Design workshop investigating assistance cards for people with dementia

rica

Contents

Executive Summary

This research was completed by Rica in partnership with Innovations in Dementia (iD) and the Great Camden Minds DEEP group (Dementia Engagement and Empowerment Project). It is part of a three year project funded by the John Ellerman Foundation to develop and carry out consumer research with people with dementia.

The aim of the research was to investigate the positive and negative opinions that people with dementia have about the design and use of assistance cards and to propose their own design to meet their needs.

The research was informed by five participants with mild to moderate dementia and three helpers who work closely with people with people with dementia.

The workshop consisted of three sections; an exploration of where assistance cards might be of use, a review of existing assistance cards and finally a design session informed from the previous sessions.

Feedback from participants highlights three areas for designers to consider when designing assistance cards for people with dementia:

Trust and security

One of the main concerns among participants was unscrupulous people getting hold of contact information on the card or being aware that the holder has dementia.

Although the likelihood of this happening might be quite small, this is perceived as a very real risk and makes some people with dementia nervous about using assistance cards.

One way of alleviating some of the anxiety behind using these cards in public would be to have limited personal information on the card which centres on the holder's needs rather than stating that they have dementia.

Simplicity and directness

Participants want assistance cards to have a minimum of information on them while allowing the reader to quickly understand the situation. To achieve this, the group was in favour of having straight forward instructions printed on to the card such as: "I need help with…" or "I need to talk to an official" or "speak slowly to me".

Easily identifiable

A key requirement for assistance cards to work well in the real world is for the cards to be easily identifiable. This, from the holder's perspective, is being able to find them easily in their pockets, wallets, purses or bags; and, from the reader's point of view, to be able to quickly understand the nature of the card and what is being asked.

The solution that the Great Camden Minds group suggested was to place a blue border around the card's edge so that it would stand out from other cards. This same blue border could be used to signify a need for assistance. It was recognized that awareness of its function should be publicised internationally to gain maximum benefit from the use of assistance cards.

Acknowledgement

Rica

The Research Institute for Consumer Affairs (Rica) specialises in consumer research with older and disabled consumers. Founded through the Consumers Association, publishers of Which?, Rica became independent in 1991.

Rica has its own consumer research forum consisting of over 750 people. Rica is a disability-led organisation; ten of the charity's twelve Trustees have a disability. Rica carries out commissioned research work with industry, other charities, service providers and policy makers to improve products and services. With grant funding Rica also publishes free consumer reports based on independent research.

www.rica.org.uk

1. Introduction

In March 2018, the Great Camden Minds DEEP group approached Rica with an interest in being involved in Rica's research into accessible products and services for people with dementia.

This research is part of a three-year project funded by the John Ellerman Foundation, completed in partnership with Innovations in Dementia (iD) and local groups developed through the Dementia Engagement and Empowerment Project (DEEP).

Following a meeting with the Great Camden Minds DEEP group to discuss potential research, the design of assistance cards was chosen as a topic to explore.

The aim of the research was to investigate the positive and negative opinions that people with dementia have about the design and use of assistance cards and to propose their own design to meet their needs.

2. Background

The Alzheimer's Society estimates there are 850,000 people with dementia in the UK. People with dementia need and want to be consulted about environments, services and products, just the same as other consumers. Conversations and surveys with people with dementia, and their carers, indicate that their main areas of concern relate to the practicalities of everyday living. Group work, especially with those living alone, reveals that it is the increasing inability to cope with the day-to-day activities that frustrates and depresses them and leads them to withdraw from even trying.

3.   The participants and environment

All names used in this report are pseudonyms.

Five participants attended the workshop; three women (Jane, Sally and Mary) and two men (John and David). All the workshop participants belong to the Great Camden Minds DEEP group and have mild to moderate dementia or Alzheimer's.

Also in attendance were two people from the Camden Carers Service (Anne and Kate) who are responsible for the running of the Great Camden Minds DEEP group. There was also a person from Age UK (Sheila) present throughout the workshop.

It was important that a venue familiar to the participants was used for the workshop, therefore Argenta House in Camden was chosen as this is where the group meet monthly.

4.   Method

The workshop took place on Friday, 20 April 2018, at 2pm, and lasted approximately two hours. Prior to the workshop Robert from Rica visited the group and discussed potential topics for investigation raised by the group. After considering these topics at their next DEEP group meeting they settled on investigating assistance cards and how these might be designed better to help people with dementia when out and about.

4.1 What problem are assistance cards trying to help with?

The problem highlighted by one member of the group, who unfortunately was not able to attend the design workshop, was how to find the right sort of assistance when in need and in an unfamiliar place. The example of, what to do when disorientated at a foreign airport, was used to highlight the difficulty that can be experienced.

During the design workshop we explored this question in greater depth to see where such cards might or might not be of use and what the concerns of the group were.

Two researchers from Rica attended the workshop, one (Robert) coordinating the workshop and the other (Emma) taking notes. Both had the same prompt sheets for discussions and took notes and audio recordings. See Appendix A for the prompt sheets.

4.2 The workshop was arranged in three parts:

4.2.1 Part one – Understanding the need for assistance cards

The first part of the workshop was used to collect stories from the participants about times when they got into difficulty or became anxious and where the use of an assistance card might have helped them. This took the form of a round table discussion with each participant being asked in turn for their story or opinion.

It is important to understand why and where the participants might use assistance cards so that the context and scope could be better understood. We were also interested in finding out what the barriers were in using these cards and how they might be removed.

This task took approximately 20 minutes.

4.2.2 Part two – Review of existing assistance cards

In the second part we used examples of existing assistance cards currently available from businesses and charities and critiqued their design to see what people thought were their positive and negative features.

A Rica researcher wrote the good and bad features on post-it notes: good features on green post-its, and bad on red post-its. These were used in the third part of the workshop.

This review discussion lasted for approximately 20 minutes.

4.2.3 Part three – Designing our own assistance card

Following a short refreshment break all participants, coordinators, carers and researchers reconvened as a group to design an assistance card that matched their wants and needs. For this session, use was made of differently sized cutout squares of paper with prompts printed on them, such as needs, quote, image, 'I need help with' and so on. Some blank squares of paper were included for the group to write on, and put their names if they wanted. These were designed to be placed onto a sheet of A4 paper which represented the magnified assistance card for the group to design.

The prompts, and the green post-it notes from the earlier session, were discussed as to their suitability for inclusion on to the sheet and a design settled on.

This task took 20 minutes and was followed by a short discussion to see if the design of their card would have helped if it had been used in the situations described in their stories in the first session.

Researchers used prompts to ensure the discussion touched on specific areas, but active listening was used to expand on participant experiences and potential areas of interest.

5. Results

5.1 Understanding the need for assistance cards

5.1.1 Overview

The participants discussed the issues behind finding the right kind of assistance when out and about and in need. They considered the effect of disclosing their dementia when wanting help: on the one hand they recognised the increased likelihood that the person being told would then have a better understanding of the situation and therefore be able to offer appropriate help, while on the other hand the participants felt uncomfortable with telling people this information and thus being pre-judged.

The participants also said that assistance cards would be used by people who still had a certain amount of independence and were able to go out without someone accompanying them.

5.1.2 In what situations might these cards be of use?

When the participants were asked to think of situations where having an assistance card might have helped them in the past only Jane offered a situation.

Jane found herself leaving a bus or coach and not knowing which way to turn. She was completely lost and anxious. It was in this situation that Jane felt a card might have helped her, however she had reservations.

"I wouldn't have gone up to anybody and mentioned dementia, I wouldn't want a card like the Alzheimer's thing that says 'I've got Alzheimer's'" – Jane

"I would like to have something like a badge that didn't say anything but was green with purple spots on or something. The trade would know and officials would know, but my travelling companions wouldn't know" – Jane

This concern about disclosing their dementia was also mentioned by David.

"People might take a dim view if I indicated that I [had] dementia" – David

Jane also talked a about a member of the group (George) who could not make the meeting but had a particular interest in assistance cards. George's scenario was also to do with travelling but in his case he wanted to see if there was some kind of assistance passport that he could use to help him when travelling abroad. George felt that such a card might assist him at passport control.

John said he felt no need for an assistance card while Mary said she was always accompanied when outside.

> *"I don't think I've got as far as that, I feel very, very, confident, that lady over there [Sheila] looks after me very well"* **– John**
>
> *"I don't go out shopping, I don't go out on my own"* **– Mary**

The group was undecided about showing assistance cards to the general public with some, like Jane and David, being worried about being pre-judged, while others were more willing to give people the benefit of the doubt, expecting people to be more understanding.

5.2 Reviewing the design of existing assistance cards

5.2.1 Overview

Three cards were reviewed in this part of the workshop: Transport for London, First Group and CaronCares. Two of the cards are provided by transport providers (Transport for London and FirstGroup) while the third was designed through CaronCares, an organization providing self-employed personal assistance to older people and Dima, a software designer of ICE (in case of emergency) cards.

While the group discussed these cards, the positive and negative points as seen from the group's perspective were written down onto green and red post-it notes. These were used later in the workshop to help inform their card design.

### 5.2.2 Transport for London – Travel support card

This card is available online and needs to be printed, cut out along the dotted lines provided and then folded to make a small credit card sized card. There is space to put your name and emergency contact number. There is also a space to write down how someone might be able to help the owner of the card. See Figure 1.

The group thought the personalisation of the card to be a useful feature. This gives the owner of the card space to write down something relevant about their needs and how people might be able to help them. A suggestion as to what might go in to this space was provided by Mary.

> *"I would put on it, 'I might be confused and if so speak slowly and in English'"* – Mary

They also liked the minimal amount of information that the card had on it and the fact that it does not mention the word 'dementia'.

Figure 1.Transport for London, Travel support card
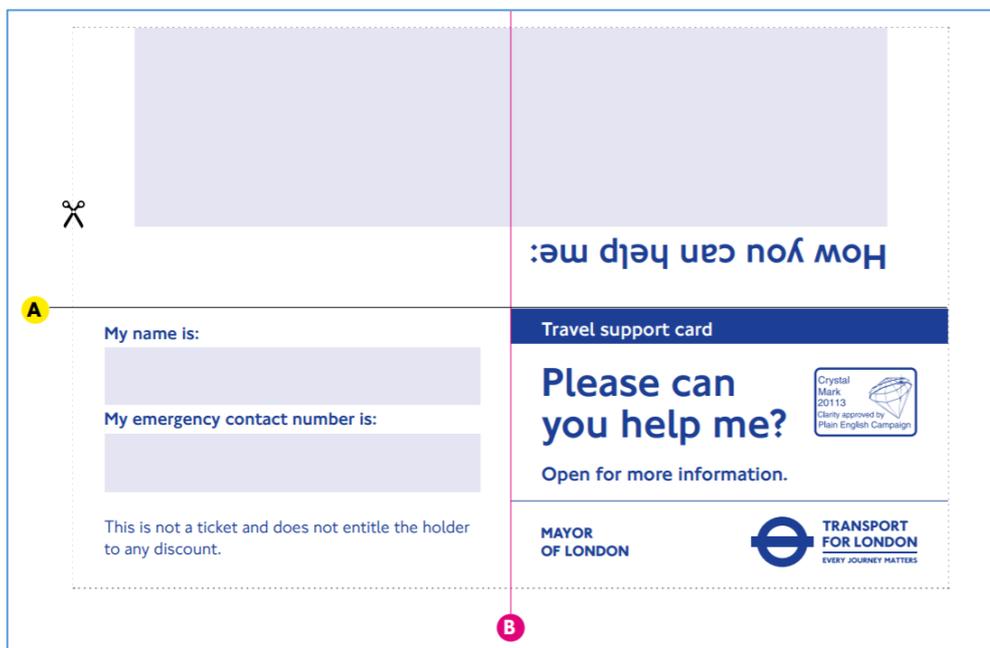
There was a worry about putting person information onto cards and its possible impact on security. Another feature they thought could be improved was to make the card stand out a little more than it does, so that it could be easily found in a purse or wallet.

Jane pointed out that these cards should be placed inside other documents where they might be used.

> *"For example, a pocket in the back of the new passport for these cards"* – Jane

Lastly there was some discussion about knowing what to put into the 'How you can help me' space.

5.2.3   FirstGroup – Safe journey card

FirstGroup have provided a selection of cards with different messages on them for people with different needs. To use them, the appropriate card to your needs should be selected and torn off from the rest and the spaces left for additional information filled in. Figure 2 shows the front of the cards and Figure 3 the backs.

Figure 2 Safe journey card, fronts

Figure 3 Safe journey card, backs

Although the group liked the instructions that these cards gave they wondered if these might cause offence and the drivers react badly. Another area of concern was the material used which the group thought would deteriorate and become unusable. This led to some debate as to how to make the card more robust which is talked about in the next (Designing our own card) section.

It should be noted that FirstGroup has made some improvements to the design of these cards, which can be found on their website.
https://www.firstgroup.com/uploads/node_images/Safe_Journey_Card.pdf

5.2.4   CaronCares – CaronCares card

The group liked the simplicity of this card and the ability to have their own message included on to it. However, they did not like disclosing their dementia. As with the Travel support card it would need to be printed on to a thick card to make it more robust.

Figure 5 CaronCares card front

Figure 4 CaronCares card back
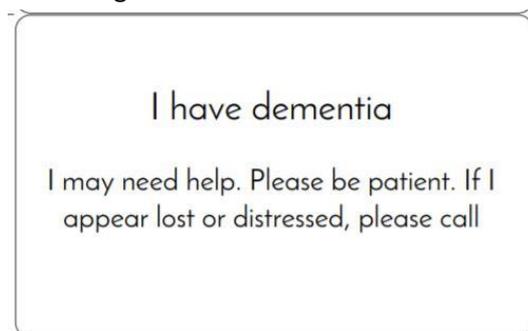
5.2.5   Summary of liked and disliked features

Figure 6 shows the post-it notes collected during the workshop. These post-it notes were used to help fill in Table 1, which shows a comparison of the three cards with their features shaded green for liked and red for disliked.

The red post-it notes read: Disclosing that I have dementia, Not specific enough about condition, Doesn't stand out / not distinctive.

The green post-it notes read: Discloses that may need help, Needs to be kept with relevant cards, Bracelet, Information App on smart phone

Of the three assistance cards reviewed, the FirstGroup assistance card was favoured the most, with the visibility of the card being the only disliked feature. It is worth noting that the newly redesigned card from FirstGroup is a lot more brightly-coloured, which might help solve this. Although without reviewing the new design it is not clear if the colour scheme would meet with approval.
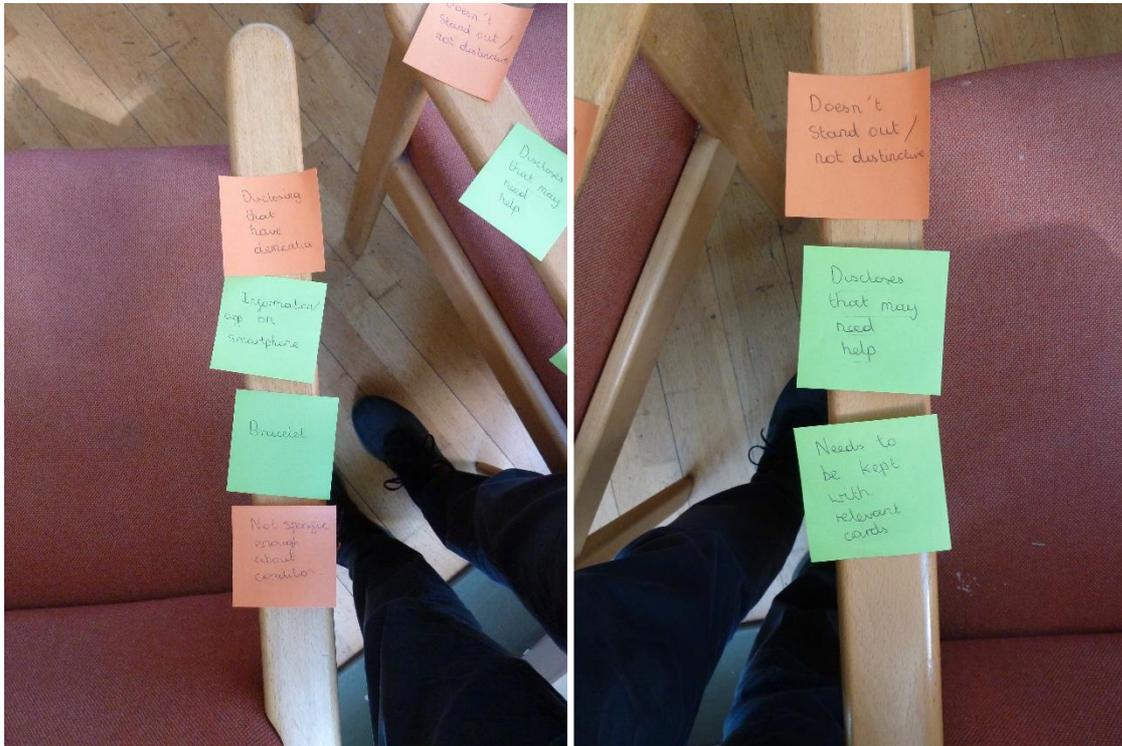
Figure 6. Good and bad features on post-it notes

Table 1: Comparison of features across cards

| Card	Mentions dementia	Mentions needs	Material used	Personal details	Space for own message	Visibility of card
Travel Support	No	No	Printed	Contact	Yes	Poor
Safe journey	No	Yes	Printed	No	Yes	Poor
CaronCares	Yes	Yes	Printed	No	No	Poor

5.3 Designing our own assistance card

5.3.1 Overview

For this part of the workshop the group used the insight gained reviewing existing assistance cards to help inform the design of their own card. A blank sheet of A4 paper was used on to which card elements were placed, such as 'Needs', 'Image' or 'Contact details'.

5.3.2   Design

The group's main requirement for the card was to design something that was simple, to the point and easily found when needed. The result of this session can be seen in Figure 7.

Figure 7 Group's design
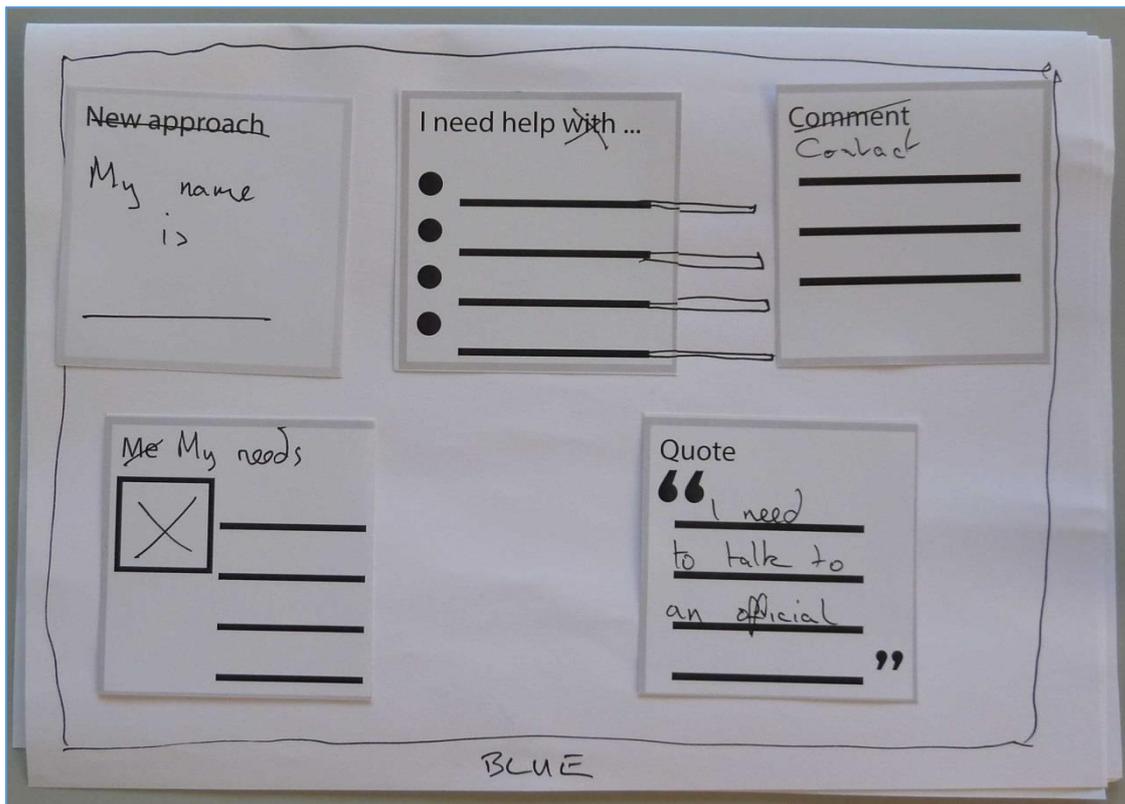
Although there was some discussion to reach consensus, the group felt happy with their decisions. There were four elements to their design: name, contact, help needed and a blue border to make it easily found and identifiable.

The direct approach used in this design was best explained by Mary.

> *"Be sure with them, 'I need help'" – Mary*
>
> *"My name is …, I need help would you please contact so and so" – Mary*

An instruction placed on the quote card asking to talk to an official was also added. It was thought that, in most cases where a person needs help, an official would be best placed to offer it.

> *"I need to talk to an official"* – Jane

It was felt that some guidance on how to communicate with the card holder could be helpful, such as asking people to speak slowly or to understand that the holder might be a little confused.

> *"Speak slowly to me"* – John

There was a wish to design an element on the card which could be easily recognised by officials across all countries. The group decided to create a coloured border to the card. Blue was chosen for the border on their card design because it could be easily recognised while being discreet and not stigmatising the card holder. To design such a card would have some design challenges, however, because of cultural differences and language.

Further design considerations were the size and durability of the card. The group suggested the card should be kept with other documents such as a passport or ticket wallet. This would mean making the card to a similar size to that of a credit card.

> *"Big enough to read but smaller enough to go into your purse"* – Mary

Paper was thought to be an inadequate material for the card since it could be easily torn or stained. Plastic was the preferred material.

5.3.3   Different methods

The use of assistance cards helps the owners of these cards to communicate discreetly with somebody who can help. This might be an official or a member of the public and, through reading these cards, they should be able to quickly understand the situation and respond accordingly.

Other ways of achieving the same effect though using different devices was discussed.

Jane thought that wearing a bracelet with some key information placed on it would be both discreet and not easily forgotten and left at home.

John thought there was opportunity for using smart phones with an app installed to achieve the same result as an assistance card. This method could be easily configured to the needs of the individual. This idea was slightly tempered by the group recognising that not everyone would necessarily have, or be able to use, a smartphone.

6 Conclusions and recommendations

The Great Camden Minds group had differing views on the need for, and design of, assistance cards. Although there were many suggestions about what information should be included in their card design, consensus was found in the approach to the design: it should be straightforward and direct.

Feedback from participants highlights three areas for designers to consider when designing assistance cards for people with dementia:

6.1 Trust and security

One of the main concerns among participants was about unscrupulous people getting hold of contact information on the card or being aware that the holder has dementia.

Although the likelihood of this happening might be quite small, this perceived risk is very real and makes some people with dementia nervous about using assistance cards.

One way of alleviating some of the anxiety behind using these cards in public would be to have limited personal information on the card which focuses on the holder's needs rather than stating that they have dementia.

6.2 Simplicity and directness

Participants want assistance cards to have a minimum of information on them while allowing the reader to quickly understand the situation. To achieve this, the group was in favour of having straight forward instructions printed on to the card such as: "I need help with …", or "I need to talk to an official", or "speak slowly to me".

6.3 Easily identifiable

A key requirement for assistance cards to work well in the real world is for the cards to be easily identifiable. This from the holder's perspective is being able to find them easily in their pockets, wallets, purses or bags, and from the reader's point of view to be able to quickly understand the nature of the cards and what is being asked.

The solution that Great Camden Minds suggested was to place a blue border around the card's edge so that it would stand out from other cards. This same blue border could be used to signify a need for assistance. It was recognized that awareness of its function should be publicised internationally to gain maximum benefit from the use of assistance cards.