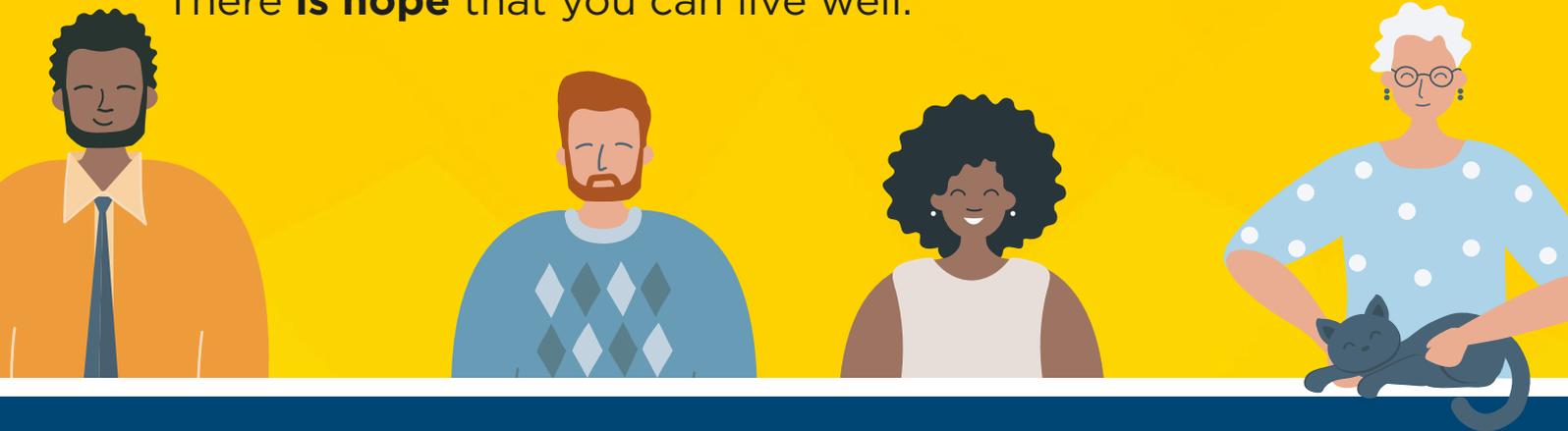


Living with Dementia

My Life, My Goals

A practical guide full of hope to help you **set and reach** your goals

This guide has been created with people living with dementia. There **is hope** that you can live well.



Cognitive rehabilitation = ways to help with some of the changes that dementia can bring. For example, it can help people find ways around memory issues, word finding problems and keeping focused. Its aim is to make everyday life easier for people with dementia.



Sunflower: a message of **hope** by Jacqui

You can read more about cognitive rehabilitation research by visiting <https://bit.ly/3d9zv8a>

About this guide

My Life, My Goals has been created by people with dementia, with input from researchers.

We want this guide to give you hope:

- **Hope** that there are ways of managing any difficulties
- **Hope** that there are solutions to problems
- **Hope** that you can live a good life with dementia

This guide has been created as part of a research project about 'cognitive rehabilitation' carried out at the University of Exeter.

This guide is full of our ideas to help you think about your goals. A goal reflects your desires and wishes. What makes your heart sing or brings joy to your life? What simple changes could make your life easier? This guide will help you, step-by-step, try to achieve your goals and create **YOUR own plan**.

Best wishes

Allison, Chris, Dave, Emily, Jacqui, Keith, Ken, Roy and Sue

Published September 2021

Meet the team...



Allison



Chris



Dave



Emily



Jacqui



Keith



Ken



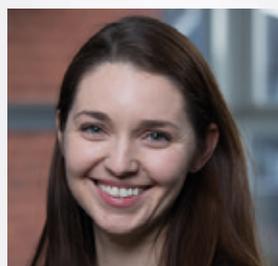
Roy



Sue



Linda



Ola



Rachael

How to use this guide

We hope this guide is easy to use and inspires you to work on your own goals.

You do not have to read this guide from beginning to end. Some of the sections may be more relevant. Each section is colour coded. We hope this helps you to return to the information you find most helpful.

There are also short films that accompany this written guide - you will see this symbol  and an internet link to the films.

This is the symbol where there is an internet link 

Some sections have task boxes like this.

A task for you:

This is an example of what a 'task for you' box will look like.



You will need to do some work to get the most from **My Life, My Goals. Take your time - there is no rush.**



Why these resources are important



To view the film go to: <https://bit.ly/2XiQjEN>

How dementia affects everyday life

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My Life, My Goals

How dementia affects
everyday life

How dementia affects everyday life

Dementia has probably brought a lot of changes to your life.

Some might be related to dementia itself. For example, changes in your cognitive abilities can make it harder to do some of the things you **need** to do or **enjoy** doing. (Cognitive abilities includes thinking, knowing, remembering, making judgements and solving problems).

Or it might be harder to do things because you are feeling stressed or worried.

Perhaps you have even lost your confidence or had a bad experience with someone.

These changes can make your day-to-day life feel more difficult.

“ I’ve got spatial awareness problems. I find it hard to judge distances. It’s difficult at times. I can knock my head on things. I think they are further away, and they are actually really close. It’s a funny one that. **Dave** ”

“ If we say the wrong thing - sometimes people you don’t know so well look at you a bit funny. I talk too much. The trouble is, once I start talking I carry on. Then I say silly things. Sometimes people look at me, and I think “I must have offended them in some way”. It’s most embarrassing. **Roy** ”

Story:

I've been doing my art classes - watercolours - which I really love doing. We were supposed to be painting a little French Bulldog... but I didn't see a little French Bulldog in my head. My Bulldog had big whiskers on. Although the art therapist said, "This is wonderful and impressionist of a French Bulldog"...it wasn't what I could see. I have a problem with what I see and getting it out of my head". **Jacqui**



A task for you:

How do you feel about your dementia? How does it affect you day-to-day?



The impact of a dementia diagnosis



To view the film go to: <https://bit.ly/3CfhoHs>

Message of hope

Keep coming back to this booklet - every time you will see something different.

My Life, My Goals

What are goals?

What are goals?

A goal is your **wish for the future** – something that you would like to do. Working on a goal can have a real impact on your life. It gives you a focus. It can improve how you feel about yourself and make you feel more confident and in control.

You may have worked on goals before in your life. For example, a goal to:



- **Save** money for a special purchase



- **Drink** five glasses of water a day

The best way to achieve your goal is to **make a plan** and then a **commitment** to carry out your plan.



Imagine you are saving money for a family trip.

The money doesn't magically arrive in your wallet or bank account – you need a plan. A good plan is **SMART**:



Specific

You know exactly what you intend to do.

e.g. save £50 a month by walking instead of catching the bus

Measurable

You'll be able to track your progress.

e.g. you can calculate how many months it will take you to pay for your trip

Achievable

Your goal should be realistic and possible.

e.g. my plan is to have a weeked together – rather than a two week holiday

Relevant

The goal should matter to you.

e.g. I would really like to spend quality time with my family

Timely

A deadline can help you to plan and gives you something to work towards.

e.g. I want us to have a weekend away in September

This is known as a **SMART** plan. A SMART plan is great for keeping you motivated.

Setting simple goals can help with the impact of dementia. It can become a helpful habit – to think about some solutions and make plans.

Your goals don't have to be huge. Small victories can add up to a lot of good things.



I just take one day at a time. I try to break things down into baby-steps. It stops me getting stressed and I feel more in control of my life.

Sue

You won't always need a big plan to change something. Sometimes you have to work around a problem e.g. finding the right word when you want it. Other times you might want to address the problem directly e.g. learning how to use the TV remote. There are lots of tips and strategies from other people with dementia that might help you to work around a problem in section 5.



Getting started



To view the film go to: <https://bit.ly/3tFnHRy>

My Life, My Goals

Your goal – what
would you like to
work on?

Your goal – what would you like to work on?

Keep your goals simple and specific. Choose something that can be changed. Avoid things that can't be changed.

There may be a lot of things that have changed in your life since dementia. Here are some of things that we have found difficult:

- remembering names
- finding the right word
- cooking a meal
- using the TV remote control
- speaking on the telephone
- playing golf



Story:

Music is my first love. But I'm having more challenges with my music making. What you don't want is for someone to straight away say, "Well don't do it then." It feels like it is being snatched away from you – that you had no choice. Sometimes life just hits you over the head and you can end up feeling there's no point trying. You want somebody to be thinking along the road with you – coaxing you, helping you. **Chris**





A task for you:

Think about the things that have become more difficult for you. What would 'fill your heart with joy' to work on? What would make a difference in your life?

It is helpful, at this point, to think about why you have chosen this goal.

Perhaps it is about:

- Needing to be able to do something
- Being independent
- Wanting to do the things that you enjoy
- Being part of family life

Also think about what might have been causing your difficulties with this goal so far.

It could be:

- Something that has changed because of your dementia e.g. not remembering how to do part of the task
- Not having enough information
- Feeling anxious
- It went wrong last time - so you have lost your confidence
- Feeling generally un-motivated

Story:

When I burned my food and couldn't remember how to plan a meal, I came face-to-face with my limitations. I went backwards in how I was feeling. But it's very normal that we will have obstacles. Instead I will write down all my successes! Even a little success - I jot it down. When I'm feeling down, I go back and say, "Yes, I did that." It can be your lighthouse. **Emily**



Are you struggling to think of a goal? These prompts may help:

- What would you like to start doing in your life? Are there things you would like to learn?
- Are there hobbies and interests you would like to start again? Maybe things that you have stopped doing due to your diagnosis, or loss of confidence?
- What do you find difficult to do around your home because of memory or thinking? Would you like to manage these things better?
- Are there things you would like to do with your family or friends?



Deciding on a goal



To view the film go to: <https://bit.ly/3ny6qc4>

My Life, My Goals

Getting ready to work
on your goal – leave
stress behind

Getting ready to work on your goal – leave stress behind

Before you can begin making changes to your life, you need to be in a positive frame of mind. Ken says the first challenge is to leave stress behind!

● Here are some of the ways that we do this:

- **Nature** – I go for a walk, being near the sea.



“

I find it grounds me; it removes me from my stress

”

- **Music** – playing and listening to music. Listening through headphones can be good.



“

Music takes me away; it relaxes me and gives me a sense of achievement

”

- **Meditation and yoga**
- **Walking**
- **Art**

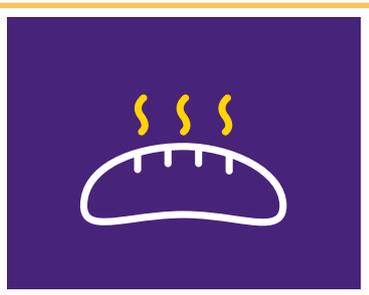


“

Art brings me into the moment
- it allows me to be me

”

- **Watching travel videos** - go on a journey with someone else
- **Gardening** - make it a daily routine
- **Jigsaws** - concentrating on the pieces is very mindful
- **Cooking and baking** - find the ways to carry this on



“

When I'm baking bread, my
whole body is engaged. It
is creative

”



You can read more stress reducing tips here
<https://dementiatip-share.org.uk/our-tips/>

A task for you:

What helps you to relax and feel more positive?



Story:

For me it would really be trying to get out into nature if at all possible. You know - going for a walk through a nice park. Just sort of walking out and looking into the fields. It grounds me and removes some of the stress I have if I stay in the house - a feeling like it just gets worse. So for me, whatever the weather is, I put on a heavy coat, put my hood up and go. **Allison**



Story:

I like to go out and I have a bench at the front of the house. Lorries go past and honk and wave at me. I like that. That takes the stress away. It's about people. **Roy**



Story:

I've got my new greenhouse up. I plant my seeds, and I check in the greenhouse every day. I ask everybody if they are OK in the greenhouse!

Jacqui



Story:

I take my dog out and we go for a walk in the woods. Even in the winter you can hear the bird song. Even when it's covered in snow. You're the first people in – beautiful colours, its sensational. And it can't not de-stress you.

Ken



Leaving stress behind



To view the film go to: <https://bit.ly/3k9J2iT>

My Life, My Goals

Getting ready to work
on your goal – making
some simple changes

Getting ready to work on your goal – making some simple changes

We have found it helpful to make some adjustments to how we go about our lives. But be warned – what works for one of us can make it harder for someone else! It is often trial and error to find the right solutions and everyone is different.

- **Simplify things**

Adjust chores or tasks to make them simpler.

Example

Instead of cooking an elaborate meal that consists of three or four dishes, cook one or two dishes



- **Slow things down**

Take more time.

Example

Speak more slowly so that you have some thinking space



- **Adapt**

If you can't do things the way you used to, try a different way.

Example

Instead of relying on memory to bake delicious cakes, go back to following a recipe – the cake will still be delicious



- **Stay focused**

Don't let yourself go into 'automatic' mode but try to keep your mind on what you are doing.

Example

When doing something routine like cleaning your teeth, stop and check you are doing it right - that way you will notice if you have put soap on the brush rather than toothpaste



- **Make things more difficult**

This may sound strange, but sometimes making things harder causes you to think about what you are doing - rather than doing it automatically.

Example

Difficulties with visuospatial awareness can make it hard to use a knife safely while cooking. Placing the knife on the side of your non-dominant hand means you have to reach across your body to pick it up and put it down again. If you are right-handed try putting the knife down on your left side. This is safer and allows you to judge distances better



- **Prepare**

Plan ahead to avoid making mistakes or getting in a muddle.

Example

When cooking, start by putting all the ingredients out on the counter-top in the order in which you will need them



- **Build in enough ‘buffer time’**
Give yourself enough time for things to go wrong.
- **Make use of aids**
These could be anything that helps: a clock that tells you the day and date as well as the time, a set of written instructions by a household appliance telling you how to operate it, or a virtual assistant like Alexa.
- **Use humour**
Humour can help defuse difficult situations and manage stress.
- **Connect with others**
Share ideas with other people who experience similar challenges and understand what it’s like.
- **Make a safety net for your problem areas**
Get some solutions ready, even if you don’t need to use them yet. These can become a habit.



**Message
of hope**

Try to stay hopeful and positive – otherwise you’ll be dragged right down and be in a place you don’t want to be.

My Life, My Goals

Choosing a method
that works for you

Choosing a method that works for you

To achieve your goal, you may need to learn some new techniques. Everyone learns in different ways. Have a think about the best ways for you to learn something new. By choosing the method that suits you best you'll have more chance of success.

“

It's not an all or nothing, it's finding that resource and that little bit of help when you need it. Not being afraid to ask for that help as well. Sometimes we are bit like, "Well I've been doing this all my life, why can't I do it anymore?" Because there is a challenge that has come along with dementia and that is why you can't. It's that acceptance.

Sue

You could:

- 1 Divide your goal into different steps. Start with the easy ones and work up to the more difficult ones**

Example

Write down all the instructions for making a Spaghetti Bolognese. Start by doing the one or two steps you feel comfortable with – e.g. peeling the carrots or browning the mince – before handing over to your co-chef. In time, see if you can take over some of the other steps.

- 2 Watch someone else complete the task and then copy what they did**

Example

Re-programming the heating for winter-time. Watch someone else do it and then immediately try it for yourself. You may want to copy this task a step at a time, rather than all at once.

- 3 Do it as you learn. Have a go**

Example

Learn how to use a TV remote control by using it regularly. It can help if you break the actions down into easy steps. For example, start just by turning on/off. Work up to finding the TV guide. Keep practising. Offer to be the person who is in charge of the remote control!

- 4 Use prompts at the right time to help you learn gradually. In time it could become a habit**

Example

Learning to use a calendar to remember the date. Family members might initially remind you to check the calendar. After a while they may just point at the calendar as a reminder. In time you will develop your own habit to check the calendar. You may need to ask your family members to stop reminding you as you develop the habit.

- 5 Keep repeating the different steps before you forget. Then leave more time between each step. Think of it like 'rehearsing' a script**

Example

Your friend has a new grandchild. You want to remember her name, which is Megan. Write down the name in case you need to check. Repeat the name after a short time (15 seconds). If you were correct, give yourself 30 seconds before you test your memory again. Every time you remember, double the amount of time before you test yourself again. If you don't remember, go back to a shorter time interval and build up from there.

- 6 Build up a story and use your different senses to help you remember. You could sing, use a rhyme, write the story down**

Example

Try and create a story about a fact. If you are trying to remember someone's name, the story could be "She has the same name as my Aunt." You could then imagine the sounds and scents that make you think of your Aunt. Or maybe visualise the colours in her clothes or her rooms.

My Life, My Goals

Working on your
goal – “My Plan”

Working on your goal – “My Plan”

It's time to make your plan!

Choose a goal that is important and meaningful to you. You should **want** to work on this goal.

Writing your plan can help you think about the steps needed to achieve your goal. It can be overwhelming to aim for your end goal without thinking about the many steps needed to get there. This isn't like making a New Year's resolution – you want your goal to be **SMART**. Section 2 tells you about **SMART** goals.

Before you start, look at your goal again. Ask yourself:

- Is this the goal I want to work on?
- Is this goal important to me? Have you chosen this goal to please someone else? It doesn't mean this shouldn't be your goal. But it might affect your motivation
- Do I feel motivated to do some work on this goal? If you're not feeling particularly motivated choose another goal – one that perhaps makes your heart sing!
- Will I need any help? Who could I ask to support me?
- Is my goal **SMART**?

Words of encouragement

“

One of the hardest things is knowing how to start. I guess it's a bit like an author sitting in front of a blank page. That's the hardest bit - breaking that inertia. Once you get on a roll and start to be able to think around the problem - then off you go. **Chris**

“

You have to set a goal that is easy for you to achieve in a very short time. That is the kickstart. Once you have experienced that small success, the motivation will come back. **Ken**

“

If I do it myself it's my independence. I'm doing it, nobody else. I can look at something and try to plan it. If I get stuck, I can ask people. But at the end of the day I can say I've done this and I've done it myself. It's great. I'm in control of it. **Keith**

“

It's not a race.
It's a journey -
not a destination.
Sue

“

If I've done something
it's got two choices
- it either works or it
doesn't work! **Dave**

My Life, My Plan

See examples of other people's plans on

Page 34

Date:

My Goal:

This goal is important to me:

Yes

No

I feel motivated to work on this goal:

Yes

No

Who will support me to work on this goal?

What do I need to do before I start working on my goal?
What will help?

1

2

3

What could make it hard for me?

1

2

3

What can I do to get around any difficulties?

1

2

3

4

My commitment - this is what I will do

It is helpful to work through your task step-by-step. It might not take many steps, or it might take lots.

Step 1

Step 2

Step 3

Step 4

Step 5

My commitment - this is what I will do....continued

It is helpful to work through your task step-by-step. It might not take many steps, or it might take lots.

Step 6

Step 7

Step 8

Step 9

Step 10

What if My Plan doesn't go according to plan?

Often things don't turn out how we hope. The best approach is to make some tweaks and try again.

Do you need to change some of your planned steps? Did some steps work better than others?

Maybe the method you chose doesn't work for you. For example, perhaps you learn better 'by doing' rather than trying to remember?

Do you need someone (or someone else) to support you? This might just be someone who gives you motivating feedback.

Here are some of our tips for '**dusting yourself off**' and trying again.

“

Don't beat yourself up about it. It's something that happened, you tried it, it didn't work. Let's go back to the drawing board, let's start it again. Let's find something different this time that will actually work. Don't give up. **Sue**

“

Sometimes you can get really frustrated with something and you'll have to walk away for a while. It's always worth coming back and having another go, look at it from a different angle. **Chris**

“

It's not an all or nothing, it's finding that resource and that little bit of help when you need it. And not being afraid to ask for that help as well. **Ken**



Learn to laugh at yourself. Putting the kettle in the fridge and the milk on the kettle stand. At one time I'd cry because I thought I'm getting worse and worse. But if I did it now, I'd laugh.

Sue



Be kind to yourself. Just because one mishap happens it doesn't mean that's the end of the world. You need to keep it in perspective - it is simply one mishap. **Allison**



If you can't - move on, and say "OK, I've given it a go but I wasn't successful there. There's a hundred other things I can be really successful in changing and achieving." And that's what you have to do - you have to move on, to be prepared to move on and not get stuck in the mud with it. **Chris**



When things don't go to plan



To view the film go to: <https://bit.ly/3hu2c1p>

My Life, My Goals

Example plans

Example plan: One

Background: I used to bake my own scones but find this too challenging now. I would like to serve something I've baked myself when my family come to visit.

Date: 28 June 2021

My Goal: I will bake a cake, biscuits or scones once a week, using a recipe from my cookery book

This goal is important to me:

Yes



No

I feel motivated to work on this goal:

Yes



No

Who will support me to work on this goal?

I might ask my husband John to help

What do I need to do before I start working on my goal?
What will help?

1 Deciding what to bake

2 Having all the ingredients

3 Deciding when to bake

What could make it hard for me?

- 1 I don't remember all the steps and ingredients anymore**
- 2 Getting all the ingredients out and measuring the right quantities is difficult**
- 3 I get frustrated quickly and give up when something goes wrong**

What could I do to get around any difficulties?

- 1 Having a simple written recipe to hand, perhaps re-writing into short bullet points?**
- 2 Getting all the ingredients out before I start mixing**
- 3 Starting in the morning when I feel best and allowing plenty of time**

My commitment - this is what I will do

It is helpful to work through your task step-by-step. It might not take many steps, or it might take lots.

Step 1 Get the recipe ready. Note each step on the white board

Step 2 Get all the baking items ready (scales, bowl, spoons, dishes)

Step 3 Get out all the ingredients

Step 4 Measure out the quantities (perhaps John would do that with me?)

Step 5 Follow the recipe and cross out each step when done

Step 6 Set the audible timer to alert me when the cake is ready

Example plan: Two

Background: I would like to go out more and meet other people who live with dementia. I would like to learn how others cope with poor memory and hopefully have a good time chatting and laughing at our forgetfulness.

Date: 28 June 2021

My Goal: Attending my local dementia support group meetings

This goal is important to me:

Yes



No

I feel motivated to work on this goal:

Yes



No

Who will support me to work on this goal?

My neighbour could help sometimes

What do I need to do before I start working on my goal?
What will help?

1 I need to know the venue and date

2 I need to check how to get there

3 I need to remember about the meeting on the day

What could make it hard for me?

1 I might feel too anxious or sad to leave the house

2 I might forget about the meeting or mix up the date

3 I might get lost on the way there or back

What could I do to get around any difficulties?

1 Make sure in advance that I know my way to the venue meeting. Perhaps my neighbour wouldn't mind walking with me once or twice until I feel more confident

2 Have a back-up plan to make sure I know the way - I do my shopping myself in a local shop, so I know the area and can find my way around, but need something just in case. Ideas: drawing a map, writing down the landmarks for the way there and back, practising the route a few times with my neighbour

3 Make sure the meeting is my calendar so that I know when to go

My commitment - this is what I will do

It is helpful to work through your task step-by-step. It might not take many steps, or it might take lots.

Step 1 Find out the date and venue details (ring the phone number given by GP)

Step 2 Write down the meeting in the calendar - I commit to go at least four times to give myself a chance to learn the route and see if I actually like the meetings

Step 3 Plan the route using a map

Step 4 Have a practice walk with my neighbour to check the route is correct and note the landmarks

Step 5 Write a step-by-step instruction how to get there and back using the landmarks noted

Step 6 Leave early to avoid feeling rushed and anxious

Step 7 Take a few deep breaths and count to 10 if feeling anxious

My Life, My Goals

Strategies and
solutions from people
with dementia

Strategies and solutions from people with dementia

● Slow down and avoid unnecessary stress

At times I can hear the words quite clearly in my head. But trying to get them out can be a bit of a problem. My coping strategy for that would be to try and slow myself down. Because of this problem I don't use the telephone unless it is with family or very good friends. I find it hard to keep a train of thought on the phone.



● Use trial and error to find the best solution



The word just disappears – obliterated. I did try a word association technique to help me get back to the word. I was taught a technique where you have a series of letters to help bring you back. Like when you were back at school – to help you remember Henry VIII's wives. But then I spent all my time trying to remember what the link was to help me try and remember the word! So the gap got even longer. Now I just say whatever word that comes out.

● Get expert help

I was having trouble with the telephone. I couldn't get the words out. People on the phone found I was talking too fast. I began to talk rubbish. I then wouldn't answer the phone anymore. I had four sessions with a speech and language therapist. She helped me to explain to other people how they could help me. Strategies include: reducing background noise, speaking at a steady pace, discussing one idea at a time and giving time for pauses.



Jacqui

● Technology can help (if you make it work for you)



Dave

I find it hard judging distances. I have a problem with my spatial awareness. I used to play a lot of golf. There was a problem - I didn't know how far I was from the green. You drive off - and I didn't know where I was. I was lucky enough to be able to buy a watch that tells me how far away I am from the green. You drive, you go to your ball, you look at your watch...and it'll say "100 yards". Then I've got a book with all the clubs in...so I've got over that problem.

● Learning by doing

When my friend goes away, I need to be able to put the heating on. We have a little piece of cardboard by the boiler. We've written what buttons I press and everything. But when she is at home she still gets me to do it, so that when she is away it doesn't become a panic. It means I always do it. It's a routine thing.



Jacqui

● Avoid 'all or nothing' thinking – simplify tasks



I used to do a lot of cooking. I started making that many mistakes. I thought, "Right I can't cook any more." But I realised I was doing more than one thing at a time. I started breaking it down to doing just one thing at a time – not just in the kitchen, but in life in general. When I feel like things are getting a bit hectic, I realised it's when I'm multi-tasking. It's being aware of things like that and calming yourself down.

● Divide tasks into smaller steps

Up to now I still cook. It's just that the number of dishes has reduced. I used to cook three dishes plus one soup, but I found this is too overwhelming for me. Now I cook two dishes only. I put a lot of time into the preparation. I cannot remember the sequence of things to put in. So I have to put the things on the worktop in the order that I will use them. In this way, I can still enjoy cooking. I still make mistakes – but it minimises the mistakes, so I don't feel put down.



● Practice helps



At first I used to want to throw the remote controls across the room and say, "I can't use these, I can't do it, I can't do it, you do it." Now I noticed that very gently both the TV remotes are put on the arm of my chair. So that has become a thing that I do. The more that I do it the better I become. Sometimes when I'm tired I throw them back at her!

● Get yourself out of auto-pilot

I cut my hand a few times when I was preparing food. So I came up with a strategy. Because I'm right handed I put a basket on my left side. So, whenever I use the knife, which is on my right side I will cross over my mid-line body to tell myself, consciously, that I'm handling a knife. That knife goes into the left side where the basket is. I find if I put the basket on my right side (which is my dominant hand), I will not remember to put the knife in the basket. It will be left on the chopping board. I will pick up the chopping board, not knowing the knife is still there. That's how I hurt myself, or drop the knife onto the floor.



Emily

● Follow written instructions



Allison

I love cooking and I love baking. But I was getting really muddled and confused. If I get myself to focus on one task, I can usually manage it. Things I would have been making for years and years, I'm now back to needing the instructions beside me. But that's fine - it means that I can still do them. I use Alexa a lot as a timer. I'll be specific. I'll say oven timer, and washing machine timer. So when the timer goes off it tells me what I have to do.

● Do one thing at a time

I must only focus on one particular thing at a time. If my mind starts thinking about anything else, then things go wrong. For example, I meant to put the toothpaste on my toothbrush. I have one of those squirty soap things. I was in auto-mode, and instead of putting the toothpaste on there, I put a squirt of this soap on there. I wasn't just thinking toothbrush, toothpaste, clean your teeth. I was thinking a bit about a conversation I'd had earlier. I find, as long as I don't allow myself to go into auto-mode then that's alright. But I do go into auto-mode, then all manner of things start happening.



Chris

My Life, My Goals

Our message
for people who
support us

Our message for people who support us

Other people can lift you up, they can also bring you down – usually without meaning to. We have some words of advice for those people who support us:



My family are brilliant, really supportive and whatever – but if I let them they'll just take over because it's easier for them to do it than to watch me struggle with it. **Keith**



Sometimes people expect you to not be able to achieve things. I have found that being positive and upbeat around the subject of dementia all the time sometimes makes other people cross. They say that I don't fully understand what it is about. I do understand because I am living with it all the time. **Chris**



It's important that people can support you in an upward way. Dementia can feel like a downwards spiral. Help us to keep striving. **Dave**

“

We want to try to stay in control. We need to be able to say, “I really want to still be able to try this – how can you support me to do it?”

Emily

“

The best support is gentle - it's done in a gentle supportive way that you can accept easily. It's not overpowering. It doesn't make you feel small. That is a skill that the other person has to learn as well. **Allison**

“

I was in really dark place. I couldn't see a way out. They gave me permission to hope and to think I could. I would never ever have become who I am without the words they said to me.

Ken

Being with other people who have dementia

Other people with dementia can be very supportive. They understand your situation. It can take the pressure off. That's the value of peer-to-peer support and this resource.

**Message
of hope**

Give things a try. You might have some doubts, but once you start, it gains momentum.

Key Messages:

- Understand that we can achieve things – don't set your expectations too low
- Let us do things for ourselves and give us time – don't rush to take over
- Support us to try things, and see how you can help
- Learn how to support us gently and unobtrusively – don't make us feel small
- Give us permission to hope – lift us up, don't pull us down



The right kind of support



To view the film go to: <https://bit.ly/3tF8ikq>



The importance of knowing other people with dementia



To view the film go to: <https://bit.ly/3zgxVZU>

My Life, My Goals

A final message
of hope

A final message of hope

We wrote this booklet because we wanted you to have hope. This is your life. These are your goals. We hope this booklet gives you some ideas and helps you to make a plan. We wish there had been something like this when we were diagnosed.

Goals are important for everyone. We are designed to strive and overcome challenges. That is why we have been successful as a species. If you have that taken away you can think “what’s the point?” Setting goals is how we can stay on top of some of the challenges that dementia brings.

Knowing that other people with dementia are finding solutions has been really helpful for us. For many of us, it tempted us back into life.

“

You put your little toe in the water and before you know it you’re back in - swimming with the best of them in this dementia shoal of fish.

Chris

Message
of hope

Look at the good things in life. I can’t do much about dementia. All I can do is to make it so my life is worth living.

Funding Acknowledgement

This resource was created during 2021 as part of the GREAT into Practice (GREAT-iP) project. GREAT-iP was funded by Alzheimer's Society through grant AS-IGF-16-002. to Clare, L., Kudlicka, A., Woods, B., Oyeboode, J., McCormack, B., Knapp, M., Pool, J., Evans, S., Litherland, R., Bryant, J., Townson, J., Owens, C., Henderson, C., Ukoumunne, O., Morgan, V., Lawrence S., & Norris, C. Maintaining independence through goal-oriented cognitive rehabilitation: **GREAT into Practice (GREAT-iP)**.

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