

SAFER WALKING

TECHNOLOGY ENABLED CARE
AS PART OF DEMENTIA CARE

A Practice Support Note



Scottish Centre for
Telehealth & Telecare



Scottish Government
Riaghaltas na h-Alba
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Foreword

Enjoying ordinary everyday life, getting out and about, feeling independent and safe and secure is important to every citizen.

Living with dementia can bring its own challenges. For example it is estimated that 40% of people with dementia will experience feeling lost or getting lost. 5% of people with dementia repeatedly feel lost or get lost. However, many of these challenges can be met by using some of the Technology Enabled Care (TEC) products that are available today.

The purpose of TEC is to make use of a wide range of technology to enhance health, wellbeing and care so that people feel safe and confident at home and in their community. A package of technology can be tailored to meet individual requirements and can let carers and families know how a person is doing - or if they need help.

Whilst the focus of this Note is on how Safer Walking TEC can support people living with dementia to lead as full a life as possible, it is recognised that the information in this document could have an application across other care groups who may also benefit from Safer Walking TEC – such as people with cognitive impairment, learning difficulties and some long-term conditions.



Walking is good for you

Walking, even for short distances, helps to alleviate mild depression and delivers many physical and psychological health benefits.

However, for someone with dementia the main hurdle to continuing to enjoy the health benefits of walking may be the concern that they will become lost or disorientated and may not be able to find their way home. This may also be a major concern for carers, relatives and loved ones.

Continuing to get out and about in the community, staying physically active, maintaining social contacts and routines and regaining independence beyond the home can be supported by products that use Global Navigation Satellite Systems (GNSS) such as Global Position System (GPS) – (see more about the technical aspects of this in the Appendices). For simplicity, we have referred to these products as ‘Safer Walking TEC’ in this Practice Support Note.

Safer Walking TEC products offer confidence and reassurance to people with dementia, their carers and families. They can also support people living with dementia to stay in touch with friends and relatives. Staying connected is very important to people living with dementia as a loss of socialisation can be debilitating – both physically and mentally.

Safer Walking TEC can support a person to have the confidence to get out and about with more safety, to regain or retain independence, to keep fit and healthy, to encourage socialisation, to reduce isolation and to support and reassure those who care for them.

The ability to find someone if they are lost or feeling lost, or a person with dementia being able to inform someone that they need help, means that people with dementia do not need to feel alone when it matters most.



Who is this Practice Support Note for?

This Note has been written to support everyone who cares for someone with dementia. The care team around the person with dementia may include health and social care practitioners and carers and families – all as equal partners in care.

What is the purpose of this Practice Support Note?

This Note has been written to support conversations, assessment, decision making and care planning for the care team and the person with dementia when considering the use of Safer Walking TEC.

It is designed to raise awareness of the range of products available so that everyone can begin to have confident and informed conversations about the benefits of Safer Walking TEC - whether it is used as a stand-alone intervention or a part of a wider range of support measures.

The aim is that the potential benefits of Safer Walking TEC can be confidently explored and realised as a therapeutic intervention set within a rights-based, person centred, outcomes focussed care plan.

What is in this Note?

This Note describes the benefits of using Safer Walking TEC and outlines some practical considerations around the features and use of these devices.

Importantly the Note explores the issues of capacity and consent when considering the use of Safer Walking TEC and describes some basic principles that should underpin practice.

This Note has been written in partnership with representatives from TEC Scotland, Scottish Centre for Telehealth and Telecare (SCTT), Alzheimer Scotland, Police Scotland, University of Stirling and representatives from Scotland's health and social care partnerships.



SECTION 1

THINKING ABOUT USING SAFER WALKING TEC?

The benefits of technology enabled care (TEC) for people living with dementia are already well recognised through the provision of telecare products and systems.

Technology in the broadest sense (products, systems and processes) can support people with dementia to live richer and more independent lives. However, the full range of technologies available to citizens in everyday life, including Safer Walking devices, are currently underutilised in support of people living with dementia.

The use of Global Navigation Satellite Systems (GNSS) technology which includes GPS (Global Position System - see technical footnote in Appendices) is now commonplace as part of location, tracking and wayfinding products and systems. These can provide people, organisations and businesses with reassurance, confidence and a sense of safety.

GNSS and GPS technology have become a normal part of everyday life for many people; from using satellite navigation systems (Sat Nav) in cars, parents knowing where their children are by using a Smart Phone app, to health and fitness apps which gather information on how many steps we have taken and how far we have travelled over a period of time - even showing our exact routes and progress.

We recognise the potential of this everyday technology and how it can be used for the benefit of people living with dementia to support community living and individual wellbeing as part of Safer Walking TEC.

Safer Walking TEC can enable the individual to walk and travel with increased safety and independence. It can also reduce stress and distress for family and friends who care for a person with dementia by offering a greater degree of reassurance, whenever the person they care for is out and about.



THINKING THROUGH USING SAFER WALKING TEC

First of All - Know the person

It is important to know what matters to the person with dementia; their hopes and wishes, skills, strengths and abilities and understand how their dementia impacts on their physical and psychological function. Thought should also be given to the impact of other health conditions and sensory impairments such as sight loss that may also be present.

How much does getting out and about contribute to a person's quality of life? What would the impact be on that person if that activity was taken away? What are the risks of not facilitating Safer Walking?

The choice of Safer Walking device(s) should match the person's skills, functional ability and needs and support them, through positive risk taking, to achieve their desired outcomes and maintain or enhance, their quality of life. This Note provides further guidance to support consideration of these elements.

Why are you thinking about Safer Walking TEC?

It is important to clarify and describe the problem so that the best Safer Walking TEC solution can be designed.

Is the device to be used to only support safer walking or does it need to be able to alert someone if the person has had a fall or travelled outwith a geographical area that has been put in place?

Is the person already using a Smart Phone? Is the device to be used as a two-way communication device or simply as an alert? Does the person have to be able to operate the device or does it only need to let someone know the location of the device?

Is the person with dementia able to consent to using Safer Walking TEC? Have a look at Section 3.

A helpful question to think about is "would a Safer Walking TEC device truly meet the expectations, needs and outcomes" of the person with dementia and look for the simplest solution.

How will the Safer Walking TEC be used?

Is the device to be used as a stand-alone intervention or is it a part of a wider range of measures? If the device is to be used as a part of a wider package of TEC products, it is important to think about the interface with other pieces of equipment that are already in place or being planned.

What about the response?

Who will be able to see the information from the device? Who will respond to the information? Who will ensure the device remains charged? Who will respond to an alert?

HOW TO CHOOSE A SAFER WALKING TEC DEVICE

When choosing a Safer Walking TEC device, it is useful to have a list of the features, characteristics, qualities and attributes you want the device to have. This list should be compiled from what you know about the person with dementia, what you want the device to be able to do, how it will operate and who will support the use of the device and support the person.

The information below will help you check out your thinking:

Formats and features to think about when choosing a Safer Walking TEC device

Safer Walking TEC, as with all technology, is always subject new development. Safer Walking TEC devices that support dementia care need to be as user friendly as possible to ensure ease of use and discretion.

However, product choice is vast - with varying suppliers, costs, functionality and device capabilities. Before reaching a decision about specific device solutions, it may be helpful to consider the following;

Common Formats of Safe Walking TEC Devices

- 1 Devices that look and feel like a mobile phone handset; these often have limited numbers of buttons for ease of use.
- 2 Devices which can be worn on the wrist, function as a watch and offer other features such as a pedometer.
- 3 Smaller devices which can be attached to a key-ring or carried in a bag or pocket. These could also be worn as a pendant around the neck or around the wrist like a watch.
- 4 Numerous Smart Phone apps which are available and can be downloaded direct to your Smart Phone. A lot of these apps are free of charge and have become increasingly popular in recent years.

Practical Product Features

A number of product features are listed below; however, each product should be reviewed carefully to ensure that it meets the individual's specific needs, preferences, level of function and skills. Importantly, regard must be given to the wishes and choices of the person and their family. When choosing a device look at:



DESIGN

Dimensions and size of the device

Lightweight and discreet

Water and dust resistant

Journey mapping function

A geo-fenced area can be enabled which provides an alert if the device leaves a predefined area

Simplicity of operation

Ability to disable or switch-on key functions of the device

How the device is worn

Battery life - how quickly can it be charged and who will undertake this



ACCESSIBILITY

Easily available and downloadable to a Smart Phone as an app

Can be accessed via numerous devices - computer, Smart Phone, tablet, Smart TV or games console - that have internet connectivity

Roaming SIM that doesn't restrict to one network provider

Can be used outwith the UK



NOTIFICATION AND RESPONSE

Can call multiple responders at the same time with one press of the button

Some devices can activate a two-way, clear and auditable conversation with the responder

Direct dial to a response centre, alarm receiving centre (ARC) or a person - or people
Notification and response

Email sent when battery is low



COST

The cost of purchasing products and any on-going running costs will differ across devices. The person's financial circumstances should therefore be considered.

Services may be provided by local authorities or health and social care partnerships (HSCPs), however they may also have costs associated with responder services.



Where you can find out more about Safer Walking devices

Health and Social Care Partnership (HSCP) representatives involved in the assessment and delivery of technology enabled care can provide information and advice regarding Safer Walking TEC and give details about the products and services that are available locally.

The Telecare Self-Check Online Tool is an easy to use online tool that allows you to find helpful information on telecare services in your area that could help you live independently at home for longer. The tool asks 6 – 12 questions and will take about 5 minutes to complete. Once you have completed the tool you will be given useful information relating to your answers. **Visit:**

www.telecareselfcheck.scot

Your local **Alzheimer Scotland Resource Centre** may have some “products on display” (PODs) that people can look at.

Dementia Circle has information about products, including Safer Walking TEC devices, that may have been tried and tested by people living with dementia and describes their experience of using technology.

<http://dementiacircle.org/>



SECTION 2

PUTTING SAFER WALKING TEC INTO PRACTICE

Some key principles to underpin your practice

Safer Walking TEC has the potential to support people with dementia to maintain their independence, enhance their freedom and reduce the risk of harm.

Many people will view Safer Walking TEC as a positive way to help them continue to be safely engaged within their local community and do the things they would normally do. For others it may be an unwelcome intrusion in their private lives.

For these reasons, it is crucial that organisational and practice policy, process and procedure reflect rights-based approaches, positive use of legislation and encourage early discussion and supported decision-making to ensure the positive and empowering use of technology.

As with the application of all technologies, ethical issues including the benefit to the person with dementia are paramount.

Critically, Safer Walking TEC should not be imposed upon people or replace social support but be a means of augmenting the human contacts that are crucial to good dementia care and practice.

Key Principles

- Technology should enhance, and not be used as an alternative to, high quality care and support of people with dementia and those who care for them.
- The health and wellbeing of carers and families must also be thoroughly considered.
- Safer Walking TEC can reduce stress and distress for people living with dementia and support safer walking and positive risk-taking approaches.
- Safer Walking TEC can also provide positive benefits to family members and carers of people with dementia by providing them with reassurance and a greater degree of confidence.
- The use of Safer Walking TEC should enhance the quality of life of people living with dementia and help them live as full a life as possible without putting them - or others - at risk.
- Practitioners should be prepared, knowledgeable and be able to show and explain the potential of a range of products (devices, apps and systems).
- Practitioners should be conversant with the benefits, limitations and alternatives to Safer Walking TEC for the person, carers, families and service providers.
- Conversations about the use of Safer Walking TEC must be appropriate to people with dementia to support them to make informed decisions. We know that good communication skills are at the heart of achieving the informed decision-making and consent of people with dementia.
- People should have time to understand the possibilities of Safer Walking TEC and be given time to try out products.



SECTION 3

THINKING THROUGH CAPACITY AND CONSENT

Ethical issues, including the topic of capacity and consent, may in practice become central to the provision of technology enabled care such as Safer Walking TEC. This section of the Practice Support Note is designed to help you think this through.

Let's think about decision making capacity and legal capacity

Firstly, it is important to note that there is an important distinction between decision-making capacity and legal capacity.

A person's **decision-making capacity** relates to their ability to make decisions about the things that affect their day-to-day life. Having decision-making capacity includes being able to understand a decision, the choices available, the consequences of making a decision, and the ability to act on and communicate a decision.

Legal capacity is the ability to hold rights and make decisions which may be enforceable by law. This could include making decisions about medical treatment or entering into a contract such as a tenancy agreement.

This distinction is important because the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) states that every person with a disability has "legal capacity on an equal basis with others in all aspects of life". However, a person with dementia may need support to make decisions in order to exercise their legal capacity.

Many people with dementia will be able to decide for themselves whether Safer Walking TEC will be of benefit to them. Where people with dementia have an impaired decision-making capacity, they should have access to whatever support they need to help them make decisions for themselves or, where this is not possible, to ensure that decisions made on their behalf, by an attorney or guardian, fully respects their rights, will and individual preferences.

The use of Safer Walking TEC can raise emotive and contentious issues for practice including managing potentially competing rights.

For example, the use of Safer Walking TEC may potentially be seen as an invasion of privacy but equally may enhance a person's freedom to more safely enjoy their normal activities in their community.

As in all good practice, a balance must be struck between the benefits to the person with dementia, the benefits to the health and wellbeing of carers and families and potentially competing rights. It has been suggested that different considerations should apply when looking at technology as part of care planning, but this is no different to any other area of practice consideration and the same principles should apply.



Informed decision-making

Many people with dementia will be able to make informed decisions about their own lives, particularly if they have an early diagnosis and are supported to plan ahead. With appropriate information about the technology options open to them, many will be able to decide for themselves how they wish to use Safer Walking TEC now and also ensure that their wishes and preferences about how it can help them as the illness progresses are documented in personal plans.

Supported decision making

Supported decision-making is a human rights-based approach which can ensure that the person's ability to participate in decisions which affect them is enhanced, and that the outcomes that are important to them can be achieved.

Supporting informed decision making and consent

Many people with dementia may not be able to fully understand the various options or implications to be able to make a decision about using Safer Walking TEC and will need support to do so.

Supporting informed decision-making from people with dementia requires appropriate communication to help people to express what is important to them.

Equally important is the appropriate presentation of information particularly around the potential benefits of a Safer Walking TEC intervention that can maintain or improve quality of life, independence and safety and with the potential to reduce risk.

Practitioners involved in discussion, assessment or provision of Safer Walking TEC should use positive language and terminology, and be able to exercise their judgment when considering the person's mental capacity.

It is good practice to document that verbal consent has been asked for and received.



If consent is withheld

Some people will decide that they do not want to use Safer Walking TEC. If the practitioner is quite clear that the person with dementia understands the possibilities and limitations of using Safer Walking TEC and they refuse to consent to its use, the practitioner should record the person's decision and reasons not to use Safer Walking TEC.

It should be emphasised at this time that the person can change their mind or they can reconsider the use of Safer Walking TEC if their circumstances, or views, change.

When the person is unable to provide informed consent

Some people with dementia may not have capacity, even with support, to make a decision about Safer Walking TEC.

In such circumstances those with appropriate authority such a welfare attorney or guardian may consider whether Safer Walking TEC will be of benefit to the person with dementia.

In these circumstances, the principles of the Adults with Incapacity (Scotland) Act 2000 must always be considered to ensure that the decision to use - or not use - Safer Walking TEC is appropriate.



Important questions for you to consider in such situations are...

- When does Safer Walking TEC stop being an aid to independence and become a restriction on autonomy or independence?
- Would confidentiality and the privacy of the person be compromised? Who would have access to information about the person and their movements or location? How would that information be used? Could a person with dementia be followed?
- Does the legitimate need to use Safer Walking TEC outweigh the level of risk of not using Safer Walking TEC?
- On balance, do the benefits to the person outweigh the risks of not using Safer Walking TEC?

Putting the Principles of the Adults with Incapacity (Scotland) Act 2000 into action

Those considering the use of Safer Walking TEC must think about and take into account:

- The **benefit** of Safer Walking TEC to the person (safer walking or travel, greater freedom of movement and independence)
- The **least restrictive option**, or minimum intervention, needed to achieve the intended benefits
- The **past and present wishes of the person** with dementia if these are known or can be ascertained
- While Safer Walking TEC should not be used solely for the benefit of others, it may be the expressed wishes of the person with dementia that their family or friends are reassured where possible
- The views and wishes of **relevant others** who might have an interest in the person's welfare such as relatives and welfare attorneys as far as is reasonable and practicable to do so
- How the technology can **encourage the person** to use existing skills or develop new skills



WHAT WOULD BE GOOD PRACTICE?

Good practice is open discussion with the person with dementia, families, carers and professionals to reach a consensus based on their collective knowledge of the person and the person's wishes in the broader sense of their quality of life, outcomes, independence and safety.

If there is a conflict of interest, advocacy services should be considered to ensure that the wishes and preferences of the person with dementia are fully considered.

If the decision is to proceed to use Safer Walking TEC, the decision should be recorded along with the reasoning behind the decision and who was involved in reaching that decision.

Reviewing decisions made on behalf of the person with dementia

A person with dementia's decision-making capacity can change. The process of consent or making decisions on behalf of the person with dementia should be formally reviewed at least annually.

Timetabling of reviews should be dependent on the individual needs of the person using the Safer Walking TEC and their individual circumstances.

Local policy on the use of Safer Walking TEC

There should be clear local policy which takes these principles and good practice guidance into account.

The background of the entire page is a stylized teal map of a city, showing streets, parks, and landmarks in various shades of green and blue.

What legislation, strategy and policy should underpin my practice and care planning when thinking about Safer Walking TEC?

The key principles and values underpinning this support to practice note are founded in

Human Rights Act (1998)

Adults with Incapacity (Scotland) Act (2000)

United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)

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

Charter of Rights for People with Dementia and their Carers in Scotland (2009) – Cross-Party Group on Alzheimers

Standards of Care for Dementia in Scotland (2011) – Scottish Government

Promoting Excellence Framework (2011) – Scottish Government

Talking Points – Personal Outcomes Approach (2012) - Joint Improvement Team

Right Risks and Limits to Freedom – Good Practice Guidance (2013) – Mental Welfare Commission for Scotland

Equal Partners in Care (2013) - Scottish Social Services Council

Decisions about Technology (2015) - Mental Welfare Commission for Scotland

Technology Charter for People Living with Dementia in Scotland (2015) – Scottish Government

Supported Decision Making (2016) Mental Welfare Commission for Scotland

Scotland's National Dementia Strategies (2010 -13) (2013-16) (2017-20) - Scottish Government



APPENDICES

BACKGROUND to this PRACTICE SUPPORT NOTE

The TEC Programme in Scotland has its focus on person-centred- and community delivered- care that is underpinned by increased adoption of modern technologies.

Central to a focus on care supported by technology is recognising the importance of a shift to greater self-management and independence.

“Supporting & Empowering Scotland’s Citizens - National Action Plan for Technology Enabled Care” (Scottish Government - August 2016) states that, as one of the cross cutting enablers of the plan, “the benefits of using technology must be clear to users/ carers and clinicians/staff and result in more efficient and more effective care”.

The Technology Charter for People Living with Dementia in Scotland (Scottish Government 2015) outlined a vision whereby people living with dementia in Scotland will benefit from technology to help them live a healthy life - safely, securely and confidently as full citizens in society. This is a fundamental right, and work is on-going with the Focus on Dementia Programme and Alzheimer Scotland to embed technology-based solutions in every post-diagnostic conversation taking place across Scotland.

Commitment 11 of Scotland’s third National Dementia Strategy (2017 – 2020) states “We will implement the Technology Charter for People in Scotland with Dementia, ensuring that everyone with a diagnosis of dementia and those who care for them are aware of, and have access to, a range of proven technologies to enable people living with dementia to live safely and independently. We will continue to explore innovative ways in which technology can be used and adapted for people living with dementia”.

www.gov.scot/Resource/0052/00521773.pdf

Within the Health and Social Care Standards (2017) it states 1.22 “I can be independent and have more control of my own health and wellbeing by using technology and other specialist equipment” which includes the use of mobile phones and apps and 3.23 “If I go missing, people take urgent action, including looking for me and liaising with the police, other agencies and people who are important to me.”

<http://www.newcarestandards.scot/>

This note is designed to support national strategy and initiatives by raising awareness of Safer Walking TEC products and aims to support health and social care practitioners and other members of the care team when they are considering the use of Safer Walking TEC.

TECHNICAL FOOTNOTE

Whilst GPS (Global Position System) is the commonly used term to describe location, wayfinding and tracking systems and is now part of everyday language, it is important to note that GPS is part of an overall legal classification of systems known as Global Navigation Satellite Systems (GNSS).

GPS is an American system. However, most SmartPhones today will use both GPS and GLONASS which is a Russian system with global coverage with Galileo (which is a European system with global coverage) increasingly being used. There are other systems such as QZSS for Japan and surrounding area and BeiDou/COMPASS which is a Chinese system with global coverage.

According to a recent European GNSS study nearly 60% of receivers, chipsets and modules today already support at least two GNSS constellations.

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North Ayrshire Health and Social Care Partnership

Police Scotland
Renfrewshire Health and Social Care Partnership

South Ayrshire Health and Social Care Partnership

TEC Scotland

University of Stirling

Scottish Centre for
Telehealth & Telecare

KEY CONSIDERATIONS WHEN CHOOSING A SAFER WALKING TEC DEVICE

STEP 1: KNOW THE PERSON

What matters to the person? What are their hopes and wishes? Why is getting out and about important to the person?

What strengths, skills and abilities do they have?

What challenges do they face in getting out and about?

How would getting out and about with more safety benefit the health and wellbeing of the person, their carers and families?

What are the potential risks? What is the likelihood of harm?

What are the risks of not supporting the person to get out and about?

Balance out the risks, the benefits of getting out and about and what can be done to minimise any risk

Reach an agreement between the person and those who care for them

Risks can change over time so schedule in a review

STEP 2: THINK THROUGH RIGHTS, CAPACITY AND CONSENT

Many people with dementia will be able to decide for themselves whether Safer Walking TEC will be of benefit to them

What are the benefits of Safer Walking TEC to the person?

Would the technology encourage the person to use existing skills or develop new skills?

What is the least restrictive option, or minimum intervention, needed to achieve the intended benefits?

Take into account the past and present wishes of the person with dementia. Is it the expressed wishes of the person with dementia that their family or friends are reassured where possible?

If the person has an impaired decision-making capacity, ensure access to whatever support they need to help them make decisions for themselves

Strike a balance between benefits to the person with dementia, benefits to the health and wellbeing of carers and families and any potentially competing rights

STEP 3: BUILD A PROFILE OF THE DEVICE

Understand the impact of the person's dementia on their physical and psychological function

Take into account what you know about the person, their skills and abilities

Are there impacts from any other health conditions or sensory impairments that also need to be considered?

What does the Safer Walking TEC device need to be able to do?

What features and qualities must it have?

What about initial cost, ongoing costs? Who is going to buy or provide the device?

Is it standalone or part of a wider range of support measures?

Who will charge the device?

Who will respond to alerts?

STEP 4

Bring together the information and your thinking from Steps 1,2 and 3 and create a profile or description of the Safer Walking TEC device you require. Look for the simplest solution



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