs, while professional carers meet others. However, despite the efforts of these informal and formal carers, not all the needs of people with dementia can be met. The reasons for this include the limited time that both informal and formal carers can give to the person with dementia, and the lack of, or limited availability of, professional services attuned specifically to the concrete needs of individual people with dementia.

With respect to support for social contacts, some authors (White and Dorman 2000) analysed the contents of messages posted on an Alzheimer mailing group and concluded that the opportunity to share, unburden or vent, is perceived as empowering and helpful to carers. Almost every Alzheimer association offers a website where people with dementia and their carers can join forums, post messages or chat with fellow sufferers. Many Alzheimer associations also have a 24-h telephone support service for emotional support and information on regional support services like Alzheimer café's and meeting centres.

In 2003, another study suggested that with the use of multimedia as a source of reminiscence, patients could exhibit more control of the direction of the conversation. A touch-screen display was developed to convey photographs, video or music, and it was also compared to traditional reminiscence methods. As a result of this study, the patients using the multimedia system showed stronger and more prolonged engagement during the conversations (Fig. 3.4).

Through several other studies, such as “Televisits”, contact between elderly people living in a nursing home and their family via videophone was demonstrated to promote social contact. In a similar study, Sävenstedt and others (2003) showed that a videophone as a means of communication between patient and family reduced feelings of guilt in family members, allowed more frequent visits than was possible with face-to-face visits and let family members see the physical and emotional state of the patient on a daily basis. In some cases the conversations were more focused and of better quality than during face-to-face visits. In most cases, however, more emphasis was placed on the family member to direct and lead the conversations which was seen by many as demanding. The relationship between staff and family

Fig. 3.4 People with dementia can feel better if they can maintain social contact

members improved as a side effect of staff helping the patient use the videophone. These are some of the results that ACTION (2009), a videophone service for frail older persons who prefer to stay and live in their own homes but who are in need of support from nurses and relatives, has extracted after performing tests. Family carers feel safer and more competent in their role of caring and the older people and their relatives develop informal support networks with other families more readily and with greater ease.

Internet-based applications designed to provide carers with clinical, decision-making and emotional support were evaluated in field trials and the preliminary results showed the system to be beneficial both to carers and people with dementia. As a consequence of that, several European projects (SOPRANO (SOPRANO 2009), TeleCARE (TeleCARE 2009)) and other private systems (doc@home (doc@home 2009), SafetyNet (SafetyNet 2009)) have been designed in order to provide a systematic approach to the management of the care of patients with long-term conditions or chronic diseases in their own homes and other locations remote from the clinicians' office. Besides this, these solutions also enable the provision of flexible individualised and supportive services and healthcare in order to promote independent living and integration of people with functional impairments into social life.

3.5 Enhancing Feeling of Safety

However, enhancing Alzheimer patients' feelings of safety might be the main essential area most frequently mentioned as unmet by both sufferers and their carers since they can live in a normal way, maintaining their contacts and doing their daily activities more easily and calmly if they feel safe. With regard to this matter, beneficial effects of computer systems have been observed on orientation, feelings of anxiety and independency in patients suffering from Alzheimer's disease. Besides this, implementing monitoring technologies and detection devices or alarm systems inside and outside the home of elderly persons is potentially useful to

enhance (perceived) safety and security of the person suffering from dementia as well as carers. Over the last few decades, detections devices and alarm systems have been developed for different Alzheimer's associations. Investigation and diagnostic groups have been focusing on protecting patients from dangers such as fires, gas leaks and floods with such devices. COGKNOW shares this principle in making use of several sensors and alarms that notify to the tenant if something goes wrong in the house. As a consequence of this and since COGKNOW is specifically designed to solve and help mild dementia patients, these people could find in this project an appropriate and satisfactory service.

Nowadays scientists and researchers are becoming more aware about the problems suffered by people with dementia. For that reason, several systems were and are already being developed as well with the purpose of helping these persons in emergency situations using ambient and unobtrusive devices. This is the case of EMERGE (2009) and SAFE21 (2009); two projects financed by the European Commission, which aim to develop a solution that provides early assistance to the patient, and build on existing social alarms that provide an emergency response to a call initiated by a user, respectively.

The non-interference with the daily life activities of the dementia sufferer is, as we mentioned before, a very important aspect which should be taken into account in the development of new help systems. In that way, a straying prevention system that can counteract Alzheimer's sufferers wandering was developed in 2006 (Lin et al. 2006). The system consists of indoor residence monitoring, outdoor activity monitoring, emergency rescue service and remote monitoring that can be accessed via a number of mobile devices such as a mobile phone, PDA, notebook or computer. The indoor monitor detects movement between certain areas within the home. Outdoor activities, accompanied or unaccompanied, are monitored in a pre-set activity area, which is activated by pressing a button on the location tracking device. Message or alarms, respectively, are generated and forwarded via Global System for Mobile communications (GSM) if the patient leaves the home environment or the activity area. In case of an emergency, the person with dementia can activate an emergency button which sends a message to the call centre where the situation, location and geographical information and location coordinates are analysed and relayed to care providers, search teams and family members. Conversely, through the secure remote monitoring facility included in the system, family members or care providers can also access patient's location information at any time by logging onto the system. In this way both relatives and carers will be able to be calmer and Alzheimer sufferers more independent and free (Fig. 3.5).

As was illustrated previously, current new technologies have also a remarkable role in being assistive carers. An example of that is found in a fully automatic multisensor system, composed of Infra Red (IR) sensors connected to a personal computer installed in a patient's room, which was evaluated by some authors (Chan et al. 2002). This smart tool system proved valid in assessing and recording data on activities such as getting out of bed, mobility and travel patterns of a psychotic patient with moderate cognitive decline and behavioural disorders.

Fig. 3.5 COGKNOW
personal digital assistant

Besides all of this, in 2005, applying a user-driven design approach, a smart home environment consisting of different services and devices that aimed to assist people with dementia in various areas was developed and evaluated (Orpwood et al. 2005). During the night, for example, a lighting system was activated if a patient had left the bed. On returning to bed the lights would fade off after a few minutes. However, failure to return to bed after a pre-defined period of time would result in the communication system telling the patient that it is night time and they should not go to the exit during the night and verbally remind them to return to bed. In addition to the night monitoring, the system incorporated a cooking monitor service, which detected problems and potential dangers during the cooking process. Although the cooker monitor was a very useful tool and during evaluations this device worked well, it caused some irritation to users when the cooker was turned off under false positive situations. This situation disclosed that every system developed to help Alzheimer's sufferers had to take into account not only their possible oversights but also their feeling of independence and control of the situation.

Alzheimer disease mainly affects memory and mental functioning (e.g. thinking and speaking), but it can also lead to other problems such as confusion, changes of mood and disorientation in time and space. According to this last matter, in a study comparing four biomechanical activity devices to index wandering, Algase and others (2003) found the Step Watch particularly able to assess the amount and daily course of wandering behaviour in people with dementia. In this context, boundary alarms (activated by a wristband) or electronic tagging with bracelets and monitoring stations were found to be effective, reliable and successful in detecting wandering as well as reducing patient and carer stress. This is the intention of some products such as SIMAP (2009), GPS Columba (2009) or Keruve (2009), which make use of small, portable and discreet devices implementing new GPS technology in order to locate the person anywhere and all the time. A bedside monitoring system was also tested in a hospital setting with three floor lighting about wandering detection. It relays an alarm to a personal handheld device alerting the carer so that the necessary intervention can be performed (Figs. 3.6 and 3.7).

Fig. 3.6 Columba GPS bracelet

Fig. 3.7 Keruve locator for Alzheimer disease persons

Regarding to the problem of disorientation, there are more help systems such as the personal handy phone system that, worn by the patient as a pendant, could transmit the patient's position with an accuracy of 60 m to a personal computer. The computer generates a map of the area, and then automatically sends this map via e-mail to the carer who can view it on a mobile phone.

On the other hand, COGKNOW not only considers all these aspects, but also takes into account the possibility of showing the way back home to the wandered person. Carrying a Personal Digital Assistant (PDA), Alzheimer's patients could be located everywhere at any time as long as, besides Global Positioning System (GPS) that indicates the position on the PDA, information can be sent to a server using any kind of data communication such as General Packet Radio Service (GPRS). Patients could also use the GPS to go to the place they want or even be helped by making a call to the emergency contact since the PDA has implemented GSM technology as well. Besides all of these technologies currently available, COGKNOW looks at the future making its PDA a multipurpose device, which will be able to implement new technologies in an easy and simple way, allowing giving better attention to Alzheimer's patients' problems.

3.6 Conclusion

To conclude with this chapter and, after revising the principal technologies and ways for helping people who suffer mild dementia, we can say that there are many products, devices and services available in the market which can make the life of those persons easier as well as help carers and family members to take care of them. However, and despite all big efforts for covering most of Alzheimer's sufferers needs, these people cannot find a service capable of helping them with their daily activities at the same time that it reinforces their memory, enhances their feeling of safety and maintains their social contacts. That is the objective of COGKNOW system. All the devices integrated in its architecture cover and settle the needs shown in many studies of Alzheimer's patients. Moreover, COGKNOW also uses all the current industry standards and available technologies, which turn it into a solution of great potential value and help for people who suffer this ailment.

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