Dementia and co-creation

A practical guide to designing products and services

Alzheimer's Society
United Against Dementia

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Acknowledgements

Alzheimer's Society would like to thank everyone who has been involved in creating this guide.

We would especially like to thank the people affected by dementia who shared their personal experiences and views on why co-creation is so important.

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Tim Little
Keith Oliver
Trevor Saloman
Alexander Watson
DEEP MemoryBilia group

Our thanks go to the design consultants, expert researchers and entrepreneurs for their time and expertise.

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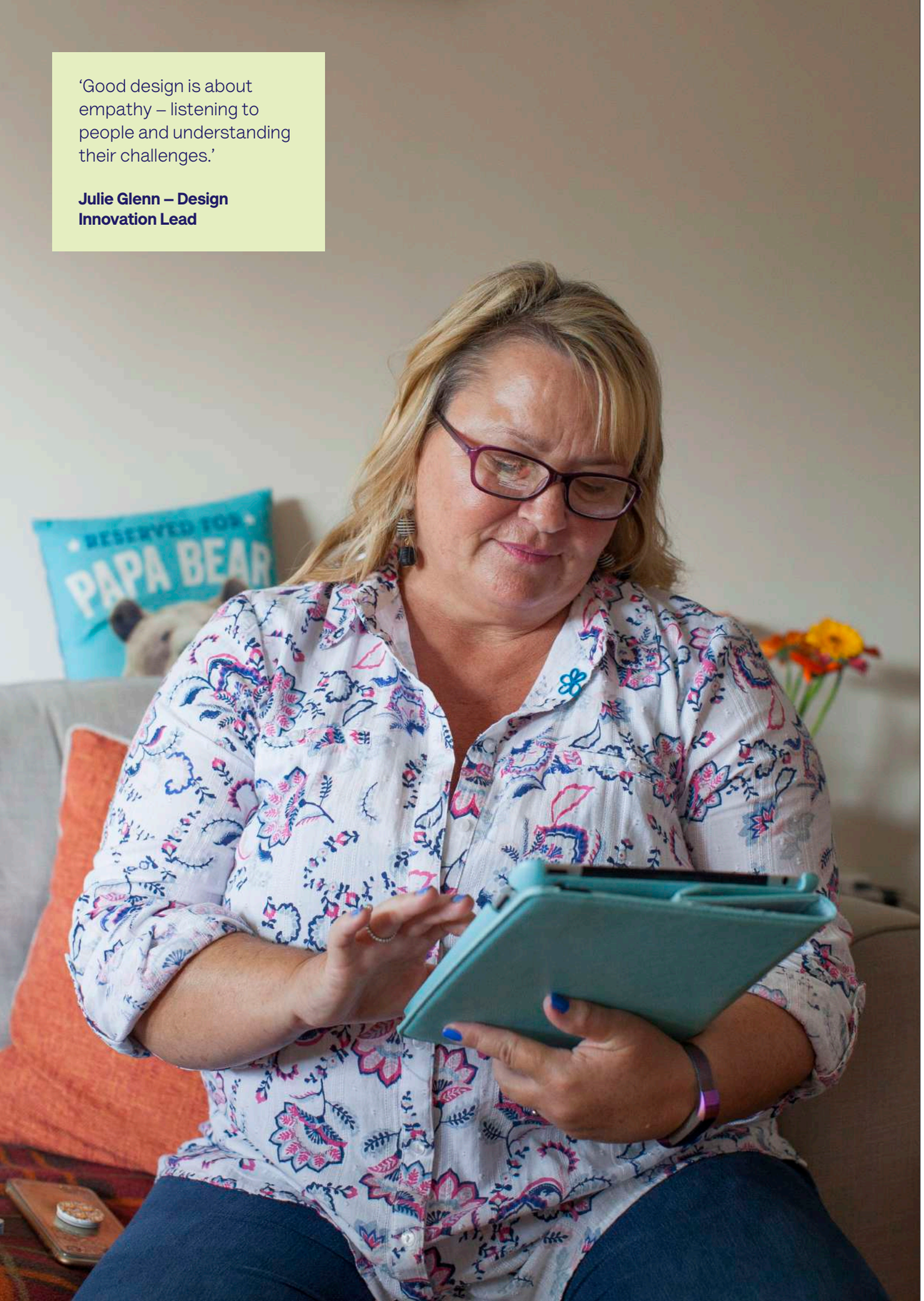
Contents



'Good design is about empathy – listening to people and understanding their challenges.'

Julie Glenn – Design Innovation Lead

Foreword

Julia Glenn
Design Innovation Lead: Healthy Ageing Challenge Fund at UK Research and Innovation

I have always been interested in how stuff works and why people like to use some things and not others. Ten years ago, following a career as a software engineer in investment banking, I switched to working in social innovation and business start-ups – most recently helping to design services for people with cognitive impairment. I wanted to make this move as my mum had been diagnosed with dementia and she remains the inspiration for my work to this day. The most interesting and important thing that I learned, was that it is people, their caregivers and families that show the way to successful design. Technology is always advancing to do great, new things but unless people enjoy something or see how it tangibly benefits them, whether in the moment or longer term, there is no point to it as it won't be adopted over time or at scale.

Good design is about empathy – listening to people and understanding their challenges. Dementia does change the way people behave, but the person who liked the things they liked before dementia is still inside - and by listening, observing and learning there is so much opportunity to innovate to lessen some of dementia's impact, even if it is in the moment. People-centred design and our focus on it, can help to bring each person to the centre – and put their dementia in the background.

It is encouraging to see the rise in innovative products and services coming to market, which support people with dementia – especially those that focus on giving joy and independence. There has never been a better time to innovate in this space with once emergent technologies, like machine learning and voice recognition maturing to a point of sophistication where they can bring real benefits to people's lives. There is much more work to be done to make such innovations more personalised and widely available - and this is absolutely achievable by using the right tools to design together with people affected by dementia. In this guide Alzheimer's Society offers a diverse set of co-creation resources, and as an authority on co-creation and dementia, it is excellently placed to support innovators of all kinds.

I wish everyone the best of luck with their design endeavours!

Introduction

Involving people affected by dementia in each stage of the design process is vital to achieve maximum impact. Here, we provide practical guidance and case studies, to help you put people first in your product or design process.

When we refer to 'people affected by dementia', we mean those living with the condition and those who care for them, for example their partners and children.

When using this guide, it is vital to keep in mind that no two people have the same experience of dementia. Therefore, the approaches we describe are intended to be adapted as appropriate for each project and individual. Following the principles on page 5 will ensure you embed this approach throughout your project.

The guide was developed by the Innovation team at Alzheimer's Society, with input from a panel of co-creation experts, including designers, involvement specialists, researchers, social entrepreneurs, and people affected by dementia.

Alzheimer's Society is the UK's leading dementia charity. As an organisation, we aim to involve our growing Dementia Voice network of 170 000 people affected by dementia in everything we do – from reviewing publications, to selecting research projects to fund and campaigning for change.

Our award-winning Innovation team works together with people with lived experience of dementia to co-create bold solutions to everyday challenges. We ask people what matters, we listen to their experiences, we support them to build their ideas and we involve them in testing them out. With each unique project, we learn more about how to best facilitate co-creation and we're pleased to be able to share what we have found works well so far.

Although the intention is to inform the development of digital solutions for dementia, much of the guidance can be applied to products and services of any format and any audience. It is commonly said that by designing for dementia, you design for all.

When designing from a place of **empathy first,** real innovations can arise as the end user, which is usually a person affected by dementia, becomes **a central participant in the design process.**

01 Understanding dementia

Understanding dementia

What is dementia?

The word 'dementia' describes a set of symptoms that can include memory loss and difficulties with thinking, problem-solving or language. A person with dementia may also experience changes in their mood or behaviour. These changes are often small to start with, but for someone with dementia, they have become severe enough to affect their daily life.

Dementia is caused when the brain is damaged by diseases, such as Alzheimer's disease, or a series of strokes. Alzheimer's disease is the most common cause of dementia, but it's not the only one.

The specific symptoms that someone experiences depend on the parts of the brain that are damaged and the disease that is causing the dementia.

There are around 900,000 people estimated to be living with dementia in the UK. This number is expected to rise sharply in the coming years[1].

Latest figures indicate that 14% of people have mild symptoms of dementia, 28% have moderate symptoms and 58% have severe symptoms[2].

Does dementia affect everyone equally?

There are disparities in the way that dementia affects different groups of people.

For instance, 65% of people living with dementia in the UK are female[3].

3% of people with dementia are from black, Asian and ethnic minority communities – around 25,000 people. This number is expected to double by 2026, with the steepest increase expected in South Asian communities[4]. Research suggests these communities often face delays in dementia diagnosis and barriers in accessing services.

Further reading

Alzheimer's Society website has comprehensive information about dementia, including the different types of dementia and their symptoms
alzheimers.org.uk/about-dementia

The NHS Well Pathway for Dementia
england.nhs.uk/mentalhealth/wp-content/uploads/sites/29/2016/03/dementia-well-pathway.pdf

DEEP guidance on language about dementia
dementiavoices.org.uk/wp-content/uploads/2021/05/DEEP-Guide-Language.pdf

65%
of people living with dementia in the UK are female

900,000
people are estimated to be living with dementia in the UK

58%
of people living with dementia in the UK have severe symptoms

References

[1] Alzheimer's Society, 2021

[2] Wittenberg et al (2019) Projections of Older People with Dementia and Costs of Dementia Care in the United Kingdom, 2019-2040

[3] Prince, M et al (2014) Dementia UK: Update Second Edition Alzheimer's Society

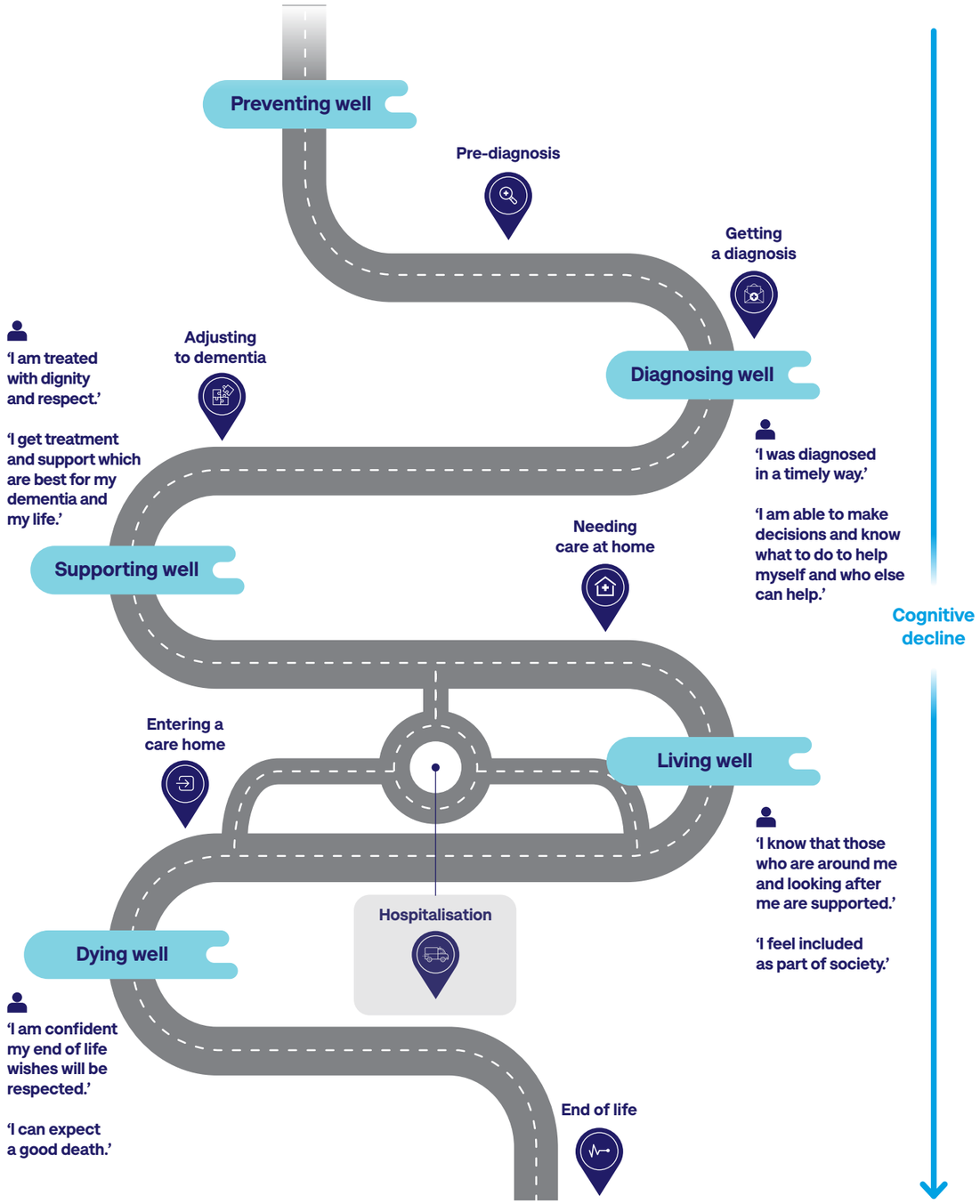
[4] Lievesly, N (2010) The future ageing of the ethnic minority population of England and Wales. London: Runnymede Trust

What are the different stages of dementia?

The diagram gives an overview of the stages of dementia that typically bring the most challenges. This is to help us consider the needs an individual may have at each stage, including the form of support required.

It is important to note that this 'journey' isn't reflective of everyone's experience of dementia. For example, hospitalisation can happen at any stage.

This diagram shows that each person's experience of dementia is unique – it's non-linear and the impact of the symptoms vary from person to person. It's also worth noting that people may have multiple conditions, so it's important to include a range of people in your design process.



This gives examples of some of the needs which might arise at each stage.

Pre-diagnosis
- Understand what dementia is
- Understand dementia risk factors
- Investigate changes in mood or behaviour

Getting a diagnosis
- Outlining post-diagnostic support
- Information about medications
- Disclosing diagnosis to others
- Advanced care planning

Adjusting to dementia
- Emotional support
- Managing medication and self-care
- Community support
- Managing mental health
- Information about what to expect next

Needing care at home
- Benefits advice
- Navigating the social care system
- Finding and funding agency staff
- Making the home safe

Hospitalisation
- Receiving person-centred care
- Contact with friends and family
- Maintaining physical and cognitive function
- Carers able to communicate with healthcare professionals

Entering a care home
- Finding an appropriate home
- Maintaining family and community connections
- Meaningful activity
- High-quality personal care

End of life
- Death with dignity, free from distress
- Respect for spiritual, emotional and emotional needs
- Bereavement support

Potential innovation opportunities

How might we increase awareness of the symptoms of dementia?

How might we help a person identify they are having minor lapses in their memory?

How might we prompt people to reach out about cognitive changes they have noticed?

How might we help people affected by dementia find meaningful occupation?

How might we design safe home environments for people affected by dementia?

How might we compensate loss of cognitive function?

How might we facilitate advanced care planning?

How might we enable people affected by dementia to exert greater control over their own care and decisions about their future?

How might we empower people affected by dementia to share their life stories with loved ones?

How might we enable safe and independent leisure activities for people affected by later stage dementia?

How might we support people with later stage dementia to communicate their needs?

How might we enable people affected by dementia to die with dignity?

How might we disrupt this linear pathway and develop routes for recovery between transition points?

02

The value of designing with people affected by dementia

'I fear innovators are often stuck away in offices remote from reality.'

Alexander – family member

The value of designing with people affected by dementia

Involving people affected by dementia in design results in design solutions that **improve quality of life** and make the world better for everyone.

In a design context, involvement has benefits for people living with dementia, their carers, and innovation professionals. Innovators have a social responsibility to approach projects with compassion and respect, learning from people's personal experiences of dementia to create products and services that achieve the most positive impact for people. Given the nature of dementia, this means seeking to understand how each person perceives the world and how you can best support them.

'Unless you include people with experience of dementia, it ends up being a theoretical idea, which could help. But in reality it doesn't help at all. You need people affected by dementia to know whether the money you have invested is worth it.

I'm not an ideas person, but being involved with something like that, I can use my knowledge to help. All I've done in the rest of my life, I can still put it to use. I feel like I am doing it for my mum.'

Janice – Carer

Benefits for people affected by dementia

When referring to 'people affected by dementia' we mean both people who are living with dementia, and those informal carers around them, for example family and friends.

- It results in products and services that truly meet people's needs.
- Involving people with a diverse range of personal characteristics leads to innovations, which tackle existing health inequalities, rather than perpetuating them.
- People who are often overlooked have an opportunity to make their voices heard.
- Making a difference to the world around them provides people with a purpose.
- Taking part in a novel activity provides social interaction and a form of cognitive stimulation for people with dementia.
- Positioning people affected by dementia as 'experts by experience' challenges traditional hierarchies of power and knowledge.
- Demonstrating people's ability to be involved in research and design reduces stigma and dispels myths about how dementia affects individuals.

Benefits for innovators

When referring to 'innovators' we mean anyone designing or improving a product or service to the challenges faced by people affected by dementia.

However well intentioned, for a designer without personal experience of dementia, it's all too easy to second guess what could help someone.

- By working with people directly you ensure you focus valuable time and resources in the right places, spotting unexpected opportunities for potential solutions that could make a real difference.
- Recognising people not as anonymous 'users', but as real people with real lives helps you to consider this in your design. Developing products which are inclusive will ultimately make your product accessible to a wider audience.
- Potential customers and investors are more likely to believe in the quality of a product that has been co-created with people.

We will touch on the value of co-creation in each of the research, development, and testing stages on page 26.

Alexander's story

Dementia is often combined with other conditions, which interact to create a unique experience for each individual.

Alexander's mother is blind and has Alzheimer's disease. Her experience highlights how involving people in the design of product can prevent fundamental issues from arising.

'I think the next generation of inventors do need to get out on the ground and in people's shoes to co-create solutions. I fear innovators are often stuck away in offices remote from reality.

Without any visual stimuli to help my mother during the day and night, and with my exhausted father needing a rest, she heavily relies on Alexa to answer her many questions... what day, what year, what time is it? She asked Alexa what her husband's name was and the reply was 'she should know'! Not an answer for someone who is seeking motivation and help.

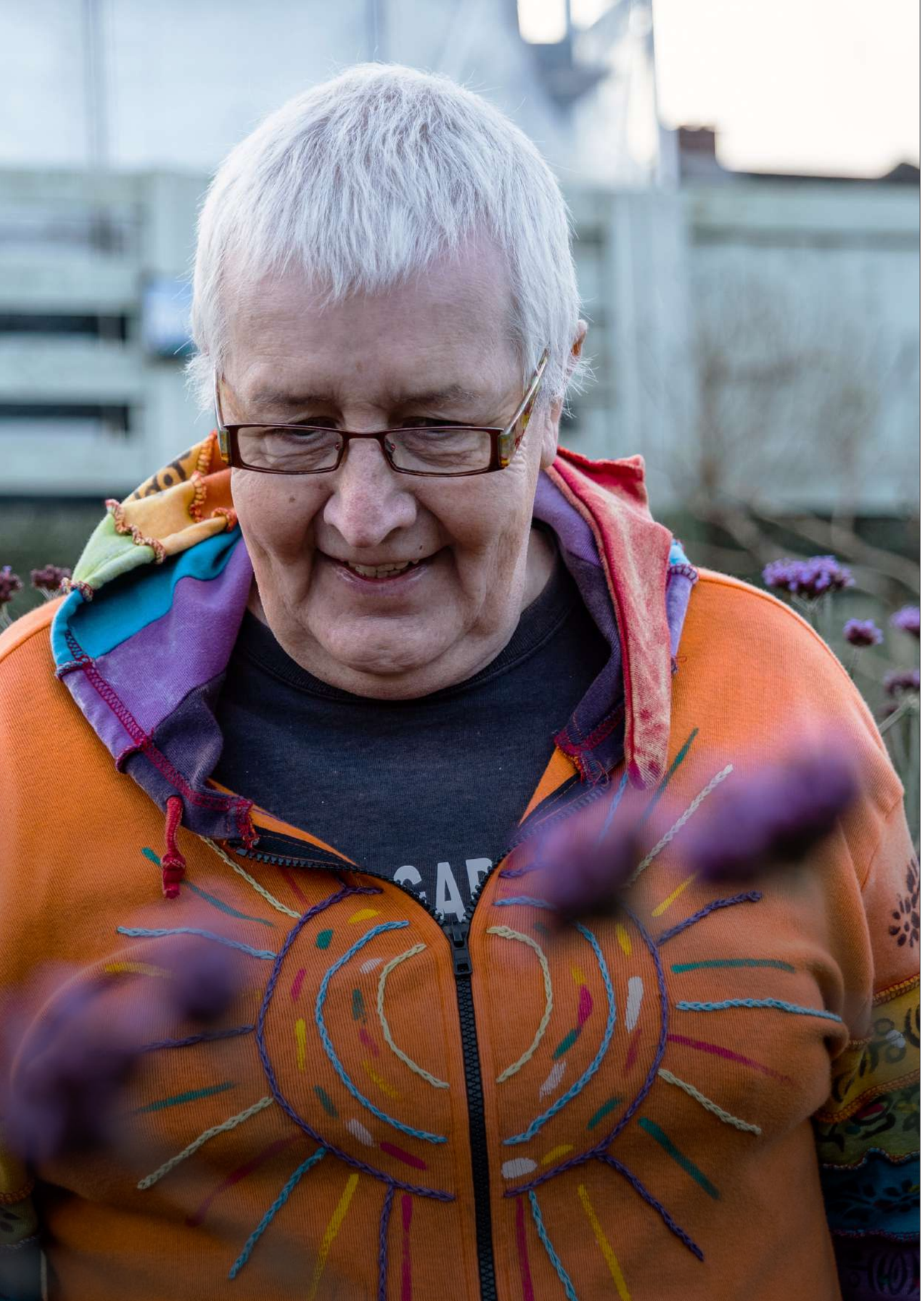
The multiple speaking watches she has, all have setting buttons that cannot be locked and as she fiddles with them all day long so the time, date and year are always wrong. So, each time I visit I need to help her reset it. The basic build quality is poor so all the buttons have fallen off. These are not just toys, but lifelines for people who feel lost and isolated.'

Alexander – Family member

03 Principles for designing with people affected by dementia

'Take these, use them, and bring yourself to the project'

Keith – Living with dementia



Principles for designing with people affected by dementia

A volunteer from our Dementia Voice Network developed these five principles based on their experience of dementia. Following them will give your work the greatest chance of success.

Respect

- Respect everyone's skills, knowledge and experience equally.
- Recognise people's contribution and keep them updated on the project at regular intervals.
- Adapt to people's preferred communication channel.

Support

- Enable people to work together by providing the right support, learning and skills development opportunities.
- Pay people's expenses promptly.
- Be person-centred and flexible in your approach. Use a range of methods to meet the needs of everyone involved.

Transparency

- Have open discussions as a group to manage expectations and ensure everyone understands the purpose of the project, understanding their role and responsibilities and has a shared sense of ownership.
- Be honest and open during the co-creation process.
- Provide consistent and clear information throughout the process with everyone involved.

Commitment

- Always listen actively. Act on what people tell you.
- Involve people affected by dementia across all stages of your project, ensuring involvement is meaningful to the individual.
- Recognise that everyone has something to contribute to the project. Co-creation is a process of sharing and learning from each other.

Fairness

- Provide a variety of opportunities for people to be part of the project.
- Invite people with different experiences and backgrounds to get involved.
- Make sure opportunities are inclusive and accessible for all.

04

What is co-creation?

'At its core, co-creation is about designing **with** people, not **for** them.'

What is co-creation?

At its core, co-creation is about designing **with** people, not **for** them, to produce a high quality product or service that is appropriate for the individual and makes a positive impact on people's lives.

The design process should almost always involve people living with dementia. It may also involve people in informal caring roles and any other relevant groups, for example healthcare professionals.

Co-creation provides opportunities to share and learn from each other, enabling designers to understand and empathise with the experience of living with dementia, and for those with dementia to have their voices heard.

There are various terms associated with co-creation, such as user-centred design, co-design, participatory-design, co-production and co-research. There are overlaps in how these terms are used, with some people using them interchangeably, and others drawing clear distinctions between the different approaches.

Co-creation is the process of working with others to develop a new product or service. It could be anything from shaping the scope of a project, to designing the end-product.

Examples of co-creation include:

- bringing together people with personal experience of dementia and healthcare professionals in workshops to generate ideas for how to improve hospital discharge processes
- working with an individual with moderate dementia to develop a reminiscence product centred on their own life story
- giving people affected by dementia a smartwatch to wear to understand how they use it, and inviting and acting on regular feedback.

Visit the 'case studies' on page 50 for real-life examples.

> 'If I came to your house to do your electrics I could tell you where I think all your sockets should go. I could fit fancy light fittings for you but it might have nothing to do with you or your personality and the way you think and the way you want your house laid out.'
>
> **Tim – A retired electrician who lives with dementia with Lewy Bodies**

Co-creation throughout the innovation process

The traditional design model has three stages of an iterative process:

1. researching a topic
2. developing ideas
3. testing a solution

There are benefits of involving users and subject experts at each stage.

Researching a topic
Involving people affected by dementia in research provides rich insights into their lives. It helps build empathy, challenge assumptions, and highlight unexpected issues. This leads to outcomes that are truly appropriate for the people they're designed for.

Developing ideas
Innovation stems from working with others to open-up new possibilities. Co-creating at this stage also prevents a team from pursuing a solution that contains fundamental barriers to people living with dementia.

Testing a solution
Gathering real world feedback helps designers to improve products and services. This increases the chance of producing a quality product, which has a real impact on people affected by dementia.

> 'Why wait until the last minute to involve people with dementia in a project – you might waste hundreds of hours on something that doesn't work.'
>
> **Keith – Living with dementia**

> 'From idea to fruition, it's best to involve people affected by dementia. A perfect world scenario would be to embed them in the team from concept in order to optimise the eventual project outcome. Making sure that people impacted by dementia are involved through all phases will deliver greater certainty that the deliverables effectively meet the needs of those touched by the disease.'
>
> **Trevor – Carer**

Further reading

'The Right to a Grand Day Out – A story of co-production'. An example of a coproduction project, and discussion of basic principles and methods for collecting evidence
innovationsindementia.org.uk/wp-content/uploads/2020/07/A-story-of-co-production-%E2%80%93-The-Right-to-a-Grand-Day-Out.pdf

Scoping review on co-production technology solutions with older people by the University of Sterling
stonewater.org/media/5529/scoping-review-report-final.pdf

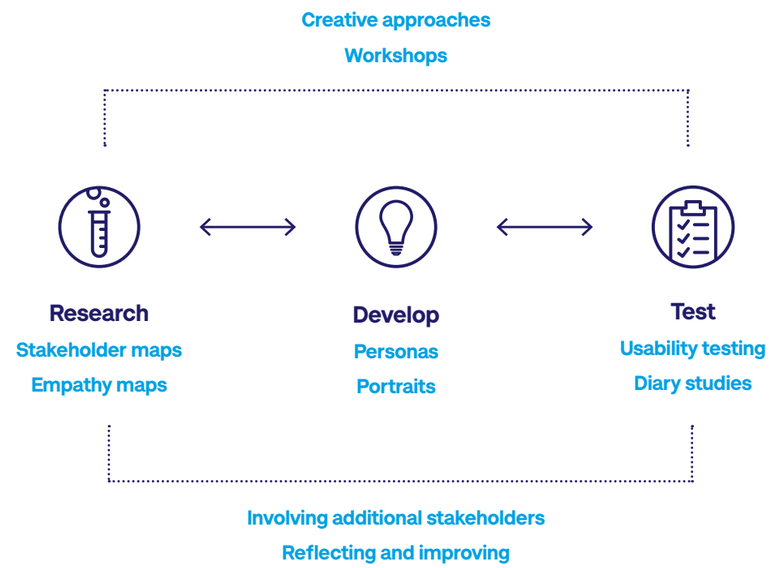
05

How can you co-create effectively?

An important aspect of working collaboratively is taking time to reflect on what has worked well and what could be improved.

How can you co-create effectively?

There are a selection of methods that are frequently used in co-creation. You should always be tailor them to the nature of your project and the needs of individuals involved. Whatever the stage of dementia, there are always steps that can be taken to involve people in co-creation.



Involving additional stakeholders

Where the primary audience for an innovation is people affected by dementia, involving people with different experiences and those with professional expertise can also be valuable. It can help to identify and understand the issues from a different perspective.

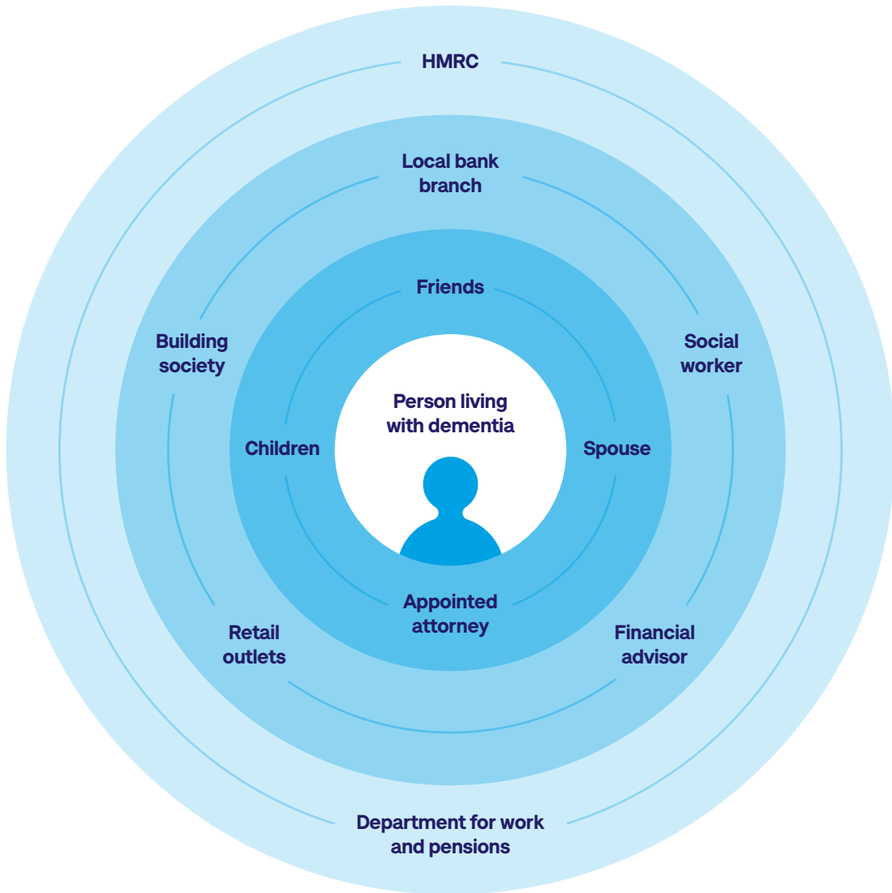
Examples include family, friends, social workers, clinicians, innovators and entrepreneurs in the space and other members of the community. Bringing in subject experts, such as researchers or policy makers, can also contribute high level insights.

It may be that the intended users are not people affected by dementia, but rather people in a professional or informal support role. In this instance, people affected by dementia might play more of an advisory role, with much of the hands on co-creation involving these other groups.

Stakeholder maps

A stakeholder or system map can be a useful tool to help think through who should be involved. The primary user is placed in the centre and surrounded by the other people and organisations that are involved.

This example of a simple stakeholder map considers people involved in challenges around finances and dementia.



Empathy maps

Empathy maps are a way to place yourself in someone else's shoes, identifying what they think, feel, and do. When built together with others they can help ensure all members of a team have a shared understanding of a user's experience and needs.

Personas

Personas are fictional characters that convey the characteristics of a typical user – for example, a person living with dementia, a carer, or a healthcare professional. Personas can include details such as age, living arrangements, challenges and wishes. They ensure the user is represented throughout the design process, particularly when it's not possible to have actual users present.

Including people affected by dementia in developing personas

When working with a small group of people affected by dementia there is a risk of ending up with a product which is not suitable for a wider audience. One way to overcome this is to facilitate the group to develop generic personas themselves. This may help both people affected by dementia and the design team to step outside of their own personal circumstances and experience and design for others' needs. For an example of how this can work in practice, read about the SCAMPI project on page 50.

Portraits

A portrait is an outline of a real person, rather than a fictional one. This facilitates user-centred design, even when the user is unable to engage explicitly in co-design activities due to the severity of their dementia symptoms. Portraits can be used to design for specific people, or as inspirations for designs for a wider group.

Portraits played a central role in the LAUGH (Ludic Artefacts Using Gesture and Haptics) research project led by Professor Cathy Treadaway at Cardiff Metropolitan University. Using the Compassionate Design approach, they developed a series of innovative playful devices that engage, comfort and bring joy to people with late-stage dementia. You can read more about the project on page 52.

Workshops

The purpose of creative workshops is to identify challenges and generate ideas to address them.

They provide a key opportunity for people affected by dementia to come up with their own ideas based either on their own experiences or the personas.

It can also be of value to involve other stakeholders to represent a different perspective. Often, the best ideas come from collaboration between people with different experiences and viewpoints. Creative thinking games can help people to think differently to normal, producing new ideas that they would not have thought of otherwise. It is important to note, however, that not everyone will find it easy to participate in these games. Facilitators should regularly check in with the group and design workshops to be flexible.

> 'My father had Alzheimer's and I supported my mother as best I could. I realised, and this was re-enforced when my wife had her Alzheimer's diagnosis, that actually [as a son] I was an outsider looking in, and it's a very different perspective from being the insider looking in'.
>
> **Trevor – carer**

Creative approaches to co-creation

Many co-creation approaches require people to process complex information and contribute verbally. While this will work well for most people with mild to moderate dementia, those living with advanced dementia or with a hearing impairment or language challenges may find it difficult to take part. In these circumstances, it might be more appropriate to take a more hands-on approach. Working with art cards, drawings, images and sensory materials allows people to communicate what they think, how they feel, and may offer a more authentic response.

In the Making It Together project, Dr Gail Kenning and her colleagues at the University of Technology, Sydney, demonstrated how inviting people with advanced dementia to handle objects provided designers with the insight they needed to develop prototypes for new products, whilst the people affected by dementia benefited from an enjoyable experience. Read more about this project on page 55.

Diary Studies

A vital part of the testing process is giving a prototype to people to trial in the context it's intended for, for example in their home. This is an opportunity to gather rich insights into how it is used and and an opportunity for people to suggest how to improve its potential. Depending on the product, the look and feel of testing may vary. One approach, which can be dementia friendly, is asking people to keep a diary.

Testing

When conducting usability testing for a digital solution with people affected by dementia it is important to adhere to the principles on page 23 – respect, support, transparency, commitment, and fairness. Further to this, using the co-creation checklist on page 42 will help ensure your testing sessions are inclusive.

The REAFF framework developed by Arlene Astell in 2009 can be a helpful way to assess whether a digital solution meets the needs of people affected by dementia.

Principle	Definition
Responding	Technological solutions must be responsive to the needs of people with dementia
Enabling	Technological solutions must enhance the life of the person with dementia and not disable them in anyway
Augmenting	Technological solutions must build on and extend the retained abilities and skills of people with dementia
Failure-Free	Technological solutions must be intuitive and accessible and not undermine the confidence of a person with dementia

Reflecting and improving the co-creation process

An important aspect of working collaboratively is taking time to reflect on what has worked well and what could be improved. When involving people affected by dementia, reflection is especially important to ensure you are making it easy and accessible for them to be involved. Take time to gather feedback from the people involved and act promptly on their suggestions. You can collect feedback at the end of focus groups and creative workshops, or via surveys at key points in the project.

Further reading

The MinD persona toolkit, a three-step guide to creating a personas for people affected by dementia
designingfordementia.eu/wp-content/uploads/2020/04/Toolkit-A4-2104.pdf

The Compassionate Design Toolkit
laughproject.info/wp-content/uploads/2018/04/Compassionate-Design_toolkit.pdf

Guidance on conducting user interviews
nngroup.com/articles/user-interviews

An example of using a 'test and learn group' in app development
innovationhub.alzheimers.org.uk/blog/post/3156430

Templates for co-creation activities including stakeholder maps and empathy map
gamestorming.com

The Dementia Experience toolkit – detailed guidance on different methods of working with people affected by dementia to understand and improve their experiences of services
alzheimers.org.uk/dementia-experience-toolkit

MinD design and research tools to actively include people affected by dementia
designingfordementia.eu/resources/mind-tools

Guidance on conducting diary studies
nngroup.com/articles/diary-studies

Digital accessibility best practice guidelines

Include people with differing experiences of dementia in all stages of web and interface design

Digital accessibility best practice guidelines

Dementia has an impact on individuals' cognitive function, making it more challenging to process thoughts and understand written information. The nature and severity of impairment varies for each person and there is no one-size-fits-all solution for accessible design. We have, however, established some broad principles to make your product or service more accessible for more people.

The following section consists of two parts – writing for dementia, and maximising website and interface accessibility. These have been informed by the work of DEEP (Dementia Engagement and Empowerment Project) and Alzheimer's Society's user experience team.

Writing accessibly for people affected by dementia

People with dementia have the right to know about things that affect them. This means information should always be presented in a way that is as easy to understand as possible. Language, style, length and format can all make a big difference.

Style and language

Information should be clear, easy to understand and presented in a positive way. Here are some suggestions from people with dementia about how to provide accessible written information:

- Present information logically, one piece at a time.
- Keep language simple without being patronising. Remember you are writing for an adult audience.
- Write concisely.
- Be clear with the words you use and avoid jargon.
- Avoid using inaccurate labels to describe people. For example, you should only use 'patient' when a person is receiving care in hospital. Don't use negative terms, such as 'sufferers', to describe people.

Layout

- Text set out in one column can be much easier for the eye to follow than two. If you must use columns, leave a gap, or use images or colour to distinguish between them.
- Set your font size at 12pt or above. DEEP recommends a font size of at least 14pt with 20pt for headings.
- Limit yourself to 80 characters per line (100 for online).
- Avoid italics and all capital letters.
- Use an open source sans-serif font. The simplicity of the letter shapes is more readable.
- Maintain consistent size and colour of headings types and for the body of your text.

Maximising website and interface accessibility

Dementia is non-discriminatory; it affects people from all backgrounds and across generations. This means that people affected by dementia are very diverse, with differing symptoms and varying levels of digital literacy. As such, you should aim to include people with differing experiences of dementia in all stages of web and interface design to inform the final output.

However, there are still things you can do to proactively improve web accessibility. In addition to the following guidance, please refer to the W3C Web Content Accessibility Guidelines.

Navigation and Interface design

- Use clear breadcrumb navigation to help people understand where they are on a website.
- Use obvious 'Home' and 'Back' buttons. Do not rely on using a logo only to link to the homepage.
- Avoid hiding navigation, for example in 'Hamburger' menus.

Colours and contrast

While all adults may experience changes in their vision over time, each type of dementia can cause additional damage. This often causes perceptual problems, which can lead people to misinterpret some things they see. Together with other dementia symptoms, this means that the world can become a disorienting and stressful place.

- Use a high contrast colour scheme to improve readability and confidence. Ratios for contrast should be 7:1 and 4.5:1 at a minimum.
- Set text on a plain background, rather than on patterns or images.
- Avoid the use of blue, especially for important interface components.

Images and multimedia

- Make sure images are relevant and not simply used for decorative purposes. Diagrams and pictures alongside text can sometimes be helpful. However, too many images can be confusing.
- Consider including icons, which can be helpful for people who have language impairments.
- Use photographs instead of illustrations, especially cartoons, which can be difficult to interpret and can seem patronising.
- Use autoplay where video is the only focus or simple playback controls.
- Always provide subtitles on video and a transcript with audio.

Screen readers

- Include a text alternative with all images and other non-textual content. For example, images should have descriptive embedded captions so that screen readers can inform users with visual disabilities about its contents.

Overlay accessibility tools

- Website add-on products, otherwise known as overlays, allow user-based control of things like font size and colour to improve readability. These features may seem beneficial, however, most people with accessibility needs will already have the necessary features on their computer.

Further reading

Alzheimer's Society website accessibility guidelines
alzheimers.org.uk/about-us/accessibility

W3C web content accessibility guidelines
w3.org/WAI/standards-guidelines/wcag

AbilityNet factsheet on dementia-friendly website and digital design
abilitynet.org.uk/factsheets/designing-dementia

Practical tips and guidelines for user research with older people
rikwilliams.net/ux/user-research/older-people-tips-guidelines

10 usability heuristics for user interface design
nngroup.com/articles/ten-usability-heuristics

Factsheet about web accessibility overlays
overlayfactsheet.com

Co-creation checklist

This checklist outlines the key points you should consider when planning any co-creation activity

Co-creation checklist

Identify individuals to get involved

- People with dementia
- Family carers

Consider the characteristics of the people you will need to involve and where you can reach them.

Recruit more people than you need for a co-creation activity as other commitments, illness or caring responsibilities can cause last minute changes to plans.

Further reading

The Dementia Experience Toolkit includes links to organisations that may be able to help you recruit people
alzheimers.org.uk/dementia-professionals/dementia-experience-toolkit

Consider ethics

- Avoid harm
- Adhere to professional and legal standards
- Obtain approval from ethics committee if appropriate
- Follow safeguarding processes

Safeguarding
When working with people affected by dementia, it's always possible that people may share experiences that cause concern about their safety or wellbeing, or someone else's. Make sure you are aware of the relevant safeguarding procedures to follow if this happens.

Having difficult conversations
There may be very rare occasions when a person is inappropriate in what they say or do. It's important to talk to the person about this if appropriate at the time.

- Find a quiet and private space to hold the conversation.
- Be clear about expectations – you might like to set up a group agreement or group contract with everyone at the beginning.
- Be sensitive. The person may not realise they did anything inappropriate. It may not have been intentional.
- Remember that there are many things that can affect a person's abilities, for example the weather, dehydration, changes in medication, environment, general health or tiredness.
- Consider whether it could have been avoided, perhaps by having more frequent breaks.

Further reading

Alzheimer's Society guidance on safeguarding and dementia
alzheimers.org.uk/get-support/legal-financial/safeguarding

Consider reimbursement and payment, such as:

- Out-of-pocket expenses
- Compensation for time
- Any impacts on benefits

- If people are attending a meeting or event, don't ask them to pay for things in advance. Take steps to avoid financial difficulties being a barrier to involvement in your project. Book train tickets on people's behalf. Pay for taxi fares. Offer lunch.
- If you need to pay for expenses, make it easy to claim and ensure the money is reimbursed as soon as possible.
- Making payments or giving rewards to people to compensate for their time can be complex and payments for involvement activities are seen as earnings even when someone is retired.

Further reading

Alzheimer's Society payment guidance
alzheimers.org.uk/dementia-professionals/dementia-experience-toolkit/how-recruit-people-dementia/remuneration-and-reward

National Institute for Health Research (NIHR) payment guidance
nihr.ac.uk/documents/payment-guidance-for-researchers-and-professionals/27392

Provide adequate information

- Use clear language
- Offer a written format
- Give information about yourself
- Provide context
- Inform people of what they will be doing

Talking to someone about an opportunity

- Be kind, considerate and thoughtful in your approach.
- Take an interest in the person you're contacting.
- Ask how they might like to be involved and what's the best way to communicate with them.
- When making the initial introduction tell the person a little about yourself. You could provide a photograph if you're writing to them or emailing them.
- Tell them why you're excited about the project and working with them – ask for their help.
- Provide context for them, for example, if you have been given their name by someone they know.
- Make a connection with the person. Building trust and respect is really important.
- Remember, even if the person with dementia can't remember the specifics of an event or a conversation, they will remember how you made them feel being part of that activity.
- Be clear about the level of commitment involved, for example, how often you will meet, what you'll ask them to do as part of the project.
- Provide the date(s) and time(s).

Co-creation checklist continued

- Give people time to decide if they want to be involved. They have busy lives and they may need to organise their diaries to accommodate you.

Inviting people to an activity or meeting

- Provide some information about what you'd like to discuss. Make sure this is short and to the point. You may want to include three or four questions that you'd like to discuss. Some people may want to prepare, some will not.
- If you're including a Zoom link in your invitation, include this towards the beginning of the invite so that participants don't need to scroll to find it.
- Make the date/time/venue of the meeting clear by using bold.
- Include an itinerary if a person is travelling.
- Resend your invitation a few days before or on the day of the meeting as a reminder. Some people might also appreciate a text reminder – you can ask people what they'd prefer.

Writing clearly

- Present information logically and write concisely. Avoid jargon and acronyms.
- Make sure sentences only contain one idea and aren't unnecessarily long.
- Use bullet points to highlight important information, such as dates and times of meetings.
- Be as specific as possible, so avoid relying on terms like 'next week'.
- Paragraphs should make sense on their own. The person should not need to remember the content of the first paragraph to understand subsequent ones.
- Don't try to include too much information. White space is important.
- Check whether a person needs information in print. Reading text on a screen can be very difficult for people.
- Give examples where necessary to help provide clarity for people.

Further reading

DEEP guidance on running a discussion with people affected by dementia
dementiavoices.org.uk/wp-content/uploads/2013/11/DEEP-Guide-Collecting-views.pdf

DEEP guidance on the use of language about dementia
dementiavoices.org.uk/wp-content/uploads/2021/05/DEEP-Guide-Language.pdf

Gain informed consent

- Assume capacity
- Gain consent to take part
- Gain consent to use personal information and photos

- In England and Wales, The Mental Capacity Act (2005) dictates that you should assume someone has capacity to give consent to take part in an activity, unless demonstrated otherwise.
- For some people with dementia, their capacity to consent to participate can fluctuate based on factors such as time of day.
- Consent is also required if you want to capture photographs, people's quotes, film clips or audio.

Further reading

Alzheimer's Society guidance on gather informed consent
alzheimers.org.uk/dementia-professionals/dementia-experience-toolkit/how-recruit-people-dementia/consent-and-capacity

Alzheimer's Society guidance on the Mental Capacity Act (2005)
alzheimers.org.uk/get-support/legal-financial/dementia-mental-capacity-act

Make activity inclusive

- Find a venue
- Plan travel
- Decide methods of involvement
- Provide adequate support

When working with people affected by dementia, it is important that any activity is well planned and thought through in advance. You also need to consider the needs of the people you are involving.

Providing adequate support

- Find out about any needs people might have. These might include needing help with hearing, large print, getting around or access to a prayer space.
- Things can change over time and this might affect the level of support someone may need. Be prepared to adapt your activities to suit a person's changing needs. Remember, we never want to set up people to fail.

Further reading

'Information About Me' form template
alzheimers.org.uk/sites/default/files/2019-04/information_about_attendees_form_draft.pdf

Co-creation checklist continued

Make activity inclusive continued

Preparing the meeting venue

- If you are meeting at a venue, you need to make sure that the space is dementia inclusive..
- Make sure you have clear signs at the venue inside and out.
  - o Include signs outside to let people know they are in the right place when they arrive.
  - o Clearly direct people around the building, including identifying toilets and the room where the meeting is taking place.

Further reading

DEEP guidance on choosing a meeting place
dementiavoices.org.uk/wp-content/uploads/2013/11/DEEP-Guide-Choosing-a-meeting-space.pdf

Download dementia friendly signs
alzheimers.org.uk/dementia-professionals/resources-professionals/resources-gps/dementia-friendly-signage

Arranging travel

- Consider if it might be more appropriate for you to travel to meet a person in their home or local area rather than have them travel to you.
- If people need to travel, chat to them beforehand and organise their travel in a way that works for them.
- Make sure support is available for people as they arrive. This might be at the station or at the venue, and to show them to the meeting place.
- Make sure you have contact details for the person on the day in case you need to get in touch. You should also request an emergency contact for them.
- Send photograph of the building where the meeting is taking place and of the people they are going to meet. You should also include relevant contact numbers.

Further reading

DEEP travel itinerary template
dementiavoices.org.uk/wp-content/uploads/2019/08/My-Itinerary-for-attending-a-DEEP-Gathering.pdf

Meeting as a group

- Allow people time to get to know everyone.
- Plan regular breaks for people to chat informally and for refreshments. Be alert to the group needing to take breaks earlier than planned. Have water, tea and coffee (or whatever drinks the people prefer) close during the session. You might also consider having biscuits and fruit available.
- Raise one issue or question at a time and consider how the issues that you want to discuss can be broken down.
- Use 'I want to speak please' cards or ask people to indicate if they have a point to make to avoid people speaking over each other.
- Check understanding as you go along. Consider using prompts or cues.
- Check that everyone has heard if someone in a group asks a question.
- Check in with the quieter members of the group and invite them to contribute. Reassure them that it's fine if they haven't got anything to contribute and that there will be the opportunity to send any thoughts after the session.
- If a topic could cause conflict:
  - o Consider breaking into smaller groups for discussion.
  - o Summarise the points people are making to show that you have taken them on board.
  - o Use breaks to give time for people to step away from discussions and to diffuse any tension.

  - o Refer the group back to any group agreement you've created together, setting out how you would all like the group to run.
- Before the end of the session, share themes that have arisen.
- Thank people for their time and input and outline what will happen next.

Further reading

Tips for a dementia-friendly welcome
alzheimers.org.uk/dementia-professionals/dementia-experience-toolkit/research-methods/tips-dementia-friendly

DEEP guidance on involving people with dementia as members of a steering or advisory group
dementiavoices.org.uk/wp-content/uploads/2016/03/DEEPGuidance_involvingpeoplewithdementiainadvisorygroups.pdf

About 'I want to speak please' cards
innovationsindementia.org.uk/2019/03/i-want-to-speak-please

Holding virtual meetings

- Speak with participants ahead of the meeting to find out about any support they might need to use the necessary technology
- When screen sharing a screen/presentation – be sure to keep it short and simple.
- Try and limit this to less than 20 mins or when sharing a screen after a short period return to the gallery screen view. Some people prefer to see everyone's faces.
- Be aware of having too many people in the meeting and therefore too many 'boxes' on the screen.
- If you would like to record the session, make sure you ask people at the start of the session whether this is ok, and share with people how you are going to use the recording and how long you plan on keeping the recording.

Further reading

DEEP Guidance for Zoom meeting hosts
innovationsindementia.org.uk/wp-content/uploads/2020/11/ZOOM-%E2%80%93-Guidance-for-meeting-hosts-1.pdf

DEEP guidance for Zoom meeting participants
innovationsindementia.org.uk/wp-content/uploads/2020/11/ZOOM-%E2%80%93-Guidance-for-meeting-participants-1.pdf

Reflect

- Seek feedback from collaborators
- Ask what worked well
- Ask what could you change to improve it

- Take time to reflect on your co-creation activity. What worked well? How could you be more inclusive? What might co-creation look like in the next stage of your project?
- Where possible, reflect collaboratively with the people you are involving. This might involve co-designing an evaluation plan.
- See the Bring Dementia Out case study on page 55 for an example of how this might work in practice.

Co-creation checklist continued

Provide feedback

- Acknowledge their role
- Explain next steps
- Continue to inform them about the project

Explaining next steps

People affected by dementia should know what you plan to do with the results of their work, otherwise it can be disheartening for people and feel like a waste of time.

- Recap the information you have collected at the end of the activity.
- Share timelines and next steps.
- Be clear about how the information shared will be used.
- Offer further opportunities – let people know if they can be of further help.
- Provide 'end of project' feedback.

Saying thank you

It's important to acknowledge the role that people affected by dementia have played in your work and to say thank you.

- Consider sending a personal thank you, perhaps a card or handwritten letter.
- Send an invitation to an event, for example the launch of a project or publication.
- Share photographs of involvement as a reminder (makea sure you have consent to take the photographs).
- Acknowledge the person's contribution in publications they helped to design.
- Give people or groups equal billing if you have worked together on a piece of work.
- Put people or groups forward for awards.
- Invite people to stay involved with your work or the work of others.
- Give a thank you gift if appropriate.

Being involved can be a much bigger deal to a person affected by dementia than they might let on! Don't let their contribution go unrecognised.

'Acknowledgment is so important; it means a lot.'

Person living with dementia

Case studies

Case study

Self-Care Advice, Monitoring, Planning and Intervention (SCAMPI)

City, University of London

This case study illustrates how people affected by dementia can be incorporated into a design process using a variety of novel techniques.

The aim of SCAMPI **(scampi.city.ac.uk)** was to co-design a new intelligent computerised toolset that helps people affected with chronic conditions, such as dementia and Parkinson's, to live independently at home.

With its simple user interface, the SCAMPI toolset enables people to create and monitor quality-of-life plans and to carry out day-to-day activities. An intelligent computational model gives advice and recommendations based on these plans and activities. Sensors placed in the home aid monitor activities of the user.

Recruitment

The SCAMPI team recruited four people with earlier stage dementia who lived in their own home and with their informal carers. They did this with the help of Alzheimer's Society and by visiting local dementia support groups.

The recruits all gave informed consent in line with Mental Capacity Act 2005 and guidelines developed by the British Psychological Society. The information and informed consent form were provided to all participants in large print and in simple language, following the Dementia Engagement and Empowerment Project (DEEP) guidelines.

Co-design workshops

The project involved four workshops, each lasting about three hours and spaced several weeks apart. Participants were able to take frequent breaks and take time out in a quiet room if needed.

The aim of these workshops was to:

- understand the potential users' backgrounds and needs
- obtain their input to the computational model and sensor technology
- develop and evaluate the emerging app design.

A particular feature of the PERCEPT approach is that personas are co-created with workshop participants to reflect users. This novel approach allowed the research group to create personas which were ground in lived experience and acted as a successful tool for the participants to think outside of themselves. The personas were then integrated into all aspect of the co-design process.

The structure of the workshops was as follows.

References

Bourazeri, A. & Stumpf, S. 2018. "Co-Designing Smart Home Technology with People with Dementia or Parkinson's Disease." In Proceedings of the 10th NordiCHI Conference. **doi.org**/10.1145/3240167.3240197

Neate, T., Bourazeri, A., Roper, A., Stumpf, S., & Wilson, S. 2019. "Co-Created Personas: Engaging and Empowering Users with Diverse Needs Within the Design Process." In Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems (CHI '19), 650:1-650:12. **doi.org**/10.1145/3290605.3300880

> 'For the co-design of the user interface, we developed the PERCEPT (PERrsona-CEntred Participatory Technology) approach. We aimed to deeply involve future users in all aspects of conceptualising, designing, and evaluating the app.'
>
> **Dr Stumpf – Co-investor on SCAMPI**

Workshop 1
Introductions, co-creating personas and reflecting on goals and activities

- Started with time for everyone to introduce themselves to each other
- Co-created a first draft of personas, giving them names and a backstory
- Ran an exercise to establish how people used technology themselves – researchers used a floorplan of a hypothetical small home that they could alter and annotate with technologies, either with pre-produced laminated cards of devices or by writing on the floorplan with a marker. At the end of this exercise, they were asked what technologies and devices would be used by each of the draft personas. The researcher took notes so there was no need for people to handwrite things if they were unable to
- Held a discussion about the goals and activities they want to achieve in their daily lives. At the end of the exercise, they returned to the draft personas to flesh them out with goals and activities
- As homework people took pictures of different aspects of their lives and technology use – there were mixed levels of engagement, but results helped the researchers get to know people living with dementia and empathise with their experiences.

Workshop 2
Exploring the use of sensors and gaining input to the computational model

- Summarised the first workshop to remind participants of what had been achieved so far
- Updated the personas, if necessary
- Mapped goals and frustrations to current computational model
- Asked people to complete sentences to explain how they would use sensors to map their behaviour – people affected by dementia struggled to come up with answers spontaneously and laminated prompts would have worked better.

Workshop 3
Designing the user interface using basic prototyping

- Used the co-created personas' activities and goals to encourage participants to create the designs focusing on the wider user base, rather than drawing on their own personal preferences
- Used post-it notes, pens, buttons, checkboxes, drop-down lists etc. to capture and organise insight
- The researcher sketched designs and asked the group if they represented what they had envisaged.

Workshop 4
Evaluating the user interface design

- Presented an interactive prototype on tablet computer
- Role played the likely experience of the prototype from the perspective of the co-created personas, known as a simplified cognitive walk through. They asked questions such as 'Will Fred see what to do next?'. Researcher noted any issues. By this point even participants with dementia who sometimes struggled to remember recent events indicated that they could remember everything about the personas
- Created updated version of the software
- Carried out UX testing with a larger group of users, following a typical think-aloud setup and a debriefing interview. This was based on the user's own experience of the sensory technology as well working with participants of the study to capture the likely experience of the personas to ensure product would be accessible to a range of people.

Case study

Ludic Artefacts Using Gesture and Haptics (LAUGH)

Cardiff Metropolitan University

This case study illustrates how using a Compassionate Design approach can meaningfully involve people with advanced dementia in product creation and development.

The LAUGH project **(laughproject.info)** was a three-year design research project funded by the UK government. It was based at Cardiff Metropolitan University and led by Professor Cathy Treadaway.

The project brought together health and care professionals with designers, technologists, and materials scientists to understand how playful objects can assist in the care of people living with advanced dementia. The research team worked with people living with dementia and their families to develop and evaluate a range of designs to improve the quality of life of those living with the advanced stages of the disease. One of the successful products developed from this research was HUG™, which is now commercially available **(hug.world)**.

The Compassionate Design approach

A person living with advanced dementia is unable to relate to the world as it is perceived by others. They inevitably have less physical interactions with the material world and often become increasingly isolated and withdrawn.

The design challenge then, was to meet the person where they are, in the world that they perceive – with a desire to make it better for them. This approach can be described as 'Compassionate Design'[1]. By ensuring empathy is a central constituent of the design approach, a positive intention to improve their quality of life is embedded in the design process. Compassionate Design prioritises three vital design constituents in designing products:

1) personalised
2) sensory
3) connecting

The LAUGH project tested Compassionate Design theory in practice[2].

The initial stage of the project involved a series of workshops and creative events involving 'experts' (carers, health professionals and technologists) and visits by the research team to care homes, to meet 'experts by experience' (people living with advanced dementia). Members of the local Alzheimer's Society Service Users Reporting Panel (SURP) also contributed their experiences.

This helped to inform the design team about dementia and enabled identification of key themes that are universally important to people in the advanced stage of dementia. These themes were used to guide the development of a small collection of prototype objects. Each one was 'bespoke' (designed for a specific person) but also guided by a universal theme, to ensure it would also be likely to be

appropriate for others at a similar stage in the dementia journey. Six universal themes were identified for people living with the advanced stage of the disease[3].

In order to generate bespoke design concepts, a 'portrait' of the individual was developed. This included a description of a person's preferences, interests and brief life-story as well as a pencil sketch of them. Where a person was unable to provide this information themselves (due to the progression of the disease), it was provided by family members and care professionals who knew the person well.

Designing and testing HUG™

The concept for HUG™ was initially developed for a woman living with advanced dementia who was receiving end of life care. She had once been the life and soul of the care home where she lived However, when the design team first met her, she had lost verbal communication skills and no longer socialised with the other residents. She was largely bedbound and when she did try to move, she frequently fell; her hands were contorted and stiff, and she was unable to use her fingers.

The staff told the researchers that the only thing she really needed was a hug. A portrait was developed by the design team with her carers and family. Initial ideas were then explored in a co-design workshop with dementia experts, designers and technologists, and the universal theme 'nurturing' was used to guide concept development.

The LAUGH design team developed these early design concepts into a prototype for a wearable object to be cuddled. The object had extended, weighted arms and legs, designed to wrap around the body, to provide the sensation of both giving and receiving a hug. Inside the cushion-like body, a small programmable electronics module (with speakers) contained a playlist of the woman's favourite music. In addition, a simulated electronic heartbeat module provided the sensation of a beating heart.

An expert group of care professionals provided feedback to make sure the final product was safe and appropriate for people with dementia.

The design team then introduced the prototype HUG™ to the person it was designed for. They made observations of her using the product over a period 3 months. This evaluation included observations from both the design team and those who knew her well and who could interpret her body language and understood her needs. Video was used to document the evaluation process and three members of the design research team as well as professional caregivers coded and recorded her responses during the evaluation visits. Interviews with professional staff were undertaken by a psychologist to provide additional information about how she had responded to HUG™ from day to day[4].

The impact of HUG™ on the woman's wellbeing was significant. Not only did she become more engaged with life, but her general health improved, and she had no further falls. Her ability to communicate verbally and desire to socialise returned, and HUG™ became her object to nurture (her baby) and to nurture her (give her a cuddle). HUG™ also became a focus for interaction and conversation with other residents and caregivers and helped her to relax. She lived a further nine months after receiving HUG™ with much improved quality of life[5].

A further larger study, funded by Welsh Government, has recently been undertaken in NHS hospital and care home settings. Findings from this larger study corroborate the initial evaluation of HUG™[6].

Ludic Artefacts Using Gesture and Haptics (LAUGH)
case study continued

This LAUGH case study shows how a Compassionate Design approach, which places an individual person living with dementia at the very heart of the design process, can also result in successful product design that is of benefit to many and not just the single individual for whom the product was originally designed. HUG™ is now being manufactured and is available to buy online from Alzheimer's Society online store. HUG by LAUGH® is an Alzheimer's Society Accelerator partner.

References

[1]Treadway, C., Fennell, J. & Taylor, A. 2020a. "Compassionate Design: a methodology for advanced dementia." In: K., C., AND, C. C. & P., C., eds. 6th European Conference on Design4Health, 2020 2020a Amsterdam. Sheffield Hallam University, 667-673.

[2]Treadway, C., Taylor, A. & Fennell, J. 2018b. "Compassionate design for dementia care." In: International Journal of Design Creativity and Innovation. 7.

[3]Treadway, C., Fennell, J., Prytherch, D., Kenning, G., Prior, A. & Walters, A. 2018a. "Compassionate Design: How to Design for Advanced Dementia." Cardiff, Cardiff Metropolitan University.

[4]Kenning, G., Treadway, C., Fennell, J. & Prytherch, D. 2018. "Evaluation or 'anecdote'? Understanding the impact of design." In: Christer, K., Craig, C. & Wolstenholme, D., eds. 5th conference on Design4Health, 2018. Sheffield: Sheffield Hallam University.

[5]Treadway, C. 2018. "LAUGH: playful objects in advanced dementia care. The Journal of Dementia Care. 26, 24-26.

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Case study

Making It Together (MIT)
University of Technology, Sydney

This case study of the Making It Together (MIT) project shows how people with advanced dementia can take part in and benefit from co-creation projects.

People living with advanced dementia may be affected by cognitive and physical limitations, including memory loss, impaired judgement, neuropsychological symptoms, dexterity and mobility. However, this doesn't stop them from making important contributions to co-design projects.

Research shows that special consideration is needed, as people may not be able to fully conceptualise the design and development process or think ahead to future outcomes[1]. This means that they will not necessarily have the sense of reward or satisfaction that many people get in seeing a project come to fruition.

In the MIT project, eight people with advanced dementia across two aged care facilities in New South Wales, Australia, took part in three 90-minute workshops about 4 weeks apart. The aim was to develop age-appropriate objects and activities to engage, entertain, or simply occupy older people and people living with advanced dementia[2,3].

The principle of reciprocity was central to the workshops, which had two purposes. They were used to collect data for the designers and researchers about how people reacted to objects and materials. They were designed to be an interesting shared experience for the participants and family members of carers.

Workshop 1
Fiddle bags

- Participants were given personalised 'fiddle bags' containing textiles, threads, beads, nuts and bolts, padlocks, books, images and a range of objects and audio and video to stimulate curiosity or engagement. Together with a family member or carer, they took the objects out of the bag one at a time and were encouraged to talk about the object, to tell stories, ask questions and say what they liked or didn't like about it
- Workshops were audio and video recorded for post-event analysis. Researchers also made brief notes as participants spoke about the objects. Family members and carers were encouraged to write down the answers on brightly coloured questionnaires. Designers and researchers analysed these data and used them to create a prototype object or activity.

Workshop 2
Initial prototype

- People with advanced dementia tried out the updated prototype together with family members or carers. Data were collected and analysed in the same way as the first workshop. It was then used to further develop the prototype into either a final prototype.

Workshop 3
Final prototype

- The group repeated workshop 2, but this time testing the final prototype.

Making It Together (MIT)
case study continued

Across all workshops audio and video recording allowed the designers and researchers to focus on the working with the people taking part, rather than needing to make extensive notes in situ about the activities which can be off-putting. While participants were advised that recording was being carried out, and consent for the recording had been given, all participants soon ignored the recording equipment and got on with what they were doing.

The recordings allowed all comments, movements, gestures and non-verbal communication to be captured. This way input was gained both from those who were able to talk, tell stories, answer questions, and those who were non-verbal. Their responses could be observed providing insights into likes, dislikes, frequency of engagement and intensities, for example laughter and excitement. This supported the observations that designers and researchers made in the workshops and then discussed in a debrief meeting immediately after each session.

When working with people living with advanced dementia, it's important for participants to contribute to the level of their ability. For some this was touching, holding, talking, storytelling, and moving around. For others, their engagement was more contained with little movement, speech and or gesture. However close analysis of expressions and engagement over time provided insights into their feeling towards the prototype. The data was analysed thematically, and for intensity of expression and frequency of engagement.

The questionnaire was designed to look informal, with bright colours and prompts for topics of discussion, rather than formal questions to maintain the informal nature of the engagement.

Finally, the project team requested consent from all participants and their family member or legal guardian. This involved explaining the project and intentions and providing consent forms in plain language. They also used a process consent approach as outlined by Dewing[4]. This meant that after consent, if we recognised participant responses that suggested participants no longer wanted to engage, this was regarded as a withdrawal of consent. Participants could, however, rejoin the engagement if their behaviours suggested they wished to take part in the project again.

Overall, the project resulted in 12 prototype products. Their co-creation was reliant on carefully designing a reciprocal engagement where individual's needs and abilities were catered for and each participant had a designated support person (known to them) throughout the process.

References

[1]Viard, A., Piolino, P., Belliard, S., de La Sayette, V., Desgranges, B. & Eustache, F. 2014. "Episodic Future Thinking in Semantic Dementia: A Cognitive and fMRI Study." PLoS One. 9 (10)

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Case study

Bring Dementia Out

Alzheimer's Society Innovation team

Bring Dementia Out was an innovation aiming to raise awareness and break down stigma, so that LGBTQ+ people affected by dementia could feel more comfortable in coming forward to access information and support. It was co-created by Alzheimer's Society in partnership with the LGBT Foundation, National Dementia Action Alliance, the National LGB&T partnership, Switchboard and a group of experts by experience.

The scoping, research and development stages involved both personal and professional experience of the intersection of LGBTQ+ and dementia through:

- one-to-one conversations
- focus groups
- an ideas workshop

When reflecting back on these activities, the team decided to invite back a selection of people with personal experience to involve them more deeply in building and testing a solution. When asked how they would like to be involved, they expressed a preference for meeting as a group over one-to-one conversations as they found it helpful to bounce ideas off each other. The result was a working group including six experts by experience and representatives from the partner organisations. The working group established an open and trusting environment, where people were free to share thoughts and suggestions at any time.

When it came to planning a pilot, the working group took part in an activity to identify the desired outcomes and impacts and how they would be measured. This meant that success was measured against what they felt was important, rather than something Alzheimer's Society imposed on them.

Quantitative and qualitative evaluation data were collected throughout the pilot, culminating in an evaluation and celebration event. This took place away from the office environment and included food and decorations to make it feel light-hearted. The project team recapped what the group had achieved throughout the project. They then presented evaluation findings and facilitated an activity where the working group considered what these meant for the next stage of the project.

After the success of the innovation project, Bring Dementia Out is now led by one of the partner organisations, LGBT Foundation, with support from some of the other partners who were initially involved in its development. The innovation has also inspired other LGBTQ+ and dementia groups and initiatives to form, which include people with lived experience right at the heart of their work.

> 'You need lots of empathy and understanding. Be bubbly, don't treat it as a classroom, but as a social gathering – that makes people feel at ease – and always be willing to learn even things like if the room is too hot or the lighting or you need a drink. All those little things help.'
>
> **Working group member**

Glossary

Breadcrumb navigation
an element of web design to show your users their location on the website and how they got there.

Compassionate design
reflects the specific and sensitive needs of vulnerable people, such as people living with dementia. It's rooted in three design principles:

- **personalised** – design to retain a person's sense of self and maintain their dignity
- **sensory** – design to experience the present moment
- **connecting** – design to encourage high quality connection with others.

Hamburger menus
an icon on a website or app consisting of three horizontal lines. When clicked it opens-up to reveal a list of links to other pages.

Innovator
anyone designing or improving a product or service to the challenges faced by people affected by dementia. Examples include engineers, designers, researchers, software developers and entrepreneurs.

Iteration
the process of repeatedly improving a design based on testing and learning.

LGBTQ+
stands for lesbian, gay, bisexual, trans and queer or questioning. The '+' recognises inclusion of wider spectrums of sexuality and gender.

People affected by dementia
includes people who have dementia, as well as those who care for them, for example, their family and friends.

Personas
fictional characters that represent the characteristics of a typical product/service user – for example, a person living with dementia, a carer, or a healthcare professional. The persona can include details such as age, living arrangements, challenges and wishes.

Person-centred
approaches that focus on an individual's needs, strengths, and preferences.

Portraits
descriptions of real people that can help stimulate ideas.

Stakeholder
anyone with an interest in the topic, product or service. This can include people living with dementia, informal and formal carers, researchers, clinicians and engineers.

User-centred design
designers focus on and involve users and their needs in each phase of the design process.

User testing
evaluating a product or service by testing it with representative users. This helps to uncover problems, discover opportunities and learn more about users, so you can improve the product or service.

UX design
stands for 'User Experience'. It is the process of designing a product, usually a digital one, in such a way that it is easy to use.

People affected by dementia need our support more than ever. With your help we can continue to co-create new products and services to improve lives.

To make a single or monthly donation, please call us on **0330 333 0804** or go to **alzheimers.org.uk/donate**

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United Against Dementia