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joint improvement team



The Dementia Services
Development Centre



Telecare and sensory impairment

Using telecare effectively in the support of
people with sensory impairments

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Preface

This book explores how telecare can contribute to the support, protection, and quality of life of people with a sensory impairment. It also considers the importance of telecare in providing support and reassurance to carers.

This is one of a number of publications funded by the Scottish Government's National Telecare Development Programme², in pursuit of the strategic goal of raising awareness of the importance of telecare in contemporary health and social care services. The other books in this series are:

- Telecare and dementia – using telecare effectively in the support of people with dementia
- Telecare and physical disability – using telecare effectively in the support of people with severe physical disabilities and long-term chronic conditions
- Telecare and learning disability – using telecare effectively in the support of people with learning disabilities

The books are written for assessors, care and support staff and their managers, telecare service managers and development staff. Senior managers should also find them useful in informing service planning, and they should help raise awareness, expectations and generally advance understanding among service users and carers.

Each book also contains case studies and a training programme intended to help trainers when designing both awareness-raising and skill-development programmes. Programme directors responsible for basic and post-basic programmes for nurses, housing staff, social workers or occupational therapists should consider these as a sound basis for a module on telecare.

Examples of equipment which might contribute to the safety and quality of life of the person utilising telecare are featured in each book. The aim is to support readers by providing information on some of the wide range of telecare products available. The books do not endorse any specific product or supplier, but provide examples of what is currently commercially available or emerging on to the market. Where possible, details of suppliers/manufacturers have been provided at the end of each book.

As we grow older and take on caring responsibilities or become disabled, technology can help us maintain our independence and quality of life.

1: Introduction

We all rely increasingly on technology in almost every aspect of our lives. Within our homes, devices such as microwaves, DVD players and flat screen TVs enhance the quality of our lives and reduce the amount of time we spend on the drudgery of housework. We rely on computers and mobile phones for information, social contact and entertainment, and to help us make informed choices about purchases and services. Away from home, technology such as GPS (global positioning systems) and satnav (satellite navigation) – often incorporated into our mobile phones – has the potential to guide us, keep us in touch, and keep us safe.

People who are more vulnerable and dependent because of sensory impairment ought to have the same access to, and benefits from, this increasingly cheap and accessible technology. As we grow older and take on caring responsibilities or become disabled, technology can help us maintain our independence and quality of life. It can also overcome some of the limitations of specific conditions. One purpose of this book is to raise awareness of these issues and provide practical guidance on how to introduce technology to potential service users.

Demographic change, and the key social policy agenda of shifting the balance of care from institutions to care at home and in the community³, also requires us to maximise the benefits of technology. There is now plenty of evidence to show that telecare can release significant resources from within health and social care systems and facilitate changes in the balance of care⁴. It also has the potential to improve important outcomes such as independence and feelings of safety.

This book will outline how telecare can contribute to improved outcomes for service users. It includes sections on:

- definitions of telecare (along with the related concepts of telehealth, assistive technology, environmental controls, and telehealthcare)
- the importance of good needs and risk assessment if telecare is to help meet those needs and manage those risks
- ethical dilemmas and how these can be resolved
- how needs may be met using telecare as part of a package of care and support
- issues particular to carers
- case studies and an outline training programme

Definitions: what is telecare?

In this book the term telecare is used to describe the use of equipment within and outwith the home to monitor changing needs and risks, and to provide alerts and information that enable improved and informed responses to those needs and risks.

Demographic change, and the key social policy agenda of shifting the balance of care from institutions to care at home in the community, requires us to maximise the benefits of technology.

The definition below is the one used in the National Telecare Development Programme in Scotland. It forms part of the 'shared vocabulary'⁵ agreed and published by the Scottish Government, and is consistent with definitions used in the English and Welsh development programmes.

There is a wide range of telecare equipment, and the scope and sophistication of applications has developed considerably over the last 25 years.

Telecare is the remote or enhanced delivery of health and social services to people in their own home by means of telecommunications and computerised systems. Telecare usually refers to equipment and detectors that provide continuous, automatic and remote monitoring of care needs, emergencies and lifestyle changes, using information and communication technology (ICT) to trigger human responses, or shut down equipment to prevent hazards.

First, second and third generation telecare

There is a wide range of telecare equipment, and the scope and sophistication of applications has developed considerably over the last 25 years. The following informal classification, based on 'generations', provides a way of distinguishing between different stages of development and application.

First generation telecare refers to equipment that forms part of most community alarm services. It is used to describe user-activated alarm calls (by push button, pendant or pull cord) to a control centre where a call handler can organise a response of some kind. This is usually via a neighbour, relative or friend acting as a 'key-holder'.

Second generation telecare evolved from the introduction into basic community alarm services of sensors such as smoke, gas, heat and flood detectors. Second generation telecare now includes sensors which can monitor not just the home environment, but aspects of lifestyle, physiological measures and vital signs. These sensors can collect and continuously transmit information such as when doors are opened, whether taps are running and the use of electrical appliances. Through passive infrared sensors (known as PIRs), movement both within and outwith the home can be detected. This provides much more sophisticated and comprehensive support for managing risk and improving quality of life. Second generation telecare can also be used to provide data about someone's lifestyle, movements and routines, which can be used for needs assessments.

Third generation telecare developed from improved and increased availability of broadband, wireless and audio-visual technology. It offers the potential for virtual or tele-consultations between the service user and their doctor, nurse or support worker, thus reducing the need for home visits or hospital appointments. Furthermore, it provides increased opportunities for people (particularly those unable to leave their homes alone) to 'visit' libraries, shops and maintain contact with family and friends.⁶

Telehealth

In this book the term telehealth refers to the use of monitoring and measuring devices to collect information about vital signs (such as temperature, blood pressure and blood sugar level), symptoms or health conditions in the patient's

home. This information can then be transmitted from the device to a call handler, nurse, or other clinician, who can then advise the patient by phone, text or email on how to manage their symptoms and condition. Clinicians can be alerted to significant changes in a patient's condition, and the patient advised or reassured appropriately. This can take place without the need for a home visit, visit to a surgery, or other consultation. Telehealth is often used to enable people to manage chronic conditions, for example high blood pressure or diabetes.

Telehealthcare

The Scottish Government has published a paper on long-term conditions⁷ which includes a definition of telehealthcare, illustrating how this term emphasises a holistic approach to the person, who should be at the centre of the service:

There is increasing convergence between telehealth and telecare, with the introduction and expansion of remote monitoring as part of the 'telehealthcare' package available in a person's home. Telehealthcare offers a range of care options remotely via phones, mobiles, broadband and videoconferencing. It can improve the patient's experience of care by reducing the need for travel to major cities and hospitals to receive care and treatment. It has been used successfully to provide treatment for dermatological, cardiac and neurological conditions. It enables care to be delivered in remote communities, allows GPs to consult specialists remotely to avoid unnecessary referrals and enables networks of learning for clinicians and maximisation of skill mix for teams.

Assistive technology

Assistive technology is another collective term for devices for personal use designed to enhance the physical, sensory, and cognitive abilities of people with disabilities to help them function more independently.

Environmental controls

Environmental controls are equipment systems that enable people with higher levels of physical impairment or chronic health problems to control access to their home, to summon emergency help and to operate domestic appliances. For instance, a single remote control unit can enable a wheelchair user to control temperature and open and close windows, curtains and doors (in addition to the more conventional functions of controlling TVs, DVD players, and audio equipment).

Telecare as part of a personalised service

Telecare should not be seen as the *solution*, a single one-dimensional response to needs or risk. It is not an alternative to direct care by carers, although it can reduce the need for check visits, 'supervision', or visits to clinics (such scenarios will be explored later in this book). Telecare is effective when it forms part of a personalised programme or package of care and support, and is accepted as such by the service user, their informal carers and other staff/services.

Telecare is not an alternative to direct care by carers, although it can reduce the need for check visits, 'supervision', or visits to clinics.

To be effective telecare requires:

- informed, skilled and personalised outcomes-focused assessment of needs and risk
- resolution of ethical dilemmas around capacity, informed consent and choice (for each individual in each situation)
- training and education for the service user, carers, personal care and support staff in how the equipment can be used or misused and how it should be tested and maintained (for example, battery replacement)

Telecare services

So far, this introduction has only discussed equipment. The term 'telecare services' sets the delivery of equipment in the wider context of health and social care services. In a practical sense, this means efficient, up-to-date monitoring or call centres with trained staff who have access to personal health and social care data and response protocols. These staff will be available every day of the year, and will be skilled in making judgements about the information and alerts sent by the equipment, and in facilitating the most appropriate response possible. Such centres are absolutely essential to the effective use of most telecare equipment. While different agencies may organise their call handling or monitoring staff in different ways, the presence of someone who can interpret the information, provide reassurance, follow detailed individual protocols, and understand the basics of how equipment works is essential to ensuring the maximum benefit to the service user.

Appropriate response arrangements must also be in place, incorporating individualised response protocols which ensure the best possible response to the immediate need or situation. Traditionally this has relied on 'key-holders' – relatives or neighbours who, when contacted by the call centre, would call on the service user and solve the problem or contact services as necessary. Increasingly, in response to higher levels of dependence and more complex needs, agencies are deploying teams of trained carers, who can respond to an emergency and provide personal care, reassurance, or contact other emergency services as necessary.

In order for telecare services to have maximum impact on wider policy goals such as changing the balance of care, they need to be conceived as part of, and located within, local health and social care strategies for different client and patient groups. Service planners need to articulate how telecare developments will enhance home care and housing support services not as an 'add-on', but as an integral part of health and social care service options.

Risk and reliability

No equipment can be 100 per cent reliable forever, in the same way that no 'human' service is completely and consistently reliable. Equipment will come with a manufacturer's guarantee, but in the event of a fault an engineer will need to be called out, and there may therefore be gaps in service provision, even when monitoring is required '24/7'. Equipment which relies on mobile phone signals, internet access or landlines to transmit information will, on occasion, experience the lapses in service that affect these systems. To counter these risks, telecare services need to include backup, testing and business

To be effective, telecare requires an informed, skilled and personalised outcomes-focused assessment of needs and risk.

continuity arrangements (although of course equipment purchased privately will not have these safeguards as standard).

'Interoperability' is a significant issue. This refers to the problems that arise when equipment developed by one manufacturer does not work with the call handling or monitoring system which is already in place, and which was made by another company. Progress has been made in resolving this issue, partly due to the introduction of a new (voluntary) British Standard⁸. However, interoperability remains a problem, especially when equipment does not comply with this standard.

It is very important that these issues are taken into account when care packages are being put together through the use of proper risk assessments and appropriate risk management arrangements.

Access and availability

This book includes examples of equipment that has the potential to contribute to the safety and quality of life of people in need. The examples have not been selected to promote the products of any particular company, but instead to raise awareness of what can be done and what is (or will soon be) available. Where a product is featured, details of the company that sells or manufactures it have been included (see pages 38 and 39).

Companies specialising in telecare equipment are increasingly able to personalise their products to meet the needs of individual users. Furthermore, they recognise the importance of developing new applications from this starting point. Manufacturers would argue – with some justification – that the scope of what telecare equipment can do is limited by our imagination, rather than by the technology. The cost of equipment is falling, and public bodies now have procurement arrangements in place which should further reduce this cost. In addition, companies welcome contact with service users and professionals to help them understand needs which might be met through new applications.

Some telehealth equipment – blood pressure monitors, for example – can be bought on the high street, and this is a trend that is likely to increase as expectations and understanding of the potential of telecare increases. However, an important part of a telecare service is the response. There needs to be some way in which the information or alert generated by the equipment can be transmitted to someone with the skills and technology to generate a fast and appropriate response.

The major providers of telecare services are local authorities – increasingly in partnership with health authorities. Purchasing budgets are (or should be) available to enable practitioners to access equipment as part of a care and support package. Alternatively, service users should be able to purchase equipment using their individual budgets, or direct payments. In recent years budgets have been enhanced by government telecare support grants, and although some of these schemes may now be coming to an end, health and social care partnerships will continue to explore means of transferring resources so that telecare can develop further using the savings generated.

One consequence of the development in telecare services over recent years is that many authorities have recruited telecare coordinators, or have designated telecare 'champions' within local services. These staff can advise on availability and access, and should find these books helpful in their task of promoting the use of telecare among different client and patient groups.

Telecare equipment needs to be complemented by up-to-date monitoring or call centres with trained staff who have access to personal health and social care data and response protocols.

2: Assessment

An effective and efficient outcomes-focused needs assessment is essential if the potential of telecare is to be maximised. At its best, telecare forms part of an individual ('personalised') package of care and support. To achieve this, individual needs must be identified and telecare then considered as part of the potential personalised response.

General and specialist assessment of need

Throughout the United Kingdom, community care needs assessment is now conceived of as a multidisciplinary process^{9 10 11 12}. In Scotland, much work has been done to encourage the use of 'shared assessments'¹³ which gather core data on each individual (such as their name, age and ethnic group) along with information on physical, psychological, spiritual, and physiological needs. The process involves skilled interviewing to elicit what the person's needs are, and what their perception of those needs is at that time. There is an opportunity for a relative or close friend who is a carer to contribute – with the permission of the person. The assessment concludes with a summary of needs, followed by proposals for meeting them immediately (where necessary) and/or as part of a planned programme of care. (This will be dependent on resources being available and on eligibility criteria.)

The possibility of utilising telecare should be introduced during the assessment phase. Just as the person's need for home care, aids or adaptation, counselling or day services is considered, questions in the assessment form ought to trigger a discussion of telecare. During the assessment itself, it is essential to explain what telecare is, using language the person will understand and can relate to. One approach is to start with the (universally familiar) community alarm service, then move to a general discussion of environmental monitoring equipment (flood and smoke detectors for example), before moving on to personal safety and health monitors, where appropriate. At this stage the assessor will be considering the potential contribution of telecare in general terms, as well as introducing the concept to the person and their carer(s).

In some areas, a 'core package' is offered to anyone with community care needs. This might consist of a community alarm and smoke and flood detectors, along with a security device for the front door. Increasingly, in new or refurbished supported or sheltered housing schemes, such equipment is installed routinely. Opinion is divided on whether such an approach is cost-effective or not. Be that as it may, it does not obviate the need for individual needs assessments which will ensure that any additional equipment will meet identified needs.

All assessment documentation should therefore include a section prompting the assessor to consider telecare as part of the total response. It is also important that the assessor has access to information leaflets detailing the range of

At its best, telecare forms part of a personalised package of care and support.

telecare that is available locally, what it is for and who is eligible – along with any costs which need to be met by the service user.

If the assessor believes that telecare can form part of the response and the person agrees, a more detailed assessment is then required. This should include the precise combination of devices which can best meet (in combination with other services) the person's needs, as well as clarifying issues around installation and response. This stage is often referred to as the 'specialist assessment'.

Specialist assessments

This secondary assessment stage is designed to personalise the provision of telecare by identifying items of equipment that appear to best meet the person's needs. At this stage additional factors – such as the design of the property and the availability of telephone lines, wireless networks and mobile phone signals – will need to be considered. The person's familiarity with electronic equipment will also be taken into account, along with any other telecare equipment already installed. In addition, their routine (for example when they like to go to bed and their sleeping pattern) will also be recorded to ensure that the equipment supports the lifestyle and degree of independence they want. Finally, the integration of the equipment with the rest of the support package, and the need for and availability of a response, will all have to be detailed.

There is no 'best' way of carrying out a specialist assessment. How it is carried out, and by whom, is likely to depend on local arrangements. In some areas, a telecare 'champion' will have been identified within the community care team. This person will have received additional training in telecare and regular updates on the range of equipment available. One of their responsibilities will be to undertake this specialist stage of the assessment, or perhaps to supervise and guide other team staff when such an assessment is needed.

In other areas this task is carried out by a dedicated telecare service. This group will include staff who carry out the call handling, monitoring and installation functions, and they will have links to any response service. The manager of the service, or a designated person, will be asked to take forward the specialist assessment and carry out any installation that is necessary.

Risk assessment

Risk assessment is a critical component of a good needs assessment. It takes into account the degree of risk experienced by the person, thereby identifying ways in which telecare can assist in the management of risk (by the person themselves, as well as by services). It includes risks in the home as well as outside. These may include risks:

- of fire if the cooker is left on
- of flood if the bathwater is left running
- of scalding in over-hot bathwater
- of unwelcome visitors
- of getting lost
- of harassment
- of hate crime

Shared assessments gather core data, such as the person's name, age and ethnic group, along with information on physical, psychological, spiritual, and physiological needs.

The most basic equipment, such as flood, smoke and carbon monoxide detectors, reduces risk in obvious ways. For people with cognitive impairments (for example arising from brain injury) and some sensory impairments, going outside and travelling can be particularly risky. If the nature of such risks is identified, then appropriate equipment can be selected. This process is illustrated in later sections of the book.

While telecare can be important in the management of risk, it cannot eliminate risk completely. No equipment yet devised is 100 per cent reliable. Routine testing and maintenance (for instance battery changes) are essential to maximise reliability. Even so, malfunctions can occur. Service users – or more often their friends, children or grandchildren! – may inadvertently trigger or disable alarms, and monitoring centres will not always be aware of this. So it is important to allow for reliability and human error in any risk management plan.

Using telecare to enhance assessment

Some companies have developed equipment which can log detailed information about a person's movement, lifestyle and routines within their home. This is used for needs and risk assessment purposes, as distinct from safety. An example is 'Just Checking'¹⁴, a portable activity-monitoring system designed for people with dementia (although not necessarily limited to that group). Small wireless movement sensors are triggered as the person moves around their home. These generate an activity chart which can be accessed via a secure website. This very detailed timed data can provide a much more accurate picture of a lifestyle than is possible from conversation with a person with cognitive impairment, or from carers who do not live on-site. Support, protection and care arrangements can then be targeted more accurately in a person-centred way.

Carers' assessment

In Scotland there is now a duty to offer informal carers an assessment of their needs arising from their caring responsibilities. This focuses on how they can be helped to sustain their contribution to the care of a person in need¹⁵. Research has confirmed the extent to which telecare can reduce pressure on carers; support them in their caring role; increase peace of mind about the safety and wellbeing of the person they care for; and enable them to sleep better¹⁶. It follows that a good carers' assessment will include consideration of the potential of telecare to indirectly benefit carers by helping them continue to care.

Recent research confirms, however, that many carers are unaware of the availability of telecare. It cannot be assumed that carers – especially 'new' carers – will be aware of the possibilities telecare offers. Equally, carers will have their own anxieties, and perhaps guilt, about using technology. They may be concerned about its reliability or whether they will understand it and be able to make it work. These issues will be considered in more detail in later chapters of this book. At this point it is important to emphasise that information needs to be made available to carers, and that where a carer's views are sought at the needs assessment stage their perspective and needs should be included and recorded.¹⁷

Research confirms that many carers are unaware of the availability of telecare.

3: Principles, rights and ethics

The previous chapter described the importance of carrying out a careful needs and risk assessment before introducing telecare. However, while good assessment will ensure that the use of telecare is person-centred and needs-led, it will not necessarily answer the question of whether telecare is 'right' for an individual.

As an example, consider the needs of a person with Down's syndrome who is in the early stages of dementia. The assessment process may indicate that a GPS-enabled wristwatch could reduce the person's exposure to risk when she is away from home. It will enable her carers – and a control centre – to pinpoint her at any time so that they can organise help if she becomes lost or experiences harassment. But the device could also be used to restrict her freedom to go where she pleases, which is a fundamental human right. The telecare device could be perceived as a kind of electronic tag, and this has associations with surveillance and the criminal justice system. Seen in this light, the ethical questions associated with telecare are more sharply exposed.

It may be difficult to comprehensively establish the needs and risks of a person who could benefit from telecare, whether they have dementia, a brain injury, or significant sensory impairment. To carry out an effective assessment, a system like 'Just Checking'¹⁸ might be introduced to their home on a temporary basis. This will provide comprehensive data on the person's movements and routines, including eating, sleeping and toileting. Although the resulting assessment will be very well-informed, this does not necessarily justify the invasion of privacy that is also involved. Similar dilemmas arise with the use of systems such as Betavista which allow control centre operators to see the person in their own home (albeit when an alert is triggered), as well as talk to them on a phone line.

Ethical dilemmas such as these should be considered using the case studies featured later in this book. The purpose of this chapter is to briefly describe an ethical approach to telecare, summarise some principles which need to be considered when decisions are being made, look at the relevant legislation and provide some hints for practice.

It is important to stress four things at the outset:

- each person's needs, choices and beliefs must be a fundamental consideration in any decision
- there are few absolute 'rights and wrongs' which can be universally applied to every situation
- ethical issues are not unique to telecare. Indeed, the principles, values and legal obligations discussed here apply to other care and support settings
- no one acts in a value-free or value-neutral way – we all have our value positions. The important issue is understanding these, articulating them as necessary (particularly to service users and carers) and

This chapter describes an ethical approach to telecare and includes an overview of the relevant legislation and some hints for practice.

understanding and thinking through any conflict that may emerge with the values of others, particularly service users and carers

Personal value systems

We all take up value positions and have opinions on issues like the smoking ban, how children should be disciplined and capital punishment. Some people consider these issues to be 'common sense' or 'obvious', but in practice they are complex. Our personal values are influenced by the way we were brought up, our education, the apparent values of our community and by our life experiences. For those working in care and support services, there are also our professional values. These are often expressed through codes of practice¹⁹ and feature prominently in our professional education at every level. As a result we learn – and try to integrate into our practice – core values such as a commitment to confidentiality, treating people with respect, maintaining dignity and individuality, and challenging racism, discrimination and injustice.

It is important that practitioners are aware of these values, and how they come to be part of their own value system. It is also important to appreciate that they may not always be shared by individual service users and carers, with the resultant need to resolve conflicts that arise from different value positions.

Principles

Some writers have developed statements of principles, or ethical theories, which can help ensure that the use of telecare is ethically sound. For example, Bjørneby et al (1999)²⁰ have proposed these principles:

- **autonomy** – people should be able to decide what they want to happen or be done to them
- **beneficence** – we should try to do good to the people we care for
- **non-maleficence** – we should try to avoid doing people harm
- **justice** – people should be treated fairly and equally

In addition to these principles, Bjørneby suggests that the perspectives and views of all those involved in the service should be sought in relation to both its implementation and the likely impact of its non-implementation.

Kemshall and Pritchard (1997)²¹ highlight the values and rights which they believe underpin community health and social care services. These include:

- a commitment to ensuring that all users and carers enjoy the same rights of citizenship as everyone else in the community, with equal access to service provision, irrespective of gender, race or disability
- a respect for the independence of individuals and their right to self-determination, including taking risks, and minimising any restraint on that freedom of action
- a regard for the privacy of the individual, intruding no more than necessary to achieve the agreed purpose
- respect for the dignity and individuality of every user and carer
- to maximise individual choice in the type of services on offer and the way in which those services are delivered

When making decisions about telecare, maintaining respect for the independence of individuals and their right to self-determination – including taking risks – is essential.

- a responsibility to provide services in a way that promotes the realisation of an individual's aspirations and abilities in all aspects of daily life

Cox et al (1998)²² describe a set of core values that should be incorporated into any person-centred service designed for someone with dementia:

- that the person using the service should have maximum control
- that real and informed choice should be a key part of any service
- that people who use services should be valued and respected as unique individuals
- that continuity of care is built into service delivery in a way that keeps the person in touch with their past and present
- that the person is not discriminated against on the basis that they have dementia or because of any other differences, and that they receive their fair share of good quality and appropriate services

These values and principles provide the basis for rules of practice that will ensure an ethical approach.

The law

In Scotland, three important Acts of Parliament have been passed since 2000: the Adults with Incapacity (Scotland) Act 2000; the Mental Health (Care and Treatment) (Scotland) Act 2003; and the Adult Support and Protection (Scotland) Act 2007²³. In addition to sharing a common purpose of protecting the rights of vulnerable people, these uphold a common set of principles: that any intervention must be intended to provide a benefit to the person which could not be reasonably obtained without that intervention AND that this is the 'least restrictive' option available. All three Acts also include a requirement to consider the person's views, along with those of significant others, like carers and family.

Capacity and consent

There will be many occasions when the introduction of telecare raises issues of capacity and consent. The assessment process may indicate the presence of significant risk that telecare (in conjunction with other services) has the potential to reduce. Despite this, the person may refuse the service or be reluctant to accept it. This might be because they disagree with the perception of the risk and/or want to retain the right to choose the way they live.

When working with people who may benefit from telecare but also lack sufficient capacity to make decisions about risk and quality of life, there may be justification for overruling these fundamental human rights. However, these are very significant judgements which should be made carefully and legally. It may transpire that a person's capacity is not impaired after all, but instead their means of communication, or ability to communicate, has not been properly considered. This is generally apparent when the person has a hearing or speech impairment, or perhaps has had a stroke, but may be less obvious when the person has dementia or a learning disability.

Where decisions are made on behalf of an individual who lacks the capacity to make choices for themselves, the course of action should be time-limited,

There will be many occasions when the introduction of telecare raises issues of capacity and consent.

regularly reviewed and limited to the particular services and decisions under consideration. Such decisions should never be considered as final or permanent.

Policy and procedures

Individual agencies will have policies, procedures and guidelines in place which ensure that staff remain within the law when delivering services – including telecare services. Implicit in these are the values of the agency, and of the community that it seeks to serve. For instance there will be commitments to equal opportunity, privacy, dignity and confidentiality, alongside procedural commitments to legality, cost-effectiveness and quality.

It is vital that practitioners are aware of these procedures and follow them. In the context of this chapter, practitioners should also be alert to conflicts between the values of users and carers and the values of their agency. These issues are often encountered in the area of risk and personal safety. Agencies have a duty of care, and in some cases their policies and procedures may conflict with the aspirations or expectations of the user, or their carer. For instance, procedures may prioritise the reduction of risk, as distinct from the freedom of someone to take risks and to make their own decisions. Practitioners need to be alert to these conflicts, and to make them explicit to users, carers and their own agency management. They must also ensure that the resolution of the conflict is recorded accurately and transparently.

Practitioners need to be alert to conflicts between the values of users and carers and the values of their agency.

Practice guidance

In summary, the following guidance is suggested:

- be aware of your own personal and professional value systems – and how these might conflict with the person you are working with and their carers
- be aware of the procedures of your agency, particularly those which are designed to protect the person's right to choose, to dignity, to privacy and to confidentiality
- ascertain as fully as possible the views of the person, their carers and other staff working with them. Do you understand what they are saying to you?
- are there issues of capacity to consent? If so, what are the legal issues around overriding their right to choice and consent?
- in what ways might the telecare solution limit this person's freedoms and rights? Is there an alternative which does not challenge their right to choose?
- how are the decisions to be made recorded? Has a record been provided to everyone who should have one? When is the decision to be reviewed?

4: Telecare and sensory impairment

This chapter describes how telecare can help with the support and care of people with significant sensory impairment. It begins with some definitions, then goes on to discuss advantages and potential barriers with suggestions for overcoming these, before outlining some case studies. Where possible, photographs of the pieces of equipment referred to have been included. Numbers identifying pictures also link in to manufacturers' contact details on pages 38 and 39.

Definitions: whom are we talking about?

Visual impairment. This group includes anyone who has a significant visual impairment. The person may be registered as blind or partially sighted, although the definition can also include those who are either not yet registered or who have chosen not to be registered. The World Health Organization defines profound blindness as the inability to count fingers at ten feet, and low vision as the inability to count fingers at 20 feet.²⁴

Hard of hearing. Members of this group have a hearing impairment that is described as mild or moderate. In the majority of cases their hearing loss will be acquired.

Deaf people can be divided into two groups. Those who have been deafened (ie they have lost their hearing since birth) and so use spoken and written language, and those who are congenitally Deaf, who usually distinguish themselves by using a capital 'D'. This group consider themselves to have a separate identity and culture. They see themselves as part of a linguistic minority and do not perceive themselves as being disabled. Their first language is BSL (British Sign Language). Written language may be difficult for this group, because BSL has a different sentence structure. Consequently, communication via pen and paper is not appropriate.

Deafblind. Those who are deafblind may have congenital sight and hearing loss, although in the vast majority of cases this will be acquired. A deafblind person may have been born deaf and later acquired a visual impairment; have been born blind and later developed a hearing loss; or have lost both their sight and hearing later in life. The 1988 *Breaking Through* report²⁵ defined deafblindness as follows: 'persons are regarded as deafblind if they have a severe degree of combined visual and auditory impairment resulting in problems of communication, information and mobility'. The needs of this group are complex and unique.

Incidence rates

In Scotland in 2008 19,959 people were registered as blind and 15,957 as partially sighted, representing 4.3 per cent of the population. The number of people who are partially sighted appears to be growing, while figures for those registered as blind are showing a gradual decline. The figures above are likely to be an underestimate as research suggests that only 25–33 per cent of the visually impaired population choose to be registered. Of those who are, 76 per cent are aged over 65 and 65 per cent are over 75²⁶.

It is estimated that one in seven people are affected by hearing loss. Those with a mild or moderate hearing loss may have difficulty following speech. Those with a severe or profound loss will rely on lip-reading or British Sign Language to communicate. In Scotland in 2004 there were estimated to be 758,000 people with a hearing loss. Of those, 701,000 were in the mild/moderate category, and 57,000 had a severe or profound loss. As with the visually impaired population, incidence of hearing impairment is greater among older people. Half of those who have a hearing impairment are over 65, and two thirds are over 75²⁷.

Deafblind UK estimates that four people in every 10,000 are deafblind²⁸. However, it is expected that the number of people with a visual impairment, hearing impairment or dual sensory impairment are likely to increase by approximately 15 per cent²⁹ over the next ten years as a result of environmental changes and an ageing population.

Acknowledging that the number of people with a sensory impairment is likely to increase, the Scottish Executive published *Community care and mental health services for adults with sensory impairment in Scotland: an action plan* in 2004³⁰. More recently, the Scottish Government endorsed the Scottish Vision Strategy³¹ and launched an implementation plan in June 2009. These documents recognise the need for improved specialist services for people with sensory impairment.

The needs of people with sensory impairment

Common symptoms experienced by those with a sensory impairment include:

- loss of mobility
- withdrawal from society
- psychological issues

The impact of sensory impairment on the individual, and the potential solutions, vary from person to person. If a person has complex needs there may be a failure to recognise that these include a visual impairment or hearing loss. As a result, other factors may be used to explain issues such as falls, withdrawal or changes in mood. Consequently, some of the simple solutions may never be implemented.

For those with visual impairment or deafblindness in particular, any change in environment or routine can cause disorientation and confusion. This generally means that it is preferable and more reassuring for the person to have their own home adapted to meet their changing needs, than to move to alternative accommodation. Installing appropriate technology has the potential to allow someone to stay in their own home and help them to navigate around it safely. Conversely, moving to unfamiliar surroundings may increase the likelihood of

The impact of sensory impairment on the individual, and the potential solutions, vary from person to person.

falls, reduce independence, and – crucially – increase levels of disorientation and the likelihood of admission to long-term care.

One of the most distressing aspects of sight loss is the disorientation of time and place. Even with the assistance of devices such as talking clocks, it may be difficult for the person to determine whether it is 2pm or 2am. Sleep disturbance can become an issue, which in turn can lead to confusion. Issues that affect Deaf and hard of hearing people include isolation from the community and the inability to communicate effectively with others without technology.

Telecare as part of a response

Telecare can play a major part in enabling people with sensory impairments of any kind to live at home safely and enjoy a good quality of life. It can also enable access to the workplace and allow continued participation in the community. Telecare can help older people in particular to continue living independently in their own home with a greater degree of safety. Advances in technology mean that people with a sensory impairment can now cook independently, be aware when callers are at the door, and be alerted to dangers such as fire or flood. They can also maintain their independence by reading their own mail, accessing information through the internet and continuing to use television and radio for both relaxation and information. Equally, telecare can enhance independence outdoors and facilitate travel. No one with a sensory impairment should be forced to remain at home while they wait for support from services. Instead, through the effective use of appropriate technology their ability to be independent should be maximised.

Some types of telecare that are suitable for people with a sensory impairment have been available for a number of years. However, in the past costs were often prohibitive. In recent years the technology has advanced significantly and become much more affordable and accessible. There is now the potential for this technology to dramatically improve quality of life.

Examples of telecare for people with sensory impairment

Mobility aids. A variety of devices are available which use GPS technology ① ② to provide visually impaired (VI) users with directional information, along with audio cues about hazards. They are of particular benefit to working VI people, enabling independent travel to and from their place of work. Many railway stations and some town centres have systems in place that enable a VI person to navigate safely using information that is transmitted at strategic locations, such as junctions.

Computer hardware and software. There are a range of software packages ③ ④ and hardware devices ⑤ available which allow VI people to use computers and access the internet. Some of these are completely voice activated and are designed for those with no useful residual vision. Others can dramatically enlarge the text on the screen, or may combine the two approaches.

Telecare can play a major part in enabling people with sensory impairments of any kind to live at home safely and enjoy a good quality of life.



BSL web clips are also now available and are becoming more prevalent on a number of websites. These enable deaf sign language users to access information in BSL, their first language, rather than English, which many find difficult to understand.

Remote interpreting is also now more widely available. There are only 56 interpreters in Scotland registered with the Scottish Association of Sign Language Interpreters. However, using webcam technology to enable remote interpreting has increased the number of appointments each one can offer. Travel time is eliminated and the deaf person can benefit from increased flexibility and availability of interpretation.

Loops **6** are devices that are used to enhance the effectiveness of hearing aids for those who use them, and/or to assist people who choose not to use a hearing aid. There are wired and wireless types. With wired versions, a cable is installed around the room and connected to a small amplifier. This can be linked to a television via a SCART or phono socket, or used to pick up sounds via a microphone. When a hearing aid user switches their device to the 'T' position they are able to hear the TV in the area where the wire is placed. Wired loop systems **7** are also suitable for large buildings like halls or churches, making it easier to hear the person who is speaking (and who wears the microphone). An **infrared loop** is connected to the TV and broadcasts sound from it wirelessly. The user can then listen to the TV using a special set of headphones or a neck loop. This system avoids the need to install a wire around the room.

A **personal listener** 8 9 is a hand-held battery-operated device that uses a microphone to pick up sound and provide amplification, either to headphones or a neck loop. Personal listeners enhance the volume and clarity of conversations and other sounds, and can be used in most situations including chatting with friends, watching TV or listening in noisy environments.



Doorbells. A wide variety of (usually cordless) doorbells ⑩ are available that combine loud variable chimes and flashing lights. These may flash up to 20 times to alert a person that there is someone at the door. They are generally appropriate for those who are hard of hearing. Profoundly deaf people may use a pager system (see below), or a system which flashes all the lights in the house.

Pager systems enable deaf people to remain independent in their own homes. Pager alerts can be linked to devices including doorbells, textphones, smoke detectors and baby alarms. The user wears a small vibrating pager that is linked to a number of transmitters ⑪. When one of the devices is activated, it triggers a different vibration signal on the pager, alerting the wearer to a caller or danger. Pager systems are appropriate for people who are either hard of hearing or profoundly deaf.

Telephones. Amplified phones ⑫ are now more affordable than they have been in the past. In addition to traditional style phones, textphones ⑬ ⑭, which enable communication by typing, are available and can be beneficial to both deaf and deafened people. A screenphone has recently been developed which can be used by people who are deafened and hence unable to hear the phone, but have speech. Other varieties of phones include traditional phones with big buttons ⑮, big button mobiles, talking phones and automatic dial devices. Some phone companies will supply an amplified bell ⑯ free of charge to customers who are hard of hearing. Others may qualify for an amplified bell or phone flash ⑰ supplied by social services.

Traditional **smoke detectors** are not suitable for deaf or deafened people as they will be unable to hear them. They are of limited use someone who is hard of hearing, who may only hear an alarm when they are wearing their hearing aid (and hence are unlikely to hear it at night). To overcome this, smoke detectors ⑱ are available that incorporate flashing lights, combined with a secondary unit that vibrates and can be placed under the pillow.

Deaf people who use pager systems can have a **baby alarm** ⑲ added to their system if they have a young child, prompting a vibration alert when the alarm is triggered. Equally, hard of hearing people generally struggle to use conventional baby alarms because these are principally noise activated. They may need a flashing light or a vibration alert instead.

A range of **alarm clocks** ⑳ ㉑ ㉒ is available for hard of hearing, Deaf and deafened people. Deaf and deafened people tend to rely on vibration style alarms to wake them, though some prefer a flashing light. People who are hard of hearing would often rather hear an audible alarm, and louder models have been developed to meet their needs. The main disadvantage of these is that they tend to wake everyone else in the house. Multifunctional clocks that combine vibration, flashing lights and an audible alarm are now available.

Talking microwaves ㉓ can enable a person to cook for themselves, rather than relying on home care services to deliver and prepare food. The microwave will 'tell' the person with a visual impairment the time setting, clock setting, temperature etc.

Specialist medical devices such as talking blood pressure monitors **24** can assist a person with a sensory impairment to monitor and manage healthcare conditions independently.

Case studies

The following case studies are intended to help the reader think about ways in which telecare can support someone with a sensory impairment. The cases illustrate a number of situations where technology can successfully support the person and their carer.

Case study 1

Jim and Janet are a married couple in their 70s. Jim is profoundly deaf and uses BSL to communicate. Janet is profoundly deaf and blind due to Usher syndrome. She communicates using a deafblind manual, hands on signing and BSL. Previously, when Jim left the house, he would leave the front door unlocked so that expected visitors could let themselves in. This was because Janet could not hear or see anyone at the door. However, this also meant that strangers could enter and leave the house without Janet knowing, leaving her in an extremely vulnerable situation. To counter this, a vibrating pager system was connected to the doorbell **25**, alerting Janet to callers when Jim was out. The door could then be locked, preventing any unannounced callers. The pager system means that Janet can be at home alone and remain independent. It also means that her carer doesn't need to be with her 24 hours a day.



Case study 2

Mr R is a 56-year-old man with no residual vision. Due to a change in personal circumstances he is now living alone. His former partner did most of the cooking, shopping and daily housework. Mr R would like to maintain as much independence as possible, particularly with regards to cooking. He would also like a way of keeping in touch with friends and family so that he can increase his social activity and minimise his isolation. Following some training and the provision of talking kitchen scales **26**, talking tin labels and a talking microwave, Mr R is now able to cater for himself. He now orders his shopping online using voice recognition software on his computer. The computer also helps him keep in touch with friends, and using a magnifying mouse **27** he can read his own mail. A support worker visits him once a week, but he doesn't need any home care and has been able to continue living independently.



Case study 3

Mr J is an 84-year-old man who lives alone. He is completely blind and quite frail, so is unable to go out independently. Mr J has a passion for music and has an extensive collection of CDs. Having been provided with a PenFriend audio labeller **28**, he has been able to label all of his CDs. The same labeller can be used to identify medication and food items **29**. As a result, Mr J can choose music for himself, enhancing his enjoyment of his main pastime. He is also able to manage his own medication and identify food in his cupboards.



Case study 4

Mrs G is 28 and lives with her husband and baby daughter. She has significant sight loss, but using her residual vision she can dress, feed and bathe her daughter. However, because of her inability to discern fine detail, she was unable to measure the amount of milk to be given to her daughter. This meant that her partner, who worked full time, had to check that all the bottles were made up before he went to work. With the help of talking kitchen scales **26**, Mrs G is now able to measure out the food for her baby, meaning that she can make up bottles independently. This means she no longer has to rely on her husband or a home help for support. Using a talking combination oven **30** and talking tins, Mrs G can also now cook family meals independently. The technology has helped her to remain independent and maintained her self-esteem.



Case study 5

Mr L worked for the Secret Service during the war and was compiling his autobiography when his vision started to deteriorate due to macular degeneration. He had always been very independent and struggled at having to rely on others for help with tasks like reading his mail. The thought of not being able to finish his autobiography was devastating. Things changed when Mr L was provided with a MonoMouse **31**, an electrical magnifier that plugs into his TV and magnifies whatever it is held over. This means that Mr L can now read again. He is delighted to be able to finish his researches and ultimately complete his autobiography. He has regained much of his former independence, as the MonoMouse also means he can read personal documents such as bank statements and bills without having to ask others for help.



Case study 6

Mr S, who was already registered blind, needed to retrain due to a further reduction in his vision. He wanted to go to university but needed support to take notes, prepare assignments and to get to and from university. A combination of technologies enabled him to do all these things independently. With the addition of speech synthesis software **3** **4** to his computer (which can 'read' text on the screen to him), he is now able to access course notes and carry out research online. He uses a combined MP3 player and voice recorder **32** to record lectures and store text books. A navigational system in the local railway station means he can also travel to and from university independently.



Case study 7

Mr H is an elderly man who lives alone in an upstairs flat. An internal staircase leads to the main door, which is on the ground floor. Mr H is very frail and registered blind. The door is recessed at the back of the building and no one directly overlooks the doorway. When the doorbell rings, he struggles to get down the stairs to open the door, and is reluctant to make the journey if he doesn't know who is calling. As a result he has been leaving the door open, which is placing him at risk. Following an assessment, a door entry system (incorporating an intercom) **33** was installed with handsets beside his chair and in his bedroom. He is now able to identify callers and let them in if he chooses, without having to go downstairs.



Case study 8

Mr P has a dual sensory loss. He has been visually impaired since birth and his hearing has subsequently deteriorated. Because of his general health and dual sensory impairment, Mr P has been unable to work. He has no light perception so is unable to watch TV or read print. As a result he has limited access to resources. He has always lived with his mother, who although elderly is still very supportive. Having been provided with a DAISY player **34** and the RNIB talking book service, Mr P now has access to unlimited fiction and non-fiction books, which provide both entertainment and education. He also receives local and national newspapers on CD. These enable him to keep up to date with what is happening in both his local and wider community.



Case study 9

Mr A lives with this wife who is hard of hearing. He has long-standing breathing difficulties and sometimes experiences problems during the night when he needs oxygen and inhalers administered. Sometimes when he shouts for his wife, who sleeps in another room, she doesn't hear him and this has become a cause for concern. Mrs A's hearing is sufficiently bad that she struggles to hear on the phone. She cannot type, so a textphone is not an option. Even if she could use the phone, she maintains that she would freeze during a crisis and wouldn't be any use if she had to make a call. To solve the problem Mrs A has been issued with a pager system with alerts connected to the doorbell, a smoke detector and a baby alarm. The baby alarm picks up Mr A's shouting if he is in distress, causing the pager to vibrate and wake her, so that she can administer his medication. Mr A has also been issued with a pendant **35** which he hangs on the bed head. When pressed, this lets the mobile warden service know that he is having difficulties and his wife hasn't heard him. Alternatively, if his medication isn't working, Mr A and his wife can use the pendant to call the emergency services. As a result of these interventions Mrs A can sleep easier at night and is able to remove her hearing aid. She had previously been wearing this so she could listen for her husband, but it was uncomfortable and she still often didn't hear him. Now if she needs to she can summon emergency help without having to talk over the phone.



Case study 10

Mrs T is in her late 70s and has severe hearing loss. She also has short-term memory problems and has lost her sense of smell. She is very independent, and lives alone in a first floor flat, refusing home care and other services. Her niece, who is her only close relative, doesn't live locally and works during the day. In the morning Mrs T often forgets to put her hearing aids in, and even when she does remember her arthritis makes this task difficult. As her niece isn't nearby and she doesn't want carers in her house, no one is available to help her. Concerns were raised when Mrs T's niece arrived at her home and heard the smoke detector from outside the house. Mrs T was completely unaware of it. Although Mrs T still felt able to continue caring for herself, she agreed that this incident meant she was at risk if a fire broke out, and accepted a visit from an assessor. Following her visit, a passive smoke detector, gas detector **36** and carbon monoxide detector **37** were fitted in her home. The devices are connected to a remote control centre which responds if any of the alarms are activated. This means she can continue to live independently, confident that if a similar problem recurs there would be an appropriate response from the emergency services, day or night. Her niece also feels more comfortable knowing that Mrs T has these safeguards in place.



Case study 11

Mr M is 41 and lives alone. He has no perception of light and previously could not tell if his lights were switched on or off. Because of this he often left them on all day or overnight, increasing his electricity bill. Having been issued with a light indicator, Mr M is now able to tell when the lights are on. He is also able to orientate himself better around the house as he can use the indicator to determine the location of windows. His electricity bill has also dropped.

Issues to consider

Not everyone immediately wishes to embrace new technology and the changes that it may bring. Many of the devices that are relevant to people with a sensory impairment rely on the individual being 'digitally aware'. As a result some people are put off at the outset or feel unable to use the technology.

For many people with a sensory impairment living in isolation, there is no substitute for human interaction. Indeed, for deaf or deafblind people to use a telecare device effectively, they first need information and instructions to be translated for them, and this stage of the process necessitates training and personal contact. Introducing telecare in isolation would be of no benefit. When considering telecare, a person-centred approach should be taken with the person encouraged and enabled to make choices to shape and define their own care package. This will ensure that it best suits their needs and maximises their independence.

Members of the Deaf community see themselves as a distinct cultural minority group and believe that some advances in technology threaten their culture and diversity. Many are not supportive of technology like cochlear implants, which enable deaf people to hear sounds and develop speech.

In general, electronic assistance devices for deaf people can be split into two categories – those such as cochlear implants which attempt to 'normalise' deaf people, and those which acknowledge that the needs of deaf people are different. Devices such as textphones would fall into the second category. It is important to be aware of these sensitivities when assessing the appropriateness of telecare for someone with a sensory impairment.

Issues for carers and for care and support staff

The benefits of electronic assistive technology are potentially significant for carers too. Simple solutions can provide a great sense of relief to family members and carers. With appropriate technological support, people can remain safe both in their own homes and outdoors. Technology can enable them to enjoy higher levels of independence, with the result that they need less time and support from carers. Devices such as pagers and alarms mean that individuals can call on assistance more easily if required, and this provides a degree of security for relatives and carers. As a result, relationships are less likely to be strained.

However, there are still a number of hurdles to overcome before telecare can be deployed effectively. Firstly, carers may not be aware of the availability of telecare to support them in their caring role, or appreciate its potential. Secondly, it cannot be assumed that the carer of a person with sensory impairment

For many people with a sensory impairment living in isolation, there is no substitute for human interaction.

will be supportive of the use of technology – or that they will monitor its use. Likewise, partners and older children may have concerns about adaptations to laptops, mobile phones and domestic equipment – perhaps because of inconvenience, anxiety about change, reliability or stigma. Older parents in particular may have had different experiences of caring, often fighting for services at a time when they simply did not exist. As a result, they are often more reluctant to seek help or support³², and this can be reflected in a reluctance to work towards more independent living for their son or daughter. These views must be taken into account before bringing new technology into the family home.

Good planning at an early stage can avoid the need for crisis decisions being made as the parent ages. To be effective, telecare needs to be part of a long-term care package that is regularly reviewed and incorporates the needs of the person with a sensory impairment, along with those of their parent or carer. For consistency, respite carers and those offering short breaks need to be aware of any use of technology by the person. Implementing telecare effectively is likely to require clear explanations for carers, as well as for the person with a sensory impairment.

Carers and care staff also need appropriate training and support in the use of telecare. Although use of mobile phones and the internet is widespread, it should not automatically be assumed that staff or family members will be familiar with them. Staff may have no desire to use these technologies themselves, so may have difficulty incorporating them into their daily work. What may be seen as a reluctance to support a person with a sensory impairment may in reality be due to feelings of uncertainty about the technology which need to be acknowledged. These issues can be overcome by support and training. In some cases the carer or staff-member may learn alongside the person with a sensory impairment, which can prove beneficial for both. Training and support for staff are essential, and should form part of personal development plans which will ensure that this area of work is recognised and acknowledged. Additionally, clear lines of accountability and reporting are needed. If necessary, job descriptions and person specifications should be expanded for both existing and new staff to reflect their expanded role.

It is important that more than one staff or family member is familiar with any technology that is introduced. There will normally need to be someone on shift at all times who is familiar with how each piece of equipment works. Equally, call centre staff need to be aware that the person they are responding to has a sensory impairment and understand the necessary communication and response arrangements. These should be in the individual response protocol that is established at the time of installation. Discussing this plan regularly at team meetings will mean that staff are familiar with the issues they may encounter, rather than becoming stressed when they face a problem or receive a call. This is especially important in organisations where there is a high staff turnover or regular use of agency staff.

When telecare is first introduced, paid staff may have concerns about their job security and be fearful of being replaced by technology. Although the introduction of telecare may open up possibilities for new or different roles, this need not be at the expense of contact time and social interaction with people who have a sensory impairment – especially those living alone, for whom loneliness can be a very real issue. Instead, routine 'supervision' or check visits can be replaced by equipment, freeing up staff time for more worthwhile social interaction.

Carers and care staff also need appropriate training and support in the use of telecare.

5: Training programme

This section contains content and a suggested timetable for a one-day training programme on how telecare can contribute to the care and support of people with a sensory impairment. It may also provide a basis for a longer programme for specialist assessors or 'telecare champions' if combined with 'shadowing' experiences and visits to a control centre, response team, and contact with service users already experienced in telecare. Similarly, it may be of value to course leaders of qualifying programmes for social workers, occupational therapists and community nurses.

It is an outline programme which skilled trainers will need to adapt to the particular training needs and circumstances of local groups.

Handouts A to D provide important additional information about sensory impairment. These can be used as advance reading for participants, or useful information to take away. Alternatively, the information in these handouts can be used as part of a discussion or quiz at the start of the session.

Aim

To support participants in the development of their knowledge, skills and understanding required to introduce telecare into individualised care packages.

Objectives

- to learn how telecare can contribute to the support of people with sensory impairments and their carers
- to develop practice in needs and risk assessment, and care planning, so as to maximise the benefits of telecare
- to increase knowledge of the legal and ethical framework for good practice
- to understand the wider policy and strategic context for telecare

Timetable

9.00 Welcome and introductions

- domestic arrangements
- discuss agenda and clarify expectations of the course. Refer to the aims and objectives to confirm what the course can and cannot provide. Invite participants to discuss, briefly, with each other, their current knowledge and understanding of telecare, their perceptions and anxieties about technology, their expectations of the day, and their individual training needs

9.30 Definitions of telecare and telehealth

This could be a 'teaching' session with a presentation and handout based on the definitions provided in the introduction to this book. Key learning points are:

- the meaning of terms such as telecare, telehealth, telehealthcare and an introduction to the 'generations' of telecare
- the lack of commonly accepted standard definitions, and the extent to which terms are interchangeable, and changing
- the speed with which technology is developing in all areas of our lives
- the effect of this on service user and carer expectations

In this session it will also be important to remind participants about the nature and impact of different sorts of impairment, and so begin to explore the ways in which technology can support people with different conditions. Assuming that participants will already be working in the field of sensory impairment, the key learning points will include:

- understanding that the successful introduction of telecare depends on understanding the different forms of impairment (see handouts C and D)
- being able to develop and use appropriate communications skills (see handouts A and B)
- taking a person-centred approach to care and support and encouraging higher expectations among the family and carers of people with sensory impairments. This includes developing a proactive approach which engages the person in meaningful and enjoyable activities
- being open to new and changing ways of providing support

Gather together any thoughts and initial reactions at this stage. Some of the definitions may be new to participants, and time is available to ask questions about these throughout the day. Reassure participants that they will have the opportunity to apply these to practice later.

10.15 How can telecare help support people with sensory impairment?

This should be an opportunity for participants to see pictures of, and, if possible, actually touch and feel equipment. It is important to explain the kind of support needs for which pieces of equipment may be useful, and to talk through examples of equipment which may be in development but not yet available.

Local providers and suppliers may offer to put on a display of equipment, at no charge. If there is a local 'smart house' it may be possible to hold the training session there – or to organise a visit at the end of the day or during the lunch break.

Ask the group to look at the illustrations of equipment and share their ideas about each item's uses and limitations. Participants may have additional valid suggestions about uses and limitations based on their own experiences. Ask the group to split into pairs and think about a person they know who may benefit from some of these adaptations or interventions, along with someone who would be unlikely to benefit from them.

10.45 Break

11.00 Case studies – telecare in practice

In this session, participants will look at a variety of different scenarios in pairs and think about what equipment would be useful. It is also important that they think through the implications – for example:

- what is the need that is to be met (the importance of careful assessment; avoiding simplistic solutions; not ‘just giving out bits of kit’)
- the different perspectives of the service user, their family and support staff
- differing attitudes to risk
- how telecare can supplement other kinds of support but is not intended to replace them
- the importance of maximising levels of independence and retaining personal skills
- encouraging/enabling individuals to remain in their own homes/communities for as long as is safely possible
- fostering a feeling of security for individuals and their families
- improving quality of life
- providing greater choice

Ideally, participants will share their own experience and ‘cases’ with colleagues. This book also contains some case studies which can be used as an alternative, or in conjunction with participants’ own experience. The trainer will need to decide how best to use some or all of these – perhaps giving the initial scenario first, then comparing the solution suggested in the book with the group-members’ own ideas.

12.00 The importance of good assessment

Bring participants back together as a single group and compare the ideas that emerged in the previous session. Encourage debate about how telecare contributed to the support of the individuals in the case studies in the following ways:

- draw out the importance of good assessment. Refer to the section on assessment in this book. If necessary, develop a handout or use an example of a local assessment tool
- make sure risk is considered, and well as need
- highlight the differing concerns and benefits as seen from different points of view
- bring any difficult issues into the open, such as staff reluctance or how carer concerns should be addressed
- highlight what the problem is and who the telecare is intended for. Are there consent issues, or differing perspectives on risk, need, capacity or consent?

13.00 Lunch

14.00 Telecare may be the solution ... but is it ‘right’???

This is an opportunity to discuss with participants the rights and wrongs of using telecare, looked at from their own perspective, as well as their employer’s and

professional perspectives. Chapters 2 (Assessment) and 3 (Principles, rights and ethics) may provide the basis for a short introductory talk. Alternatively, this could be an interactive session in which the following kinds of questions are posed:

- telecare can involve the monitoring of people's private lives. Is that 'right'?
- some equipment restricts people's freedom to do as they want or go where they want in order to 'protect' them. What is the right balance between risk and protection and how do we achieve it?
- telecare can be used to support a 'normal' lifestyle – getting up in the morning, going out during the day and going to bed at night. Is telecare being used to 'impose' a conventional lifestyle?

Stress that people with a sensory impairment should only have their movement restricted or monitored with permission, and where this complies with the law and care regulations. Discuss what permission means where there is significant cognitive impairment and talk through what the law dictates in this area. These issues can be discussed in the context of the case studies from the previous session.

Participants need to be clear about the legal constraints on this (and any other) part of their support service. They have a responsibility to make decisions that are both ethically defensible and legal. An approach based on individual assessed needs will always present ethical dilemmas which need to be resolved.

15.00 Policies, procedures, and strategy to support the use of telecare.

This session provides an opportunity for participants to explore and gain a better understanding of local policy and procedures. It should include discussion of local assessment tools to ensure that participants understand when and how telecare can be introduced into the assessment process. Local procedures for accessing telecare, as well as for installation, testing and responding to call-outs, should be discussed and explained, along with charging policies and budgets.

It may also be useful to discuss local strategy. How does the use of telecare fit with local joint strategies for people with sensory impairment? If time is available, it will be useful to look at the national strategy too and discuss how telecare can contribute to national policy goals such as Shifting the Balance of Care. (Resources are available on the National Telecare Development Programme website – www.jitscotland.org.uk/action-areas/telecare-in-scotland/)

16.15 Conclusions and evaluation

Ask the group if the discussions they have had during the afternoon have influenced the way they would now approach the case studies introduced earlier in the day. Do they now feel more confident about making a recommendation and supporting a person with a sensory impairment to make an informed choice about telecare?

Summarise and ask what the participants will take away from the day. The discussion could include areas of new technology and the potential for the future use of telecare and telehealth as a way of supporting people with a sensory impairment.

Handout A: Communication and guiding someone with a visual impairment

People's visual impairments vary from partial sight to total vision loss. This means that some people can see considerably more than others. Check with the person how much they can see and what help they need.

- use the person's name to let them know you are talking to them
- use your name so they know who you are. If necessary, let them know if anyone else is present. If you are meeting them in a professional capacity, be clear about who you work for – you may not be immediately recognisable as, for instance, a nurse, because the person may not be able to see your uniform or name badge
- explain what you are doing or have come to do. This can be as simple as saying "I'm crossing the room", or (perhaps in hospital) "I'm just putting your meal tray in front of you". Make sure you explain procedures. If you are a home help, let your clients know what you are doing and remember to put things back where they were. For instance, say "I'm just unplugging the lamp so I can plug in the vacuum cleaner", but remember to plug the lamp back in afterwards
- ask them where they would like you to sit in relation to them – for instance to their left or right, or facing them. Take the location of windows into account. The person may want you to take a well-lit seat so that they can see your facial expressions and body language as well as possible
- use touch appropriately. For instance, lightly touching their forearm if they need orientation to your physical whereabouts
- sometimes people worry about the language they use and are concerned about being patronising. They may be unsure about using explanatory phrases such as "See what I mean?" or "Let's have a look at this". In practice, this usually doesn't cause any offence as people understand these are common turns of phrase
- always let the person know you are leaving the room, even for a short time. It is very embarrassing for them to find they are talking to themselves because they are unaware they are on their own. It is also important to let them know whether doors are closed or have been left open
- be aware that a visually impaired person may not be able to see your facial expressions or body language, and as a result may misread what you are trying to communicate. Try to be specific and descriptive in your responses
- when written communication is appropriate, find out what format the person requires to enable them to access their mail. Options include large print, audio, Braille or Moon
- assistance that is offered unsolicited may be refused. If someone asks you for help, it is very important to listen to what they actually want help with. Someone with a white cane who is standing at a junction doesn't always want to cross the road
- never leave a blind person in an unfamiliar place without giving them a landmark to orientate themselves by. They may feel more secure by a wall or a bench
- guide a visually impaired person by asking them to take your arm. Communicate clearly with the person about where you are and when negotiating obstacles such as kerbs, traffic and steps

Handout B: Causes of deafness

Hearing loss can be sensorineural, conductive or a mixture of the two. **Conductive hearing loss** causes a loss of volume. It occurs when the outer and/or middle ear fail to work properly. Sounds are not carried all the way to the inner ear. Potential causes of a conductive loss include:

- a build-up of fluid in the middle ear
- wax in the ear canal
- damage to the ear drum as a result of infection or injury
- problems with or injury to the bones or membranes which carry sound from the outer ear through the middle ear to the inner ear

Sensorineural hearing loss, also known as 'nerve deafness', causes distortion of sounds. It occurs when the inner ear or hearing nerve is damaged. About 90 per cent of people who have a hearing loss have a sensorineural hearing loss. Potential causes include:

- the natural ageing process
- exposure to loud noise – industrial or music, for example
- infections
- congenital deafness or genetic factors

While hearing aids may reduce the effect of a hearing loss, no hearing aid can restore normal hearing. The effectiveness of a particular hearing aid depends on the degree of hearing loss.

Handout C: Clear communication principles

- **do** make sure you have the person's attention before you start talking
- **do** face the person and maintain eye contact
- if possible, introduce the topic of conversation to help avoid guesswork
- **do** speak clearly and slightly more slowly than usual, but retain your natural rhythm and intonation (for instance, say 'responsibility' rather than 'res-pon-sib-il-it-y')
- **do** position yourself three to six feet from the person, and at the same level as them, ie both standing or sitting
- **do** move away from background noise or switch off TVs or radios
- when communicating with a deaf person, ensure they have the light behind them and that your face is in good light
- in general, use gesture and facial expression, although bear in mind that not everyone likes this style of communication
- **do** repeat or rephrase things if necessary. If this tactic is unsuccessful, write things down

- **don't** shout – this distorts the face and voice
- **don't** over exaggerate your lip movements
- **don't** slow your speech too much – this creates extra syllables which are confusing when lip-reading
- **don't** obscure your face with your hands, smoke or eat whilst speaking
- **don't** look away – speech movements are very quick and can easily be missed
- **don't** give up and say "It doesn't matter". Use a pencil and paper if necessary

Handout D: The 20 losses of blindness

I. Basic losses to psychological security

- Loss of physical integrity
- Loss of confidence in the remaining senses
- Loss of reality contact with environment
- Loss of visual background
- Loss of light security

II. Losses in basic skills

- Loss of mobility
- Loss of techniques of daily living

III. Losses in communication

- Loss of ease of written communication
- Loss of ease of spoken communication
- Loss of informational progress

IV. Loss of appreciation

- Loss of the visual perception of the pleasurable
- Loss of the visual perception of the beautiful

V. Losses concerning occupation and financial status

- Loss of recreation
- Loss of career, vocational goal or job opportunity
- Loss of financial security

VI. Resulting losses to the whole personality

- Loss of personal independence
- Loss of social adequacy
- Loss of obscurity
- Loss of self-esteem
- Loss of total personality organisation

Carrol, Thomas J, *Blindness, What it is, what it does and how to live with it*,
Little, Brown & Co., 1961

Additional resources*

For further information about telecare and the National Development Programme in Scotland, please contact the Joint Improvement Team via their website:

<http://www.jitscotland.org.uk/action-areas/telecare-in-scotland/>

The website for the equivalent programme in England is:

<http://www.dhcarenetworks.org.uk/independentlivingchoices/telecare/>

Other websites

Information and general advice from the Disabled Living Foundation:

<http://www.livingmadeeasy.org.uk/telecare-167/>

Consumer reports on telecare equipment:

http://www.ricability.org.uk/consumer_reports/at_home/

Home Farm Trust is a national charity supporting people with learning disabilities and their families. For more information about what they call 'personalised technology' email personalisedtechnology@hft.org.uk or visit http://www.hft.org.uk/What_we_do/Assistive_technology

The AT Dementia website brings together information about assistive technology that has the potential to support the independence and leisure opportunities of people with dementia: <http://www.atdementia.org.uk/>

Information on assistive technology for people with dementia:

<http://www.atdementia.org.uk>

Telecare Services Association (TSA):

<http://www.telecare.org.uk>

Social Care Institute for Excellence – Dementia Gateway. This section of the website looks at the use of technology:

<http://www.scie.org.uk/publications/dementia/environment/assistive.asp>

Centre for Usable Home Technology:

<http://www.cuhtec.org.uk/>

Centre for Accessible Environments:

<http://www.cae.org.uk/>

Enable:

<http://www.enableproject.org/>

Dementia Services Development Centre:

<http://www.dementia.stir.ac.uk>

DVDs

Telecare – supporting Scotland: a different approach. DVD which includes seven 'digital stories' illustrating, in the words of users and carers, the impact of telecare. Available through

<http://www.jitscotland.org.uk/action-areas/telecare-in-scotland/>

Telehealth in Action. Scottish Centre for Telehealth:

<http://www.sct.scot.nhs.uk>

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*All websites accessed 24.02.10

Supplier contact details

The images of equipment featured in this book represent a small subsection of the range currently available. The contact details below have been included to assist purchasers in assessing what is available from whom, but in many cases the same device is available from more than one supplier. The publishers in no way endorse any particular supplier or product. The lack of inclusion of a particular product does not imply that it is inferior to any device featured. Purchasers are responsible for researching the full range of products available and reaching their own conclusions about what is most suitable for them or their clients.

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<p>CH Byron Electrical Ltd 10 25 34 Sherwood Road Bromsgrove B60 3DR Tel: 01527 557700 www.chbyron.com</p>	<p>Cobolt Systems Ltd 23 30 The Old Mill House Mill Road Norwich NR13 3TL Tel: 01493 700172 www.cobolt.co.uk</p>	<p>Dolphin Computer Access Ltd 4 Technology House Blackpole Estate West Worcester WR3 8TJ Tel: 01905 754577 www.yourdolphin.com</p>
<p>Freedom Scientific 3 11800 31st Court North St Petersburg FL 33716-1805 USA Tel: 001 727 803 8000 www.freedomscientific.com</p>	<p>13 14 17 18 21 Geemarc Telecom SA 5 Swallow Court Swallowfields Welwyn Garden City AL7 1SB Tel: 01707 372372 www.geemarc.com</p>	<p>Hearing Products International Limited 6 7 8 9 20 Echo House 26–27 Haigh Park Stockport SK4 1QR Tel: 0161 480 8003 www.hear4you.com</p>
<p>HumanWare Europe 1 2 32 Russell Smith House 2 Bullmatt Business Centre Northampton Road Rushden NN10 6AR Tel: 01933 415800 www.humanware.com</p>	<p>RNIB 28 29 34 PO Box 173 Peterborough PE2 6WS 0303 123 9999 www.rnib.org.uk</p>	<p>RNID Products 11 16 22 1 Haddonbrook Business Centre Fallodan Road Peterborough PE2 6YX Tel: 01733 361199 www.rnid.org.uk/shop</p>

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<p>Terraillon UK Ltd 26 2 The Waterhouse Waterhouse Street Hemel Hempstead HP1 1ES 01442 270444 www.terraillon.co.uk</p>	<p>Tomy UK Ltd 19 St Nicholas House St Nicholas Road Sutton SM1 1EL Tel: 020 8722 7300 www.tomy.co.uk</p>	<p>33 36 37 Tunstall Healthcare (UK) Ltd Whitley Lodge Whitley Bridge DN14 0HR Tel: 01977 661234 www.tunstallhealth.com</p>
<p>Tynetec Ltd 35 Cowley Road Blyth Riverside Business Park Blyth NE24 5TF Tel: 01670 352371 www.tynetec.co.uk</p>	<p>Ultratec Inc 12 450 Science Drive Madison WI 53711 USA Tel: 001 800 482 2424 www.ultratec.com</p>	

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