



Dementia and digital
participation for
health and wellbeing:
Supporting carers
and people living with
dementia

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Chapter 1

Overview

In the UK, around 850,000 people are living with dementia, many of whom are supported by friends and family members. Carers and people living with dementia are at risk of social isolation and reduced wellbeing. Supporting the health and wellbeing of people living with dementia and their carers is a priority for NHS England (as set out in the NHS Long Term Plan) and the UK Government.

Digital participation can play a valuable role in improving quality of life through offering a source of information and advice, providing practical support, enabling social connections, as well as being a source of relaxation, entertainment and a way to pursue interests. Yet digital exclusion remains a significant issue among carers and people with long-term conditions.

As part of the NHS Widening Digital Participation Pathfinder programme, Good Things Foundation supported Leeds Library Service to deliver a Dementia Pathfinder in Leeds. This experimented with ways to support local organisations, carers and people living with dementia to engage with digital to improve their lives. The approach built on existing community assets, working with organisations and groups across the city, training Digital Champions, lending digital devices, and providing resources and ongoing face-to-face support.

This report describes how the pathfinder was designed, what it did, where it had impact and what was learned.

Key findings

- Overall 798 people were engaged in the Leeds Dementia Pathfinder over 12 months. This comprised carers and people with dementia, staff, volunteers and stakeholders.
 - 81 carers trained as Digital Champions
 - 91 staff and volunteers trained as Digital Champions
 - 69 carers trialled iPads or Alexa (in carers' groups &/or in their own homes)
- Many of the carers had no or low digital confidence. Carers using digital for the first time - or who had only used digital in a limited way - reported a range of benefits:

- Practical benefits around getting health information or managing medication.
- Wellbeing benefits around online peer support, relaxation, reminiscence, fun.
- The social aspect of digital was particularly valued. Carers described how engaging in digital improved their relationships. This might be with the person they cared for, or with other members of their local carers' group, or with other carers online. Some felt more confident to support the person they cared for to use digital themselves.
- Providing equipment and face-to-face support in local places where carers already met, alongside the Digital Champion training, helped to build digital confidence among carers, and also among staff and volunteers in dementia-related services. Some staff and volunteers themselves lacked digital confidence and skills.

Ingredients for change: conditions for success

- **Include people with dementia and carers in digital strategies:** Leeds Library Service is part of a cross-sector collaboration in Leeds promoting 100% digital inclusion. This pathfinder created a mechanism to advocate for the specific needs of people who might otherwise miss out: people living with dementia and their carers.
- **Person-centred design - start with what matters to carers:** Giving carers of people with dementia an opportunity to say what support might benefit them, and doing this in a community setting that they trusted, was felt to be vital for success. Leeds Library Service were then able to purchase equipment that was

more likely to benefit carers, and work in ways that built engagement with digital over time.

- **Make the most of community assets:** Working with existing local partners and building on community assets was an important focus for the pathfinder. Early on, Leeds Library Service did a mapping exercise to update existing information about services for carers and people with dementia.
- **Provide Digital Champion training to carers, as well as staff and volunteers:** Digital Champion training proved a positive way to build digital confidence. Making this available to a wide range of people helped to build wider buy-in from local organisations and carers' groups, and increase the potential for sustainability.
- **Embed digital activities in community and carers' groups:** Integrating digital as an ongoing part of carers' groups and memory cafés helped both carers and support workers to develop digital confidence, in a supportive and social setting. It gave people the confidence to try digital in different ways and supported sustainability. Several co-ordinators described how using digital is now part of their regular offer.
- **Support carers to develop online peer support, alongside local groups:** A closed Facebook group set up as part of the pathfinder proved a popular way for carers to engage with each other and share learning, as well as using it as an opportunity to socialise and learn about what is happening in their local area. Membership is continuing to grow and the signs are positive that this will be sustained. This also provides an additional route for local services to keep carers up-to-date.

Leeds Library Service and other local partners are committed to building on success, sharing learning, and sustaining momentum beyond the end of the pathfinder.

Dementia and Coronavirus

This pathfinder evaluation was completed in March 2020, before the coronavirus lockdown. Since then, Leeds Library Service has continued to find ways to support digital inclusion locally, and also nationally - for example contributing to a national list of dementia-friendly apps which drew on the work supported through this pathfinder.

Many of the practice insights and ideas featured in this report reflect a very different context for community organisations and engagement - hence the emphasis on going where people already meet and feel comfortable, social learning and peer support, face to face contact and being able to try things out together as well as in your own home. While some of these approaches are not possible currently, the overarching message from the Leeds Dementia pathfinder is more important than ever. Digital technology, tools and support can play a huge and valuable role in improving lives and wellbeing for people with dementia and their carers - reducing social isolation, improving connectedness with family, friends and communities, and supporting people with practicalities of living with a long-term condition.





Chapter 2

Wider context: Dementia, caring and digital

Dementia refers to a range of conditions that cause damage to the brain, which in turn can impact a person's memory, thinking, language and ability to carry out everyday tasks (Mental Health Foundation 2015). In the UK, there are around 850,000 people living with dementia, set to rise to 1.6 million by 2040 (Wittenberg et al 2019). People with dementia are supported by around 700,000 informal carers, who are estimated to generate £11.6 billion of savings to health and social care services (Alzheimer's Society 2018). People living with dementia want to carry on living as normally as possible, for as long as possible, but they can feel cut off from society and the communities they live in (Crampton, Dean, and Eley 2012).

The importance of supporting people with dementia to live well and participate in their local community is a priority for NHS England and acknowledged in the NHS Long-Term Plan. Beyond the NHS, initiatives are underway to drive change in wider attitudes and support. The Dementia Engagement and Empowerment Project (DEEP) brings together groups of people with dementia from across the UK to influence services and policies. Dementia Friendly Communities are forming to improve local understanding about dementia, while Dementia Friends (led by the Alzheimer's Society) aims to raise public awareness. Some initiatives are finding powerful ways to harness digital for change: through the Dementia Diaries project (led by DEEP), people with dementia are sharing their stories and diverse experiences online.

For carers, there is wide recognition that many experience poor wellbeing, social isolation and struggle to manage their own health (Carers UK 2019). Levels of reported happiness of carers is over a third lower than the general population (Carers UK 2019). Research about carers of people with dementia found that 90% report frequent feelings of stress or anxiety, and four-fifths find it difficult to talk about the emotional impact of caring (Alzheimer's Society, 2018). A focus on carer wellbeing is now enshrined in law through the 2014 Care Act.

Charities like Carers UK and Carers Trust provide valuable online support. Digital technology can improve quality of life through supporting everyday tasks, providing access to support,

and enabling social participation (Good Things Foundation, 2016). However, digital exclusion means that some carers are not accessing these benefits. Adults who have no or low digital skills are more likely to be older, have a disability or health condition, more likely to be living on a low income and/or have fewer qualifications (Good Things Foundation, 2018).

Some carers and people living with dementia may lack the confidence and the resources to give digital a try, and the time to dedicate to learning new skills (Good Things Foundation 2016). There is limited guidance on how to ensure that the benefits of the internet extend to people living with dementia and their spouses or other family carers. Even in Leeds, where the local authority and partners are committed to an ambition of 100% digital inclusion through the Digital Leeds programme, barriers persist (Care Connect, 2017). This is the context for the Leeds Dementia Pathfinder for Widening Digital Participation.





Chapter 3

Leeds Dementia Pathfinder for Widening Digital Participation

Good Things Foundation worked with Leeds Library Service to explore how digital can improve the lives of carers and those living with dementia. Over 8,000 people in Leeds are living with dementia and that number is forecast to grow.

The Leeds Dementia Pathfinder is aligned to the 100% Digital Leeds programme for digital inclusion, working with partners across the city. It is also linked with the Leeds Health and Wellbeing Strategy on harnessing the benefits of technology to increase independence, improve wellbeing and help manage health conditions.

Supporting people with dementia is an aim of the Leeds Health and Care Plan Outcomes, with the Digital Inclusion Coordinator post funded through the aligned Leeds Integrated Better Care Fund. The co-ordinator role is in the 100% Digital Leeds team, providing training and resources to help local organisations integrate digital inclusion into the support they offer.

The Leeds Dementia Pathfinder supported a range of activities. Data was collected across each to assess impact (see the table for activities and data collection). As well as lending iPads to carer groups and dementia memory cafés, Leeds Library Service tested innovative approaches to technology - virtual reality as reminiscence therapy and voice activated devices.

Designing the Leeds Dementia Pathfinder

Co-designing the Leeds pathfinder involved:

- Two workshops at the beginning, one for stakeholders who work with people with dementia and another for people living with dementia and their carers.
- A mapping exercise to identify local groups for carers and people living with dementia, identifying groups still running and finding ones that were not advertised.
- Focus group sessions, run through a local carers group, to explore the kinds of digital technology (if any) being used; perceived barriers and aspirations.

These informed the intervention model and Theory of Change (which sets out the desired outcomes and the activities which would help achieve them). Good Things Foundation and Leeds Library Service worked together to consider what and who would need to be in place, and to design and collect data to understand whether the pathfinder made a difference.

Through co-design and feedback, the pathfinder became focused on:

- Prioritising carers of people with dementia, enabling them to use digital to help improve their lives in ways which worked for them and the person they cared for.
- Delivering Digital Champion training to relevant staff and volunteers across Leeds, equipping them with digital resources to embed digital in regular sessions and cafés.
- Creating a closed Facebook group for carers for online social contact, sharing life hacks and providing emotional support alongside local meet-ups in their community.

Delivering the Leeds Dementia Pathfinder

The intervention model (outlined in the accompanying How To guide) delivered through this pathfinder was innovative in:

- Working to strengthen the local infrastructure by embedding digital inclusion in places where people living with dementia and their carers already go;

alongside

- Working with carers of people with dementia, enabling them to use digital to improve their own wellbeing.

At the time and within the resources available, this was felt to be the best route to ensuring people living with dementia can benefit from digital. While people living with dementia were supported to use digital themselves where they wished to, this was not the main focus and is a gap which would benefit from further investment and practice development.

1) Digital Champions training for memory workers, volunteers, informal carers

Providing Digital Champion training in trusted community settings was a key component. Leeds has almost 50 dementia memory cafés, a number of peer support groups and networks. Many groups meet in neighbourhood spaces and Leeds Library Service had previously done targeted work in three of these neighbourhoods as part of 100% Digital Leeds.

Providing digital support through existing community services can make it easier for carers to participate, where they may not otherwise feel they have the time to fit digital classes around their caring role. A total of 81 carers received Digital Champion training. Digital Champions training was also carried out with staff and volunteers working in memory cafés, Dementia Peer Support Coordinators, Memory Support Workers and staff working in complex needs day centres. A total of 91 volunteers and staff members were trained across 16 organisations working with people living by dementia.

2) Providing digital equipment

Providing equipment (through loans) was important both for carers groups running sessions (as they may not have the resources to purchase the items needed), and for carers themselves (who may be unsure about what kinds of technology would be suitable for them). This enabled carers to have a go on devices in a familiar and informal environment. Loans of 4G-enabled iPads, VR headsets and Amazon Echo (Alexa) devices were made.

Before purchasing digital equipment, carers and people with dementia had a chance to consider what they might be interested in and how it could fit their needs. Other practical factors also had to be considered, such as WiFi connections for using Alexa. New equipment was introduced in carers groups through presentation and allowing people to try things out for themselves. The box below provides more details about the equipment that was lent out.

iPads

40 iPads were provided to both carer support groups and memory cafés, where staff and volunteers incorporated use of iPads into existing activities through linking to themes around reminiscence, music, games, hobbies and interests.

Amazon Echo (Alexa)

12 Amazon Echo devices (Alexa) were lent out for people to try at home as well as carer groups. This voice activated technology was chosen as it has previously been trialled successfully with similar user groups, and as it is linked with the NHS to provide health information. Most popular uses were: playing music and games, news and weather updates, setting reminders (for medication or appointments), and accessing information.

Virtual reality headsets

Seven virtual reality headsets were trailed with memory cafés and carer groups. Leeds Library Service also ran four sessions using headsets at memory cafés and recovery hubs (this aspect is ongoing and impact is yet to be assessed).

3) Supporting carers groups to use digital in home and community settings

The Leeds Library Service digital coordinator visited groups where equipment was lent each month and built up a relationship with those who attended. Many conversations centred around what carers had enjoyed doing in their lives prior to becoming a carer, which enabled co-ordinator to tailor the approach, such as suggesting apps and resources linked to hobbies.

4) Setting up a closed Facebook group for carers locally

Reflecting discussions that carers could feel isolated, a closed Facebook group was set up to help carers feel more connected. Carers discuss any topic of interest, as well as sharing experiences and learning. Some staff also joined the groups to share information about local events, and engage in relevant discussions. The idea was discussed at earlier sessions, to give people a chance to ask questions and gauge

interest. In one group, many carers either had a Facebook account or were willing to set one up - so the idea was tested here first.

5) Developing resources and building momentum across Leeds

The mapping exercise of memory cafés, peer support, dementia and carer groups enabled more effective partnerships with Leeds Alzheimer's Society and Leeds Older People's Forum, and extended existing networks to include some

groups which had not been linked in. Digital Champions training was identified as an important way to build buy-in from individuals and organisations across the city, and start to build momentum. This was supported by taking a responsive approach to feedback from Digital Champions - for example, creating a local list of dementia-friendly and age-friendly Apps, or providing additional equipment for accessibility.



Leeds Dementia Pathfinder Theory of Change

Intended outcome	Activities	Outputs	Data collection
<ul style="list-style-type: none"> Carers use digital technology to support their wellbeing Carers use digital technology to increase social connections and reduce isolation 	<ul style="list-style-type: none"> Lend equipment (Amazon Echo (Alexa), virtual reality headsets) Ongoing digital support at range of venues: memory cafés /complex needs centres/ care homes/carer groups Set up closed Facebook support group for carers 	<ul style="list-style-type: none"> 37 iPads lent to 6 memory cafés; 2 care homes, and 3 complex need centres. 24 were used in the groups and 13 were taken home by carers 6 VR headsets lent (4 for use during groups and 2 were taken home) 11 Amazon Echoes were taken home and trialled with carer and person cared for in different living situations (at home/care home support); stages of dementia; different relationships (e.g. spouse, parent) Closed Facebook groups set up for two dementia carer support groups (22 members to date) 	<ul style="list-style-type: none"> 45 surveys and 5 focus groups collected at the outset <p>ipads users</p> <ul style="list-style-type: none"> Completion of 5 ONS Wellbeing 4 item scale at beginning and end of intervention Observation notes One-to-one interviews with 5 participants 4 Case studies, 1 Digital Champion, 3 participants <p>Facebook users</p> <ul style="list-style-type: none"> Social isolation question (8 responses at beginning and end of intervention) User questionnaires (8 responses) <p>Alexa users</p> <ul style="list-style-type: none"> 7 one to one interview with 8 participants Completion of 8 'activity logs' Case study
<ul style="list-style-type: none"> Organisations, staff and carers across the city are enabled to support people with dementia to use digital technology 	<ul style="list-style-type: none"> Lending equipment Digital Champions training Ongoing support visits to groups at range of venues Develop resources to support use of digital Awareness raising 	<ul style="list-style-type: none"> 3 iPads, 1 VR headset and 1 Alexa lent to Dementia Coordinators to take to venues across the city. 172 people received Digital Champion training Developed a local service map Developed a local list of dementia-friendly and age-friendly Apps. 	<ul style="list-style-type: none"> 2 face-to-face in-depth interviews and 6 questionnaires with 8 Digital Champions





Chapter 4

Impact and insights

Good Things and Leeds Library Service wanted to learn whether the pathfinder was contributing to improvements in the lives of carers, and the lives of people with dementia. So, at the beginning of the pathfinder, Leeds Library Service sent questionnaires and ran focus groups with five carer groups across Leeds to learn how carers could be supported to use digital. The box below summarises what carers identified as barriers and aspirations.

Perceived barriers identified by carers

- Frightened of pop ups in apps asking for financial details
- Too many apps to choose from
- Not knowing how to use digital technology
- Not knowing how to download apps
- Too many icons and functions, these are not always accessible visually
- No device, Wi-Fi or access
- Lose patience quickly
- Forget login and passwords
- Tired of repeating the same instructions to the person cared for
- No digital skills
- It's complicated

Perceived benefits identified by carers

- Have opportunity to chat to other carers when feel frustrated or tired
- Have easier conversations with the person cared for
- Have meaningful, memorable activities to share and do with person cared for
- Feel more connected
- Have resources to help encourage reminiscence and share good memories/photographs

Analysis of 45 completed surveys showed that a majority (two-thirds of survey participants) did not use digital at all. Of the 15 carers who used digital already, some felt they had 'low level' digital skills. The most frequent tasks they used digital for was to play games (6 out of 15), followed by keeping up with news and sport (2 out of 15). A number felt unsure as to how digital might benefit them; only a few said they could see no way in which digital could be of benefit to them. In one focus group where carers were asked their age, nearly all (90%) were over 65 years old. This picture chimes with wider evidence around older people's use of digital (see Good Things/Centre for Ageing Better 2019). Only one carer had used social media or Alexa, which confirmed the potential value of finding ways to support carers to explore and test different digital tools through the pathfinder.

As well as specific concerns relating to digital, carers also talked about challenges around their caring role, such as: the person they cared for becoming agitated or angry, or experiencing low moods and being repetitive at times; challenges of tasks such as washing and dressing; financial problems, or where careers and relationships had broken down due to pressures of caring. The financial costs of devices and data did not come up strongly in this pathfinder - which may reflect reticence about discussing money in public, lack of information about costs (as equipment was provided), or that this was less of an issue for those involved.

Making a positive difference in people's lives

Carers reported a range of positive outcomes through participating in the pathfinder, including feeling happier, relaxed, less isolated and more supported in their carer role. Improved quality of life was also identified for some people living with dementia - often through rekindling interests or memories, also through supporting self-management of medications.

Five carers provided responses to questions used in the ONS wellbeing survey¹ both before and after their involvement in the pathfinder.

1. 4-item wellbeing measured used across ONS surveys, based on five responses where the questions were completed at the beginning of the intervention and just over three months later

Although a very small sample, their responses indicate that digital participation and the support they received improved their wellbeing:

- Four of the five carers reported they felt happier, and were more satisfied with their life, with an overall average score of 7.2 compared to 6 at baseline.
- Carers were less likely to say they had felt anxious the day before when compared to the beginning of the project – scores reduced from an average of 5.6 to 3.6.

More broadly, through observations, qualitative interviews, case studies and the ‘activity logs’ (used by eight carers who were trialling Alexa in their home), we found these ways in which carers’ reported benefits from digital participation: (1) practical support for their caring role; (2) improved psychological well-being; (3) improved social connections; and (4) more confidence, including digital confidence.

1) Practical support for the caring role

An exciting aspect of the pathfinder was enabling carers to trial digital technology that was new to them – including voice-activated technology through Alexa. Several carers used Alexa to access health information or to support managing medications. Carers described Alexa as “convenient” and even as “exciting”.

Some carers used Alexa to access health information online. They felt reassured as the advice was provided through a trusted source:

“Having NHS information and advice so easily, I can ask [Alexa for] advice around health symptoms and I know it's NHS approved information.” (Carer)

One carer said they used it to find out more about dementia; another used it for ‘in the moment’ advice about a nosebleed:

“Peter had a nosebleed last week and I could ask Alexa “What do I do for a nose bleed” and she told me what to do and gave advice and guidance from the NHS website which was really great and reassuring.” (Carer, Alexa User)

Several carers used Alexa to set reminders for medication. One carer said she could now take naps, where she previously felt anxious about doing so in case she missed medication times. Another carer said Alexa had meant the person she cared for was better able to maintain his

health independently, bringing benefits for both of them:

“My husband takes so much medication that I had four reminders on my phone, Alexa has taken that strain away from me as she is the one now reminding him to take his medication, we have even added the extra.... are you sure you have taken your medication? My phone is no longer bleeping all day which is fantastic!”

One carer said she felt able to go on holiday, where she did not feel comfortable doing so before without family support, as she was reassured that Alexa would convey the reminders.

Significantly, one carer explained how using the Alexa reminder function had changed her relationship with her father – moving from a relationship where she was frequently prompting him to take tablets and do daily exercises, to one where they enjoy each other’s company:

“Using these reminders and features of Alexa has been life-changing... I don't feel like a broken record anymore, I can talk to my Dad and chat about other things other than just asking him to do these tasks all day, when I speak to him he can be chatting about a memory or we can laugh about something on the TV.”

Some carers talked about how Alexa had reduced the practical and also the emotional pressures of their caring role – in ways that would not have come to light without being able to borrow the equipment and try things out in a supported way:

“I didn't realise all that Alexa could do and how it can support me in my everyday life”.

While many carers benefited from being provided with digital devices and digital inclusion support, helping them to release time for other things, nonetheless the time pressures experienced by many carers could be a barrier to participating and accessing support on offer. It was not always possible for carers to find the time to realise the benefits of digital and online support.

Case Study: Diane and John

Diane is a full-time carer for her dad John, who has been living with dementia for seven years. He also has physical health issues and very low communication skills which make it hard to leave the house. Before introducing an Alexa device into her home (as part of the Leeds Dementia Pathfinder), Diane had over 20 reminders and alarms on her phone to prompt her to remind John to take his medication and carry out daily exercises: *"I feel all I [did was] give him instructions"*.

Diane couldn't initially see how Alexa would change her everyday life or be of benefit to her or her Dad. However, after hearing another carer sharing great feedback she said she felt more confident to give it a go.

Since installing Alexa, Diane has programmed medication, exercise and appointment reminders into the app so that it now reminds her dad to do these daily routines. As she says *"I can't tell you how great it is, I don't feel like a broken record anymore...when I speak to him he can be chatting about a memory or we can laugh about something on the tv"*. Diane has also created prompt cards with useful phrases that her dad can say to Alexa which he uses. Diane is also sleeping better, as knowing the reminders are programmed into Alexa means she can relax, and also through playing meditation music and calming ambient sounds.

Alexa has also been beneficial to her Dad John's health and wellbeing, as Diane puts it: *"he has now become so much happier, it makes me so emotional to think how much it's changed his life and mine...I can't imagine our lives without it"*.

2) Improving psychological well-being for carers and people with dementia

Of the eight carers who kept 'activity logs' about using Alexa at home, four said it reduced agitation in the person they cared for. More generally, carers who trialled Alexa and iPads reported improved moods - both for them and the person with dementia whom they cared for:

"It's made me happier" ... "I find it has helped me so much to have a bit of my life back, a little bit of the old me" (Carer, iPad user)

A few carers referred to the beneficial effect of digital equipment on the person living with dementia - contributing to feeling calmer, happier and finding joy through digitally-enabled experiences. One carer said that his wife had now rekindled her hobbies after he added various jigsaws and puzzles to an iPad. Another who had served in the Royal Navy "came alive" when a Digital Champion found a YouTube video of old navy songs and photos:

"[He] started tapping his feet, clicking his fingers and smiling... which resulted in him sharing stories of his days on the ships" (Digital Champion)

Many carers described how using digital technology helped to strengthen their relationship with the person they care for, through sharing jokes and memories:

"It's given us both an activity to do together using the games on it and listening to songs we used to listen to when we got married and his mood has definitely boosted and he seems happier, which makes me happier" (Carer, Alexa User)

"Finding something like this iPad to give me enjoyment in the everyday, giving myself some 'me time' and to use it to have more lovely moments with [my wife], it's given us both a bit of our old life back" (Carer, iPad User)

Carers reported using digital technology for relaxation, enjoyment and also respite from the caring role. Six of the eight carers who completed 'activity logs' said that Alexa had helped them to relax - often through playing music. Another said she could now use her mobile phone to catch up with friends and socialise on social media, rather than it being used as a reminder for various medications. A few carers said they had been able to reconnect with their own interests

- one carer who had to stop attending a painting class was now using painting apps; another could catch up with Rugby through following the scores and fixtures online.

3) Increased social connectedness

As noted above, many carers talked of examples where digital technology gave them an opportunity to improve the quality of their relationship with the person they cared for - through supporting hobbies and having a laugh together. There were other ways in which participants in the pathfinder used digital to reduce isolation and increase connections with others - other family members, and other carers in their community.

As a result of local digital sessions, some people with dementia and their carers have started to use digital to reconnect with family and keep in touch through Skype and Facetime - supporting face-to-face interactions as well as online communication:

"He used to struggle to interact with the grandchildren as he couldn't have a conversation - but [the] music and game apps have been great, [they are] doing jigsaws together and YouTube".

The social aspect of the pathfinder has been actively encouraged, choosing digital activities that all could enjoy together. For example, using Google Earth to help people reminisce about their childhood, or digital games that people play together. One Digital Champion explained how they ensured there was a social element to sessions, for example giving one iPad to two people to encourage them to play together. Another Digital Champion talked about how using iPads had cultivated new friendships in the dementia memory café:

"Playing songs they loved in their youth via YouTube and using radio apps has had such a positive effect on the [memory] café and brought friendships together."

Case study: Dennis and Sheila

Dennis is 84 years old and cares for his wife Sheila, who lives with dementia. Though Dennis has a computer in the spare room, he struggles to use it, as Sheila would get sad if he left the living room. Dennis talked about how their life had changed since his wife was diagnosed, as they longer socialise, and he can no longer go and watch sport. He explains that the hardest thing for him is feeling so alone: *"Even though I'm not alone, ... I can't have conversations like I used to, I do get very lonely"*

Since borrowing an iPad Dennis has been able to take part in hobbies again, downloading apps so he can keep up with his favourite sports. He also uses the iPad to enjoy quality time with Sheila: *"I've tried game apps with Sheila as she has a short attention span these have really helped. It gives us an activity to do together which is nice"*.

Dennis also enjoys using the iPad to help support reminiscence: *"YouTube has given us access to music we used to listen to years ago, reliving fond memories... I put Dolly Parton on YouTube and love seeing Sheila sing along, she taps her feet and clicks her fingers"*

Returning to hobbies and doing meaningful activities with Sheila has improved Dennis's wellbeing, as he puts it: *"it's hard to put it into words, but finding something like this iPad to give me enjoyment in the everyday, giving myself some 'me time' and to use it to have more lovely moments with Sheila, it's given us both a bit of our old life back"*

Leeds Library Service also supported one carer group to set up a closed Facebook group. A small survey sought views on perceived benefits. Of the eight responses, all bar one said they had found the Facebook group to be useful and planned to keep using it. Members said they talked about any difficulties they were experiencing, asked for advice, and shared messages of support and encouragement. Several carers said the peer contact had reduced their feelings of social isolation and helped them make friends:

"Knowing you are not alone and [that] others go through the same problems"

"Talking to others experiencing similar problems and feeling not alone"

Some talked about how the Facebook group had also led to better face-to-face interactions, where it gave the carers something to talk about when they met in the group.

4) Increased confidence, including digital confidence

Many of the carers had low digital skills prior to the pathfinder, with most reporting that they had not used an iPad or an Alexa. Carers who trained as Digital Champions improved their own digital confidence, as well as their confidence to support other carers and/or people they cared for to try out different kinds of digital technology. There were examples of people living with dementia being supported to use digital technology for practical tasks (such as boiling an egg), for entertainment (such as completing digital jigsaws independently), as well as reminders, relaxation and reminiscence.

Some carers progressed quickly from very low use to using digital in their everyday lives. One carer who learned to send text messages and use social media through the pathfinder was surprised at what she had achieved:

"I've learned all sorts! I'm nearly 81 years old, and we always used public telephones. I never thought I could do this."

5) Finding digital tools that work for you

Consideration of and knowledge about accessibility of devices and software was brought in by the Digital Skills Co-ordinator - into training digital champions and supporting people (carers and people with dementia) to try out digital technology. This might be about

visual or physical accessibility (e.g. one carer with arthritis found the iPad stylus suited her best), or cognitive (some game apps proved popular across the memory cafés as they worked well for people with a short attention span). One recurring issue for some older carers was accidentally pressing the power off button on iPads. Memory Co-ordinators took this on board and now use more protective iPad cases.

Accessibility was an important aspect in supporting independent use of digital technology by people living with dementia. A few carers commented on the approachability and usability of voice activated technology (Amazon Echo Alexa) by people with no or low digital skills. One carer said it was good as there was no need to use a remote control. Another carer explained: *"he hasn't got any knobs or switches to confuse him"*.

Among people living with dementia, there was varying interest in using the digital devices provided through the pathfinder. With Amazon Echo, a few people with dementia engaged with the device independently. Most were either unable to use it or had no interest in doing so. One carer noted: *"One of the drawbacks is having to remember to say Alexa."* Concern about financial safety was also raised:

"She asked it to play Jerusalem and it said you need an Amazon subscription so a worry if they sign up to it and run up a massive bill as it is connected to Penny's account."

Overall, though, one of the most beneficial and replicable components of this pathfinder was providing carers and people with dementia with opportunities, plus face to face community support, to try out different digital devices and software: to have a go at using different types of digital technology in familiar environments where people already met and felt safe (such as memory cafés and carers groups) and then in their own homes.

Practical pointers for supporting carers to build digital confidence

Provide carers with the opportunity to train as Digital Champions: the training enabled carers to see how technology could improve their lives and support their caring roles. Carers built their own digital confidence, as well as confidence to support other carers and people living with dementia to have a go at using digital if they wished.

Embed digital into existing sessions or support: bringing digital devices and support into existing carers groups and memory cafés seemed to work well. This reflects wider learning about going to where people are, and providing digital support in familiar, safe and trusted spaces.

Keep sessions fun, responding to people's interests: sessions were shaped to offer something that people wanted, in a way that suited them. Having fun was more important – sessions didn't have to focus on practical, health-related or caring-related issues.

Provide face-to-face support, at people's own pace: introducing digital slowly and providing ongoing, face to face support (through the Co-ordinator and trained Digital Champions) helped to overcome fears about learning new things and giving digital a go.

Be ready to support people at different stages: most carers were first time users of digital devices but a few already owned and used a tablet or smartphone. More digitally confident carers were able to try out different types of digital device, as well as providing peer-to-peer support.

Recognise social as well as practical benefits: carers were able to experience a range of benefits – from using digital for specific practical tasks (medication reminders or NHS health information), to relaxation and reminiscence, to accessing online peer support with other carers.

Pay attention to accessibility: the digital skills co-ordinator worked with digital champions to spot and address accessibility issues – from getting the right font size, using voice activation, providing the right accessories or identifying more accessible apps.

People living with dementia may need ongoing support to benefit from digital: some carers supported people living with dementia to use digital as a joint activity. In a few cases, carers supported the person they cared for to use digital independently (e.g. making a sign next to a device with a reminder about how to activate Alexa, where this was otherwise a barrier).



Sustaining positive change across the city

Ensuring that interventions actually lead to meaningful system change which is sustained beyond the lifetime of a funded intervention can be a challenge. Evidence tells us that building relationships based on shared values (REF) and taking steps to identify local assets (REF) offers an effective approach. These principles were followed closely by Leeds Library Services. The memory cafés and day centres who engaged with the pathfinder have enhanced their offer through embedding digital inclusion, and are continuing to share learning with Leeds Library Services. This is promising for longer-term sustainability.

Digital Champions training

Upskilling staff and volunteers who provide services across the city was one of the main intended outcomes of the pathfinder. This was taken forward through providing Digital Champion training to staff and volunteers – as well as carers – across Leeds. This helped to secure buy-in as well as laying the foundation for sustainability beyond the pathfinder.

Many who trained as Digital Champions said that their confidence to use digital was increased through the training. Though some had used digital before, the training supported them to try different kinds of digital. Learning about dementia-friendly and age-friendly apps was perceived as particularly useful.

As workers had already established trust and relationships with carers and people living with dementia, increasing their own digital confidence meant they could help advocate for its benefits and encourage people to have a go. As one staff member put it:

“The training was helpful. Good positive reinforcement, especially for lower skilled or less confident people being encouraged that they can discuss and try tech with their service users.” (Memory Coordinator)

Embedding digital inclusion into existing support

It is important to ensure that sustainability is factored into any intervention approach, to ensure that organisations feel confident to continue embedding digital into their service

offer, as well as feeling confident about promoting the benefits. The Dementia Peer Support Coordinators and groups working with people affected by dementia across Leeds now routinely use iPads and Alexa as part of their regular support offer.

Those trained as Digital Champions were interviewed to assess their thoughts, and most said they felt more confident exploring digital activities and supporting people to use them during sessions. All said they intend to continue using digital during their regular sessions:

“It’s hard to imagine our sessions without digital in them now because it’s part of the everyday.” (Digital Champion)

“Using the digital technology has made the sessions more interactive, the carers and their loved ones are socialising more, there’s more energy and buzz in the room and they all seem so much happier. We can’t imagine our sessions without using the digital now, it’s a really invaluable resource for our group” (Digital Champion)

There is some evidence that a ‘social multiplier’ effect is happening: other staff and volunteers who weren’t involved initially have observed positive effects on their colleagues, and are now showing an interest in receiving digital champions training themselves.

Developing local resources to support digital inclusion

As well as making use of existing national resources (such as the health modules on Learn My Way), the Leeds Library Service has developed its own dementia-friendly and age-friendly App list. This was in response to Digital Champions reporting that they found it difficult to identify appropriate, accessible Apps. The list has been shared widely and is now used in memory cafés across the city. This helps to further embed digital activities, through providing easy access to resources that carers and people with dementia can try out.

Extending existing networks

Through getting existing organisations and services together during the initial Digital Champion training, Leeds Library Service built on and also extended existing networks in the city – as some carers’ groups and cafés had not previously been connected. This network

has been further supported through a locally-created list of dementia-friendly Apps. Alongside supporting networks between agencies and carers groups, the pathfinder has had success in supporting the development of an online peer support network for carers: membership of the closed Facebook for carers continues to grow and is used regularly.

Continuing to try new things

To celebrate and share learning, Leeds Library Service organised a networking and celebration event in partnership with Leeds Older People's Forum and Dementia Friendly Leeds. Leeds Library Service has also started a new partnership with Invisible Flock to trial a digital art and creative element with carers of people with dementia.

Case study Digital Champions Training

Jane, who supports the running of a Memory Café explained how members had been reluctant to try out digital: *"phrases that we hear a lot are 'I'm too old' or 'It doesn't interest me'".*

When Jane took part in a Digital Champion training session, it helped her to start thinking about how to support carers to develop the confidence to give digital a go: *"It got us thinking about how we can turn those conversations around, how we make it relevant and enticing."*

Jane felt that introducing digital into the sessions had led to a positive atmosphere, where using the iPads had contributed to laughter and development of new friendships.

Through learning about new apps, Jane felt more confident tailoring the digital offer to people's interests, which encouraged initially reluctant members to go online and try other new things, as she puts it: *"So many of the members are now facetimeing or skypeing their family who live far away which they couldn't do before."*

Due to the positive impact of introducing digital, the Memory Cafe plans to continue using iPads during the sessions: *"It's hard to imagine our sessions without digital in them now because it's part of the everyday."*

Jane said they are looking to extend the offer through training other volunteers to become digital champions (who are keen to get involved after seeing how rewarding it is) and through supporting members to make use of the NHS App.





Chapter 5

Conclusion

The Leeds Pathfinder was based on principles of co-design with people, and co-production with existing community assets - local carers groups, dementia memory cafés, support workers and service providers. Digital cannot address all the hurdles that carers face, but this research has highlighted ways in which providing community-based, face to face support and the opportunity to give different kinds of digital a try can help people find what works for them.

This pathfinder was focused on supporting carers, and in turn - some carers supported people with dementia to use digital together or independently. The work of national projects like DEEP and Dementia Diaries illustrates the power and benefits of digital for people living with dementia. More action research led by and with people with dementia on this is needed, especially in the light of new forms of digital technology (such as wearables and voice activated software), with implications around online safety and understanding about data.

Ensuring that interventions actually lead to meaningful system change which is sustained beyond the lifetime of a funded intervention can be a challenge. Leeds Library Service has worked hard to address this through focusing their approach on building relationships, working

with existing local and community assets, and taking a person-centred approach. As a result, the memory cafés and day centres who engaged with the pathfinder have enhanced their offer and appear committed to continue to share learning with Leeds Library Service. Digital has become something that is a 'regular service offer' in some sessions and groups. The network between groups and services has been extended, and useful resources developed in response to local ideas, such as the dementia-friendly Apps list. The closed Facebook for carers continues to see increased membership and is used regularly. Leeds Library Service is also trialling a digital art and creative element with another partner.

The Leeds Pathfinder has undoubtedly laid the foundation for digital to be part of the service offer for carers of people living with dementia.





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