

Dementia

A How To Guide for
digital inclusion in health

January 2020



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Introduction

We know that dementia can have a significant impact on people's lives - those living with dementia and those who care for them. NHS.UK says

“Dementia can affect all aspects of a person's life, including relationships with family and friends”

The worlds of people who live with dementia may start to shrink, as their social circles and the activities that they take part in diminish.

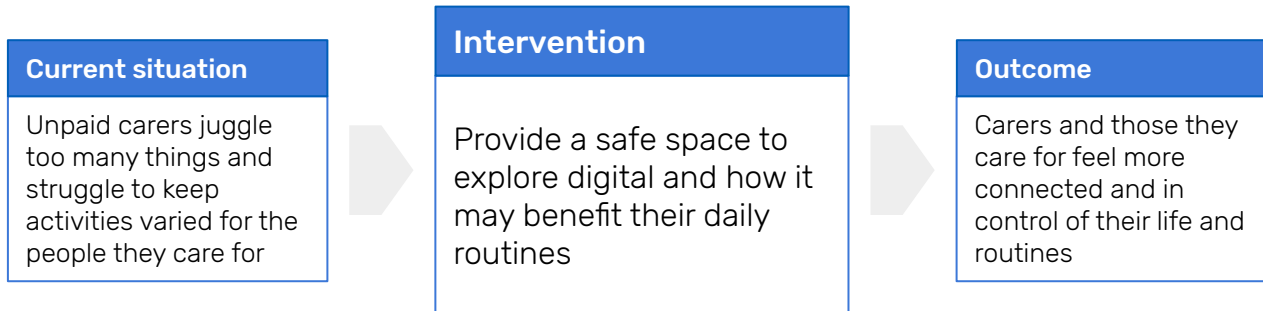
This pathfinder was set up to see if digital can provide more interesting activities (both digital and physical), give respite to carers (mainly spouses) and provide opportunities to share.

Helping carers have choice and be less restricted can have a positive affect on their own wellbeing and the quality of their relationship with the person they care for.

Many areas have a network of memory cafes (or dementia cafes). These are places where people go to spend time together with others who understand their lives and the struggles they live with.

These trusted places - filled with trusted people - provide the ideal place to introduce digital in a safe and social way.

This guide shows what we did and what we learned so other areas can try something similar.



Intervention model

STAGE 1: Making connections

1

Attending carers groups and memory cafes building relationships with staff and carers

1a

Focus groups to determine barriers and ideal outcomes (Co-Design)

STAGE 2: Training

2

Training staff, volunteers and carers as Digital Champions

STAGE 3 Support

3

Support some Dementia Cafe sessions starting to use digital

3a

Call out to carers for involvement in using Voice Activated Technology at home

4

Set up a closed Facebook Group

4a

Provide equipment to carers and help set up of equipment

STAGE 4: Try This

5

Provide initial list of things to try and be built on locally

5a

Encourage sharing ideas around using the technology within the groups

Stage 1: Making Connections

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Stage 1: Making Connections

Understanding local Dementia Assets

It's important to spend time understanding what is already going on in the local area. This could be NHS Memory Support Workers, 3rd Sector Organisations' Memory Cafes and a raft of things in between. You may not find everything at once, but building relationships in the first instance is vital to gain buy in. **NOTE:** it is the people in these roles that are trusted by people living with dementia (and the people who care for those people) and will therefore be best placed to introduce the benefits of digital.

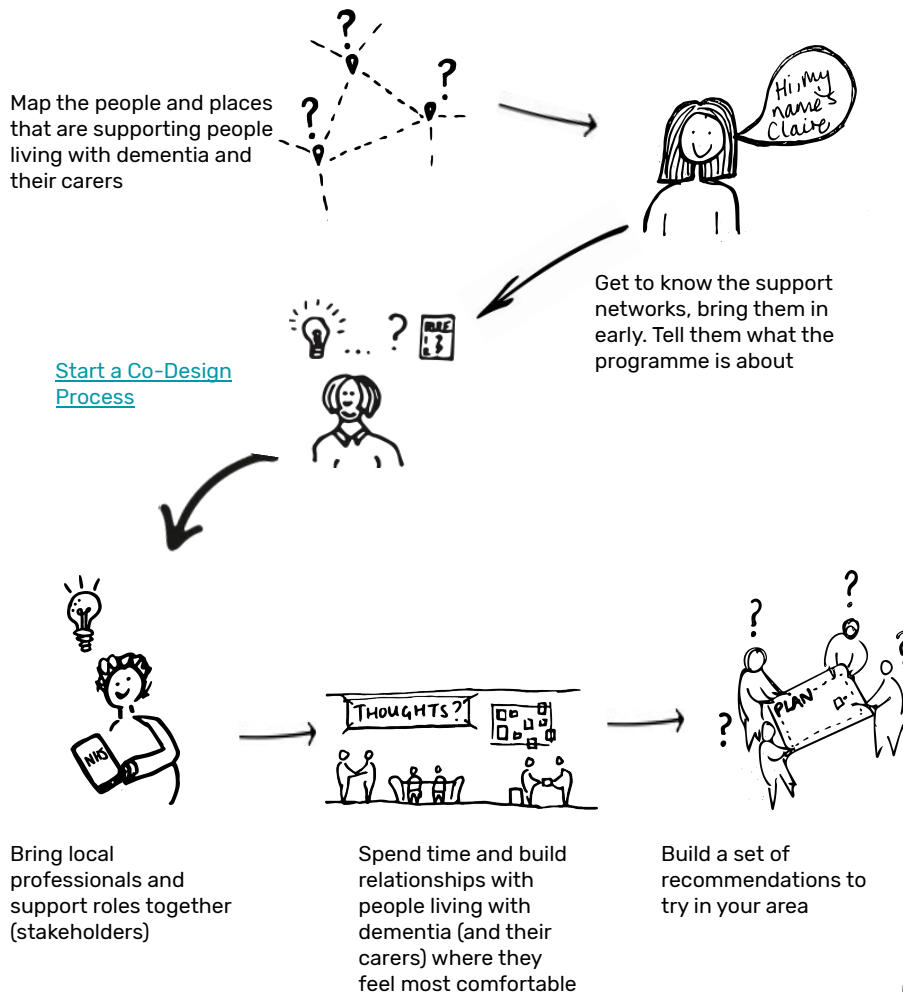
Co-Design -with, not for

New programmes need to be relevant to local areas. This guide can be a start but it won't (and can't) have all the answers for every local area. Begin the co-design process by spending time in Memory Cafes and dementia carers groups (or your local equivalent) and find out about what people and carers need and what challenges they currently face, as well as what Health Professionals already offer. This will help you develop some recommendations and things to try in the short term

Here's what we did in Leeds:

[Stakeholder co-design session](#)

[People and Carers Co-design Session](#)



Stage 1: Making Connections

People who are needed (not exhaustive)

Senior Stakeholder from local NHS or Council who can advocate for the project and align it with local priorities/strategies

Memory Support Workers who have contact with people living with Dementia and their carers on a day to day basis

Staff and Volunteers who spend time supporting carers and people living with Dementia at weekly/monthly gatherings

Organisations who work with people living with Dementia and their carers

Digital Project Manager/Digital Champion Trainer to run the project, map the provision in the area, make contact and start co-design sessions

Resources that are needed

List of the provision and/or people whom you will be contacting

Facilities to conduct co-design session

Examples of how this has worked for other areas and the impact it has had (see evaluation)

Stage 1: Making Connections

Don't:

- Be afraid to start small. If you can't get everyone involved at this stage that's ok
- Get caught up on the term 'digital'. It is off putting to people and professionals. This is just about finding ways to support things that are already doing amazing work

Do:

- Remember that this guide is just a start. Your area may need/want different things
- Ask each new person you meet who you should talk to next. They have informal networks that will be vital
- Map out what has already been done or is happening in your local area and link in.

Don't:

- Forget to keep a growing list of people and places
- Forget to say "I don't know, but let's find out". You shouldn't have all the answers at this point
- Provide the solutions, suggest solutions as responses to people's challenges.

Do:

- Remember everyone is an expert in their own life. Not us! Work with them - not for them
- Build relationships. This is more about relationships than it is about digital
- Understand sensitivity is key, carers support groups are a place for carers to share their challenges and receive advice and support.

STAGE 2: Training

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STAGE 2: Training

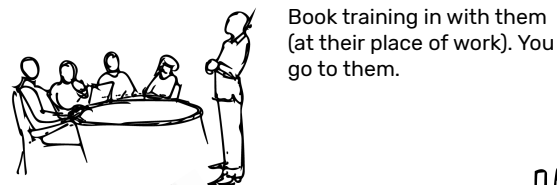
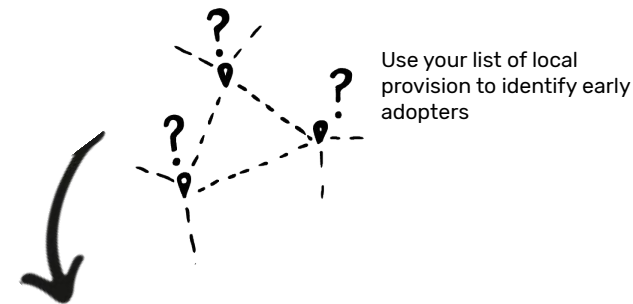
Through the Co-Design process you will have developed a list of people who support those with dementia and are willing to be involved in the project.

The next step is to train those people as “Digital Champions” - it works better when trusted individuals become digital champions instead of parachuting strange people into sessions as “Digital Champions”

[Here, you can find the training materials that were used in Leeds.](#)

Be aware that everyone is busy and you will be asking for people’s time to come and be trained. Certificates can help, as it can be used as evidence of CPD (Continued Professional Development) and also brings people together as part of a movement.

For those carers who are initially interested in digital you can also train as informal “Digital Champions” - find the [training materials here](#).



Give training ([example here](#)). Allow them to explore the devices. Establish that they don't have to have all the answers to be Digital Champions



Carers who want to be involved can be trained also. [Example here](#)

Provide a certificate as a “Digital Champion”.



STAGE 2: Training

People who are needed (not exhaustive)

Memory Support Workers who have contact with people living with Dementia and their carers on a day to day basis

Staff and Volunteers who spend time supporting carers and people living with Dementia at weekly/monthly gatherings

Dementia Carers - they will champion digital with their loved ones.

Digital Champion Trainer to facilitate a round of training and show opportunities for digital

Resources that are needed

Training Slides for things to cover with trainees

A room to deliver training in

Certificates to help with confidence and create your own 'digital champion' movement

Tablets to use during the sessions

Handouts to support with using the equipment and suggested resources.

STAGE 2: Training

Don't:

- Think everyone is going to be comfortable being labelled a "Digital Champion". Use whatever term is appropriate
- Try and make digital the solution to all problems. This is about helping carers and people living with dementia to expand their worlds.

Do:

- Make sure everyone is aware that they don't have to have all of the answers when talking to people. This is about exploring together
- Try and get groups together to train up at once. They will be able to share ideas both now and in the future
- Identify people's digital skills and pitch it at the right level.

Don't:

- Be afraid of offering to go to some memory cafe sessions with your new digital champions to support them setting up
- Use Jargon
- Expect all digital champions to have high level digital skills, everyone has a different skill set and previous experiences with digital.

Do:

- Offer examples of how it has worked in other places, but allow for the new digital champions to explore things for themselves
- Understand not everyone may be enthusiastic and positive, but having some positive people driving the work can make a massive difference and impact on others.

STAGE 3: Support

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STAGE 3: Support

Tablets and Wifi

Some infrastructure needs to be in place i.e. tablets and WiFi

The dementia cafes (or other community assets that you use) may not have digital equipment for municipal use. Provide them with tablets (either through a lending scheme or purchasing cheap ones).

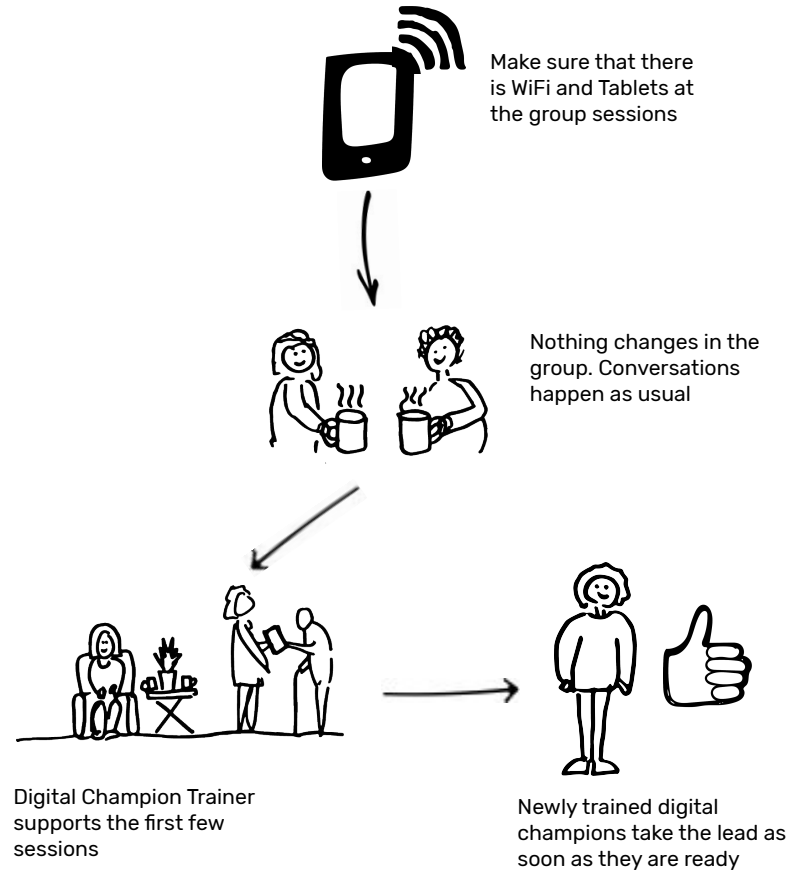
Note: Tablets offer greater usability for people who may have dexterity issues. We suggest a ratio of 1 tablet per 5 group session attendees

These tablets can be introduced slowly to sessions. Their use is by no means mandated.

Support

The digital champion trainer can support the first few sessions, helping people play with the tablets and using them as a conversation starter. Your newly trained digital champions will have the relationships with the people you are supporting. It's therefore crucial that they take the lead in sessions as soon as possible. Using apps and digital resources linked to people's hobbies and interests really works as a 'hook'.

See **Stage 3** for tips and ideas of what to try first



STAGE 3: Support

Keeping in Touch

Unpaid carers of people living with dementia often experience emotional (and wider) strain. Meeting in sessions and talking to people in similar circumstances gives them room to vent, share ideas and seek comfort in others. However, often weekly/monthly can only go so far. Introducing a closed facebook group for the carers can help

- 1) Carers keep in touch and organise meeting up socially
- 2) Share ideas of things they have done
- 3) Take care of each other by providing emotional support (from someone who understands!)

Introducing facebook can also have positives in the carers keeping in touch with their family and friends. Our user research shows that carers can become isolated from family and friends and their historic support networks

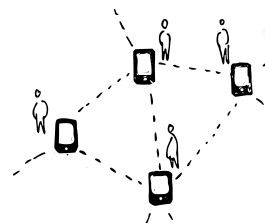
It can also build friendships and change group dynamics in the carer support groups as carers know each other better, and feel more comfortable opening up to each other.



Carers share things informally but don't tend to meet up outside of the groups



Introducing social media to the carers and suggesting a closed group to support each other



Carers stay in contact in between group sessions



Carers find opportunity to stay in regular contact with other (family/friend) support networks

STAGE 3: Support

At Home - Alexa

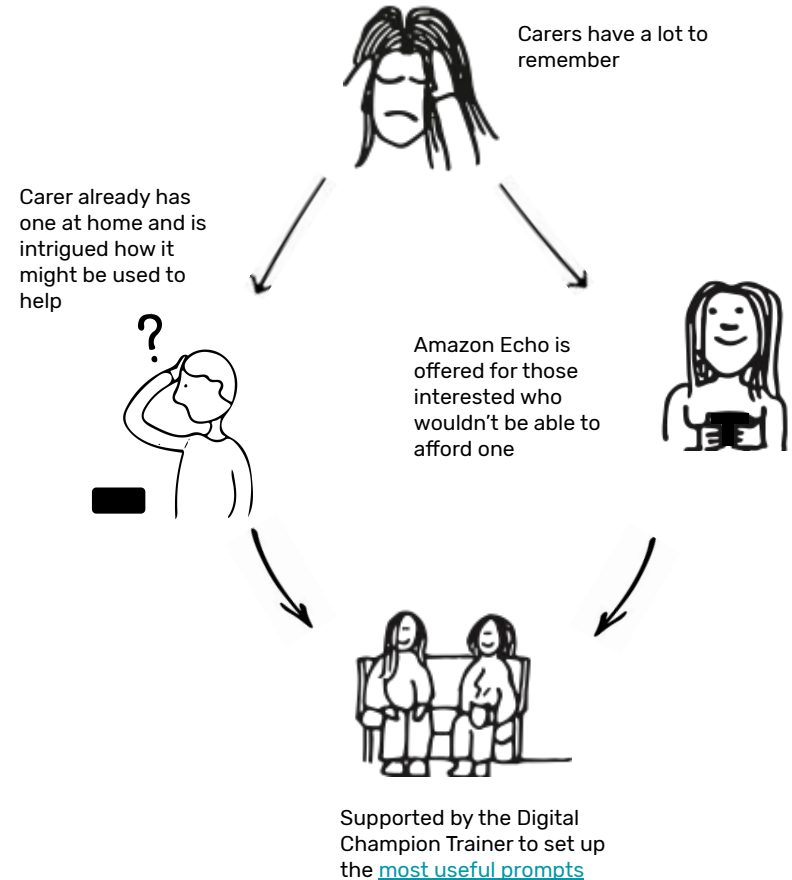
Being an unpaid carer for someone living with dementia comes with a lot of life admin. Doctors appointments, meetings, medication, shopping, trying to think of fun things to do etc

An Amazon Echo can help with some of these things.

- 1) Reminders can be set for appointments and medication
- 2) Smart household appliances can be controlled through voice commands
- 3) Music and games can be played
- 4) It provides a social presence in the home for carers
- 5) Alexa tells jokes to support with mood boosting

If people already have an Amazon Echo (or similar voice activated technology) at home offer them support to set up the most helpful parts of it. This would be done by the Digital Champion Trainer in the first instance.

For those who don't have one at home consider purchasing some and offer them to those carers along with support on [how best to use it](#).



STAGE 3: Support

People you need

Digital Champions Trainer to support early sessions using tablets and also help set up Amazon Echos

Digital Champions who have been newly trained - they are the people who usually run the Dementia Cafes and/or group sessions

Group session attendees made up of carers and people with dementia

Memory Support Workers who visit carers and their loved ones regularly

Resources you need

Tablets we recommend 1 per 5 attendees

WiFi in the place that the group session is held

Amazon Echo's (or other voice activated technologies) for people to try at home

Optional

Headphones for people to explore music or videos without disturbing the rest of the group

VR Goggles to immerse in something that is interesting to that person. Also, something with a gimmick can be quite engaging for digital. VR can support with relieving agitation and confusion - symptoms of Dementia.

STAGE 3: Support

Don't:

- List too many Alexa skills for carers to use otherwise it feels prescribed and they tend to stick to just using those, instead encourage them to explore new ones relating to their interests/lives.
- Forget to inform carers about data sharing with Amazon and to be cautious with adverts for subscriptions/ in app purchases on equipment

Do:

- Set the equipment up with carers, provide how to guides/handouts and support with setup of Amazon Accounts for Amazon Echo's
- Encourage carers to share experiences they have with the tech in group sessions and offer each other hints and tips.
- Enable the carers to take ownership of the facebook group, choosing the group photo and promoting it to new members.
- Be aware some carers will need time to decide whether they would like to trial the equipment.

Don't:

- Worry if carers don't come forward to trial some of the equipment in the first instance. As they see others having positive experiences with it they will then be interested later down the line.

Do:

- Check carers have Wi-Fi if they are interested in trialling Amazon Echo's
- Be aware of the likelihood of inconsistent attendance of carers due to busy lives, and potential for high turnover of attendees
- Get the buy in from the staff and volunteers to manage the Facebook group, actively posting in the first instance. Carers will then comment and become more active in using it.
- Use the platform for a digital social group that suits the carers best, if most have WhatsApp choose that over Facebook, go with the majority.

STAGE 4: Try This

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STAGE 4: Try This

The Dementia groups that we worked with in Leeds compiled a list of accessible apps and tools that they have found useful.

[See list here.](#)

NOTE this is not an exhaustive list. It is just a starting point for other groups.

“The useful apps fall under the following categories:

A selection of free, age-friendly apps available from the Apple App or Google Play store. This app list has been crowdsourced from organisations who work with older people. ”

The list of apps falls into the categories opposite

Health:
Finding trusted and relevant information about conditions and symptoms

Fun:
Interesting activities for people to try and keep amused

Practical:
Using digital to make administrative and everyday burdens easier

Interests:
Investigating or reliving things that interest a person (or used to interest the person)

STAGE 4: Try This

People you need

Digital Champions who have been newly trained - they are the people who usually run the Memory Cafes and/or group sessions

Group session attendees made up of carers and people living with Dementia

Memory Support Workers who visit carers and their loved ones regularly

Resources you need

[List of age friendly apps](#) for groups and individuals to try

Tablets we recommend 1 per 5 attendees

WiFi in the place that the group session is held

Optional

Headphones for people to explore music or videos without disturbing the rest of the group

VR Goggles to immerse in something that is interesting to that person. Also, something with a gimmick can be quite engaging for digital. VR can support with relieving agitation and confusion - symptoms of Dementia.

STAGE 4: Try This

Don't:

- Think that people will automatically take to this. Have patience
- Push digital. This is about 'incidental digital' to help when it is most helpful

Do:

- Make sure you set up any home devices with the carers in their home.
- Remember you are pairing the unfamiliar with the familiar. This is the hook for people.
- Find carers within the groups who are enthusiastic and are champions of trialling the tech.

Don't:

- Be afraid of not knowing an answer. Learnt things together
- Think it's once and done. Digital moves quickly so stay interested and keep involving carers and people living with dementia in your investigations into new tools

Do:

- Share what you have learnt with your local Dementia networks
- Keep trying new things
- Stay in touch with the groups
- Encourage carers and staff and volunteers to share ideas and experiences with others
- Keep the approach informal and support the 'embedding' of digital within the sessions rather than the sessions being all about 'digital'.

In your area

This is how we did it in Leeds. We have tried to make the model as flexible as possible allowing for local context and local needs.

To embed this into another area we recommend;

- Bringing together as many Dementia groups as possible
- Training digital champions who already spend time with people living with Dementia and their carers
- Adapting the approach to the people you're working with so it meets their needs.
- Spend time in the groups understanding Dementia and take the time to listen to carers.

If you would like to discuss how you might be able to try something in your area please contact pete@goodthingsfoundation.org

Assets

Evaluation

Design workshop - [stakeholders](#)

Design workshop - [User Research](#)

Training Slides - for [Digital Champions](#)

Training Slides - for [Carers](#)

List of [things to try](#)

[Prompts for Alexa](#) (Amazon Echo)