

# dementia care

## solutions for independent living

key information for health and social care professionals and carers



# forewords

“Dementia is a major public health problem. It has a devastating impact on people, families and society at large. There is evidence of high levels of unmet need. We need action now and telecare has been proven to have great benefits in the management of those unmet needs.

Our report, Dementia UK, independently produced by the London School of Economics and Institute of Psychiatry at King’s College in March 2007, describes for the first time ever, the economic and social impact of dementia in the UK. We believe it is the most comprehensive analysis to date and we expect it will be significant in making dementia a national health and social care priority. The role of telecare should not be underestimated and this guide helps explain the true benefits.”

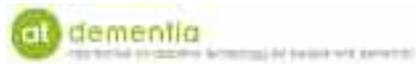
Clive Evers, Director of Knowledge Management  
Alzheimer’s Society



“Telecare plays an increasingly important role in supporting people with dementia. When used appropriately – in a way that complements the support provided by families, friends and paid carers – telecare can actually enhance independence and increase the possibilities for a person with dementia to remain in their own home, or in supported community settings for much longer.

Telecare can also contribute to the peace of mind of families and friends, offering the security of knowing that when a person experiences difficulties, help will be summoned. These developments mean that where there have been specific concerns over risk and safety there are now often real alternatives to explore as an alternative to residential care.”

Simon Burrow is Director of the charity  
that operates atdementia.



## contents

1 Introduction.....	Page 3
2 The true impact of dementia .....	Page 4
3 What is telecare?.....	Page 5
4 Dementia care at home .....	Page 6/8
5 Dementia care in a residential setting .....	Page 9
6 The technology - suggested solutions .....	Page 10/11
7 Case studies .....	Page 12/13
8 Caring for carers.....	Page 14
9 Next steps .....	Page 15

# introduction



## What is dementia?

Dementia is an umbrella term used to describe a collection of symptoms, including a decline in memory, reasoning and communication skills, and a gradual loss of skills needed to carry out daily activities.

Dementia is one of the main causes of disability in later life, contributing 11.2% of all years lived with disability among people aged 60+, more than stroke (9.5%), cardiovascular disease (5%) and all forms of cancer (2.4%).

## UK dementia statistics

- Affects 700,000 people, that's one in 88 of the population
- Financial cost is over £17bn pa, made up mostly of accommodation, lost earnings and unpaid tax
- Two thirds (425k) of people live in the community, one third (244k) in a care home
- Two thirds of people with dementia are women (446k) and one third are men (223k)
- Affects 1 in 14 people 65+, 1 in 6 over 80, 1 in 3 over 90
- Key risks from assessment are falls and walking about (60% experience walking about)

### Sources

*World Health Report Global Burden of Disease 2003*

*Dementia UK Report, London School of Economics and King's College for the Alzheimer's Society Mar 07*

## How can technology help?

Dementia currently affects around 700,000 people in the UK, a figure set to double in a generation and rise to over 1 million in 20 years time. There are 11,860 people with dementia from BME groups. It is noteworthy that 6% of all people with dementia among BME groups are young onset, compared with 2% for the population as a whole.

It is currently estimated that 150,000 people with dementia live alone, and many of those living in their own homes rely on support from an elderly carer who may have their own health issues.

As more is understood about dementia in its various forms and the effect it has on both sufferers and carers, innovative models of support are being developed. In the past there has been little alternative to residential care for many people living with the effects of dementia as the disease progresses. This change of environment in itself can prove distressing and often detrimental.

Technology has a key role to play in facilitating the shift from traditional models of residential care to supporting people with dementia in a way that promotes independence and enables them to stay in familiar home environments for as long as possible. This guide outlines this role and gives examples of telecare in practice.

# the true impact of dementia

The facts and figures surrounding dementia and the financial cost of the disease can be measured and worked out, however, the **emotional and psychological impact** on those with the condition and their families, friends and carers, is infinitely harder to quantify.

Dementia is an incurable, progressive condition that breaks down the structure and chemistry of the brain, affecting a person's ability to **remember, understand and communicate**. But from a personal perspective, what does this mean for the people who are living with the condition and those around them?

For the person with dementia, short term memory loss is usually the first symptom, followed by a deterioration of motor movements, poor spatial awareness, visuo-perceptual difficulties, confusion, lack of motivation, and inevitably, the **loss of independence** and the ability to be able to care for themselves. Telecare sensors help promote personal health and well-being, and those for environmental monitoring, safety and security can help provide support for people with these symptoms, helping to enhance independent living.

Imagine no longer recognising your family and friends, losing a lifetime of memories and living with constant anxiety because you don't know where you are, or where you belong. **Dementia is an unstoppable condition**, breaking down every aspect of a person's existence and leaving in its wake a trail of frustration, misery and pain.

Equally distressing for carers, dementia leaves them to cope with the strain induced by watching their loved one deteriorate into someone unrecognisable. Carers can be under **immense pressure** to provide round the clock support, and this often comes hand in hand with guilt which is felt when they can't be around. Telecare can help relieve some of these pressures by using technology such as bed occupancy and property exit sensors to protect people, enabling their carers to take a well earned break, knowing they will be contacted immediately if they are needed.

Carers often feel like there is nowhere to turn, that they are alone, and there is no foreseeable end to the situation. With this in mind, **telecare technology** can assist carers in even the smallest way, and give a little independence back to the person with the condition. Applied in the correct way, it is extremely worthwhile.



## what is telecare?

Telecare has been defined as 'The continuous, automatic and remote monitoring of real time emergencies and lifestyle changes over time in order to manage the risks associated with independent living'.

*"In an ageing population, something extraordinary is possible with telecare – something that will change the quality of life for people with dementia, their families and carers."*

**Secretary of State for Health, May 2007**

Telecare facilitates the expansion of existing social care services by providing a means of managing additional risks, thereby helping to provide an alternative to institutional care.

Unobtrusive sensors are placed around the home, which automatically raise an alert if they detect a possible problem such as smoke, gas, flood, fire, a fall or exit from a property at night.

The sensors are wireless and can therefore be easily installed and packages altered to provide truly tailored care. They also operate on a dedicated radio frequency which guarantees their integrity. Sensors raise a local, audible alarm, as well as alerting a carer, key holder or the monitoring centre, whichever is appropriate. Individual sensors are detailed throughout this guide under appropriate applications.



## dementia care at home

It is acknowledged that most people as they become older would choose to remain in their own homes with appropriate support, rather than have to move into sheltered or residential care. This is also the case for people with dementia and those who care for them. Enabling people with dementia to choose from a spectrum of housing options relies on the creation of a tailored care package, which must include decisions from all stakeholders about what is an acceptable level of risk and how these risks will be managed.

Technology can play a key role in this, by managing personal and environmental risks to support independent living.

### Risk - walking about

60% of people with dementia experience walking about as a problem. Whilst good practice would emphasise the importance of establishing an underlying cause of this behaviour where possible, the property exit sensor can be useful both in the home and residential settings. The system is unobtrusive, but helps to prevent people with dementia coming to harm through leaving their home inappropriately, often for prolonged periods of time, unable to return unassisted.

The alarm can be set to take account of individual circumstances and habits. With a simple system of PIRs (Passive Infra Red sensors or movement detectors as found in burglar alarms) and door contacts, the alarm can be set to only alarm during the hours of darkness, or to alarm if a person has left their dwelling for a longer than usual length of time or at an unusual time of day. This simple solution ensures that people with dementia need not be prisoners in their own homes, and also relieves some of the strain of caring for someone who walks about.

Tunstall is currently trialling **“safer walking technology”**, which allows freedom for the user to walk about in a safe environment and sends an alarm call should the user go outside a pre-set safe zone. When an alarm is received, the 24 hour monitoring centre locates the user and contacts the carer to ensure the most appropriate help is provided, greatly reducing the risks associated with becoming lost. The wrist worn device looks like a digital watch and uses voice communication via the hands free GSM/GPRS phone. The Alzheimer's Society points out that technology for safer walking has the potential to offer benefits to people with dementia and their carers in specific circumstances.



## Mrs B

Mrs B was referred to Aragon Housing Association by her Social Worker. She is in her 80's, living alone and had started to show signs of memory problems.

### The concerns

- Mrs B had been walking about from her home during the night, and on several occasions had to be escorted home by her family.
- This was causing her family a lot of stress as they were extremely worried about her safety.

### The solutions

- A Property Exit Sensor was installed which alerted Careline if Mrs B tried to go out at night. The movement detector fitted with this allowed the Careline operators to determine if Mrs B has actually left the property or not. When the sensor was activated, staff could speak to Mrs B and encourage her to remain inside, calling her family only if she did go out.

### The outcome

Mrs B's family were reassured by the equipment and their anxiety was considerably reduced.

The telecare equipment enabled her to remain safely at home for a further 16 months whilst supporting her independence and giving her family peace of mind.

Of the 90 calls made to Careline in 3 months the operators were able to speak to Mrs B and persuade her not to leave the house, thereby keeping her safe and secure at home.

The family were only called out on 3 occasions demonstrating the success of the equipment in keeping Mrs B safe at home.





## Risk - cooking

Cooking and eating can present particular problems for people with dementia. Often they can't remember when they have eaten, and as a result eat too little or too much. Electric kettles may be placed on gas rings for example or pans left to boil dry. Fire hazards such as these can be monitored by the temperature extremes sensor. Placed in the kitchen where smoke detectors can be too sensitive to use, it monitors for a rapid rate of rise in temperature and will warn of possible fires.

As dementia may cause people to omit certain steps in activities of daily living such as cooking, gas cookers can pose a particular risk. While it may be preferential for a person used to cooking on a gas stove to continue to use this method, the risks of harm may be too great. This means an alternative cooking method, such as an electric or microwave oven must be used, which may lead to further confusion. A solution is to employ a gas detector which will raise an alarm if it detects dangerous levels of gas in the property, from a gas ring being left on unlit.

This was the case for Mrs Smith (names have been changed) in Northampton, who lived alone near her daughter and left the gas on so regularly that residential care was being considered. A Project Worker suggested she try the gas detector and shut off valve which alerted the local monitoring centre if it detected gas and automatically turned off the gas supply to the cooker. The monitoring centre in turn alerted Mrs Smith's daughter or the local response team who could then assess the situation and turn on the gas supply again. Mrs Smith remained in her own home for a further 18 months, before entering residential care.

## Risk - bogus callers

People with dementia are particularly vulnerable to distraction burglary. A simple button near the front door acts as a visual reminder to exercise caution when admitting unexpected callers. Pressing the button provides two way communication to the monitoring centre, who can provide support and reassurance. Hearing the monitoring centre is often enough to cause the potential thief to flee, and as all calls are recorded this also provides evidence which is admissible in court.



## dementia care in a residential setting

Residential care options for people with dementia have expanded over recent years, and new models which focus on choice and independence have been developed. For mild to moderate dementia, supported 'extra care' housing which provides individual tenanted dwellings around a central hub has begun to replace traditional EMI residential and/or nursing care in many areas. Many Local Authorities and Housing Associations are beginning to provide purpose built supported living environments where the emphasis is on maintaining the tenants' skills and encouraging them to exercise a degree of control over their own lives.

### Technology focus

Although longstanding technology such as warden call systems have proved invaluable in sheltered settings, until recently they have been unable to offer the full range of telecare sensors. Communicall Connect has been developed to make this possible, and now as well as benefiting from the reassurance provided by personal triggers and pull cords, on-site staff can be alerted

to situation such as overflowing baths or pan fires. The bed occupancy sensor can also be employed to ensure carers are aware that a tenant/resident has left their bed for a prolonged period, or has failed to get out of bed in the morning.

This system provides peace of mind for carers and privacy and independence for tenants. As staff will be notified if an incident should occur, they are able to tailor work patterns around individual need rather than following standardised routines for every tenant. This flexible approach facilitates person-centred care and also means resources are used when really needed. For example, rather than opening their door to check a tenant is safely in bed during the night, technology can be employed so that the scheme manager will be alerted if they leave their bed and/or their room for a prolonged period of time. Thus tenants are not disturbed unnecessarily, and carers can devote their time to people when and where they really need it.

# the technology

## Suggested solutions



### Property Exit Sensor

As 60% of people with dementia are prone to walking about, this sensor specifically monitors for people leaving a building at unusual times of day and night. It can also detect if a main exit door has been left open and can be linked to external lighting to provide added protection.



### Bed Occupancy Sensor

This specially designed pressure pad fits under the mattress provides an early warning by alerting that the user has left their bed and not returned within a pre set time period, indicating a possible fall. The sensor can also be programmed to switch on lights, helping people find their way to and from bed easily.



### Flood Detector

The Flood Detector will raise an alarm if sinks or baths overflow, or if a washing machine door is opened mid-cycle, protecting both people and property.



### Temperature Extremes Sensor

Monitors for low and high temperature extremes in addition to the rate of rise in temperature. Helps minimise the risks associated with changes in temperature including the build up of heat in a kitchen and the risk of sustained periods of cold weather.



### Carer Pager

Enables carers to be notified of alarm calls when they are at home or in the garden rather than routing them to the monitoring centre.



## CO Detector

Sends an alert to the monitoring centre if dangerous levels of CO are detected. As CO is odourless and colourless the potentially lethal gas is difficult to detect.



## Natural Gas Detector

Provides an early warning of dangerous levels of gas. Can be linked to the Gas Shut Off Valve to automatically cut the gas supply off, if a leak is detected.



## Gas Shut Off Valve

When combined with the Natural Gas Detector, this solution automatically cuts off the gas supply to an appliance when a leak is detected.



## Enuresis Sensor

Placed between the mattress and sheet, this sensor provides immediate warning on detection of moisture, allowing effective action to be taken. The sensor eliminates the need for carers to make physical checks during the night, promoting dignity and independence.



## Medication Reminder

Provides an effective solution to support medication compliance by automatically dispensing medication and providing audible and visual alerts to the user each time medication should be taken. If the user fails to access the medication, an alert is raised to the monitoring centre or designated carer.



## ADLife - Activities of daily living monitoring

Provides an unobtrusive method of capturing a person's behaviour patterns so if a deviation from the norm occurs, it can be identified, the cause investigated and preventative action taken.

# case studies

## Focus on Northamptonshire Safe at Home project

Northamptonshire County Council's pioneering Safe at Home project enabled people with dementia to remain independent for longer, receiving the care and support they need in their own homes through the use of assistive technology. The project brought the local agencies in Northamptonshire equivalent savings of over £1.5 million over the 21 months during which research took place.

Emerging from ideas developed from the EU-funded ASTRID project that was led by Northamptonshire County Council, Safe at Home began as a small-scale project in 2000, and an initial evaluation published in 2002 provided evidence that supported a decision to expand the project. A second evaluation of this larger project was undertaken from June 2002 to March 2004, and involved 233 individuals and their carers.

A group of people with dementia were given assistive technology appropriate to their needs and a comparator group with similar age and gender profiles was established in Essex. The report highlighted how by integrating assistive technology solutions into existing care provision, four times as many individuals were able to remain living independently in their own homes over the research fieldwork period.

The technology provided valuable help and reassurance for people with dementia and their carers in Northamptonshire. Carers reported feeling less stressed as a result of the use of technology and to some improvements in the well-being of those who were being cared for were reported.

One carer involved in the project commented that: *"It means I no longer need to visit my mother four to five times a day and night to check on her safety. Now my visits are more social."*

For the full case study please visit [www.tunstall.co.uk/casestudies](http://www.tunstall.co.uk/casestudies) or call 01977 660479.



## Sara and Alice

Sara lives in Croydon and cares for her 76 year old mother, Alice, who has severe dementia.

### The concerns

Due to her inability to turn on the lights, Alice had fallen several times whilst going to the bathroom in the middle of the night.

This was affecting Sara's sleep as she was so worried about her mother falling over.

When Sara was out Alice repeatedly left the gas cooker on unlit, whilst trying to make a cup of tea. Sara was concerned that a serious gas leak may start as a result.

### The solutions

A Gas Detector has been fitted above the cooker to ensure that if Alice were to leave the gas on, an alert would be sent to the Croydon Careline and the appropriate action would be taken.

An automatic light system was installed so that if Alice were to wake up in the night and get out of bed, the lights would come on automatically. This means that Sara can relax in her own home, knowing she doesn't need to get up every time Alice does.

### The outcome

Sara is thrilled with the telecare solutions: *"Since the equipment has been installed I have started to go out again, and I know Mum will be ok. The equipment really gives me peace of mind."*



For more information on how telecare can support carers download Tunstall's Support for Carers Solutions Guide from [www.tunstall.co.uk/guides](http://www.tunstall.co.uk/guides) or call **01977 660479** for a copy.



## caring for carers

Nobody would want the personal care provided by family members, or formal carers to be replaced by telecare technology. However, telecare can restore confidence to older people and those with long term needs, which will in turn stimulate them to do things for themselves. Carers will therefore need to understand the potential and the limitation of telecare and be comfortable to work alongside it. Telecare can offer to friends, relatives and neighbours a cost-effective way of being alerted when lifestyle patterns change enabling them to identify and respond to any deterioration before it becomes acute.

Standard 7 of the National Service Framework for Older People focuses on the mental health needs of older people and those who care for them. Carers for those with dementia suffer immense and almost constant emotional and physical strain, and respite from their role is made difficult by the adverse effect it can have on the person they are caring for. Often this strain is at the point of becoming unbearable before they will seek support, and carers have reached the stage where they feel residential care is the only solution.

Employing technology earlier in this process can mean people with dementia can remain at home for longer, but also that carers receive the support they need before they reach breaking point.

Technology can allow a carer to have a good night's sleep, safe in the knowledge that should their loved one leave the house, cause the bath to overflow or even leave their bed for a prolonged period of time, they will be alerted quickly and appropriately. It can enable them to manage difficult situations in a effective and reasonable way. Such technology can also make spending a short time away from the house a possibility for the carer, which can make an enormous difference to the quality of everyday life.

Tunstall telecare sensors can all link to a personal pager used by the carer, which vibrate in the event of a sensor being activated and display a message telling the carer where in the home a problem may be occurring.

## next steps

Each person experiences dementia in their own way, and the disease progresses differently for everyone. This is why providing truly tailored care and support is essential, whether it is provided at home or in a more residential setting. Telecare offers a platform of constant reassurance around which care can be planned.

For further advice or information on how telecare can support people with dementia, please call us on **01977 660479** or email [enquiries@tunstall.co.uk](mailto:enquiries@tunstall.co.uk)





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