

# Dementia voices, hopes and opportunities:

testimonies from people  
with dementia during the  
Covid-19 pandemic.

# Innovations in Dementia is a not-for-profit Community Interest Company (CIC)

People with dementia are at the heart and start of all our work across the UK. We promote a positive but realistic view of dementia, demonstrating that, although it is life changing, it does not have to be life ending. We support people with dementia to live with hope and keep control of their lives.

Innovations in Dementia hosts the UK-wide DEEP network (over eighty involvement groups of people with dementia), the Dementia Diaries project (first hand testimonies by people with dementia) and the Dementia Enquirers programme (putting people in the driving seat of research). These projects, and others, come under the umbrella of the Dementia Voices programme, funded by The National Lottery Community Fund.

In mid 2020, we were fortunate to be given additional funding for the Dementia Voices programme from The National Lottery Community Fund. This was for a series of projects responding to the needs of people with dementia during the Covid-19 pandemic.

For more information visit:



[www.myid.org.uk](http://www.myid.org.uk)



[www.dementivoices-id.org.uk](http://www.dementivoices-id.org.uk)



October 2022

# Contents

Introduction	1
The early days of Covid-19	3
The challenges of lockdown	7
Some joys of lockdown	8
People with dementia have the solutions and strategies	9
How we supported 'A Good Life with Dementia' courses	12
Thinking differently about dementia—thinking differently about lockdown	13
The power of DEEP friends	15
Moving to an online world—a note about the 'digital divide'	20
Hidden talents, new experiences	21
Getting on with the job	25
Learning from Dementia Voices—lessons from a post-pandemic world	27
References	29

# Introduction

“But for now we lie, half awake, half dreaming  
Waiting to see if our clock is about to stop  
Waiting for the warming sun to rise on us again  
Waiting to pass into a new land  
The same but profoundly different”

**George Rook, 2020**

In March 2020, the UK entered its first national lockdown in response to the Covid-19 pandemic. Life changed overnight, and in ways that couldn't have been anticipated or prepared for.

Initially, like many organisations, we weren't quite sure how to respond. How could we best support people with dementia? What sort of adjustments were needed to work in a different way? How could our programmes of work be delivered?

But of course, the solutions and approaches were all there in the huge resource of thousands of people with dementia connected, at a grassroots level, through the Dementia Voices programme.

Dementia Voices seeks to harness the collective potential of people with dementia by:

- Supporting more people with dementia to have their voices heard and finding new ways to achieve this
- Ensuring these voices can have maximum impact in the places where they can do the most good (including between people with dementia)
- Placing more control in the hands of people with dementia themselves



Dementia Voices is made up of over eighty groups of people with dementia, across the UK, as well as individual Dementia Diarists who have made over three thousand audio and video diaries. These networks of people with dementia have huge reserves of wisdom, practical knowledge, experience and humour.

Dementia Voices comes out of people's lives – taking place in their neighbourhoods and communities, achieving influence, social change and peer support via the marshalling of human stories. Dementia Voices is not top-down, where views are gathered to fit structures such as questionnaires or consultations. Instead this knowledge is generated by people with dementia. It is experiential, of high value and can disrupt the status quo, changing understandings of life with dementia.

A substantial amount of dementia research was undertaken and reported during the pandemic, with an acknowledgement that Covid-19 was placing unprecedented pressure on dementia health and social care systems and a concern that people with dementia were likely to be disproportionately affected by Covid-19 measures (Alzheimer's Society, 2020).

At the time, there was perhaps an assumption that the pandemic would have only a negative impact on people with dementia and their families. Alzheimer's Society reported findings from a survey in July 2020 (just after the first national lockdown) that half of those living with dementia said the pandemic had a negative impact on their mental health and one in three people reported having lost confidence to go out and carry out daily tasks. But as the pandemic progressed, it became clear that the situation for people was varied. Some people coped well, others coped with difficulty or were only just coping. There were positive impacts of the pandemic and even unexpected benefits (O'Rourke et al, 2021). Resilience was highlighted as a characteristic that helped people (Daley et al, 2022).

This report is about the experiences of people with dementia connected to the Dementia Voices programme, during the Covid-19 pandemic. These testimonies are not structured through research questions but convey the knowledge, wisdom, aspirations and hopes that people with dementia live with day-by-day.

# The early days of Covid-19

Life changed overnight for everybody in March 2020 as the UK responded to the Covid-19 pandemic with its first national lockdown. The contacts, daily activities, routines and social options that shaped time were radically altered, with no opportunity for planning or adjustment. It was a challenge for everyone, in different ways. We all had to find ways of coping and adapting whilst the world around us changed.

“We are all trying to find our way in a world which seems to have lost its familiar landmarks and moorings. We are trying to counter fear and uncertainty with hope, pragmatism, humour and courage.

People with dementia have been doing the very same thing every day for years. Coping with isolation, stress and uncertainty, and have much to teach the world. Your voices and experiences have never been more important.

Let’s all work together to rise above this challenge! Stay safe.” Steve, Philly, Rachael, Damian and Rachel N.

**DEEP News March/April 2020**

March/April 2020

**our deep News**  
The Newsletter from the UK  
Network of Dementia Voices

**DEEPLY strange and extraordinary times**

**'People all over the world are trying to find their way in a world which seems to have lost its familiar landmarks and moorings.'**

At the time of writing we have just been told we must all stay at home. The DEEP network has thrived on coming together in person. Groups in the DEEP network just cannot meet up face to face for the foreseeable future. We are very much aware of how devastating this must feel for very many people. Members of the network describe the groups as 'life-giving' and 'life-affirming' and so much more. It may feel like the world has just become a much, much smaller place. We face the challenge of how we can stay connected. The challenge is already being faced with courage, commitment and love as we hope you will see in these 8 pages.

We all want to ensure the safety, health, welfare and well-being of us all.

We hope that you will be able to receive a copy of Our DEEP News in the coming months. You may have a copy in your hand, you may be reading it on a computer or listening to an audio version. Let us know if we need to do anything differently so you can get your own copy.

What we want to do is share what you are doing, spreading ideas, hopes and love... and not a virus. We hope, in some small way, it helps.

We want to bust the blues of the bug!  
**Stay safe x**

**Contents:**

A message from the Innovations in Dementia team .....	Page 2	Bust the blues of the bug.....	Page 4, 5 & 6
Meet the Shropshire DEEP Hub .....	Page 3	Dementia Diaries .....	Page 7
		Closing thoughts & contacts.....	Page 8

At the same time access to dementia health and support services dropped significantly, with family carers filling the gap (Giebel et al, 2021; Wheatley, 2022). These findings have perpetuated existing health inequalities, with a sustained drop in dementia diagnosis rates for the first time ever (Alzheimer’s Society, 2022).

At Innovations in Dementia we had some moments of shock, before remembering the old adage of ‘keep busy’! We embarked on making a series of films with people with dementia for Covid-19 volunteers who had stepped up and into local communities. They were practical in focus, with the aim of supporting volunteers who may not know much (if anything) about dementia, to be guided by people with dementia themselves in their approaches. The goal was to keep people with dementia at the centre of these interactions. In fact, it was our film about using Zoom that received the most attention, viewed by 5500 people who hadn’t previously used Zoom and who valued this accessible guidance.

And there was a timely reminder from people with dementia that **being** is more important than **doing**!

“It seems like forever, because I’ve been living in a different reality and I’m trying to get my bearings and understand it. I never know what day it is, I’m being more forgetful, from forgetting to turn my calendar over and using the tips and strategies. They no longer work now and I don’t understand why. It’s like – you know the bubbles, when you blow bubbles. I’m trying to become not a human-doing, but a human-being.”  
**Agnes**

We tried to think about the stories and possibilities that might emerge during the pandemic.

We wondered about the potential of local communities to step up as dementia services closed or changed, for example, via the newly formed Covid-19 volunteer hubs? Perhaps people with dementia would be ‘held’ by their neighbourhoods and neighbours, with people looking out for each other and providing informal circles of support? Maybe alternative models of community support would emerge, driven by community feeling, daily interactions and noticing when things are amiss?



However, this was not the dominant narrative emerging from Dementia Voices as the pandemic wore on. The reality was that services and support were disappearing, and people with dementia had real fears about loss of skills, enthusiasm and confidence that had been built up prior to the pandemic.

Professionals that we were in contact with were at a loss to know how to continue to best support people and were feeling demoralised and sad about the deteriorations they were witnessing. Covid-19 volunteers were mostly having contact with carers of people with dementia, with people with dementia themselves largely hidden. The experiences that were discussed were largely about loss and desperation.

Penny Unitt is the facilitator of the Budding Friends DEEP group that is run by AGE UK in Exeter. Penny struggled to think of anything positive from her experience of supporting people with dementia during COVID-19. On the



contrary she discussed clients whom she described as becoming totally deskilled and demoralised during lockdown, and she was despairing of finding anything that she could do to bring them back.

The STAND group in Fife gave similar reports. One man with dementia had been very active in a workshop project where he was able to use his woodworking and DIY skills. Since the pandemic he had been unable to attend the project. His carer reported that he had experienced significant decline and worried that he would never be able to recover his skills, enthusiasm and level of engagement in what was a very dementia friendly community. Another woman with dementia spoke of her efforts to learn how to take the local bus into town. Her husband and carer said that it was going to take a lot for her to be able to regain those skills and confidence.

**This is not to say that neighbourhood circles of support have not emerged throughout the pandemic, as this Dementia Diary from Dory in March 2020 shows:**



And this afternoon a gentleman who lives down the road, I only ever say hello to him, but he knocked this afternoon to say if ever I need anything, any shopping or if I'm not feeling well, I must give him a shout. And he said you know I really mean that, you must give us a shout for anything you need. So I thought, although there is, you know, these people who just think of themselves, there's, I think, there's more kind people than bad, so thank you to all those kind people.



<https://bit.ly/3yNxgRG>

Scan the QR code above or use the link to listen to Dory's audio diary.



In this report you will read about the stories and experiences of people with dementia, as they occurred and were reported on through the Dementia Voices programme from March 2020 to June 2022.

This report has been generated through the Dementia Voices projects–DEEP, Dementia Diaries and Dementia Enquirers. With additional funding from the National Lottery Community Fund, we also have been able to run some extra projects, in direct response to the needs of people with dementia during Covid-19. These are:

- Getting Along
- A Good Life with Dementia
- Tip-Share
- Dementia Creatives
- ‘How to’ films (to help people with dementia to use technology and on-line communication platforms)
- A scoping project with libraries to explore the potential for peer support groups of people with dementia



You will also read about some of this work within this report.



Getting  
Along



Dementia  
Tip-Share



Dementia  
Creatives

# The challenges of lockdown

It was the challenges of the Covid-19 pandemic, particularly in light of the first national lockdown, that affected people. Many people described it as “having dementia all over again”.

**Chris described lockdown as almost like a bereavement:**

“One minute I was out, and the next thing is I was literally in lockdown. So, all your emotions go along with that and it is difficult to know how to make things better for yourself sometimes, especially when you have a bit of a dip because nothing seems to motivate you then.”

**Steve found the lockdown emotionally tough:**

“It’s just being home and being vulnerable I guess. Can’t go out, can’t go anywhere, depression’s raised its ugly head again.”

**Lorraine really missed social contact:**

“I feel totally on my own now ‘cos I live alone and it’s not an experience that I really like or appreciate. I miss, miss the contact with people desperately... hugging my children and my grandchildren and giving them a kiss and coming in for a coffee. And the things that you really do take for granted that make your day. And at times I am struggling with this.”

It was also common to hear people say how scared they were of losing their abilities—the ability to speak, to socialise, to get out and about.

**Glenda realised quite early on in lockdown, how much she missed socialising:**

“I’m just worried—will I be able to cope with people when all this is over? Will I be able to go on stage and talk and do the things I usually do? I’m finding my speech is getting difficult because I’m not speaking much to other people.”

**Wendy expressed similar fears in a poem:**

“When this is all over, Will we be able once more  
To take a simple trip, To walk into a crowded room?  
When this is all over, We’ll all need support  
To discover a new normal, To discover the world once more.”

# Some joys of lockdown

It wasn't all negative though. Many people found comfort and positivity in the world of nature – or in their own gardens.

## **Mhari enjoyed digging the garden:**

“There are lots of bees, absolutely millions of lovely, lovely bees, lots of birds... and yes all seems to be OK, and I have enjoyed my little garden.”

## **Keith also enjoyed sowing seeds and sitting outside in the sunshine:**

“No matter how big or small a garden one has, one can sow a few seeds in pots and get some great pleasure from them and then the occupiers are thinking about their watering and nurturing them... or just (sit) outside on a patio or garden with a cup of tea or a cup of coffee and just take in what the world is providing us on these Spring sunshine days.”

## **Wendy walked much more than usual, and explored new parts of her local surroundings. Like others, she found that:**

“This lock down has reduced traffic fumes, reduced pollution like we've never known it, allowing nature and the world to breathe once more. So maybe now, amidst all this trauma, we have to learn to slow down and appreciate what we have around us, whatever that may be...”

## **And Ronald wondered:**

“I used to wonder where have all the birds gone. As I rarely saw and never heard them, I now know they were just stifled and crowded out by the traffic and people. All day long now I hear birds singing.”

## **But these feelings of happiness were sometimes tinged with guilt. George realised:**

“I am enjoying this silence. Many are not...they will be alone, staring at walls, unable to get the food they enjoy, wander around, maybe see familiar faces passing their windows. And many will not understand why. They will not remember why.”

# People with dementia have the solutions and strategies

Quite quickly, however, creativity and ingenuity emerged. When the world had shrunk to moments, minutes and days, people with dementia recognised that they had a repertoire of invaluable responses available to them, learned from their experiences of living with dementia.

## As Jacqui points out:

“People with dementia are some of the best mindfulness teachers, since they are living in the moment like no-one else.”



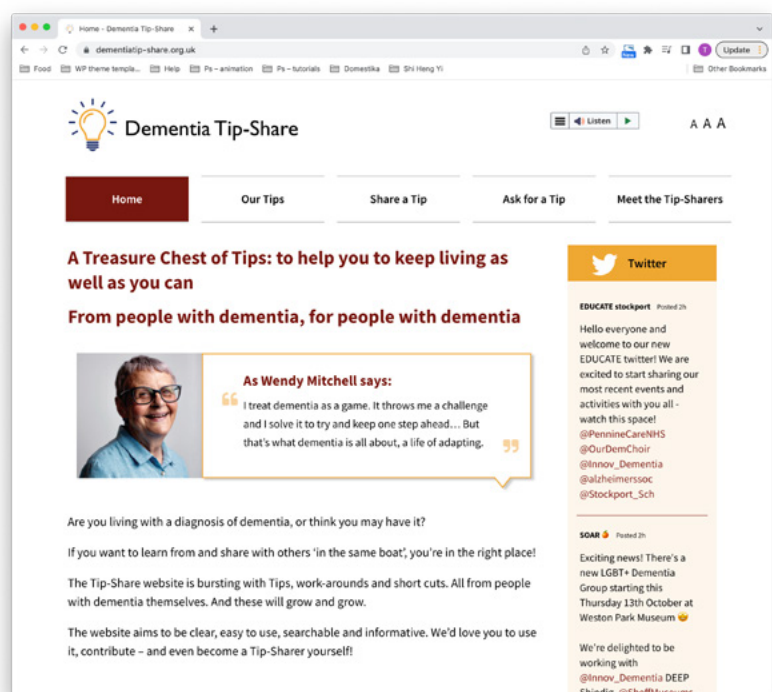
The helpful thing about these solutions was the sharing of them with others, and the subsequent learning of new strategies. Here are some ideas from the Beth Johnson Foundation peer support group, a group in the DEEP network:

- **Sue** has been using this time to be active, participating in online exercise classes most mornings, Yoga, and learning Welsh on a free app called Duolingo.
- **John** has been continuing to enjoy his arts and crafts and try new projects. He has been enjoying the slower pace of life even taking a break from the ironing!
- **Rita** has been watching quiz shows. Countdown and the Chase have been keeping her mind occupied during the day, and not to mention the two word searches she does before bed.
- **Maq** reckons that ‘Keeping in touch has never mattered more’ from a quick text, call or video chat. He has also noted the importance of taking media breaks, watching the news but in small doses, monitoring social media usage.
- **Shelagh** thinks that sometimes it’s the small things that make the big difference. Shelagh likes to take each day as it comes, keeping in touch with people, eating lunch outside and she’s our Zoom expert with all the calls she’s making!

- **Gordon** has an idea he'd like us all to try—go through the alphabet letter by letter and write down words starting with that letter e.g. in the kitchen, countries, anything that comes to mind. Hobbies Annual is a good standby magazine as there is a good variety of new hobbies to try in there. There is always the option of Open University too.
- **Fred** has been going out for walks as and when he can, getting in the fresh air when possible.
- **Dave** has been completing jigsaws and puzzle books regularly and using a free app called 'Wordscapes'—a very addictive and challenging app to keep you busy!
- Other general suggestions we came up with together are – baking your favourite sweet treats, getting out in the garden or park, making full use of talking electronics such as Amazon Alexa for reminders to take medication, meal reminders and other daily prompts, keeping up with old hobbies as well as trying new ones and most importantly, staying in contact with others for support.

.....All with the hope that we can all be together again soon!"

In response to this rich source of lived ideas we set up an online platform called Dementia Tip-Share, a treasure chest of tips from people with dementia for people with dementia. The Tip-Share website is full of ideas, solutions and short cuts to help people to live with dementia more easily. It has been designed with people with dementia, to be clear, easy to use, searchable and informative. Although it was set up as a place for people with dementia to share tips in response to the coronavirus situation, it has expanded to many other areas including life both in and outside the home, emotional and family life, friendship and peers, connecting and communicating, money and legal matters and health issues and symptoms.



Another area we looked at was relationships. The National Lottery Community Fund funded Innovations in Dementia to provide a series of Getting Along programmes to support couples to well,... get along...

During lockdown there has been a huge rise in domestic abuse worldwide. The UN has described it as a **'shadow pandemic'**.

We took fifteen couples through the programme seeking to equip them to avoid the many traps that dementia can set within relationships.



**'You get the second-guessing and the not quite understanding that goes on and all that niggling, draining stuff'**

**'I've enjoyed it. You get to see the other person's point of view'**

**'You're the only person who's been so frank about the reality of what we are living'**

We also were able to put on a series of virtual Getting Along facilitator programmes and we trained thirty-two new facilitators from organisations around the UK. Age UK Salford have adopted the approach to complement their 'Empowered Conversations' programme that had hitherto focused only on care partners.

We have since been commissioned by East Riding of Yorkshire Council to develop twenty community-based staff who are now able to include Getting Along as an established part of their dementia services offer.

# How we supported 'A Good Life with Dementia' courses

A Good Life with Dementia is a post diagnostic programme created **BY** people with dementia **FOR** people with dementia.

Although many services halted during the lockdown, people continued to be diagnosed with dementia. It wasn't all negative though. create a new Good Life course that could help many people living with a fairly recent diagnosis who might still be left with a host of unanswered questions and uncertainty about the implications of their diagnosis.

We worked together with members of STAND – a peer group in the DEEP network of younger people with dementia to co-create a course specific to Fife, Scotland. The resultant facilitator packs meant the group have been able to run their course locally several times and they have now been commissioned to run what is effective. Interest in the Good life approach has grown and we have also been commissioned to co-produce five more Good Life courses across East Yorkshire.



# Thinking differently about dementia—thinking differently about lockdown

The way you think about a situation also makes a difference. At Innovations in Dementia we want to inspire different conversations about dementia. We want to shift the way that dementia is discussed, but also the ways that people with dementia are involved—by supporting people to be in the ‘driving seat’, identifying and following their own route maps. People with dementia have described our role as a circus safety net, hopefully not needed but supplying confidence and back up for when things don’t quite go according to plan.

## **Agnes changed the words she used to describe the situation:**

“I have a thing ‘I’m Locked Down, I’m in prison, I can’t get out’. And then my daughter changed it round and she said, ‘Mum, let’s put a positive spin on this. You’re sheltering from the C Storm, you’re self-sheltering from this virus.’ So I’m indoors and I’m sheltering from the storm and while I’m sheltering, I’m gathering information about myself and I’m learning new skills and the new thing I have learned today is, how to use WhatsApp.”

## **And Wendy drew on her positive attitude that she has built up over a lifetime:**

“My glass half full personality looks for the positives to survive, whereas glass half empty folk find that so difficult and are immersed in the sadness. I wish I could give them some of my excess sparkle, some of my excess smiles.....I must really annoy them... Dementia once more has unwittingly given me a chance to forget the tragedy that’s around us. I’m sure it would be furious to know that the bubble of happiness I can enter is giving me a way to survive these times...”



**As George says:**

“We may not have the care and support some of us need. We definitely won’t have the face to face company and touch that we all very much value. But it does me no good to think about how things ought to be. How things might be in a perfect or even imperfect world. No, I am feeling much more relaxed than for years. The evenings are getting lighter and, sometimes, warmer. My seeds are growing. So my message is... don’t dwell on difficulties, find something new to do.”

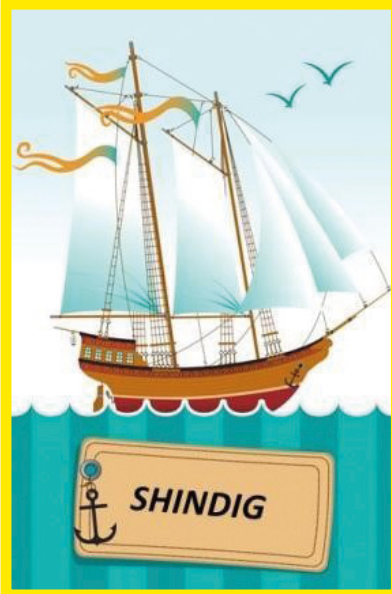
**Roy, meanwhile, took lockdown as an opportunity:**

“He says his attitude is to “try and be cheerful.” During the first lockdown his daughter suggested he take his beloved bench and place it at the front of the garden overlooking the road. What started off as a casual wave here and there turned into a daily occupation, with people honking their horns, runners passing by clapping and neighbours shouting encouragement. Roy says he feels fortunate to have so much love and support, but he knows a lot of people don’t have that. He thinks we all should be encouraged to wave, smile and talk to each other.”



# The power of DEEP friends

People with dementia who attend DEEP groups are bonded by their regular face-to-face contact with people in the 'same boat'. DEEP is anchored around unity, opportunity, rights, humanity, influence and love. It is a powerful movement of interconnected people with dementia.



We are the Shindig crew,  
Get your oar in the groove,  
If we all pull together, we can make things move!  
Shindig is the anchor that keeps us all together,  
Sailing through all kinds of weather  
This is a place.  
A safe space  
To come together, be involved  
To share our voice  
Share our views.  
Alongside others sitting in the same boat.

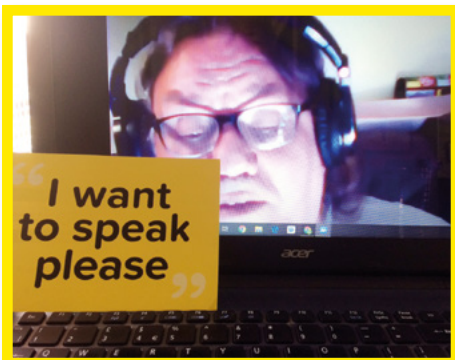
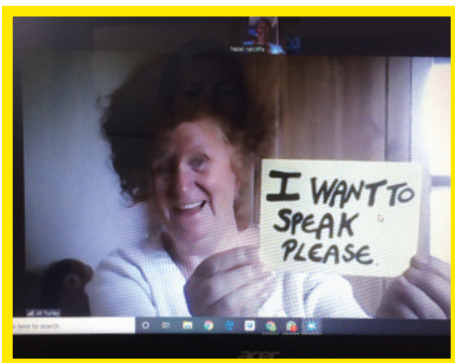
But in March 2020 the face-to-face groups stopped.

Many DEEP groups moved to online meetings. One benefit of this was that people could 'visit' a different group in another part of the country, without any physical travel involved! Groups did a lot of work to support people to use new technology to connect to platforms such as Zoom, WhatsApp and Facebook. People surprised themselves about how quickly they were able to learn.



The Buddies group in Leamington Spa said this about connecting through Zoom:

- It's important. It's the highlight of my week.
- Little Buddies have grown out of this group with people staying in touch outside of the meeting with each other as well.
- Staying in touch has been a lifeline for me.
- Initially organisations contacted me but it died away. This (Zoom meeting) is regular.



But there were some obstacles. Some members of groups did not have the equipment to access life online, others were reluctant or unable to do so. Some host organisations of DEEP groups (like the NHS) had very rigid rules around setting up online meetings, meaning there was a long delay in setting up communication channels. Also, some facilitators employed by larger organisations were redeployed or furloughed during the pandemic.

There were other solutions though, for example chats on doorsteps and at garden gates, a letter writing club and home deliveries of cream teas. 'Thinking of you' cards, 'Miss you' cards and even MP3 players were sent to group members who weren't accessing online meetings. Our DEEP News, the monthly newsletter of the DEEP network, was packed full of inspiration and ideas from people with dementia with practical tools and ideas for surviving and thinking differently about the pandemic. We increased the number of hard copies and helped groups with the costs of posting them out to individual members. Our DEEP News was a great emotional support to people living with dementia.

Other initiatives were devised that people with dementia could do alone but which reminded them of the bigger DEEP network. The growing of sunflowers introduced a fun element of competition; the knitting or crocheting of squares were, in time, stitched together by the Fabulous Forgetful Friends into a (very large) symbolic DEEP hug blanket.





And when lockdowns eased, people found ways to gather safely.

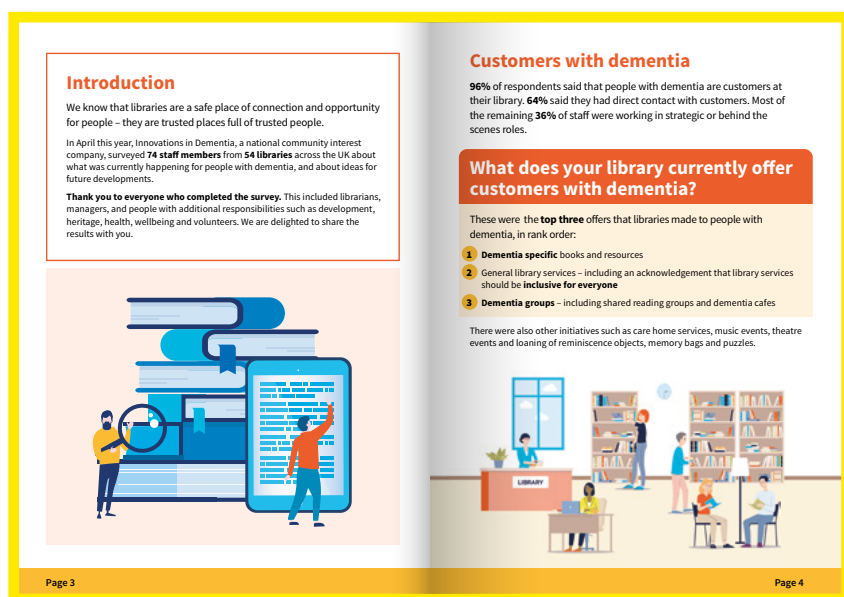
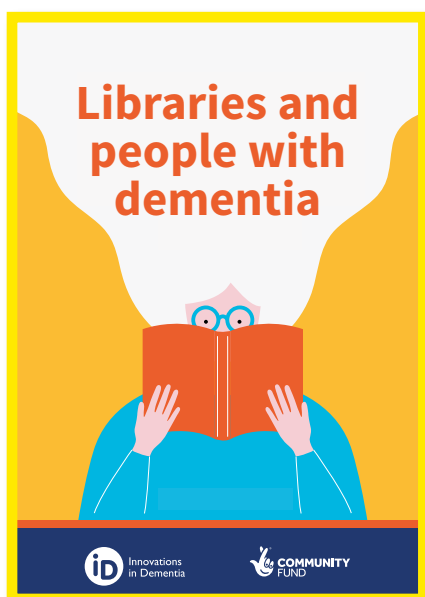


# Moving to an online world—a note about the ‘digital divide’

The pandemic may have exacerbated existing digital exclusion in the UK. University of Cambridge reports that 22% of the UK’s population lack digital skills, a figure from pre-pandemic. A digital inclusion evidence review in 2018 by Age UK reported that the majority of people over the age of 75 are not on-line. Over 79% of all digital exclusion is among those age 65 and older.

There is no doubt that many people with dementia were left very isolated during the lockdowns of the pandemic. Although many people were supported to get online, many were still not able to be connected. The joy in many DEEP groups was the creative ways in which people sought to keep in touch with each other, often replacing physical contact with online contact.

Innovations in Dementia has been doing some post-lockdown work with the public library network. We have been finding out what their experiences are of engaging with customers with dementia. We hope to use these findings to build relationships between libraries and people with dementia including opening up access and support to use library computers. Perhaps this may be one way to bridge the digital divide.



# Hidden talents, new experiences

Covid-19 lockdowns gave people time. It wasn't unusual for people to start to explore new hobbies and interests. Creativity was highlighted as a means to wellbeing during the pandemic (e.g. Tang et al, 2021) and people with dementia were no exception to this finding.

People with dementia became gardeners, poets, photographers, painters, song writers, knitters, woodworkers and much more. Gail even developed a craft kit with instructions to make a DEEP face mask!



## Stay Home – by Cheryl

He said stay safe and stay at home  
I stayed at home as he did say  
I only managed for a day  
So off to my sisters I did go  
For how many weeks I did not know  
Stay home and save the N H S  
My nails are broken my hair's a mess  
It's ten weeks now and who knows  
when  
I will be able to go home again



## Isolation – by Pat

- I** Inspiring me to take up painting once again
- S** Speaking to friends and family feels like sunshine after rain
- O** Observing baby birds taking off on their first flight
- L** Listening to children laughing makes my heart feel light
- A** Acknowledging waves from strangers and their happy smiling faces
- T** Taking different walks and finding lots of pretty place
- I** Inhaling the freshness of pollution free air and the beauty of nature all around everywhere
- O** Ordering on line now that was quite an education
- N** Numerous skills I have achieved and all thanks to isolation



“Time and Place”—a poetry project which was to have taken place in Canterbury, Kent—became an online poetry class instead, with people with dementia taking part from across the nations.

“Many writers were trying poetry for the first time. All were delighted with the poems they produced as we explored our kitchens, hallways, lounges, bathrooms, bedrooms and gardens. We stopped in the hallway to write about shoes, we paused at the dining table to pen a haiku, and we sat in the sunshine to compose limericks about our love or hate relationship with gardening.” Time and Place publicity

A new project called ‘Dementia Craftivists’ also took off, with people with dementia using their creations to make supportive and enjoyable links across communities.

The Craftivists are ordinary people with dementia living in the community who, since the start of the pandemic, have been using craft to show that ‘they still can.’



The project was all about the pride in creating something from scratch while sending, if they so chose, their own message to others. Some of the Craftivists offered to help others to learn new skills, through online demonstrations or tutorials. Some of the sessions were one-off or a short course– including concrete models, woodwork and card-making–whilst a watercolour group is still running independently a couple of years on.

Some of the things created had their own messages on them too. This element was effectively a very democratic process of ‘gentle protest’. Some of the Craftivists left them to be found by anyone... on a bench or on a beach. Sometimes people would be aware that another person was having a hard time–and would post them a handmade gift with a message of solidarity.

The Dementia Craftivists were particularly keen to reach out to those with dementia who were living through the pandemic in care homes. They teamed up with NAPA (National Activity Providers Association), with a small grant from the Rayne Foundation. Because of the pandemic, all activity had to be conducted over Zoom. The main aim was to forge links – and provide peer support–between people with dementia in the community and those living in care homes, through creative activities.

NAPA selected five care homes and, between December 2020 and February 2021, several Craftivists offered a session on a craft of their choosing. The topics were:

- card-making
- tiny books
- poetry – “Memories in Words”
- pebble painting
- clay leaf impressions

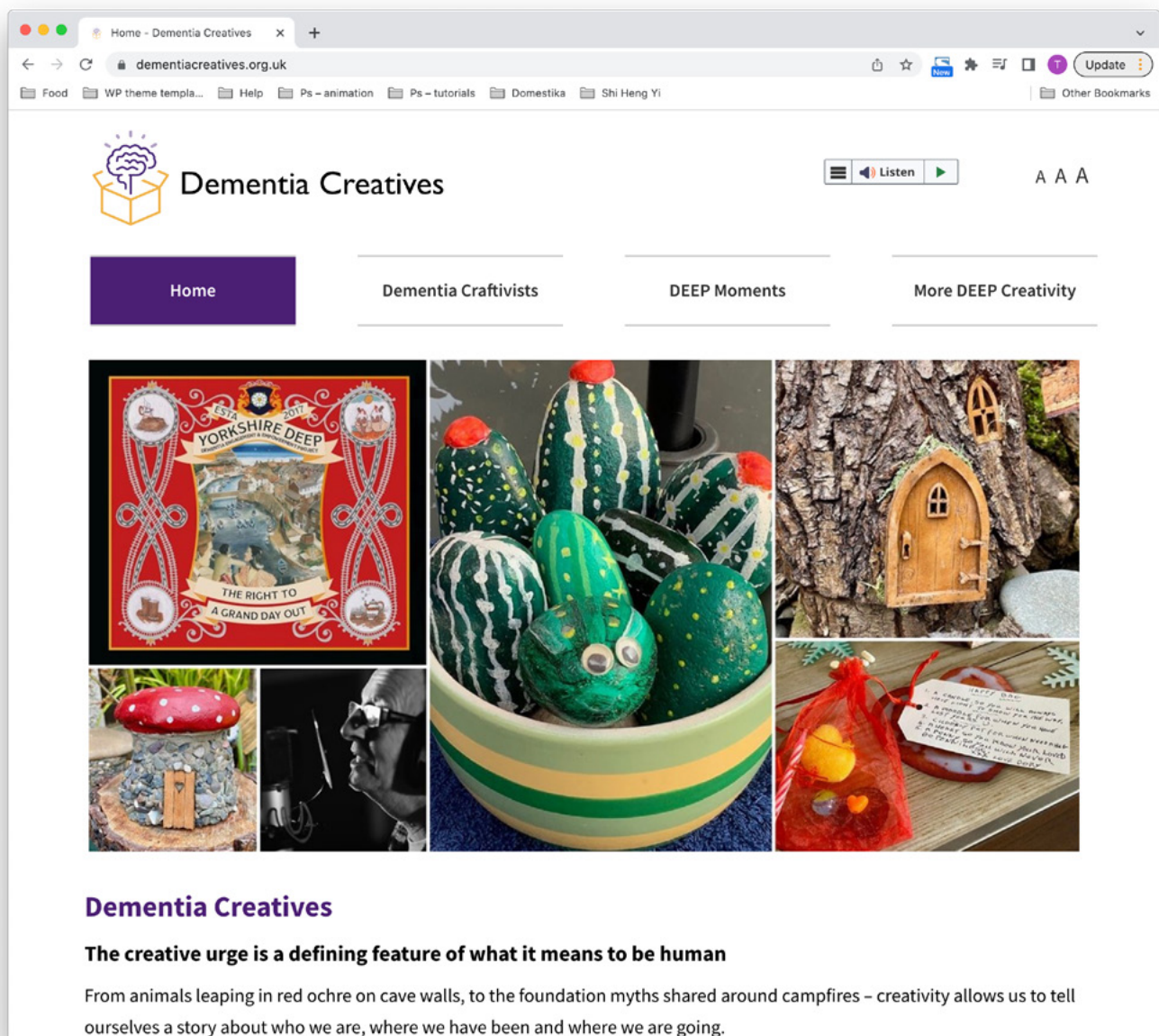
These activities were selected because they were relatively accessible, fun, and did not require too much in the way of materials and cost. Kits were sent to the care homes in advance of the session, together with YouTube links when available. There was also a final online celebration event/party for all participants.

Key outcomes of this project were:

- improved self-esteem and confidence in all involved
- stronger connections between the community and care homes
- a challenge to the negative portrayal of people with dementia, instead showing them as having valuable skills and expertise to share

You can see more about creative projects by visiting

<https://dementiacreatives.org.uk>



The screenshot shows the homepage of the Dementia Creatives website. At the top, there is a navigation bar with the site's logo (a brain inside a box), the name "Dementia Creatives", and a "Listen" button. Below the navigation bar are four menu items: "Home" (highlighted in purple), "Dementia Craftivists", "DEEP Moments", and "More DEEP Creativity". The main content area features a collage of six images: a red poster for "YORKSHIRE DEEP" with the text "THE RIGHT TO A GRAND DAY OUT", a bowl of green and white watermelon-shaped craft items, a miniature wooden door set into a tree trunk, a red mushroom-shaped craft, a black and white profile of a man's face, and a red mesh bag containing small yellow and orange items with a handwritten note.

**Dementia Creatives**

**The creative urge is a defining feature of what it means to be human**

From animals leaping in red ochre on cave walls, to the foundation myths shared around campfires – creativity allows us to tell ourselves a story about who we are, where we have been and where we are going.

# Getting on with the job

DEEP engages and empowers people living with dementia to influence attitudes, services and policies that affect their lives. We all have the power to influence and change what happens in the dementia world: in our home, our street, our town or our country. The pandemic may have come as a shock but it didn't stop us for long!

DEEP groups were busier than ever over the pandemic. The pandemic allowed people and groups to pause and allowed them time to carry on working on things of interest and importance to them (rather than responding to researchers' questions about their experiences in the pandemic—of which there were many!) Here are some examples:

- Scottish Dementia Alumni launched their booklet on dementia and self-management, a second resource for GPs
- Speak out with Dementia was formed—a new virtual LGBTQ+ support group for people with dementia and carers
- Knowledge is Power had recently been launched in Wales—handy hints for people with dementia in Wales by people with dementia. A Scottish version of Knowledge is Power, was then created in Scotland. An England version is being created at the time of writing.
- Five DEEP groups (Thred, Budding Friends, Forget Me Nots, Beth Johnson Foundation and STAND) carried out Dementia Enquirers research projects on different issues relating to people with dementia during Covid-19. You can read their reports here: <https://dementiaenquirers.org.uk/individual-projects/>
- Dissatisfied and bamboozled by long and wordy dementia strategies, the members of Minds and Voices met weekly to create a dementia strategy for York that was clear and easy to understand and to act upon (whether you are a person with dementia, a care partner, a service provider, shopkeeper or bus driver). They drew not only on their own experience of being diagnosed and living with dementia in the York area, but also on the conversations they'd been having for several years as a group of peers. The 8-page document can be found here: <https://bit.ly/3AAC8uU>

## Do you see what I see?

Twenty two DEEP Moments films were launched in June 2020, created by members of Ashford Phoenix, Pathways in Bradford, Beth Johnson Foundation peer support group and SUNshiners, working with filmmakers from Biggerhouse. The filming was done before the pandemic impacted. It was bittersweet working at a distance, sometimes by Heath Robinson techniques, to edit, finalise and view the films.

These are films of DEEP Moments in time—connecting together in a patchwork of stories and messages and portraying the importance of peer support, the connectedness between people with dementia and the diversity of people’s lives with dementia. The films are joyful, sad, honest, funny and wise and are what people wanted to make about themselves. They are about the trust, safety, confidence and laughter that being a part of a peer group in the DEEP network brings; they are also stories of group members – their joys, relationships, loves, struggles, friendships and where they find themselves in this world of dementia. Their stories are all different, with dementia visible in the foreground and background, sometimes at the same time.. “You don’t see what I see”, reminds Tracey – these are films that provide a window into people’s worlds.



# Learning from Dementia Voices—lessons from a post-pandemic world

The previous pages provide just a small amount of what people experienced.

These are the ten key things we have learned with people with dementia throughout the pandemic. We hope this learning will serve as a call to action to think differently about dementia.

1. People with dementia can rapidly lose self-confidence and skills if they are not used or bolstered (particularly during an acute crisis such as a pandemic, but also during periods of ‘austerity’ and cost of living crises).

**Recommendation:** Providers, commissioners and policy-makers should ensure that crises such as pandemics do not result in closure of ‘non-essential’ services or withdrawal of support. They need to be very creative about how support can still be made available. Our experience has shown that there are low-cost solutions, especially in the form of peer-support (see lesson 3).

2. People with dementia and their supporters may well need extra help in a pandemic or other crises to adjust to changes in relationships that are already under pressure.

**Recommendation:** Commissioners and providers should prioritise and invest in relationship-focused approaches.

3. Given the opportunity, peers can support each other—promoting new, meaningful, honest connections, and also improving self-confidence. Many people with dementia can stay connected – and support others at the same time – through online groups and gatherings.

**Recommendation:** Commissioners and providers should recognise and resource the power of peer support, whether face to face or online, to create more and widespread connections. They should also ensure that their systems don’t unintentionally prevent people with dementia from making and sustaining connections with each other.

4. People with dementia CAN lead change and develop and shape services. They are an untapped, underused resource.

**Recommendation:** Providers, commissioners and policy-makers should support and resource people with dementia to take the lead in shaping services, through ongoing open conversation, across local, regional and national networks.

5. People with dementia have experiences and skills which they can use to make supportive and enjoyable links across communities – and to show that ‘they still can.’ They have an abundance of skills to share themselves – external ‘tutors’ are not needed. Our role can simply be to respond to ideas and to help make things happen.

**Recommendation:** We should all support more interventions in which people with dementia can share their skills with each other, rather than being ‘done to’.

6. People with dementia can use their creativity to influence how we think about and frame dementia – and to make links with people in specific situations such as care homes. These activities and connections improve self-esteem and confidence with all involved, and challenge the negative portrayal of people with dementia, showing them as having skills and expertise to share.

**Recommendation:** Commissioners and providers should make more opportunities for people with dementia to use and develop their creative talents to affect our perceptions.

**Recommendation:** Commissioners and providers should support more interventions in which people with dementia in the community can make connections with those living in care homes.

7. People with dementia can and do find ways to adjust to new difficulties. And are keen to share their strategies and tips with each other.

**Recommendation:** Promote awareness of the capacity that people with dementia have to find and share their own strategies

8. People with dementia have a unique and invaluable contribution to make to the education of professionals and the general public.

**Recommendation:** People with dementia should be supported and resourced to take the lead in dementia-related learning and development.

9. People with dementia are capable of planning, designing and delivering their own research, with support as needed.

**Recommendation:** Research funders, academics and RECs should do all they can to encourage people with dementia to be ‘in the driving seat’, making reasonable adjustments to improve the accessibility of the system.

10. Our overarching message is that people with dementia CAN create, express themselves, welcome, befriend, research, host, lead, teach and learn together... and therefore they should be enabled and supported to do so.

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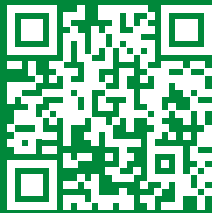
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## Innovations in Dementia

Is a not-for-profit Community Interest Company (CIC). People with dementia are at the heart and start of all our work. We promote a positive but realistic view of dementia, demonstrating that, although it is life changing, it does not have to be life ending. We support people with dementia to live with hope and keep control of their lives.

To find out more scan the QR code below.



[www.myid.org.uk](http://www.myid.org.uk)

