Dementia-friendly technology

A charter that helps every person with dementia benefit from technology that meets their needs

Acknowledgements

We are very grateful to colleagues from the following organisations who have voluntarily helped create this charter:

ADASS West Midlands Telehealthcare Network including Dudley, Staffordshire and Sandwell Councils

Advanced Digital Institute

Alzheimer's Society

Association of Directors of Adult Social Services

Bournemouth University, Dementia Studies Unit

British Assistive Technology Association

BT

Bury Council

Children's Charities' Coalition

City University London – especially the design students (tireless work on section 3)

Design Council

Doncaster Dementia Strategic Partnership

Halton Borough Council (work across whole charter) particularly Richard Harding

Hertfordshire County Council

Just Checking

Local Government Association

London Borough of Croydon, AZTEC Centre

London Fire Brigade

Mid Cheshire Hospitals NHS Foundation Trust

National Museums Liverpool

NHS England

NIHR Dementia and Neurodegenerative Diseases Research Network (DeNDRoN)

One Voice for Accessible ICT Coalition

Public Health England

Registered Nursing Home Association

Sanctuary Supported Living

South London and the Maudsley NHS Foundation Trust (especially section 2)

Stockport Council (especially section 3)

Telecare Services Association (especially tireless work on section 4)

trueCall Nuisance phone call blocking

Tunstall Healthcare (Chair of the working group)

University Hospitals Birmingham NHS Foundation Trust

Westminster Rehabilitation Services - Central London Community Healthcare NHS Trust

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Rose's story

Supporting independence through dementia-friendly technology

Rose has dementia and at times her recall is very poor. She recently moved into a new flat in an extra care building in Hull, which she loves.

During the day staff are around to support Rose in her new surroundings. But during the night the building is not staffed, which has led to a few issues. Rose has woken up during the night and become disorientated. This has led to her to walking down corridors, sometimes knocking on the doors of neighbours, and one time she left the building.

Rose agrees to have a bed sensor and door sensor fitted in her flat. Because she doesn't have any close family members, an arrangement is set up with Hull City Council that its out-of-hours care team will respond to any alerts triggered by the sensors.

The sensor on the door sends an alert to the out-of-hours team if Rose leaves her flat between 10pm and 7am and doesn't return within five minutes. In addition, within the same hours, if Rose leaves her bed and doesn't return within 15 minutes, an alert is also sent, which may indicate a fall.

So far, the out-of-hours team has been called out seven times in four months. This has provided reassurance to Rose and prevented her from disturbing other residents or leaving her building at unsocial hours. If this solution had not been implemented, there was a real possibility that Rose would have been placed in 24-hour care.

Introduction to the dementia-friendly technology charter

Jeremy Hughes, Chief Executive, Alzheimer's Society

Technology offers huge potential benefits for people with dementia, whether it's a familiar gadget such as a mobile phone and TV or a specific piece of technology to remind someone to take medication. It can enable people to live independently for longer, reducing stress on people affected by dementia. It can also potentially enhance the quality of life for both people with dementia and carers, and give them greater choices about their care.

This charter offers an antidote to a common problem: the lack of public awareness relating to technology that can support people to live well. People with dementia and carers do not know what to ask for or what is available to them, especially if they are the ones paying for the technology themselves. The charter will also assist professionals working in dementia, allowing them to better inform people with dementia and their carers of products that may assist their care or enhance their lives. It will also show them how they can set up assessments to help identify the assistive technology that would benefit a person affected by dementia.

We know from people with dementia and carers that it is very important to personalise technology for each individual and not present it as part of a 'set menu' or 'dementia package'. Assuming that every individual with dementia requires, or will benefit from, the same piece of assistive technology is unhelpful. People with dementia experience very different symptoms that require different responses.

Technology should not be seen as a 'quick fix' for people with dementia, or used as a replacement for human interaction and care for people with dementia. Technology should be seen in the context of complementing the care and support provided to an individual to enhance their quality of life. We also strongly believe that the development of technology should include people with dementia in the design process. With these principles championed by this charter, we hope to see a significant improvement in professionals raising awareness of technologies that improve quality of life and many more people affected by dementia accessing and benefiting from them.

> "We know from people with dementia and carers that it is very important to personalise technology for each individual."

Alistair Burns, National Clinical Director for Dementia, NHS England

Dementia is the illness most feared by people in England over the age of 55, yet in the past it has not received the attention it needs.

People with dementia and their carers want, and deserve, treatment and care which fits their lifestyles and allows them to access services when it suits them. Assistive technologies can play a key role in empowering patients to live more independently and enable care closer to home.

Our ambition is to create an environment that supports and encourages the use of technology enabled care services to deliver person-centred, convenient and efficient care. This charter will raise awareness among the public and health professionals of how technology enabled care services can support the provision of the best care for people with dementia and their carers.

David Pearson, President of The Association of Directors of Adult Social Services

Two-thirds of people with dementia live in their own homes, and there are over half a million family members and friends who care for them. Technology cannot replace the personal care that a carer provides, but it can go some way to helping people with dementia feel safer and carers manage, and reduce worry. It should also complement the provision of home care and other services.

There are a whole range of technologies that can help, from alarms, to a variety of sensors, to reminders and apps. Technology can be used to help people with dementia keep in touch with their families through prompts, and record information to help those who provide care and support understand more about the person they're helping.

We need to introduce the idea of assistive technology early in someone's dementia journey, perhaps making it available at the point of diagnosis. And we need to be better at explaining to people how using technology can help and support them in their lives.

Councillor Gillian Ford, London Borough of Havering, Deputy Chair of the Local Government Association's (LGA) Community Wellbeing Board and represents the LGA on Integrated Care and Dementia

We all know about the benefits of technology and how it is helpful for people to be aware of all the options available to them to improve their control over everyday tasks.

This charter is about ensuring professionals who aim to meet the needs of people with dementia are up to date with new developments, enhancing these people's options on how best to manage their health, safety and other needs. The charter and its principles will ensure people are able to explore the limits of what's available and to find the right tools to stay in control of their lives.

Ron Dobson, Commissioner, London Fire Brigade

We all need to take fire safety seriously, but fire can pose a much greater risk for people living with dementia. This charter is a key document which aims to raise awareness of the importance of identifying and eliminating fire safety risks in the homes of people living with dementia. In particular, it points to technology enabled services, such as monitored smoke detectors, as potentially life-saving solutions for people living with dementia.

We encourage all local fire and rescue services to work innovatively and in partnership with other agencies to help people stay safe, well and independent at home. We are also proud to have played a part in the development of this charter.

Aims and objectives of the dementia-friendly technology charter

As a result of the Prime Minister's Dementia Challenge and Dementia Friendly Communities campaign, Alzheimer's Society set up a task and finish group on dementia-friendly technology in October 2013.

There was overwhelming consensus that the main task of this group should be the production of a dementia-friendly technology charter within six months, covering assistive technology and consumer electronics.

The overall aims of the charter are:
- To help every person with dementia have the opportunity to benefit from technology appropriate to their needs.

- To outline and encourage the implementation of high-level principles and best practice for organisations that provide services to people with dementia.

Who is the charter for?
- Commissioners of services for people with dementia.

- People living with dementia and their family and friends.

- Providers of technology and services.

- Health, housing and social care professionals.

What do we want to achieve in the first year following the launch of the charter?
- The charter to be published and communicated across all relevant channels.

- Work towards having all clinical commissioning groups, local authority and housing commissioners, including the **integration pioneers,*** to sign up to the charter.

- All service and technology providers to sign up to the charter.

Hyperlinks* – throughout this document there are a number of hyperlinks to redirect you to further information. If you cannot access this information by clicking on a hyperlink, please see page 30 for a full list of web addresses that hyperlinks refer to.

What does signing up to the charter mean for my organisation? Recommendations for commissioners, providers* and suppliers.

- The statutory right to a social care assessment should always include a consideration for dementia-friendly technology.

- A single, simple to use and regularly updated online resource detailing dementia-friendly technology should be developed.

- All commissioners and providers should develop accessible and easy to find information that lists where dementia-friendly technology is available in their local area. This information should also reference and include a link to this charter.

- Technology providers should take into account the specific needs of people with dementia when developing care services that use technology.

*This includes providers of health, care, housing and support services, as well as technology service providers.

The charter draws on findings from a joint report with Alzheimer's Society and Tunstall – **Dementia-friendly technology: Delivering the National Dementia Challenge**. Given the wealth of technological solutions available to care for people affected by dementia at the moment, the group broke these thematically down across three domains aimed at supporting, managing and improving people's lives.

a. Safety — technology aimed at keeping people with dementia safe and providing carers with support.	**b. Health** — technology aimed at supporting people with dementia to manage, assess and treat co-morbidities and improve health outcomes.	**c. Enhancing** — technology aimed at improving the quality of life for people with dementia.

Technology can be invaluable in helping people with dementia remain self-sufficient and carry on living their lives as independently as possible.

Whilst not a solution for everyone, technology enabled solutions can manage risks in a cost-effective manner. More importantly, they can also improve the quality of life for people with dementia and their loved ones.

**Ali Rogan,
Chair of DFT task and finish group
@AliRogan**

Living with dementia

Many technologies have been developed to improve the quality of life for people with dementia. These help a person remain independent, control their environment, aid communication, keep them safe or support the people caring for them.

Dementia is an umbrella term used to describe various disorders of the brain. These disorders all involve a progressive loss of memory and the ability to carry out everyday tasks, with an increasing impact on daily life. Although dementias tend to follow a broadly similar pattern of progressive mental decline, the impact is different for every individual. It can depend greatly on what a person was like to start with and the particular areas of their brain that are affected.

As a result, a particularly individualised approach is needed when choosing technology. Not only is everyone who has dementia unique, with his or her own individual life history, but as the disease progresses the needs and abilities of each individual will change. Any technological solution needs to be the right solution for an individual at a particular time in their dementia journey.

How does dementia affect you?

The feedback below is from members of Alzheimer's Society Service User Review Panels, ensuring that this charter reflects the views and experiences of people with dementia.

Okay when indoors. Problem when out and about.

Using the right words.

Difficulties taking in information.

Feelings of panic when there are too many people

Dislike of myself – it hurts.

Going into a strange world – another planet, no choice.

Reduced level of ability – handwriting, spelling, driving memory.

Family just accept it – particularly grandchildren.

Other people treat you differently.

Things to consider

The type of technology a person with dementia may benefit from will depend on the degree of memory loss they have and their confidence, ability and interest in using technology. Also, the level of support that carers or professionals can provide should usually be considered too.

Normal routine

- It is usually best to find solutions that can be integrated into a person's normal routine. This will help to cause minimal disruption and encourage people with dementia to see the technology as something that's harmless and doesn't restrict them in any way.

Safety

- If safety is potentially an issue, it is important to ensure that appropriate expertise is sought to identify and evaluate safety risks.

Communication and understanding

- Proposed technological solutions need to be explained in a form that is understandable to a person with dementia and their family. All formal and informal carers should be present during this discussion.
- A written explanation of how the technology service works should be provided as well.
- A professional who performs an assessment of a person's technological needs must be aware of the issues they may have with retaining information and using the equipment or service.

Ethics and capacity

- It is important to have clear ethical guidelines. These should cover fair access to technological solutions, avoiding unintentional harm, respecting privacy and confidentiality, and ensuring data security.
- It should always be about keeping the person with dementia at the centre of decisions. Their views and consent should always be sought. If they can't offer these, a best assessment of their views must be made.
- The Mental Capacity Act (2005) provides a legal framework to support decision making.
- Following an assessment, if a person with dementia lacks the capacity to consent to a technological solution, those making decisions on their behalf will have to make a choice for them. They will need to take into consideration a person with dementia's best interests and previous wishes.

Appropriateness and ongoing review

- It is key that the appropriateness of a technology solution is regularly reviewed. Have needs changed? Have living or family circumstances changed? We recommend a 12-month annual review and regular service reviews as a minimum.

Not a replacement

- Technological solutions are not about replacing human contact or restricting independence. Technology can only be effective when combined with good care. As a person's dementia progresses, technology is about helping the person affected maintain independence, choice and self-determination so they can live life to the full.

Supporting carers

- Technological solutions also need to support the many unpaid family members and friends who help maintain the well-being of a person with dementia.

General thoughts on technology solutions

Everyone is different: some people see them as intrusive, others view them as another way to stay as independent as possible.

They can offer families peace of mind.

They need to be user friendly.
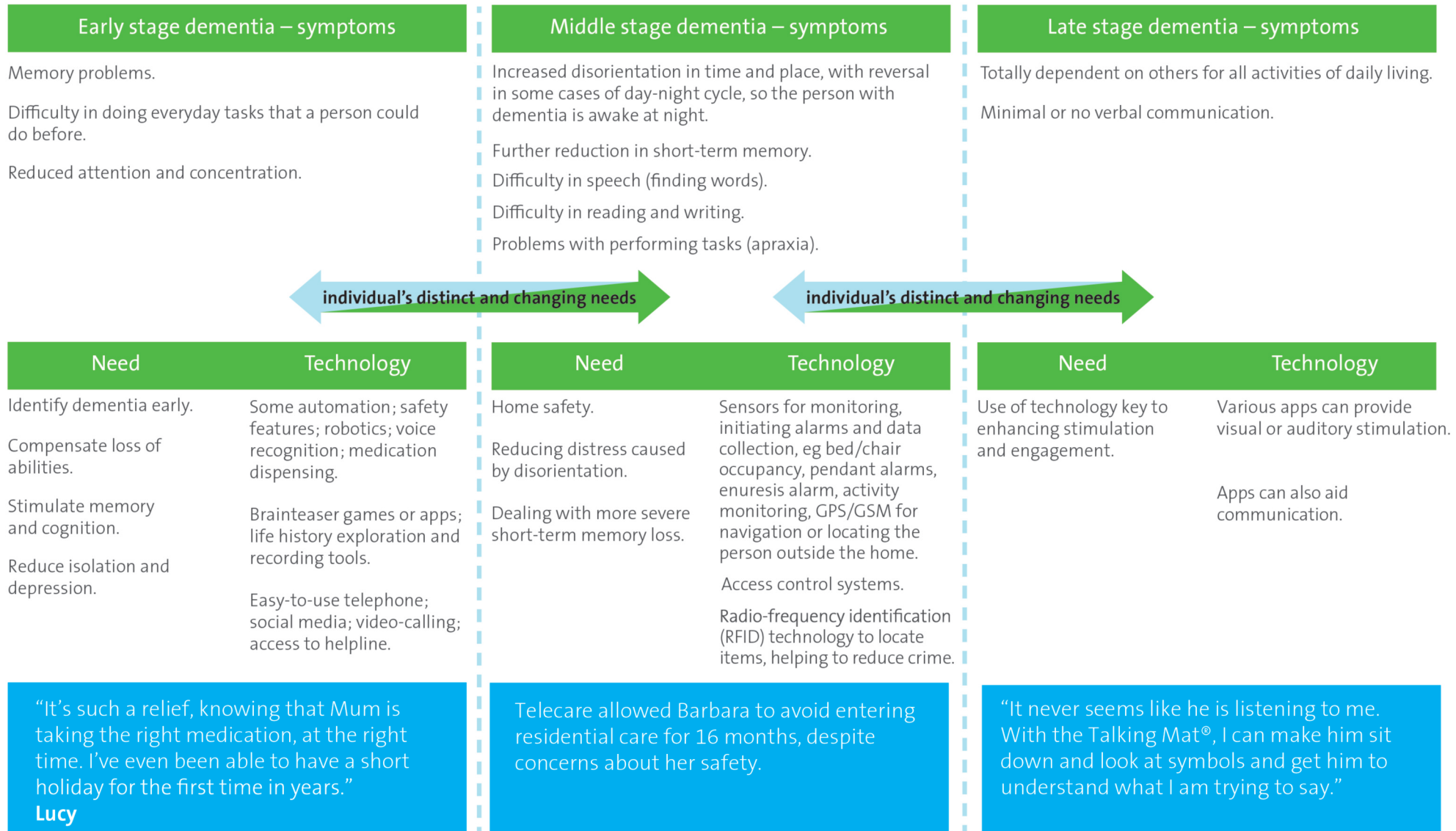
They should be introduced earlier, in order for people with dementia to have a say about what's right for them and familiarise themselves with the technology.

They seem like a good idea, but you would need to get used to them.

This feedback is from members of Alzheimer's Society Service User Review Panels.

See factsheet Assistive Technology - devices to help with everyday living *

Understanding people's needs to identify the right technology solution

Although every person with dementia will have different needs, it is possible to identify technology that may be useful in a number of broad circumstances.

Early stage dementia – symptoms	Middle stage dementia – symptoms	Late stage dementia – symptoms
Memory problems. Difficulty in doing everyday tasks that a person could do before. Reduced attention and concentration.	Increased disorientation in time and place, with reversal in some cases of day-night cycle, so the person with dementia is awake at night. Further reduction in short-term memory. Difficulty in speech (finding words). Difficulty in reading and writing. Problems with performing tasks (apraxia).	Totally dependent on others for all activities of daily living. Minimal or no verbal communication.

← individual's distinct and changing needs →   ← individual's distinct and changing needs →

Need	Technology	Need	Technology	Need	Technology
Identify dementia early. Compensate loss of abilities. Stimulate memory and cognition. Reduce isolation and depression.	Some automation; safety features; robotics; voice recognition; medication dispensing. Brainteaser games or apps; life history exploration and recording tools. Easy-to-use telephone; social media; video-calling; access to helpline.	Home safety. Reducing distress caused by disorientation. Dealing with more severe short-term memory loss.	Sensors for monitoring, initiating alarms and data collection, eg bed/chair occupancy, pendant alarms, enuresis alarm, activity monitoring, GPS/GSM for navigation or locating the person outside the home. Access control systems. Radio-frequency identification (RFID) technology to locate items, helping to reduce crime.	Use of technology key to enhancing stimulation and engagement.	Various apps can provide visual or auditory stimulation. Apps can also aid communication.

"It's such a relief, knowing that Mum is taking the right medication, at the right time. I've even been able to have a short holiday for the first time in years."
Lucy

Telecare allowed Barbara to avoid entering residential care for 16 months, despite concerns about her safety.

"It never seems like he is listening to me. With the Talking Mat®, I can make him sit down and look at symbols and get him to understand what I am trying to say."

Safety risks should be assessed at every point in the journey

How technology services can support people living with dementia and their family and friends

There is now a wealth of technological solutions available aimed at supporting, managing and improving the lives of people affected by dementia. They can be categorised broadly into three categories:

- **Safety –** technology to help people with dementia and their carers live as full a life as possible, without putting themselves and others at risk. These include automated reminders to remind people to pick up keys and lock the door when going out, or not to go out at night on their own. Other examples include smoke alarms, heat detectors, carbon monoxide alarms, domestic fire sprinklers, nuisance phone call blockers, temperature sensors, flood detectors, fall detectors, pendant alarms and locator devices and medication reminders.

- **Health –** technology aimed at helping people with dementia manage their other physical health. These include automated reminders to remind people to take their medication. In addition, automated or remote health monitoring technology that measures blood pressure or monitors vital signs can be extremely helpful.

- **Enhancing –** technology to improve the quality of life for people with dementia. These include location prompts to tell people where they are or automatic calendar clocks which always give the correct time and date. Video footage, digital photos or recordings could help people to reminisce and have happy thoughts. During the late stages of dementia, a Talking Mat® or similar app which allows people to communicate by selecting pictograms could be helpful.

All of these solutions should be used to support and complement, not replace, carers and the numerous social networks, care services and sources of information available.

What difficulties do you think could be made easier by technology?

This feedback is from members of Alzheimer's Society Service User Review Panels.

Alarms and sensors for independence

Peace of mind and reassurance.

It's like having someone come and stand by you.

Feels a bit like 'Big Brother' is watching you.

It might be irritating – being told what to do.

Safer walking technologies

It would be like being watched, someone keeping an eye on you.

It might be nice, as it would be like someone walking alongside you, able to lend a hand if you got lost.

Medication dispensers

This would be really useful – I always find it difficult to remember whether I've taken my tablet.

There is no battery indicator – this could be a problem.

The different stages of the journey

This section outlines the importance of considering technology throughout a person with dementia's journey, as they and their carers and family members cope with the illness.

The four key stages in the progression of dementia that we look at are:

Before diagnosis – early support

After diagnosis – a bit more help

Help in a crisis – support for learning / re-learning skills for daily living

More complex needs – coping with multiple needs

What we know is that at all of these key points people are often not aware of what assistive technology is available to meet their needs. This is why it's so important that professionals who come into contact with people affected by dementia know about the latest technology solutions and talk about them.

It's also important that commissioners of services develop a greater understanding of how technology can lead to good outcomes and incorporate the use of technology into their commissioning strategies.

If a person is coping with other illnesses as well as their dementia, it's vital that a holistic needs assessment is carried out involving all of the professionals who are helping to manage the person's different illnesses.

Simply, through a person with dementia's journey, we must put the individual at the centre of any processes that aim to develop the right care or support for them. To help professionals and commissioners do this, we have outlined over the rest of this section key actions and best practice for each of the above stages.

Before diagnosis – early support

My name is Mary and sometimes I forget things. I live by myself and want to keep it that way for as long as I can. My daughter and her family are close by and I know she worries about me forgetting things. I have agreed to go to see my GP. What can I do to stay independent if my GP says I have dementia?

I need to know where to go to ask for support when I need it.

Your health professional can signpost you to relevant sources for advice on technology.

Your local council can tell you about what services are available in your area.

I may not be aware of the risks to my own safety.

Your local council can provide a personal assessment which should give you a list of potential risks and how to manage these.

My family help me a lot, but they have their own lives.

Service providers can help you and your family understand how you can gain independence and at the same time provide peace of mind for your family.

How do I know it's working?

I feel supported, safe, well and independent.

I need to know what technology is available and how it can benefit me.

Your local council may be able to provide a list of technology they recommend and support.

I need to feel confident about using technology.

Service providers should provide information about the benefits of using their services and make available education and training.

There are a number of resources where advice is available, including the Assistive Technology Dementia website www.atdementia.org.uk, your GP, the Dementia Platform, and third sector organisations such as Alzheimer's Society and Age UK

Before diagnosis – what community and primary care needs to have in place

Local councils and occupational therapists

- Assessments for care and support carried out by councils and occupational therapists (OT) consider the role that technology can play in promoting independence and managing risk and safety.
- Councils and OTs know where to go to for advice on technology that can support individuals living with dementia.
- Carers' assessments also consider the role that technology can play in improving the life of a person caring for someone with dementia.
- A specialist assessment takes place to underpin the issuing of technology, such as an OT assessment. This takes into consideration an individual's abilities and challenges, as well as their broader environment.
- To support an assessment of a person with dementia's technology needs, an assessment of their cognitive, visual and auditory functions should also take place.

Health professionals

- Health teams know how to signpost people affected by dementia to relevant sources of information and advisers.

Service providers

- Service providers are up to date with technology and what is appropriate to meet a person's needs. They understand the benefits of using technology and show evidence of where it has helped.
- Service providers work with councils to showcase equipment and technology, and make it available for people affected by dementia to try.

Technology that could help Mary

- Because Mary takes a mixture of pills, a **medication reminder** will prompt her to take the right one at the right time.

Medication reminder

- A monitored **smoke detector** will make sure Mary receives an immediate response should there be a fire in her property.

Smoke detector

After diagnosis – a bit more help

My name is Joseph and I'm starting to need help with everyday tasks. My family tell me that my memory is getting worse, and I'm often becoming frustrated, but I don't know why. I can't drive anymore, but I still want to be able to live my life. My daughter helps me a lot, but she has her children to think about as well. How can technology help me and my family?

I need to know who to ask for support, but how will I know they are properly trained?

Your health professional will direct you to support services that are skilled and knowledgeable about technology.

Your local council will provide advice and guidance to you and offer support from people that are skilled in understanding your needs.

I may not be aware of the risks to my own safety.

Your local council will talk with you and your family about these risks and look at ways that they can be minimised.

My family help me a lot, but they have their own lives.

Service providers have information and advice to support you whatever your needs.

What happens if I go into hospital?

You will receive a discharge plan that covers all your needs. You will be advised about what short-term options are available to help you stay at home.

There's lots of information and I find it confusing.

Your local council and health teams will help you understand what is available for you and what the best solutions are for your needs.

How do I know it's working?

Service providers will work with you to help you understand how the technology works and tell you who will maintain it.

I don't want strangers, eg engineers, coming into my home.

Service providers will give you information about who is coming to visit you and when they will come. Staff working with you will be aware of your needs and understand your condition. The relevant checks will be taken to ensure your safety.

What if my family need to go on holiday?

You will be given information about the short-term support available to you to help you live at home safely.

After diagnosis - what community and primary care needs to have in place

Local councils and occupational therapists

- Dementia advisers are trained in the range of technology available and know about the latest developments. They also know where to direct people to for further support.
- Dementia cafés, day services, Citizens Advice Bureaux, banks and solicitors are aware of technology services that can help people with dementia and can direct them to these services.
- Assessments for care and support always consider the role that technology could play in promoting independence and managing risk and safety.
- Councils make technology an integral part of their living well, well-being and public health agendas.
- Hospital discharge plans include the use of technology to help people once they are back home.
- Respite or short-term support services make use of relevant technology to help people with dementia stay in their own home.

Health professionals

- They have an appreciation of the technology available and know how to direct people to relevant advisers.
- They expect technology to be included in the home support that is offered following a person's discharge from hospital.
- Memory clinics or memory management services, and community mental health teams are aware of technology services and actively direct people to them.

Service providers

- Staff who advise on or install technology and show individuals and their family how to use it receive training on dementia and know how to communicate appropriately with people with dementia.
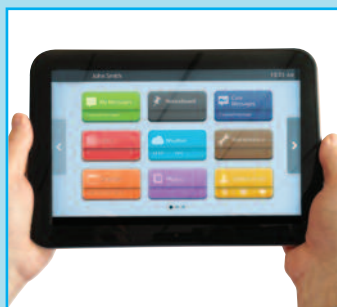
Technology that could help Joseph

- A **dementia clock** provides a simple visual aid to differentiate day from night.
- **Apps** on a **tablet** provide Joseph with key tools to keep busy and stay in touch with friends and family.
- An **activity monitoring system** shows Joseph's daily routine and reassures his family that all is well.
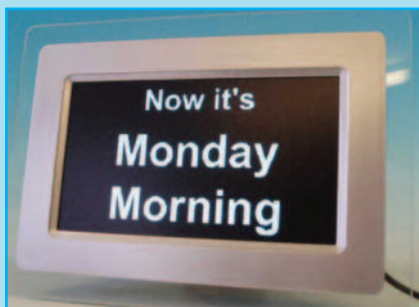
Dementia clock

Tablet-based app

Activity monitoring system

For further case studies please see pages 25-28.

Help in a crisis – re-learning skills for daily living

My name is Sahid. I live with my wife. I've just been in hospital following a fall while everyone else was at work. It got my wife really worried, and I know she wonders how we'll cope when I get home. I don't like being in hospital and want to get home as soon as possible. I know I will need help when I get home, can technology help?

I've had a spell in hospital – what can I do to prevent having to go back?

> Your health professional will direct you to equipment that can help prevent you from falling at home.

> Your local council and health professional will plan your discharge, look at your needs and provide short-term support to help you get back home.

My family need to know what is available to support me to remain at home.

> Your local council can provide a personal assessment which should give you a list of potential risks and how to manage these.

As someone who is paying for equipment themselves, I'd like the option to rent equipment.

> Service providers will provide clear and easy-to-understand information that advises you of what is available for you to rent or purchase from them. Contracts will include what you should expect from the equipment and what to do if you have any problems with it.

I need to go home as soon as I'm well enough.

> Your local council will plan your discharge, look at your needs and provide short-term support to help you get back home.

I'd like to continue to do things I'm used to and still feel safe.

> Your local council will work with you and your family to identify risks and work with you to deliver safe solutions.

> Your health professional will provide follow-up care after discharge to ensure your support plan is working to meet your needs.

Help in a crisis – what community and primary care needs to have in place

Local councils and occupational therapists

- Home intervention or reablement teams make use of technology as part of their services.
- Home intervention or reablement teams advise on technology that offers individuals greater independence or manages risk at the end of the intervention period. They know where to direct people to source equipment themselves.

Health professionals

- They expect technology to be included in the home support that is offered following a person's discharge from hospital.
- Those who identify social care needs and make a referral expect technology to be part of the support that is offered.
- Hospital discharge teams work with NHS community rehabilitation teams that provide equipment and technology to people with dementia.

Service providers

- Service providers offer people the opportunity to rent equipment or technology before buying it so they can test it out.
- The time it takes for a person to access equipment or technology is vital. Therefore, technology services and service providers must react to the needs of a person in a timely manner.

Technology that could help Sahid

- A **fall detector** will give Sahid more confidence by sending an alert to his wife or a 24-hour response centre should he fall.

- A **pager solution** will notify Sahid's wife if he needs help at any time.

- A **bed sensor** will alert Sahid's wife if he leaves the bed at night and does not return within a short period of time, because he has fallen.

Fall detector

Pager solution

Bed sensor

More complex needs – coping with multiple needs

My name is Su. I live with my husband. I have professional carers who come by once a day to help out. As well as dementia I have heart disease and diabetes, so I also get regular visits from a nurse. I like to keep busy but find that I forget what I'm doing and move on to something else. My husband is scared that I'll forget to turn the gas off or burn myself when cooking. But I have always cooked meals for us, and I want to keep doing it.

How can I better manage my diabetes and my heart condition?

Your health professional will advise you of the local support and technology to help you manage your health conditions, including telecare and telehealth devices.

I had a problem whilst cooking, but I'd like to keep doing it as long as I can. What can I do to keep safe?

Your local council will provide you with information and guidance about the range of equipment that is available for you to still cook independently. They can also provide a skilled person to show you how to use equipment safely around your home.

I don't like beeping sounds. Will the technology beep at me?

Service providers will show you the equipment and how it can or cannot be adapted to meet your individual needs. They will also tell you who to contact if there is a problem.

My husband really needs support.

Each local area will have a carers' support service that can provide advice and assistance to carers about the range of options available to them.

Service providers will provide information about the different equipment and options available to help with caring and explain the benefits and limitations of each product.

Will my nurses and carers be aware of the technology options for me?

Your local council and health teams should be aware of the range of support available to you and provide you and your family with information about your choices.

My continence needs to be managed in a more dignified way.

Your local council and health teams will provide you with support that addresses your personal care needs whilst respecting your need for dignity.

More complex needs - what community and primary care needs to have in place

Local councils and occupational therapists
- Carers' assessments consider the role that technology can play in improving the life of a person caring for someone with dementia.
- Carers are encouraged to help their family member make use of telehealth devices to manage other health conditions and reduce their number of medical appointments.

Health professionals
- Telehealth devices are used to take routine measurements in a person's home. A spouse or family member is trained to help individuals with dementia use this technology.
- Community nurses encourage people with dementia and their family to manage their conditions, making use of telehealth.

Service providers
- Service providers leave clear, easy-to-understand instructions and/or train a spouse or family member to help an individual with dementia use any technological devices.

Technology that could help Su

- A **telehealth system** would support Su by checking her vital signs at home, allowing for any deterioration of her heart failure to be picked up quickly by her doctor.

- A **gas detector** installed in the kitchen will ensure an alert is sent should Su forget to turn off the gas.

- A **property exit sensor** will warn her husband if Su leaves her home when it's not expected or during the night.

Telehealth system

Gas detector

Property exit sensor

For further case studies please see pages 25-28.

Page 21, Section 4: What does a good quality technology service look like?

Page 22, Section 4: What does a good quality technology service look like?

Components of a good quality technology service

1 Service blueprint

Organisations who refer people to or commission services must clearly understand:
- **what is available***
- where and how people can access services.

Organisations that deliver services must:*
- consider the outcomes they bring about.

2 Standards

Appropriate service, ethical and technical standards must be adhered to when an organisation commissions, refers a person to or implements a care service that uses technology.

The standard that covers this type of service is the **Telecare Services Association Integrated Code of Practice***

Areas to be considered include:
- technical standards such as BS8521
- ethics and consent (see section 5 below)
- data confidentiality.

3 Timely referral

Clearly understand the points in a person's journey when they should be referred to receive care.

Ensure access to information about the latest care services that use technology is available.

4 Timely assessment

The starting point for an individual is the assessment of their wants and needs, including physical, cognitive and emotional, and any risks associated with them.

What is the capacity of the individual to give informed consent?

Following this assessment, a specialist technology plan for the individual can be developed.

Jim's story

"I'm getting more forgetful, which included leaving the gas on yesterday. Luckily, Jayne, my daughter, came round and switched it off before I blew the place up. I want to feel safe and secure in my own home. I also want to remember to take my pills on time. My blood ressure has been all over the place lately."

"I'm not going out as much, as I'm worried I'll forget where I live. That happened to my friend and the police had to bring her back. I'd be mortified if that happened to me. Jayne wants to speak to me about power of attorney. Not sure I'm ready for that yet but maybe I need to sort it out, just in case."

Carol, Jim's carer, introduces him to his new service. Jayne, Jim's daughter, is also there for the discussion. After it's been set up, Carol will check to see how Jim is getting on with it. Because it is a new service, it may be difficult for Jim to get to grips with it first of all.

Jim's service includes smoke detectors linked to 24/7 monitoring, a gas shut-off device and a GPS location service for when he goes out. All of this technology will provide Jim with greater reassurance and improved safety and security.

5 Ethics and consent

Any service offered is subject to informed consent.

The **Social Care Institute for Excellence*** has useful guidance.

Also, refer to **the Deprivation of Liberty Safeguards*** (DOLS).

The personal wishes of a person regarding their health must be obtained. Power of attorney may be applicable in some cases.

9 Re-evaluation

To improve services, organisations that refer people to or commission services must continually re-evaluate:
- **what is available***
- where and how people can access services.

Organisations that deliver services must:*
- re-evaluate the outcomes they bring about.

8 Response

This is the provision of routine and emergency response services that go to the home of a person with dementia or find them outdoors if a GPS tracking service is being used.

The response to any alarms raised must be appropriate to meet the ongoing needs of an individual.

The response should take into account the physical and mental ability of the individual concerned.

7 Monitoring, where appropriate

A 24/7 monitoring service is often a central part of a care package that features technology. The person with dementia must be assured that:
- all elements of the service will work together
- only one centre will monitor
- confidentiality will be upheld at all times
- equipment will send an alert to a monitoring centre if there are problems.

6 Service set-up

The service should be set up to meet the needs of an individual, as outlined in an assessment of them.

The service set-up and installation must comply with service standards set out in the Telecare Services Association Integrated Code and be mindful of ethical principles and consent.

Ensure information about the latest care services that use technology is available.

*See page 30 for a full list of hyperlinks and references.

Key questions for service commissioners and providers

Recommendations for commissioners, providers and suppliers

- The statutory right to a social care assessment should always include a consideration for dementia-friendly technology.
- A single, simple to use and regularly updated online resource detailing dementia-friendly technology should be developed.
- All commissioners and providers should develop accessible and easy to find information that lists where dementia-friendly technology is available in their local area.
- Technology providers should take into account the specific needs of people with dementia when developing care services that use technology.

As a commissioner of dementia-friendly technology and telecare services, can you answer positively to the following questions?

Do you: promote and provide easy-to-understand information, advice and demonstrations on dementia friendly technology and telecare services and how people can access it? ☐

Do you: have a procedure in place for people with dementia to receive an assessment to understand how care services that use technology could meet their needs? ☐

Do you: have assessment tools in place to identify the risk a person with dementia may be at in their home and away from it? ☐

Do these tools also: fully assess the person with dementia and their carers' needs with regards to their capacity to manage by themselves, their best interests and what options would be the least restrictive for them? ☐

Do you: have a process in place to ensure your installation service for dementia-friendly technology and telecare services fully takes into consideration the needs of people with dementia and their carers? ☐

Do you: have an ongoing development programme for your dementia technology assessment teams to ensure they keep up to date with the latest dementia-friendly technology developments? ☐

Do you: have procedures in place to ensure that the appropriate ongoing management of dementia-friendly technology takes place following installation. This includes: ☐

- monitoring centre with dementia aware staff ☐
- client-centred local emergency response services ☐
- ongoing monitoring of equipment call alerts ☐
- client-centred protocols prepared for monitoring centre ☐
- ongoing case reviews for client and equipment ☐
- ongoing equipment testing and maintenance ☐
- equipment recovery as appropriate ☐

Do you: provide dementia-friendly technology and telecare services that improve the quality of life for people with dementia and their carers by helping them to remain independent, have more choices and stay in control of their lives? ☐

Do you: have a process in place that supports people affected by dementia who are paying for equipment and technology themselves to access dementia-friendly technology and telecare services? ☐

Do you: have a policy in place for your dementia-friendly technology and telecare services that makes sure personal data is kept secure and remains confidential? ☐

Do you: ensure that technology is always used in the context of a wider care and support plan for an individual, so the technology complements and enhances other types of care and support? ☐

The range of assisted technology available is constantly changing. We are regularly identifying new suppliers, but each supplier has a varying understanding of what people with dementia and their carers require.

Key questions for assessment teams

We have compiled the following questions for assessment teams that provide dementia-friendly technology and telecare services to consider.

- Who will benefit from the technology: the user, carer or service provider?
- Has a full assessment of the person with dementia been completed and all the risks identified?
- Have you obtained the consent of the person with dementia or their family?
- Have you considered ethical issues such as making sure someone is safe while respecting their privacy?
- What risks does the person with dementia face and how would the technology reduce these risks?
- What are the limitations of the technology to be used?
- Does the technology connect to other devices? If so, is compatibility an issue?
- Does the use of the technology match what the manufacturer has produced it for?
- Is battery life an issue? Who will be responsible for battery management?
- Does the product need to be waterproof?
- What can go wrong with the chosen technology?
- If the technology fails, what are the associated risks of the failure?
- What are the maintenance arrangements for the product and is it covered by a warranty?
- Who is responsible for equipment testing and how often will this take place?
- Who will be responsible for reviews of the technology and whether it is benefiting the person with dementia or their carers?
- How does technology fit into the wider care and support plan for an individual?
- Will the care and support plan have to be changed in any way if technology is introduced into it?

Key questions for people with dementia and their family and carers

We have compiled the following questions for people with dementia and their family and carers to consider before buying or using dementia-friendly technology.

- How will dementia-friendly technology help me?
- How does it work, who will show me how to use it, are the instructions easy?
- Do I need a phone line or internet connection to use the technology?
- How much will it cost, is there an initial cost or an ongoing charge, what happens if I fall behind on payment?
- Who do I contact if something breaks or if I have a problem?
- Do I need to change batteries or charge them, and how often do I need to do this?
- Who will install the equipment and will I experience any disruption to my life?
- If my needs change, will the technology support me as my dementia progresses?
- What happens if I move home?
- What evidence or information is there to help me decide what technology I need?
- Is my dementia too advanced for a dementia-friendly technology product?
- Would it help to install dementia-friendly technology before I need it?
- Is there a 24-hour response service to support me in an emergency?
- Is there a helpline I can call if I have any concerns?
- Is there a response service that will come out if I fall or a particular alarm is triggered?
- What would trigger a response service and how long would it take for someone to come to me?

Appendix A:
Best practice case studies

Blocking nuisance calls

- Concerns

  Anne has dementia and lives on her own. She has been a victim of several scams and has willingly given her credit card details to cold callers and sales people. This has resulted in her buying multiple insurance policies to cover household appliances and inappropriate health products. It has been distressing for Anne when she's discovered what's happened without any recollection of it taking place. This makes her feel vulnerable and that she has been taken advantage of.

- Solutions

  A call blocker only allows calls to come through that involve known and trusted numbers; it intercepts unrecognised numbers. Nuisance calls have now been eliminated.

- Outcomes

  There has been a direct impact on Anne's well-being. She is more confident and positive, and less worried about being able to cope in her home.

Managing falls (case study from Hertfordshire)

- Concerns

  Edith has rheumatoid arthritis, as well as memory and eyesight problems. Occasional falls have become more frequent as her condition has worsened. Edith's husband was increasingly worried about her and was even considering moving from their home of 40 years into sheltered or residential care.

- Solutions

  Edith and her husband already had a telecare home unit, so it was simple to add a fall detector. If Edith falls, the monitoring centre is alerted and will check if help is needed. A bed occupancy sensor has been fitted so that if Edith gets out of bed in the night and doesn't return within a set time, an alert is sent to the monitoring centre. The centre then speaks to Edith or her husband to check everything is okay.

- Outcomes

  Edith's family are relieved that this system is in place. It gives them peace of mind and allows Edith's husband to get a good night's sleep.

Best practice case studies

Managing dignity (case study from Hull)

- Concerns

  Gary had a mild stroke and was then diagnosed with vascular dementia. He lives alone and made it clear that he wanted to self-manage his conditions as much as possible. Over time, Gary started to have continence problems during the night. This did not happen every night, but when it did he found it difficult to change the bedding and his nightclothes, so he lay in his wet bed until the morning. This was very uncomfortable and also carried the risk of his skin breaking down.

- Solutions

  Because this problem did not occur every night, it was decided a nightly pop-in call by a carer would have been disturbing for Gary. Instead, it was agreed that an enuresis sensor should be trialled on Gary's bed to alert his local out-of-hours service when he had been incontinent.

- Outcomes

  This solution worked really well. The response time from the out-of-hours telecare service team was very fast, allowing Gary to change with assistance and settle back into bed with minimal disturbance. This helped to maintain Gary's dignity and independence; it also prevented expensive and unnecessary nightly pop-in calls.

Enabling dignity*

Managing risk (case study from London Fire Brigade)

- Concerns

  Mrs B is 96 and lives alone. Although she has dementia, she had maintained her independence as much as possible, and still did her own cooking. One summer evening she left the grill pan on and forgot about it. Some oil in the pan overheated and caught fire. Alarmed, Mrs B tried to put out the fire with a damp mop. She also tried to turn the grill off, but in doing so, possibly through panic, turned on three gas rings on the cooker's top. At this point Mrs B retreated to her living room, where she was overcome by fumes.

- Solutions

  A smoke alarm linked to Mrs B's telecare system was activated and immediately sent a signal to the alarm remote monitoring centre. The centre contacted the fire brigade, which triggered a swift emergency response. In a short time, fire fighters using breathing apparatus forced entry into Mrs B's home and found her unconscious on a living room armchair. The crew removed her from the smoke-filled room, brought her round and helped her into the care of the ambulance service. They turned off the gas rings, damped down the remains of the fire and ventilated the house. Mrs B suffered from smoke inhalation and was kept in hospital overnight for observation; otherwise she was fine.

- Outcomes

  It is very unlikely that the outcome would have been as positive if the smoke detector hadn't been linked to a telecare system. Today, Mrs B is still cooking.

*See page 30 for a full list of hyperlinks and references.

Best practice case studies

Supporting carers (case study from Warwickshire)

- Concerns

  Hannah, who has vascular dementia, has two homecare visits a day, and receives support from her daughter, who lives locally. Recently, she walked to her local shops but forgot how to get home again. A passer-by helped her home, and knocked on a neighbour's door to check he had brought Hannah back to the right house. The neighbour rang Hannah's daughter and complained that Hannah was often 'wandering'. He also suggested that Hannah now needed to be looked after in a care home.

- Solutions

  An activity monitoring system was installed to see how often and for how long Hannah went out. It showed she went out two or three times a week for just under an hour – the time it takes to walk to the shops, do a little shopping and walk back. Hannah's daughter used the system to manage her mother's care, logging on from work to see that care visits and her mother's weekly visit to a lunch club were taking place as planned. She could also see if Hannah went to bed as normal each night. Hannah's son, who lives in New Zealand, also logged on to the monitoring service. This made him more informed about his mother, which helped him to discuss worries and problems with his sister and support her from the other side of the world.

- Outcomes

  Hannah stayed in her own home for a further 25 months.

Managing memory loss and taking medication (case study from Hertfordshire)

- Concerns

  Lucy cares for her mum, Val, who has early onset dementia with rapid deterioration of memory. Val takes lots of medication, but due to her memory problems she was either overdosing or not taking her medication at the right time. Lucy was so worried that she took away the medication and delivered it herself at the correct time. Val also needed to visit the hospital weekly due to changes in her condition.

- Solutions

  Val was provided with a medication dispenser linked to a telecare home unit which dispenses her tablets. The unit flashes and sounds an alert each time Val needs to take her medication. If Val doesn't remove the medication, an alert is raised to Lucy or the monitoring centre to let them know.

- Outcomes

  Since the medication dispenser was installed, Val's condition has stabilised and she only needs monthly hospital visits. Lucy has now been able to go on holiday for the first time in many years, safe in the knowledge her mum's medication is being monitored whilst she is away.

Best practice case studies

Making the most of local support (case study from London Borough of Ealing.)

- Concerns

  Graham is 82, lives in sheltered accommodation and has no family in the UK. He has Alzheimer's disease and diabetes. He was receiving a care visit in the morning, lunchtime and early evening, but he was often not in when carers called. He was beginning to look increasingly 'unkempt' and seemed to be deteriorating mentally. Residential care was being considered.

- Solutions

  An activity monitoring system was installed to monitor Graham's routine. Graham went out each day at lunchtime, sometimes not returning until after 6pm. It turned out that he went to a local café, where he was welcomed and encouraged to stay and chat. In fact, the café staff would come and call for him if he did not turn up. Throughout the night he was getting up and using the bathroom every two hours, which meant his sleep was interrupted and affecting his mental functioning.

- Outcomes

  A support worker accompanied Graham to his GP, who diagnosed that Graham was probably not taking his medication regularly. He also identified that he had an enlarged prostate, which was pressing on his bladder. A medication dispenser now prompts Graham to take his medication. Care visits were changed to two a day. The morning visit focusing on personal care and the later evening visit, which takes place after Graham comes home, checking on general well-being. Graham is still making the most of his local café.

Whilst these case studies are focused on home support, many of the solutions mentioned are applicable in a communal living setting. Solutions involving social media are a developing area and one which will grow in popularity.

Appendix B:
Links to further advice and support

Links to further advice and support

- **The Telecare Learning and Improvement Network** produces a monthly newsletter that summarises all that's happening with regards to dementia and telecare and telehealth.

  For the latest edition, visit **www.telecarelin.org.uk**

- **Local telecare information** – all local authorities have links to telecare information on their websites. Simply search 'telecare' and your local authority's name, to find out about services and support in your area. For example here is Hertfordshire's e-market place: **www.hertsdirect.org/services/healthsoc/supportforadults/manageathome/washdresstoileting/stayindequip/telecare/**

- **Dementia Gateway** is for anyone who wants to understand dementia better: what it is, what it means for daily life, and what we can do better to support people living with dementia, including family and friends.

  Helpful resources on the site include written information, films, activities, e-learning and much more. These have been developed by a wide range of dementia experts and people with dementia, their families and carers. To find out more, **visit www.scie.org.uk/dementiagateway**

Information for service commissioners and providers

- **Integrated code of practice** – Telecare Services Association (TSA) has produced a telecare and telehealth integrated code of practice.

  You can find out more about this and access a matrix that sets out the code of practice in an easy-to-understand way at **www.telecare.org.uk/standards/telecare-code-of-practice**

- **Good Governance Institute** has developed a quality standard for telehealthcare. To find out more, visit **www.goodgovernance.org.uk/Telehealthcare**

- **National Institute for Health and Care Excellence** (NICE) has an evidence library that you can search for a wealth of information on dementia. To find out more, visit **www.evidence.nhs.uk**

- **NICE quality standard –** how people with dementia should be supported to live well. Visit **http://publications.nice.org.uk/quality-standard-for-supporting-people-to-live-well-with-dementia-qs30**

- **The Dementia Roadmap –** local information for professionals in North Somerset, South Gloucestershire and Devon **www.dementiaroadmap.info**

- **Scoping of assistive technology services in the UK –** a paper on this subject is available for a fee from the following website; an abstract is available for free – **http://dem.sagepub.com/content/early/2014/05/05/1471301214532643.abstract**

Information for people with dementia and their families and carers

- **Alzheimer's Society** provides local advice and support services across England, Wales and Northern Ireland. To find out more, visit **www.alzheimers.org.uk/contactus** or call our national advice line on **0300 222 11 22**. It's available seven days a week.

- **Assistive technology factsheet** – Alzheimer's Society produces a factsheet on the equipment and technology that could help people with dementia and their carers in their everyday lives.

  To download it, visit **www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=109**

- **AT Dementia** is a charity that provides information on assistive technology that can help people with dementia live more independently. For more information, visit **www.atdementia.org.uk**

- **Mi (More independent)** is a government funded initiative being piloted across four regions in the UK. Its website offers advice and information about technology and support that helps people to live independently and which organisations can provide further support.

  To find out more, visit **www.moreindependent.co.uk**

- **Funding care** – NHS Choices' website features a helpful section titled How can I pay for my care? For more information, visit **www.nhs.uk/CarersDirect/social-care/Pages/funding-your-care.aspx**

- **www.livingmadeeasy.org.uk** – clear, practical advice on daily living equipment.

- **www.asksara.org.uk** – products and ideas that may help with a range of daily activities, health issues and living at home.

- **www.cfoa.org.uk/12247** – specialist advice on fire risk and information about free home fire safety visits in your area.

- **www.dementia-pal.com** – families can use this online guide to tell professionals what support they need in a simpler and more effective manner.

- **www.mickshouse.info** – one man's insight into telecare.

Hyperlinks

Page 5. Integration pioneers

www.england.nhs.uk/2013/11/01/interg-care-pioneers/

Page 6. Dementia-friendly technology: Delivering the National Dementia Challenge report

www.alzheimers.org.uk/site/scripts/download_info.php?fileID=1921

Page 8. Assistive Technology - devices to help with everyday living

www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=109

Page 21. What is available?

www.telecare.org.uk/consumer-services/telecare-and-telehealth

Page 21. Organisations that deliver services must

www.telecare.org.uk/service-provider-directory

Page 21. Telecare Services Association Integrated Code of Practice

www.telecare.org.uk/standards/telecare-code-of-practice

Page 21. Social Care Institute for Excellence

www.scie.org.uk/publications/ataglance/ataglance24.asp

Page 22. The Deprivation of Liberty Safeguards

www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=1327

Page 26. Enabling dignity

http://uk.tunstall.com/Uploads/Documents/Hull%20City%20Council%20-%20Creative%20use%20of%20telecare1.pdf

Alzheimer's Society is the UK's leading support and research charity for people with dementia, their families and carers. We provide information and support to people with any form of dementia and their carers through our publications, National Dementia Helpline, website, and more than 2,000 local services.

We campaign for better quality of life for people with dementia and greater understanding of dementia. We also fund an innovative programme of medical and social research into the cause, cure and prevention of dementia and the care people receive.

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