

# Carers guide to “Technology Enabled Care Services”

*Paper written by Ali Rogan, with support from ADASS Carers Policy Network and Carers UK  
April 2015*

Draft 1.1 26.2.15



## Background to this document

Following a lively workshop with members of the Association of Directors of Adult Social Services (ADASS) Carers Policy Network ([see back page for members?](#)) with presentations and discussions facilitated by Tunstall Healthcare and Carers UK, there was an overwhelming consensus that technology enabled care such as telecare, can be an enormous help to carers but awareness of what was available and how to get it was limited.

Therefore it was agreed that a guide to technology for carers would be of great help. This document therefore covers:

1. Executive summary
2. What technology is out there to support carers?
3. How does technology support carers - Real life case studies
  - a. Lucy is a working carer supporting Mum who lives with dementia
  - b. Family supporting Dad who is now struggling to cope on his own with various health conditions
  - c. Single parent supporting two children with learning disabilities
  - d. Supporting a partner with a life changing physical disability
  - e. Supporting a husband with lung disease and hospital stays
4. Top 5 things carers need to know when choosing technology enabled care
5. Further help and advice
6. Information about the authors

## 1. Executive Summary

Suggest this is an intro by Grainne Siggins / Luke Addams

The work of the policy network

Touch on Care Act

Why this document is important

Telecare is a way of reassuring families and reducing the 'burden' on them; some members of the workshop felt telecare provided an alternative emergency response, or gave their families and friends 'peace of mind'.

Also I suggest an intro by Carers UK??

Touch on

- Key stats
- Carers UK research on technology awareness and benefits
- **thoughts?**

## 2. What technology is out there to support carers?

### Technology solutions for everyday life

We use a range of technology enabled solutions in our everyday lives:

- Internet for information, online shopping and banking
- 'Apps' for clever living: travelling, planning, news, events, turning on our heating!
- Mobile and ICT systems for remote working
- Skype and video conferencing for real-time communication at a distance
- Facebook for keeping in touch

And our everyday lives include caring too however do we even think about technology to help us?

### Types of Technology Enabled Care Services

Add simple definitions and suitable photos of

Telecare

- *Telecare is a system of monitors and sensors which can include a basic alarm service, able to respond 24/7, e.g. if someone has a fall. It can include sensors such as motion or fall detectors and fire and gas alarms that trigger an alert to a response center staffed 24 hours a day, 365 days a year. It can include location devices that can find someone, e.g. if someone with dementia wanders outside the home*

Telehealth

- Telehealth supports people with long-term health conditions, by enabling them to measure their vital signs such as heart rate, blood pressure, oxygen saturation and temperature in their own homes, on a daily basis. An easy to use monitor and supporting medical devices relevant to the patient's condition are installed in their home, and the patient simply answers a series of tailored questions about their symptoms when prompted by the monitor. The information is automatically sent to a monitoring centre for technical and clinical triage. If results are outside of parameters set for that individual, their clinician will be alerted.
- Televideo
- Mobile apps
- Assistive technology
- **What else?**

### What do carers need?

Here's some feedback from the workshop about what carers told us they need:

- We need support systems to connect people to each other and to timely assistance
- There needs to be choice, it can't be forced on someone and it must be easy to use
- There is a need for 'holistic' assessment of all aspects of a person's lives
- Carers and families often felt reassured knowing someone else involved
- Frictions and worries can be reduced around technology-enabled medication support – people calm down when less worried about something.
- We need to reduce risks of delaying requests for help. With telecare I hear people say "I don't want to bother anyone, it's very late or I'd rather wait for my carer"

Technology enabled care is not a replacement for personal support but it can help provide reassurance just to check someone is up and about, manage risks around falls, or to give

someone confidence that someone is there for them at all times, and there is someone to talk to.

Is a diagram like this helpful?



Or a grid like this?

Main issues carer's face	How telecare can help
Stress/anxiety - Constant pressure (physical and emotion)	Support 24 hrs a day, always there
Regular breaks / Respite care	allows freedom to go out to shops, visit friends
Worsening health	Preventative nature of telecare/telehealth has been know to reduce level of hospital admissions
Getting to grips with medication	Medication reminders
sleeplessness = lack of concentration	bed sensor alleviates the worry of epilepsy, enuresis, walking about, falls
Isolation, loneliness	Response centre is there for you to talk to, 24 hrs a day. Telecare allows you to go out

### 3. How does technology support carers? Real life case studies

Is it helpful to add some stats like this throughout?

- More than 3 million people – one in seven of the workforce in the UK – juggle the responsibilities of caring and paid employment.

#### **A: Lucy is a working carer supporting Mum who lives with dementia and struggles with medication and memory issues**

##### CHALLENGE

- Lucy works full time but cares for her mum, Val, who has early onset dementia
- 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 overdosing on Warfarin, which could have led to blood loss if she had cut herself.
- She also was prone to leaving the gas fire unlit which was a constant worry
- Lucy 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. It was proving difficult getting time off work and her bosses were beginning to complain

##### SOLUTION

- Val was given a monitored medication dispenser, linked to a Lifeline home unit and 24/7 monitoring centre 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 the monitoring centre who let Lucy know and she speaks to her mum to talk her through what to do, however if she sounds confused she will also pop home from work
- A monitored temperature extremes and gas detector were also made available should there be a gas leak or potential fire

##### OUTCOMES

- Val's condition has stabilised and she only needs monthly hospital visits.
- Lucy: "It's such a relief, knowing that mum is taking the right medication at the right time, I've even been able to have a short holiday for the first time in years."

#### **B: Family supporting Dad who is now struggling to cope on his own with various health conditions**

##### CHALLENGE

- My dad has been on his own since mum died 3 years ago. At 79, he's got a heart condition, incontinence, is generally very frail and unable to get around the house, even with his walking frame and we thought we'd lost him three times.
- My sister works full time as a teacher and has taken on the largest proportion of caring for dad as she lives nearby. My brother lives down south and I work long hours.
- My sister is finding it very difficult juggling her job with caring for dad – calling round at 6.30am to get him out of bed and give him his breakfast, calling by at lunchtime to feed him and leaving a flask of tea for the afternoon and again at dinner time.
- In addition, the district nurses visit regularly to give him warfarin, change his catheter and dress his ankle.
- We worry a lot about his health and the last straw was when he fell out of bed and had been unable to move all night. My sister thought the only solution was for her to give up her job to look after dad full time.

##### SOLUTION

- We got dad a telecare package and pendant and in first four weeks he'd used it twice. The first time was when he'd fallen in the evening and within minutes the

Careline had called my sister who was round to see him straight away. However the second time he fell awkwardly and unfortunately his arm was twisted around his back, so he couldn't reach the pendant on his wrist. My sister visited the next day and called the ambulance and he spent quite a bit of time recuperating. I've now suggested we get a bed sensor installed.

#### OUTCOMES

- The whole family feels so much more secure and has peace of mind that should dad need help, they'll know about it straight away. **My sister was seriously considering giving up work** or going part time and now she feels she doesn't have to as the burden has been shared. I think the telecare is brilliant and although my dad was reluctant at first, he knows it relieves the worry for us.

### **C: Single parent supporting two children with learning disabilities**

#### CHALLENGE

- Lisa is a single parent to Chris and Elliot, both of whom have learning disabilities. They're boisterous boys and she's finding it harder to cope as they get older. It's also much more difficult to make ends meet financially.
- Chris will be leaving school soon, and he'd like to live independently but that seems a distant dream. Lisa worries about what would happen if she's no longer able to care for them.

#### SOLUTION

- Lifeline home unit and carer pager – receives alerts from sensors around the home. It notifies Lisa via a pager when she's at home, and a monitoring centre when she isn't.
- Bogus caller button – Lisa's sons can raise an alert at the local monitoring centre if they answer the door in her absence.
- Bed occupancy sensor – lets Lisa know if one of the boys gets out of bed at night and doesn't return safely after a short while.
- Property exit sensor – tells Lisa if one of the boys leaves the house in the evening.
- Heat detector – detects a rapid rise in temperature in the kitchen, indicating a possible fire.

#### OUTCOME

- Technology has enabled the family to stay together, Lisa is able to get a good night's sleep for the first time in years

### **D: Supporting a partner with a life changing physical disability**

#### CHALLENGE

- Six months ago Maria's partner Tim was involved in a serious motor bike accident, which has resulted in him having to use a wheelchair. Tim has just come out of hospital and Maria's been off work for several weeks to be with him, but her boss needs her back at work, and they need the money. Tim is fiercely independent and doesn't want Maria doing everything for him – in fact he'd much rather she was back at work. He's sleeping downstairs in the living room at the moment.

#### SOLUTION

- Lifeline home unit and carer pager – receives alerts from sensors placed around the home. It notifies Maria via a pager when she's at home, and a monitoring centre when she isn't.
- Minuet watch – a wrist worn watch which also enables Tim to call for help if needed.
- Chair occupancy sensor – raises an alert if Tim falls out of his wheelchair.
- Bed occupancy sensor – lets Lisa know if Tim falls out of bed, enabling her to have a good night's sleep without checking or worrying.

#### OUTCOME

- Maria and Tim's relationship is much improved and Tim has his independence back

## **E: Supporting a husband with lung disease and hospital stays**

### **CHALLENGE**

- Denise's husband Jon lives with Chronic Obstructive Pulmonary Disease, and has had several hospital stays. Denise is constantly anxious about him. She doesn't drive, so when he's in hospital she has to take two buses and travel for over an hour to visit him. Although Denise tries to reassure Jon, she's worried about the future.

### **SOLUTION**

- Blood pressure monitor, Thermometer and Pulse Oximeter – these devices enable Jon to easily take his blood pressure, temperature and blood oxygen levels and pulse rate at home, which are then transmitted wirelessly to the mymedic unit
- mymedic telehealth unit – receives the readings from the medical devices above and transmits this data, along with answers to the questions Jon answers about his symptoms, to the monitoring centre for technical and clinical triage. A nurse or GP will then act on any readings that are too high or too low, whereby minimising the trips to hospital

### **OUTCOME**

- Telehealth enables Jon to take his vital signs daily, allowing any problems to be detected early, and helping to reduce admission to hospital. This also gives Jon and Denise reassurance that his condition is being closely monitored.

## **F: Keeping in touch**

Add more examples to demonstrate other types of technology , apps, tablets etc

#### 4. Top 5 things carers need to know when choosing technology enabled care

This section tries to summarise the feedback from the workshop regarding people's concerns about technology.

##### 1. Negative perceptions about technology

There is still a lot of stigma out there associated with technology, eg doesn't it increase social isolation and loneliness? Isn't Skype an excuse not to visit us as much? It can be great but it's not an end in itself. Some technology actually can work extremely well to improve loneliness as there will be access to a person and support at all times.

Perceptions of cost can also put people off, even though the benefits in the long run far outweigh the costs, but for those on low incomes this could be a big issue. You need to be aware of the likely cost to install and run it, to cover the risks of repairs and breakdowns, ease of maintenance and insurance.

##### 2. Access to technology

A lot of people just don't have smart phones and tablets to use apps. Access to a mobile signal and the internet is patchy particularly in rural areas. Not everyone is digitally included. There could be genuine concerns about reliability and worry if you lose it or break it. Not all technology solutions require access to smart phones and mobile signals. There are some very useful, simple technologies out there that could help.

##### 3. Understanding the benefits to me

You need to take into account the perceived utility - will it work, will it do what I want it to do, will it deliver the outcomes around things that bother me, respond to my care and support needs or their carers: how does it affect the balancing of risks?

West Sussex local carers group is doing some work with tracking device. A lady has epilepsy, occasionally gets lost and periodically forgets where she is. So a wrist worn bracelet is really helping her. Instead of describing the technology as a tracking device, it's sometimes better to describe it in words that explain the outcome, eg as something that can enable you to go out on your own.

##### 4. Lack of options and awareness

It is possible that you will be picking from a menu of limited choices, particularly if you are a self-funder. Commissioners ideally needs to address technology and expand the range of options available.

Knowing what's available is a very confusing picture. For instance, there are hundreds of apps out there – the "find me" app could be life changing. It's often better to have the ability to see it, touch it, see it working in situ, within a reasonable timescale and in a convenient location.

Information needs to be available conveniently and in a reasonable time frame and be provided by someone you can trust eg an occupational therapist, GP or carer. Perhaps we need an easy guide to technology resource in all carer's centres

##### 5. Worries about the services surrounding the technology

How is the technology in the home connected to the monitoring centre? The connection can either be via a telephone line in the home, by a mobile signal or wifi.

How do I know how good the monitoring centre is, and will keep my information be secure? All telecare monitoring centres follow strict rules in relation to security and you can ask if the centre is TSA accredited (Telecare Services Association).

Who comes into my home to install the technology and will they make a mess? What happens if something goes wrong with the equipment or service? This will depend on what service you need, but generally it is an accredited, CRB checked engineer who will make minimal mess.

How safe is the technology – could you get a shock from it? What accreditations should we look out for to prove the technology is good? It is worth checking the product literature for **standards such as (AR TO ADD)**

## 5. Further help and advice

### **How can I get telecare for the person I care for?**

The first thing you should do is to contact your local authority's social services department and ask to be assessed for social care. Depending on your assessment and whether your local authority offers a telecare service, you may be offered telecare as part of an overall package of care and support.

### **Do I have to pay for telecare?**

When carrying out your assessment, your local authority may also financially assess you. Depending on your financial status you may be eligible for telecare free of charge, or there may be a minimal fee to pay (from around £4 per week).

### **What if my local authority does not have a telecare service?**

Some local authorities do not offer a telecare service. If you live in an area that doesn't, we'll be happy to advise you. Visit [XXX](#) for more information.

### **How do I get telehealth for the person I care for?**

If the person you care for has a long-term condition and you feel they could benefit from telehealth then we recommend that you speak with your GP, specialist nurse or hospital consultant to see whether a telehealth service is available in your area. Why not show them this brochure to illustrate how it could help?

### **What other links and advice?**

## 6. Information about the authors

Authors

ADASS Carers Policy Network is XXX

We would like to thank the members who attended the workshop and everyone else who contributed to this paper

Do members wish their names to appear? If so please send name, title, org

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