

**Forward**  
with dementia



A guide to living with dementia

# Co-designed online support for people and their families after a diagnosis of dementia

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Louise Robinson, Marie Poole  
Bill, Margaret and Jane



# Outline for today

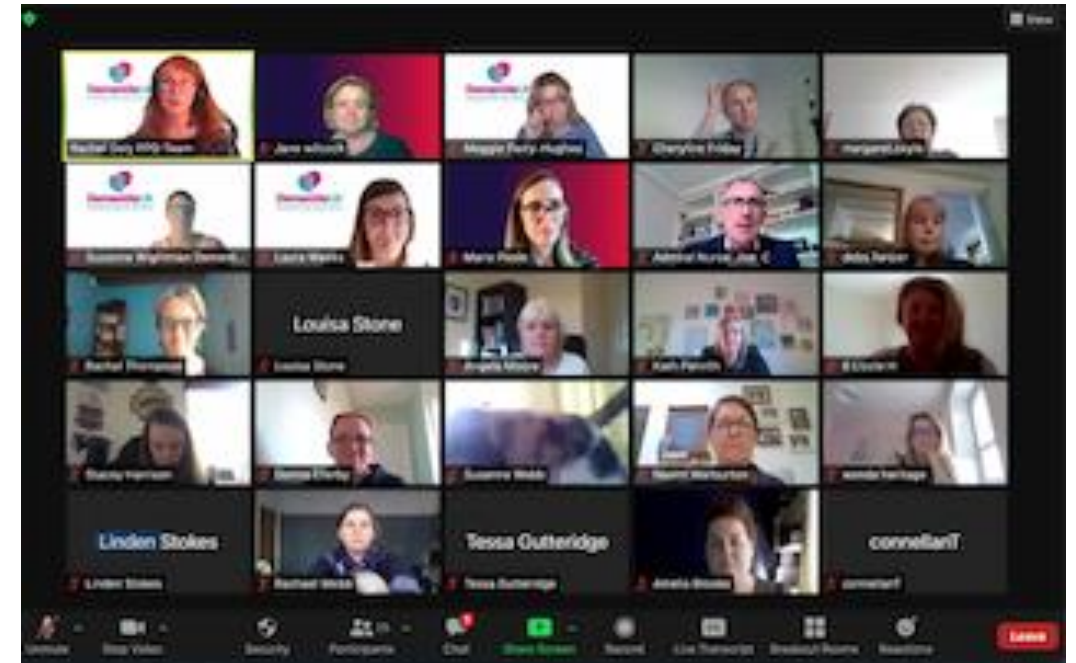
- To share the background to “Forward with Dementia”
- Update on the study
- To feed back on preliminary findings for social care support
- Share ideas and make new connections

My wife Jo was given her diagnosis during lockdown and I, like many others had no experience of what to do next. Who do I turn to? What help is available? Where can I find out everything I need to know? The realisation that I didn't know what I didn't know was overwhelming.

Bill, husband of Jo

# Combining Research and Lived Experience

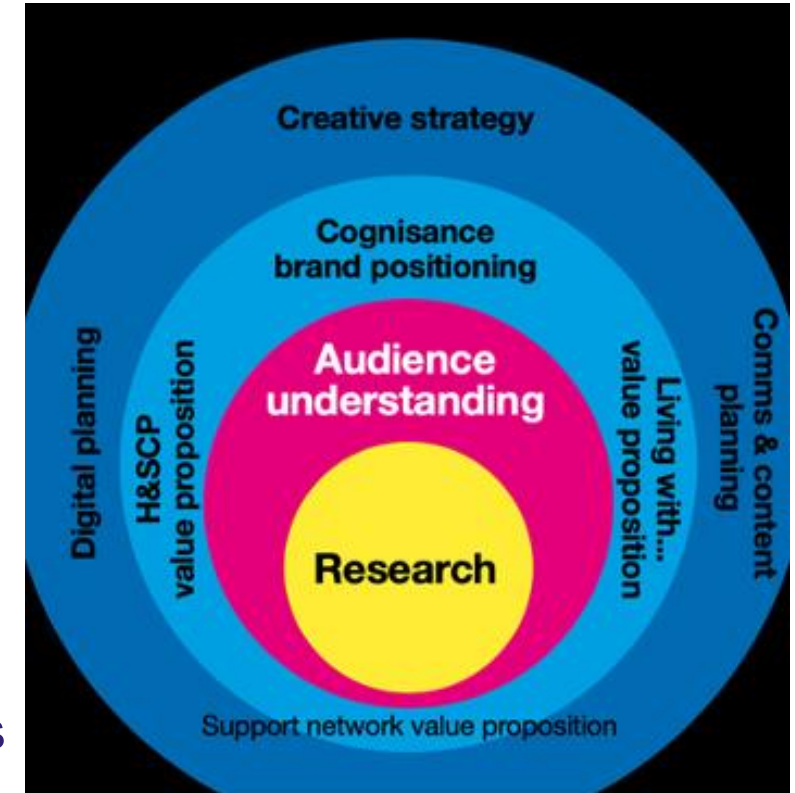
- We set out **co-design and deliver** in **partnership** with people with dementia, care partners and health care professionals, toolkits and campaigns to improve post-diagnostic support.
- In each of the five partner countries we recruited people living with dementia, carers, health care professionals and members of key organisations such as the Alzheimer's society –These made up our 'local working groups'



# Our approach

## Co-design workshops focus on:

- Key messages
- Motivators for information seeking
- Experiences of dementia diagnosis and post diagnostic support
- The purpose for the intervention and
- The tone and branding appropriate for the key audiences for a resource that should focus on the first twelve months post-diagnosis. When people feel lost.





# What did the local working group members tell us?

- Key motivators for the toolkits led to the need to focus on a practical and empathetic resource that was *tailored* to the individual.
- These will function to support communicating the diagnosis, post-diagnostic support and planning for the first-year post diagnosis

## Your Toolkit Articles

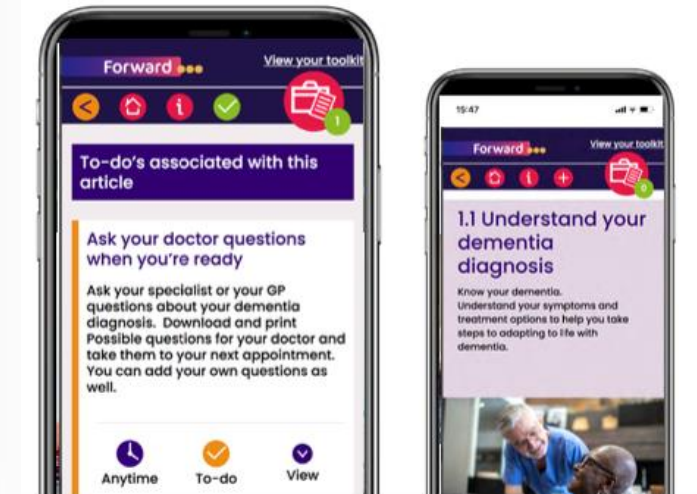
This is where you can collect, share, email or print articles that can help you move forward. Be sure to email, share or print them before you close this browser window.

See all article categories

Coming to terms with dementia	
<b>How to talk about dementia and what to expect</b> Sharing the diagnosis helps you to come to terms with...	<div>Read</div>
<b>How you feel about yourself</b> Be confident and positive, you are not your dementia ...	<div>Read</div>
<b>Emotional reactions to having dementia</b> Managing your feelings is a key step in moving forward...	<div>Read</div>
<b>Manage how others treat you</b> Strategies for when others treat you differently because you have...	<div>Read</div>
<b>Manage how you tell others</b> Your diagnosis affects others. Share your diagnosis and move forward...	<div>Read</div>

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## Your Toolkit Articles

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Hearing (and giving) a diagnosis	
<b>1.1 Understand your dementia diagnosis</b> Know your dementia. Understand your symptoms and treatment options to help... Your To-do's:	 Read
<b>1.2 Adapting to your dementia diagnosis</b> You can adapt to dementia and continue living your life ... Your To-do's:	 Read

[View more resources in this category](#) >

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## Remember, save your Toolkit

To make sure you can revisit your toolkit at the point you left off and see the articles and To-do's you selected copy this unique link and keep it safe.

<https://toolkit.forwardwithdementia.org/en/zBKfJs3f>



[Email me my link](#)



[Copy my link](#)



[Help me bookmark](#)

[See plan view](#)

[Exit toolkit](#)
[Toolkit](#)
[How to build](#)
[View all](#)
[See just my To-Dos](#)

2

### Ask your doctor questions when you're ready

Good Job!

Ask your specialist or your GP questions about your dementia diagnosis. Download and print Possible questions for your doctor and take them to your next appointment. You can add your own questions as well.

Anytime
 

Remove To-do

1.1 Understand your dementia diagnosis

Know your dementia. Understand your symptoms and treatment options to help...

1.2 Adapting to your dementia diagnosis

You can adapt to dementia and continue living your life ...

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### You are about to leave the toolkit

It is really important that you save your unique link below to access your Toolkit in the future.

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Forward

with dementia

A guide to living with dementia

- Supports people in their first year following a dementia diagnosis: practical guide that can be linked to pre-existing NHS resources.
- Connect newly diagnosed patients, and their carers, to information and support via a website and planning via the toolkit
- Challenges negative stereotypes and helps people take positive steps to access information and support
- For people with dementia, carers and health professionals. All sections can be downloaded or printed as PDFs. The personalised toolkit can be shared with others through a unique URL.

A vertical poster for 'Forward with dementia'. The top section has a dark blue background with the title 'Forward with dementia' in white, followed by 'A guide to living with dementia' in smaller white text. Below this, the main headline 'Find your way forward with dementia...' is in large white font. The middle section contains three lines of white text: 'For people recently diagnosed with dementia and those who care about them.', 'For stories, practical suggestions, planning tools and answers.', and 'For free, for you and on any device.' Below the text is the website URL 'forwardwithdementia.org/support' in orange. A yellow QR code is positioned below the URL. At the bottom of the text area are social media icons for Facebook, Twitter, and Instagram, followed by logos for 'UCL', 'Newcastle University', and 'Alzheimer's Society'. The right side of the poster is a vertical strip of seven photographs showing diverse people: a smiling couple, a man with a dog, two men looking at a tablet, a man and woman in raincoats, a woman smiling, a man in a flat cap, and two women walking. The bottom of the poster features three more photographs: a man in a flat cap, two women walking, and a man and child gardening.

**Forward**  
with dementia ●●●

A guide to living with dementia

**Find your  
way forward  
with dementia...**

For people recently diagnosed with  
dementia and those who care about them.

For stories, practical suggestions,  
planning tools and answers.

For free, for you and on any device.

[forwardwithdementia.org/support](https://forwardwithdementia.org/support)

QR code

Facebook Twitter Instagram

UCL Newcastle University Alzheimer's Society



# Co-producing support for social care needs after a dementia diagnosis



By working in partnership with people living with dementia, carers and social care practitioners, dementia organisations and other experts we will:

- Develop strategies to include groups whose voices are often not heard in research
- Through interviews explore current experiences, information needs and gaps for dementia *social* care supports
- Co-produce targeted information and practical tools for a guide to dementia related social care



# Update

- A Patient and Public Involvement Partnership group was formed. First meeting held in June to strategically plan recruitment of diverse participants
- Qualitative interviews and workshops-to gather info on social care information needs & experiences post diagnosis
- Interviews with 15 caregivers, 3 people living with dementia, 7 social care practitioners (social workers, occupational therapists, home care workers). Two group workshops with people living with dementia and carers.





# Preliminary themes from interviews

- Lack of dementia awareness/training (especially about “soft skills”)
- Rapport building with caregivers, as key sources of information
- Resources to address emotional responses of care workers
- Moving from person being the “object of care” to “subject of care”
- Learning about care system and how it is structured because it changes frequently (e.g., ICS)
- Distinct needs of underserved communities - positive attitudes and openness more important than training
- Information on finances, benefits, pension, council tax, allowances, dementia-friendly banking apps
- Very negative experiences of hospitalisation – a dedicated section would be helpful
- Structural issues of services – staff overturn (impact on consistency of service, rapport building)






# For discussion

1. What are your views on the emerging themes identified through the interviews?
2. Are there any areas we have missed that would be worth including in the section for social care practitioners?
3. How can we maximise recruitment of social care practitioners to the study?

# What are your views on the emerging themes?

1. Lack of dementia awareness/training (especially about “soft skills”) 
2. Rapport building with caregivers, as key sources of information
3. Resources to address emotional responses of care workers
4. Moving from person being the “object of care” to “subject of care”
5. Learning about care system and how it is structured because it changes frequently (e.g., ICS)
6. Distinct needs of underserved communities - positive attitudes and openness more important than training
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8. Very negative experiences of hospitalisation – a dedicated section would be helpful
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Are there any areas we have yet to hear about that would be important to include as information or practical tools for social care practitioners?

## Practical tips if you care for someone

[Medicines: tips for carers](#)

[How to feed someone you care for](#)

[How to help someone you care for keep clean](#)

[How to care for someone with communication difficulties](#)

[How to move, lift and handle someone else](#)

[How to deal with challenging behaviour in adults](#)

How can we maximise  
recruitment of social care  
practitioners to the study?





# Thank you!

For further info, or to participate in the study,  
please contact:

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Partners in the COGNISANCE Collaboration

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**Website: <https://www.forwardwithdementia.org/en>**

**Twitter: @ForwardDementia**

**Instagram: [https://www.instagram.com/forwardwithdementia\\_gb/](https://www.instagram.com/forwardwithdementia_gb/)**

**Facebook: <https://www.facebook.com/ForwardDementiaGB>**

**You Tube: Forward with dementia International**