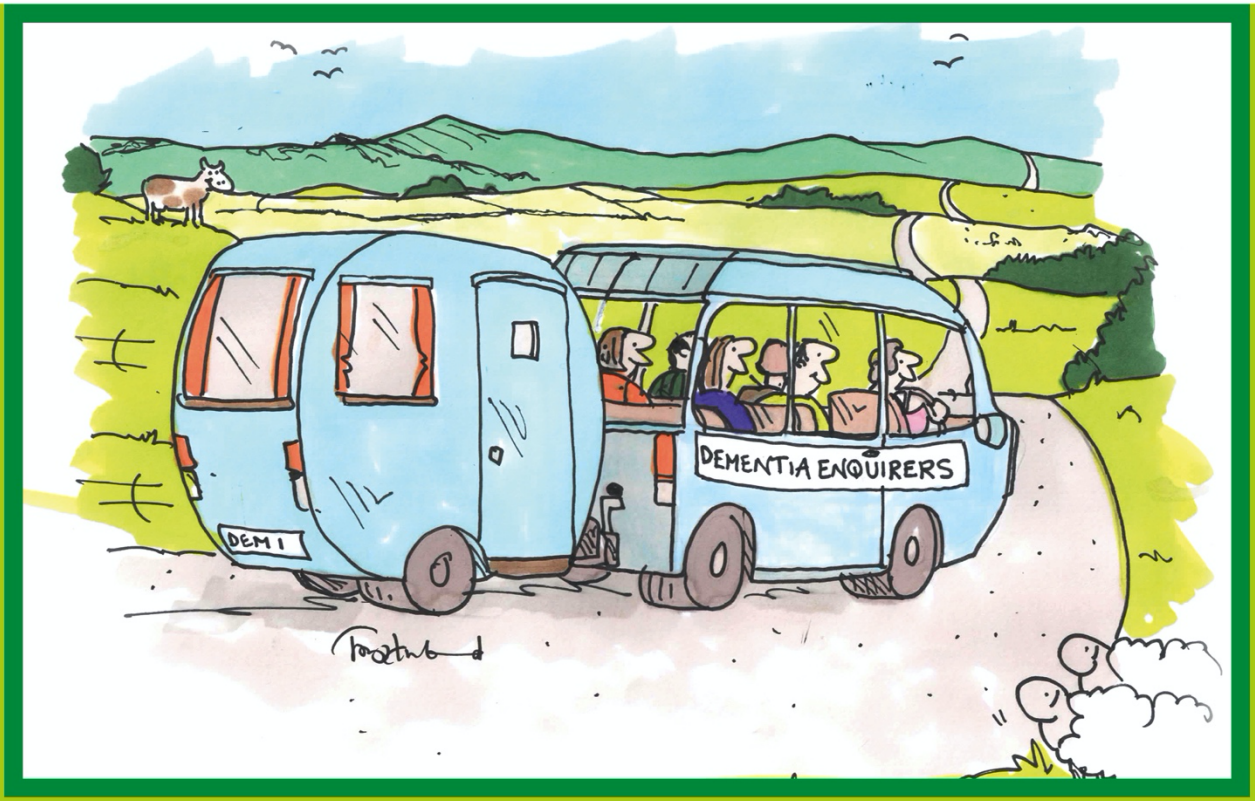
EDUCATE Stockport

Dementia Enquirers Report



The EDUCATE Echo Project

Editor: Jacqui Bingham

July 2020

Dementia Enquirers

COMMUNITY FUND

Innovations in Dementia

Key messages from Dementia Enquirers projects

1. People with dementia can lead their own research projects – both drawing on previous life skills and learning new ones to explore the questions that most interest them.

2. The research questions that people with dementia generate can be different from existing research questions. They are based on lived experience – on topics that will make a real difference in people's lives.

3. "Being in the driving seat of research" doesn't mean that you have to do everything yourself. Team work and support can really help. But controlling the research and leading the way gives people with dementia a huge boost in confidence.

4. Making the language and processes of research more accessible helps everyone!

5. Research *between* people with dementia makes communication and engagement more possible, because having something in common increases trust.

Date of publication May 2021

You can download this report here:
https://dementiaenquirers.org.uk/individual-projects/educate-in-stockport/

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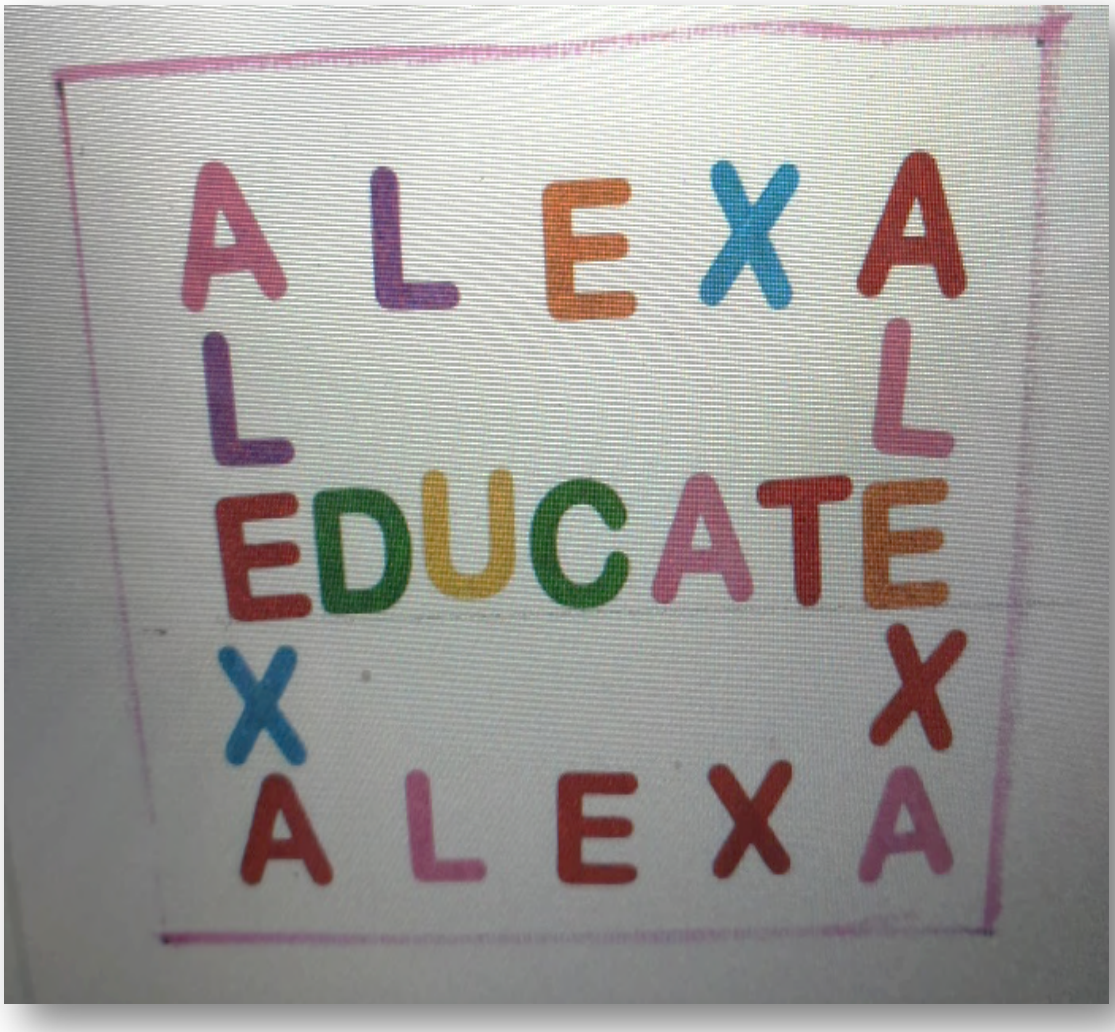
Logo designed by Steve Clifford



Accessible Summary

This report is about a research project carried out by a group of people living with dementia. We are all members of the EDUCATE Stockport group. The work was funded through Dementia Enquirers. The idea was to test out people with dementia being ‘in the driving seat’ of research.

The Project Team chose to look at how people with dementia used Amazon Dot Echo (Alexa) and what benefits or difficulties they experienced.

Our Project Team comprised five people with dementia and two supporters. 18 participants were each given one/two Amazon Alexa Dot devices, and support to use them for whatever they wanted.

The project found that those who got most benefit from using Alexa were those with poor short term memory, but no language or visual problems. Those people with problems using or understanding language or meaning benefitted the least.

Alexa could help with everyday tasks like cooking, answering the door, controlling the central heating, remembering appointments and taking medication. It was also helpful with activities and leisure pursuits. But support was often needed for account setup, installation, trouble shooting, and suggesting new functions. It was necessary for some of those living with care partners, as well as those living alone.

This project has very usefully highlighted that people understand the ‘driving seat’ in many different ways.

Overall, the main conclusion was that Alexa has a lot to offer many people with dementia. But she is only as good as the support around her. Alexa needs to become more accessible and the necessary support systems need to be better understood.

Background

Without the right support, those of us who are living with dementia are at risk of being limited or marginalised in what we do, especially as our roles and abilities change following diagnosis[1]. But we have a right to take part in meaningful occupations which meet our needs and values, both personally and culturally[2]. We also know that taking part in meaningful activities can affect our health[3] both physically and mentally. And it can shape our personal sense of well-being[4].

Supporting us to stay meaningfully occupied helps us to keep a sense of identity, feel competent[5] and stay in control of aspects of our lives[6].

Smart Assistant devices - such as Amazon Dot Echo (Alexa) – have a role to play here, as they can help to keep life regular, structured and independent. While human contact cannot be replaced, technology is certainly becoming more accessible and more part of everyday life. Lots of people with dementia in the UK use technology every day - navigating a smart phone or using a tablet/computer to access the internet. This trend will continue as the current tech-savvy generation progresses through the lifespan. However, the benefits of using the Alexa device are likely to be different for each of us.

There are currently very few all-round, digitally-robust smart interventions specifically designed for those living with dementia. Most devices offer isolated assistance with individual activities of daily living. However, Amazon Dot Echo (Alexa) offers smart ways to control our homes, and provides stimulation in the form of music and leisure applications. It also aids everyday life by storing and recalling reminders, alarms, updates and lists. All of these have the potential to be extremely useful for those of us who are living with dementia.

[1] Townsend & Wilcox., 2004, O'Sullivan & Hocking, 2013
[2] Whalley-Hammell, 2008
[3] Durocher, Gibson & Rappolt, 2013
[4] Yerxa, 1998
[5] Taylor, 2017
[6] Rodin, 1976, Kielhofner 2002, Taylor, 2017

Introduction

This small project was carried out by the EDUCATE group, as part of the Dementia Enquirers programme, which is facilitated by Innovations in Dementia and funded by the National Lottery Community Programme. The aim of the Dementia Enquirers programme is to test out what it means for people with dementia to be 'in the driving seat of research'… by choosing their own topic and methods, carrying out the research and producing the findings (with as much support as they want/need.)

EDUCATE (the Early Dementia Users Co-operative Aiming to Educate) is a group of people in Stockport living with dementia, who raise awareness about dementia. We use our 'lived experience' to improve understanding about dementia. Our main activity is helping to deliver training courses alongside professionals. We also have an allotment, a Reading Group and an Intergenerational Choir. We meet regularly to support each other, and discuss the opportunities and difficulties facing people living with the condition. More information can be found here at **www.educatestockport.org.uk**.

We had previously been involved in an EU Robotics project. One of our members pointed out that Alexa could perform many of the functions of the robot at a tiny fraction of the cost. Other members recognised that this kind of technology could enhance the independence of people with dementia. The Dementia Enquirers grant gave us a chance to explore Alexa's potential benefits, and also the challenges involved in making the device accessible to people with different abilities, problems and diagnoses.

The Project Team comprised five of us (all people with dementia) - Jacqui Bingham, Joan Palmer, Stephen Clifford, Caron Anderton and Alan Bancroft. We had two supporters: Mark Perry (EDUCATE Facilitator) and Rebecca Spooner (Support Worker).

Our team agreed on the following research questions:

- What do people living with dementia stand to gain from using voice technology such as Amazon Dot Echo?

- What is the full extent to which it can help us (or anyone disabled)?
- How effective will it be in daily activities/ reminders/ leisure pursuits?
- What help do we need to set it up?
- How can it be adapted to the needs of different people ?
- What are the barriers to us making use of this technology?
- What difference will this project make to people living with dementia?
- What drawbacks might there be?

Project participants

The Project Team agreed that Alexa Dot devices should be installed in the homes of 10 people living with dementia. This was extended to a total of 18 people, due to interest shown by people supported by Older People's Services who were not members of EDUCATE. So both volunteers from EDUCATE Stockport, and service users known to the Pennine Care Younger and Rarer Dementias Team, were invited to join the project. All participants had a clinical diagnosis of dementia.

An overview of the project was explained to individuals from the two groups, either on a one-to-one basis or during attendance at EDUCATE meetings. Participants were given the details of who from the Project Team to approach if they wanted more information.

Once an individual had shown interest in the project, an initial visit/phone call was conducted, with consent. As some of the project participants were recruited from an NHS community team, initial visits/phone calls were carried out by the project support worker who is employed by the NHS, in order to comply with data protection regulations (GDPR). During the initial visit/phone call, the project was explained in more depth to the potential recruit (and carer, where appropriate). Following this, individuals were given some time to think about the project before deciding if they wanted to take part.

Nine (9) male and nine (9) female participants aged between 47-79 were then provided with one/two Amazon Alexa Dot devices.

Out of the 18 participants, the diagnoses were;

7 people with a young onset dementia, 6 with Alzheimer's Disease and 1 with Vascular Dementia

1 person with Frontal Temporal Dementia

3 people with Alzheimer's aged over 65

1 person with Vascular Dementia aged over 65

2 people with dementia and MS

2 people with Posterior Cortical Atrophy

1 person with Lewy Body Dementia

1 person with Semantic Dementia

Of the 18 participants, 7 had previously used, or had existing knowledge of using, Alexa to varying degrees.

5 of these 7 participants had either been gifted Alexa devices by family members, or had purchased one themselves. However they had only accessed basic functions, and had not explored Alexa Skills, which can provide stimulation or increasing levels of independence.

2 of the 7 participants were moderately skilled in using Alexa and had agreed to contribute to the project in order to support other individuals living with dementia. They also wanted to see if they could increase their own skills/knowledge.

The remaining 11 participants in the project had not previously owned an Alexa device, and had no existing practical knowledge of using an Alexa.

Methods

The EDUCATE Alexa enquiry set out to discover how Alexa can help *individual* people with dementia who have different strengths and problems.

The format of the project involved:

- purchasing Alexa Dot devices for the participants
- identifying meaningful interests/tasks relating to the things they wanted
- individually supporting the participant to explore the Alexa device
- actively recording if the device was useful in terms of facilitating (or obstructing) a subjective sense of wellbeing/independence.

The study used a mixed methods approach. Data was quantified based on the number of times individuals accessed support, in addition to recording the Alexa Skills that were used by participants. The information was produced by people with dementia using Alexa, supported by the installation and support workers. We have recorded all the feedback we have received. For example, What has Alexa been used for? What skills have been used by participants? Are these new skills? How often, and why, did they ask for support?

Support available

As the study was led by people living with dementia, participants provided a wealth of qualitative feedback about the individual level of support received. This helped to guide the study and the support choices that were made available.

Support was *not* prescriptive, but instead was guided subjectively by the participant. The participant was informed at the initial visit that they could have support (as much or as little they felt necessary) to aid their use and exploration of the device. Follow-up was agreed on an individual basis. However some of the participants preferred a more informal arrangement, in which they could ‘shout for help’ when required.

Some of the support methods/tools used within the context of the project included:

- Group forums
- Initial learning styles/barrier/interests identification form*
- Individualised flash/prompt cards*
- A generic printed prompt sheet, designed to help participants start interacting with the device*
- Phone support (trouble shooting, talking things through, providing support/reassurance to build confidence)
- One-to-one home visits (installation visits, enabling new skills, trouble shooting, talking things through, providing support/reassurance to build confidence)
- Multi-disciplinary visits (with consent) to incorporate the use of Alexa into an existing treatment plan (speech and language/occupational therapy).

Example of how qualitative feedback guided the study

During an initial visit, the participant was struggling to remember the name of the device (i.e. 'Alexa') as the cue to start of a request. Following a discussion between the participant and the support worker, this was raised at the next Alexa project team meeting. It was concluded that each Alexa issued as part of the project would have an 'optional' printed 'ALEXA' label attached to the top, as a cue to the start of a request, potentially making the device more 'dementia friendly'.

The project also had access to an additional technical support worker where required (on an ad hoc basis), to ensure that support was available to participants whenever it was needed.

Findings

During the enquiry, some people used Alexa a lot and some not so often.

The most-used enabled functional application was orientation of day and time, followed by general reminders and weather updates. Then came medication reminders, to-do lists and routines, shopping lists and routines.

The enabled leisure/wellbeing applications were used in this order of frequency:

12 Radio

11 News updates

10 Find my phone

9 Amazon music

8 Trivia Blast

7 Music playlist

4 Football news flash: history trivia: ambient noise: smart plug

3 Mindfulness music: sleep and relaxation

2 Hive: Calm my Dog: Burglary Alert: Audible: TV guide

1 Tune my Instrument: Spotify: brain workout.

We found that Alexa could help with everyday tasks like cooking, answering the door, controlling the central heating, remembering appointments and taking medication.

It was also helpful with activities and leisure pursuits. Listening to personal choices of music, doing quizzes and listening to radio programmes and audio books were amongst the examples given.

The case studies (see Appendix 4) seem to show that the benefits of using Alexa can be different for each individual according to their

personality and lifestyle, their home environment, their support network and the particular problems dementia causes them.

Those who got most benefit from using Alexa were those whose main problem was poor short term memory, without any language or visual problems. Those people with problems using or understanding language or meaning benefitted the least.

Another question the project tried to answer was how much support and technical assistance was needed to enable people with dementia to use Alexa. We found that some people with dementia can clearly manage by themselves. One participant was already proficient in the daily use of Alexa, but all the others needed and wanted regular support after the initial set up. Several participants had an Alexa already, but were not using it apart from very basic functions, because they had not previously had enough support. Support was needed for account setup, installation, trouble shooting, and suggesting new functions. It was necessary for some of those living with care partners, as well as those living alone.

Written advice and instructions can be helpful, but for most people living with dementia this is not enough. We found that a relationship with someone who has an understanding of the range of problems dementia causes was essential, and should be built into any assistive technology initiative. One Project Team member felt that designers from the tech companies should have been involved, to help them understand how many people with dementia are still excluded by this generation of technology.

Roles and expectations of the Project Team members

Jacqui Bingham saw the Dementia Enquirers article in the DEEP newsletter and was very inspired to take part with EDUCATE. She gave the printed synopsis of the grant to Ruth Chaplin, her keyworker, when she was visiting her house. In the application Jacqui was put down as the lead of the project. Jacqui's understanding was that being 'in the driving seat' would mean that the Project Team (the people with

dementia) would be in control of the project and make the decisions…not the professionals. However, Jacqui says:

> *"But this never happened. The professionals took charge of the project, which caused frustration and disappointment, as I felt that it should have been led and run by the project team. I was also disappointed that the project team members could not, due to GDPR regulations, accompany Rebecca on the installation and follow up visits."*

In the event, Jacqui took on the role of writing up/editing the report, using the information given by Rebecca and Mark, and input from the project team.

In 2015, **Steve Clifford** had been involved in an EU robotics project, testing a domiciliary 'care bot'. At the time he questioned the value of spending millions on a robot when a lot of its functions could be carried out by Alexa. Steve's insight created the momentum leading to this enquiry. Steve feels that:

> *"We've steered it in the way we wanted it to go…The information we produced is very good, it's very clear."* However he says that: *"I'm frustrated that the makers [Amazon] haven't been contacted to let them know about our input. Surely it would help them improve their product and services by learning from us? It would be so beneficial to invite them to a meeting, because their technicians will be planning ahead. This needs to happen, because technology changes all the time, as we found out with the other project we were involved in. Some of us can use it, but we have people in EDUCATE who can't use it now who could benefit if it was easier to use, and that applies to lots of people with disabilities."*

Joan Palmer has embraced the challenge of technology throughout the 10 years she has lived with dementia, often describing the frustration and anxiety she experienced when things don't work. Joan was also involved in the Mario project, helping test functionality and identifying barriers to use. She brought home to us the importance of relational support in overcoming barriers to using technology, by describing how her grandson was able to explain things to her in a way others couldn't.

When asked if she had been given an opportunity to be in the driving seat of the project, Joan said:

> *"We all go around and we say how we've been using it [Alexa]. I speak up, that's being in the driving seat isn't it? [But] sometimes it goes over my head when we're talking about it. If I had to do anything like writing or designing logos, I'd be up all night worrying about it. One or two of the others could do that, they'd be well away! I think we've covered everything, it's been really good. I'm looking forward to reading the final report."*

Joan gave a presentation about the project to the Pennine Care NHS Foundation Trust Occupational Therapy Conference in November 2019. She found sharing her story at the conference very affirming, and her presentation featured in the monthly blog of Pennine Care's CEO Claire Molloy, who wrote:

> *"I loved hearing about their virtual personal assistant 'Alexa project', which is changing some of our service users lives in remarkable ways. This work is helping people stay independent, with Alexa reminding them to take medication, attend appointments and do exercises, as well as assisting them to order food and taxis, dictate texts and get help".*

Alan Bancroft was away in the USA for part of the project, but when involved, he was an active and insightful participant. His view is that:

> *"I don't think anyone person can be 'in the driving seat', it's more like we all were. So you'll need a minivan! I would need more one-to-one, face-to-face support to go through the report line by line, as it were. Unfortunately, that's not possible at the moment (due to Coronavirus). Overall, the important thing has been about finding out how it can help people with dementia and other illnesses. In my case, that would be help with my language. I was interested to see that someone testing Alexa had help with something called 'errorless learning techniques'. I now want to know if that could help me, not just with Alexa, but generally."*

Caron Anderton played a very valuable role, offering many concrete suggestions. When asked about being in the driving seat, she says:

"I've used it to listen to music mainly, but I've started listening to stories on it as well. I've got directions from it instead of using my phone, and that was interesting. I've been able to learn from the others at the meetings, because they know more about this than I do. I get panicky if I get too much information at once, because it's too much to take in.

I used to have my daughter here to help with phones and computers, but now I have to wait for Peter to come home from work. I like some written instructions to follow and then eventually it will sink in. I used to learn like that even before I had dementia. So it's been about learning.

It's been really good for me. I go into my room, draw the curtains and put my lights on and listen to my favourite music or a story. It's my own little space after the stress of the day. It really helps me chill out."

Mark Perry, one of the facilitators, comments:

"We've approached the enquiry as a partnership. Our questions to the project team as facilitators were:

'What can you as people with dementia teach us about Alexa that can help others using or designing this kind of technology ? You've asked some questions about Alexa, how can we help you answer them?'

We've tried to help by providing sufficient occupational therapy input to allow people with dementia the time and space to discuss, set up and practice using Alexa. This has enabled participants to explain its uses, benefits and problems to us in their own personal and environmental context.

We have been inclusive, bringing together people living with a range of diagnoses, abilities and problems, enabling the testing of Alexa in unique personal circumstances.

The explanations provided by the participants have been shared with project team members, who have also contributed their own, and been used to help answer the project team's original questions.

While facilitators have made opportunities available to people with dementia to take on project team work – chairing meetings, designing logos, helping design feedback forms and writing the report , most project team members were clear they did not want these roles and identified some of them as overwhelming.

By answering their questions, project members wanted to learn about Alexa and help others to do the same. They did this as experts by experience, using their ability to learn and teach at the same time, helping to produce the valuable information that can now be shared and evaluated. This approach comes naturally to group members, as they have been using it for many years when helping deliver dementia training. This is our take on 'being in the driving seat.'

In conclusion, this project has very usefully highlighted the ambiguity of the 'driving seat' aspiration, and the many different ways in which it can be interpreted. One member felt that she could and should be in a real leadership role (with assistance where needed), while other team members, and the group facilitators, felt that the main fieldwork and data collection should be done by a professional, with the Project Team as advisors. This misunderstanding led to some changes in the support arrangements mid-project.

It is fair to say that this caused a certain amount of difficulty for the project – which, with hindsight, could have been reduced by very early agreement about expectations, skillsets and roles. However this is valuable learning for both Dementia Enquirers and EDUCATE.

Reflections and conclusions on the use of Alexa

There are some **barriers to accessibility**. Firstly, Alexa's 'voice' is non-human, and individuals can find this disturbing or cold. The device would be more dementia friendly if this was addressed. Secondly, a few participants were initially concerned about having an Alexa device in their home, due to media stories regarding Alexa 'listening in to conversations'. The project team also raised the problem of privacy and security with voice recognition technology, and felt that people with dementia could be vulnerable in this respect.

But there are also **clear benefits.** Some individuals were able to use multiple functions and apps, with Alexa helping with everyday tasks and with activities, entertainment and leisure pursuits. Alexa can be different for each individual according to their personality and lifestyle, their home environment, their support network and the particular problems dementia causes them.

Those who benefit most from using Alexa were those whose main problem was poor short term memory, without any language or visual problems. Those people with problems using or understanding language or meaning benefitted the least. However, even for those who only mastered one simple function with support, engagement in occupation was the result. Lots of examples are demonstrated in the case studies.

The project indicated that **supported learning** helped participants to foster resilience and confidence in trying out new technology. With this support, individuals were able to demonstrate new learning, and could regain some element of enjoyment/independence in things that may have previously presented as a challenge. It was important that the support worker had a good communication style and 'emotional intelligence'.

It is also clear that any assistive technology initiative must ensure **personal support** for account setup, installation, trouble shooting, and suggesting new functions -whether or not the person is living alone. Written advice and instructions are not usually enough.

Considerations for the future

As a nation we are becoming more tech-savvy. How much scope is there to create specific dementia applications?

As Alexa stores information regarding preferences, is there scope for Alexa to 'travel' with an individual through their dementia journey? Using life stories, music playlists (accessible to carers), knowledge of likes and dislikes, recording of advanced directives, end of life wishes etc?

It is noted that there has been increased use of technology during the recent COVID-19 outbreak. Alexa, and other smart applications such as WhatsApp, have been accessed by many as a means of connecting with friends and family, the community and groups, keeping up to date with local and national news, providing stimulation, and reducing levels of social isolation and loneliness.

Overall, our **main conclusion** is that for many people with dementia Alexa has a lot to offer - but she is only as good as the support around her. We hope that those supporting us and those designing technology can learn from our experience, so that Alexa becomes more accessible and the necessary support systems are better understood.

APPENDICES

Appendix 1: Information collected from feedback questionnaires

Q1. Do you feel having an Alexa has increased your level of independence?

Answers –

YES = 6

MAYBE = 4

NO= 3

Comments:

- “I can safely cook meals again for my family”
- “Alexa has helped me to become even more independent than I was before”
- “Absolutely, it’s great”
- “I can now contribute to things I was not able to before, such as helping adding to the shopping list for our family shop”
- “No, not really used it as much as I thought I would”
- “Yes, I no longer have to ask my wife”
- “It’s been absolutely perfect, a blessing. I wasn’t sure about it at first but now I would not be without it”
- “Really helped”
- “Definitely”

Q2. How many times a week on average do you use Alexa?

Answers –

1-3 – 4

3-5 – 3

6-8 – 0

8-10 – 2

10+ – 4

Q3. Do you get enjoyment from using Alexa?

Answers –

Yes – 8

Occasionally – 4

No – 1

Comments –

- “She tells me jokes”
- “Love the music and the interaction”
- “I’m amazed sometimes at the answers”
- “I love the music and quizzes”
- “Definitely from the music”
- “Yes, it is a very useful tool”
- “It give me lots of enjoyment”
- “All the time”
- “Alexa has been a quick and easy way to access music which prompts memories of past occasions and people from the past and present”

Q4. Do you feel having an Alexa has been of benefit?

Answers –

Yes – 11

Occasionally – 2

No – 0

Comments –

- “Undoubtedly”
- “A very useful tool”
- “Anyone would benefit”
- “Definitely”
- “Most definitely”
- “I did try to programme Alexa with reminders and information for my wife for those periods when I left her on her own. But it was easier for me to text and ring her with the information - with the added benefit that I could check that she had acted as required (got up, had breakfast, had a shower etc)”

Q5.What type of things do you use Alexa for?

Answers/Comments –

- “Shopping lists, reminders, timers, news, general questions, music and radio”
- “Information about lots of things - music, reminders, news, games”
- “Alarms, reminders, weather, shopping lists, news, music, playlists, sleep sounds, meditation, reminders, spellings and general enquiries”
- “Meanings of words, general knowledge, music, radio, books and weather”
- “Smart plugs, music, HIVE, shopping lists, reminders, drop in, calls, news, timers, weather, general questions and alarms”
- “General questions, music and reminders”
- Radio, searching things, podcasts, music, news, books, HIVE and reminders”
- “Music and weather”

- “Music, news, reminders and weather”
- “Random questions, quizzes, music, playlists, weather, news, medication reminders, night light”
- “I set a reminder when I’m cooking so I don’t forget. I put music on and ask her questions”

Q6. Do you ever find Alexa difficult to use?

Answers –

Yes – 1

Sometimes – 5

No – 7

Comments –

- “She doesn’t always hear and understand me. I have got a new phone now and can’t work out how to put the Alexa app on – I wish I could understand it better myself”
- “The practical support has helped me get over any problems. If help had not been there when I was building my confidence, things may have been different. However, now that I am confident I can try to deal with most problems myself, but know help is there if I need it”
- “Support was really helpful and saved me having to ask my family, so this made me feel good. I’m proud of myself because I can use it”
- “At first, but not now”
- Good to be able to call on support when I have needed it”

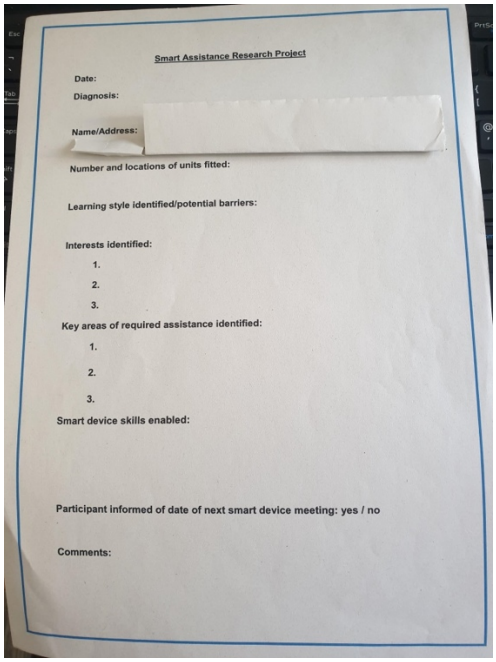
Q7. Is there anything about Alexa that you do not like or would change?

Comments –

- “Security reassurance – don’t like the thought of it being Big Brother”
- “More help built in – you should be able to tell Alexa your diagnosis so she can adapt to your needs”
- “Nope”
- “I wouldn’t change anything”
- “People with dementia should get one free”
- “Generally it is really good”
- “It would be good if there was a local helpline for sorting out technical issues going forward”
- “No, it’s ok so long as I have someone to help me with it. I can’t do it by myself”
- “It would be good to integrate with our video doorbell”

Appendix 2: Project Tools

Initial instillation/learning style/barriers identification form



Smart Assistance Research Project

Date:

Diagnosis:

Name/Address:

Number and locations of units fitted:

Learning style identified/potential barriers:

Interests identified:

1.
2.
3.

Key areas of required assistance identified:

1.
2.
3.

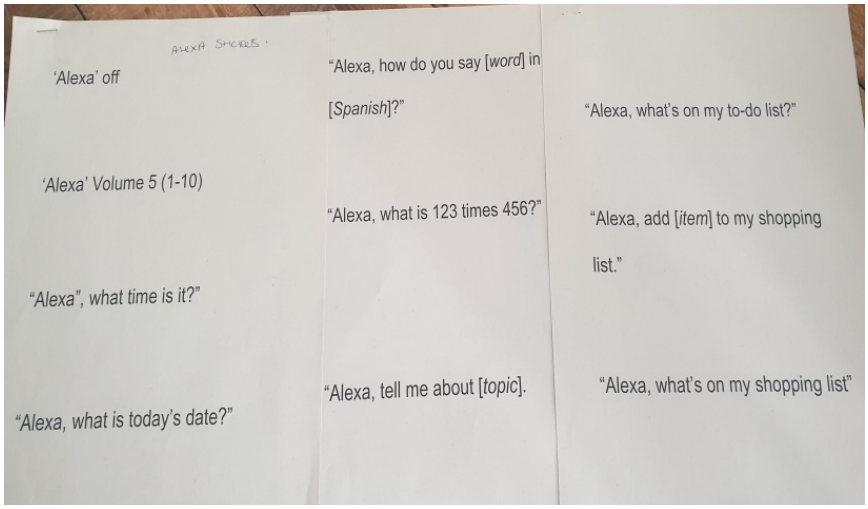
Smart device skills enabled:

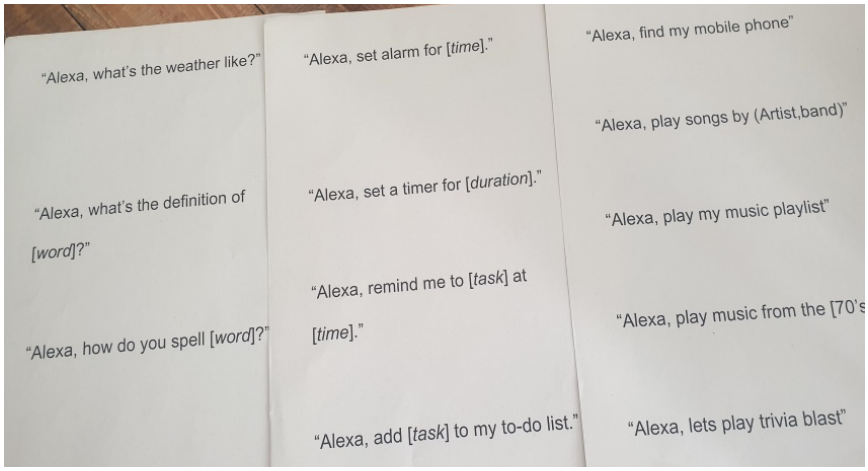
Participant informed of date of next smart device meeting: yes / no

Comments:

Example Laminated Flash/Prompt Cards

Generic Prompt Sheet





Top Ten Tips for Making the Most of Alexa during Self-Isolation

These were sent out to all EDUCATE members in April 2020.

EDUCATE
People with dementia raising awareness

Pennine Care NHS
NHS Foundation Trust

Top Tips For Using Alexa During Self-Isolation / Social Distancing

1. Set up a series of routine reminders to try and keep your day on track.

Examples –

Alexa remind me to feed the dog at 8.00am

Alexa remind me to ring 'Sam' at 3.00pm

Alexa remind me to make lunch at 12.30pm

Alexa remind me to take my medication at 9.00 am

2. Ask Alexa to play relaxing/outdoor sounds to lift your spirits.

Examples –

Alexa play the sound of birds

Alexa play beach sounds

Alexa play rain sounds

1

3. Ask Alexa to set a timer

Example –

Alexa set a 20 second timer (whilst you wash your hands with soap and water)

Alexa set a 30 minute timer (so you remember to take dinner out of the oven)

4. Ask Alexa to read you a Poem / Limerick or a free book.

Example –

Alexa read me a free book (Alexa will give a choice of titles)

Alexa read me a poem

Alexa read me a limerick

5. Ask Alexa for a news update

Example –

Alexa play BBC News

Alexa tell me some good news

2

6. Ask Alexa to play you some music from your favourite era.

Example –

Alexa play Motown music

Alexa play music from the 80's

Alexa play Northern Soul Music

7. Ask Alexa for a weather update.

Example –

Alexa weather update

Alexa what's the weather like in Stockport, England

8. Use Alexa to help keep orientated to the time of day.

Example –

Alexa what time is it

3

9. Ask Alexa a random question

Example –

Alexa how many Kangaroos are there in Australia

Alexa what is your favourite food

Alexa what year was Albert Einstein born

10. Ask Alexa for a daily affirmation or meditation

Example –

Alexa read me a daily affirmation

Alexa start meditation music

Alexa start mindfulness session

9. Ask Alexa to tell you a joke

Example –

Alexa tell me a funny Joke

This information document was produced in collaboration with members of EDUCATE Stockport and Pennine Care Service Users (Younger & Rarer Dementias Team Stockport)

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Appendix 3: Meeting/event notes

Pennine Care Occupational Therapy Conference 6th November 19

Attended by:

Joan Palmer (Alexa Project Team/EDUCATE Member), Rebecca Spooner (Young and Rarer Dementias Support Worker/ Alexa Project Support Worker)

Joan gave a short and informal presentation to Pennine Care Occupational Therapists and support staff, with regards to what the Alexa project was seeking to explore. She was able to give an excellent account of her experience of using Alexa, highlighting many of the ways Alexa had improved her independence and participation in everyday tasks and leisure activities (more info included in case studies).

The presentation was well received. We even featured in the monthly blog of Pennine Care CEO Claire Molloy, who wrote:

> "I loved hearing about their virtual personal assistant 'Alexa project', which is changing some of our service users lives in remarkable ways. This work is helping people stay independent, with Alexa reminding them to take medication, attend appointments and do exercises, as well as assisting them to order food and taxis, dictate texts and get help".

Appendix 4: Case studies

Example 1

Number of units installed – x1 Alexa Dot

Learning style identified/potential barriers –Guided roped learning style preferred (talking it through and repeated practice with support) due to deteriorating visual processing skills.

Interests/Potential areas of assistance identified/Skills enabled – Following initial discussion, working in collaboration with the participant from discussing some of barriers in the home environment, we set out to look how Alexa could enable the participant be more independent in the home. Some of the areas the participant was particularly interest in exploring included -

- Music – Working in collaboration with the project support worker easily accessible playlists of favourite music were set up to allow the participant to access music in the moment independently i.e. – 'Alexa' play Jazz playlist.
- HIVE heating – Beforehand the participant had relied on their partner to control the temperature in the house. The participant already had HIVE heating installed within the home, which can be paired with Alexa (support worker was able to assist with this). Participant can now control temperature via Alexa voice command. 'Alexa' change my home temperature to 20 degrees'.
- Alexa call assist - Due to visual processing skills participant was unable to use their mobile phone to make and answer calls. Working with the project instillation/support worker, incoming and outgoing calls were enabled, pairing Alexa with the participant's mobile phone contacts to allow phone calls to be made and received via voice command i.e. 'Alexa' call Sam. Although this adapted approach did not replace using a mobile phone, it allowed the participant to make and receive calls independently.
- Bird watching – The participant had previously been a keen bird watcher, however due to mobility and visual deficits, taking walks in the countryside had reduced (no longer able to do this independently). After sharing this with information with the project

support/instillation worker, an Alexa skill that played British bird sounds was enabled. The participant purchased a wireless speaker for the Alexa devise and gained enjoyment from sitting in the garden with the skill playing and guessing the bird calls they could hear through the app, in a way helping the participant with to reminisce and reconnect with nature (stimulation).

- Audio books – Reading was something that the participant had previously gained great enjoyment from; however deficits with visual processing had become a barrier to participating in this occupation. To try and overcome this barrier the 'Audible' Alexa skill was enabled to allow the participant to access talking books.

Example 2

Number of units installed- X1 Alexa Dot

Learning style identified/potential barriers –

Participant has difficulties with expressive language and production of fluent speech, which is further impacted upon anxiety. The participant was motivated to use Alexa, however required physical support time and reassurance in mastering the skills required in order to do this.

Interests/Potential areas of assistance identified/Skills enabled –

- Music playlist – The participant particularly like Motown music. Laminated flash cards were produced by project support worker. Following initial instillation visit a follow up visit along with a speech and therapist was carried out (with consent) in order to go through some errorless learning techniques. Using the technique along with the flash cared gave the participant an opportunity to practice lanague skills whilst engaging in an occupation that was meaningful ('Alexa' play Motown music').

Example 3

x1 Alexa Dot installed

Learning style identified/potential barriers – Visual prompt sheets/Step by step guide. Participant has difficulty performing fine motor movements with their hands and therefore support worker spent time with participant to produce personalised prompt/crib sheets around the areas of Alexa that the participant had identified as valuable to them. Mood, new learning and motivation were also all identified as potential barriers in using Alexa effectively.

Interests/Potential areas of assistance identified/Skills enabled –

- Reading - The 'Audible' skill (talking books) was enabled via Alexa. The participant engaged well with this skill initially, however after a short period decided that as they were still able to read and follow books independently they preferred to continue with independently reading books for the time being. Despite turning the pages at times presented a challenge, the participant felt that they were able to manage this at this time. However the participant gave the feedback that it even though they probably wouldn't use the Audible skill at that particular time, it was reassuring to know, that should a time come when physically holding or following the words on a page became difficult they could still enjoy the occupation of reading in a different format.
- Accessing radio and news updates – The participant highlighted that they like to keep up to date with current news/culture and used to enjoy doing this by listening to the radio in their car (the participant was previously employed in a job that involved long hours spent driving). The participant gained satisfaction in enabling the BBC radio 4 skill on their Alexa as this allowed them to use voice activation to access the radio programme and get regular news stories and access to music.
- Reminders and prompts – Although the participant was unable to use the Alexa app, with support the participant was able to establish which regular routines and activities were important to them, these were set up by the project support worker as reminders on Alexa so that important regular events were not forgotten. Reminders were

also set up to remind the participant of when their personal assistant would be arriving, this allowed the participant to feel ready and not surprised when people turned up at their home, this instilled a sense of taking back control in terms of being reminded of the content of the day rather than things just happening and feeling unprepared.

- Orientation – The participant found asking Alexa to remind them of the time, the day of the week and for weather updates helped them to stay orientated to the present.

Example 4

Number of units installed – X2 Alexa Dot

Learning style identified/potential barriers –

Despite volunteering and consenting to take part in the project, the participant was initially very sceptical in terms of the benefit Alexa and their abilities around new learning.

Installation visit identified participants preferred leaning style was quite methodical in terms of following a 'self-created' step by step list. In order to work with participant to build confidence, support visits were initially tailored around navigating the basic functions of Alexa. The participant was provided with generic Alexa prompt sheet to encourage experimentation and interaction with the device outside of support visits. Support worker spent time with participant going through functions allowing the participant time to write down their own individual mini navigation guides.

Interests/Potential areas of assistance identified/Skills enabled –

Some of the initial functions included getting Alexa to recite the most up-to-date football news and accessing, music.

Over the coming weeks the participant's confidence increased in terms of using the device independently. The nature of support visits subsequently changed, instead of going through basic aspects, the participant became more inquisitive about other areas that Alexa may be able to aid with and thus increased levels of independence.

As the participant had been able to control the subjective pace of support accessed in terms of content, frequency and duration, this helped the participant foster feelings of wellbeing in terms of being able to take ownership of their own learning. Once levels of confidence increased, the service user was able to master accessing the Alexa App via their mobile phone, which opened the possibility of enabling Alexa skills increasing the functionality of the device.

- Shopping list - One of the functions that proved particularly helpful in terms of improving daily function and increasing independence was the 'shopping list'. This function allowed the participant to add items to their shopping list in the moment, from which Alexa is able to compile a list over time. Previously the participant had found sitting down and writing a list all in one go challenging, often forgetting items or having to rely on their partner for support. The shopping list function enabled the participant to catch the thought while it was at the forefront of their mind. One example shared included, whilst making lunch the participant noticed that they were running low on butter, in that exact moment they were able to say 'Alexa' add butter to shopping list' the item was added there was no longer any anxiety around having to remember, worrying that they might forget or finally getting home from the shops trip and realising they needed butter. By compiling the list throughout the week the participant was then able to access the app list and whilst walking around their local supermarket checking off each item as it went into the basket.
- Sleep and relaxation - A second Alexa devise was fitted in the participant's bedroom. The participant had confided that they were struggling to fall to sleep at night 'can Alexa help me with this?' Working together a suitable Alexa skill was found that played timed ambient noise, helped the participant to relax and drift off to sleep. The participant also found that being able to get a good night's sleep positively impacted on their cognition, which had previously been negatively impacted upon if sleep was disturbed.
- Medication reminders – With support, routine medication reminders were set up via the participants Alexa device and phone app (as participant is able to navigate the Alexa app they are able to receive reminders both when in the house via their Alexa device and when

out of the house via their phone app. Previously the participant had relied on their partner to remind them to take her medications.
- Music playlist – Recently, with support the participant has been able to compile a playlist which allows access to specific songs without having to remember the full names off artists and song titles.

The participant now accesses support on a less frequent basis. Support is more around trouble shooting or when adding a new skill to Alexa. The experience of using Alexa here appears to have been a very positive one. Going back through the time spent supporting the participant it would seem that the only barrier here has been fluctuations in internet strength within the participants home with sometimes results in Alexa becoming less responsive which can be frustrating.

Example 5

Number of units installed X1 Alexa Dot

Learning style identified/potential barriers –

Visual prompts/repetition

Interests/Potential areas of assistance identified/Skills enabled –

- Instrument tuning skill – participant can play multiple instruments and found this skill very helpful as it enabled him to tune his instruments in an interactive way that didn't involve him setting up any equipment.
- Trivia games – Working alongside the participant various trivia games were enabled. The participant lives alone and fund that this skill combined his love for general knowledge and an opportunity for stimulation.
- Mindfulness/meditation skill
- Reminders & lists
- Morning News update

Example 6

Number of units installed- X1 Alexa Dot

Learning style identified/potential barriers –

Roped learning/repetition/Visual prompts. Participant owns business along with spouse and is therefore required to remember meeting etc. Participant has young family that all engage in their own leisure occupations therefore the participant has responsibilities as part family. Participant was able to navigate Alexa mobile phone app.

Interests/Potential areas of assistance identified/Skills enabled –

- Smart Home
- Reminders
- To do list
- Medication routine
- Find my phone
- Trivia

Example 7

Number of units installed-

X2 Alexa Dot (Lounge/Bed room)

Learning style identified/potential barriers –

The participant had existing knowledge of using, however had only really explored accessing music and other basic functions such as asking Alexa to recall the time/weather etc. The participant was able to write down their own easy to follow instructions and navigate the Alexa app with a little support from their spouse.

Interests/Potential areas of assistance identified/Skills enabled –

- Routine for Medication – The participant is required to wear a medication patch that needs to be changed following a regular pattern. The participant relied on their partner to remember this as they would often forget. Project support worker was able to assist in

setting up a routine reminder so that Alexa follows the pattern of the patch and reminds the participant via the device and mobile phone to change the patch on the appropriate day, thus increasing levels of independence.

- Music/Choir playlist – The participant is a member of a choir, via Alexa a playlist was set up with the current choir playlist to allow the participant to the list of songs they wanted to practice.
- History trivia
- Shopping list
- Timer food – There has been a few instances were food had been left in the oven longer than it should have. The participant was able to learn how to set a timer on Alexa so that they could use it when putting food in the oven, Alexa would sound an alarm when it was time to check on the food.
- Night light – As part of the participants diagnosis they occasionally have very vivid dreams and hallucinations during the night. The participant found the nightlight function on Alexa helpful as they could leave a low light on easily when required.

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