Dementia Enquirers

Bringing people with dementia into the heart of research

Summaries of Dementia Enquirers projects

Between 2018 and 2023 Dementia Enquirers funded 25 research projects,* led by people with dementia.

This is a summary of the projects.

The link to each project's full report is listed below each summary.

*one project did not progress because of Covid-19.
Thred merged two of their projects into one report.

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Ashford Phoenix (Kent)

Therapeutic values of involvement in practical music making

Ashford Phoenix are a group of like-minded people living with a diagnosis of dementia. They endeavour to improve understanding around dementia, both in the public arena and in NHS services. They meet monthly to discuss campaigning and dementia advocacy.

The group wanted to find out if people with dementia would benefit most from creating a piece of music by all learning a new instrument, rather than just being participants in music sessions. One member of the group had taken part in an on-line poetry course over Covid-19, and had noticed the significant impact creating poetry had on him. He wondered how music might affect him. It is well documented that music has an impact on people living with dementia. However, this is often as passive recipients. The group wanted to turn this idea on its head and be in the driving seat of music making.

The group planned, organised and took part in twelve music sessions, facilitated by a local musician. They learned the ukulele and composed a piece of original music. At each session they completed before and after questionnaires relating to their mood and cognition. They also took part in focus groups at the beginning, middle and end of the project. One-to-one interviews were also completed at the halfway stage of the sessions.

The results showed a positive effect immediately after sessions on group members' mood, but not a change in cognition between sessions. Focus group and interview data indicated the project has given group members a focus, and de-stigmatised the idea that people with dementia cannot achieve goals or learn new skills.

The group felt this project adds to the literature on the impact of music on dementia, particularly due to the way in which the group have been at the forefront on the planning and reporting of this research.

To read the full report visit **https://bit.ly/3leCFhg**

Scan me

Beth Johnson Foundation (Stoke-on-Trent) Project 1

Discrimination and dementia

Beth Johnson Foundation (BJF) in Stoke-on-Trent was one of the pioneers of advocacy, starting in 1989. In 1998 the dementia advocacy project was established including this peer support and advocacy group. They aim to influence professionals from a grassroots perspective, by raising awareness about living positively with dementia.

BJF explored the question "Does class, ethnicity or intellect affect the dementia pathway?" Members of the group had found that their different life experiences had a bearing on their own dementia pathway. The group used their own experiences to generate a long list of questions, which they narrowed down to five by reaching a consensus via discussion. Further focus groups took place, and the themes that emerged were discussed as a whole group – which led to findings and recommendations.

The group found that class, intellect and ethnicity all have a bearing on the dementia pathway. The impact of this can be both positive and negative. Class was perceived as employment and financial status which can give people money to pursue hobbies and make necessary lifestyle changes. Class can also make you feel more confident to access support. Intellect was considered to be your education level and ability to access or understand information. Again, this can lead to more confidence to seek guidance and to speak out, including challenging ideas. Ethnicity can result in linguistic and cultural barriers. Dementia information is often published only in English, making it easily misunderstood or inaccessible to many.

BJF advocacy group acknowledged that the dementia pathway is different for everyone. However, there are additional impacts of class, intellect and ethnicity in terms of how people adjust to their diagnosis and how others support them. An individualised response is needed and assumptions should be avoided.

To read the full report visit **https://bit.ly/3Ym8R18**

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Beth Johnson Foundation (Stoke-on-Trent) Project 2

The pros and cons of living with dementia during Coronavirus

Beth Johnson Foundation (BJF) in Stoke-on-Trent was one of the pioneers of advocacy, starting in 1989. In 1998 the dementia advocacy project was established including this peer support and advocacy group. They aim to influence professionals from a grassroots perspective, by raising awareness about living positively with dementia.

The Beth Johnson Foundation project was one of five projects funded in response to the Covid-19 pandemic. This funding stream acknowledged the restrictions that would impact the way that projects could be delivered.

They interviewed each other to collate 'stories of Covid', resulting in a range of films.

To view the films visit **https://bit.ly/3JYIsSD**

Scan me

Beth Johnson Foundation (Stoke-on-Trent) Project 3

Exploring the experiences of dementia testing

Beth Johnson Foundation (BJF) in Stoke-on-Trent was one of the pioneers of advocacy, starting in 1989. In 1998 the dementia advocacy project was established including this peer support and advocacy group. They aim to influence professionals from a grassroots perspective, by raising awareness about living positively with dementia.

The group were interested to explore people's experiences of being tested for dementia. They were aware that they had all had different experiences, and there didn't seem to be any consistency.

The group decided to focus their research on the Addenbrooke test as they are most familiar with this process. The Addenbrooke cognitive examination is a screening test which considers attention, orientation, memory, language, visual and visuospatial skills. It is often used in the detection of Alzheimer's disease and fronto-temporal dementia.

The group developed a questionnaire asking about the dementia testing process. Completed questionnaires were received from forty two people. They conducted follow up interviews with twenty three people.

Most people said that no social history was taken during diagnosis. Over half had someone to accompany them during the test. Seventeen people did not have the test explained to them. People reported a range of different environments for testing, including a GP surgery, the hospital, a memory clinic in the community and home. A lot of people felt negative after the test, including feeling dismissed, frustrated, unsure about next steps and patronised.

The group also spoke to staff at a memory clinic and a GP to gather their views on the testing process.

The group recommend that, whenever possible, people are tested at home, that the process is explained in advance and a follow-up is offered to everyone.

To read the full report visit **https://bit.ly/3YANUip**

Scan me

Budding Friends (Exeter)

How Covid and lockdown has made me feel

Budding Friends is a group of people with dementia, carers and volunteers who meet once a week all year round. It is based around an allotment, with indoor activities taking place over winter.

The Budding Friends project was one of five projects funded in response to the Covid-19 pandemic. This funding stream acknowledged the restrictions that would impact the way that projects could be delivered.

The group explored how the Covid-19 pandemic and lockdowns had affected the physical and mental wellbeing of people with dementia. They were very aware of the changes that members of their group had experienced, including moves into residential care. They interviewed people with dementia from the group, people with dementia from the local community, carers whose partners were in residential care and carers whose partners had died, some during the pandemic.

People with dementia described boredom, anxiety, isolation and deterioration of cognitive and physical abilities. Carers expressed a lot of distress, especially if their partner was in a care home. Visiting was minimal, and there were limited opportunities for true engagement. Carers felt that, if their partner has still been living at home, the decline would not have been so great.

The group concluded with recommendations relating to future pandemics for people with dementia, particularly in relation to the way the care home sector responds.

To read the full report visit **https://bit.ly/3logpli**

Scan me

DEEPNess (Isle of Lewis)

The necessary components of a dementia responsive teaching video

DEEPNess is a not-for-profit organisation, run by people living with dementia and cognitive impairment for people living with dementia and cognitive impairment. An offshoot is DEEPNess Dementia Media, a platform for tools around living well with dementia.

DEEPNess wanted to find out what type of video content works best for people with dementia. They were mainly interested in finding content to help people with dementia use technology. The group knew that much instructional video (e.g. on You Tube) is chaotic and wild and not dementia responsive.

Fourteen people with dementia took part in the project. They also acted as an Expert Advice Group. The Expert Advice Group were asked to watch three videos (made by DEEPNess) and then say which video was best for them, in response to a set of questions. The videos were of a young woman, an older woman and a middle-aged man. Discussions took place in a focus group.

The results showed that the content had to be clear, told slowly, and said more than once. The person on the video was not that important.

The group were a little disappointed that the focus group discussions resulted in a lot of agreement. They reflected that one-to-one interviews may have provided a much wider range of responses.

To read the full report visit **https://bit.ly/3Yp7ZZG**

Scan me

ECREDibles (Scotland)

Setting up a research peer support group

The ECREDibles is a new co-production group for people living in Scotland interested in research. It is led by people with dementia, working in partnership with the Edinburgh Centre for Research on the Experience of Dementia (ECRED). The group offers peer support to share ideas, information and inspiration about research projects and to co-produce its own research based on ideas from people with dementia.

The ECREDibles wanted to find out how a group of people with dementia could work in partnership with a university in order to lead research. This was an exploratory project, looking at whether a replicable model could be created to share across universities.

The partnership with ECRED has provide formal, contracted support to write research and funding bids, intern support hours and skills, staff support time, budget hosting and the advantage of a formal partnership with a university.

The group has many recommendations about how people with dementia can be fully involved in this university partnership. Suggestions include rehearsal sessions on Zoom, recording minutes of meetings as audio files, shared files, sending reminders, providing travel support.

This work is ongoing.

To read the full report visit **https://bit.ly/3x6wQ8u**

Scan me

EDUCATE (Stockport)

The EDUCATE Echo Project

EDUCATE stands for Early Dementia Users Co-Operative Aiming to Educate. It gives people with dementia a voice through involvement in training or speaking to others about their experiences of having dementia.

EDUCATE looked at how people with dementia used Amazon Dot Echo (Alexa) and what benefits or difficulties they experienced. EDUCATE describe the marginalisation that many people with dementia experience following diagnosis. Alexa offers ways to keep people with dementia connected as well as keeping life regular, structured and independent. The group felt that technology such as Alexa has the potential to be useful for people with dementia.

Eighteen interested people with dementia were provided with an Alexa. People were supported to identify meaningful interests/tasks relating to the things they wanted. Individual support was given to people with dementia to explore Alexa. Qualitative feedback was recorded about how people felt using Alexa.

The project found that those who got the 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 set-up, installation, trouble shooting and suggesting new functions.

The group concluded 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.

To read the full report visit **https://bit.ly/3JY6ugr**

Scan me

Forget-me-nots (Canterbury)

The impact of Covid in relation to technology, relationships, coping and physical and mental health

Forget-me-nots is a group of older people with dementia. The aim of the group is to help people with dementia and to communicate to healthcare staff to help reduce the stigma surrounding dementia.

The Forget-me-nots project was one of five projects funded in response to the Covid-19 pandemic. This funding stream acknowledged the restrictions that would impact the way that projects could be delivered.

The group wanted to explore the impact of Covid for members of their group. During the pandemic, the group had been forced to meet on-line, which had been a struggle for many members. They wanted to find out how best to support people with dementia during Covid-19, but also in the future.

The group created a list of questions for structured interviews looking at different aspects of people's struggles with the pandemic including technology, relationships, coping strategies, challenges, physical/mental health issues and any positives. People with dementia took on the role of interviewer. There was also a questionnaire of closed questions and tick boxes asking about use of technology before and after Covid-19.

The results showed that use of technology had increased since the pandemic and, although a lot of people required support, it was considered to be a real positive. Contact with professionals had reduced, although personal relationships were able to be maintained and even strengthened. People reported a decline in their dementia, although a range of coping strategies were shared.

The group concluded with recommendations relating to care and research.

To read the full report visit **https://bit.ly/3YEeZkO**

Scan me

Forget Me Nots research group (Swindon)

Post-diagnosis dementia support

The Forgets Me Nots research group was founded by three researchers living with dementia. Their goal is to improve the lives of people with dementia by valuing their expertise and lived experience. They want to influence everyone.

The group wanted to find out how people who have been diagnosed with dementia in the past four years experience their post-diagnosis care. They also wanted to explore ideas about how to improve post-diagnosis support. From previous work they were struck by the different approaches to post-diagnosis support in different parts of the country (and even within the same city!) The group had all had a difficult time post-diagnosis and wanted to explore if things had changed.

Five focus groups were organised, with eighteen people with dementia. Beforehand people were sent a simple booklet explaining the topics that would be covered in the focus group. There was space so people could make notes under each topic. Because online meetings could feel impersonal, a packet of biscuits was sent to each participant to enjoy in the tea break.

Results included difficulty navigating (and finding out about) the benefits system, the postcode lottery of post-diagnosis support, a lack of support services (being left to 'get on with it'), the value of peer support, the perception that dementia is not treated equally, and feeling stigmatised.

The group made recommendations for improving dementia support.

To read the full report visit **https://bit.ly/3KcxmcX**

Scan me

Great Camden Minds

Access to printed information as a person with dementia

Great Camden Minds is a dementia involvement and peer support group. They describe themselves as a 'friendly bunch' with an interest in making things in Camden more dementia friendly.

The aim of this project was to discover how easy it is to find information on dementia services in Camden for older people with dementia. The group all found dementia paper-based information important. The group were all over the age of 75, don't use computers, smartphones and the internet, and often struggled with telephone calls. They noticed that it was becoming harder to get information, by themselves, about dementia. They lived independently and like to find things for themselves.

The group carried out a tour of local services over a three-month period. This included 15 GP surgeries, dentists, gyms, community centres and local libraries. They struggled to find any printed leaflets on local dementia services, help and support or even references to dementia.

The group found there is a significant lack of printed information – leaflets, posters, flyers – on dementia in Camden.

The group recommended that services develop more written information for people with dementia, and that this is accessible and relevant. They are working on an Easy Read version of a leaflet that summarises dementia services, help and support in Camden.

To read the full report visit **https://bit.ly/3I9z4KA**

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Lifting the Cloud (Derby)

Researching visitor attractions in Derby through the eyes of a person with dementia

Lifting the Clouds is a peer support group of people with dementia and carers. It keeps people engaged and reduces social isolation. They are passionate about raising awareness of dementia and trying to improve experiences for people with a diagnosis of dementia.

The group wanted to create a booklet that could help anyone with dementia who was visiting Derby as a tourist. This would be a guide to attractions and any difficulties they may incur which could impact their visit.

The group created a questionnaire which highlighted significant areas that could possibly be challenging for a person with dementia. Some people filled in the questionnaire during their visit, others took it home and filled it in later. At the end of a visit the group also had a discussion about their experiences.

All of these results informed the development of a new booklet: 'Derby Visitors Attractions: through the eyes of a person living with dementia'. You can read the booklet here **https://bit.ly/3qt49z8**

To read the full report visit **https://bit.ly/3KcDJgn**

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Minds and Voices (York)

Living with dementia with and without a care partner

Minds and Voices (York) is a fun, friendly and welcoming peer support group for people with dementia in the York area. They are keen to change people's perceptions of people with dementia. They say "We still have a great deal to contribute and strongly believe that you CAN live as well as possible with dementia".

Minds and Voices looked at "the pros, cons and particular needs of those living alone with dementia and those living with a care partner."

This was a conversation that unfolded often within group meetings, with different people having different preferences.

Minds and Voices carried out a literature review, a series of individual interviews and a focus group involving nine people with dementia in total – four people who lived alone and five who lived with care partners. They asked people to comment about their individual circumstances, and then to reflect on how they might feel if their circumstances changed.

They found that people who lived on their own felt they had many advantages, although loneliness was highlighted as a disadvantage. People who lived with a care partner enjoyed the company, fun and reassurance. However, they commonly found the frustration that dementia can bring to a relationship difficult.

Minds and Voices recommended that service providers and others should know more about people's individual circumstances. They should help people think ahead to if and when these circumstances change. They should not assume that someone living alone is in a risky situation. They advise that people with dementia talk (to each other) and also about the future.

To read the full report visit **https://bit.ly/3jRdzEO**

Scan me

Our Voice Matters (Hartlepool)

How community-based activities can have an impact on people living with dementia

Our Voice Matters is a peer support group of people living with dementia. They identify ways that Hartlepool can be more dementia friendly. They also spread the word about living well with dementia.

Our Voice Matters wanted to know what the impact of community-based groups was on people with dementia. People with dementia knew that they had thrived by being involved in different activities and groups in Hartlepool. They thought a lot of this success was down to encouragement at diagnosis, which gave them the confidence to start or join groups.

They created a survey and had group discussions with people with dementia to find out about the impact of being engaged in activities. They also created a survey for professionals to find out about their experiences of organising activities in the community. The group found that attending group activities provided a range of benefits including (a) making friends; (b) socialising; (c) having fun; (d) relaxing; (e) enjoyment; and (f) finding out about other things available in their area.

The results from people with dementia and professionals helped the group to create some top tips for people starting a group and those who are attending a group for the first time.

To read the full report visit **https://bit.ly/3Xj9YNu**

Scan me

Riversiders (Shrewsbury)

Annual dementia reviews

Riversiders (Shewsbury) is a peer support group run by people with dementia. In addition to being a group where members support each other and chat, they have also been advocating locally for improved dementia care and support.

Riversiders wanted to explore the experiences of people with dementia in relation to the GP annual review process. Annual reviews are specified in the General Practice Contract and reflected in their electronic record system. Group members felt that annual reviews were varied, with many people not having one. The group wanted to find out (a) the proportion of people with dementia who have had an annual review at their GP practice; (b) the content and quality of the reviews; (c) whether the reviews were felt to be worthwhile by the person with dementia.

The group created a questionnaire – an online version and in paper copy, and circulated through the DEEP network. seventy three questionnaires were completed.

The results showed that few people with dementia get an annual review from their GP practice that is any way meaningful to them, in terms of wellbeing and future planning. Care plans were only given to two people, and future care planning was not discussed at all (even though it is specified in the record system used by many GPs).

The group are aiming to engage with GPs and NHS England to improve annual reviews and primary care for people with dementia generally.

To read the full report visit **https://bit.ly/3JV2jlr**

Scan me

Riversiders (Shrewsbury) with Minds and Voices (York)

DEEP groups and Admiral Nurses working together

Riversiders (Shewsbury) is a peer support group run by people with dementia. In addition to being a group where members support each other and chat, they have also been advocating locally for improved dementia care and support. Minds and Voices (York) is a fun, friendly and welcoming peer support group for people with dementia in the York area. They are keen to change people's perceptions of people with dementia. They say "We still have a great deal to contribute and strongly believe that you CAN live as well as possible with dementia".

Riversiders and Minds and Voices were interested to know how much Admiral Nurses and DEEP group interacted, if at all. They wanted to find out (a) how many Admiral Nurses know about and meet DEEP groups and (b) how many DEEP group members know of and have access to Admiral Nurses. They created two different surveys, one for DEEP groups and one for Admiral Nurses.

They found that most Admiral Nurses had heard about DEEP, but not all were sure what DEEP is. Most thought it would be beneficial to have contact with a DEEP group, but only 8% had. Half of people with dementia had heard of Admiral Nurses, though only 17% knew what Admiral Nurses do. Admiral Nurses and people with dementia could each see the benefits of making contact. Admiral Nurses saw the benefit in learning directly from people living with dementia. People with dementia could see the benefits of Admiral Nurses providing support, knowledge and information.

Riversiders and Minds and Voices recommended that Admiral Nurses and DEEP groups explore opportunities to build relationships with each other. The project concluded with a fruitful meeting with Dementia UK (who host Admiral Nurses) to implement the recommendations from the research project.

To read the full report visit **https://bit.ly/3JSWPru**

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Scottish Dementia Alumni (Scotland)

Dementia through our eyes resource

Scottish Dementia Alumni is a group of people living with different diagnoses of dementia for several years. They campaign with the wisdom of lived experience.

The group wanted to develop an interactive game for children aged between eight and ten to educate them about dementia. Raising awareness of dementia amongst children is a priority for Scottish Dementia Alumni "so that everybody grows up knowing about dementia" (James McKillop). The group worked with Science Ceilidh in order to overcome group concerns about how challenging it might be to work in schools.

The project started with a framework for the game from Agnes, a group member. Children would move forward in steps for 'yes' or 'no' answers, with printable stepping stones, reaching a 'home' point. Game questions were developed by talking about what they needed children to know and their expertise. The game was tested out, by the group, with children in schools.

They noticed that the children changed their behaviour during the course of the game, as they learned about dementia. At first they ran quickly to the answer points, not taking much time to think. But as the game progressed, they took much more time to re-read the possible answers and discuss between themselves which answer was best.

The game and accompanying resources are available here **https://bit.ly/3Qx0xqF**

The group intend to develop the game further.

To read the full report visit **https://bit.ly/3Ym5uHm**

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SHINDIG (Sheffield)

To Drive or not to Drive with Dementia? That is the question

SHINDIG wanted to explore the experiences for people with dementia of driving, or having to stop driving. It was formed in 2012 and is a forum where people living with dementia are supported to share their views, opinions and experiences of living with dementia in Sheffield.

SHINDIG wanted to explore the experience of driving, or having to stop driving, of people with dementia. This was an issue that was regularly discussed informally and at organised forums at SHINDIG meetings.

The group felt strongly that there should be a strong emphasis on safety and moral codes. They therefore applied successfully for formal ethical approval from a local university.

Online interviews and focus groups were carried out.

The results of this project have not yet been made public as they are being written up for a dementia research journal.

To read the full report visit **https://bit.ly/3lpOWzP**

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STAND (Fife)

Contributing to the new Fife Dementia Strategy

STAND stands for Striving Towards a New Day. It is a peer support group for people with dementia and their family and friends. STAND also hosts a number of meeting centres.

STAND's project was one of five projects funded in response to the Covid-19 pandemic. This funding stream acknowledged the restrictions that would impact the way that projects could be delivered.

The FIFE Dementia Strategy was being refreshed at the time of this project. STAND members wanted to consult with people with dementia about what should go into the Dementia Strategy. They wanted to consult people face-to-face with a blank sheet of paper and not on a formed strategy.

Sadly, Covid-19 had a major impact on the group's plans for this project. A questionnaire was developed by the Health and Social Care Partnership, and workshops were planned. However, uptake by people with dementia was low.

Subsequently, STAND were able to organise their own event in June 2022, as part of DEEP's 10 year anniversary celebrations. 50 people affected by dementia were in attendance.

A blank sheet was given to people asking: "What matters to you about living with dementia in Fife?" However, people found such an open-ended question to be too difficult. The priorities of STAND members were therefore used to guide discussions about what should be in a Fife Dementia Strategy:

- Accessing self-directed support at an early stage in the disease process
- Accessing peer support
- Receiving care at home
- Being actively involved in creative and artistic opportunities

STAND learnt a lot about running an enabling consultation with people with dementia. They are awaiting the report of their event, which will be fed into the Fife Dementia Strategy.

To read the full report visit **https://bit.ly/3HOkvKR**

Scan me

SUNshiners (Dover, Deal and Shepway)

Dementia as an invisible disability

SUNshiners is an activist group for people in the early stages of dementia. They aim to reduce stigma and raise public awareness of dementia. They also support the NHS through guiding recruitment and service development.

SUNshiners wanted to explore the invisibility of dementia, and the pros and cons of letting others know about their diagnoses. They were interested to find out (a) what the public knew about dementia; (b) what they thought about the invisibility of dementia; (c) why they might want to know if people have dementia.

The group created a questionnaire – an online version and in paper copy. Some of the questions were closed, and others were open ended. The online version was circulated via friends and colleagues. The paper version was left in shops, cafes and groups with a stamped addressed envelope.

The group were astounded to receive 347 responses to their survey! An academic researcher helped the group to think about the best ways to sort out these results and to make categories. The majority of people filling in the survey thought it was a negative that you can't always see dementia, because then others won't recognise symptoms and understand experience. Most people thought that people with dementia should retain the right to vote and also that it would be helpful to know if someone had dementia on initial meeting.

People recognised that the answers were dependent on variabilities such as symptoms and access to support.

To read the full report visit **https://bit.ly/3jIpF35**

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Thred (Liverpool)

Transport and dementia (projects 1 and 2)

The Thred group in Liverpool focus on improving local, regional and national transport systems to make them accessible and inclusive for people with dementia and their carers. Their strapline is "dementia, no barriers, no borders".

Thred led a project on "How can urban and rural transport systems help people diagnosed with dementia live independently for longer?" They also had additional funding for a second project in response to the Covid-19 pandemic.

From their previous work, Thred knew that transport plays a major part in the quality of life of people with dementia and their carers. They decided to compare how people's experiences in a rural areas differed from living in an urban area. They were interested to find out whether transport can promote independence or if it contributes to social isolation.

Thred met with people with dementia in England, Scotland and Northern Ireland, and held Zoom meetings with groups in North and Mid-Wales. They also created a survey that was completed by 57 people.

From their research they found that the majority of people with dementia are reliant on public transport. They regard public transport as critical in terms of staying connected. Helpful staff, accurate signage and information, and improved reliability of services would help people to use public transport more. There was a sense that transport providers do not do enough to encourage people with dementia (and other hidden disabilities) to feel confident to travel.

Thred concluded that public transport is important for people with dementia. It allows people to connect with places and shapes how people live their lives. Increasing the support and awareness of dementia by public transport providers would benefit society and the economy and would also help people with dementia feel more confident.

To read the full report visit **https://bit.ly/3lnaw7Y**

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Thred (Liverpool) Project 3

Route to independence

The Thred group in Liverpool focus on improving local, regional and national transport systems to make them accessible and inclusive for people with dementia and their carers. Their strapline is "dementia, no barriers, no borders".

Thred built on their previous Dementia Enquirers projects to explore what would help people with dementia build their confidence to travel by public transport.

They created a survey for people with dementia and carers. They also carried out some interviews. Additionally, they led discussions with train/bus/airport organisations to gather information. They asked people about their experiences of travelling by public transport, what would encourage people to use it more, and what plans they put in place to prepare for a journey.

Thred found that the biggest problems people with dementia experience when travelling by public transport are unhelpful staff and navigating transport hubs. 60% of people found travelling by public transport difficult. The most important areas to improve were availability, accessibility and signage.

From their findings Thred have created a travel checklist for using public transport. They also recommend that transport providers read the report and address the barriers highlighted.

To read the full report visit: **https://bit.ly/40Z2m61**

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Up and Go (Leeds)

Can a dementia diagnosis open doors to new opportunities?

Up and Go is a group of people with dementia and supporters. They offer ideas that help their local community and environment to become more dementia friendly. They have a say in how local services are run and suggest how to improve them based on their experience and understanding of life with dementia.

Up and Go wanted to learn about how people with dementia in Yorkshire are taking up new opportunities. People with dementia in Up and Go have said that the group has opened up opportunities for them. They wanted to make sure other people with dementia are not missing out.

The group developed a survey to gather the opinions of people with dementia on the new opportunities they had, or did not have, following diagnosis. They also wanted to find out how people felt about this. The survey was online and in paper form. The group also had a field trip – to a llama farm! They reflected together afterwards on the impact of this new opportunity.

Of the people who filled in the survey, 5 in 6 people had found a new opportunity after dementia diagnosis. 2 in 3 people identified their new opportunity as starting a new group or activity. 1 in 6 people didn't have access to any new opportunities. The most common reasons for this were needing support to attend or not being bothered/having a lack of energy. The field trip showed that, with the right support in place, people with dementia can actively take up new opportunities that are enjoyable and socially-bonding experiences.

The group Recommended, amongst other things, that new opportunities should be a priority after a dementia diagnosis. Professionals play a key role in helping newly diagnosed people to access groups and activities.

To read the full report visit **https://bit.ly/3xs6ePi**

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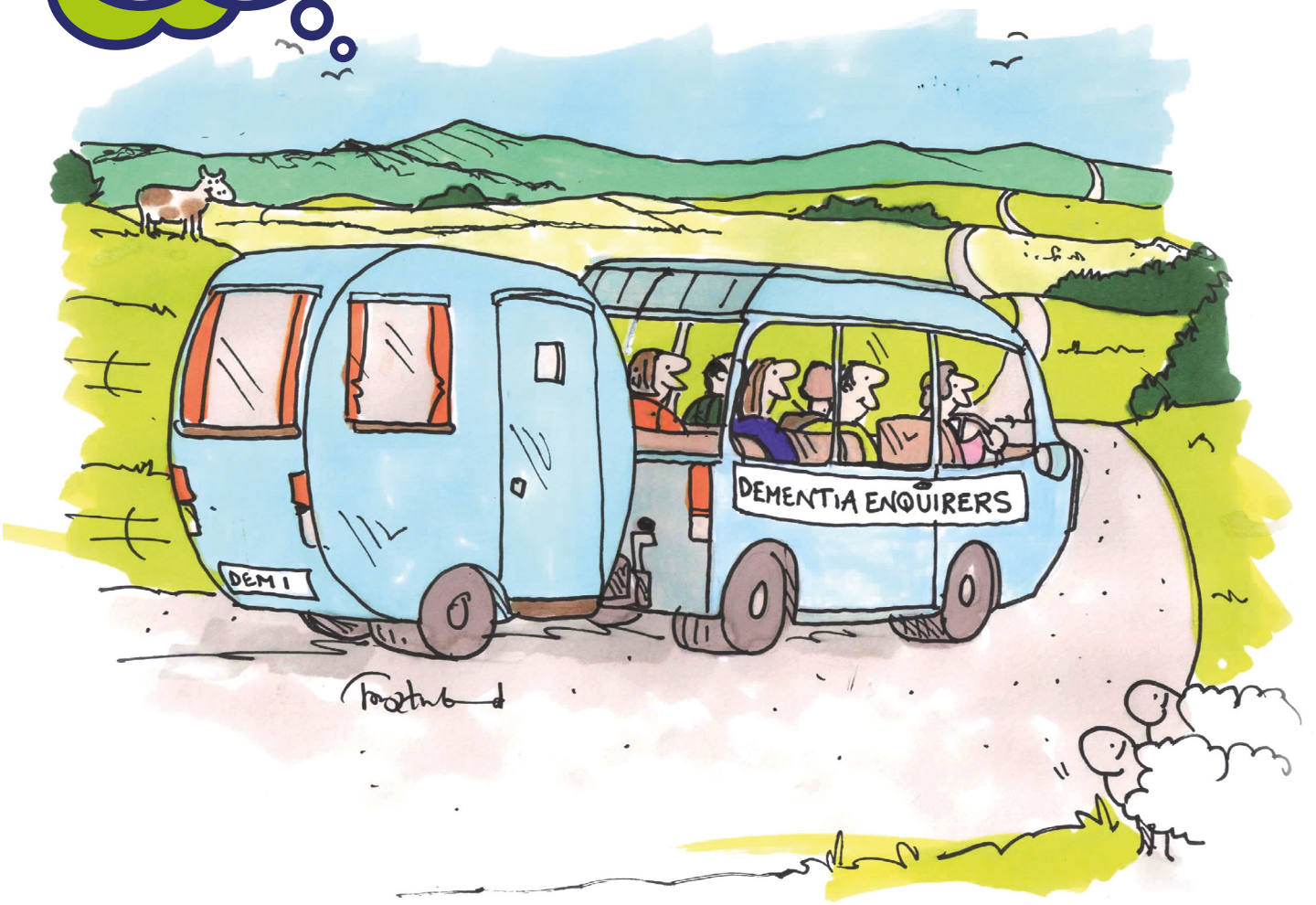
Dementia Enquirers

Bringing people with dementia into the heart of research



For more ideas from Dementia Enquirers visit **www.dementiaenquirers.org.uk**

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