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Getting more out of every day with memory difficulties

A guide for people living with memory difficulties









All about me

People living with memory difficulties and their family members and friends have suggested to us it can be helpful to fill out the following information. This is so those supporting you know some things about you. If you would like to, please fill in the All about me section below.

A family member or friend can help if you need them to.

Also, if you want, why not stick a photo of yourself in the space below.

A photo of me

My name is	
My date of birth is	
My address is	
Who will support me use this booklet	

My importan	t phone numbers are
Things I like	doing (babbico/interseto/things with formily)
Things I like	doing (hobbies/interests/things with family)
Things I don'	t like doing

Well done for taking the first steps to improve your everyday life and learning to live well with memory difficulties.

Seeking help to live well with memory difficulties can often be a difficult step to make. However, having memory difficulties doesn't mean you can't aim to make more out of every day. There are lots of things you can do to help you live as well as possible.

This self-help booklet has been closely developed with people experiencing memory difficulties and their friends or family. It's based on an approach that has helped many people in a similar situation to you.

You, and a family member or friend, will also be supported by a Wellbeing Practitioner from BeMe. BeMe is an NHS service provided by Cornwall Partnership NHS Foundation Trust - they provide talking therapies to people across Cornwall who may be experiencing difficulties with how they are feeling to help them to make more out of every day.

Your Wellbeing Practitioner is called

is a health professional with specific training to help people experiencing memory difficulties enjoy everyday life.

You, a family member or friend, and will work through this self-help booklet together, as a team.

How does the booklet work?

This booklet will help you start to do more and feel better

– a little at a time.

There will be two face-to-face meetings with, and a family member or friend, to introduce this booklet.

During these sessions will help you make a start on the booklet.

Each week over the telephone will speak with whoever is supporting you to work through this booklet over the telephone, to see how things have gone.

When you have completed the booklet there will be a final face-to-face meeting with



This workbook also contains a Living with Memory Difficulties Story about Shirley.

Shirley is experiencing memory difficulties and finding it hard to live every day well. Her story describes the difficulties she was experiencing and how she worked through this booklet to help improve her wellbeing and make more out of every day.

You might find it useful to see what Shirley did when working through the different stages of this workbook.

Important

As we are all individuals with different situations, your life situation and difficulties may be different to those experienced by Shirley.

Shirley's story is designed as an example of how the booklet can be used and whilst there may be some similarities, we understand it cannot represent everyone's unique situation.

Shirley's Living with Memory Difficulties Story



Shirley is living with memory difficulties.

Shirley was also finding it hard to live well and found herself feeling quite flat and fed-up. She worked through this self-help booklet with help from her husband George.

Shirley is 73 years old and lives in Cornwall with her husband George.

They've been married for over 50 years and have two children, Samuel and Nicola, and three grandchildren. Before Shirley retired she was a florist and had always loved listening to music, seeing her grandchildren, knitting and walking her dogs in the countryside.

George started to notice that a few things seemed different in Shirley.

She began forgetting the names of their grandchildren, started to loose things all the time and made some mistakes around the house.



They went to see their GP who felt Shirley should go to see a local memory service.

Shirley felt very unsure but eventually agreed to go if George went with her. The memory service ran some tests and found that Shirley had indeed started to experience memory difficulties. They both felt shocked, scared and hopeless. They knew it was important to get help as soon as possible and not let things go on too long.

Over the next few months Shirley experienced some more changes.

She began struggling to find the right words when speaking with people at the local Woman's Institute and stopped going. She became less interested in seeing friends and no longer wanted to walk her dogs which she had always loved doing.

George began to get quite worried about Shirley.

She was doing less and less, seemed quite fed-up and was no longer 'living well' which she had always done before.

Both Shirley and George got some support.

They were visited by their Memory Nurse and George talked about how he was concerned about Shirley. The Memory Nurse recommended that they see a Wellbeing Practitioner called Gail, who they met a week later. She asked some questions to identify what the main problems were, and recognised that Shirley wasn't getting as much out of everyday life as she had done before. However Gail said that with Shirley's hard work and the help of George there was something that could be done.

Gail introduced them to a self-help booklet called

"Getting More Out of Every Day with Memory Difficulties."

Again, the couple felt uncertain at first. But they felt reassured when Gail said she had supported many people in a similar situation to theirs to use the self-help booklet, and that they were not alone in this.

Over the next few weeks with the support of Gail, Shirley and George started to work through the self-help booklet. Slowly, Shirley found herself doing a lot more activities and she began to find herself living well again, despite her memory difficulties.

There will be more about how Shirley got on at the end of this booklet.

When working through this booklet you will complete the following steps:

Step 1

Understanding more about how I fee

Step 2

Setting goals

Step 3

What activities are you currently doing?

Step 4

Identify activities

Step 5

Organise activities

Step 6

Plan activities

Step 7

How did it go?

Step 8

Staving wel

Step 1

Understanding more about how I feel

Experiencing memory difficulties is likely to be stressful and difficult at times – you might find yourself feeling frustrated, tired, flat and fed-up. However, you don't have to feel this way. There are ways of helping you live well with memory difficulties and get more out of every day.

There are lots of different theories about what may affect our wellbeing, such as:

- Difficult stressful life events such as having memory difficulties
- Giving up on activities we used to do
- Types of thoughts that go round and round in our heads

Whilst all of these things may have some role, it's likely the way we feel is influenced by a mixture of them all.

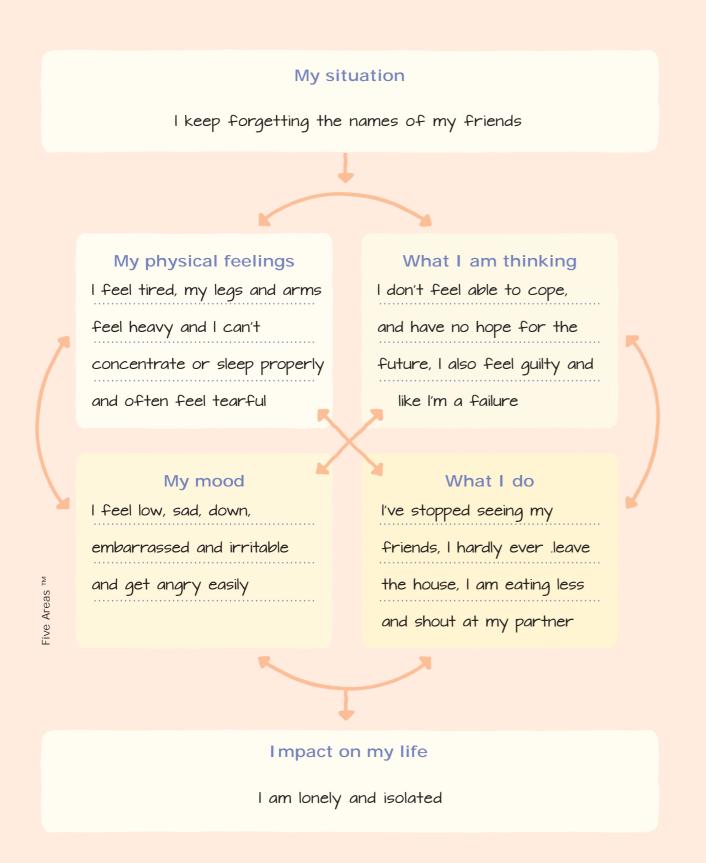
When we aren't living as well as we could, we experience changes in:

- The way our body feels physically
- How we think about things
- Things we do and don't do

We know that each of these areas impact on one another – like a cycle or a cog in a machine and can affect our wellbeing. Understanding this cycle of wellbeing will help you see that the way you feel can affect your memory difficulties and have a big impact on your life.

The Wellbeing Cycle

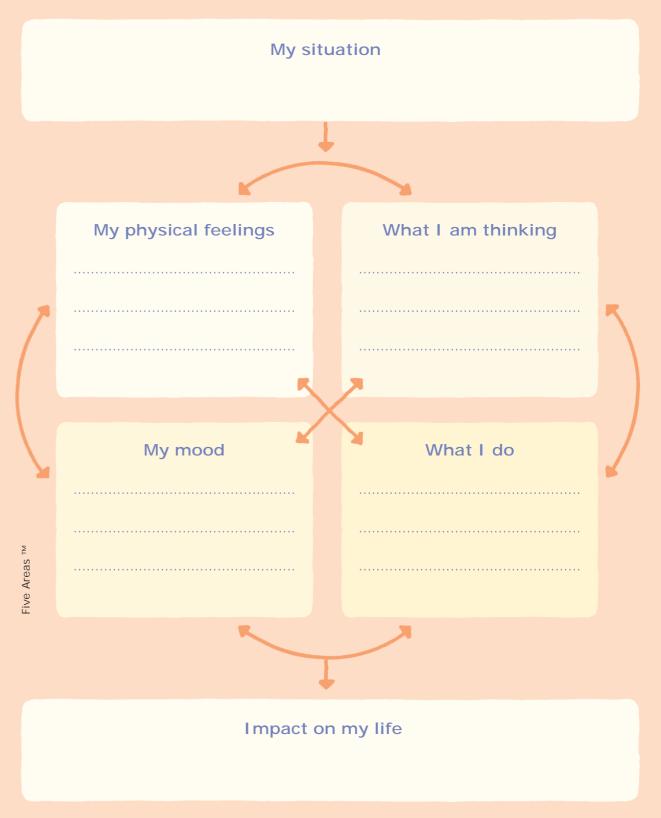
When we are not living as well as we could and no longer making the most out of every day, our wellbeing cycle can become negative. Here is an example:



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Your Wellbeing Practitioner will help you complete your My Wellbeing Cycle Worksheet during your first session.

My Wellbeing Cycle Worksheet



How to live well with memory difficulties

When people experience memory difficulties they may stop doing many of the things they used to. This might be because some activities become harder due to memory problems. Experiencing memory difficulties is scary to many people and it's understandable people may begin to stop doing their normal activities.

People also often stop doing activities when they are feeling low or fed-up as well. They may feel they are too tired. They may not feel bothered as no longer feel they will enjoy the activities like they used to. Or some tasks may simply seem much harder than they used to.

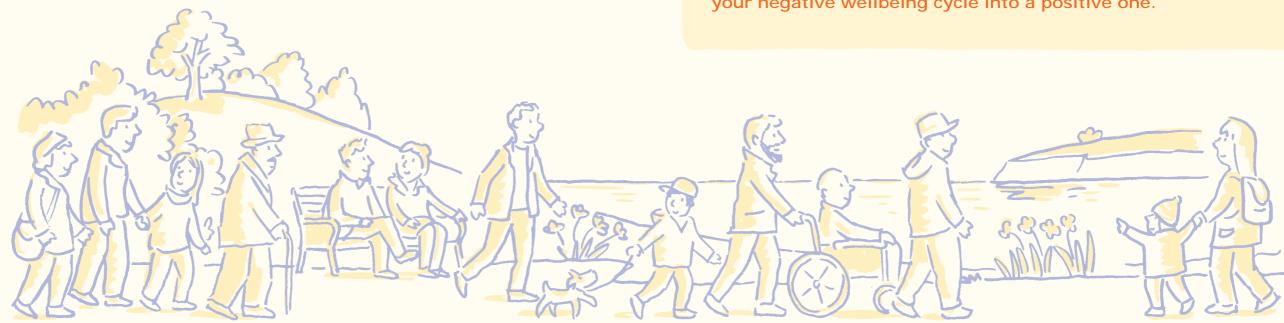
However, stopping activities means that we're not making more out of every day and living well with memory difficulties:

- You may no longer be doing activities you enjoy
- You may not be seeing friends and family
- You may no longer be doing tasks that used to give you a sense of achievement.

Stopping activities can therefore affect your wellbeing cycle in a negative way.

However by working through this booklet you can turn a negative wellbeing cycle into a positive cycle making more out of every day by starting to do things again - a little at a time.

With the support of a family member or friend the next step is to think about some things you may like to do again. This will turn your negative wellbeing cycle into a positive one.



Setting goals

Before we start to look at how we can live every day as well as possible, it's really helpful to think about what you would like to get out of this booklet.

When setting your goals for this booklet try and think about the following:

Be specific

Try to think about some specific things you would like to do again. Be detailed and clear; this may include dates, times or number of times you want to do the activity, so you know when you have reached your goal.

I will meet with my friend Clare twice a week

Be positive

Focus on what you can do and want to do rather than what you can't.

I will help my partner cook a meal three times a week

Be realistic

Set goals you can achieve over the next few weeks.

I will go for two walks a week somewhere different with my husband Your family member or friend can help you set some goals if you find yourself struggling.

Write down as many goals on the My Goals for the Booklet Worksheet below as you like. The number of goals you decide to set is up to you and what you feel you can manage. Set more goals for yourself as you go along. To do this you may find it helpful to work as part of a team with a family member or friends.

My goals for the Booklet Worksheet

My first goal
My second goal
My third goal
My fourth goal

What activities you are currently doing?

The next step is to record what you are currently doing.

Keeping a written record for a week can help you see:

- Things you've stopped doing and what they are
- If there are things you've started doing more of
- What activities have remained the same

Use the blank My Starting Point Diary Worksheet on the next page to write down what you do over the next 7 days. If you already use your own diary this might help you fill in this worksheet.

A family member or a friend can help you with this if you need them to.



For each activity try to always consider the following:

What' you are doing? For example:

Went for a walk

'Where' you are doing it? For example:

In the park

'Who' you are with? For example:

My daughter

'How' did you feel?

After you have done each activity rate how it made you feel by circling the most appropriate face:







Happier

No difference

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Sad

Week number: 1

Date:

		Mo	onday		Tu	uesday	,	We	dnesda	ay	Thu	rsday		F	riday		Sa	turday	,	Su	ınday	
	What																					
Morning	Where																					
Mo	Who																					
	Feeling	60	<u></u>	60	60	00	66	60	00	66	 60	<u></u>	66	60	00	66	60	<u></u>	66	60	00	66
	What																					
Afternoon	Where																					
Afte	Who																					
	Feeling	60	00	60	60	<u></u>	66	60	<u></u>	60	 60	<u></u>	60	60	00	60	60	<u></u>	66	60	00	66
	What																					
Evening	Where																					
Eve	Who																					
	Feeling	60	<u></u>	60	60	00	60	60	00	60	 60	<u></u>	60	60	00	60	60	00	66	60	00	60
Co	omments																					

Identify activities

The next step is to start thinking about things you could start doing again.

Most people's lives are made up of three different types of activities and it's important we have a balance of these in our lives:

The things we do most days or quite often

For example, help to do the weekly shop, help to make dinner, do the washing up.

The things we have to do

For example, pay a bill, attend hospital appointments, take medication.

The things we enjoy

For example, go to coffee mornings, walking the dog, listen to music.

Try to think about activities you would like to do in each of the three categories above. Speak to a family member or friend if you're struggling.



Use the Identifying Activities Worksheet on the next page to write down things in each of the three categories.

My Identifying Activities Worksheet

Talk to a family member or friend if you need any help to do this.

Help! I've had to stop some activities and I am not sure what to do?

Sometimes memory difficulties mean some activities might be too hard to achieve now. This can understandably be upsetting. But before you start to give up on too many activities, there may still be lots of things you can do to adapt the old activities so they are still achievable. Or maybe if you still think you need to give them up think about replacing them with new ones you can still do, that give you the same pleasure as the old ones.

Identifying New Activities

Sometimes changes in our memory may mean some activities are no longer achievable. However, the value of an activity you can no longer do may still be important to you. What we value about an activity is often why we found it important, beneficial, helpful, or useful to begin with.

For example:

I used to love doing the newspaper crossword and I miss the sense of achievement I got from completing the crossword.

I can't work anymore, but I really miss socialising with my old colleagues.

Work used to get me out of the house too.

It's important to think about whether there are other activities you could achieve that might bring a similar value.

Try thinking about the following:

- What activities can I no longer do?
- What did I value about the activity?
- What was important to me about the activity?
- Are there other activities could bring the same value that I could achieve?

For example:

I find the newspaper crossword too difficult but I enjoy completing jigsaw puzzles with my daughter.

Completing jigsaw puzzles with her gives me a similar sense of achievement and its great chatting to her when we do them too.

I have had to give up work, and really miss socialising with people and getting out the house. However, I found a local memory café and my wife and I go each week and really enjoy socialising with people there.

Last month we even all went down to the river for a while and ate lunch. It gets us both out of the house too!

Adapting Activities

Memory difficulties may make carrying out certain activities more difficult.

Also, other things can get in the way of activities too. For example, finding it hard to travel, other physical health conditions, or having less money.

However, it's very likely there are still activities you can achieve, but in a slightly different way. It's important to try and think about different ways of achieving activities, so try to think about the following:

- Do I need more time to complete the activity?
- Do I need to practice the activity more?
- Could I achieve this activity if someone else was supporting me?
- How could I modify the activity? For example, may be you could break the activity down into smaller tasks?

Meet Harry

Harry used to read all the time. He loved reading novels, but found it more and more difficult to read.

His daughter took him to their local library and they found some audio books instead. Whilst Harry missed being able to read a book, he really enjoys listening to audio books and found the library had a good range to choose from.

Meet Sandra

Sandra found herself giving up cooking but she struggled to remember recipes anymore.

This was very upsetting as she used to cook for her family every day. However, Sandra's husband helped her to write down some recipes she loved into smaller steps, so she could still manage to cook. Although Sandra doesn't cook as many different dishes as she used to, she is still managing to cook which is an activity she has always loved.

Meet Peter

Peter used to love gardening. But he found himself doing it less and less now finding it too overwhelming.

Peter spoke to his friend Mike, and Mike suggested why not try to break down doing the gardening into some smaller tasks. For example, weeding a flower bed; raking some leaves; watering the plants.

Peter found this much more manageable and was able to do a little bit every day which he loved as it got him out of the house.

àQ|

Step 5 Organise activities

The next step is to put activities you listed in **Step 4 Identifying Activities** into an order of how difficult you feel they are to achieve.

For each activity think about how difficult you would currently find doing the activity, putting them into the categories below:

These are not necessarily activities you have to do on your own, but could be supported by a family member or friend.

Less difficult to do now

With a little help from a friend or family member these are the things you could do to start off with, but may still be a little bit difficult.

Difficult to do now

These are things you would find difficult to do right now even with support.

More difficult

These are things you would find really very difficult to do at the moment and think they will still be difficult in the next week or so.

Use the **Organising Activities Worksheet** on the next page to put each of your activities into the three categories.

My Organising Activities Worksheet

Talk to a family member or friend if you need any help to do this

Less difficult to do now
Less difficult to do flow
Difficult to do now
Difficult to do flow
More difficult to do now

Plan activities

The next step is use the My Next Steps Diary to start planning activities you're going to try and do this week.

Start with some activities from your Less difficult to do now list. If you can include an activity from each of the three categories:

- Things we do daily or often
- Things we have to do
- Things we enjoy

The number of activities you want to include in the diary is up to you – however it's best to start doing things again a little at a time.

Spread your activities out evenly over the week

Important

The activities you like doing, and how much you do them, is completely down to you. For some people going to the garden centre once a week for a cup of tea may be enough! Try and plan activities that feel comfortable and manageable for you.

When you fill out your activities try to write down:

- What' you are doing.
- 'Where' you are doing it.
- 'Who' can support you and how will they support you.

After the activity rate your mood on the diary using the smiley faces.







Happier

No difference

Sad

Also use the 'comments' box to record how trying out the planned activities goes.

Next put some activities into your My Next Steps Diary on the next page.

Work as a team - ask your family member or friend if you need any help.

Week number: 1

Date:

		Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
	What							
0	\//horo							
Morning	Where							
Σ	Who							
	Feeling	60 00 60	60 00 60	60 00 60	60 00 60	60 00 60	60 00 60	60 00 60
	What							
noon	Where							
Afternoon	Who							
	Feeling	60 00 60	60 00 60	60 00 60	60 00 60	60 00 60	60 00 60	60 00 60
	What							
Evening	Where							
Evel	Who							
	Feeling	60 00 60	60 00 60	60 00 60	60 00 60	60 00 60	60 00 60	60 00 60
Co	omments							

How did it go?

Completing the activities in your diary may, or may not, have been easy, it's important to review how things are going each week.

- Don't worry if some days you feel better than others. Just make a note of it in the comments box. This is normal and to be expected.
- If you're not able to do an activity on the day planned, it's okay to move it to a different day.
- Think about why you weren't able to do any of your activities, it may have been due to your memory difficulties or for other reasons.
- If you've struggled, ask a family member or friend to help you overcome any difficulties.
- It can take time to start to feel better again.
 This is very common when we are not living as well as we could be.
 However, over time as you keep doing activities you will likely find that once again you are making more out of each day and your wellbeing cycle will become a positive one.

What next?

Over the next few weeks you will hopefully notice that you are beginning to do more and getting more out of every day.

It's important to keep building on these steps by doing more difficult activities. It's up to you when you do this and what you do.

Some weeks you may find things are quite easy to achieve. Other weeks might be a struggle. This is normal and to be expected.



Important

It can take time to start to feel better again and make your wellbeing cycle positive. However, over time as you keep doing activities you will likely find that once again you are making more out of each day.

Staying well

Well done for finishing all the steps in this booklet so far, now for the final step staying well!

It's important to make the steps you've learnt in this booklet part of your daily life. If you need to, talk to your family member or friend if support would be helpful.

Experiencing setbacks and difficulties in life is normal, especially when we have memory difficulties. Everyone dips in their wellbeing from time-to-time, this is perfectly normal and to be expected. However, it's important to keep an eye on your wellbeing, just in case you experience a dip and it doesn't improve on its own.

At the beginning of the booklet you wrote down the physical feelings, thoughts you were experiencing and what you were doing more of in your My Wellbeing Cycle Worksheet.

These may be warning signs that you may not be living life as well as you could be again:

Write down the warning signs that show your wellbeing is being affected in your My Warning Signs Worksheet on the next page.

You might find it useful to look at My Wellbeing Cycle Worksheet that you filled in during Step 1 to remind you.

My Warning Signs Worksheet

My physical feelings
What I was thinking
What I was doing
My mood (How did you feel?)

Next it can be helpful to write down the things you've found helpful in enabling you to make more out of every day in your My Staying Well Toolkit Worksheet.

You can refer back to these in the future if you find yourself feeling that you are not living as well as you could be.

My Staying Well Toolkit Worksheet

Talk to a family member or friend if you need any help to do this.

What activities helped me feel better?	

What	t skills	s hav	e I le	arnt v	orkin/	g thro	ough t	his boo	oklet?		

What techniques have I learnt from this booklet that were rea	ally helpful?

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	I	K III	IUI-	

Once you've finished this booklet it can be helpful to find a regular time to check-in to see how you're doing.

You may find this regular 'check-in' useful to continue for a number of weeks after finishing the booklet to help ensure you're keeping up the activities that have helped to make more out of every day.

My Checking-In Worksheet

wy checking-in worksheet
What activities have I been able to keep up?
What has helped me keep up these activities?
What activities have I stopped?

What has led to me stopping some activities?
What could I do to help me start doing those activities I can still manage again?
Am I experiencing any warning signs?
If I have given up any activities that I really enjoy or value, are there any ways I could do them a different way, or do part of them?

What to do in the Future

If you start finding activities more difficult here are some handy tips:

- Think about how you can adapt activities so you can still do the activity but in a slightly different way.
- Break hard activities down into smaller ones if you can.
- Ask for help or support from a family member or friend.

You could also take this booklet to other types of support you may have in the future, for example:

Activity Groups

Memory Cafes

Cognitive Stimulation Therapy

This booklet is designed as a guide to help you to make more out of every day with memory difficulties, both now and in the future.

Therefore, it's important to keep active and living well despite difficulties with your memory.

Shirley's Living with Memory Difficulties Story

With the help of George and Gail, her Wellbeing Practitioner, Shirley found herself doing more and more activities.

At first she still felt tired and struggled a little, but over time she noticed things got a little easier and she felt less tired. George told her she found the weekly telephone support from Gail really helpful.

Shirley had a bit of a set-back one week and found it really difficult to complete the activities in her diary. She wanted to give up the workbook completely. However, George spoke to Gail over the telephone and he realised that Shirley had put too many activities in her diary that week, which were just too tiring to do. After this things seemed to go much better.

Some days are still better than others but both Shirley and George continue to get much more out of every day and have noticed how their wellbeing has improved. They continue to do well, and have just come back off holiday again, a short break to Jersey organised by a local Memory Café they now regularly attend.



About the authors



Professor Paul Farrand is an Associate Professor within the Clinical Education, Development and Research (CEDAR), Psychology at the University of Exeter. His main clinical and research interests are in the area of low intensity cognitive behavioural therapy (CBT), especially in a self-help format. Based upon his research and clinical practice he has developed a wide range of written self-help treatments for depression and anxiety, including people with physical health conditions.



Dr Joanne Woodford is a Research Fellow within the Clinical Education, Development and Research (CEDAR) at the University of Exeter. Joanne has a special interest in developing and improving access to evidence based psychological interventions for people with depression. She has developed a range of written self-help materials for people with depression, carers and people with physical health difficulties.



Dr Martin Anderson is an Associate Research Fellow within the Clinical Education, Development and Research (CEDAR) at the University of Exeter. Before joining the University of Exeter, he worked with Cornwall Partnership NHS Foundation Trust as a Primary Care Practitioner helping people experiencing memory changes. Prior to this he practiced as a mental health nurse in research and training.



Laura Lovis began her training in supporting self-help as a Wellbeing Practitioner in 2010. She has since worked at the University of Exeter as an Associate Lecturer on educational programmes, designed to train Wellbeing Practitioners in how to guide self-help interventions. During this period Laura was also involved the development of self-help materials for people with memory difficulties and their family members and friends. Laura is currently working as a Wellbeing Practitioner within the NHS.

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