

Support for Carers

solutions for independent living

key information for health and social care professionals and carers



All the reassurance you need

Tunstall

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CARERS UK

the voice of carers

www.carersuk.org
Carersline: 0808 808777

Foreword

Carers UK is the voice of the UK's six million carers. That's six million people who give up their time and energy to look after someone in need, quite often to the detriment of their own health. Carers give so much to society, yet as a consequence of caring, they can experience ill health, poverty and discrimination. Carers UK is fighting to raise awareness of the true value of carers' contribution to society and to ensure they get the practical, financial and emotional support they need. We are here to provide information and advice for carers, and we believe telecare could be a fantastic source of support for them.

Telecare has been heralded as one of the key elements in modernising and transforming care services, harnessing technology to provide greater choice about services and supporting the right to live at home. Telecare has huge potential, transforming the lives of carers, by giving them 24 hour peace of mind and reassurance. This guide provides a useful introduction to what is available and how it can make a difference to carers lives, across the UK.

Imelda Redmond, Chief Executive, Carers UK

Introduction

Key statistics summary

- There are around **6 million** carers in the UK
- **1 in 8** people in the UK is a carer
- Over **1 million** people care for more than one person
- **58%** of carers are women, **42%** are men
- **3 million** people juggle caring with their job
- Carers save the economy **£119 billion per year**, an average of **£18,473 per carer**

The current situation

With around 6 million carers in the UK, and the figure likely to double over the next 40 years, the UK is sitting on a demographic time bomb. As people are living longer, the question over who will provide care and support to those who need it remains ever prominent, and with the lack of formal carers available, the pressure on relatives, friends and neighbours to become carers is set to increase dramatically. Caring for someone is no easy task and the responsibility for someone else's welfare 24 hours a day, 7 days a week can be physically, mentally and emotionally draining. Carers often feel invisible, that there is no help or support out there, and nowhere for them to turn. This guide aims to

summarise the telecare options available which can be used to provide support and peace of mind for both carers and the person they are caring for.

Definition

According to the Department of Health the word carer “refers to a person who will look after a relative or friend who needs support because of age, physical or learning disability or illness, including mental illness.” This does not include any paid formal care staff or care workers. For the purpose of this guide this is also the type of carer being referred to.

Statistics from Carers UK



The true impact of caring

One in eight people in the UK is a carer. These people are **dedicated** husbands, wives, sons, daughters, relatives, friends or neighbours, who give up their time to provide for someone in need.

The pressure of caring for someone else can be **extremely demanding**, physically, emotionally and mentally. Amongst the stresses and strains of looking after someone, carers often forget to concentrate on their own health and wellbeing, therefore the statistic that people who provide high levels of care are twice as likely to be permanently sick or disabled, is hardly surprising. A further **concern** is that carers are also growing older, elderly couples are often left to look after each other and parents who are caring for their children are also getting older.

Mr R is 80 and cares for his wife who has Parkinson's disease:

"On some days I'm very tired, it's hard work doing all the household chores and I don't always sleep well because I'm worried about my wife getting out of bed on her own."

Providing **constant care** for someone can have a huge impact on a person's time, energy and independence. Carers often don't have time for themselves, to socialise, take part in a hobby or go out for the day, and equally the

person who is being cared for can have their independence and privacy reduced by constantly being looked after by someone else.

Mrs O looks after her 75 year old husband who has Coronary Heart Disease:

"Being a 24 hour carer means I have to be there constantly for my husband. It would be nice to go out for the day, but I daren't leave him alone."

The challenges above are complex and differ greatly with each individual case. Tunstall has recognised these challenges and developed **telecare** and **telehealth** solutions to go some way towards relieving stress and providing support, peace of mind, independence and dignity to carers and those they care for.



The Government's view

Carers often feel there is a lack of support available to them. Many carers feel the Government needs to be more aware of carers' needs, that there should be clear policy guidelines to help carers and that the several different Government departments who deal with carers need to work together more.

Mrs S from Hampshire cares for her 19 year old daughter who has Cerebral Palsy. She found that when her daughter turned 18 the level of support she received from her local authority was significantly reduced:

"When I tried to get help it felt like doors were being slammed in my face. No one wanted to know about the difficulties we face every day."

In November 2010, the Coalition Government announced the next steps of the Department of Health's National Strategy for Carers which would seek to ensure the best possible support for carers was made available. This included taking steps to improve the quality of life for carers by providing personalised support to them and those they support. In 2011, the Government also announced a £1.35 million fund for community projects which would improve early identification of carers and give them greater, more informed choice about the options available to them. This includes providing carers with practical advice about the options available to people with various long term care needs.

For more information on Government support services available for carers, visit www.carers.gov.uk.

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'*.

Telecare offers a non-intrusive platform of support for carers, providing peace of mind and helping to restore independence for both the carer and the person they are caring for.

Whilst telecare isn't intended to replace people, it can support carers in many different ways. For example, a bed occupancy sensor can allow a carer to have a good night's sleep, by alerting them if the person they are caring for gets out of bed in the night. It can help carers to manage difficult situations in an effective and reasonable way and can make spending time away from the house a possibility. Today, tailored, flexible telecare solutions are being used to develop new models of care, which are transforming the lives of carers and the people they care for by supporting and enhancing their health, independence and wellbeing.

Caring for different situations

Carers look after a huge variety of people, of all age groups and with many different issues or conditions. This section of the guide aims to summarise three main groups of people being cared for, the different issues being dealt with and the benefits telecare can bring.

Older People

- In the UK 16.5% of people are over the age of 65, with 1.4 million people being over the age of 85
- The over 85s are the fastest growing age group in the UK and out of this group two thirds of men, and three quarters of women have a long term illness or disability
- Older people are more prone to accidents and falls, as well as related illnesses such as dementia, osteoporosis and heart disease

Case Study

Mr D who has hearing and visual impairments, cares for his wife who has moderate dementia. Mr D was worried as his wife had a tendency to walk about at night, set the microwave going for long periods of time and open the washing machine mid cycle. A system has been installed to call Mr and Mrs D's daughter if Mrs D leaves the

house between 10pm and 9am, and also monitors for floods, extremes of temperature and gas leaks. Mr D said: *"It has given us back part of our lives we wouldn't have had otherwise."*

Learning Disabilities

- The term learning disabilities is a generic term for anyone with a significantly reduced ability to understand new or complex information or to learn new skills, with a reduced ability to cope independently which started before adulthood with a lasting effect on development
- As life expectancy of people with learning disabilities increases, a growing number of carers are getting older and may have health problems of their own
- It's estimated that a third of people with learning disabilities living in the family home are living with a carer aged over 70, many of these are sole carers and most of these are women

Statistics from Office for National Statistics



Case Study

Sarah, like 50% of people with learning disabilities, also has epilepsy. Sarah's mother, Joan, used to sleep in the same room as her daughter due to the risk of tonic clonic seizures, which could sometimes occur up to five times in one night. Joan couldn't get a good night's sleep due to the constant worry of what would happen if she didn't wake up. Joan had an epilepsy sensor fitted in Sarah's bed, allowing her to return to her own room for the first time in 15 years, reassured that she would be alerted if Sarah needed her help.

Physical Disabilities and Illness

- Physical disabilities is an umbrella term for any condition that leads to loss of physical movement or weakness or change in motor

control, conditions such as Cerebral Palsy, Spina Bifida, Multiple Sclerosis, Muscular Dystrophy or damage to the spinal cord. Physical illnesses refers to a huge variety of conditions including Cancer, Heart Disease and HIV/AIDS

- Caring for someone who is physically disabled can be extremely physically and mentally tiring
- People with physical disabilities often have limited dexterity and may be prone to falls

Case Study

Mr W cares for his mum who has severe ME, Osteoporosis and Fibromyalgia, a painful illness which affects the immune system causing extreme fatigue, joint and muscle pain. To manage the risks associated with falling, a bed occupancy sensor and fall detector were provided to ensure that if she were to fall, an alert would be sent to the monitoring centre where the appropriate action would be taken. Mr W said: *"Having telecare installed means I can go out to work, and not have to worry that Mum will fall and hurt herself."*

All names have been changed throughout this document.

The technology - suggested solutions



Lifeline Home Unit and MyAmie Pendant

The Lifeline home unit receives alerts from telecare sensors placed around the home and automatically raises an alarm with a carer or monitoring centre.

The MyAmie pendant can be worn on the wrist or around the neck and allows the user to call for help simply by pressing the red button.



CareAssist

A portable telecare alarm for onsite carers that can receive telecare alerts and display not only the type of sensor activated but also either the location of the sensor or the name of the person the sensor has been assigned to.



Property Exit Sensor

This sensor specifically monitors for people leaving a building at set times of day or night, and notifies the monitoring centre or carer. It can also detect if a main door has been left open and can be linked to external lighting.



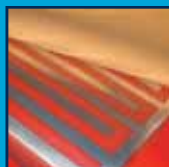
VitalBase^{FALL} Fall Detector

The VitalBase^{FALL} is a wrist worn fall detector which will detect if the wearer falls and remains immobile, and will alert a carer or monitoring centre.



Epilepsy Sensor

Placed under a mattress, this sensor monitors an individual, to alert if tonic clonic seizures occur. Upon detection of tonic clonic shakings, an alarm call will be raised to the monitoring centre or carer to ensure the appropriate action can be taken.



Enuresis Sensor

Placed under a bed sheet, this sensor provides immediate detection of moisture, allowing effective action to be taken, and eliminating the need for carers to make physical checks during the night.

All telecare sensors must be linked to a Tunstall Lifeline home unit and monitoring centre or carer.

Flood Detector and Smoke Detector

These detectors raise a local audible alarm upon detecting flooding/smoke, and will also alert a carer or monitoring centre.

Bed/Chair Occupancy Sensor

This pressure pad fits under the mattress and 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.

Bogus Caller Button

Fixed near the door, this button will provide reassurance in the event of an unexpected caller. It can be used to summon assistance or verbal prompts can be given via the Lifeline unit. Such incidents will also be automatically recorded and may be used in evidence.

Gas Detector and Shut Off Valve

This solution, upon detection of natural gas, automatically cuts off the gas supply to an appliance when a leak is detected.

Carbon Monoxide Detector

Sends an alert to the monitoring centre if dangerous levels of CO are detected, due to a blocked flue or fault in a fuel burning appliance.

DDA Vibrating Pager

The DDA Vibrating Pager is linked to the Lifeline Connect+. When a telecare sensor is activated, the Lifeline sends a signal to the pager, via the MyLife DDA transmitter, which alerts the wearer by vibrating and lighting LEDs to identify the sensor activated.

Medication Reminder/Dispenser

Provides effective solutions to support medication compliance. Can be used to provide other reminders if required.



Case Study 1

Jenny cares for her son Jason, who was diagnosed with autistic spectrum disorder at the age of 3.

The concerns

- Jason used to play out in the garden, but on one occasion he became very stressed and disappeared, returning one hour later
- The sedation medication that Jason was taking led to nocturnal enuresis
- Jason started to get up during the night. He would cook breakfast at 4am and once went out looking for milk at 6am
- Jenny is a single parent and was under so much strain, she was receiving psychiatric help

The solutions

- Jenny can now get a good night's sleep as she had a bed occupancy sensor installed which notifies her if Jason gets out of bed and doesn't return within 15 minutes during the night
- An enuresis sensor was also installed so if an accident occurs during the night, Jenny will be alerted. This means she no longer has to make physical checks during the night

The outcome

"Telecare has changed our lives. The enuresis is managed and is very rare. Jason is less aggressive and easier to manage. I can now sleep well at night without worrying about accidents" said Jenny.



Case Study 2

Stephen cares for his dad, Peter, who has chronic obstructive pulmonary disease, a long term lung disorder characterised by difficulty in breathing and fatigue.

The concerns

- Stephen was under incredible pressure as Peter needed daily monitoring and was repeatedly being admitted to hospital due to exacerbations in his condition
- Stephen was considering giving up his job to care for his dad full time

The solutions

- Peter was provided with a Tunstall **mymedic** telehealth solution and can now monitor his own vital signs at home. His results are then transmitted to his clinician who can check and make sure Peter is ok
- Peter's confidence has been restored as he knows that if his condition grows worse, the clinician will pick up on it and take the most appropriate action, such as adjusting his medication
- The equipment has relieved the pressure on Stephen as Peter can now monitor his own condition, and doesn't need to rely on Stephen to take him to and from hospital to have his vital signs measured

The outcome

- Stephen can now relax at work, safe in the knowledge that his dad's condition is being monitored regularly



Case Study 3

Lucy cares for her mum, Val, who has early onset dementia with rapid deterioration of memory.

The concerns

- Val was taking lots of medication and due to her memory problems, was either over dosing or not taking her medication at the right time. There was a serious incident where over dosing on Warfarin could have led to blood loss if she had cut herself
- Lucy was so worried that she took all Val's medication away and hand delivered it herself at the correct time. Val also needed weekly hospital visits due to fluctuations in her condition

The solutions

- Val was given a Tunstall medication dispenser, linked to a Lifeline home unit which dispenses her tablets and provides audible and visual alerts each time Val needs to take her medication. If Val doesn't access her medication, an alert is raised to Lucy or the monitoring centre to let them know

The outcome

- Since the telecare solution was installed, Val's condition has stabilised and she only needs monthly hospital visits. Lucy has now been able to go on holiday for the first time in many years, safe in the knowledge her mum's medication compliance is being monitored whilst she is away. *"It's such a relief, knowing that mum is taking the right medication at the right time"* she said.



Case Study 4

Child A, is aged 14 and has a life limiting condition, Duchenne Muscular Dystrophy.

The concerns

- Following the death of his mother he was being cared for his siblings, his older sister aged 16 and younger sister aged 9 as well as a family friend
- The children needed additional support in order to be able to stay safely at home together

The solutions

- Tunstall's Lifeline Connect+ along with three smoke detectors, a DDA paging system, carbon monoxide detector and minuet watch were provided and linked to a 24-hour response service
- Child A knows that if he activates his minuet watch, he can get help immediately from the Care Link Call Centre for the short times that his oldest sister is out of the house
- The paging unit also alerts his oldest sister if he needs assistance during the night

The outcomes

- This practical and emotional support was presented in the Family Court as part of the evidence of the interventions that had been put in place to keep these young people together as a family unit. The telecare played a very important part in the evidence, and without it there was a distinct possibility that the family would have been split up
- Not only have the children benefited from being able to remain together as a family, but the costs to the local authority are much lower than the alternatives of providing additional care or placing the children into foster or residential care

Thanks to Wakefield Council for allowing us to include this case study.



Telehealth

Tunstall's telehealth solutions offer a way of delivering tailored care for patients with long term conditions in their own homes, improving quality of life and preventing avoidable hospital admissions.

Tunstall's telehealth solutions can be of benefit to carers as they can reduce the need for hospital visits, and provide peace of mind and reassurance that the person they are caring for is being monitored daily, and any exacerbations in their condition will be picked up and dealt with accordingly.

Tunstall's **mymedic** monitor enables patients to measure their vital signs, such as heart rate, blood pressure, blood glucose levels, oxygen saturation and temperature, in their own homes.

The monitor records the results and transmits the data via a secure server to the patient's clinician, who can view the data and take action if a potential problem is detected.

For further information on Tunstall's telehealth solutions please visit www.tunstall.co.uk/telehealth or call 01977 660479.



Where can carers go for help?

The following websites contain lots of helpful information and advice for carers:

The Government's directory of information for carers - www.direct.gov.uk/CaringForSomeone

The Department of Health's official website - www.carers.gov.uk

Carers can also visit their local authority's website to find out about help and support for carers in their area.

Carers UK - www.carersuk.org - provides information and a virtual community to carers, as well as a search function to find your nearest Carers Centre.

www.youngcarers.net - provides 7 days a week support from youth workers to young carers.

www.carers.org/professionals - is a resource for professionals.

The Princess Royal Trust for Carers - www.princessroyaltrust.org.uk

Carersline - **0808 808 7777**

Counsel and Care - www.counselandcare.org.uk

Advice Service - **0845 300 7585**

Mind carers fact sheet www.mind.org.uk/Information/Factsheets/Carers

The statistics in this document have been sourced from:

www.carers.gov.uk

www.carersuk.org

www.statistics.gov.uk

www.news.bbc.co.uk

About Tunstall

Tunstall is the world's leading provider of telehealthcare solutions, with over 2.5 million users globally. Tunstall's solutions support older people and those with long-term needs, to live independently, by effectively managing their health and well-being.

Tunstall provides technology, expertise and advice to millions of people enabling them to lead independent more fulfilling lives.

For more information on how telehealthcare can improve quality of life, visit www.tunstall.co.uk or call 01977 660479.



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