

learning disabilities

solutions for independent living

key information for health and social care professionals and carers



forewords



Hello Everyone

My name is Louise and I live independently in Supported Housing, provided by Nottingham Community Housing Association. I think it is important to talk about how telecare has increased my independence. When staff are not on site, I can contact SMaRT using the Tunstall Lifeline who will give me any support or advice I need. It is important to tell people about SMaRT because I think it is a great service. We now don't have staff sleeping over, but we have SMaRT at the end of our Lifeline, ready to give support over the phone and at my home if needed. We practised lots and when the day came we were ready to go!

I have learnt new skills and I feel that I am setting a positive example for people with Learning Disabilities. I would like to say that SMaRT is brilliant for me. It has made a difference to my life. I know that I can call them at anytime. I feel safer and I have better support services when I need it. I know that if things change for me I can have different sensors in my flat to support me so that I can still live in my own home. My family are happy because they know that I like SMaRT and I can contact someone immediately if there is a problem.

I hope you like this guide and find it useful. Using telecare has made a difference to my life and I think other people like me can live their own lives safely, with more choice and independence.

Thank you everyone. **Louise, Service User, Nottingham Community Housing Association**

"We believe that Assistive Technology has a crucial role to play in empowering individuals and enhancing the employability of people with learning disabilities and their family carers.

Technology offers us all an exciting opportunity to work with people with learning disabilities to help drive forward developments which can potentially have a huge impact on their independence and well-being. Telecare has the potential to offer real alternatives to traditional models of care for people with learning disabilities and benefits can be realised in a variety of living, community and work environments. We look forward to being part of these new opportunities."

Steve Barnard, Director of Information Systems, HFT



contents

1 The true impact of learning disabilities	Page 3
2 Introduction	Page 4
3 What is telecare?.....	Page 5
4 Support for learning disabilities at home	Page 6/7
5 Support for learning disabilities in a supported housing setting	Page 8/9
6 The technology - suggested care packages.....	Page 10/11
7 Case studies	Page 12/13
8 Focus on the TATE Project	Page 14
9 Caring for carers	Page 15

the true impact of learning disabilities

As recently as the 1980s people with learning disabilities, who for any number of reasons could not live at home with relatives, were condemned to a life in long-stay hospitals, overshadowed by short life-expectancy and stereo-typed by prejudiced perceptions. Such scenarios have resulted in people not only facing the challenges of living with a learning disability but also of trying to readjust to life after thirty years of institutionalised care.

For the person with a learning disability life can very often be a round of frustrations and constant battles to prove their ability to live as independently as possible, which can lead to depression, loneliness and feelings of being undervalued.

Over 60% of people with learning disabilities live with family carers who often sacrifice their own lives in order to support the individual they are caring for. Who supports them? The devotion with which carers look after their loved one often goes hand in hand with relentless worry and guilt felt when they can't be around.

Given this stark reality, we now have an opportunity to use technology as part of the support framework to help people with learning disabilities live independently within their own homes in their communities.

Thankfully, today we are part of a new dawning of opportunity for people with learning disabilities and their family carers. Led by people with learning disabilities themselves, the focus is changing to empower people to make informed choices about the way in which they want to live their lives and technology has an important part to play. Innovative projects are highlighting that where people are supported with telecare to live as independently as possible, their quality of life and well-being improves. This increases confidence and encourages people to take part in life in their local communities, resulting in much more fulfilling lives and associated reductions in mental health issues and social exclusion.



introduction



What is a learning disability?

A learning disability is a permanent condition generally resulting from the way the brain develops before, during or after birth, which affects the way in which a person learns, communicates or carries out every day tasks. It can mean that the person may take longer than usual to learn or communicate but it does not prevent someone from leading an active and fulfilling life with the right level of support.

There are various causes of learning disability, such as:

- Down's Syndrome
- Fragile X Syndrome (which can result in a learning disability)
- Cerebral Palsy
- Autism

(the latter two although not learning disabilities themselves, result in an individual having learning disabilities as part of their overall condition).

The extent of a person's learning disability is often referred to as mild, moderate or severe and this can also be related to the amount of support that person may require.

Many people with severe learning disabilities also have physical disabilities of some sort, resulting in very complex support needs.

Source: www.mencap.org.uk *Foundation for People with Learning Disabilities*

UK learning disability stats

It is estimated that in the UK:

- Up to **1.5 million** people have mild learning disabilities¹
- Up to **350,000** people have severe learning disabilities²
- Combined NHS and Local Authority expenditure on children and adults with learning disabilities is approximately **£4.6 billion a year**^{3 and 4}
- Of people with a learning disability who live at home with parents or other relatives over a third are living with a **carer aged over 70**⁴
- 20% of people with learning disabilities have Down's Syndrome and over 50% of people with Down's Syndrome aged 60+ have dementia. The 80% of people with learning disabilities who do not have Down's Syndrome are four times more likely to develop dementia as the rest of the UK population⁵

¹Source: *Learning Disability Coalition*

^{2,3}Source: *Foundation for People with Learning Disabilities*

⁴Source: *Pressures on learning disability services, ADSS report October 2005*

⁵Source: www.alzheimers.org.uk

support for learning disabilities at home

Approximately 60% of people with a learning disability live at home¹ with family carers and telecare technology can provide a vital role in supporting both the individual with learning disabilities and their carer. The benefits telecare can offer rely upon the creation of a tailored care package, which must include decisions from all stakeholders about what is an acceptable level of risk and how these risks will be managed.

Risk - walking from the home

James is 19 and has autism. He lives at home with his parents who both work and at times James was found to be leaving the house and going across the road and entering the property of a neighbour, who was fortunately very supportive of the situation. When new neighbours moved into the area this behaviour became more of a concern. An unobtrusive property exit sensor was fitted which raised an alarm if James left the property when his parents were not at home, enabling the monitoring centre to contact them to deal with the situation.



Risk - cooking

Cooking and eating can present particular problems for people with learning disabilities. Electric kettles may be placed on gas rings for example or pans left to boil dry. Fire hazards such as these can be monitored by the temperature extremes sensor. Placed in the kitchen where some detectors can be too sensitive to use, it monitors for a rapid rate of rise in temperature and will warn of possible fires.

Gas cookers can pose a particular risk as people can become distracted resulting in cookers being left turned on. A solution is to employ a gas detector which will raise an alarm if it detects dangerous levels of gas in the property.

Risk - bogus callers/bullying

People with learning disabilities are particularly vulnerable to distraction burglary and in some cases both verbal and physical bullying. Hearing the monitoring centre via the Lifeline unit is often enough to cause the potential thief or bully to flee, and as all calls are recorded this also provides evidence admissible in court.

CCTV equipment can also be installed so that the person at the door can be seen prior to the door being opened. This has proven very popular, especially with younger people with learning disabilities. Training and support can soon result in people understanding that they only open the door to people they recognise.



Risk - epilepsy

It is estimated that up to 50% of people with learning disabilities also suffer from epilepsy which can be a limiting condition both for the individual and their carer.

Susan suffers from severe epilepsy. She can have several tonic clonic seizures in any one night. For the last fifteen years Susan's mother has slept in the same room as her daughter to ensure that she wakes up if and when Susan has a seizure. Susan's mother has not had a good night's sleep during that time due to the constant worry of what would happen if she were not to wake up. An epilepsy sensor was fitted in Susan's bed allowing her mother to return to sleeping in her own room reassured that an alert would wake her to allow her to help Susan as and when required.

'Source: Valuing People, 2001

Please note - all names have been changed.

learning disabilities in a supported housing setting

Grouped or supported housing care options for people with learning disabilities have expanded over recent years, and new models which focus on choice and independence have been developed. For mild to moderate learning disabilities, supported living housing which provides individual tenanted dwellings, often as assured tenancies, have begun to replace residential and/or nursing care in many areas. Many Local Authorities and Housing Associations are beginning to provide purpose built supported living environments where the emphasis is on developing the tenants' skills and encouraging them to exercise a degree of control over their own lives. For people with severe learning disabilities, care and support needs will be more complex but supported living is still proving to be a proactive way forward, offering people more choice and fulfillment in their lives.



Technology focus:

Telecare Overlay™ has been developed to enable grouped housing systems to support the full range of telecare sensors, and now staff can be alerted to situations such as overflowing baths or pan fires. The bed occupancy sensor can also be employed to ensure carers are aware that a tenant/resident has left their bed for a prolonged period (indicating a possible fall), or has failed to get out of bed in the morning.

This system provides peace of mind for carers and privacy and independence for tenants. As staff will be notified if an incident should occur, they are able to tailor work patterns around the individual need rather than following standardised routines for every tenant. This flexible approach facilitates person-centred care and also means resources are used when really needed.

Case study

Mr X had moderate learning disabilities and was prone to enuresis incidents but would refuse to pull the cord to alert staff. Consequently, he would not be changed until staff physically checked him and although this was written into his care plan at regular intervals Mr X was still at risk of skin complaints and exposed to a lack of dignity. An enuresis sensor was fitted and now carers are alerted when an incident occurs and can proactively support Mr X.



Focus on The Papworth Trust - Saxongate, Supported Living

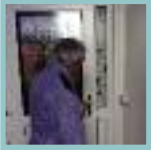
The Papworth Trust is a disability charity providing a range of housing, employment, training and rehabilitation services which enable people to have equality, choice and independence. Two years ago they opened their innovative Foundations for Living housing project.

Foundations for Living (FFL) is a landmark scheme in Huntingdon, Cambridgeshire which demonstrates how mainstream housing and community learning facilities can be designed to be accessible to all; including disabled people. The project includes wheelchair accessible housing for 24 people built alongside housing for sale, the Saxongate Community Learning Centre, and a support team to enable disabled people to become part of their local community. Saxongate provides a range of inclusive learning opportunities and advice on issues including employment and housing support.

Tenants with learning disabilities are supported with telecare technology which enables them to live more independent lives knowing that they can summon support in an emergency. All tenants are assessed and reviewed to ensure appropriate telecare sensors are provided to support individual needs.

FFL is having a huge impact on the way people are able to live their lives. **Janet lived in residential care for over fourteen years but recently moved into Saxongate and her own home for the very first time in her life.** She is delighted with her new home and values the support the technology gives her. She is able to use the technology to summon help in an emergency, view visitors via CCTV cameras connected to her door entry system and is reassured by her fall detector which will raise an alert should she experience a fall in her flat.

the technology



Property Exit Sensor

This sensor specifically monitors for people leaving a building at set times of day and night. It can also detect if a main exit door has been left open and can be linked to external lighting to provide added protection.



Bogus Caller Button

Fitted near the door, the discreet bogus caller button can be used to call for assistance at a 24 hour monitoring centre, when a stranger requests entry into the home.



Bed Occupancy Sensor

This pressure pad fits under the mattress and provides an early warning by raising an alert if the user has left their bed and not returned within a pre set time period, indicating a possible fall.



Flood Detector

The Flood Detector will raise an alarm if sinks or baths overflow, or if a washing machine door is opened mid-cycle, protecting both people and property.



Temperature Extremes Sensor

Monitors for low and high temperature extremes in addition to the rate of rise in temperature. Helps minimise the risks associated with changes in temperature including the build up of heat in a kitchen and the risk of sustained periods of cold weather.



Carbon Monoxide Detector

Sends an alert to the monitoring centre if dangerous levels of carbon monoxide gas are detected. As carbon monoxide is odourless and colourless the potentially lethal gas is difficult to detect.



Natural Gas Detector

Provides an early warning of dangerous levels of gas. Can be linked to the Gas Shut Off Valve to automatically cut off the gas supply, if a leak is detected.



Gas Shut Off Valve

When combined with the Natural Gas Detector, this solution automatically cuts off the gas supply to an appliance when a leak is detected.



Enuresis Sensor

Placed between the mattress and sheet, this sensor provides immediate warning on detection of moisture, allowing effective action to be taken. The sensor eliminates the need for carers to make physical checks during the night, promoting dignity and independence.



Epilepsy Sensor

Placed under a foam mattress (or a mattress cover if using a sprung mattress), this sensor monitors an individual's vital signs, including heart rate, to alert if tonic clonic seizures occur. Upon detection of tonic-clonic shakings an alarm call will be raised to the monitoring centre or carer to ensure the appropriate action can be taken.



Home Alert Carer Pager

Provides additional peace of mind and reassurance to carers by immediately notifying them of alarm calls from telecare sensors when they are in the home or in the garden.



DDA Vibrating Pager

The DDA Vibrating Pager is linked to a Lifeline Connect+. When a telecare sensor is activated, the Lifeline home unit sends a signal to the pager, via the DDA transmitter, which alerts the wearer by vibrating and lighting up one of 4 LEDs for up to four different alarms (or telephone line ringing). This means that both visually and hearing impaired users can be quickly made aware of which telecare sensor has been activated, helping them to respond accordingly.



Telehealth Monitor

The RTX3370 and RTX3371 help patients with long-term conditions monitor their vital signs at home including blood pressure, pulse, weight and oxygen saturation via a range of medical devices.



CareAssist

A portable telecare alarm for onsite carers that can receive telecare alerts and display not only the type of sensor activated but also either the location of the sensor or the name of the person the sensor has been assigned to.

case studies



Focus on Nottingham Community Housing Association

Nottingham Community Housing Association (NCHA) offers housing with care and support to a variety of vulnerable people, including people with learning disabilities. Three years ago NCHA took the decision to change the way that their services were delivered. They wanted the support they offer to focus on building a more individual relationship and to encourage people to use the technology to gain greater confidence, make choices and take responsibility for their own lives with planned support.

After reviewing the care and support given to tenants and listening to the views of people with a learning disability, a decision was taken to withdraw sleep-in carers over a period of six months and offer everyone a Lifeline home unit. Tenants had said that they wanted more independence and did not want staff in their home all the time. This decision would have been unthinkable without the reassurance of telecare. A system of telecare linked to remote viewing of CCTV was introduced together with an extensive programme of training for tenants with fantastic results. All tenants are delighted with the new service, with no return to use sleep-in staff.

All tenants now undergo reviews to determine whether needs have changed and extra telecare sensors are used to support individuals to continue living independently.

For the full case study visit www.tunstallhealth.com/casestudies or call 01977 660479.

Keith and Emma

Keith and Emma live together in a supported living flat. Keith has epilepsy and when he has a severe fit he needs instant support but also Emma needs support as she gets very frightened. Because of the risk to Keith a member of staff slept-in every night, just in case Keith had an epileptic fit. On review it was seen that this had happened only once in eighteen months. We now use an epilepsy sensor connected to a Lifeline Connect+ and if necessary a waking night staff member from the adjoining property can be summoned immediately to help Keith and support Emma.



Daniel

Daniel is in his forties and has Downs Syndrome. He has lived independently but supported, alone in a house in Chichester for some years, although his family do not live far away.

The concerns

- Recently Daniel has been diagnosed as having mild onset dementia, a condition often associated with Downs Syndrome in middle to later years. This has resulted in Daniel leaving his home and not knowing where he is or how to get back. The situation deteriorated to the extent that care professionals were looking at whether Daniel would have to move into full-time residential care
- Daniel is at risk from floods and cooking accidents due to a tendency to turn gas or taps on and then get distracted
- Daniel is also at risk from bogus callers whereby people may falsely try to gain entry to his property

The solutions

- Daniel's home was fitted with telecare sensors that will raise an alert if gas or water is detected

- Daniel also had a property exit sensor installed so if he opens the door between certain times an alert is sent to Chichester Careline who can then initiate the appropriate response
- A bogus caller telecare solution has also been installed to reduce the risk to Daniel from people trying to gain false entry

The outcome

The introduction of the telecare equipment in Daniel's home has allowed him to remain living independently, much to his delight. His family were initially concerned as to whether the burden of responsibility on the technology for Daniel's well-being was too high but are now extremely happy with the outcome and the fact that Daniel has been able to continue living in his own home.

Vince Foote, Manager for Chichester Careline who monitor Daniel's telecare equipment said: *"If it wasn't for the technology, the likelihood is that Daniel would have been forced to move into full-time residential care. As it is, we are alerted to situations which may pose a potential risk. We have worked with Daniel, his family and his professional care team to ensure that we can address any such situations as effectively as possible".*



focus on the TATE project

The original objective of the TATE Project was to explore the use of assistive technologies and develop software and IT solutions. As an extension TATE decided to work with Tunstall to extend the idea of developing a core set of technology which could complement assistive technology from Possum Controls. The real potential is in providing individualised solutions.



The project had three main objectives:

1. To demonstrate how assistive technology can support independent living for people with learning disabilities and their carers, increasing their employability and allowing them to take a full and active part in the communities in which they live
2. To involve people with learning disabilities and their carers in the design, implementation and delivery of assistive technology devices within a variety of living environments
3. To develop life skills software to enable people with learning disabilities to develop their skills in key areas, thereby enhancing their employability

The project achieved these objectives by:

- Identifying barriers to the implementation of assistive technology for people with learning disabilities and their carers
- Developing an assessment tool for staff and carers
- Testing assistive technology systems within different housing environments

The project worked with key stakeholders in the private, public and voluntary sectors to effectively mainstream and disseminate key learning points from the partnership. The partnership challenged paternalistic culture for the support of people with learning disabilities and enabled both staff and those with learning disabilities to explore new ways of working together to empower individuals to take decisions in their own lives.



Since the TATE Project ended in 2008 HFT has been building on the lessons learned from the project and striving to implement and embed the use of Assistive Technology across all of its services.

For more information on the project and the outcomes please email personalisedtechnology@hft.org.uk

caring for carers



Nobody would want the personal care provided by family members, or formal carers to be replaced by telecare technology. Carers will therefore need to understand both the potential and the limitation of telecare and be comfortable to work alongside it. Telecare can offer to friends, relatives and neighbours a cost-effective way of being alerted to identify and respond to potential risks before they become acute.

Carers for those with learning disabilities can suffer immense emotional and physical strain, and respite from their role is made difficult by the adverse effect it can have on the person they are caring for. Telecare can offer families the opportunity to spend time with other siblings secure in the knowledge that should the son or daughter with learning disabilities need help or support they will be alerted. A good nights sleep can be a rare occurrence for family carers and technology can improve this situation by offering reassurance that should their loved one need their help they will be alerted quickly.

Telecare can also play a vital role supporting the third of people with learning disabilities who are living at home with carers over the age of 70. In many cases there can be a dual support role with the person with learning disabilities also providing care and support to their elderly carer. Telecare can make it much easier for either person to summon help if the need arises and allow families to remain living together.

Sarah

Sarah has learning disabilities and lives at home with her 82 year old mum.

Risk - Sarah's mum slipped one day in the bathroom and fell, breaking her hip. Sarah was able to pull her cord and summon help for her mum but Sarah's mum did have to stay in hospital. Could Sarah stay at home?

Solution - extra telecare sensors were installed into the house which allowed Sarah to remain supported in her own home. Had the telecare not been fitted it is likely that Sarah would have had to go into residential care until her mum was released from hospital.

Outcome - Sarah did not have to go through the emotional trauma of moving to an unfamiliar setting whilst she was worrying about her mum and Sarah's mum was able to concentrate on her recovery reassured that help was available through the technology if Sarah needed it.

For more information on how telecare can support carers download Tunstall's Support for Carers Technology Guide from www.tunstallhealth.com/guides or call 01977 660479 for a copy.

summary and next steps

The nature and extent of learning disabilities is unique to each individual and this means that the support required is also unique. This is why providing truly tailored care and support is essential, whether it is provided at home or in a supported living setting. Telecare offers a platform of constant reassurance around which care can be planned.

For further advice or information on how telecare can support people with learning disabilities, please call us on 01977 660479 or email enquiries@tunstall.co.uk

about Tunstall

Tunstall is the world's leading provider of telehealthcare solutions, with over 2.5 million users globally. Tunstall's solutions support older people and those with long-term needs, to live independently, by effectively managing their health and well-being. Tunstall provides technology, expertise and advice to millions of people enabling them to lead independent more fulfilling lives.

For more information on how telehealthcare can improve quality of life, visit www.tunstallhealth.com or call 01977 660479.

- **Tunstall DVD** - The Tunstall training and education DVD contains essential information about how telehealthcare solutions are benefitting individuals and healthcare providers. For your copy call 01977 660479 or email enquiries@tunstall.co.uk

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