



TEC stories

HOW TECHNOLOGY ENABLED CARE HAS TRANSFORMED PEOPLE'S LIVES

A RESOURCE FOR SOCIAL CARE DIRECTORS AND COMMISSIONERS





The voice of technology enabled care

TEC Services Association (TSA) is the not-for-profit industry body for technology enabled care services. It represents over 350 organisations including telecare and telehealth service providers and suppliers, commissioners, digital health businesses, housing associations, emergency services, academics, charities and government bodies.

www.tsa-voice.org.uk
@TSAVoice



Think Local Act Personal (TLAP) is a partnership committed to personalisation and community-based approaches across social care, health and housing. TLAP brings together central and local government, people with lived experience, commissioners, providers and social enterprises to promote innovation and shared learning through networks, events and resources.

www.thinklocalactpersonal.org.uk
@tlap1



The Association of Directors of Adult Social Services (ADASS) is a charity that aims to further the interests of people in need of social care in England. It promotes high standards of social care services and influences the development of social care legislation and policy.

www.adass.org.uk/home
@1adass

Thank you

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Disclaimer: ADASS, TSA and TLAP do not endorse any particular brand in this publication.

THESE STORIES, REMARKABLE AS THEY ARE ON THEIR OWN, COLLECTIVELY PROVIDE A STRONG NARRATIVE THAT SHOWS THE INVENTION AND CREATIVITY OF PEOPLE WHO NEED SUPPORT AND WHAT DIGITAL TECHNOLOGY CAN DO FOR THEM.



THE INITIATIVE FOR THIS PUBLICATION COMES FROM A SINGLE IDEA, A CAVEAT AND A BELIEF.

The idea is that when people tell their own stories, using their own words those stories carry weight and influence in a way that professionals, public bodies or commercial enterprises struggle to achieve.

So, people telling their own stories in their own way is a powerful vehicle for greater understanding and change.

The caveat is that the impact new technology has had on everyday life has not been felt to the same extent within social care (or health care), yet.

Then the belief: when I became President of the Association of Directors of Adult Social Services (ADASS) I highlighted what I believed to be the 'opportunity' presented by digital technology. It gives people greater opportunity to be engaged with a wider community, to make their own decisions, be better informed and be more independent and for social care (and healthcare and housing) in turn to be more individually tailored - personalised.

These stories, remarkable as they are on their own, collectively provide a strong narrative that shows the invention and creativity of people who need support and, what digital technology can do for them.

All we have to do to ensure that people can take advantage of what digital technology has to offer, is open our minds and our practice to facilitate this transformation.

Glen Garrod

President of ADASS and Executive Director of Adult Care and Wellbeing at Lincolnshire County Council

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5 STEPS TO EFFECTIVE TEC COMMISSIONING

From fall detectors and alarm pendants to a myriad of apps designed to help people maintain their independence, technology enabled care (TEC) is revolutionising the way we support and care for vulnerable people.

It enables us to monitor inactivity and dehydration, reduce the risk of falls and other causes of avoidable hospital admissions, be proactive by sending public health messages, support independence in the community and so much more.

The speed at which technology is evolving is both a boon and a headache for commissioners, but we do know it is essential to include people with lived experience in the design, development and delivery of the technology that could transform their lives.

Nathan Downing, TSA Associate - Business Strategy and Service Transformation, explains how to make the most of TEC.

WHAT ARE THE POSSIBILITIES?

Moving from analogue to digital TEC could be about more than a simple replacement. Is this an opportunity for a fundamental redesign of TEC?

Emerging digital technology is already impacting health and care:

Big data analytics have cut A&E waiting times by **30 min** in some hospitals

Research shows that **artificial intelligence** is as good as human experts at recognising skin cancers

100s of UK councils use GPS tracking systems to **monitor people with dementia**

PEOPLE ARE MORE TECH SAVVY

The average UK home has **8.3** web connected devices. By 2020 this will rise to **29**

20-30 billion devices will be connected to the 'internet of things' globally by 2020

10.7% of UK patients ordered repeat prescriptions online in the last 6 months

3 million wrist-worn health and fitness wearable devices were sold in the UK in 2015

1 Shift the culture within your organisation to one that embraces technology and involves people with lived experience in developing it. Accelerate the switch from analogue to digital, put the emphasis on proactive rather than reactive provision and ensure it's outcomes rather than outputs led so that it is driven by the citizen. Move away from 'just in case support' in favour of an empowering, enabling approach.

2 Quality is key - it's vital to engage with services that can demonstrate quality and safety as part of a robust delivery model, with the ability to evidence audited compliance to the recognised certification that the Quality Standards Framework, independently run by TEC Quality, provides: www.tecquality.org.uk

3 Lay the foundations for a robust TEC offer - don't just prescribe equipment, referrals should focus professionals on mitigating risk and achieving outcomes through TEC. Create a mechanism to track the impact of TEC and the benefits it delivers for each person in the shape of savings and cost avoidance.

4 Be clear on governance - a strategic owner is very important as any TEC programme cuts across health and social care and the programme needs to be prioritised correctly. It will also enable strong leadership in prioritising a training programme that raises awareness and brings about culture change throughout the organisation.

5 Work in partnership - it's vital that those who are using the TEC are fully engaged in discussions and in shaping solutions. It's also important to demonstrate the clear benefits of TEC to partners across health, housing, social care and the voluntary and independent sector. Provide clarity on 'what's in it for me?' for each partner.

Wherever possible, make the most of opportunities to take TEC further. That could include embedding digital technology within housing provision to support vulnerable tenants (for example, through wellbeing clinics using video calling) and enabling wider efficiencies in areas such as repairs.

TEC creates ways to collaborate with domiciliary care, such as by setting up virtual care visits. It also feeds into the wider smart city agenda by utilising data sharing across public services to identify how to proactively support and drive self-care.



Rt Hon Paul Burstow
President, Technology Enabled Care Services Association (TSA)

In so much of our lives, technology has transformed the way we do business and the way we live. It is part of our everyday experience.

Yet in health and social care, the deployment of technology to enable people to lead independent lives is still in its infancy. There are, of course, beacons that mark the way to a digital future but challenges to widespread adoption remain.

By giving a voice to those who are already using a rich array of technology - from apps to smart devices - to enable them to lead the lives they choose, this publication offers commissioners and practitioners alike a case for change.

The message from these stories is that technology is just a means to an end. The end, in the words of the Care Act, is promoting the wellbeing of the individual.



Clenton Farquharson MBE
Chair of Think Local Act Personal (TLAP)

In the debate about the future of healthcare and social care it's easy to lose sight of what we're actually trying to achieve.

And in tying ourselves in knots over how to change the system we open up what we at Think Local Act Personal (TLAP) have come to call the 'rhetoric versus reality gap'.

That's why we strive to ensure that those with care and support needs have their voices heard and play a leading role in reshaping services.

There's nothing like real life stories to bring home what's going wrong and what's going right, such as the way investment in technology is transforming people's day-to-day lives.

As a disabled person myself, I'm excited by the fact that technology enabled care and support is finally moving towards the forefront of the debate.

Just buying bright, shiny devices is not the answer. But by focusing on the outcomes that matter to people, technology can be life enabling.

At a time when the pressures on adult social care have never been greater, business as usual is unsustainable.

The case for making technology part of the solution is compelling. Supporting independence, generating actionable intelligence to prevent crisis, safe discharge from hospital care, support for family carers and making the best possible use of health and care staff are just some of the benefits.

The TSA is delighted to be partnering with the Association of Directors of Adult Social Services (ADASS) and Think Local Act Personal (TLAP) in producing this publication.

But we still need to hammer home the potential it offers and personal accounts are a powerful way to do that.

In this publication you'll find inspiring stories from people of all ages and backgrounds. They're using everything from apps to smart sensors to enhance their independence, better manage long-term health conditions and show that technology can enable a better quality of life. But we mustn't forget the importance of relationships and people being involved in decisions about what matters to them.

What is particularly encouraging is those with care and support needs are starting to drive the agenda, adapting technology to suit their needs and in doing so demonstrating the difference it can make.



Colin's story

Colin has a double-star distinction in IT, he is an avid fan of technology, and loves his iPhone X and gaming consoles. He also loves to prove to the world that his complex disabilities do not stop him from enjoying everything that technology has to offer.

Aged 24, he was the perfect candidate to help Leeds and York Partnership NHS Foundation Trust to develop and test a new digital tool designed to support young people through transition into adulthood.

He and his mum, Susan, have worked closely with the trust and developers of the Let Me Show U! (LMSU!) app, basing advice on their own difficult experience of Colin's transition from school to college.

LMSU! is a digital tool that can be used across devices, including desktop computers and as a mobile app. Now nearing the end of its development, it is hoped that it will help to fill what Susan describes as the "big black holes" that appear when a young person is in transition.

IT PUT COLIN ON A LEVEL PLAYING FIELD - ONLINE HIS DISABILITIES MAKE NO DIFFERENCE TO WHAT HE CAN DO.



Not being able to speak doesn't mean you have nothing to say.

LEVELLING THE PLAYING FIELD WITH TECHNOLOGY

By assembling important information about the young person, the tool helps to deliver consistency in support and empowers them to have a voice in their future.

Colin explains that the app is his "communication", a speech alternative that breaks down the barriers to him relaying what he wants and needs.

One way that he plans to use the app is to upload videos showing how he should to be lifted in and out of his wheelchair. A new personal assistant (PA) or physiotherapist could then watch the video on the app, provided that Colin has given them access.

In preparation for the app's launch, Susan has compiled information about Colin, ranging from his medication to his social activities, ready to load on to LMSU!.

She says this process has made her plan for all eventualities, something she believes is useful for a parent with a child approaching transition.

"As a parent of a disabled child, I think you can become a bit complacent that some things are 'just life' and you get on with it. Getting ready for LMSU!, we have gone through all aspects of Colin's support; all the things that could happen and every detail that we want those working with him - like his PAs, physios and occupational therapists - to know.

"We went through Colin's transition without having those foundations in place and it meant that when situations arose, those around Colin weren't well placed to deal with them."

It wasn't just Colin and Susan's experience of transition that made their perspectives so vital in the app's development process.

Colin understands better than most how technology can transform lives. From childhood, he began using a head switch so that he could play with mainstream toys. As he grew older, he used a communication aid and then moved on to a laptop, again powered by his head switch.

When he discovered that the iPhone's IOS7 system could integrate with his head switch technology, life really changed.

Susan explains: "When Colin got his first iPhone he got total control over his life. He started banking online, he was texting his siblings to make dates, he orders us takeaway for our tea! It put Colin on a level playing field - online his disabilities make no difference to what he can do."

When imagining life now without his technology, Colin says he "couldn't cope". He's passionate about helping other people with disabilities to explore different types of technology.

Colin volunteers at the William Merrit Disabled Living Centre in Leeds, which provides advice and opportunities to try out equipment. He has also helped to deliver a workshop at his local Apple store on how iPhones can be integrated with assistive technology.

Susan was also an early adopter, having bought a mobile phone when Colin was aged just three. For her, this was the difference between him going to school and not going.

"Sending any child to school is daunting, but when they have disabilities it is so terrifying. What if something happens and the teachers can't reach me? I had to get a phone to know I was contactable, and it gave me a life."

Colin and Susan have a mantra, which is never to say "I can't do it" but to ask "How can I do it?"

They believe that the technology like LMSU! has a lot of potential to give more people more opportunities.

"Everyone has very different needs so will use it differently," says Susan. "For any young person though, it gives them a voice. Some of Colin's friends are non-verbal and I often think they must feel so trapped.

"Not being able to speak doesn't mean you have nothing to say. This technology is a way of making them heard."

Alice's story



A ONE-BUTTON SOLUTION TO HELP TACKLE LONELINESS

It gives me contact with my friends and family, it keeps me company.

Alice is in her early 80s and lives in London. She is a very sociable lady, with friends, interests and close ties to her community, but she misses her family who live in Ireland.

Alice has no experience of using computers or smartphones and the lack of 'real time' communication has, at times, made her feel lonely.

Through a project between her local church and Norwegian start-up firm, No Isolation, she was invited to test a piece of communication technology designed for older people who find new technologies intimidating and difficult to use.

KOMP is like a television. It has a simple user interface with only one large graspable button, a built-in camera, loudspeakers and a microphone. Using Wi-Fi, it can receive photos, text messages and video calls. Content is shown on a continuous loop and once set up, requires no logins or passwords.

"It's a marvellous machine and a really lovely thing to have in my home," says Alice. "It gives me contact with my friends and family, it keeps me company."

When Alice can't attend family events, she is video-called live.

"At my brother's recent wedding anniversary, I felt like I was there. I can see everyone and hear what they are saying. I don't feel like I'm missing out."

Relatives and friends can connect with Alice on her KOMP using an app. This makes the technology accessible to all generations of Alice's family, increasing their usage. Once connected, they see the photos and messages she has been sent.

She says: "They don't miss a trick! They love to see what I am up to and it gives us lots to talk about when they see the funny messages my friends have sent me."

1.1M PEOPLE IN THE UK AGED 75 AND OVER ONLY HAVE CONTACT WITH FAMILY AND RELATIVES ONCE A MONTH OR LESS, ACCORDING TO EUROSTAT.

Alice is in control of who she invites to see her content, how long content stays on her KOMP and she can choose whether she wants to join a video call.

In just five months, the KOMP has transformed how she communicates with loved ones, and it is alleviating feelings of loneliness. Alice would like to see it used more by older people, perhaps including people living with dementia and those who have difficulty leaving the house.

"Nights can feel very long when you're alone. Having a KOMP has made a big difference to my life and I would recommend it to anybody who feels isolated or lonely."

A HELPING HAND WHENEVER IT'S NEEDED

Sam's story

Sam, from Dewsbury, experiences mental health issues. A range of situations - coupled with previous traumatic events - cause her to feel anxious and things became so extreme she lost her voice and had to take long periods of time off work.

Commuting to her job in Leeds, Sam found her days getting increasingly difficult. Busy trains, often running late, would cause anxiety attacks and she would often "sit and sweat it out".

Sam would arrive at work feeling shaky and tearful and face the conflicting noises of an office, adding to her anxiety.

She could no longer work and was referred by her community mental health nurse to the not for profit Community Links Engagement and Recovery (CLEAR) service.

CLEAR gave her Brain in Hand, a mobile phone based tool providing immediate and personalised support. In a planning session they helped her to identify all the situations that can trigger anxiety, developed coping strategies and entered these into the software.

If Sam is on a busy train and feels her anxieties heightening, she takes out her phone and is reminded to take some deep breaths and to play a word game to distract herself from the situation, relax and continue her journey.

Brain in Hand has a traffic light system. If Sam is struggling, she can press a button to issue a 'red' alert to the team at CLEAR, which triggers them to call her. If they receive three consecutive 'amber' alerts, they'll also check in with Sam.

Phone calls can make Sam feel anxious, so this works well. "Having to pick up the phone and tell someone I'm not OK can be very scary. Just pressing a button and receiving a call from somebody asking if I'm OK makes a huge difference."

Sam uses the system to regularly check in on herself and reduces 'red alert' moments.

"I have reminders set for every three hours to ask myself how I'm doing. If I'm feeling a bit 'amber' I know I need to take a moment, have a bit of Sam time, and do something nice to stop it escalating."

Not only has she returned to work, Sam has started volunteering at her son's school and gets valuable 'Sam time' every Friday at a craft group.

Since being discharged from CLEAR, Brain in Hand has helped the process to feel gradual rather than abrupt.

"It came at the right time for me, I wanted to go back to work. Having this app has given me the helping hand I needed to become more independent and transition out of my support from CLEAR. It gave me confidence."

Having to pick up the phone and tell someone I'm not ok can be very scary. Just pressing a button and receiving a call from somebody asking if I'm ok makes a huge difference.



KIRKLEES COUNCIL ESTIMATES AN ANNUAL SAVING OF £6,600 FOR EACH PERSON USING BRAIN IN HAND - A TENFOLD RETURN ON INVESTMENT.



Rachel's story



EMBRACING TECHNOLOGY AND REDUCING DEPENDENCE

This isn't about saving money. It's actually about enabling.

Person-centred planning has been life changing for Rachel and her sons, Shaun, 28, and Greg, 30, who have learning disabilities and autism. A dynamic approach to how their funding is spent and a creative attitude towards assistive technology have resulted in significant cost savings and increased independence.

Rachel, from Somerset, was introduced to person-centred planning (PCP) when Shaun and Greg were teenagers. Before this time, she describes her family's approach to receiving specialist support as "passive". PCP opened her eyes to the need to ensure the services they were receiving were meaningful and preparing the boys for adulthood.

Rachel carried this attitude forward into adult services. Opting out of local authority commissioned services, Rachel's sons were given more choice and control through direct payments.

Since taking this step, the family have used an online costed-support planning tool called the 247Grid. This helps them to manage their personal budgets.

The visual weekly grid encourages Shaun and Greg to plan activities and allocate costs to the support, while keeping an eye on the weekly support budget. It prevents overspending, while empowering the family to make informed decisions about how and where the budget is spent.

The grid uses colours to indicate progress and areas of high dependence

on support. Blue celebrates progress towards independence and red identifies where 1:1 support is needed.

Greg has tasks that are important for him to do every week; these go in the grid first and are mostly red areas. He also loves swimming, volunteering in his community, dog walking and meeting up with his friends.

"Greg is very motivated to improve his independence around the red tasks on his grid, as he knows this frees up money to pursue his other chosen outcomes and interests," says Rachel.

Social workers also find the planning tool useful as comparing grids allows them to see progress over a period of time.

Greg also had the support of an online platform called My People and Places, where he could find others with direct payments and shared interests. They would pool their budgets to share support and save money. But local government cuts have resulted in the closure of this website, which Rachel believes was "short-sighted".

She explains: "Pooling budgets is one of the greatest benefits of taking a direct payment but finding others to pool budgets with is now impossible. Direct payments and Individual Service Funds give the opportunity to pool budgets, so it's essential local authorities give people the platform to do it."

Rachel has creatively used many everyday digital gadgets to empower her sons and reduce their reliance on paid support.

Simple digital keyrings store photo prompts that Greg uses to travel by bus or on foot, as a shopping list, or as a 'what to do in an emergency' reminder.

Greg also uses a fitness watch to monitor his 'inactivity' level.

"It visually rewards activity and therefore motivates Greg to be proactive towards everyday tasks and daily exercise." Rachel explains.

Greg is a big fan. He says: "The man on the watch keeps me moving. If I keep going and do enough steps cleaning my house, shopping and walking every day, a star appears. So cool!"

Technology also plays a big part in Shaun's wellbeing. Instead of accepting a residential care bed, many miles away from his community, Shaun purchased a house via HOLD - a home ownership

scheme for people with long-term disabilities. Supervision and prompting techniques are provided in his home with the use of assistive technology.

Shaun has a Careline 'on call' system and room sensors, a chair sensor, a bed sensor and an interactive smoke detector. Gadgets including a tipping sensor on his water bottle, which vibrates if not used every hour, contribute to his health and wellbeing.

Shaun's autism means that he is very sensitive to noise and he finds interacting with people, including personal assistants, unsettling. Before he was using technology, Shaun would get stressed having somebody with him all the time and would repeatedly shout "enough noise" and "people away, away".

He embraces and trusts his assistive technology. It is silent unless it is needed, doesn't seek interaction and it is dependable and predictable.

Shaun's feedback has been positive: "Quiet house now, just my noises."

This 24-hour background support gives Shaun the full supervision he needs while giving his family the confidence to reduce the presence of paid staff.

As a result, Rachel has reduced Shaun's annual budget from £42,000

to £14,800. The residential care he was offered was costed at £1,700 per week, whereas his package of support in his own home came to £810 per week. Incorporating a wide range of assistive technologies, this quickly reduced even further to £285 per week.

After opting out of traditional day services, Greg's direct payment remains steady at £350 a week. By using the digital planning tool and assistive technologies to manage and pool his budget where possible, he has significantly increased his skills, his community presence and his ability, over time, to reduce reliance on paid support.

ASSISTIVE TECHNOLOGY ENABLES 24-HOUR BACKGROUND SUPPORT THAT PROVIDES SHAUN THE FULL SUPERVISION HE NEEDS WHILE GIVING HIS FAMILY THE CONFIDENCE TO REDUCE THE PRESENCE OF PAID STAFF.

"This isn't about saving money," says Rachel. "It's actually about enabling.

"By reaching their greatest potential and reducing their reliance on social care funding, the surplus underspend achieved produces the savings. It's a win - win."



USING A BROAD COLLECTION OF ACCESSIBLE TECHNOLOGIES, MADLEEN LIVES AN INDEPENDENT LIFE. SHE DOES NOT NEED A LOT OF SUPPORT, IS ABLE TO WORK FULL TIME AND RAISE HER CHILDREN ALONE.



Madleen's story

AN INDEPENDENT LIFE WITHOUT COMPROMISE

Madleen, originally from Germany, lives in Kent with her three young children. She works full time for the Royal National Institute of Blind People (RNIB) as a Tech for Life coordinator, a role that she brings personal experience to - as Madleen is blind.

Tech for Life is more than just a job for Madleen. Technology gives her independence, a message she is keen to promote to other blind and partially sighted people.

Madleen was born blind with a very small amount of sight but lost this entirely when she was just 14. At work, she uses a screen reader and braille display for her PC. She also has these technologies for her smartphone, meaning that she can use apps for shopping, identifying bank notes and products, banking, email and GPS navigation.

This technology puts Madleen on a level playing field with sighted people.

"I can just run text through my app or screen reader and read it, just like anyone else would have access to the same information in writing."

Madleen makes use of talking bathroom and kitchen scales and has speech control incorporated into many other household items.

More mainstream products are now accessible to blind and partially sighted people. Madleen owns an Amazon Echo, which she describes as a "fascinating development".

She also considers digital and audiobooks as important progress, explaining: "Looking back just five years ago, I had to say to RNIB customers that only 5% of books are accessible to blind or partially sighted people."

Now we have access to digital versions of nearly everything that is published.

"We can now say to friends and sighted people around us, 'Oh thanks for the title of that book, I'll look it up on Kindle or iBooks.'"

Madleen lives an independent life. She does not need a lot of support, is able to work full time and raise her children alone.

"I can't even begin to say how thankful I am for the development and change of technology," she says. "Without it, I would need support from a sighted person just to access my apps for shopping, banking, reading and emailing. I could not keep down a full-time job doing what I do, my life would not be worth living."

Madleen set herself a goal to live an independent life and feels she has achieved this.

"I use social media, I communicate with friends, I can bank and shop independently. My choice is not limited anymore. I feel included."

I can just run text through my app or screen reader and read it, just like anyone else would have access to the same information in writing.

He is so motivated to do more and the technology he uses is giving him the freedom to do it.

Paul's story

CONNECTED AND IN CONTROL

A self-confessed metalhead and lover of fast cars, Paul, 31, wants to be connected to the world. He wants the access to information and entertainment that many take for granted.

After suffering an acquired brain injury from a fall, he has impaired speech and very limited use of his limbs. Until recently, activities like browsing the internet, watching TV and even switching a light on have not been possible without support.

Paul, who lives in Liverpool, began rehabilitation in 2011 at a specialist neurobehavioural rehabilitation centre, where he uses two separate pieces of assistive technology. An environmental control, powered by a knee switch, enables Paul to watch TV on his own, play DVDs and record programmes. He can also change the room temperature and lighting, using the switch.

He also uses a communication aid, the Grid Pad Three. Paul explains that he wanted "more opportunities and ways to communicate with family and friends".

Ace Centre, the charity which provided the technology, carried out a bespoke assessment to establish Paul's needs with help from his occupational therapist and speech and language therapist.

Paul was involved in the whole process, he says, adding: "I was included in all trials of equipment and my opinion was valued."

With a bespoke stylus and thumb switch he uses social media, browsing

content and chatting to friends and family. He can access information on the internet, without relying on somebody else to support him.

The technology also has a speech aid which Paul rarely uses because he is determined to continue improving his speech. He hopes communication technology will improve further so that he can do more.

It could be "more like a mobile phone", he says, with the ability to send text messages. He adds: "I would like it to be compatible with more apps, so I can do gaming and use WhatsApp."

Overall though, he is "delighted" with his assistive technology.

Paul's occupational therapist, Stuart, believes that his life has improved since using this technology.

He explains: "Paul is a funny and lively guy, his personality shines through and it's important that he can express himself and connect with the outside world. He can now send an email to his mum and dad, or research the line-up for a festival, whenever he wants."

"He can control his environment without staff coming in and out to change the TV channel or switch his light off. He is so motivated to do more and the technology he uses is giving him the freedom to do it."



PAUL USES SOCIAL MEDIA, BROWSING CONTENT AND CHATTING TO FRIENDS AND FAMILY. HE CAN ACCESS INFORMATION ON THE INTERNET, WITHOUT RELYING ON SOMEBODY ELSE TO SUPPORT HIM.

KEEPING RESIDENTIAL CARE AND HOSPITAL AT BAY

Albert's story



From his living room in Newcastle, **Albert, 81, is about to call his granddaughter. This happens at teatime every Tuesday and it's important because yesterday Albert forgot his granddaughter's name. In fact, last week he couldn't even remember where she lived.**

But today, Albert has a screen on his lap. He sees a reminder to 'call Charlotte' and photos of her latest diving trip in Dubai pop up. Albert touches a picture of his granddaughter's face to video call her. When he doesn't want to Skype, he presses 'message Charlotte' and writes a letter instead.

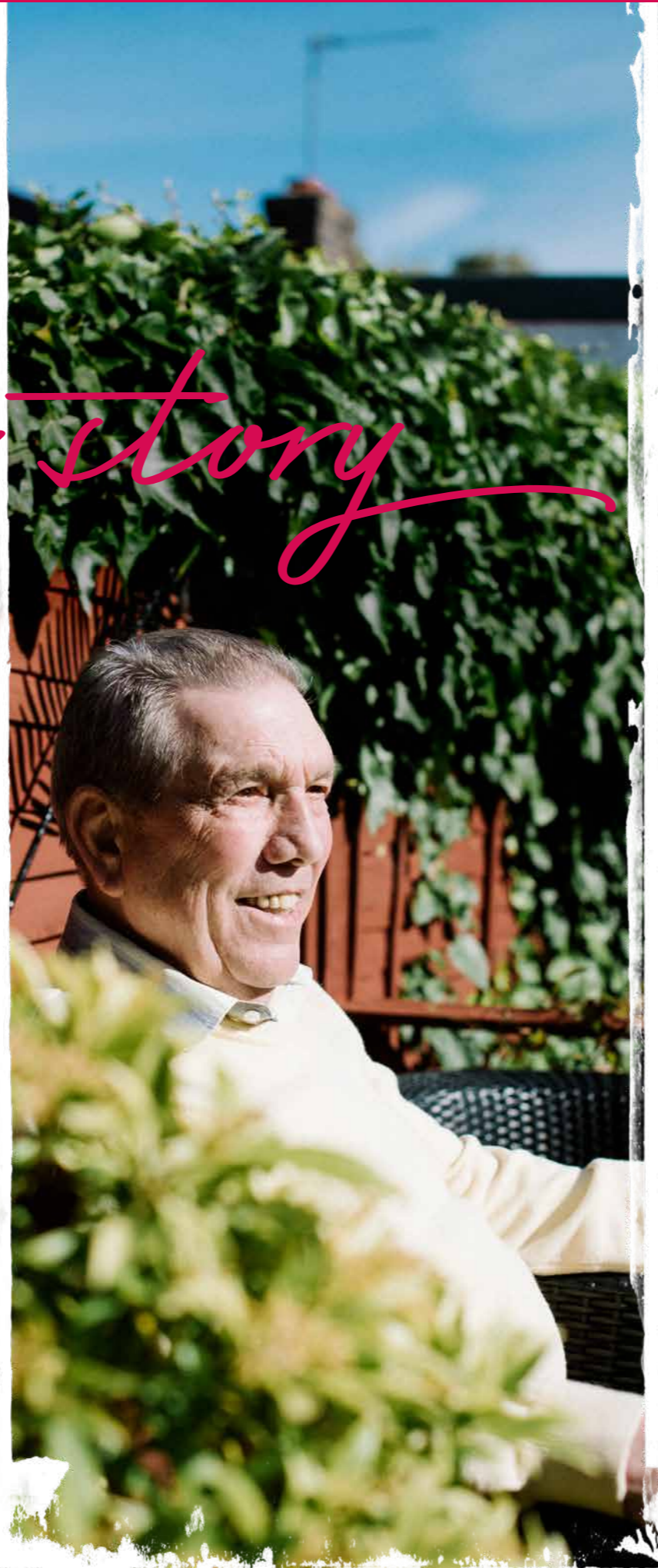
Albert has dementia and last January he lost his driving licence. Six months later, his granddaughter, Charlotte moved to Dubai. Both were big blows. A former engineer, Albert was the 'go-to' person in his family for emotional and physical support. He also cared for his wife who has osteoporosis.

"Before he was diagnosed, my dad would walk around the block and chat to the neighbours", explains his daughter, Rhonda.

"He had a hip replacement and keeping active was important. But now he has to have someone with him. The problem is that my mum's mobility is really poor."

This sudden loss of independence meant Albert became withdrawn. His delusions quickly escalated, and he began having mini-strokes. In just five months Albert went to A&E seven times, with two overnight stays. He was then transferred to respite care for eight weeks.

We listened to what he truly wanted and gelled the technology with everything else that was going on in his life.



"He presented himself well in the nursing home but underneath he wasn't coping," says Rhonda. "He didn't know the difference between the men's and women's toilets."

At the end of his stay, Albert was diagnosed with Parkinson's and mixed vascular dementia.

"Dad was depressed," Rhonda explains. "On top of the new diagnoses he also had angina, diabetes, mobility problems and bleeds behind the eye. Different consultants were dealing with him and it felt like no-one was looking at dad as an individual and co-ordinating his care."

This frustration continued when Albert was discharged because he wasn't offered telecare or digital tools to support him at home.

"All we got was an assessment for adaptations; physical things like grab rails. I knew there were lots of technology that could help dad and us as a family," says Rhonda. "But I also knew that kit on its own wasn't going to work."

The family asked Albert what he wanted. His answer was clear: conversation. "I get up and I don't know what date or month it is. I don't know what the weather is like. I don't know what to talk about."

But there was also something else he wanted support with. "I need your mam to be ok."

The problem was that Elizabeth wasn't ok. She was constantly worrying about him. She wanted someone to make things simple: "There are so many appointments - I feel confused. And I want your dad to feel like he's the head of the house as he's always been."

The family found a simple digital programme via Grandcare that could help. Daily prompts on a tablet now remind Albert to take his medication, do his exercises or listen to his favourite music. Images pop up of today's weather or his grandchildren's travels. When his 12-year old grandson comes over, Albert can press a button and they play online games together.

Technology can only take you so far, says Rhonda. The key is everyone in the family playing their role so that Albert can interact with the whole family and lead as normal a life as possible.

The app has also made things more manageable for Elizabeth. The same programme that helps Albert connect with his family also helps his wife manage his care. Diary alerts remind her of his next appointment and she brings the tablet along so specialists can see his health data.

A small device also goes into Albert's shoe and tracks his location. If he falls, sensors alert a telecare response service. As his needs change the technology can be stepped up, for example to monitor blood pressure and feed health data through to health and care professionals.

SINCE COMING OUT OF RESPITE CARE 18 MONTHS AGO, ALBERT HASN'T ONCE HAD TO VISIT A&E OR GO BACK INTO RESPITE. HE HASN'T NEEDED A CARE PACKAGE FROM THE LOCAL AUTHORITY.

The results have been remarkable. Since coming out of respite care 18 months ago, Albert hasn't once had to visit A&E or go back into respite. He hasn't needed a care package from the local authority.

"It's about progression of need," Rhonda explains. "If we hadn't got my dad - and mum - the support they really wanted then I'm sure my dad would now be in a care home and the mini-strokes would have got worse. He would have hated an off-the-shelf arrangement where a different carer comes in every day. From day one he told us that formal care was something he didn't want."

Importantly, Albert's family don't feel it was the kit alone that slowed his illness. "Technology met my dad's needs partially but it was the human touch that made it really work," Rhonda believes.

"If we'd just bought some boxes of equipment - a pendant alarm, a GPS tracking device and put Skype on his tablet then we wouldn't have got those 18 quality months. But we listened to what he truly wanted and gelled the technology with everything else that was going on in his life.

"We use the technology as a family, his health doctors use it and so do his friends. The result is dad feeling relaxed and empowered and, importantly, himself."

A HELPING HAND 24 HOURS A DAY

People leave our services when they have more confidence and can be independent, but the app means that they are not alone.



Danuta's story

Danuta, from Poland, has lived in the UK for six years. She has longstanding illnesses and relies on help from health and social care services. Faced with a complex system of benefits, support services, and a language barrier, Danuta found the process of getting help very difficult.

A friend recommended Advocacy Centre North (ACN), part of Newcastle CVS, to Danuta where she was matched with an advocate. Danuta learned about disability rights, applied for benefits and had her flat adapted to make it more accessible.

She was then introduced to an app developed by ACN. DIY Advocate enables people to articulate their situation or problem and identify solutions by answering a series of questions. The content is used to formulate an action report which can be saved or sent to a service or support worker.

As Danuta is more confident using written English than spoken, the app suited her. It has helped her resolve issues that would have required the support of her advocate.

After a care assessment, she was concerned about an administration fee, she was advised she must pay to have a carer. Danuta used DIY Advocate to articulate the problems she would have in paying this and to find information that supported her case. This gave her the confidence to work with social services to resolve the issue.

Following the sudden death of her mother, Danuta began to consider what would happen in the event of her own death.

She explains: "I and my family had known my mother's wishes on her funeral service. But despite the hope

that I will live a long time, I realised that none of my relatives know what my opinion is about how I would like to be treated at the end of my life."

Danuta has used her app to find information and to create an action plan, which includes preparing official documents and telling her family in Poland what they contain.

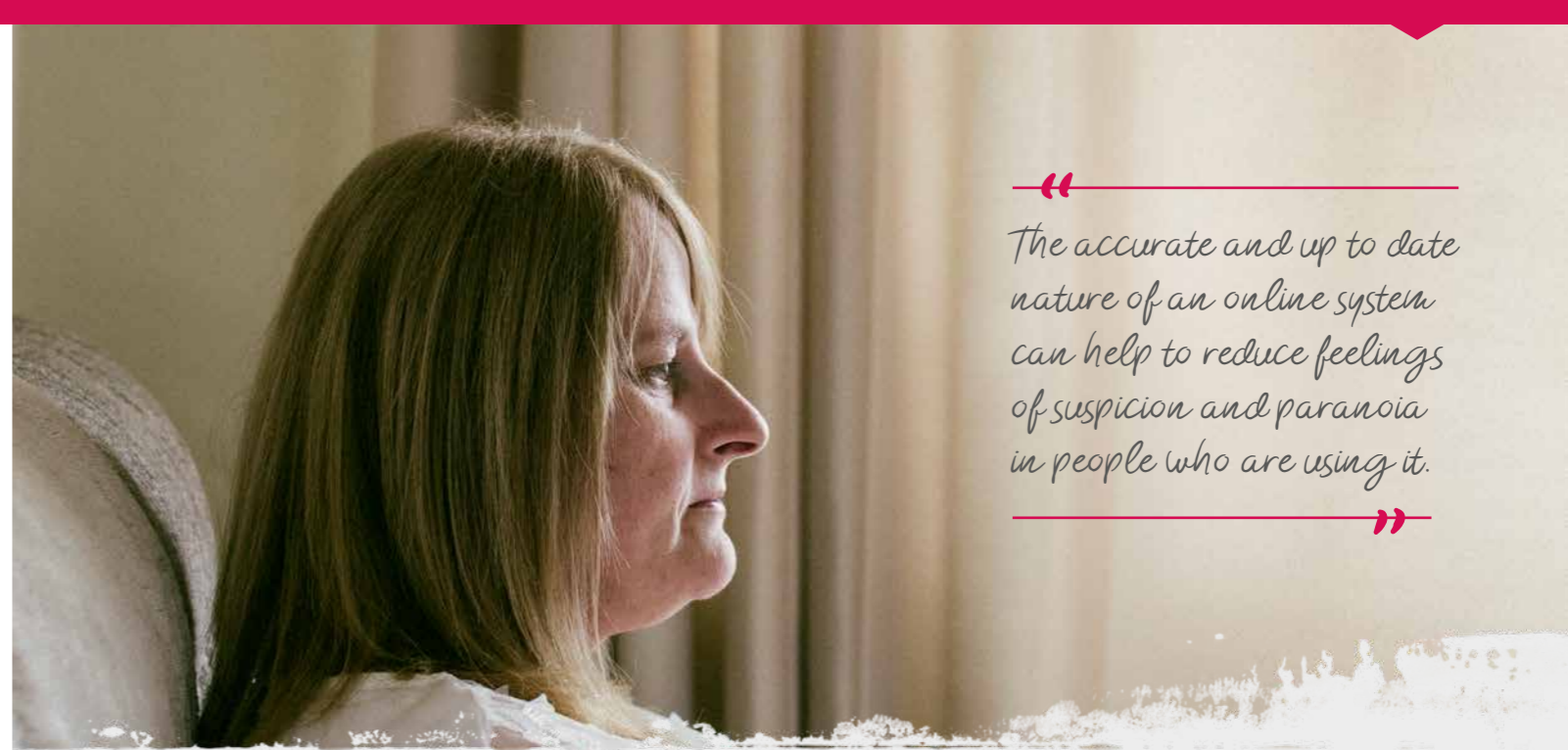
"DIY Advocate helped me to cut off the stress associated with the fact that in the event of an emergency situation I am not prepared for it."

Shervin Nouri, who was Danuta's advocate at ACN, believes the app is empowering people who previously relied on their services.

AS DANUTA IS MORE CONFIDENT USING WRITTEN ENGLISH THAN SPOKEN, THE APP SUITED HER. IT HAS HELPED HER RESOLVE ISSUES THAT WOULD HAVE REQUIRED THE SUPPORT OF HER ADVOCATE.

"The app is that extra bit of help to enable them to self-advocate," she says. "It is efficient and available 24 hours, we know people like it because we have started to receive less 'simple questions' - they can find this information quickly using the app."

"People leave our services when they have more confidence and can be independent, but the app means that they are not alone."



The accurate and up to date nature of an online system can help to reduce feelings of suspicion and paranoia in people who are using it.

Debs' story

Debs has been in the mental health system since the age of eight. She has attempted suicide and been told by a psychiatrist that she will always be ill. But Debs changed her life through non-clinical therapy and is now advising on technology that can help others do the same.

She was in the waiting room of a psychiatrist when she picked up a leaflet for an Art for Wellbeing project. This is one of many services that fit under the banner of 'social prescribing', a range of non-clinical local services that a person can be referred to by GPs, nurses or themselves.

For Debs, deciding to attend an art class changed her life. "It started to feel like there was fire in my belly," she says.

She began to advocate social prescribing to other people who use services and professionals and was asked by Elemental, a 'tech for good company', to review its social prescribing software.

The software offers an online referral system for GPs and other professionals, as well as individuals wishing to self-refer themselves to a social prescribing hub. It connects them with opportunities in their community, filtered by location, cost, ability and the type of support needed. It also offers referral makers the ability to track monthly progress of their patients.

Debs offered a unique perspective and identified some initial barriers for people with mental health conditions.

She explains: "Suspicion and paranoia are common symptoms, so coming across anything that asks for personal information can be very off-putting. You have to word things carefully. You have to show that you need information for good reasons, to help them, and you have to put the person in control."

While Debs advocates having different routes into social prescribing for people with mental health issues, she is confident about the benefits of digital

platforms. She believes the accurate and up to date nature of an online system can help to reduce feelings of suspicion and paranoia in people who are using it.

"If somebody with a mental health condition turns up to an activity and it is full, or the doors are locked because it's been cancelled, they could convince themselves that the building has been shut to keep them out," she says.

"They will probably have plucked up a lot of courage to get there, and then to feel 'shut out' will have a huge impact on their mental health."

SO FAR ELEMENTAL'S SOCIAL PRESCRIBING SOFTWARE HAS BEEN USED IN MORE THAN 40 LOCATIONS AND BY OVER 300 GPs TO MAKE AND MANAGE REFERRALS.

"With the online system, it can be kept up to date so that notifications of cancellations or full classes can be added to avoid this kind of situation."

These insights have made Debs' contribution to the development of the software incredibly valuable. She describes them as "things you wouldn't normally think twice about" and believes that her involvement - as well as other people using it - has resulted in true co-production.

OPENING DOORS TO SOCIAL PRESCRIBING



Loren's story

BUILDING CONFIDENCE, TRUST AND RELATIONSHIPS

Loren, 19 and from Sunderland, recently left children's care services. She has struggled with mental health issues throughout her life, with frequent hospital admissions and going missing becoming symptomatic of her feelings of isolation. Despite being surrounded by people, she didn't know how to reach out and ask for help.

Loren describes herself as a shy person who hasn't always had the confidence to put across her views or to disagree with somebody else's opinion. While she was always involved in her care planning, she would often go along with things that she didn't really want, feeling as though she had very little control over her life.

When she was struggling with her mental health, Loren didn't feel confident in asking for help or sharing her feelings. She would often go missing, self-harm and she spent time in psychiatric hospitals.

Loren was offered a digital tool called Mind of My Own, which Sunderland City Council offers to all children in its care to make sure their voices are heard. Accessed via a mobile phone or computer, it gives young people the chance to write statements under several categories, and then share them with whoever they choose from their support teams.

Traditionally, support workers will write statements on behalf of young people after they have met to speak about issues or prepare for meetings. This technology has been co-produced with children and young people and is designed to more accurately capture and communicate what is important to them.

Initially, Loren turned Mind Of My Own down as she thought it was a tool to help social workers rather than her. She didn't believe anybody would read the statements or do anything about their contents.

The first time she used it, however, Loren was surprised to receive a call from her support worker to confirm he had received her statement. She started using it more often, seeing and feeling the benefits of making her voice heard.

Loren used the tool to help her prepare for review meetings, a scenario she had struggled with in the past. The process gave her more control over the meetings and eased feelings of anxiety and nervousness beforehand.

She explains: "I could fill it in a week before my meeting and know my views wouldn't be left out. It was like a weight lifted off my shoulders because I knew my social worker would get it, he would ring me to say he got it and ask if I wanted to discuss it before the meeting.

"He would print it out and bring it to the meeting. Immediately I felt empowered because he had brought it along and read it on my behalf. I could even include who I wanted to sit next to in a meeting, which doesn't seem like a big deal but for me it was."



One of the categories on Mind Of My Own is 'change something', which Loren found useful when she was worried or anxious about an issue, often late at night. She would write a statement and send it to her social worker, knowing that even though he wouldn't read it until morning, she could relax and go to sleep safe in the knowledge that it would then get sorted.

Loren's favourite part of Mind Of My Own is the 'share good news' category. She believes that meetings with social workers are usually arranged under negative circumstances, to overcome problems. This category encourages young people to contact their social workers for positive reasons as well.

"You want to share good things with them as well, the same way you would want your parents to be proud if you had achieved something."

Loren is now working as an apprentice with the participation and engagement team at Together for Children - a trust that runs children's services in Sunderland - and she would like to become a social worker. She has moved into her own tenancy and has not been admitted to hospital for a long time.

Loren also helps to train social care staff to use Mind Of My Own and she speaks to other young people in care about her experiences.

Since leaving children's care services, she has a new support worker and finds that she uses the tool less now. She can confidently speak to her support worker, to tell her how she is doing and to ask for more support when she needs it.

MORE THAN 70 COUNCILS, LARGE ORGANISATIONS AND NATIONAL NGOS IN THE UK USE MIND OF MY OWN. THE DEVELOPERS SAY IT SAVES SOCIAL WORKERS AROUND EIGHT DAYS A YEAR TYPING UP CHILDREN'S VIEWS.

Loren advocates the use of Mind Of My Own among young people and professionals she works with. She understands how vital it is for young people to have a voice, but also knows from experience how difficult it can be to make that voice heard.

"If I didn't have Mind Of My Own to help me build trust and relationships, and to help me work with services not against them, I wouldn't have the things I have now. I needed a tool to help me communicate and vent to people so I could receive support to deal with those things.

"Young people don't realise how powerful their voice is. If you struggle to communicate then this type of technology is the perfect tool."

If I didn't have Mind Of My Own to help me build trust and relationships and to help me work with services not against them I wouldn't have the things I have now.

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