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Telecare for older people living at home

Questions for potential users and their families

Are you considering having telecare installed at home for yourself or a family member? This leaflet may help you to understand what telecare is and to clarify whether it will meet your needs.



What is telecare?

Telecare is a general term for technical devices that provide 'care at a distance' linking someone living at home with operators in a call centre and/or other care professionals (e.g. nurses) via a telephone or computer. Examples of telecare are personal alarms worn around the neck; sensors that detect if the person is moving about and following their usual routine; devices that monitor physical signs such as weight and blood pressure; GPS devices for people who wander and may get lost (Global Positioning Systems use satellite technology to track where a person is) and webcam systems where you can see and talk to somebody via your television or computer. Some of these systems are controlled by older people themselves, others by their family carers or professionals.



Over the past three years researchers in England, Spain, Netherlands and Norway have been studying telecare and how it affects the lives of older people living at home. We talked to social workers, nurses and the engineers who install telecare devices in people's homes; to the operators at the call centres who answer the telephone when an alarm is activated; and most importantly with older people who use telecare or may use it in the future. The quotes in this leaflet reflect their experiences with a range of devices in all four countries

Seven questions to think about:

1. What problems can telecare help with? What about the other problems?

This may seem an obvious question. However, telecare may provide solutions to some problems but not to others. Things to consider:

Is telecare an improvement on what you are already doing? For instance, a telecare user in the Netherlands who used a device that monitored her physical health said:

I had to measure my weight everyday, but I did that already. The nurses from the call centre were really kind and friendly... It's just... if my weight is between 62 and 63 kilos and one day it is 63, you would get a call from them straight away. I think this is over the top!

Loneliness may be as great a concern as health problems or safety issues, particularly for older people living alone. Some users are very happy with the contacts telecare gives them; in Spain and Norway some telecare services actually provide companionship and social activity. How might this affect you? In what ways could the telecare system help you or your family with social contacts? A volunteer co-ordinator from one Spanish telecare system said:

We do have popular activities that come with telecare and people have spread the word that we organise these activities to prevent the telecare users' loneliness.

Users of a webcam support system for family carers in Norway said:

We are so happy with these contacts! It makes all the difference. You don't feel so alone anymore and you can help each other with suggestions. Or you could just blow off steam. We all became really close!



Some people are worried that telecare might take away their human contacts. Does having a telecare device mean that the home carer or nurse will not come and see me anymore? As a person from an English organisation for older people said to us:

We want to ensure that whatever the technology is, it isn't simply replacing the person who is currently giving the care. ... The huge danger is that if we go down that road to any great extent, it is so easy because of financial implications to reduce the personal input. It is so important to not replace that human contact!

The other side of this is that people sometimes find telecare contacts too intrusive and refuse to have the system for this reason. There could be too many conversations, or having the device might make them feel vulnerable. What would be important to you? A project manager for a service in the Netherlands which checks regularly on people with serious illness told us:

There weren't many refusers, but those who did, handed their telecare device back in the first week they had it. They either found the use too tiring or too confronting, meaning that they did not want to think about the impact of the disease on their lives every day.

What problems does the telecare system not provide an answer for? Telecare may not be much help when a user's memory is failing and they don't remember to use the alarm button. One English woman described her dilemma about her pendant alarm:

You've just got to remember to use it. Because the last time I fell in the garden, I couldn't get up. Never thought of pressing that to get help, I just sat there in the wet grass for a bit and then gradually I managed to get up in the end. My family said 'Why didn't you press your button?' I said, 'I never thought about it.'

2. Who else is connected to the system, and is that ok for you?

Other people linked in to the service could be professionals from homecare organisations, neighbours or family members. Some systems work by alerting family members when something is wrong, in other systems, professional carers follow up alarms. A call monitoring centre operator in England said:

Telecare is only as good as the contacts we've got. If you can't get somebody to go and check on the person, you're really struggling, because the police don't want to know every few minutes. So the more contacts we can use with the telecare the better.

How would you feel about these people having information about you? Would you feel that your privacy is adequately protected?

Sometimes compromising your privacy might seem worthwhile. E.g. if a person with dementia wears a GPS device, someone can always find out where they are. But this allows that person the freedom to walk by themselves, which may be too dangerous without the device. A woman in Norway told us how her husband loved to walk alone, but would often get lost. She obtained a GPS device, which was connected to the mobile phones of her and her daughter, so that they would always know where he was:

And it really worked very well. He used it for three years and was a free man. He could go out all he wanted. And suddenly I could join the choir again. ... I always found him. It gave me a new life.



3. How might a telecare device change your home?

People need to make space for telecare devices in their homes. There is the wiring to consider, and perhaps the beeps and the lights on the devices. You might want to consider if devices can be switched off completely rather than left on 'stand-by'. Is it clear who you can talk to if you have concerns about a device? Who could you turn to if a device breaks down?

Some users are happy to have the main device at the centre of things, but an ex-telecare user from the Netherlands told us:

The thing that bothered me was, this box you have in your living room, it made so much noise! And that was annoying me terribly. The older the device got, the more noise the thing made. And in the end it was as if I was in the room with five or six people!

4. Who is the active user of the telecare system: you or somebody else?

Different forms of telecare work in different ways. When you are watched over by sensors that self-activate, you are a 'passive' rather than an 'active' user. Other devices may need you to manage them yourself. How would that work for you? Would you be happy with a system where you are a passive user so you could forget it is there?

Perhaps it is other people who are worried for you and think telecare might be a solution, rather than you yourself. Do you share their concerns? A Spanish telecare coordinator told us that sometimes older people had been pressured to have telecare when they didn't really want it. The service regularly checks whether the system is being used:

And when an old lady answers: 'I don't want it, I have kept it in a drawer and I will never use it!' If they do not want the service, we take it out.

5. Is it worth the effort?

Many people who use telecare report feelings of safety and peace of mind. They feel looked after through the telecare system. These feelings of safety are important, but they may not always be realistic unless you are prepared to follow the instructions. For instance, one should be prepared to wear the alarm pendant in the house. If you fall and the alarm is out of reach, it is useless. One English telecare user told us that she would always take her pendant into the bathroom in case she slipped in the shower, but would often forget to wear it once she got dressed.

Some telecare involves a lot of effort from the user, and yet all this effort may not be able to keep the person safe or well. A nurse in the Netherlands told us:

One woman in the project measured her weight and her blood pressure every day. She thought this was a lot of work, but she did it because it made her feel safe. But this feeling is not always realistic. She got really very angry when she had a heart attack, in spite of the effort she had put in. We should be clear about what people can expect.

6. Can you decide how long you keep the telecare device for?

Some people are happy to use a telecare device for a specified amount of time. Others want to keep the device, even if the planned period has passed. For what period is your device intended? If it is temporary, how would you feel about handing it back?

7. What would happen if your or your family member's condition deteriorated?

Some devices may only be useful for a limited time. People with dementia may be able to use simple computer screens, but this may become more difficult as their condition changes. A GPS device would help when the main concern is the person losing their way, but not help if they cannot cross a road safely alone. Sometimes people who have alarms forget what the buttons are for. Telecare, in other words, may not be a long term solution: other forms of care may also be needed.



Ethical frameworks for telecare technologies for older people at home

We hope this leaflet helps you to think about the issues raised by telecare. The availability and nature of telecare services varies widely across Europe. For more information about our research, visit us at:

www.lancs.ac.uk/efortt/

For advice about what might be available in your area contact your local Older People's Forum or voluntary organisation

(e.g. in UK: Age UK:

<http://www.ageuk.org.uk/about-us/local-partners>)

