

## Decisions about technology

Principles and guidance on good practice when considering the use of telecare and assistive technology for people with dementia, learning disability and related disorders.



# Contents

What we do		2
About this guidance		2
About assistive technology and telecare		3
Why might assistive technology and telecare be a human rights issue?		3
Making decisions and general good practice		5
Use the principles of the Adults with Incapacity Act		5
Assess and plan		6
Use of electronic location devices		9
The use of CCTV to monitor the actions of an adult		10
The use of CCTV to monitor the actions of staff		11
Legal considerations		11
Case examples		14
Decision-making framework		16
What is currently available?	Appendix 1	18
References and literature review	Appendix 2	21

# The Mental Welfare Commission

## What we do

We protect and promote the human rights of people with mental health problems, learning disabilities, dementia and related conditions.

## We do this by

- Checking if individual care and treatment are lawful and in line with good practice.
- Empowering individuals and their carers through advice, guidance and information.
- Promoting best practice in applying mental health and incapacity law.
- Influencing legislation, policy and service development.

## About this guidance

I have the right to be regarded as a unique individual and to be treated with dignity and respect.

I have the right to be as independent as possible and be included in my community.

I have the right to access a range of treatment, care and support.

*Standards of Care for Dementia in Scotland 2011*

This guidance is for those considering the use of technology to assist with care and maintain independence when the individual concerned may lack the capacity to make the decision.

We first published guidance on the use of technology in 2007, 'Safe to wander'. Since then we have seen an increase in the awareness of, availability and affordability of new technologies.

The Commission has an active role in ensuring that people have access to treatment, care and support that is most appropriate to their individual needs and their human rights. People with mental illness, dementia, learning disability and some other conditions may be vulnerable because they are less able at times to safeguard their own interests. They can have restrictions placed on them in order to receive care, treatment and support.

The principles of this guidance may prove helpful as the use of technology evolves to support home based alternatives to residential care.

The Commission is not expert in the range and suitability of various technologies and this document does not provide practical guidance on how to introduce and include technology as part of a care package. Links to various sources of information about this are provided at the end of this document.

Our interest and expertise is in ensuring that people who may not have the capacity to consent to the use of technology, have the opportunity to benefit from it whilst having their human rights respected.

The Commission would like to thank all those who took part in our consultation event in February 2015.

## About assistive technology and telecare

Throughout this guidance we use the terms assistive technology and telecare.

Assistive technology is a term that refers to a device or system that allows an individual to perform a task that they would otherwise be unable to do and to enhance the physical, sensory and cognitive abilities of people with disabilities to maximise independence.

Telecare is the use of equipment within and outwith the home to monitor changing needs and risks and to provide alerts and information that enables improved and informed responses to those needs and risks.

## What is available?

There is a very wide range of technology available and it is developing all the time. Such technology can be used in the community and within the person's own home or in a care setting.

Technology can be actively operated by the person themselves or passively operated (used by a carer or staff supporting the person). It can also be a combination of the two.

Some technological devices are 'stand alone' but others are connected to other systems. One device (such as a mobile smartphone) can sometimes have many different functions.

The functions that technology can have include:

- alerting and summoning assistance;
- prompting and reminding;
- monitoring and checking; and
- modifying the environment.

Technology can provide alerts that something may be wrong and summon assistance. It can provide prompts and reminders to help with everyday living, e.g. appointments, medication. It can also provide a way of checking on or monitoring a person or their environment. Technological devices may also be able to take action to keep a person safe.

There are numerous types of technology now available and more is being introduced at a rapid rate. It is not possible in this document to consider each application separately so we have provided general good practice principles that can be applied to each individual situation. We also make specific comments on electronic location devices (GPS systems) and CCTV. More detailed information on technology that is currently available can be found at Appendix 1.

## Why might assistive technology and telecare be a human rights issue?

Some technologies have the potential for abuse if not used within a proper legal framework and with reference to good practice guidance. Where such technology is used, great care must be taken to ensure that the person concerned has his or her rights protected.

It is easy to see the potential benefits of technology for individuals, but care needs to be taken to ensure it never stigmatises, and it should never fully replace direct contact with care-givers.

A particular technology for one person could be the difference between feeling isolated and vulnerable in their own home or continuing to be engaged in their local community and usual activities. The same technology used for someone else could be viewed by them and their carers as intrusive and demeaning.

There is also the potential for telecare and assistive technology to stigmatise and be degrading for the user and potential for it to place limits on the personal freedom of the individual if not used discreetly. This is why we believe a rights-based approach to decision making is required.

Technology can be a valuable tool which has the potential to help people to maintain their independence and enhance their freedom. Where new technology can provide assistance without unduly restricting the individual or increasing the risks that he or she may face, its use is to be welcomed.

In our guidance Rights, Risks and Limits to Freedom, the Commission set out its definition of restraint.

*'Restraint is taking place when the planned or unplanned, conscious or unconscious actions of care staff prevent a resident or patient from doing what he or she wishes to do and as a result are placing limits on his or her freedom.'*

Those considering the use of telecare and assistive technologies clearly have to be aware of the potential for their actions to constitute restraint and to take this into account in their decision making. This includes those who are not employed to do so, but who care for someone living in their own private home.

## Making decisions and general good practice

### Consider capacity

As we mentioned earlier, people with mental illness, dementia and other conditions may, but do not always, lack the capacity to consent to technology. In law, there is a presumption in favour of capacity. Anyone who has the capacity to consent should be allowed to decide whether to use technology, and has the right to decline the offer.

Disagreeing with a suggested approach to care or treatment does not mean that a person lacks capacity. It is important to assess capacity in relation to the decision the person is facing.

Assessing if someone has the capacity to make specific decisions can be complex.

- Does the person understand the information and retain it long enough to make a decision and express their decision?
- Do they feel coerced into agreeing to the proposed device to make life easier for others?
- Do they understand what the device does, e.g. that someone may be able to look and monitor their whereabouts?

Efforts must always be taken to support someone to make a decision whenever this is possible. This may include taking extra time to explain what is being proposed, involving advocacy, and using communication aids to help promote discussion and understanding.

## Use the principles of the Adults with Incapacity Act

### The intervention must provide a benefit that cannot otherwise be achieved

What will be the benefit of the assistive technology/telecare to the individual?

When used appropriately, the benefit might be improved personal safety, increased dignity, more independence or a greater sense of freedom. Well-chosen technology may reduce the need in care settings for obtrusive levels of observation that could be distressing for the individual.

However, the use of technology may reduce personal contact with care-givers and this is unlikely to benefit the person. Technology is no substitute for appropriate levels of personal care and human interaction. On no account should technology be used by care providers merely to save on the cost of appropriate staffing.

### The intervention must be the least restrictive in relation to the person's freedom in order to achieve the desired benefit

Will technology result in the least restriction consistent with the person's dignity, safety and independence?

There is often a tension between protection and safety versus privacy and dignity. Technology may allow someone more freedom than locking doors or having someone watch them at all times. However, if the person often has to be retrieved and returned to their place of residence, it may result in increased distress and may be degrading.

Introducing technology to a person and their carer in their own home can provide the added security and reassurance for the carer that could prevent an unwanted move to residential or hospital care.

### **The past and present wishes of the person must be taken into account**

Care-givers should not assume that someone lacks capacity. People whose cognitive ability fluctuates may be capable of stating their wishes to be safe during periods of increased confusion and can participate fully in decisions.

Even when the person appears to lack capacity, every effort possible should be made to discuss risks and to help them understand the benefits of technology solutions. Supported decision making should be encouraged and advocacy may be helpful. There should be a careful record of such discussions including whether the person agrees or disagrees with the use of technology. This must be approached with sensitivity, particularly where someone has recently received a diagnosis of dementia.

The use of technology can usefully be discussed in the period of post diagnostic support for people newly diagnosed with dementia; looking at what may be helpful now and in the future.

### **The views of relevant others should be taken into account**

A wide range of people will have valuable roles to play in any decision.

Nearest and close relatives and friends will know the person best and can provide valuable information about his/her life. This may be crucial in understanding the person's behaviour. They will also have views about risks and dignity and these should be taken into account.

A welfare attorney or guardian with powers over the person's welfare may have the authority to consent to the use of assistive technology/telecare. Even if that specific power is not included in the range of powers granted, the powers may include decisions on the person's place of residence and decisions about care and support which may be affected by the potential use of technology. In such cases it is important to consult such a person on the use of technology. More information about the role and powers of welfare attorneys and guardians is included at page 16.

### **The intervention should encourage the person to use existing skills and develop new ones**

As technology develops, the opportunities it presents are increasing. People with a learning disability or dementia have tremendous potential to benefit, and there should not be an assumption that they would be unable to learn to use new technology.

If the use of technology increases the opportunity of the person to maintain existing skills and independence and to develop new skills, then it merits serious consideration.

## **Assess and plan**

Technology is sometimes considered because of a behaviour that is causing concern, e.g. increased restlessness or getting lost.

It may be that technology will provide a good solution but there should first be a comprehensive assessment of any behaviour that is causing concern.



Whilst primarily aimed at care staff, carers will also find the following helpful to consider.

### **Assessment and care planning**

Assessment and care planning is essential, particularly if there is any potential for the assistive technology/telecare to place restrictions on the personal freedom, movement, privacy or dignity of the individual.

Prior to considering introducing assistive technology/telecare, there should be careful physical and psychological assessment to eliminate any reversible cause if there is behaviour that is causing concern. This assessment should involve analysing what is actually happening, when it is happening, what triggers the behaviour and what intervention helps.

### **Physical assessment**

Any physical assessments should be multi-disciplinary and should include:

#### **Medication review**

Many medications for both physical and psychiatric conditions have side effects which can include motor restlessness, confusion and constipation amongst others. All of these side effects can contribute to the development of changing behaviour and medications should be regularly reviewed by the medical practitioner (particularly those supplied for the treatment of anxiety, depression and insomnia).

#### **Elimination**

Constipation or urinary discomfort can lead to restlessness and should be addressed. Searching for a toilet and worries about incontinence can also be an issue and toilets should be clearly identified.

#### **Pain assessment**

Some people are not able to express their pain, which can manifest as restlessness or increased confusion. The physical exercise that walking provides may prevent pain developing or provide a form of pain relief in itself. Early pressure sore development can cause extreme pain with no obvious visible injury.

#### **Other factors for consideration**

Deterioration in hearing or vision can lead to restlessness and increased confusion. It is extremely important that these are assessed regularly and that glasses and hearing aids are well maintained and available.

A person may be unsettled because he or she is too hot or too cold and trying to find a more comfortable environment. Hunger and thirst may also be a factor.

A poor sleep pattern can contribute to restlessness and it is well known that infection can increase confusion and restlessness and should be investigated quickly and treated appropriately.

## **Psychological assessment**

Understanding what the person is trying to achieve is critical to successful care planning. The person may believe that he or she has to go somewhere or do something. Most likely, in the case of someone with dementia, this will involve tasks from the person's past that he or she believes are necessary in the present. Examples would be going to work or getting the family's dinner ready. The person may believe that he or she lives at a former address and may be attempting to go there. Life story books and information from relatives and friends can be very helpful in understanding the person's present behaviour through knowledge of his or her life history.

Everyone needs stimulation and activity. A person who finds him or herself in an under-stimulating environment may well explore in an attempt to find something more interesting or meaningful to do. It would be inappropriate to use a technology solution for behaviour unless attention is first paid to appropriate and person centred activity.

## **Communication of distress**

Restlessness may be occurring simply because the person is bored and unstimulated in his or her environment. The person may not have a peer group he or she can relate to or feel cut off from their family and friends. These issues need to be fully addressed in an individual care plan.

Depression is very common among people with dementia and can require specialist input with regard to diagnosis and treatment. Depression can lead to anxiety which produces restlessness and an inability to initiate meaningful activities.

The person may be afraid of particular aspects of his or her environment, for example uncontrolled noise levels or individual phobias. Psychological assessment should also consider if there is any evidence of hallucinations, delusions or delirium as these can be extremely frightening and dangerous for the individual.

## **Assessment of risk**

Any assessment must include analysis of any risk that is being presented. This must focus on the risk to the individual, not the organisation or care facility.

Assessment should always take the views of the individual, carers and involved relatives into account. There should be a careful evaluation of the risk that is presented and the likelihood of that occurring. The risk to the individual of any proposed intervention should also be discussed and this should include psychological as well as physical safety concerns. Care establishments should have written policies on care planning and risk assessment that take into account the person's need to exercise and move freely.

## **The care plan**

If a decision is taken to introduce an assistive technology/telecare then a care plan relating to its use should be drawn up. This care plan should address:

### **How the technology works**

There should be clear, explicit instructions for staff or carers about how the system works, and training in the use of the system including maintenance and contingency plans in the event of malfunction. Training should be viewed as an on-going need, not a one-off occurrence.

The plan will include defining which areas and /or activities are considered safe for the individual and which are not. There must be clear identification of who will respond to any alarm and when that should happen if, for example, the individual refuses to comply with a request to remain in the care setting. This may involve external agencies such as the police. The police will need to be consulted if they might be asked to respond.

### **Involvement of the individual and relevant others**

There must be a clear explanation of the system given to the individual and to any relatives and visitors etc. It would be good practice to provide written information about the system.

### **Monitoring**

It is extremely important to monitor how well, or not, the system is working. This should include reports of how often the system is being triggered and the individual's reaction to it. It will be important to monitor if there has been a change in the individual's general wellbeing.

### **Review**

Regular review dates should be set and all involved professionals and care-givers, informal and formal, should be invited to the review. It would be best practice for the key worker/named nurse and unit manager to be present. There should be an identified senior manager who receives copies of the reviews. The primary purpose of the review is to consider whether on going use of the system is indicated or not.

## **Use of electronic location devices**

It is acknowledged how difficult it can be for care staff to provide a balance between the autonomy of the individual and the duty of care owed to that person by a care organisation. Carers at home may struggle to be 'on duty' all the time. This apparent tension can cause dilemmas for staff and relatives. By using technology to place limits on an individual's ability to leave their home or a care setting, there could be an opportunity to offer a less restrictive environment.

For those already in residential care, some behaviour may increase or pose a particular risk to an individual, who may then be moved to a more secure environment. This can prove unsettling for the resident and for carers. Where the use of technology can play a part to play in maintaining independence or enabling continuity of care, we think it should be considered.

The use of electronic location devices raises some particular concerns about the rights of the individual, particularly in relation to privacy.

There are different types of electronic location devices.

- A wrist band that emits a warning signal if the person wearing it goes beyond a predetermined boundary.
- Global positioning systems (GPS) inside mobile phones, watches, key fobs that can give details of the wearer's location to another mobile/tablet or call centre. For people who are less impaired, such devices may allow them to call for help or find their way home.

These devices may be considered for an individual when it is identified that they would be at risk of accidental injury or getting lost if they left their home or care setting unobserved or unaccompanied.

People who have the freedom to walk receive positive health benefits from their activity. Electronic location devices could have a part to play in promoting individual health and wellbeing, rather than confining a person to a limited area.

Whenever possible, a person should be able to walk freely, and to destinations of interest without subjecting the person to unnecessary barriers or causing unnecessary distress. The use of technology may contribute to this, but only in conjunction with good design of the living environment, stimulation, meaningful activity and appropriately trained care-givers.

The importance of enabling design, including the creative use of outdoor space, should not be underestimated although there will obviously be physical limitations in older, non-purpose build units and in peoples own homes. Ideally buildings should provide open access to safe outdoor space. The internal environment must contain destinations that are of interest, and long corridors leading to locked exit doors must be avoided.

Another alternative to electronic location devices is the adaptation in care homes and hospitals of local observation policies to meet the increased needs of the individual when necessary. Many individuals require increased levels of observation only at particular times of day and night, rather than having fixed observation levels.

Careful consideration should be given as to whether the tracking system/device will prevent the person from leaving and act as a restriction on their liberty.

## **The use of CCTV to monitor the actions of an adult**

We often hear about CCTV being used in hospitals, care homes and private homes to help manage security, particularly in relation to access to the building.

Occasionally we will be asked about the use of CCTV in communal and sometimes private areas of a care service.

Our publication Rights, Risks and Limits to Freedom has guidance on general use. The Scottish Human Rights Commission, Care about Rights, resource also give some guidance on the human right to privacy which is at stake when CCTV is used.

There may be limited situations where CCTV can be helpful in communal areas of care facilities but this must be justified by, for example, the protection or safety of individuals, and be proportionate; that is to say the minimum necessary intrusion into the privacy of individuals.

The disproportionate use of CCTV may be an intrusion into an individual's privacy and dignity which is protected by article 8 of the European Convention on Human Rights. The presence of a camera, whether or not it is activated, may be deemed a threat to individual privacy. Any such interference must be proportionate, for a legitimate aim and lawful. In particular, it must only be undertaken where there is the proper legal authorisation in place, e.g. authorisation via a guardianship order with the specific power to use CCTV in respect of the individual's welfare.

CCTV must not be used as a “blanket” measure to observe people. In some exceptional situations, it may be the least intrusive way of keeping a person safe. Where this is the case this should be the minimum interference necessary as part of a planned programme of care which is explained and discussed with the residents, recorded and regularly reviewed by the service provider and multi- disciplinary team.

The information gathered should only be viewed by the number of people necessary and should be safely stored only for as long as is necessary. It should not be unnecessarily disclosed. Those operating CCTV should be properly trained to understand the implications of these principles.

We strongly suggest that any care service provider takes the advice of the Care Inspectorate before pursuing the use of CCTV. In addition, the use of CCTV is regulated by the Information Commissioner’s Office under the Data Protection Act 1998.

## **The use of CCTV to monitor the actions of staff**

We are increasingly aware that small discreet video recording devices are being used to monitor the actions of care staff in care homes, hospitals and when adults are receiving care at home from a registered care service. These are often put in place by relatives or concerned others when there is a suspicion that the adult is not receiving proper care. These have also been used by journalists to uncover cases of serious abuse.

We are occasionally contacted about cases where the person is unable, due to their dementia or learning disability, to understand or consent to the use of the device.

We believe that the issue of covert surveillance of staff is complex and we are planning to produce a separate position statement on this.

## **Legal considerations**

As outlined in the section on general principles, the principles of the Adults with Incapacity Act can guide the process of deciding on the use of technology.

This section looks at the impact of specific principles of this Act, the principles of the European Convention on Human Rights and the provisions of the Mental Health (Care & Treatment) (Scotland) Act 2003.

### **Specific measures under the Adults with Incapacity (Scotland) Act**

Incapacity legislation in Scotland makes several provisions for delegation of decision making for people lacking capacity. A person, while capable, may grant a welfare power of attorney to take decisions on his or her behalf once capacity is lost. A welfare guardian can be appointed by the court to make decisions on behalf of an adult who lacks capacity. The views of Welfare Attorneys and Guardians must always be considered when making a welfare decision.

Hospital and care home managers should be aware of the extent of the attorney/guardian powers.

If there is no attorney or guardian with the authority to make welfare decisions, anyone faced with a decision about the use of technology will need to consider whether to seek a guardianship order under part 6 of this Act.

If the intervention is necessary and constitutes a significant intervention in the life of the adult, and the person lacks capacity in relation to this decision, it can be argued that Guardianship is necessary.

The Commission takes the view that, where a person demonstrates a purposeful desire to leave his or her place of residence, a Welfare Guardian should be appointed should it be necessary to restrict the person's movements.

Good practice guidance on the use of the Adults with Incapacity Scotland Act is available from the Commission's website [www.mwscot.org.uk](http://www.mwscot.org.uk).

## Human Rights Act 1998

The legal rights of the individual have become increasingly established with the incorporation of the European Convention on Human Rights (ECHR) into UK law.

The Act is founded on the articles of the European Convention on Human Rights. Under the Scotland Act 1999 all Scottish legislation including the Adults with Incapacity (Scotland) Act 2000, the Adult Support and Protection (Scotland) Act 2007 and the Mental Health (Care & Treatment) (Scotland) Act 2003 must be interpreted in a way which is compatible with convention rights.

Of particular relevance when considering the use of assistive technology/telecare are:

**Article 2:** The right to life. The right to life is an absolute right. There is a duty on the state/public authorities not to take away anyone's life and a duty to take reasonable steps to protect life.

**Article 3:** The right to be free from torture and inhuman or degrading treatment. This means that treatment which is grossly humiliating or undignified and causes severe physical or psychological harm is prohibited. Whether treatment reaches this threshold depends on various factors including the age, physical or mental health of the individual and the relationships involved.

**Article 6:** The right to a fair hearing. The protections of this right apply in circumstances where an individual's civil rights are at stake and will apply to guardianship and capacity determinations. The person must have the right to legal representation and an independent opinion.

**Article 8:** The right to privacy and respect for family life. This right is broad in scope and covers protection of privacy, family relationships, physical and psychological wellbeing including the right to autonomy

**Article 5:** The right to liberty and security of person. 'Everyone has the right to liberty and security of person. No one shall be deprived of his liberty save in the following cases and in accordance with a procedure prescribed by law.'

The protections under the Human Rights Act mean that nobody should be unnecessarily detained against their will except as set out in the range of circumstances in the legislation, with consideration of the alternatives and with the proper safeguards. Deprivation of liberty includes situations other than formal detention in hospital such as restrictions in a person's home. Any person deprived of liberty must be able to challenge this in a court or tribunal.

Deprivations of liberty may occur where there are restrictions placed on someone's life during their care and treatment, e.g. placing someone in hospital for physical health or psychiatric care and treatment or in a care home and their continued stay there against their will without legal authority. A deprivation of liberty can also occur when someone is living in their own home, in the community or with relatives and carers.

Article 5 protects individuals from unlawful deprivation of liberty but recognises that sometimes in the course of care, treatment and support and subject to safeguards, it is necessary to detain a person of 'unsound mind'. (For example when somebody is detained under the Mental Health Act and is required to stay in hospital.)

If the technology is preventing someone from leaving the place where they are being cared for, this is an important factor in deciding whether or not there has been a deprivation of liberty.

If it has been established or appears likely that the use of assistive technology or telecare would amount to a deprivation of liberty, then that deprivation of liberty must have a legal basis and be in accordance with a procedure prescribed by law.

The making of an advance statement by a capable adult about the care, treatment and support they would wish to receive in the event of future incapacity is recommended.

Any decision to use technology must be consistent with these provisions. In general terms, attention to the principles of the Adults with Incapacity Act will be likely to result in greater compliance with human rights principles.

## **Cheshire West**

This judgement of the Supreme Court in 2014 has wide implications for people who may lack capacity to make decisions. Briefly, it states that adults who lack capacity and are under "continuous supervision and control" and "are not free to leave" are deprived of their liberty. This will be in breach of Article 5(1) of the ECHR if done without lawful authority.

The Cheshire West decision poses challenges to the operation of incapacity law in Scotland as it currently stands. The UK Supreme Court's view on the definition of deprivation of liberty considerably broadens existing interpretations in Scotland which have been held, for the most part, by health and social services.

The ruling states that deprivation of liberty is a matter of fact and does not depend on the purpose of the intervention or the nature of the person's individual circumstances.

This is a substantial development from previous decisions of domestic courts and the European Court of Human Rights such as the HL or Bournemouth case. The implications for Scottish legislation will be the subject of debate for some considerable time yet. The Scottish Law Commission has reported on proposed legislative changes. We anticipate that the government will respond to this and consult on what they consider are necessary amendments to existing legislation.

In the meantime, services need to operate within the existing statutory framework, and be informed by the developing case law. If services are satisfied that a person who cannot consent will be deprived of

their liberty, it is necessary to consider what lawful authority justifies that detention. At the same time, unless and until Parliament or the courts determine otherwise, current legislation remains in full effect.

In short, the Commission believes that what was good practice before the Cheshire West case will in large part remain good practice now, but that the decision makes it even more necessary that there is a proper and auditable process for taking decisions on care arrangements for people who lack capacity, and that this process fully reflects the principles of the 2000 Act.

Where it is determined, in accordance with those principles, that an application for welfare guardianship should be made, it is important to identify any particular measures which may constitute or contribute to a deprivation of liberty, ensuring that the measures are necessary and justified, and seeking specific authority in the order. Such measures may include restraint or any use of physical force, preventing a person from leaving or requiring them to return to their place of residence, or intrusive surveillance, whether personal or through technology.

### **Mental Health (Care & Treatment) (Scotland) Act 2003**

This Act applies to all people who have a mental illness (including dementia), learning disability or related condition. The Act describes these conditions as a mental disorder. The Act authorises detention in hospital and can also authorise compulsory measures to ensure treatment outside hospital.

When a person with a mental disorder is being prevented from leaving hospital, then consideration must be given to whether detention under the Act is necessary. Detention affords the adult safeguards such as a right of appeal to the Mental Health Tribunal for Scotland.

It is however unlikely that the use of compulsory measures under this legislation would be appropriate to authorise the use of technology alone unless this resulted in preventing someone from leaving hospital.

Further information on the provisions under the Act can be found at [www.mwscot.org.uk](http://www.mwscot.org.uk).

### **Case examples**

Mr Brown lives alone with some support from home carers and his family. He has been diagnosed with dementia and is adamant he wants to remain in his home. He has not granted a Power of Attorney.

Recently he has been sleeping a lot during the day, is restless during the night and is noted to be more confused than usual. Home carers and family are worried that he might go out at night thinking that it is daytime. He has done this a few times previously. There are concerns the local area is not particularly safe at night time. On one occasion he brought a local man home who stole money and valuables.

It appears that Mr Brown could benefit from the use of some assistive technology.

There are various technologies that could be used to help Mr Brown stay in his own home, e.g. community alarms, notification to a call centre should he leave during the night.



Mr Brown has recently been diagnosed with dementia. This does not mean that he lacks capacity to consent but there should be careful assessment. This should involve Mr Brown, his family and carers to see if there is anything they can do to help get his sleep pattern back to normal and reduce his confusion. Assistive technology could be very helpful in this situation to allow Mr Brown to remain at home but to ensure his safety and wellbeing, for example using motion sensors, community alarm systems.

There would need to be careful explanation of any technology being introduced to see if he understood and could consent to its use. If he had capacity to consent but refused the technology then it is his right to do so. If, however, he lacked capacity and objected to its use and/or it became an infringement of his rights then consideration would need to be given to legal authorisation and in this case that would be a specific Welfare Guardianship power and this would need to be discussed with the family, his carers and the multidisciplinary team.

Mr Jones is currently in hospital, in a general hospital ward for older people, and it is thought he might have a degree of delirium. He is anxious and agitated and has walked out of the ward without staff noticing. His mobility is reduced and his balance is poor, he needs supervision with mobility. At present he is disorientated and forgets that he is in hospital.

Staff are concerned that he may leave the ward again without them noticing; it is a very busy ward and the hospital is surrounded by potential hazards, e.g. busy road, river etc.

His wife has welfare power of attorney for him.

It is often difficult in a busy general hospital ward to monitor everyone who enters and leaves the ward. The hospital does though have a duty of care towards Mr Jones to keep him safe. His current physical and mental condition is increasing the likelihood that he could come to harm by leaving him unsupervised.

Many general hospital wards now have the facility for a 'wander guard' bracelet. This is a fob that can be attached to clothing or in the form of a bracelet. It emits an alarm if the person wearing it crosses a particular boundary. This technology could be helpful in this situation. Great care would need to be taken to ensure that it was not stigmatising in any way and to establish a clear process about who responds to the alarm and to keep the alarm as discreet as possible.

If he could not consent because it was assessed he lacked capacity to do so, then staff would need to check to see if the Welfare Power of Attorney held by his wife included appropriate powers. In this case his wife is his attorney and has the relevant powers. There should be a discussion with her explaining the reasons why staff felt this was necessary and the benefit to her husband.

If there was no one with powers to consent on his behalf then there would need to be careful discussion within the team and recording in the care files as to why a decision was taken to use the technology and the benefits to Mr Jones, rather than to the staff or others.

We are sometimes asked if a Section 47 certificate of incapacity should include restraint or interventions that would constitute restraint. We do not think that the Section 47 certificate should include the use of technology as described above. The assessment and rationale for using the technology should, though, be clearly recorded in the care file and regularly reviewed.

Any hospital wards or care homes that use such technology should have a specific policy on its use for patients or residents who lack capacity to consent to its use, to ensure that patients and residents are treated with dignity and respect.

## Decision-making framework

Every situation is different but in general the principles of the Adults with Incapacity (Scotland) Act 2000 and the Mental Health (Care and Treatment) (Scotland) Act 2003 are clear on what needs to be taken into consideration when making any decision. An adult is someone who is aged sixteen years and above.

If it is identified that assistive technology is available and could be helpful, the following framework should be used:

### Capacity

Does the adult have the capacity to consent to its use?

#### If yes

- Does the adult understand and agree to its use?
- Does everyone involved understand how the technology works and how it will be reviewed?

#### If unsure

- Make sure an up to date assessment of capacity is carried out.
- Has additional support, e.g. advocacy been arranged to assist the adult in understanding the proposed action?
- Has the proposed action been discussed with the individual? Has the adult been provided with sufficient information about the proposed action; why it's helpful, what happens next?

#### If no

#### Views of others

- Is there a proxy decision maker i.e. a welfare power of attorney or welfare guardian?
- Has the proposed action been discussed with the adult and their carer?
- Has sufficient information and support been provided to the adult and their carer?
- Have the wishes of the adult and their carer been taken into consideration?

#### Benefit

- Does the proposed action take into account the adult's personal beliefs, preferences and any previously expressed wishes into consideration?
- What will the benefit be in relation to any risks? Assess the risks and benefits to the individual of the assistive technology/telecare.
- Is the proposed action the least restrictive option available given the current situation?

### **Is the proposed action legal?**

Is the assistive technology/telecare a breach or potential breach of human rights?

- In other words does it interfere with one of the rights, e.g. freedom of movement, right to family life?
- If not then apply appropriate general principles below to the decision.

### **If you feel it is a potential breach of human rights then consider**

- Is it a right that can be breached? Remember that the right not to be subjected to torture or inhumane or degrading treatment cannot be breached.

### **Is it necessary?**

Is it a proportionate response? This will depend on the individual case but some of the things to think about are:

- What would the likely consequences be of not taking or taking action?
- How likely is a perceived risk to happen and does the risk justify the proposed action?
- Does the proposed intervention represent the minimum interference necessary?
- Is it the least restrictive option? If not why not? What other actions have been considered?

### **Is it lawful?**

- Do you need legal authority, e.g. consent of an appointed welfare power of attorney or guardian? Do you need to consider an application under the Adults with Incapacity Act or the Mental Health Act? Must consider this where the adult is not agreeing or resistive to its use.

### **If a decision is taken to implement**

- Ensure all staff and relatives understand the care plan.
- Monitor implementation of care plan.
- Review care plan frequently.

### Community alarm services

Community alarm services have existed for many years and are provided by local authorities as well as other organisations or private companies. The basic community alarm comes with a pendant or watch with an emergency alarm button. The person can press the button in the event of an emergency such as a fall to summon assistance.

There are various sensors and alarms that link in wirelessly to a community alarm. These alarms are not dependent on the person pressing any buttons. If any of these sensors are activated, community alarm staff are alerted and can take appropriate action depending on the agreed protocol.

### Sensors

These sensors include smoke sensors, heat sensors (activated if excessively hot or cold), flood detectors, unlit gas detectors, carbon monoxide detectors and fall detectors (which detect if the person is lying horizontally). They can also include movement sensors which detect if a door (such as the front door) is opened, (e.g. at night time) or sensors that alert if the person has got out of bed. Alerts for carers who live in the same home also work in a similar way.

### Call systems

Similarly in care settings, call systems enable a person to summon assistance and staff to identify where the person is. Systems can also provide passive alerts, e.g. if the person gets out of bed or leaves the building. These alarms need not be audible, as noise can be distressing for some. Instead it can be a vibrating pager or visible light to alert staff. These systems can provide a record of the care given, e.g. how long it took for a call to be answered by staff. These systems could also help with identifying staffing levels to meet client needs.

### Reminders

Similar devices can provide a prompt or reminder. These can be activated by a movement sensor, e.g. when the door is opened or when the person passes a certain point or place, a message is given. They can also be activated by a timer, so that at a certain time a message is given. They are usually pre-recorded verbal prompts in a familiar voice. For example, a door sensor might be activated when the person opens the door at night and trigger a recorded message reminding the person it is not time to go out yet. Electronic devices such as tablets and smartphone can be set to provide reminders and have a calendar in them. They can be set for a prompt to be given, e.g. about an appointment. This may pop up on the screen and an alarm may sound.

### Medication

Electronic medication boxes on a timer can release medication at the appropriate time and sound an alarm. These can also be connected to a community alarm so that services or a carer are alerted if the medication is not taken.

Automatic calendar clocks which display the day and date as well as the time can be a useful visual reminder. There are also ones that automatically display whether it is morning, afternoon, evening or night to help people who may be disorientated to time of day.

## Keeping active

Technology can help people to stay in touch and reduce isolation. Simplified phones (such as ones with photos on) enable a person to get in touch with friends and relatives quickly and easily. Services such as Skype or FaceTime can also enable the person to communicate with family face-to-face via tablet or phone. In addition, technology can enable those who are caring for the person such as care workers and family members to communicate with each other more easily and effectively to help the person.

As well as promoting safety, independence and keeping in touch with friends, relatives and communities, technology can enhance quality of life by providing opportunities for meaningful activities. For example, taking or looking at photos or videos, using art apps to create art, playing games, creating or listening to music or radio or television. Touch screen technology can make this easier and more accessible for people as it does not require typing skills or learning how to use a mouse or keyboard.

In the community there is also lots of technology that can help increase independence and safety and give peace of mind or confidence. Simplified mobile phones with clear buttons (and perhaps pictures of the people to call) and an SOS button can help a person to summon assistance. There is a smartphone app which is an emergency or 'panic' button which if pressed will summon assistance automatically. There is another smartphone device which monitors movement so if the person has the phone with them and it stops moving for a period of time it may indicate if there is a problem, e.g. if the person has had a fall and is not moving.

## Tracking movement

There are various technological devices or systems which allow for a person, or the environment, to be monitored by someone else, such as a family member. These can monitor movement (you would not be able to see the person, but a graph would show which rooms and when they have been moving around in) and can be combined with alerts if appropriate if something unusual happens, e.g. if the person opens the door at night and an alert can be sent to a relative by text message. The relative or carer can check the person's movement which appears as a graph via a computer, tablet or smartphone by logging onto the system.

Some systems can monitor by sound rather than movement. Also, the person could be monitored or checked on via a camera in the person's home or room. A relative or friend or carer could view the video in real time from their computer, tablet or smartphone.

Smartphones provide other ways of checking on the person or environment, combined with sensors in the home. For example, there are apps by which the temperature of the home can be checked remotely and the temperature adjusted via the smartphone app. They can also alert if there is movement (some people may use this as an intruder alert when they are on holiday, but it can have other uses). Electric doors such as garage doors and locks can be checked and closed by an app on the smartphone combined with sensors. Lights can also be checked and turned on/off. Such systems are sometimes known as environmental control systems, home intelligence systems or home hubs.

There is also a smartphone app that enables a person who uses a mobile phone to be monitored via their mobile phone usage and which can alert a designated person if it has not been used for a certain length of time in case there is a problem.

Devices that monitor or alert can also be set to take action to modify the environment for the person's safety. For example, a heat sensor can be linked to the cooker so that when the sensor is activated (if there is excessive heat) the cooker is cut off automatically. Timer devices for electrical appliances such as irons can shut off the electricity if the item is left on beyond a certain length of time, so that if the person has forgotten to switch it off it will cut out automatically. Some appliances may have thermostats, movement sensors or timers built in for safety, e.g. if the iron has not been moved for a certain length of time it will cut out. Another example is a bed exit monitor which can be connected to a light by the bed, so that if the person gets out of bed the light automatically goes on which can reduce the risk of falls. Automatic lights which are switched on by movement are also widely available.

Many of these functions can be found in one device such as tablet systems which have prompts and reminders, monitoring systems and telephone/Skype communication systems. There are even "robot" type devices which can be controlled and moved remotely, (e.g. by a relative) around the home and the relative can speak with and see the person by means of the screen and the device.

Devices can monitor our movement, sleep, health status, number of calories used etc. There are particular devices that can monitor vital signs or alert regarding particular medical conditions or events such as seizures for a person with epilepsy or hypoglycaemia for a person with diabetes.

### **GPS tracking**

Tracking systems including smartphone apps or separate GPS or GSM devices can help a person if they become lost by giving them directions or enabling them to summon assistance or advice. They can also enable a person to be monitored by someone else and their location identified, e.g. if a person does not return home within the expected time the relative could check where they are and take appropriate action such as giving them directions or going to meet or collect them. These systems also enable a 'boundary' to be set, so for example if a person goes to their local shops without difficulty, but there were concerns or risks if they went beyond the neighbourhood area, an alert could be sent to a relative or carer if they go beyond a defined area. These devices can also be set to detect if a person gets into a vehicle, e.g. if they get on a bus because it can detect the speed at which the bus travels. GPS/GSM devices can be in mobile phones or can be a separate device, worn as a bracelet or watch or pendant. There are even shoes or shoe insoles that have GPS devices built in to them.

## References and literature review

## Appendix 2

### References

#### Legislation

Adults with Incapacity (Scotland) Act 2000

Adult Support and Protection (Scotland) Act 2007

Data Protection Act 1998

Human Rights Act 1998

Mental Health (Care & Treatment) (Scotland) Act 2003

Scotland Act 1999

#### Cases

P v Cheshire West and Chester Council and P&Q v Surrey County Council

[http://supremecourt.uk/decided-cases/docs/UKSC\\_2012\\_0068\\_Judgment.pdf](http://supremecourt.uk/decided-cases/docs/UKSC_2012_0068_Judgment.pdf)

Bournemouth case HL v UK (2005) 40 EHRR 32

#### Publications

Care About Rights, Scottish Human Rights Commission <http://www.scottishhumanrights.com/careaboutrights>

Rights, Risks and Limits to Freedom, Mental Welfare Commission 2013

[www.mwcscot.org.uk](http://www.mwcscot.org.uk)

Standards of Care for Dementia in Scotland, Scottish Government 2011

[www.gov.scot/Publications/2011/05/31085414/0](http://www.gov.scot/Publications/2011/05/31085414/0)

## Literature review

Nuffield Council on Bioethics (2009) *Dementia: ethical issues* Nuffield Council on Bioethics, London. Available at: <http://nuffieldbioethics.org/wp-content/uploads/2014/07/Dementia-report-Oct-09.pdf>

There is a list of considerations re. assistive technology on pp97 – 100

Zwijzen S A, Niemeijer A R and Hertogh C M P M (2011) *Ethics of using assistive technology in the care for community-dwelling elderly people: an overview of the literature* Ageing and Mental Health 15 (4), 419-427. They found little priority was given to discussion or description of ethics in the literature regarding assistive technology and older people living at home in the community.

Landau R and Werner S (2012) *Ethical aspects of using GPS for tracking people with dementia: recommendations for practice* International Psychogeriatrics 24 (3), 358-366 – Review of 46 articles. They felt there was a lack of ethical consensus re. use of GPS for people with dementia and took the findings from a larger research project to draw up a list of 8 recommendations for policy makers, professionals and family members/carers.

White E B and Montgomery (2014) *Electronic tracking for people with dementia: an exploratory study of ethical issues experienced by carers in making decisions about usage* Dementia 13 (2) 216-232. Interviews of 10 carers of people with dementia in a domestic setting found carers justify usage on grounds of enhanced safety and safety was given a higher priority than liberty, privacy and autonomy (although carers did feel these things were important).

Niemeijer AR, Frederiks BJM, Riphagen I I, Legemaate J, Eefsting J A and Hertogh C M P M (2010) *Ethical and practical concerns of surveillance technologies in residential care for people with dementia or intellectual disabilities: an overview of the literature* International Psychogeriatrics 22 (7), 1129-1142.

Concludes that there is no consensus re. ethics and a need for clearer policies.

Bantry White E and Montgomery P (2015) *Dementia, walking outdoors and getting lost: incidence, risk factors and consequences from dementia-related police missing-person reports* Aging & Mental Health 19 (3), 224-230 Incidence estimates of "wandering" in clinical studies vary but indicate between 10 and 35 % of people with dementia "wander". However incidence of being lost is less clear. This study found there was little research into outcomes of getting lost and factors that increase vulnerability.

Gibson G, Newton L, Pritchard G, Finch T, Brittain K and Robinson L (2014) *The provision of assistive technology products and services for people with dementia in the UK* Dementia 0 (0) 1-21.

This scoping review about provision of devices found 171 products and 331 services. The range of products was divided into 3 areas: assistive technology used 'by', 'with' and 'on' people with dementia. Most products were telecare provided by local authorities.

Robinson L, Brittain K, Lindsay S, Jackson D and Olivier P (2009) *Keeping In Touch Everyday (KITE) project: developing assistive technologies with people with dementia and their carers to promote independence* International Psychogeriatrics 21 (3) 494-502.



This small scale study (about 20 people) involved developing prototypes for devices to help independent living. These were developed with people with dementia and the study concluded that involving people with dementia in the design process was feasible and potentially made them more acceptable and relevant.

Orpwood R, Sixsmith A, Torrington J, Chadd J, Gibson G and Chalfont G (2007) *Designing technology to support quality of life of people with dementia* Technology and Disability 19 103-112.

This study came about because it was felt that the focus re technology tends to be in helping carers rather than the person with dementia and that focus tends to be on safety rather than wellbeing. Design work at the Bath Institute of Medial Engineering was carried out and the focus was on the developing technology to address the issues that people with dementia identified as important to their wellbeing.

Further information about what is available:

AT Dementia [www.atdementia.org.uk](http://www.atdementia.org.uk)

Disabled Living Foundation [www.dlf.org.uk](http://www.dlf.org.uk) (DLF also have an online service called AskSara in which participants answer a number of questions and then it gives some suggestions for technology that might be suitable for consideration.

(Both of the above two websites have information about ethical considerations in selecting technology.)

The Scottish Centre for Telehealth and Telecare [www.sctt.scot.nhs.uk](http://www.sctt.scot.nhs.uk) has a database of telecare and telehealth projects that are going on throughout Scotland

DALLAS <https://connect.innovateuk.org/web/dallas>

Alzheimer's Society (2014) *Dementia-friendly Technology: A charter that helps every person with dementia benefit from technology that meets their needs* Alzheimer's Society, London (This also has some examples of different pieces of technology can help individuals in case studies) Available from: [http://www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=2699](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=2699)

Social Care Institute for Excellence (2012) *Using ICT in activities for people with dementia: a short guide for social care providers* Social Care Institute for Excellence, London. Available from: <http://www.scie.org.uk/publications/ictfordementia/>

University of Stirling, Dementia Services Development Centre and the Joint Improvement team "Telecare and Dementia" [www.dementiashop.co.uk/node/287](http://www.dementiashop.co.uk/node/287)







Thistle House  
91 Haymarket Terrace  
Edinburgh  
EH12 5HE  
Tel: 0131 313 8777  
Fax: 0131 313 8778  
Service user and family/carer  
freephone:  
0800 389 6809  
[enquiries@mwscot.org.uk](mailto:enquiries@mwscot.org.uk)  
[www.mwscot.org.uk](http://www.mwscot.org.uk)