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# The role of reminder aids and systems to support independence in people with memory problems

## Abstract

The use of four different types of electronic assistive devices and systems to provide reminder prompts and/or messages to support independence has been considered with respect to three different potential user groups: people with acquired head injuries, adults with learning disabilities, and older people with mild to moderate dementia. It was found that all four approaches were useful in practice and were particularly suited to groups of people with specific needs and lifestyles. It was concluded that the choice of which approach was best for an individual depended on a full assessment, and that the availability of a toolkit of options would greatly benefit the more general roll-out of telecare as a means of promoting independence.

## Key words

Medication, reminders, compliance, telecare, usability

## Introduction

It is now widely recognised that the quality of life of individuals can be improved in better and more sustainable ways by supporting independence rather than providing carers to perform domestic tasks and the activities of daily living with them or on their behalf. This represents a major change in culture and a challenge for staff to take a step back and allow people more choice in their support structures. These changes are supported by arrangements for direct payments, and will be reinforced by the introduction in England of personalised budgets.

Individual budgets currently mean that service users (and their families and friends) can choose and arrange their own care packages rather than relying on the more rigid and traditional forms of care offered by local authorities and those organisations which have won contracts to deliver these services. There have been many examples of people choosing more innovative care arrangements, including the hiring of friends and family as personal assistants to

replace or supplement the hours provided by agency staff. The ability to take a more flexible approach has been universally welcomed though there have been many concerns about the capacity and the financial implications of extending this approach to other users of social care, including the rapidly increasing numbers of older people. Their needs will inevitably involve more personal support as levels of disability increase, but also more medical attention due to the numbers of people who will suffer from either chronic diseases (such as diabetes and COPD) or from long-term conditions (including Alzheimer's Disease and Parkinson's Disease). These are all associated with old age.

Assistive Technologies (AT) are, by definition, devices and systems that can aid independent living. They range from low-tech mechanical aids such as walking frames and grab rails through to more sophisticated and intelligent environmental controllers and speech synthesisers. They are, therefore, ideally suited to the new agenda for personalised care and

support, especially as their introduction is not likely to be limited by system capacity. More specifically, they often require little human intervention from a carer and release this valuable resource for more productive use elsewhere. Electronic assistive technologies are becoming an important new class of AT. Falling prices for electronic items, and increased intelligence, functionality and programmability make them an increasingly attractive form of support that is gaining popularity both with service users and with organisations commissioning them. The prospect of digital companions or robotic assistants to perform (or to help a service user to perform) many domestic tasks inspires the imagination of some service users, but scares many health and social care professionals.

There are three areas of concern to be addressed before AT can move forward to take up its position at the heart of care and support plans:

- field trials to demonstrate the value, efficacy and safety of new products
- staff training to ensure that they have the necessary skills and knowledge to be able to advise service users on the choice of AT when more options appear
- improved and automated methods of monitoring the home environment to ensure that risks are being appropriately managed.

This paper describes preliminary work performed with three client groups:

- younger people with acquired brain injuries
- people of all ages with a moderate learning disability
- older people with some form of cognitive impairment (dementia)

In each case, we looked at devices and systems that will provide them with information on when to perform specific tasks. A number of different technological approaches are described and compared, with a discussion on how telecare can be employed to ensure that performance is optimised and changes in capability or need detected.

### Reminder systems and medication management

Normal living involves performing a number of domestic tasks including bathing, preparing food, eating and drinking as well as other activities such as shopping, looking after financial affairs and taking care of wellbeing. Most actions are triggered by spontaneous needs eg. we eat when we are hungry, we go to bed when we are tired. Others occur as a result of training; effectively, we develop routines

and these enable us to get up in the morning or to take a bath or shower in the evening. Routines are an essential part of self-care and are particularly important for people who may have lost temporal orientation either as a result of an accident or because they have developed a dementia. People with a learning disability are known to rely heavily on a routine that has been prepared for them by their carers; they sometimes struggle to depart from this routine, irrespective of advice that they may receive.

A particularly important area of support for people with any form of cognitive impairment is reminders for medication. Full compliance with a physician's prescription is known to be as low as 50% generally, and perhaps even lower for older people. Some of the failure to comply is deliberate due to either a lack of understanding of the need for a particular drug or because the patient fears side effects or dependency. However, most cases of poor compliance are due to a failure to remember that medication is due or a failure to remember if it has already been taken. These issues are addressed directly with a number of medication reminder aids such as special pill boxes, alarm watches and personal pager alarm units that can be as small as a credit card.

The medication tray has been the most popular with older people over the years. It has been available in different sizes from a variety of different sources including pharmacies; the most popular varieties have a number of compartments (usually four to six) for each day of the week as shown in *Figure 1*. A relative (or a nurse or a pharmacist) puts the appropriate medication into the compartments, perhaps once a week, before closing the individual doors. The person receiving the support then opens the door at the right time and takes the medication out for consumption. This generally avoids overdosing and also provides an immediate indication of doses that have not been taken. This approach has more recently been overtaken in popularity by blister pack arrangements (also shown in *Figure 1*) which are prepared by the pharmacist and sealed to prevent contamination of tablets or the absorption of moisture from the atmosphere. The packs are made up using a number of foils and transparent sheets of plastic film, which enables the medication to be seen at a glance while the appropriate dose can be removed by piercing the foil.

While these systems offer good practical and visual ways of managing medication, they do not provide actual reminders. The systems need to be used in conjunction with electronic medication alarms to ensure that the person looks for their medication at the right time. Some recent innovations include

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medication dispensing and alarm systems. Two of the most popular models available in the UK are shown in **Figure 2** and both originate from Scandinavia; the Careousel (sold in the UK as Pivotell) and the Adidos. These units are available from, telecare equipment and service providers such as Tunstall, with an integral radio transmitter that allows a coded message to be sent to a Lifeline home telephone-dialling unit if the medication hasn't been removed within a 20-minute period. The Lifeline connects to a remote monitoring centre where the coded message is interpreted uniquely (using a secure and dedicated signalling protocol such as TT92 or TT21). This enables the call handling staff to identify the source of the alarm and to follow an agreed response procedure which might be as simple as ringing the service user and advising them to take their medication.

### Electronic reminder systems

As well as pill reminder devices, there are a number of other electronic devices that can be used for more generic reminders. These offer ways of reminding service users about daily tasks (such as preparing lunch), weekly activities (such as visiting the day care centre) and more occasional events (such as birthdays). We have considered a number of these devices and methods for use by the three different client groups described earlier. This work involved looking at the methods of programming the devices for individual use, the usability, and the potential and cost of rolling out the technologies more generally in the community, including in new supported living and Extracare housing facilities.

*The Neuropage* This is a reminder system developed by the father of a young man who suffered a brain injury and the young man's neuropsychologist. It involves messages being sent to a dedicated call centre, by phone or e-mail, where they are loaded onto the computer system, which then sends a radio signal to the patient at the appropriate times. The messages are received and displayed on a pager unit as shown in **Figure 3**.

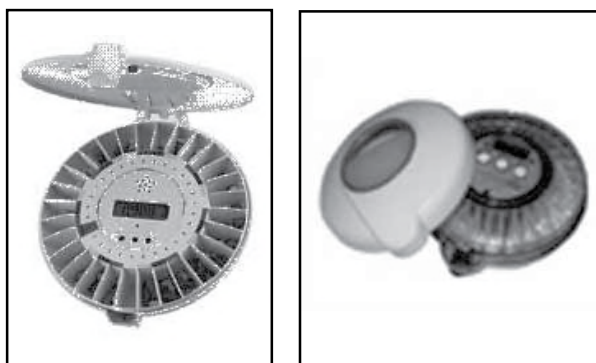
The standard cost of pager rental, airtime and unlimited messages is £60 month, plus a deposit for the pager. The pager is small enough to be carried around in the pocket or in a handbag; it could also be worn on a belt. A similar system using SMS messaging via a mobile telephone would be technically possible.

*The Lifeline Connect+* This is the most popular home unit used in telecare alarm and monitoring systems (**Figure 4**). In normal operation, it transmits coded alarm messages to a dedicated monitoring

**Figure 1** Conventional systems for managing medication over a week



**Figure 2** Electronic reminder and dispenser systems with remote alarm capability



**Figure 3** The Neuropage message receiving unit



centre following the operation of a smart sensor (such as a bed occupancy alarm) or a panic pendant. A hands-free voice channel is then opened enabling staff to speak to the service user and to employ personalised response protocols to deal with emergencies. This device has the added functionality of allowing either formal or informal carers (or monitoring centre staff) to programme the Lifeline remotely to ring the telephone and to play back a

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**Figure 4** The Lifeline Connect+ home unit with reminder function



**Figure 5** The ProActive Reminder used as a fridge magnet



**Figure 6** The front and underside of the Mem-X Reminder Device



recorded voice message at specified times of the day. There is usually no additional charge for this service once the standard monitoring charges (a few pounds per week dependent on the service provider and the type of service required) have been paid. Many local authority telecare services offer this facility, and also a number of progressive housing associations or trusts that are commissioned by social services departments or primary care organisations. Many

telecare centres that have advanced monitoring systems (such as PNC5) can provide reminders using their call-handling staff. Reminders are programmed into the system as 'parked calls' and are initiated when staff are free of emergency duties. There is usually a charge of up to £5 per week (dependent on the frequency and number of calls) for using this service.

*The ProActive Reminder* This is a matchbox-sized LCD display device which is programmed to alarm and display text messages at appropriate times. It operates like a pager, except that it has its own internal memory, clock and intelligence, and has no links to the outside world. Programming is carried out from a computer, laptop or PDA using a special lead and bespoke software. The ProActive Reminder can be provided with magnetic strips and used as a fridge magnet (**Figure 5**), and has been specifically aimed at the NHS to help reduce the number of patients who do not show up (DNS) for appointments, including those at the hospital. The device is not yet commercially available but is being used in a number of pilot studies. The likely cost will be around £40 per unit including the lead and software. A PDA could be programmed to produce similar reminders but suitable devices will be much larger and more expensive.

*The MEM-X Reminder Device* This is a lightweight unit on a cord that can be worn around the neck (**Figure 6**, left). It could be mistaken for an MP3 or MP4 player, especially when used with headphones. It was invented by a French surgeon whose mother had Alzheimer's Disease but who was able to function independently, provided that she could be prompted to perform actions by the voice of her son. The programming is performed by the carer using the buttons under a cover on the reverse of the device (**Figure 6**, right). This allows a separate message to be recorded for each time of day and for events on a daily, weekly or annual basis, as well as for specific dates or occasions such as hospital appointments or birthdays. When the alarm time is reached, the device plays a selected tune and continues until the user presses the blue button to play the message. The message replays every time the blue button is pressed until the next message is due. The devices retail at about £100 each.

### Discussion

The Neupage and the Lifeline Connect+ arrangements are examples of telecare in which responsibility for programming and control can be assumed by a remote monitoring centre. Consequently, these options are available in almost all

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cases, irrespective of the availability of family carers. The former is suited to people with a mobile lifestyle, especially younger people who are used to carrying a cellphone or a pager, and who spend considerable time outside of the home. On the other hand, the Lifeline Connect+ only operates with a landline, though it may be used with any type of telephone handset including wireless (DECT) arrangements. It will not work outside the home. Therefore, it is ideal for someone who spends considerable time at home alone, or who goes out only when accompanied by a carer, friend or relative. The option of using the monitoring centre to make reminder calls using their PNC to initiate contact and reminders is the most flexible option as it can be used with either a landline or with a mobile telephone (or a combination of the two). In each of these cases, there is no great need for training at a local level because the remote centres take responsibility for entering information in the required format. Opportunities for errors are therefore minimised, and an audit trail is available in the event of an error occurring.

The ProActive Reminder device needs to be programmed locally by a carer or, in some cases, by the individual themselves; this requires a programming device (a laptop or a palm device such as a PDA), a special lead and the proprietary software. Intuitively, the programming is simple but a number of informal carers and professional staff found difficulty in gaining the confidence to use it without close supervision. The developer has since agreed to provide a video-based programming tutorial accessible via the web. It remains the case that the programmer needs physical access to the device in order to reprogramme it.

In the same way, the MEM-X device requires a local presence for the recording of messages and for changes to the times when alerts are produced. Once the programming method had been mastered, few carers found difficulty in making changes on a regular basis. However, it was found to be time-consuming. The instructions provided with the device were found to be adequate and most carers were able to operate it within five minutes. In both the ProActive Reminder and the MEM-X device, there is no error checking capability. Thus, if problems occur it may not be possible to determine the cause.

Not surprisingly, some of the older service users found difficulty in seeing and reading the words displayed on both the Neuropage device and on the ProActive Reminder, though the latter has been configured to provide the most readable display available. In the same way, people with hearing defects sometimes struggled to understand the

messages spoken through the Lifeline Connect+ and through the MEM-X device, though the use of a familiar voice minimised this problem. Battery management does not become a problem provided that there is an available carer to take responsibility.

Each of the reminder systems proved effective with some of the volunteers. There was no single device which performed better than the others, but a number of general principles were developed based on feedback from the users and their families.

The Neuropage has been useful to many younger people who have memory problems. It provides a proven method of alerting them when actions are needed, and most users become compliant. The process of uploading new instructions is relatively straightforward, especially for people with access to email, but the overall cost of the service is high when compared with telecare and the range of options that can be accessed using a local telecare service provider's monitoring centre. The use of a pager rather than a mobile phone appears somewhat dated to potential new users. Older people with dementia lacked the confidence to manage and use this device.

The Lifeline Connect+ telecare system was the most robust approach because of the involvement of a 24-hour monitoring centre. Its versatility makes it the most effective choice for anyone who is housebound, or who spends significant time alone in the home. It also has the ability to be part of a telecare risk management system involving smart sensors which provide an early warning and response to incidents such as fire, flood, gas leaks and inappropriate exiting of the property at night. The Lifeline Connect+ and a range of sensors have a major role to play in protecting both older people with dementia and adults with a learning disability. Telecare can also be useful in protecting the properties of younger people who have a more mobile lifestyle.

The ProActive Reminder was found to be a practical way of providing reminders to all user groups, though some older service users struggled to access the message even though operation was through a single button. The small size meant that it could be carried in a pocket or left in appropriate places. The low cost would allow for several of the devices to be deployed if necessary. Ultimately, its success is likely to depend on the programming being made sufficiently easy for either carers or the service users themselves to be able to enter new alerts quickly and with confidence. Its application is not limited to any single user group.

The success of the MEM-X may depend on the way users carry the device on their person. Few of the

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individuals testing the device liked the idea of wearing it around their necks, but it was found to be small enough to be carried in a handbag or in a pocket. All service users liked the use of a relative's voice for recording messages but inevitably this restricted who could enter new messages. It was popular with all three groups but was considered to be too complex for use by people whose dementia had become moderate or severe.

None of the three test groups, nor their informal carers, objected to the use of a Lifestyle Monitoring system to monitor their actions when prompted by these memory aids. It might therefore be appropriate to introduce this form of automated data collection as a means of verifying the appropriateness and application of new items of assistive technology as an effective alternative to carers in supporting independence. The latest versions of these systems employ the Lifeline Connect+ unit as the monitoring gateway, thereby eliminating the need to install additional hardware for a limited period of time for monitoring purposes. Lifestyle monitoring functionality can therefore be switched on and off remotely.

## Conclusion

Reminder devices are becoming important instruments in the toolkit available to manage cognitive impairment. The success of different approaches depends on a number of individual factors including the confidence of the user in the use of new technologies, their hearing, their visual acuity, their lifestyle and the role played by formal and informal carers in their support plans.

A full assessment of unmet needs, risks to independence and social isolation may be necessary before the introduction of a memory aid for all three groups of people considered in this study.

The availability of a toolkit with several different items ensures that each service user can be offered the most appropriate device for their individual needs and situation. Reminder devices and systems should therefore be promoted for use with more service users, and should be included in comprehensive assessment processes, with a view to allowing more people to benefit from the considerable benefits of telecare systems as an important means of promoting independence.