

HELPING RELATIVES AND CARERS OF STROKE SURVIVORS OVERCOME DEPRESSION PROGRAMME



CEDArS

For Carers of Stroke Survivors

Behavioural Activation

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WHAT IS BEHAVIOURAL ACTIVATION?

Behavioural activation is an evidence based treatment for low mood or depression. A lot of research has shown it to be effective and many people tell us how helpful they find it with lifting their low mood or depression.

Activity in the Caring Role

When we are feeling low we often stop doing, or avoid a lot of activities we used to do. We may not get any enjoyment out of things we used to find pleasurable and important tasks may feel overwhelming and difficult to concentrate on. Many carers we have spoken with to develop this programme have experienced such difficulties themselves.

You learnt in the 'Introduction Booklet' that how you behave, what you think and how you feel physically all impact on one another in a 'vicious cycle' or 'downward spiral'. Some symptoms of depression may cause you to stop doing activities you used to do, or make you increase certain activities. For example, you might stop doing activities you used to enjoy because you can't concentrate on them and feel fatigued, this may lead you to think negative thoughts around hopelessness or helplessness.

When we go through a major life change like becoming a carer we may also stop certain activities because tasks around the caring role take over. Your days may be packed with activities focused around caring for the stroke survivor leading you to give up a number of activities you previously valued. Many carers who helped develop this programme talked about how each day seems mapped out for them.

Carers also talked about how they feel a sense of guilt if they do any sort of activity which is just for them, and outside of caring for the stroke survivor.

Therefore both your depression and your role as a carer may be impacting on the types of activity that you are currently doing.



STRIKING A BALANCE

There are three main types of activity in our lives:

Routine

e.g. dressing the person you care for, housework, cooking, gardening, food shopping

Necessary

e.g. medical appointments, giving the person you care for medication, calling your social worker, paying a bill

Pleasurable

e.g. reading, swimming, seeing friends, going to a stroke club or carers meeting

We know that it is really important to get a balance of these three different types of activity in our life

Currently you may be focusing on just one or two of these activity types. Or you may find that everything is so overwhelming and exhausting right now you have stopped doing lots of different activities. To help overcome your low mood it is important to try and increase what you are doing in each area you are neglecting.

This probably sounds really overwhelming. However with behavioural activation you are in control at all times. You will start off by doing things that you have stopped doing at the level you choose and then slowly build these up. Also you are encouraged to choose activities that are relevant to your own life and priorities.

You might be wondering how you can do some of the activities you have stopped because of the impact of the caring role. Your PWP is there to help you problem solve around these difficulties and help you to find activities that you can do.

HOW DOES BEHAVIOURAL ACTIVATION WORK?

When people are feeling low or depressed they often stop doing the things they used to do. This is especially the case when the caring role itself feels so overwhelming.

At first, doing less of certain things may make you feel better. You may feel relief around not picking up the phone to a friend or seeing the GP for your own health problems. Or you may feel better about not mowing the lawn.

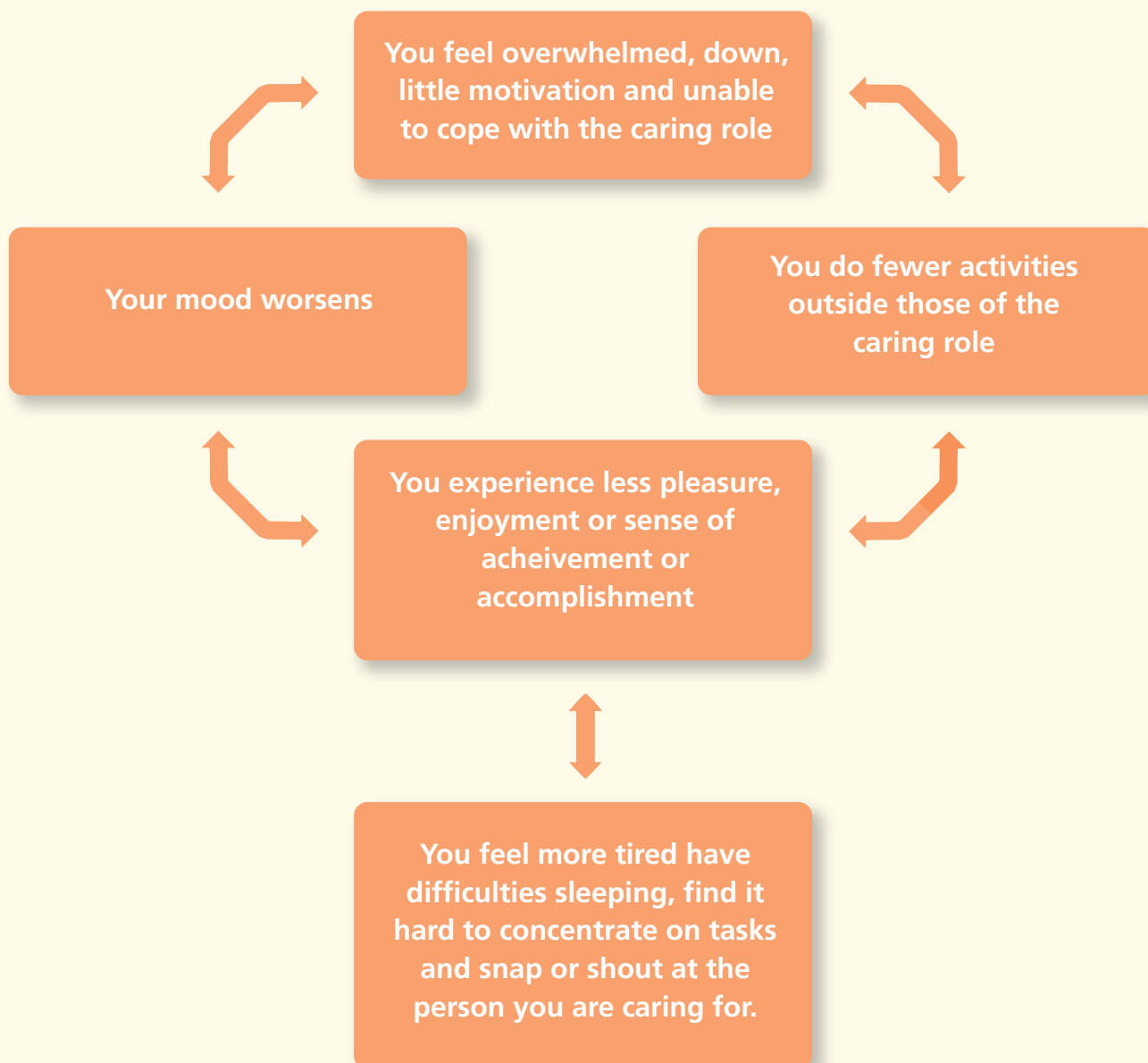
Doing less of certain activities is a normal 'self-defence' type coping response, especially if you are already feeling exhausted and overwhelmed by the tasks of caring.

Overtime you may find yourself doing less and less of these activities due to this initial sense of feeling better by avoiding these tasks. In the long term however, stopping doing certain activities can have a negative effect on your mood:

- **You may not perform roles or activities that are of value or importance to you**
- **You may no longer be doing any activities that you enjoy**
- **Tasks that need to be done may pile up and feel unmanageable**
- **You may find yourself becoming more isolated from friends and family**

Feeling worse will make it more likely that you want to do less and less, which in turn makes you feel even worse – like the 'vicious cycle' or 'downward spiral' we spoke about in the 'Introduction Booklet'. You can see this vicious cycle of low mood and reducing activity on the next page.

Cycle of low mood and reducing activity



Behavioural Activation helps you break this vicious cycle by starting to do activities you have stopped doing again. This puts the cycle into reverse and things start to improve.

We know being a carer means it can be really difficult to find the time to do certain activities and the routine of being a carer can be really overwhelming. Therefore it can be helpful to start off with doing just a little at a time.

If you need them to your PWP can help you work out ways to find time and identify activities you can do to start regaining balance in your life.

STEP 1: WHAT ARE YOU CURRENTLY DOING?

Behavioural Activation works by following four simple steps. Your PWP will help you work through these steps if you need them to.

Over the next week use the blank 'Worksheet A: My Starting Point Diary' to record what you are doing. This may feel a little overwhelming. Often carers start early in the morning with caring tasks and feel like they don't stop until the evening.

However it's not necessary to write down everything you do. Instead fill in a couple of the main activities for the morning, afternoon and evening. Or you could try grouping together lots of different activities, for example 'getting my partner ready for the day' will involve lots of tasks but you don't need to list them all separately.

There are three main types of activity that we do in our lives: routine, pleasurable and necessary:

Routine

These are activities that you do on a regular basis. For example dressing your partner, cooking, dusting or food shopping.

Necessary

These are activities that are often very important with a negative consequence if they are not done. For example giving the person you care for medication or organising Carers Allowance.

Pleasurable

These are activities that you used to enjoy before you started to feel low. Or they may be activities you have stopped doing since becoming a carer. They may also be activities you haven't done before but you think you might enjoy and would like to try. What people find enjoyable is very individual. What one person really enjoys, another person might dislike. However, some examples might include seeing friends, going out for dinner, exercise, reading the newspaper or listening to music.

When writing down activities you are doing it can be really helpful to provide the following details:

'What' are you doing – i.e. 'Getting my partner up'

'Where' are you doing it - i.e. 'Bedroom'

'Who' you are with – i.e. 'My partner'

'Type' of activity – i.e. 'R' for 'routine', 'N' for 'necessary' or 'P' for 'pleasurable'

Types of activity often overlap a lot, for example gardening may be something pleasurable and routine. Just try and put down the type of activity you think fits best.

We know from speaking with carers that they often find themselves doing lots of 'routine' tasks – recording the type of activity will help identify whether this is a pattern you are also experiencing.

At the end of each day it can also be helpful to write down comments about how the day went. For example, were there particular times of the day you felt better or worse? Were there particular activities that made you feel better or worse? Were there any people that made you feel better or worse?

Putting in as much detail in as possible will really help when you next speak with your PWP. However, we know that both depression and being a carer can make us feel exhausted and overwhelmed therefore try to do as much as you can but don't worry if you can't fill out everything.

RECORD WHAT YOU ARE CURRENTLY DOING

Worksheet A: My Starting Point Diary

		Monday	Type	Tuesday	Type	Wednesday	Type
Morning	What						
	Where						
	Who						
	What						
	Where						
	Who						
Afternoon	What						
	Where						
	Who						
	What						
	Where						
	Who						
Evening	What						
	Where						
	Who						
	What						
	Where						
	Who						
Comments							

STEP 2: WHAT IS IMPORTANT TO ME IN MY LIFE?

The next step is to think about things in life that are really important to you. This can help you identify activities to start doing again that are of importance or value to you. These are the same activities that help give your life purpose and meaning.

Caring for your
loved one

Your children or
grandchildren

Your Partner

Cooking nice meals

Seeing friends

Happiness

Although you may have many things that are important to you first of all try and think about five or so things that are really important to you right now. You can always come back to other things that are important in your life later.

Remember to write down what is important to you, rather than the things you feel you 'should' write down.

Use 'Worksheet B: What is really important to me in my life' to record the things you have identified.



Worksheet B: What is really important to me in my life?



List the five most important things in your life right now below:

1	
2	
3	
4	
5	

Helpful Hint: Sometimes people find it helpful to think about the following areas in their life:

- Relationships
- Roles and responsibilities
- Social and leisure activities
- Health
- Finances
- Religious or spiritual life



STEP 3: IDENTIFYING ACTIVITIES

The next step is to start to think about the different types of activities you have given up since becoming a carer and starting to feel down.

It is important that your daily routine includes activities that are of **importance** or **value** to you. Therefore try to identify activities in the areas of life you identified as important in Step 2.

It can also be useful to think about activities you would like to **start doing** for the first time too. Carers often find it difficult to do certain activities they did before becoming a carer, however there may be different activities you could start doing instead.

Remember to try and think about activities in the three main areas of your life: **routine**; **pleasurable** and **necessary**.

You can use 'Worksheet C: Identifying Activities' to write down a few activities in each category. Sometimes it can be difficult to think about activities to write down but you don't have to do this all at once - you might find it helpful to come back to it a few times.



Some Helpful Tips

Some activities will fall into more than one category. Just try to put the activity where you feel it fits best.

How you behave influences how you think and feel. Therefore make sure you select activities that you value and are of importance to you. These activities may help bring you a sense of pleasure, achievement, satisfaction or accomplishment.

As a carer you may have found yourself focusing on the needs of the person you care for. This can make you feel that things of importance to you are being neglected, which may then lead to feelings of guilt for having such thoughts. It is important to remember depression in either the carer or stroke survivor can increase the likelihood depression will occur in the other. Therefore it is very important that you seek to take care of yourself, for the benefit of both you and the person you care for.

Try asking yourself the following questions?

- What things have I stopped doing?
- What important things have I been putting off?
- What hobbies would I like to take up?
- Is there a particular physical activity I would like to start?
- Is there a course I would like to do or a group I would like to join?

You may find it helpful to look over your aims for treatment to try and identify activities you might want to do.

You may feel there are certain activities you have stopped doing or would like to do that are not possible to do now you are a carer. This is perfectly normal, especially when you are feeling depressed. However, even if you don't think you can do these activities anymore still write them down. Your PWP will be able to help you identify ways in which you might be able to achieve these activities in Step 4.

Remember your PWP is there to help you if you find yourself struggling with identifying activities.

STEP 4: ORGANISING ACTIVITIES BY HOW DIFFICULT THEY ARE

Next we will use **Worksheet D** to put the activities you listed in **Worksheet C** into an order of how difficult you feel they are.

Some activities may feel too difficult to achieve right now. That's absolutely fine as you will focus on the easier activities first of all.

STEP 4A

For each activity in 'Worksheet C', think about how difficult you would find it to do currently and try to put them into the following categories:

'Least Difficult' – Activities that may feel challenging right now but you think you could probably manage to do in the next week or so.

'Medium Difficult' – Activities that you think you would find really difficult to do right now, but not impossible.

'Most Difficult' – Activities that you feel would be impossible to do at the moment.

Sometimes it can be really difficult to identify 'least difficult' activities. One thing you could try is breaking down some of the activities you have identified in the 'medium' and 'most difficult' categories down.

Here are some examples that might help:

- 'Go for a drink with my friend Sarah' could be broken down into steps such as 'Ask my daughter if she can sit with my husband for an hour'; 'phone my friend Sarah to see when she is free'.
- 'Organise Carers Allowance' might be broken down into steps such as 'Phone the Carer's Allowance Unit for a claim pack' or 'organise an appointment at the Citizen's Advice Bureau' or 'find the paperwork I need to fill in the form' or 'Fill in 4 pages of the claim pack'.

Remember to write these smaller activities or steps into Worksheet C.

STEP 5: PLANNING

The final step is to begin putting activities from your 'least difficult' section into 'Worksheet E: My Next Steps Diary' on the next page.

It is important to try and get a mix of 'routine', 'pleasurable' and 'necessary' activities into your week.

Since becoming a carer you may have found yourself doing lots of routine and necessary activities, mostly around the caring role. Therefore it is important to also plan into your diary the types of activities you have stopped doing. For example, if you are doing lots of routine caring tasks but have stopped doing pleasurable and necessary activities try and fit some of these activities into your week.

It might seem overwhelming to add more activities to your busy schedule. However we know getting more of a balance between these different types of activities can really help lift your mood. Achieving just two or three activities to begin with can be enough. If you feel you can achieve more than this over the next week that's great too!

If you are struggling to find space to fit in these activities please speak with your PWP and they can help you problem solve around this difficulty. We know that this can be a common difficulty carers experience so we have added some more helpful tips to the 'Common difficulties with Behavioural Activation' section of this booklet on page 21.

When you come to do the activities they may seem harder than you first imagined. This is very normal and not a problem at all. Try to do what you can and make a note of any difficulties you experience in the 'comments' section in your 'My Next Steps Diary'. It is also important to try and make a note of activities you enjoyed too, or where you noticed your mood lift. You can discuss this when you next see your PWP.

IMPORTANT

Although you should try to start off with activities from the 'least difficult' list it is important to look at your 'necessary' activities. As 'necessary' activities have consequences if they are not done, these activities may need to be prioritised, even if they are under your 'most difficult' heading.

For example, you may have an important overdue bill to pay. If this is the case think about ways you could manage it. You may want to ask family or friends for help. Or perhaps it might be easier to break the task down, for example: 'find the bill'; 'find the number you need to call'; 'get your bank details together'; 'make the call to pay the bill'. You could also speak to your PWP who will also be able to help you overcome barriers to getting these necessary tasks done.

Putting Planned Activity into Action

When you have planned your activities for next week in your diary it is time to start to do the activities. Remember to try and write down 'what' you are doing, 'when' and 'where' you are doing the activity, and 'who' you are doing the activity with. Being really specific about the activities you have planned can help you to achieve them.

Remember to try and spread your activities out over the week. Try not to overload yourself on one particular day.

Over time you will be able to start to include some of the activities you saw as more difficult. If all goes well you will start to see more balance in your life over the coming weeks.



Things to Remember

Don't expect too much too soon

Some weeks you may find things are quite easy to achieve. Other weeks might be a real struggle. Also as a carer things may happen as part of the caring role that get in the way of you being able to achieve some of the activities you have set. This is really normal and to be expected. Remember your PWP will be learning how best to support you and help you overcome any difficulties you might experience. Also you are learning how to get more balance in your life, and feel better.

Don't expect to feel better immediately

It can take time to start to feel better again. A loss of enjoyment or pleasure out of certain activities is very common in depression and you may be achieving activities but not experiencing pleasure. This can be the same for feeling satisfaction or a sense of achievement. Many carers we have worked with also report that they can often feel guilty when starting to do activities again for themselves. However in the long term they report that this becomes better and they see the benefits of trying to get some balance again, for both themselves and the person they care for.

Don't forget you are in control

You should go at the speed you want. No one is going to put you under pressure to go any quicker than you want to. Also remember that you are not alone, your PWP is there to help and support you throughout.

Worksheet E: My Next Steps Diary

My Starting Point Diary

		Monday	Type	Tuesday	Type	Wednesday	Type
Morning	What						
	Where						
	Who						
	What						
	Where						
	Who						
Afternoon	What						
	Where						
	Who						
	What						
	Where						
	Who						
Evening	What						
	Where						
	Who						
	What						
	Where						
	Who						
Comments							



Thursday	Type	Friday	Type	Saturday	Type	Sunday	Type



COMMON DIFFICULTIES WITH BEHAVIOURAL ACTIVATION

I am doing so much already? Why do I need to become more active?

Many carers told us they are on the go from morning to night trying to juggle many things around the caring role. However, they also reported a sense of boredom, no longer doing anything for themselves and spending days not even getting out of the house.

Rather than withdrawing from the world altogether you may have found your life is very active. It is likely that most of these activities are routine and necessary activities around caring and other household tasks. However, it is really important for you to get positive feedback from things in your environment that are rewarding as this can help lift your mood. You can get this feedback from:

- a sense of pleasure or enjoyment
- a sense of satisfaction
- a sense of achievement or accomplishment

If you find yourself mainly doing only one type of activity you will not be getting this type of positive feedback from the environment you are in.

Therefore try and get a balance of routine, pleasurable and enjoyable activities. As a carer it may not be possible to get a complete balance. However trying to make sure you do activities that bring you a sense of pleasure, satisfaction and achievement is really important and will help to lift your mood. In turn this will actually help you care for your loved one even more.

I have so many new overwhelming tasks to do; I just don't know where to start!

You may find yourself doing a lot of tasks around caring, but you may also be putting off big important tasks too. Carers we have worked with often talk about difficulties taking on lots of overwhelming tasks they have never had to manage before, for example, dealing with financial arrangements, gardening or cooking.

Remember one way of working through big overwhelming tasks is to break them down. You could try thinking about steps you need to take to complete a task and planning these activities separately in your diary. Other tasks can be broken down into smaller tasks. A task like gardening can include many different activities, for example mowing the lawn, raking the leaves, weeding a flower bed, watering the plants.

If possible it can be helpful to try and get support from others. Are there friends or family who could help you with some of these more overwhelming tasks? You may also find it helpful to speak to some of the organisations listed in the 'Introduction Booklet' about sources of support too. Many of the carers we have worked with have found the organisations listed really helpful in terms of providing support, advice and information. Remember there are others there to help you if you want it.

If you find yourself struggling with working out how to break down big overwhelming tasks remember to speak with your PWP. They are trained to help carers overcome these types of difficulties.

How can I make time and space for the things I want to do?

With so many responsibilities carers often find it hard to make time for other activities, especially activities for themselves. Carers describe a sense of guilt around taking time just for them and find it difficult to leave the person they are caring for, or to get someone else to be with the stroke survivor whilst they get a break.

These types of feelings are very normal and experienced by many carers. However, for your mood to improve it is important that you try to fit in some activities that will provide you with a sense of pleasure, satisfaction or achievement.

You may be able to make time for yourself by talking to friends or family to get support. You could also try talking to social services about a sitting service, or some respite.

You may also be able to find some time by thinking about how 'important' or what 'priority level' you consider the tasks you are currently doing to be. Some people when feeling low find themselves doing lots of tasks that are not necessarily important but can help distract themselves from difficult feelings or situations. For example, doing the ironing for an hour to avoid arguing with the person you care for.

You might find it helpful to look through the activities you are currently doing and rate how important these activities are. If certain activities are not as important you may be able to replace these with other activities to help you regain some balance.

If you are struggling to make time and space for other activities outside the caring role, bring this up with your PWP and they will be able to help problem solve around these difficulties.

I've had to stop doing so much! How do I identify activities that are achievable for me now I am a carer?

The carers we have worked with to develop this programme have spoken to us a lot about having to give up many activities because of the caring role. Often these are activities they used to enjoy, for example, going on holiday, sporting activities or seeing friends. Carers talk about having little time, financial restrictions, not being able to leave the person they are caring for and the stroke survivors' physical difficulties contributing to having to give up these activities. Some activities you used to do may now feel unachievable. Or sometimes it may be that your current situation means you have to give up on some of these activities. If you find you have had to give up certain activities it is important to try and replace them with activities that bring the same value or purpose as the activity that you've had to give up.

You can try to ask yourself the following questions?

- What activities can I no longer do now I am a carer?
- What was important to me about that activity? What did I value about that activity?
- What other activities could I do that would bring me the same value but I can do as a carer?

You may find it helpful to brainstorm around these questions to try and identify some new activities that you could work towards that will provide you with similar values to the activities you have had to give up.

If you are experiencing difficulties identifying achievable activities, speak to your PWP who will be able to help you.

LOUISE'S RECOVERY STORY

I was 24 when I first got help for my low mood. I had been caring for my gran for about a year and a half and was really struggling. I found the routine of the caring role an overwhelming responsibility. I never seemed to have time for myself and had become more and more confined to the house, never having time off, seeing friends or doing the other activities I used to enjoy. I was also completely overwhelmed by so many activities around the house that were new to me, the housework seemed to be piling up and the garden was a mess.

I decided to look on the internet to see if there was any help out there and I came across a local NHS service who took self-referrals. I also noticed that they could support me over the telephone which was a massive help too because I couldn't leave my gran or afford to pay for anyone to look after her.

I phoned them up and they arranged a telephone appointment with a PWP called Stephanie 10 days later. I was really nervous about talking to a complete stranger over the telephone but knew that I really needed some help. During the phone call Stephanie asked me questions about 'what I was doing more or less of', the 'thoughts running through my head' and also what sorts of 'physical symptoms' I was experiencing. She also asked me a lot about the impact of the caring role, especially the impact on my relationships with others and on my own hobbies and interests. At first I found this quite difficult, especially around some of the thoughts I was experiencing about wondering when my gran was going to die so I could be free from the responsibility of caring. Stephanie was really reassuring however and explained that these types of difficult thoughts can be very common when caring for someone.

Stephanie explained that many carers feel overwhelmed and find themselves doing less activities for themselves, or activities they used to enjoy. She also told me being overwhelmed by the responsibility of lots of new tasks is also really common. But she also said that these difficulties were common when people were feeling depressed too. Stephanie spoke about the vicious cycle of depression and how when we are feeling low we may find ourselves experiencing physical symptoms such as exhaustion and fatigue, which may make us stop doing certain activities like big overwhelming tasks, which may lead us to thinking that we're a failure or can't cope. I found it really helpful to understand that some of the difficulties I was experiencing were not just due to the caring role, but actually symptoms of depression too.

At the end of the session Stephanie explained that she was going to send an 'Introduction Booklet' to me in the post that would explain the experience of caring and depression in some more detail and also some treatments that we could work through.

I had my first telephone support call the following week. Stephanie first recapped the previous week and then asked me what I thought about the information in the 'Introduction Booklet' and whether any of the treatments seemed particularly helpful. I told Stephanie that the 'Behavioural Activation' treatment seemed to suit me because I had stopped quite a few activities that I used to do and also found a lot of the tasks I was responsible for were really overwhelming and I was putting them off. However, I also explained that I was concerned because my days were already so full with activities I wasn't totally sure how increasing what I was doing would help, or how I could possibly fit anything else in.

Stephanie went through how behavioural activation worked and explained how stopping doing certain activities will have made me feel better in the beginning. I know I found it a relief not having to speak with a friend on the phone, or tackle the mess in the garden. However, she described how in the long term this can have a negative effect on your mood. For example, you might stop doing things you used to enjoy, or big tasks may pile up and become unmanageable, just how the garden had for me. She also explained it was really important to do activities that provide us with a sense of pleasure, satisfaction, achievement or accomplishment. However by avoiding activities of value or importance to me meant that I was getting less opportunity for such positive feedback.

I recognised that I no longer did anything that I found enjoyable and never seemed to get a sense of achievement out of any of the tasks I did.

Most of the time I felt disinterested in things I used to enjoy and many tasks around the house seemed completely unachievable anyway.

Stephanie explained that with behavioural activation we would try to work out ways of reintroducing activities of value and importance to me into my life so that I could start to get positive feedback again. She also said that carers often struggled at first to find time and space to reintroduce these activities into their lives but there were ways around this she could help me with.



Over the next week I kept track of the type of activities that I was doing.

The first step was to think about what I was currently doing during the week and use the 'Worksheet A: My Starting Point Diary' to record this.

Louise's Starting Point Diary

		Monday	Type	Tuesday	Type	Wednesday	Type
Morning	What	Getting gran ready, mainly	R	Getting gran ready, mainly	R	Getting gran ready,	R
	Where	in the bedroom and		in the bedroom and		mainly in the bedroom	
	Who	bathroom with some help		bathroom with some help		and bathroom with some	
	Who	from the carers		from the carers		help from the carers	
	What	Housework (cleaning,	R	Housework (cleaning,	R	Medical appointment at	N
	Where	getting lunch ready),		getting lunch ready),		GP surgery for my	
	Who	kitchen, on my own		kitchen, on my own		gran	
Afternoon	What	Exercises with gran in the	R	Took gran to stroke club	R	Washing clothes and	R
	Where	lounge		and did the supermarket		sheets in the kitchen	
	Who			shop			
	Who						
	What	TV in lounge with gran	P	Housework, upstairs	R	Nap, lounge	N
	Where						
	Who						
Evening	What	Getting gran ready for	R	Getting gran ready for	R	Getting gran ready for	R
	Where	bed, bathroom and		bed, bathroom and		bed, bathroom and	
	Who	bedroom, carers there to		bedroom, carers there to		bedroom, carers there	
	Who	help for 20 minutes		help for 20 minutes		to help for 20 minutes	
	What	Sleep, bedroom	R	Sleep, bedroom	R	Sleep, bedroom	R
	Where						
	Who						
Comments		I noticed although TV is		Exhausted all day		Getting gran to the GP	
		pleasurable I don't really				and back was really	
		enjoy it and we just watch				tough	
		what gran wants to					

I had to think about the types of activity I was doing and Stephanie described the three different types of activity in our lives: routine, necessary and pleasurable. Stephanie pointed out carers often find themselves doing lots of the same type of activity and neglecting other activities but it was important to try and get more of a balance.

Thursday	Type	Friday	Type	Saturday	Type	Sunday	Type
Getting gran ready, mainly in the bedroom and bathroom with some help from the carers	R	Getting gran ready, mainly in the bedroom and bathroom with some help from the carers	R	Getting gran ready, mainly in the bedroom and bathroom with some help from the carers	R	Getting gran ready, mainly in the bedroom and bathroom with some help from the carers	R
Housework (cleaning, getting lunch ready), kitchen, on my own	R	Housework (cleaning, getting lunch ready), kitchen, on my own	R	Housework (cleaning, getting lunch ready), kitchen, on my own	R	Housework (cleaning, getting lunch ready), kitchen, on my own	R
Collect gran's new prescriptions in town, with gran	N	Exercises with gran in the lounge	R	Washing clothes and sheets in the kitchen	R	Washing clothes and sheets in the kitchen	R
TV in lounge with gran	P	Housework, upstairs	R	TV in lounge with gran	P	Nap	N
Getting gran ready for bed, bathroom and bedroom, carers there to help for 20 minutes	R	Getting gran ready for bed, bathroom and bedroom, carers there to help for 20 minutes	R	Getting gran ready for bed, bathroom and bedroom, carers there to help for 20 minutes	R	Getting gran ready for bed, bathroom and bedroom, carers there to help for 20 minutes	R
Sleep, bedroom	R	Sleep, bedroom	R	Sleep, bedroom	R	Sleep, bedroom	R
		All I seem to be doing is routine stuff!				Exhausted! Even the nap didn't help	

Stephanie also asked me to try and brainstorm the five or so things that were the most important to me in my life, so we could try and get me to do more activities in these areas and to fill in the 'Worksheet B: What is really important to me in my life?'

Over the next week I kept track of the type of activities that I was doing and had a think about what was really important in my life.





Worksheet B: What is really important to me in my life?

List the five most important things in your life right now below:

1	<i>My relationship with my friends</i> <hr/> <hr/>
2	<i>Caring for my gran</i> <hr/> <hr/>
3	<i>My education</i> <hr/> <hr/>
4	<i>My health and exercise</i> <hr/> <hr/>
5	<i>My future career</i> <hr/> <hr/>



The next time I spoke with Stephanie over the telephone we chatted about what I had found during the week using the 'Starting Point Diary'.

I explained that I had noticed that I was doing a lot of routine activities around the house and the only thing I did during the week that was pleasurable was watching TV, and I didn't really enjoy that anyway. Stephanie explained that this was something many carers noticed. We then started to work through Worksheet C together, 'Identifying Activities' that were of value and importance to me that I had stopped doing, and also activities I wanted to start doing.

Working through the sheet I noticed that I was putting off some tasks that I found really overwhelming, like paying bills, speaking to social services, cleaning the car and sorting out the garden. I also noticed there were lots of activities I used to enjoy that I had stopped doing. They just didn't seem possible anymore.

Worksheet C : Identifying activities

Under each type of activity write down what you want to be able to achieve.

<p>Routine e.g., getting your partner dressed, cooking, dusting, food shopping, having a shower, washing your hair, walking the dog, or ironing</p>	<p>Pleasurable e.g., giving the person you care for medication, attending medical appointments, paying a bill, getting an M.O.T for the car, organising Carers Allowance</p>	<p>Necessary e.g., seeing friends, going out for dinner, exercise, reading the newspaper or listening to music.</p>
<p>Sorting out the garden</p> <hr/> <p>Clean the car</p> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/>	<p>Pay the water bill</p> <hr/> <p>Speaking to social services about respite</p> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/>	<p>Speaking to my friend Zoe on the phone</p> <hr/> <p>Going for a coffee with friends</p> <hr/> <p>Riding my bike</p> <hr/> <p>Reading</p> <hr/> <p>Starting a course</p> <hr/> <p>Go to the cinema</p> <hr/> <p>Get my hair cut</p> <hr/>

Also as I was now unable to go to university I really wanted to start a course but even that seemed impossible. Stephanie told me that many carers identify these same sorts of patterns – that they stop doing lots of things they enjoy and find certain difficult tasks really overwhelming. She also said that people often identify activities that they would like to do that seem impossible right now but there are ways of achieving these activities. I started filling in 'Worksheet D: Organising activities as to how difficult they are'. Stephanie explained that sometimes it can be really difficult to identify 'least difficult' tasks but there were ways of breaking down tasks into steps or smaller activities.

As I broke down some of the more difficult tasks, such as sorting out the garden, and paying the water bill, they started to seem a little bit more manageable. I also thought about some of the first steps I needed to make to find a course I could potentially do from home, that wouldn't be too demanding.

Worksheet D: Organising activities by how difficult they are

Least difficult	Medium difficult	Most difficult
Speaking to my friend Zoe on the phone	Pay the water bill	Going for a coffee with friends
Reading	Riding my bike	Starting a course
Cut the hedge back near the gate	Speaking to social services about respite	Go to the cinema
Weed one flower bed	Rake the leaves in the garden	Get my hair cut
Look up some courses online	Speak to the college about courses I can do from home	Sorting out the garden
Find the water bill	Mow the front lawn	Clean the car
Get my bank account details together		Mow the back lawn
Pay the water bill online		

Next I started to plan some activities into my diary to try out over the next week using 'Worksheet E: My Next Steps Diary'. At first it seemed really daunting as I was doing so much already. However, Stephanie and I discussed how to plan in activities and I realised that there were other activities I could do whilst my gran was watching TV.

Louise's Next Steps Diary

		Monday	Type	Tuesday	Type	Wednesday	Type
Morning	What	Getting gran ready, mainly	R	Getting gran ready,	R	Getting gran ready,	R
	Where	in the bedroom and		mainly in the bedroom and		mainly in the bedroom	
	Who	bathroom with some help		bathroom with some help		and bathroom with some	
	Who	from the carers		from the carers		help from the carers	
	What	Housework (cleaning,	R	Housework (cleaning,	R		
	Where	getting lunch ready),		getting lunch ready),			
	Who	kitchen, on my own		kitchen, on my own			
Afternoon	What	Exercises with gran in the	R	Took gran to stroke club	R	Find the water bill in the	N
	Where	lounge		and did the supermarket		lounge	
	Who			shop			
	Who						
	What	Call my friend Zoe,	P	Housework, upstairs	R	Nap, lounge	N
	Where	kitchen					
	Who						
Evening	What	Getting gran ready for	R	Getting gran ready for	R	Getting gran ready for	R
	Where	bed, bathroom and		bed, bathroom and		bed, bathroom and	
	Who	bedroom, carers there to		bedroom, carers there to		bedroom, carers there	
	Who	help for 20 minutes		help for 20 minutes		to help for 20 minutes	
	What	Sleep, bedroom	R	Sleep, bedroom	R	Sleep, bedroom	R
	Where						
	Who						
Comments	I enjoyed speaking with		Exhausted all day				
	Zoe						

Stephanie also asked me to think about some of the routine activities I did around the house and how important I considered them to be. This made me realise I often did lots of easier activities around the house that I didn't really need to do, but I did them to keep myself busy and I was putting off more difficult tasks. We started by just planning three activities for the week, to call my friend Zoe, to find the water bill and read some of my book.

Thursday	Type	Friday	Type	Saturday	Type	Sunday	Type
Getting gran ready, mainly in the bedroom and bathroom with some help from the carers	R	Getting gran ready, mainly in the bedroom and bathroom with some help from the carers	R	Getting gran ready, mainly in the bedroom and bathroom with some help from the carers	R	Getting gran ready, mainly in the bedroom and bathroom with some help from the carers	R
Housework (cleaning, getting lunch ready), kitchen, on my own	R	Housework (cleaning, getting lunch ready), kitchen, on my own	R	Housework (cleaning, getting lunch ready), kitchen, on my own	R	Housework (cleaning, getting lunch ready), kitchen, on my own	R
Collect gran's new prescriptions in town, with gran	N	Exercises with gran in the lounge	R	Washing clothes and sheets in the kitchen	R	Washing clothes and sheets in the kitchen	R
TV in lounge with gran	P	Housework, upstairs	R	Read my book, bedroom	P	Nap	N
Getting gran ready for bed, bathroom and bedroom, carers there to help for 20 minutes	R	Getting gran ready for bed, bathroom and bedroom, carers there to help for 20 minutes	R	Getting gran ready for bed, bathroom and bedroom, carers there to help for 20 minutes	R	Getting gran ready for bed, bathroom and bedroom, carers there to help for 20 minutes	R
Sleep, bedroom	R	Sleep, bedroom	R	Sleep, bedroom	R	Sleep, bedroom	R
				Reading was hard. I found it difficult to concentrate by managed a bit			

The next time I spoke with Stephanie I discussed how I got on.

I managed to do the activities but I found reading really hard. I used to be able to read loads but it was difficult to concentrate. I also still found myself feeling exhausted. Stephanie explained this was really normal and that things would get easier over time. Though I noticed speaking to my friend Zoe really helped lift my mood.

Over the coming weeks I kept planning in activities and things started to get easier. Stephanie helped me to problem solve ways of making time for activities for me. I noticed that I rushed around the supermarket each week whilst gran was at stroke club so instead I started online shopping and did something for me, like get my hair cut, whilst gran was at stroke club. My friend Zoe also suggested she come round for a coffee instead of me trying to get out. This was really nice and my gran enjoyed having Zoe over too. I also realised that when the carers came round I didn't just leave them to it and would be doing some of the caring tasks they should be doing. I started to leave the carers to get my gran ready and managed to grab 15 minutes to do something else.

Over time I managed to get some of the really big tasks done too, like the garden. It took time but breaking down sorting out the garden into smaller tasks really helped.

It was really satisfying seeing the garden start to take shape and now gran and I can enjoy it together.

I won't pretend that I don't feel overwhelmed at all anymore. The caring role is still tough and some weeks are harder than others. However, now I have a little bit more balance, I really feel my mood has lifted. Also as my mood is lifting some activities are easier to do than they were before which is saving me time too! I can now identify where I might be able to make time for important activities for me and have arranged a sitting service so I can go out and see my friends sometimes.

CEDARS LIVING EXPERIENCE GROUP

As well as interviewing a number of carers and relatives of stroke survivors the treatment booklets were also developed closely with the three members of the CEDArS Lived Experience Group.

A little about Celia

I am the sole carer for my partner who had a stroke 2 years ago at the age of 59. By the time he was correctly diagnosed with a stroke (2 weeks later) he had suffered more than one and consequently has damage in different areas. His main problems are weakness down the right hand side and extensive neurological damage. The latter took some time and a lot of research to ascertain exactly what the problems were. Initially it was a huge shock to both of us, but I bore the brunt of it as he seemed immune from worries of the present or the future.

I obtained an MA in Social Care quite late in life, after getting a degree in Politics at 42. I immersed myself in working as a frontline Social Worker with Care Leavers, aged 16-21 and helped develop the team, as the legislation for committing to this age group was new. I also helped write some of Exeter City Councils' policy on Homelessness. When my partner had his stroke I changed to part time work so that I could be his carer but found it hard to fully commit to either task. I left work after 15 months and made his rehabilitation my goal. Initially I channelled myself into basic household tasks for him-later expanding this to the outside world: using a bus pass; ordering and collecting his prescriptions; buying things in a shop etc. I think the trickle of progress has encouraged me and helped me refrain from thinking 'what was', as I cannot change that. Being involved with this project activates my brain, utilises my academic skills and hopefully keeps me at the forefront of stroke advances so that I can continue our long road ahead.

A little about Hilary

For the first fourteen years of our marriage I was a mother of three children, and a housewife, as well as doing the occasional job as for instance, a bar-maid. Our youngest daughter was born profoundly deaf, as a result of which I became interested in education. I helped out at Holiday Playschemes and helped organise and run Toy Libraries for disabled children. This led me to do an English A level when I was 34, then to get a B.Ed degree when I was 38. For a few years I worked as a Care Assistant in a Hostel for people recovering from mental illness, eventually getting a job as an English teacher when I was 44 years of age.

Life with David has obviously been very difficult since his stroke, but my experiences in life have given me a certain amount of patience, something that is greatly needed in our situation. I can communicate in British Sign Language, but David, sadly, can't. He tried to learn over twenty years ago but found it impossible to remember which hand to use, and/or which sign meant what. Anyway, it would be almost impossible to use British Sign Language as he only has the one hand now, so his iPad, with its Grid Player 'qwerty' keyboard, and space for words to be typed, is absolutely invaluable, and has 'saved our lives' nearly every day for over five years now.

A little about David

David studied psychology at University, became a Social Worker, which job he did for many years, ending up as an Assistant Manager, then became a University lecturer in Social Work. He had a severe stroke at the age of 65, caused by a clot, mostly caused by more than 40yrs of smoking even though he had given up 7 years before. The damage was in the left brain which left him with great difficulty in forming and saying words - despite sessions of speech therapy and regular exercises the damage remains very severe. David can't use the telephone, he finds social situations very frustrating (so avoids them a lot of the time!), and gets very miserable when I can't understand what he's trying to say. Another effect of the stroke was to partially paralyse his right hand, particularly the thumb and index finger, making fine movements impossible, such as cutting up food and typing. Again, despite various methods, exercises and devices the damage remains severe. Just to aggravate his disabilities, his hearing, which has been deteriorating over the last twenty years, has got even worse, limiting his social activities even more, especially in public with a lot of background noise.

In David's words: "Unlike some stroke victims, I have been lucky enough to have been nourished and protected by Hilary through our 48 years of marriage. Even so, our lives have been irreversibly damaged by the stroke, compounded by the poor hearing and compensations are hard to find. After five years I routinely get dark moods, depressed, enraged and desperate, and this has put a heavy load on Hilary as my prime carer."

ABOUT THE AUTHORS



Joanne Woodford is an Associate Research Fellow within the Mood Disorders Centre at the University of Exeter with a special interest in developing and improving access to evidence based psychological interventions for people with depression, especially for carers and relatives of people with physical health difficulties, such as stroke. Joanne has previously co-developed an online CBT self-help treatment for postnatal depression and contributed to the development of a treatment for people with chronic physical health conditions. Joanne is also involved in several educational programmes directed at training mental health professionals in the skills required to support patients in the use of CBT self-help materials.



Dr Paul Farrand is a Senior Lecturer within the Mood Disorders Centre and Director of Psychological Wellbeing Practitioner training within Clinical Education, Development and Research (CEDAR) 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.







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