



Dementia Toolkit

Living your life with hope

www.livingwithdementiatoolkit.org.uk



Guide to the Living with Dementia Toolkit

UNIVERSITY OF
EXETER



FUNDED BY
NIHR | National Institute
for Health Research



NIHR | Applied Research Collaboration
South West Peninsula



Dementia Toolkit

Living your life with hope

Welcome to the Guide to the Living with Dementia Toolkit for people with dementia and their carers.

This set of resources is based on research, and the expert experiences of people with dementia and their carers. These resources are here to:

- give you **hope** for the future
- **inspire** you through real-life examples
- offer **ideas** to help you live your life as you choose



About Us

The IDEAL research programme looks at ways of improving the experience of living with dementia. The team's main base is at the University of Exeter, but there are researchers in Bradford, London, Manchester, Newcastle and Swansea too. An involvement group of people with dementia and carers, the ALWAYSs group, advises on the research.

The Living with Dementia Toolkit is the result of:

- the research of the IDEAL programme
- co-production work with an incredible involvement group of people with dementia and carers



For this toolkit, 8 members of the ALWAYSs group joined the co-production team: Allison, Chris, David, Jacqui, Jane, Julia, Keith and Monica.

The co-production team of people with dementia, carers and researchers met regularly over an extended period to discuss ideas, feedback on design choices and much more. Facilitated by Rachael Litherland of Innovations in Dementia, this group has co-created the toolkit.

The research

The IDEAL research programme has been finding out about what helps people to ‘live well’ with dementia since 2014. We do this by asking people with dementia and carers about different aspects of their lives. We used to see people in person to talk about this. The COVID-19 pandemic changed how we work. We had to speak to people on the telephone or via Zoom instead.

The COVID-19 pandemic made us think about what kinds of resources might be helpful. The Living with Dementia Toolkit is a way for us to share all we’ve learned and brings together a wide range of experiences from before and during the COVID-19 pandemic.

The quotations you see throughout are from real people with dementia and carers. The five themes of this toolkit reflect five aspects of life that our research shows are important for living well. What it means to ‘live well’ is different for each person. This toolkit offers you a variety of options, so you can choose what you’re interested in and find out more about it.

To find out lots more about our research findings visit www.idealproject.org.uk.



Professor Alistair Burns, National Clinical Director for Dementia and Older People’s Mental Health at NHS England and NHS Improvement says:

For me, the most important evidence is the lived experience of people with dementia and their carers. It was on that basis of that lived experience and what can we do better that the toolkit emerged.



How to use this guide

We hope this guide is easy to use and encourages you to explore the online toolkit further. There are many more resources there, including videos, advice and pages that could be printed out.

There are five themes to the toolkit. These five themes all contribute to living a good life with dementia according to our research findings and what people affected by dementia have told us.

Pick and choose among the themes and resources to find something which suits you. You do not have to look at everything.

Throughout, you will see QR codes that link you to the website. A QR code looks like this:

Open the camera on your smartphone or tablet, point it at a QR code and it will open the corresponding webpage. The example to the right links to the **Living with Dementia Toolkit** homepage.



A Message for Carers

We wanted to give you a special welcome to this toolkit. Sometimes it may sound as if we are speaking directly to people with dementia, but these resources are also designed with you in mind.



Keith, who lives with dementia, says

“Both the person with dementia and the family carer are important. And the needs and the wellbeing of both are interlinked so very, very closely.”



Jane, a former carer, says

“Just do the best you can today, and that’s the best you can do. Try not to feel guilty about ‘oh, I’m not doing as well as I was yesterday or last week’, but just do the best you can do today because that’s all anyone can ask of you.”



Jane

Jacqui

Keith

Monica 😊

Chris

Jane

David

Allison

Rachael

Calvy

Some things to remember:

- You are not alone. Other people are going through similar experiences and talking to them can help.
- Your wellbeing matters too – share the care if possible.
- You might find that you have different expectations than the person with dementia. Try to find a good moment to have an open and honest conversation about how you are each feeling about dementia.
- There are organisations and support groups out there: do look for what’s available in your area alongside national things like Admiral Nurses or Alzheimer’s Society.

Point your phone or tablet camera at the QR code on the right and it will open the **Message for carers** webpage.



The Five Themes of the Living with Dementia Toolkit

The following pages are colour-coded by theme. Feel free to turn to the theme that interests you most.



Stay safe and well

Go to page 8



Stay connected

Go to page 11



Keep a sense of purpose

Go to page 14



Stay active

Go to page 17



Stay positive

Go to page 20



There will be links back to the toolkit website at various points. On the website there are lots of videos to watch and further resources which may interest you.



Welcome to Stay safe and well. This section is all about looking after your everyday needs. That way, you are in the best position to be able to do the things you want to do.



David, a former carer, says

“There are two pits to do with caring. One is the pit of time and the other is the pit of patience, and both of those pits will be heavily mined while you are being a carer. You’ve got to think about your time and how you’re going to plan it and also the patience ... there’s an awful lot you can do in terms of developing and maintaining it.”

Professor Louise Allan, a researcher at the University of Exeter, says

“People who have been looking after their own health are finding that they are living better. People who keep active maintain their muscle strength and their balance, they are less likely to have a fall and they are more likely, then, to be able to retain their independence.”





The information could have come out better and been made more simple in the beginning – [they] were talking about new words that were invented like ‘furlough’. I feel that some of the information could have been less clinical shall we say and more in common language.

A person with dementia speaking to our researchers about difficulties following guidance during the COVID-19 pandemic



5

Top Tips for Staying safe and well



- 1** Follow the latest NHS advice on staying safe.
- 2** Put signs up around the house as reminders, for example a sign in the kitchen to remind you to take your medication.
- 3** Seek and accept the help you need from trustworthy sources. Your council can put you in touch with local volunteer groups, just give them a call or visit their website.
- 4** Keep up all your usual safety measures, such as locking doors or wearing a pendant alarm in case you fall.
- 5** Don't give cash or your bank card to anyone you don't know, and never give out personal details over the phone.

On the online toolkit there are lots of resources about Staying safe and well.

Here are just a few of the topics you'll find:

- Discussions around **Rethinking risk** and how to keep on living a full life
- The importance of **Everyday independence** and tips on how to maintain your own independence
- Information on **Delirium, Technology worth knowing about** and much more!

Point your phone or tablet camera at the QR code on the right and it will open the **Stay safe and well** webpage.





Welcome to Stay connected. This theme is all about creating, maintaining and enjoying relationships with other people.



Keith, who lives with dementia, says

“It’s crucially important to stay connected to other people, because that’s how we learn from each other and we seek comradeship, friendship, love, understanding, and in turn how we can give those back to other people.”

Professor Alistair Burns, National Clinical Director for Dementia in England, says

“We know that dementia is a condition where connection is key: connecting people to their families, and their carers, connecting people to their communities, and connecting people to themselves.”





New friends from singing for health group have been great – they have been really helpful. We have continued to meet up on the village green with a flask of tea every few weeks.

A person with dementia speaking to our researchers about connections made during the COVID-19 pandemic



5

Top Tips for Staying connected



- 1** Make a list of people to phone and plan when to call each one.
- 2** Lots of phones have speed-dial options for numbers you call regularly, so see if someone can help you set this up.
- 3** Try different methods of staying connected: phone, letters or cards, email, Zoom – there's something for everyone.
- 4** Be prepared to reach out and keep up your side of the two-way communication process.
- 5** Be open to trying new groups. If the first one is not for you, another one may well be.

On the online toolkit there are lots of resources about Staying connected.

Here are just a few of the topics you'll find:

- **Strategies for having conversations** both for people with dementia and for family and friends
- Tips about **Virtual connections** and debating whether you want or need **virtual** or **face to face?** contact
- Information on **Connecting with your culture, Involving family and friends** and much more!

Point your phone or tablet camera at the QR code on the right and it will open the **Stay connected** webpage.





Welcome to Keep a sense of purpose. This section is about staying motivated and finding the things which give you purpose so you can feel fulfilled.



Chris, a person living with dementia, says

“I always say, dementia comes in ‘cans’. You just can do things. And the more you do, the more you realise you can do and the more it lifts you back up.”

Dr Rachel Collins, a researcher at the University of Exeter, says

“One of the main benefits is that planning things you enjoy gives you some sort of meaning and it also establishes a routine which is very important.”





I got a camera before lockdown, so now I take it everywhere with me and it gives me a new purpose every day to go out. I started discovering bits of the village that I didn't know existed, such as paths and country fields.

A person with dementia talking to our researchers about remaining purposeful during the COVID-19 pandemic



5

Top Tips for Keeping a sense of purpose



- 1** Work out what matters to you, not to other people.
- 2** Make a plan for the next day every evening, so it's ready for when you wake up.
- 3** Make a list of things to do and tick each one off when you finish it. Include activities to look forward to as well as tasks you need to get done.
- 4** Think about what you enjoyed doing which you no longer do – can you take that activity back up?
- 5** Remember that nothing is too small to have a purpose behind it.

On the online toolkit there are lots of resources about Keeping a sense of purpose. Here are just a few of the topics you'll find:

- **The importance of having things to look forward to** so that you engage with the future as well as the past
- **What if I live alone?** A resource dedicated to the experiences of the many people who live alone with dementia
- Information on **Hobbies and Dementia Craftivism, u3a, The power of music** and much more!

Point your phone or tablet camera at the QR code on the right and it will open the **Keep a sense of purpose** webpage.





Welcome to Stay active. This section is about keeping active in both body and mind, not just for your health but to feel good overall.



Jane, a former family carer, says

“It’s not about just the exercise on its own. I think it’s about the other things you often get with exercise. Even my walks every day that I do now, invariably I’ll meet people. I’ve got to know people in the village I’d never met before.”

Dr Claire Pentecost, a researcher at the University of Exeter, says

“Whatever people want to do, whatever makes people feel better is the key thing. It’s not something that should be considered a chore. It’s just part of normal life and how we interact with the world and how we need to stay well to be able to do the things we enjoy.”



“

I think we have coped fairly well by continuing to exercise daily.

A carer talking to our researchers

”

5

Top Tips for Staying active

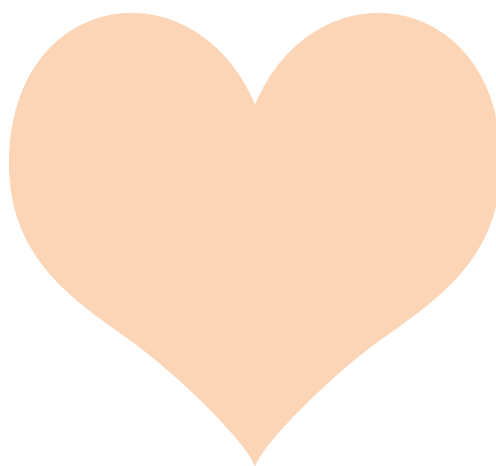


- 1** Try to have a balance of stimulating and relaxing activities.
- 2** Make sure you get plenty of daylight and fresh air – just a short walk can boost your wellbeing.
- 3** Staying active is more than just formal exercise: dancing to a favourite song counts, too.
- 4** Don't overdo it – warm up and warm down before each session and gradually build up what you can do.
- 5** Be creative with how you are active in the home: putting away the washing increases your step count and gardening is full of activity.

On the online toolkit there are lots of resources about Staying active.
Here are just a few of the topics you'll find:

- Information on **How to find dementia-accessible exercise options** and ways of doing **Exercise at home**
- Wendy Mitchell sharing her passion for walking
- **Get gardening!, Dance with Playlist for Life** and much more!

Point your phone or tablet camera at the QR code on the right and it will open the **Stay active** webpage.





Welcome to Stay positive. This section is about how you can remain positive and maintain a sense of hope amid a sometimes challenging situation.



Julia, an experienced family carer, says

“It’s also, I think, a positive attitude to admit that it’s difficult to yourself, and so when people offer to help you, take them up on it.”

Professor Linda Clare, a researcher at the University of Exeter, says

“From the IDEAL programme research we know that if people feel they can manage the challenges they’re facing, feel good about themselves, and expect more good things than bad, this is linked with better well-being, more satisfaction with life, and higher quality of life. So having hope and staying positive are an important part of living well.”





A sense of humour helps me cope. Doing what we do are the positive aspects, having a routine stops us from being negative about it. You make your own positives.

A person with dementia talking to our researchers



5

Top Tips for Staying positive



- 1** Keep doing the things you enjoy, as much as possible.
- 2** If you feel anxious or agitated, try some breathing or relaxation exercises, or listen to some soothing music.
- 3** Focus on what you can do and use the skills you have.
- 4** If you're finding things hard, talk to someone about it. Talking through how you're feeling will also help you understand what's happening.
- 5** Keep track of the good days – a simple chart of things which have gone well can remind you of the good times when you're finding it hard.

On the online toolkit there are lots of resources about Staying positive.

Here are just a few of the topics you'll find:

- Directions for **Where to read good news** and a selection of **Real-life positive stories**
- An exploration of **The role of the carer** and a resource encouraging carers to reach out called **Sharing is caring**
- **Good days and bad days, Feeling positive about ageing** and much more!

Point your phone or tablet camera at the QR code on the right and it will open the **Stay positive** webpage.



Funding acknowledgement

The Living with Dementia Toolkit was created during 2021-2022 as part of the INCLUDE project.

‘Identifying and mitigating the individual and dyadic impact of COVID19 and life under physical distancing on people with dementia and carers (INCLUDE)’

Investigators: Clare, L., Victor, C., Matthews F., Quinn, C., Hillman, A., Burns, A., Allan, L., Litherland, R., Martyr, A., Collins, R., & Pentecost, C. (2020-2021).
Funded by the Economic and Social Research Council ES/V004964/1.

INCLUDE is part of the larger IDEAL Programme of research comprising

‘Improving the experience of Dementia and Enhancing Active Life: living well with dementia: the IDEAL study’. Investigators: L. Clare, I.R. Jones, C. Victor, J.V. Hindle, R.W. Jones, M. Knapp, M. Kopelman, R. Litherland, A. Martyr, F.E. Matthews, R.G. Morris, S.M. Nelis, J. Pickett, C. Quinn, J. Rusted, J. Thom (2014-2018). Funded jointly by the Economic and Social Research Council (ESRC) and the National Institute for Health Research (NIHR).
Grant number: ES/L0011853/2.

‘Improving the experience of Dementia and Enhancing Active Life: A longitudinal perspective on living well with dementia: the IDEAL-2 study’. Investigators: L. Clare, I.R. Jones, R.G. Morris, F.E. Matthews, J. Rusted, J. Hughes, C. Victor, M. Knapp, R.W. Jones, R. Litherland, J.V. Hindle, C. Quinn, A. Martyr, S.M. Nelis, C. Ballard, A. Hillman (2018-2022). Funded as an Alzheimer’s Society Centre of Excellence, Grant number: 348 (ASPR2-16-001).

Copyright statement

Guide to the Living with Dementia Toolkit. Copyright 2022, The University of Exeter. All rights reserved: the copyright and intellectual property rights in this guide and the material contained herein are owned by the University of Exeter.



Dementia Toolkit

Living your life with hope

Contact us

We would love to know what you think of the toolkit. We want to improve it based on your feedback.

Please get in touch with us by emailing IDEAL@exeter.ac.uk

If you prefer to write to us, then please address your letter to:

Living with Dementia Toolkit

PO Box 616

Exeter

EX1 9JB

We are also on Twitter [@IDEALStudyTweet](https://twitter.com/IDEALStudyTweet)

Many thanks!



FUNDED BY

NIHR | National Institute
for Health Research



Economic
and Social
Research Council

NIHR | Applied Research Collaboration
South West Peninsula

www.livingwithdementiatoolkit.org.uk