

Briefing Paper



Dementia & Technology

Guy Kasier
E&D Systems

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COGKNOW

Helping people with mild dementia to navigate their day



What's COGKNOW?

We research for the needs of people with dementia in Europe, helping people to remember, maintain social contact, perform daily life activities and enhance their feelings of safety.

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Our project is funded under [Information Society Technologies \(IST\)](#) program, which is one of seven major thematic priorities of the European Union's [Sixth Framework Programme \(FP6\)](#) for Research and Development.

Lastest News

COGKNOW Research presented at IAHSA Conference In London - July 2009

Sun, 19/07/2009 - 20:33 by [Maurice](#)
Two of the COGKNOW research team will present about the project at the leading IAHSA conference in London, on 21-23 July 2009. Details of the conference were posted on our blog on 13 January 2009.

Business Workshop

Tue, 13/01/2009 - 13:54 by [TID](#)
A Business Workshop will be held next June 26th in Malta. COGKNOW SUMMARY It is estimated that by 2050 one-third of Europe's population will be over 60. Life expectancy has on average already [...]

6th General Meeting

Tue, 13/01/2009 - 13:48 by [TID](#)
The next General Meeting will be held the June 24th and 25th in Malta. More Information at Private Section.

Dementia & Technology

Dementia is something we all experience in one way or another in our lifetime either directly because we suffer from it ourselves, or indirectly because we know somebody close to us who is a sufferer. The older a person, the more likely they are to experience it. These figures illustrate that:

- over 50 years: 2.3%
- over 65 years: 15% mild dementia and 5% serious dementia
- over 80 years: 25% to 30%, rising to 35% over 85 years.

1. What does that mean in terms of the numbers of people suffering from dementia?

Starting at two national levels, in the Netherlands it is estimated to be 180,000 and in Belgium this estimate is currently 150,000, rising to 163,000 in 2020. Very crudely that represents just over 1% of the two countries' population, which applied to the current EU 27 population of ~ 500 million people, means that there are currently over 6 million sufferers. A significant body of people that is rising every year

Put another way, as Europe's population is ageing as is the average maximum age, it stands to reason that there will be many more dementia sufferers in the future who will need help in one form or another.

Among others this raises the question of what technologies and techniques can be used so that dementia sufferers can live at home for as long as possible and thus put off having to pay for an expensive residential or nursing home?

This article presents the results and some conclusions drawn from a search of the studies and projects that have been carried out on this subject.

2. What is dementia?

Dementia is not a disease, but a syndrome, that is to say the association of several clinically recognizable features that often occur together. For example a number of diseases can lead to dementia as in the case of Alzheimer's, that is probably the best known and widespread condition and accounts for some 65% of people with dementia. Other diseases that lead to a type of dementia are, for example, the vascular dementia caused by a cerebrovascular accident, Parkinson's disease, Pick's disease and Huntington's chorea. Sometimes these combine together, but in lay terms the common factor in them all is that something goes wrong in the individual's brain.

It should be remembered that dementia does not occur overnight and someone does not suddenly, as if they were woken up, become demented; rather it is a slow, degenerative process symptomised by the gradual failure of certain brain activities. Therefore it is more accurate to say that a person suffers from dementia, rather than that someone is demented.

Dementia can be diagnosed at three levels or phases - mild, moderate and serious. The condition often starts with forgetfulness with the sufferer not remembering where, say, they have put something down, forgetting the house keys or an appointment, etc.

Even if that person begins to feel that something is wrong, they are often, quite understandably in a state of initial denial sometimes even compensated by blaming others. Daily tasks from personal hygiene to cooking and shopping become more difficult and life in general becomes harder to manage. So, when dementia is finally diagnosed, it is worth recognising that it may well have been there for some time.

Gradually, as well as memory, speech (aphasia) can be affected and disorientation in time, space, identity and overall confusion can occur. With moderate dementia, the brain's ability to store and retrieve information gradually diminishes and the patient no longer knows who or where they are. Increasingly living in their past and experiencing it, people can be seriously affected by strong emotions that are rekindled by the memory of past painful experiences that come back vividly with all the force they originally generated. In the third phase, serious dementia, the person concerned has generally become completely introverted; as primary needs are the key focus for care, he or she is now completely dependent on others and is often bedridden. A patient can suffer from dementia for anything up to 12 years on average before the body succumbs in one way or another causing death.

3. The home carer

It is estimated that around half of dementia sufferers live at home; those living alone will probably be admitted full-time to a rest or nursing home earlier on as the condition presents itself. However, most sufferers live with their partner or sometimes a family member (son or daughter) either lives with them or close by. Caring for a dementia sufferer every day is an intensive job as for safety reasons, the dementia sufferer cannot be left alone for a second, in a manner of speaking. The kind of issues to be aware of are that the dementia sufferer may well leave the oven open, a water tap on, fall or go wandering and get lost. Safety apart the dementia sufferer also has a great need for warmth and understanding that can place even more pressure on the home carer who can be repeatedly asked the same questions by the dementia sufferer who does not remember that he has already asked them and been given the answer and can get increasingly frustrated and agitated as a result. With this level of attention home carers provide (from 2 hours a day to 24 hours a day), their own lives can get put on hold, when we consider the all too often great loss of social contact to the extent that they can sometimes no longer go out even to do the shopping.

Home of the Future

www.leonardo-energy.org

Technical aids must improve the environment of the dementia sufferer and provide even more support for the home care to ease the demands being placed on them. In most cases, the person is admitted to an institution when the home carer can no longer cope (psychologically more than physically). Research has shown that just over 10% of home carers involved with mild dementia sufferers present physical and/or mental complaints. This percentage increases to 35 to 40% for moderate dementia and exceeds 40% in cases of serious dementia. Technology must be able to support the home carer.

4. E-Tandem, a Belgian study

The Tandem Centre of Expertise, together with a few partners, conducted a study from 2005 to 2007 first to gauge the needs of dementia sufferers and their home carers and in the second phase, to assess a series of techniques that could help the dementia sufferer live at home for longer and provide support to the home carer.

This study showed that home carers need information in general on the development of the dementia syndrome and relating to particular circumstances relating to how to handle acute or crisis situations.

Therefore technical aids are certainly not the top priority for them. When they are chosen, technical aids are primarily to increase safety in the home, for example smoke detection, water leak detection, burglar alarm, fall detection, wandering detection and so on. In Maslow's hierarchy of needs pyramid, safety support is at the very bottom, as the base. The next stage up the pyramid will be sessions held to inform about general and technological support. At its very top is the personal support. So according to this the basic needs (safety) should be addressed first before tackling the information requirements and personal support.

A so-called "care kit" has been put together based on defining the needs and carrying out the literature review and study visits. This kit is a collection of selected technical aids that can be provided as a whole, but can also be used on a modular basis. The care kit consists of:

- smoke/fire alarms
- burglar alarms
- passive personal alarms with sensors
- wandering detection using chips and GPS
- camera monitoring
- video communication with a care centre via a home station.

When there is smoke, the system sounds an alarm at the care centre. This can respond appropriately by conducting a check (via voice/listening and visual/camera links) and call the fire brigade. A similar approach is adopted for burglar alarms and passive personal alarms, of course informing different central support groups. With wandering detection, an alarm is given when the dementia sufferer leaves the home, or when he walks beyond a certain distance from the home or is not back at home after a preset time. The camera monitoring can in principle only be used when an alarm is given in order to ascertain the situation visually from a distance. There is however an exception to the privacy rule, namely to give the home carer a break from the constant supervision of the dementia

sufferer; at given times the care centre can be instructed to take over the monitoring care by using the cameras and audio systems. In this way, the home carer can go shopping at a quiet time or do a bit of tidying up in the garden. The video communication is the care centre for communicating with other care givers (doctor, in-home nurse, etc.) and the family if they also have a video communication unit. A key element of this is that it reduces the risk of social isolation on the part of the home carer.

The E-Tandem study assessed the cost of various levels of care. Without going into too much detail, a comparison was done of the out-of-pocket expenses for treating and supporting the dementia sufferer in three different situations: full-time admission to a care and nursing home, a standard home care situation, and home care with technical aids. The following costs were calculated for the care per week:

Admission to a care and nursing home:	€499.00
Standard home care:	€227.40
Home care with technical aids:	€349.11

Home care with technical aids is around €150 cheaper than admission to a residential and nursing home. On the other hand, home care with technical aids is around €120 more expensive than standard home care. When the demographic data are taken into account, it is estimated that the introduction of technological support for mild dementia sufferers (25% of the group) who live at home with a home carer will be around €317 million per year for Belgium in 2020. Thus staying at home longer with technological support not only saves costs for the person concerned, but also for the government.

In a follow-up project to the E-Tandem study, an attempt was made to equip around 20 homes with technology. However, this E-Tandem live project foundered because the different technology providers were unable to integrate their systems together. The real pity about this project was the conclusion that the applications worked well separately, but there was no compatibility between them.

5. Cogknow, a European study

Another study aimed at people with a mild form of dementia is Cogknow. It is similar to the “care kit” of the E-Tandem study as far as technical aids are concerned. Here, the technology is targeted more directly at the dementia sufferer, instead of the home carer. Using a touch screen displaying icons, the dementia sufferer for example, can always call up a diary with appointments, see the time and date, turn on the radio or the CD player. Furthermore, video clips can be played to coincide with certain activities, for example when cooking, making coffee or tea, etc. Sensors are also placed in the home, primarily to ensure greater safety. The fridge can also be equipped with a sensor so that when the fridge door is open for too long, a spoken message will alert the sufferer who has early stages of dementia.

The links at the end of this article include a link to a short film on the Cogknow project. This gives an idea of the possibilities.

6. What about residential and nursing homes?

One of the characteristics of many dementia sufferers is restlessness and a propensity to wander off. In many residential institutions where no structural measures have been taken, this can lead to the use of the so-called “Swedish belt”, also called a restraining belt. A wide belt is placed around the waist of the resident. The sides are secured to a chair, seat or bed with other straps. Everything is secured with a few special locks. The person concerned can no longer get up or walk about and is confined to the place in question. This technique has been around for many years, but is nowadays met with increasing opposition. This means of restraint and deprivation of freedom has caused a number of fatalities and the use of the Swedish belt is now banned in certain countries. They will try to ban its use in the Netherlands as of 2011.

There obviously are good alternatives to replace this form of restraint. For example architectural solutions introduce the idea of building an interior garden in which the dementia sufferers are free to walk. Technological solutions in the form of electronic locks on doors that cannot be used by the dementia sufferer as a counter to wandering off. In principle, these doors can even be left unlocked as, if a dementia sufferer comes too close to an unlocked door, an RFid sensor, fitted into the shoes or clothing, will close it. Many institutions have abandoned older restraining methods and the benefits are often seen in the patient. A male dementia sufferer put it this way: “It’s a miracle. I can walk about again.”

7. Unanswered question

At a number of congresses, on many websites and in many telephone calls, a number of people working in this field (technicians and care providers) have indicated that technology can help dementia sufferers stay at home for longer up to and including the stage of mild dementia. As each case needs assessing on its own merits, nobody can currently tell us what an average time frame is in terms of how long technology can put off the time when full admission to an institution has to take place. Also the relevant data, figures or research is not available to demonstrate that this is actually so.

We believe it is a matter of a somewhat more important question of whether the longer a dementia sufferer can live at home, the lower certain costs will be.

Let us take the case, for example, with one-off costs such as the installation of the broadband link, the costs of the installation of equipment and the costs of the care coordinator, who examines what the precise requirements are and what technology needs to be installed. In our example of the care kit of the E-Tandem project, the rental of the equipment was assumed. This is probably the right thing to do when the time that the person can remain at home is relatively short. However, if this period is much longer, renting may turn out to be more expensive than buying. How long, on average, can a dementia sufferer be cared for at their [unmodified] home and how long, on average, can a dementia sufferer stay at home supported by technology? The time of diagnosis can be taken as the starting point. Further comparative long term research over a period of between 5 to 10 years could provide a firm answer to this question.

8. Could robots help?

It might seem science fiction, but robots already exist that can help dementia sufferers in their daily lives at home (see film in the links). One of the many problems in dementia is absentmindedness and forgetfulness. In Japan, a number of robots have been developed that can help mild dementia sufferers. For example, there is a robot that tracks a dementia sufferer's actions so that when the patient wants to repeat these same actions (for example, take medication), the robot responds with an audio message. The dementia sufferer can hear the message saying it is time to do something like take medication, cook, sleep and so on. Robots have also been developed that remember where a certain object has been put. These are early days in this field of development and it has to be said that a robot for every dementia sufferer is certainly not going to happen tomorrow.

9. Conclusion

The technical aids to enable elderly people to live at home for longer do not differ so much from those that can be used to help dementia sufferers and their home carers in the home situation. The difference lies primarily with the videophone (although this could also improve social contacts for non-dementia sufferers) and the GPS wandering detection techniques. In a home situation with a dementia sufferer, the emphasis is primarily on offering support to the home carer, who may or may not live in the home. Furthermore, we have seen that home care with technical support is around €150 per week cheaper than admission to a care institution.

There are already many separate techniques, but they are generally standalone. Much work has to be done on compatibility, integration and standards in the near future so that the supply of technical aids for home care for dementia sufferers can get beyond the research level and subsidised projects, in order to bring about modular standard equipment that can be installed in the home of every dementia sufferer. This means that there is still a lot of work to be done.

10. Links

Cogknow project film:

http://www.youtube.com/watch?v=UKJTMzp33Z4&feature=player_embedded#t=51

Cogknow project website:

<http://www.cogknow.eu/>

Robots for forgetful people:

<http://www.youtube.com/watch?v=NtD2vwV61-w>