Carers and telecare
Introduction

One of the greatest challenges facing the NHS is how it manages patients with long term conditions such as Chronic Obstructive Pulmonary Disease (COPD), heart failure and diabetes. The NHS already spends 70% of its budget on the 15 million people who have one or more of these conditions, and with our ageing population, patient numbers are expected to grow by 23% over the next 20 years\(^1\). The pressures on the social care system are just as great, with demographic demand estimated to require an increase in the social care workforce of between a third to two thirds by 2025\(^2\).

The impact on families is also clear – as carer numbers have risen from 5.8 million in 2001 to an estimated 6.4 million in 2011 and are expected to rise to 9 million by 2037\(^3\). The pressure on carers is also growing, and the proportion of carers caring for over 50 hours a week has doubled in the last ten years\(^4\). For many this brings a high personal cost to their ability to work, stay healthy and manage to make ends meet.

It is clear that our current approach to health and care is simply not sustainable and, alongside the importance of finding an urgent solution to the funding crisis in social care, innovation is essential. Health and social care are increasingly focussing on prevention as the best way to reduce demand for acute services, and reablement as the best way to reduce demand for community care. If the ultimate goal is the reduction of whole life health and care costs, it must also make sense to maximise the potential of technology to achieve that goal.

Carers UK’s report Future Care: care and technology in the 21st century kicked off our debate on how technology from medical equipment to web-based information applications, had the potential to deliver across the board - for older and disabled people, carers, their employers, the health and social care system and the wider economy.

By looking at carers’ experiences, this report takes this case forward by exploring in more detail the evidence and opportunities afforded by telecare and telehealth technologies and the barriers to greater take-up.

Heléna Herklots, Chief Executive, Carers UK

---

\(^1\) John Cruickshank, Healthcare without walls: A framework for delivering telehealth at scale (November 2010), 2020 Health
\(^3\) Carers UK (2011) Valuing Carers
Definitions, stats and facts

**KEY FINDINGS**

- Over 60% of carers surveyed said telecare/telehealth had given them peace of mind as a carer.
- One in eight carers said telecare/telehealth had helped them stay in work or return to work alongside caring.
- Yet almost two thirds of carers not using telecare/telehealth were unaware of the support available from technology.
- Of carers not currently using telecare/telehealth one in four would like it but simply did not know where to find it.
- Only 6% of carers said they would not want telecare/telehealth.

Evidence shows that this kind of monitoring can catch symptoms early, stop conditions getting worse and prevent avoidable hospital admissions. It can also help people to manage their own health condition as the monitors show them how what they are doing affects their health in different ways.

**How do families access it?**

Many local council social care services offer telecare and telehealth, with older and disabled people receiving it as part of their package of care and support – some have to pay a charge according to their circumstances and their council’s approach to charging for social care.

Families’ access to it tends to depend on a community care assessment and whether they meet local eligibility criteria. However, some local authorities are starting to offer telecare outside of normal assessment processes – seeing it as a preventative service for people with low or moderate needs who might otherwise not be able access services due to rising eligibility thresholds.

Telehealth is provided through the NHS and, if it is available in their area, people with long-term conditions access it via their GP, community health team or hospital specialists.

If telecare or telehealth are not available in their areas, families may be able to buy the services themselves.

**How many people use telecare and telehealth?**

- There are 1.7m telecare users in UK yet estimates show there are as many as 4.17 million potential telecare users over 50 in England alone.
- The same analysis indicated that 1,855,000 of those older people were receiving care from friends or family members suggesting a large pool of carers could also benefit from use of telecare.

5 Strategic Society Centre (2012) Who uses Telecare?

---

**What are telecare and telehealth?**

**Telecare** is a system of sensors in the home which can detect household dangers like fires and floods, or risks to older and disabled people, like falls or leaving the house alone.

When they detect a risk the sensors alert a monitoring centre who can alert family members, care professionals or the emergency services.

The idea behind telecare is that it not only summons help in an emergency but can also provide reassurance for an older or disabled person and peace of mind for their family if they need it.

**Telehealth** is a system of sensors and monitors for people with long-term health conditions to check on their health whilst they are at home.

For example, these monitors can check blood pressure and heart rate, take someone’s temperature and check their weight is right.

A main unit would take this monitoring information and ask a series of tailored questions about the older or disabled person’s health condition – relaying all this information to a monitoring centre and their GP or nurse. If anything is out of the ordinary or gives cause for concern, a medical professional can then be alerted to get them the treatment they need.
Methodology

To assess the impact of caring on carers’ lives, Carers UK’s State of Caring surveyed 4,282 carers between September 2010 and July 2011. The majority of respondents completed the survey online, with 105 respondents completing paper versions.

2,758 of the respondents were from England, 401 from Scotland, 383 from Wales and 102 from Northern Ireland.
• 75% were aged between 40-64, 14% were over 65, 11% between 25-40, and less than 1% were under 25
• 76% of respondents were women and 24% men
• Respondents were weighted towards heavy-end carers, with 75% caring for 50 hours a week or more.
• 30% were caring for a parent or parent in law, 39% for spouse or partner, 38% for their son or daughter, 3% for a sibling and 9% for a friend or other relative
• 88% of respondents were White British and 6% from Black, Asian and other ethnic minority (BAME) communities

Carer usage of telecare

Of those responding to the State of Caring survey, 17% (705) stated that they were using some form of technology like telecare to help with caring. The types of technology these carers use can be broken down into these categories:

- Environmental controls (eg. heat, light and door controls) 8%
- Personal Alarms (eg. push button pendant or watch) 74%
- Special detectors (which detect smoke, gas leaks, water spillages) 31%
- Equipment to monitor health at home (temperature, blood pressure) 10%
- Electronic medication dispensers or reminders 4%
- Movement detectors or bed/chair sensors (eg. to ensure someone with dementia doesn’t leave their home alone, or alert help if they don’t return to bed at night) 11%

By far the most popular form of technology was a telecare push button pendant or watch, as 74% of these technology users had one. More extensive forms of telecare involving sensors to detect risk and which do not depend on the user initiating the alarm had a lower uptake: 31% using risk detectors and 11% using movement detectors. 10% were using telehealth equipment.

Our survey showed usage of telecare was tilted much more towards carers who cared for an elderly person. Over half of the carers who used a personal alarm system, risk detectors or movement detectors were caring for someone over the age of 75.

However, whilst telecare has traditionally been marketed at and taken up by carers looking after older relatives, our survey showed some uptake among other carers. For instance, of those who used movement detectors, 16% were caring for someone with a learning disability and 7% were caring for someone with an autistic spectrum disorder. The numbers involved are small, but they signal that telecare has the potential to benefit wider groups of users.
Case study: telecare and dementia

Alice is 82 and a widow. She had lived independently for years but was recently diagnosed with Alzheimer's disease, so has moved in with her son Tony, his wife Alice and their three children. Tony is determined to look after Alice for as long as possible as a family, but the family had been struggling with Alice's forgetfulness – which meant she was leaving the home at night, leaving the front door open and taps running and sometimes turning on the gas but not lighting it. The worry meant Tony and Carol were losing sleep and Tony's work was starting to be affected.

A package of telecare helped the family, including a property exit sensor, and bed occupancy sensor to detect if the front door was left open or if Alice gets out of bed and does not return safely after a short while. Along with these sensors, flood and gas detectors are also tied into a central home unit which can alert Tony or Carol via a pager when they are at home or a monitoring centre if they are not.

Different services are also available in different areas:

- Alerts which contact either family members or emergency services depending on the severity of the problem.

"The sensors and alarms I have, have helped a lot in ensuring if my wife leaves her bed I am alerted immediately as she suffers with seizures and can fall without warning"

- Response services where a social care team or a warden in sheltered housing is able to respond to alerts.

"At first I was expected to attend calls made by my mother to her lifeline several times a day at all times of the day and night. I then upgraded to a response service so that if necessary the lifeline service will attend."

"Really good as if my Mum falls, the warden call people will come out with lifting aids. This means we do not have to ring 999 to get help in lifting her."

Case study: Birmingham City Council – delivering telehealthcare at scale

Birmingham City Council has invested £14 million in a large-scale, city-wide telehealthcare service in partnership with Tunstall. The deployment, which is believed to be the first of its kind in the UK, will ensure safety and support for up to 25,000 older and vulnerable residents over 3 years whilst maximising their independence and providing peace of mind and independence for their families and carers.

By making the strategic decision to extend the telehealthcare service provision to more people, the Council expects to create a systemic shift towards early intervention and preventative services, to meet growing demand for increasingly personalised care packages. Birmingham City Council has made the decision to partner with Tunstall to deliver the whole system, from assessment and response to installation and monitoring.
Outcomes

Telecare and telehealth can lead to a variety of outcomes for older and disabled people – promoting independence, acting to prevent or quickly identify health complications and providing reassurance.

Reducing stress and worry

Caring for someone can be physically exhausting, with many carers saying that their physical health has suffered or that they have been injured by caring. But constant worry about the person they are caring for can take a serious toll on carers’ health. With 9 in 10 carers responding to a Carers Week survey in 2012 saying that their mental health had been compromised by the stresses of caring.6

Of the respondents to the State of Caring survey over half said caring had a negative impact on their relationships with their spouses and other family members, and two thirds reported a worsening of their relationships with friends. Stress was the factor most identified. Over 8 in 10 (82%) cited stress as a contributor to the impact on their relationships.

This stress can take different forms – constant worry when carers of partners with serious health conditions leave the house, concern for frail parents if they are living on their own, or struggling to sleep because of fears that a child with learning disabilities will get up and try and leave the house.

“Can't go out without feeling I've abandoned my father and worry he's ok.”

Older or disabled people may also be at risk of falls or of household hazards like flooding or gas being left on; or need supervision to ensure they do not leave the house unattended or answer the door to strangers.

Telehealth can provide reassurance that health crises for people with long-term conditions will be picked up early.

“I have blood pressure/pulse rate monitors; glucose monitoring....this technology helped save my mother's life when she got heart problems.”

Of the 705 respondents who were using some form of telecare or telehealth:

- 61% reported that the technology had given them peace of mind.
- 10% said they were less stressed as a result of using telecare.

“Telecare saved my mother's life when I was away at the children's hospice with my son and she fell asleep with the cooker going. The smoke sensor enabled telecare to wake her up in time.”

“The alarm has only been used once, but it was absolutely vital at the time. I wouldn't be without it, and it certainly gives me peace of mind.”

Sleep

“It means I can sleep, on a daily timeframe. It means the trips to hospital to check my heart have reduced.”

Telecare can only do so much, and in many circumstances it must be accompanied by care and support services to make a real difference.

Just under 1 in 20 carers (4%) using telecare said they were less tired as a result of using telecare. This may be an illustration of the fact that, whilst telecare can give peace of mind if an older or disabled person is at risk during the night, telecare’s role is often to alert carers to intervene, so sleep is still interrupted.

“My husband gets up roughly every two hours at night, when he steps on the sensor a loud bell rings and wakes me so I can help him go to the toilet.”

“The pressure mat means I can be available in the night quicker, due to the alarm it activates when the person I care for gets out of bed.”

“It's a double headed dragon! You have an alarm! It goes off! It wakes you up! If you did not have the alarm all sorts of things could happen! It's a catch 22.”

Without extra support from social care services, carers may find that although telecare provides some peace of mind that they will be alerted if there is a problem, it does not mean they manage to get much more sleep.

“It enables me to call for paramedics/an ambulance in an emergency whilst being able to deal with my husband at the same time.”

“It is only there to assist in telling me when my wife has seizures at night - also to summon an ambulance quickly.”

“It has some impact but I am simply too exhausted and will never recover.”

This also demonstrates that telecare and telehealth cannot be used to substitute care services where they are needed and the difference that a response services (where a social care team, rather than family member can respond) can make.

6 In Sickness and in Health (2012) Carers Week
Enabling carers to have a life outside caring

Caring can have a serious impact on carers’ social inclusion – leaving them less able to socialise, spend time with other family members or work. Practical services, like support from care workers in the home, day centres or short breaks from caring are often needed to replace hands on caring. However worry and stress can also be significant factors to carers being unable leave the house for any length of time, or becoming stressed and anxious at work or whilst socialising.

“When you go out you feel under pressure to rush back. You keep thinking something might happen to the person you are looking after and if you are not there you would blame yourself.”

In addition to a reduction in stress and worry, the peace of mind offered to 60% of carers using telecare and telehealth can result in carers having more time and confidence to do things for themselves.

- Almost one in five (18%) of carers using telecare or telehealth reported that they had more independence as a result.

“The medication dispensers mean that I can reduce the number of times that I visit.”

“The call button means that I feel I can pop up to the local shops for a short period of time as my mother could call for assistance if there was a problem.”

This could mean that carers have more time to socialise and spend time with other loved ones and crucially to look after themselves. On top of the impact of a lack of sleep and the physical and mental strains of caring, evidence from a survey of over 3,400 carers for Carers Week 2012 showed that 39% of carers had put off medical treatment or check-ups for themselves because of caring.

Telecare and telehealth’s ability to give carers more independence can contribute to their ability to be more socially included and to have the time to look after themselves.

---

7 Carers UK, Ipsos MORI and Department of Work and Pensions (2009) One million give up work to care
8 Of carers who had given up work or reduced working hours to care 44% said their ‘cannot afford utility bills cannot afford utility bills like electricity, gas, water or telephone bills’ and 52% were in debt as a result of caring, compared to 23% of carers juggling work and care being unable to afford their utility bills and 40% being in debt.
Juggling work and care

We know that around 1 million people have given up work or reduced working hours to care.7

The State of Caring also asked about the impact of giving up work and found that over two thirds (68%) of those who had given up work to care were more than £10,000 a year worse off as a result. Because of the inadequacy of carers’ and disability benefits the impact of giving up work to care is stark. Carers who had given up their jobs or cut back on working hours were more likely to be in debt, and were almost twice as likely to be unable to afford basic utility bills.8

Telehealth and telecare can help families to juggle and work and care in several ways:

• Reducing stress – 63% of carers forced to give up work or reduce working hours cited stress as a contributing factor. However many carers also continue to work despite their anxieties about the person they care for. This brings costs to both carers’ mental health but also their productivity. A 2011 Employers for Carers survey of working carers showed that nearly half (43%) felt their work had been negatively affected by caring and that they felt tired, stressed and anxious. Reducing this workplace stress can both improve carer health and their ability to work effectively.

• Preventing absence – if telecare and telehealth can tie older and disabled people into other support systems, like neighbours, wardens or response teams the systems can prevent calls to carers at work which would otherwise force them to take time off to respond to.

• Preventing crises – through telecare mitigating against potential household hazards and telehealth acting to prevent health complications, this technology can prevent emergencies becoming crisis which result in a loss of independence and the need for higher levels of care provided by family members.

For a significant number of carers using telecare or telehealth who responded to the survey, the technology had enabled them to juggle work and caring.

• 12% reported that telecare or telehealth had helped them to keep their job or return to work alongside caring.

Giving carers the ability to stay in or return to work is not only a significant element of improving carers’ future career prospects and social inclusion – it also has a direct impact on the likelihood of carers falling into debt and financial hardship.

As a result, enabler carers to stay in work can make the difference between illness or disability leading to debt and financial hardship and families remaining resilient.
Case study: Wakefield and District Housing – juggling work and care

Anthony is 35 and suffered a shrapnel injury whilst serving in the armed forces leading to mobility difficulties and a significant risk of seizures. He had suffered a number of seizures whilst his wife was at work and the children were at school and on one occasion had seriously injured himself. The stress and worry was affecting family life and his wife had been forced to go part-time at work to support Anthony. Following referral from his Occupational Therapist Anthony had a telecare monitoring services and pendant alarm installed and Anthony said: “It’s changed my whole family’s life not just mine, my kids have been taught what to do if anything happens and I think there’s a sense of self achievement for them.

Another benefit is that my wife is back working full time. She used to phone me every ten minutes to check up and she felt stressed because it was affecting her work as a teacher. So she dropped to part time which was a massive blow as my illness not only affected me, but also my wife’s career as well as our finances. Since having telecare she’s been able to go back teaching full time which is great.

My issues of being proud and thinking I don’t need help were reassured with telecare as I know the support is there 24/7 but it doesn’t get in the way at all. The beauty of it is that help is there when you need it, but you can do what you want and get on with everyday life knowing someone is there if something was to happen. It’s priceless for what it does, it’s freedom, and you can’t put a price on that.”

However for some families, telecare or telehealth alerts alone are not enough. Without response services, alerts may help to ensure that carers are contacted if there is a problem, but carers will still have to leave work if services are not in place to respond.

“This is a bit of a doubled edge sword it allows you to go to work but you then have to get home if one of the alarms goes off to sort out the problem.”

“Unfortunately, my dad, would press the button all the time, but not talk to the operator, so I was called out of work many times; I didn’t mind it gave me peace of mind and at least my dad was not hurt in any way.”

This points to a real need for response services to be in place in order to fully deliver on the potential outcomes for carers.

“It’s difficult to find someone/neighbor who’d be around should my mum need help when I’m working 42 miles away.”

However even where telecare alone could not enable carers to work, it can provide a bridge between services and families. Many carers struggling to work and care find that things fall apart or stress becomes a factor because their jobs and services often do not quite match up. Transport to daycare or care workers are late and they cannot leave for work on time, or they are rushing home at the end of the day so that they can be there when the person they care for returns from day care, or care workers leave. Telecare can provide the reassurance that the person they care for is safe even if they are left alone for a short period.

“If I return home a few minutes after our carers have left in the morning, it gives us both peace of mind that there is an easy method to summon help, especially as my husband cannot stand or move from his chair.”
Challenges for users

Of the survey respondents using telecare nearly 7 in 10 (69%) were happy with it, with only 9% saying they were unhappy with it.

The main reason for dissatisfaction seemed to centre on worries about relying on telecare and telehealth. Whilst 14% of all users worried they could not rely on it this rose to just under half (49%) of those who were not happy with the technology. However, of those commenting on their use of technology only a handful identified specific examples of equipment failure.

Many expressed concerns that the person they were caring for would not wear or operate the monitoring equipment and therefore they could not rely on it.

“It’s ok when my mother wears her personal alarm but this is not always the case. I can rely on the alarm but not on the person who should be wearing it.”

Carers struggling to use the technology was not common, with only 1% of all users finding it too complicated and this did not seem to be the cause of dissatisfaction, as only 5% of those unhappy with the technologies reported it being too complicated.

However 9% of all users said that the technology upset the person they cared for such that they did not want to use it, rising to 17% of those unhappy with telecare or telehealth.

The unsuitability of the technology for the person being cared for was the most frequently cited reason for problems in the comments of those dissatisfied with the systems. In the majority of cases this was because they did not believe that the older or disabled person would use self-activated technology.

“We have care alarm but my father can’t remember what it’s for so I don’t think he would use the system in an emergency - he would try to phone my mobile.”

“With Alzheimer’s, mum has difficulty knowing what the alarm is for and when to use it.”

Whilst these cases may indicate circumstances are offered telecare or telehealth when it is not appropriate, it also seems that families are not being offered the right package to meet their needs. Self-activated pendant alerts, for example, may not be appropriate for people with dementia, but fall-sensors or bed sensors which set off alerts when someone gets out of and does not return to bed, may be more appropriate.

Whilst some respondents expressed concerns about whether technology would replace care services only 2% of all users and 5% of those dissatisfied, felt that the technology had done so.
Carer perceptions of telecare

With a significant majority of carers using telecare and telehealth satisfied with this support, and many reporting positive outcomes for both them and the people they care for, it is surprising that so many potential users are not offered the service.

The State of Caring survey examined all carers perceptions of telecare and telehealth to explore how families not receiving this kind of support felt about it and to understand some of the barriers to takeup.

These results indicate that the main barrier to takeup from families’ perspective appears to be awareness – with almost two thirds unaware of the technology available.

- 62% were unaware of the technology available.
- 15% would like it but did not know where to find it.
- 17% would like it but had not been offered it.

Of those who cared for someone who had recently been discharged from hospital, only 3% had been offered a telecare package upon discharge.

Of those who were aware of telecare and telehealth but not using it:
- 26% would like it but did not know where to find it.
- 30% would like it but had not been offered it.
- 26% would like it but had found it too expensive.
- 20% did not like the idea of technology in their homes.

These findings seem to show that, even when families are aware of the support many still did not know how to access it and had not been offered it. However cost also remains a significant barrier to takeup.

One in five of those not accessing telecare and telehealth simply did not want it, however they made up only 6% of the total respondent population.

“Telecare was not offered or arranged via social services – we were left to find out ourselves and arrange for this to be installed.”

“We have got a lot of what we have by luck, speaking to the right person at the right time. I just wish I was sure we knew about all that is available and how to get it.”
Conclusion

Whether it is that ‘extra bit of help’ which gives carers the peace of mind to enable them to sleep, the back-up which means carers can juggle work and care or the prevention of a potentially life-threatening health complication - telecare and telehealth have huge scope to change the lives of older and disabled people and carers. There are also clear dividends to the NHS and social care services, but also the potential for wider economic and social benefits by keeping carers healthy and resilient, able to work where possible and stay active and social. This is evidenced not only in the headline findings of the Whole Systems Demonstrators, but also by innovation at local level across the UK.

However, as it stands, this technology is not delivering all it can, as a lack of awareness and difficulties in accessing it act as barriers to take up. Too many families have never been offered the option of telecare and telehealth – despite the evidence that they are overwhelmingly likely to consider it. Only 6% of respondents to our survey would not want telecare whilst almost two thirds had no idea what was available.

In addition, we are failing to capitalise on the role technology can play in joining up other services and support. In addition to investing in response services, by linking telecare alerts into a range of statutory, third sector or community services which are able to respond, there are real opportunities to take telecare onto the next stage. There is peace of mind that carers will be alerted when they are at work so they can leave the office to go and sort out any problems – but this fails to fully deliver on the capacity for telecare to help carers stay in work. An alert which contacts a response service from the local authority or a British Red Cross volunteer would give real peace of mind.
If telecare and telehealth are to deliver on their potential, a number of stakeholders must act, quickly.

- **Local authorities** must ensure that it is routinely offered to service-users and their families.
- **Advice agencies** should ensure they are encouraging families to ask for it.
- **Providers** need to make sure that they offer services not just through contracts with local authorities but direct to the public – to bring the purchase of telecare and telehealth to the high street and accessible online marketplaces.

The fundamental challenge lies in ‘mainstreaming’ technology – so that, when ill-health or disability affects families one of the things they automatically check is what technology, including telecare and telehealth, they can access. This also applies to statutory services, where it must become part of everyday practice to check whether older and disabled people and their families are accessing telecare and telehealth, through community care assessments, local authority social care webpages and at GP check-ups.

To deliver a co-ordinated strategy to embed technology in professional practice and bring about a wider shift in public attitudes and expectations around technology and care, Carers UK is calling for the creation of a Health and Care Technology Taskforce to respond to this. There are already some identified barriers to realising the potential for transformation in the areas discussed above – challenges in integrating services, lack of awareness of technologies and what they can deliver, a fragmented market. In addition these are challenging times, and the squeeze on public services, tight labour markets, slow growth and pressures on families call for even greater creativity. If we are to make the most of the opportunities presented by technology we need some serious joined up thinking – and action.

For further information on the Department of Health/Industry ‘3millionlives’ campaign – 3millionlives.co.uk
For carer information on different telehealthcare packages – tunstall.com
For further reading and information on how to mainstream services – tunstall.com
For further recommendations around the task force Future Care: Care and technology in the 21st century is available at www.carersuk.org/professionals/resources/research-library.
This research was supported by Tunstall Healthcare and is part of an ongoing partnership between Carers UK and Tunstall Healthcare.

Publication code UK4053