



CEDArS

For Carers of Stroke Survivors

Helping Relatives and Carers of Stroke Survivors Overcome Depression Programme

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EXETER

Well done for taking the first steps to help overcome your low mood or depression. Seeking help for your low mood and depression can be one of the most difficult steps to make. This is especially so when you are a busy carer or relative of a stroke survivor with very little time for yourself.

The 'Helping Relatives and Carers of Stroke Survivors Overcome Depression Programme' is based on a psychological treatment, known as Cognitive Behavioural Therapy (CBT). This treatment has been shown to help many people with depression.

The booklets have been developed very closely with carers and relatives of stroke survivors experiencing similar difficulties to you. They are therefore targeted at overcoming the unique difficulties and challenges carers of stroke survivors with depression experience.

HOW DOES THE PROGRAMME WORK?

Whilst working through the programme you will be supported by your Psychological Wellbeing Practitioner, or PWP. Your PWP is a mental health professional who has been specially trained to help support carers and relatives of stroke survivors experiencing depression work through this programme.

The programme includes three different techniques that have been shown to help people overcome difficulties with depression:

- **Goal Setting**
- **Behavioural Activation**
- **Problem Solving**

You won't use all of the techniques, but rather you'll pick one that seems the most suited to the difficulties you are currently experiencing. If you have any problems in deciding which technique to work with, your PWP will be able to help you. You can find out a little bit more about each of the techniques by reading the 'Carer and Relative Recovery Stories' in Part 3 of this booklet.

You'll either meet with your PWP face-to-face or speak with them over the telephone on a regular basis over the coming months. How you would like to work is up to you. Your PWP will act a bit like a coach or personal trainer and help you to understand and use the techniques in the programme.

Working through the programme does involve time and commitment and you'll have homework to complete in between support sessions. From our discussions with carers during the development of this programme we also know that finding time when you are busy caring for a stroke survivor can be really tough. Therefore take your time, remember you are in control of how much you do. Working through the techniques little but often can be really helpful.

Sometimes progress will be slow and setbacks will happen, this is perfectly normal and to be expected. If you find yourself facing difficulties please speak with your PWP. They are specially trained to help people overcome setbacks and difficulties with using the techniques in these booklets.

UNDERSTANDING LOW MOOD AND DEPRESSION

The Caring Experience and Depression

Low mood and depression are very common emotional difficulties experienced by carers. Around 1 in 3 carers are likely to experience such difficulties.

Strokes often happen completely out of the blue and with every stroke being different the future can often seem very uncertain with no real guideline or template to follow to help with recovery. Understandably you may feel your entire life has been turned upside down and have little hope for the future. These are difficulties many of the carers we have worked with to develop this programme have talked to us about.

Becoming a carer of a stroke survivor involves many major life changes. You may have found yourself having to give up certain activities, goals, and things that you value, for example, work, education, plans for retirement, social activities and hobbies. Some carers we have spoken to have reported feeling resentment towards the stroke survivor due to having to give up so much they previously valued. However this resentment is often mixed up with guilt around having these difficult feelings. As a carer you may have experienced thoughts like 'Why am I moaning, why am I complaining, the stroke didn't happen to me'. From our work with carers having such thoughts is perfectly normal.

As a carer you may have found your day has become filled with activities around caring for the stroke survivor, looking after the home and finances. Understandably carers often feel like it is a huge struggle to hold everything together and feel like they are not doing a good enough job. With such little time carers also often find themselves feeling very isolated and confined to the house with little support from others.

It is important to remember that these difficulties are very common and understandable with seeing a loved one experience a stroke and experiencing such major life changes. However, there are tools and techniques that can help you overcome and cope with these difficulties.

Exactly what is Depression?

Depression or low mood are experienced by people in different ways. But there are a number of common signs and symptoms that people may experience that are listed below:

'I can't cope'

FEELING OVERWHELMED

TEARFULNESS

DIFFICULTY CONCENTRATING

KEEPING YOURSELF BUSY TO AVOID
DIFFICULT FEELINGS

LACK OF MOTIVATION

**'I just wish everything
would end'**

SNAPPING AT PEOPLE

FATIGUE

FEELING EXHAUSTED

RESTLESSNESS

DIFFICULTIES WITH SLEEP

EATING TOO MUCH OR TOO LITTLE

LACK OF ENJOYMENT

**'I can't do
anything right'**

PUTTING OFF IMPORTANT TASKS

LOSS OF SEX DRIVE

NOT SEEING OR SPEAKING TO
FRIENDS AND FAMILY

GUILT

THOUGHTS OF DEATH
OR SUICIDE

'What's the point?'

WHAT CAUSES DEPRESSION?

Although there are a lot of theories about what causes depression mental health experts still don't know the cause.

Some people think that depression is triggered by difficult and stressful life events. Others argue that some people have personality traits which can make them more likely to experience depression, for example being over self-critical or viewing the world negatively. Others argue that depression is caused by low levels of a chemical called serotonin in the brain.

Although we don't know what causes depression and low mood, it is likely that a combination of these things contribute.

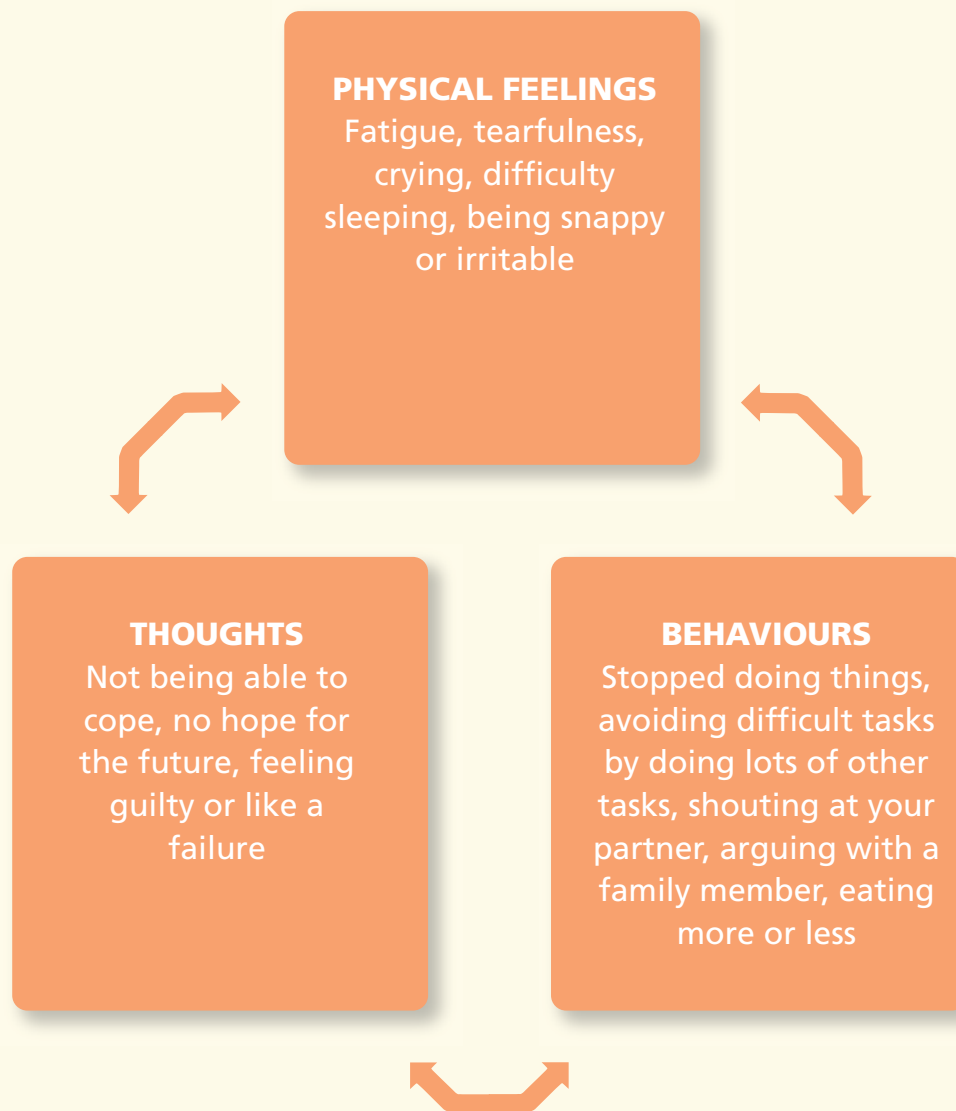
The Effect of Depression

When thinking about the different signs and symptoms of depression that people may experience it can be useful to think about how depression impacts us in three ways:

- **Physical Feelings:** You may experience **physical feelings** such as changes in appetite, tearfulness, exhaustion or restlessness.
- **What we think:** You may experience **thoughts** such as 'I can't cope'; 'I can't do anything right'; 'I'd be better off dead'.
- **How we behave:** You may also experience changes in the way you **behave**, such as stopping seeing friends, stopping activities you previously enjoyed or valued. Or you might have found yourself doing lots of other activities to try and avoid difficult tasks or feelings.

You may notice that the common symptoms of depression listed on page 4 fall into these three categories. We know that each of these areas impact on one another – like a 'vicious cycle' or a 'downward spiral'. An example of this can be seen on the next page.

The impact of low mood or depression



Depression impacts each of these three areas and one thing leads to another. You may find yourself feeling fatigued or having difficulty sleeping. This may lead to thoughts about not being able to cope which may lead you to snap or shout at the person you are caring for. This in turn may make you feel guilty and you might find yourself leaving the room and avoiding speaking with the person you are caring for.

It is important to remember each of these three areas, your physical feelings, thoughts and behaviours, all impact on and reinforce one another. This 'vicious cycle' or 'downward spiral' can be really difficult to break out of. This is what can keep depression or low mood going.

HOW DOES YOUR DEPRESSION AND LOW MOOD IMPACT YOU?

It can be really helpful to have a think about how your depression or low mood is impacting on you. So why not try to develop your own 'vicious cycle' or 'downward spiral'?

Using the diagram opposite try and think about the following:

- What physical feelings are you experiencing?
- What have you stopped doing? Or what have you started doing more of?
- What thoughts are you experiencing?

Have a go at completing this for yourself. If you struggle however don't worry as your PWP will help you.

GETTING OUT OF THE VICIOUS CYCLE

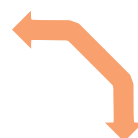
Cognitive Behavioural Therapy (CBT) is an evidence based treatment for depression and low mood which works by focusing on either helping you to change the way you behave or the way you think. Because your physical feelings, thoughts and behaviours are all linked in the vicious cycle of depression, if you can improve one of these areas the other areas will also be improved.

The focus of the three techniques used in this programme will help you change some of the ways that you behave. This will in turn help you with the difficult thoughts and physical feelings you are currently experiencing.

It is completely up to you which technique you would like to work with. The 'Carer and Relative Recovery Stories' in Part 3 of this booklet talk about the three techniques (Behavioural Activation, Goal Setting and Problem Solving) in some more detail. However, if you struggle to decide which technique is best suited to your current difficulties your PWP can help explain more about these techniques to help you to decide.



BEHAVIOURS



THOUGHTS

PHYSICAL FEELINGS



AIMS FOR TREATMENT

Before we start on the treatment it can be really helpful to think about what you would like to achieve over the coming months. It is important to remember the following things when setting your aims for treatment:

Be Specific

Try and make your aims for treatment specific. Although you might want to set aims such as 'feel able to cope' or to 'feel better' it can be hard to know whether you have managed to achieve these aims. Instead, have a think about how you would know if you were coping better, or feeling better. For example, what sorts of things might you be doing if you were feeling or coping better?

e.g. 'I will speak with a friend twice a week' or 'I will go swimming once a week' or 'I will have confidence when speaking to the care agency and be more assertive about the care my partner may require'

Strive towards achieving something

It can be tempting to write down aims such as 'shout at my partner less' or 'eat less'. However it is more helpful when our aims are more positive.

e.g. 'I will talk to my partner calmly' or 'I will eat a healthy dinner at least four times a week'

Realistic

It is important to try and set aims that will be realistic to achieve over the next few months. They may be things you have stopped doing for a long time, or things you would like to do in the future.

On the next page try and think of three aims for treatment. Your PWP can help you with this if you are struggling. Then say how well you are achieving these aims at the moment by rating them between '0' meaning 'not at all' and '6' meaning you can achieve the aim at 'anytime'. Over the next few months you and your PWP will revisit these aims to see how you are getting on.

Three aims for treatment



Today's Date

Aim 1

I can do this now (circle a number):

0

1

2

3

4

5

6

Not at all

Occasionally

Often

Anytime

Today's Date

Aim 2

I can do this now (circle a number):

0

1

2

3

4

5

6

Not at all

Occasionally

Often

Anytime

Today's Date

Aim 3

I can do this now (circle a number):

0

1

2

3

4

5

6

Not at all

Occasionally

Often

Anytime

CARER AND RELATIVE RECOVERY STORIES

Sometimes people find it helpful to read about other carers and relatives of stroke survivors who have experienced and overcome low mood or depression.

Each of the following carers has used a different technique in the programme to help overcome their difficulties. These stories have been developed very closely with carers and relatives of stroke survivors who have experienced difficulties with depression or low mood.

You may want to read each story in full over the following pages, or you may just want to read the story about using a technique that seems appropriate for your current situation.

If you are having difficulty deciding which technique to use your PWP will explain each of the treatments to you in some more detail to help you decide which one might be best for you.

Additional details about how each carer or relative has worked through the techniques can also be found within each of the specific booklets.

Sarah found herself really struggling with having to give up so much when she became a carer for her husband.

She no longer felt like she had anything to work towards anymore, except being a carer. She therefore decided to use the 'Goal Setting' booklet to help her to identify the goals she could still work towards now she was a carer but also to identify some new goals that were of value to her. You can find Sarah's recovery story on page 13.

Louise really struggled with the routine of the caring role looking after her gran and finding any time for herself.

She found many caring and household tasks really overwhelming and found herself putting off really difficult tasks. Louise also felt that she had stopped lots of activities she used to really enjoy. She felt that she couldn't do a lot of these activities now she was a carer.

Therefore Louise decided to use the 'Behavioural Activation' booklet to help her with getting more balance back into her life. You can find Louise's recovery story on page 15.

Tom found caring for his wife Mary really overwhelming.

He found it difficult to manage with the personality changes and communication difficulties Mary had experienced since her stroke. Tom also found himself having difficulty with the new tasks he had to perform around the house and really struggled taking up offers of support from his family.

Tom decided to use the 'Problem Solving' booklet to help him actively work towards solutions to these difficulties. You can find Tom's recovery story on page 17.

SARAH

My husband Brian suffered his first stroke three years ago when he was 49, it was so sudden, completely out of the blue and it turned our whole life upside-down. The stroke left him paralysed in the right hand side of his body and he was wheelchair bound. It soon became apparent that I couldn't work and look after my husband, so I had to cut short a good career to care for him full time.

Still three years later I was struggling to hold everything together. At the beginning Brian was really determined to overcome the stroke, but over time he made little improvement. He had exercises to do but didn't seem to be bothered with them anymore and put no effort in. He seemed to have given up hope, and so had I. Just before I sought help for my low mood Brian told me that often when he went to bed at night he hoped he wouldn't wake up in the morning. That devastated me.

I never felt like I was doing a good enough job for Brian. My old career was really rewarding but I didn't receive any praise or acknowledgement for the caring tasks I carried out for my husband or around the home. I had no idea whether I was doing a good job and found myself questioning everything I did for Brian and every decision I made. Brian spent most of his time sitting in a chair watching the TV and I felt that it must be my fault that he didn't want to do anything anymore. We also had to give up on so many activities that we used to enjoy together: travelling, meals out, walking.

It felt like a prison sentence, for both of us.

We used to have a great circle of friends, who were really supportive at the beginning but had drifted away over time. They didn't seem to understand that we couldn't do the things we used to do with them. The phone calls had pretty much stopped before I started the overcoming depression programme and I felt so alone.

I had never felt like this before in my life. I would find myself crying over the smallest of things. I was exhausted all the time but despite that I still couldn't sleep. I would lie in bed a lot wishing that our life was the same as it used to be. All I could manage was to care for my husband and I didn't even feel like I was doing that properly. I really wanted to try and get better but I had no idea where to start.

I went to speak to my GP about how I was feeling and he recommended that I saw a Psychological Wellbeing Practitioner who saw me at the GP Practice. At first I was pretty sceptical. I had lost so much and I saw no way of getting anything that resembled our old life back. However my PWP, Tim, helped me work through the 'Goal Setting Booklet'. He spoke to me about how focusing on goals can be really helpful for people with depression, especially if they had gone through a huge life change like I had. Tim explained to me that it can be possible to still work towards some of the goals I had, but in different ways to take account of the changes I had experienced. He also spoke about how I may need to change some of my old goals, but if they are still of value and importance to me then this can be really helpful with overcoming low mood. Tim also explained that sometimes you may need to let go of old goals, but that it was important to try to replace these with new goals that had a similar purpose and meaning to my old goals.

Things are looking much better now. I've been able to get some more balance in my life again - a bit of the old me is back!

Brian and I have been able to find wheelchair friendly walks and we're even planning a mini break away. Tim spoke to me about the importance of support and I recognised that I really missed my old friends. I showed them the information on caring, stroke and goal setting in the booklets and this helped them understand how our lives have changed. We have now been able to find some new activities to all do together. I have also been able to start doing some of my old hobbies again after being able to arrange some respite. Although I have had to change the way in which I work towards some of my goals to fit in with my new life style I now feel that I am actually achieving something for me and that I am more than just a carer. Brian seems to be doing a lot better too now with his own mood as a lot of the goals I set involved both of us.



LOUISE

I am 24 years old and had been looking after my gran for about a year and a half before I got help for my low mood. My gran needs a lot done for her. We have carers that come in to help wash her in the morning and get her ready for bed in the evening but everything else is down to me. My day starts at about 6am and I don't seem to finish until late in the evening. Each day was mapped out for me, I found it an enormous weight and the responsibility was just overwhelming.

The routine of caring for my gran really got me down but I was scared of ever coming out of the routine we had, I worried about things like 'What if I forget something really important like her medication?' or 'What if she fell if we went somewhere outside the house together'. If I ever changed the routine everything else seemed to fall apart during the day. I seemed to be stuck in the role; it was so hard to see a way of changing it or ever leaving it. I had terrible thoughts like 'when will my gran die so I can be free from all of this. These thoughts made me feel really guilty.

I found myself becoming more and more confined to the house and had stopped doing many of the things that I used to enjoy. Nothing really seemed to interest me anymore either. I once had a really bad experience when I tried to leave my gran on her own for a few hours so I could meet some friends for a drink. I thought it would be ok to leave her but when I came back I found her lying in the garden. She had tried to do some gardening and fell. She could have been there for hours. I felt I couldn't leave her anymore and became really worried about what might happen to her if I did. My friends still called me to ask me to come out, but I always said no, I just didn't bother seeing them anymore and I had recently started to ignore their phone calls completely. I also found myself getting really behind with so much around the house.

The garden was a real mess, really overgrown. It made me feel so guilty as my gran used to love her garden and sitting out there.

I had no idea where to start with the garden and I was so tired I just couldn't bring myself to even think about sorting it out. I also felt that I had no real future. I had to give up my plans to go to university.

The thoughts I had about wondering when my gran will die really scared me. Of course I didn't really want her to die, I love her so much. I just wished I could get back to normal and stop feeling the way I did but I had no idea how to stop it. I wanted to get support but I was worried about how I could leave my gran whilst I got help. I couldn't afford to get more care in. I felt so trapped.

Eventually I decided that I just couldn't go on anymore feeling the way I did so I searched on the internet for help with depression. I came across the local NHS service and saw that they took self-referrals and also could support people over the telephone, so I didn't have to find someone to care for my gran. I phoned up and they made me a telephone appointment with my PWP Stephanie. We decided to work through the 'Behavioural Activation' booklet. At first I was really uncertain. It didn't seem to make sense as I was doing so much already. My day never seemed to stop! However Stephanie explained to me that it is really important to try and get a balance of different types of activity and pretty much all I was doing was caring for my gran. At first it was really difficult to identify times in the day where I could fit anything else in! Stephanie helped me to problem solve around this, by identifying activities I was doing that were low priority, and replacing these with other activities to help get some more balance. It was tough but we managed it and I started doing activities for me again, like getting my hair cut and reading. Stephanie also helped me work out how to break huge tasks down, like sorting out the garden. This made things much less overwhelming and manageable.

My life feels much more balanced now; I even get the opportunity to see my friends sometimes!



TOM

I'm 72 years old and my wife Mary had her stroke two years ago. The day we returned home from hospital it was like someone completely different came home with me. She had been changed so much from the stroke. I felt my wife was gone and I still felt I was mourning for her.

Mary suffers from aphasia and has a lot of memory difficulties too. Her personality seemed to have changed since the stroke as well. I found it really difficult to understand her and she sometimes gets really angry, throws things and swears. I used to lose my patience with her and I would often shout back at her or leave the room out of frustration. Before the stroke Mary was one of the most placid people I had ever met but it was like she had become a different person. I had started to give up even trying to communicate with her. We were living like separate people, just sitting in front of the TV and no longer talking.

I also found it embarrassing going out anywhere with Mary. I had a really bad experience when we went to a restaurant and she got really angry because they didn't have what she wanted to eat on the menu and she swore at the waitress. She just didn't seem to understand that she couldn't have whatever she wanted. We had pretty much stopped going out at all before I sought help. Our grandchildren would often offer to come and sit with Mary so I could get a break but I would always turn them down. I was so worried she might get angry and swear at them.

We also used to have friends over but they didn't really understand her communication difficulties and often they would just talk to me and ignore Mary completely. It was so upsetting to see so I had stopped letting them come round.

I also had to give up a lot of the things I used to do.

I used to play bowls, go to local football matches, but just didn't feel like I had time for any of those activities anymore. I felt so isolated. Not only did I not see my friends but I didn't even have the relationship I used to with my own wife.

I also found a lot of the tasks around the house really difficult. I had never done the housework, the cooking, the washing, the cleaning before. Mary had done everything. Most of the time I felt so overwhelmed. I had felt like this once before when I was made redundant about 30 years ago, but I managed to pull myself out of it. This time I just didn't seem to be able to. I was so worried about whether Mary would be taken away from me. What if they think I can't cope and they put her in a home?

One week I dropped Mary off at her stroke club. I often would drop Mary off and not speak with anyone else. I didn't want the other carers thinking I couldn't cope. However by this point everything had just got so overwhelming I broke down in tears to one of the other carers. The carer told me he had experienced similar problems and seen someone at his GP surgery who had really helped him overcome his difficulties with low mood. At first I was really unsure. I couldn't really see how talking to someone could help overcome any of my problems. They just seemed unsolvable. However, I went to the appointment anyway and met with Charlotte, my PWP who supports people like me work through self-help programmes for depression. We eventually decided to work on a treatment called 'Problem Solving'. It seemed like a really practical approach and definitely wasn't 'just talking'. I had so many overwhelming problems and difficulties in my life and it seemed like a really good way of trying to cope and manage with them. It was really hard work. Some of the problems I just didn't see a way out of but with Charlotte's help we were able to identify potential solutions and work towards them.

I had also stopped doing a lot of things that were of importance and value to me but didn't see a way of doing these activities now I was a carer. However I was able to problem solve around some of these activities too. Obviously we couldn't solve everything but I am now able to play bowls again and now I have accepted my grandchildren's offer of sitting with Mary and I can get the chance to see our local football team play. Charlotte also helped me get in touch with a charity called Connect especially for people with aphasia. I was able to get some really great advice about how to communicate with Mary and our relationship is much better now. I also shared this advice with some of our friends and they come around again now too.

I won't pretend the process was easy. I still have down days. But things are starting to look much more positive now.



UNDERSTANDING COMMON COMPLICATIONS IN STROKE

Many of the carers we have worked with to develop this programme have spoken about difficulties gaining information surrounding the common health complications and difficulties stroke survivors' experience. A number of carers have also spoken about not being aware that some of these health complications quite common, leading them to feel very alone and anxious about the stroke survivor. Lack of information can therefore contribute to the levels of distress you may feel.

We have put together some information about some of the common health difficulties and complications stroke survivors may experience that carers have told us about. At the end of this booklet, in Part 6, we have listed a number of organisations that provide further advice, help and support around how to manage these difficulties.

Depression

One-in-three carers of people with stroke experience difficulties with depression or low mood which is similar to the rates experienced by the stroke survivors themselves. It is common that depression in one increases the likelihood depression will occur in the other. As such it is important both you and the stroke survivor you care for seek to take care of yourselves and try to find help if the stroke survivor you care for mood has also dropped. You may want to encourage the person you care for to speak with their GP about their difficulties as there are psychological and medical treatments available that may help.

Anxiety

One-in-three stroke survivors will experience difficulties with anxiety. For example, they may fear having another stroke, or that performing certain activities may lead to a stroke, or they may have anxiety around performing certain activities due to the physical difficulties they experience. This can also greatly impact you as a carer and the activities you can do together. Again, remember to encourage the person you care for to speak with their GP as there are psychological and medical treatments that can be effective to treat post-stroke anxiety.

Fatigue

Over half of stroke survivors will experience fatigue. This can be very difficult for both stroke survivors and carers to manage and may impact on the stroke survivors' ability to do many activities. It is important to remember fatigue is very common and you are not alone. However, there are techniques that can help manage post-stroke fatigue that can be found on the 'Stroke Association' website. Also your PWP will be aware of a number of ways that stroke survivor fatigue can be accommodated within any intervention you may seek for your depression. So if this is a difficulty for you make sure you raise it with them.

Seizures and Epilepsy

A number of carers of stroke survivors have spoken to us about difficulties with post-stroke seizures and epilepsy. Understandably seeing the person you care for have a seizure or epileptic fit is very distressing and a highly anxiety provoking situation. It is important to remember that seizures and epilepsy post-stroke are quite common.

Sleep-Disordered Breathing

Another anxiety provoking and distressing experience is sleep-disordered breathing. This is where the stroke survivor has long pauses in their breathing multiple times an hour. A number of carers spoke about how they would fear the worst when the stroke survivor stopped breathing and this led to difficulties sleeping. It is important to remember that over 50% of stroke survivors experience difficulties with sleep-disordered breathing. However, it is also important to speak with your health care providers as there are treatments available or a referral could be made to a sleep centre.

Emotionalism

Emotionalism is when the stroke survivor either cries or laughs uncontrollably and often for no apparent reason. Again, this is a common difficulty with one-in-ten stroke survivors experiencing emotionalism. Understandably this can be distressing for both the stroke survivor and carer. Many carers have spoken to us about feeling that uncontrollable crying was due to something they had done or how they can find emotionalism embarrassing. It is important to remember that this is a common post-stroke complication. Remember to speak with family and friends about how this is common which can help with difficult situations. Again, there are treatments available so encourage the person you care for to speak with their GP or stroke healthcare professional.

Whilst all of these post-stroke health complications can be understandably distressing and difficult to manage it is important to remember that you are not alone and they are experienced by many stroke survivors. The organisations listed in Part 6 will be able to provide more information about these difficulties and how to manage them. If you struggle to find organisations to help you speak with your PWP who may be able to put you in touch with further support.

STRATEGIES FOR COPING FROM CARERS OF STROKE SURVIVORS

As well as working with carers and relatives to identify common difficulties experienced to inform the development of this programme we have also identified a number of strategies that carers and relatives find helpful in supporting day-to-day difficulties and coping with the caring role. These may be strategies that you would like to try out yourself.

SUPPORT FROM FAMILY, FRIENDS AND STROKE ORGANISATIONS

Some carers spoke about how it was helpful to have support from those close to them. This was both in terms of practical support, for example helping with caring for the stroke survivor, and also emotional support and having someone to talk to. Some also spoke about support from stroke clubs and groups in terms of providing information, practical advice and helping them feel that they were not alone. However, getting others involved isn't for everyone, or you may not feel ready to take this step yet. Don't worry if this is the case. If you think you might find support from others helpful have a think about who you might want to ask, or you could think about showing them some of the sections of this programme. Also Part 6 lists a number of stroke and carer organisations that run groups nationally that may be able to provide you with this type of support if you feel this might be helpful.

COMPARING MY SITUATION WITH OTHERS

Sometimes carers reported it helpful to be around other people in a similar situation and to share their stories. This seems to be of benefit in two main ways. First simply sharing your story with others can help, and sometimes it can result in receiving some helpful practical advice. Also talking to other carers and stroke survivors can help make you more aware of the different type of difficulties faced by others, and this can sometimes help you to consider your difficulties in different ways.

BALANCE

A number of carers mentioned the importance of striking a balance between different types of activity. You may have found yourself that the routine of being a carer is really tough. Therefore it is important to try and find things that both you and the stroke survivor enjoy and value. If you are interested in finding out ways of trying to get more balance in your life you may want to look at the 'Behavioural Activation' booklet.

TIME FOR ME!

Another strategy mentioned was trying to take time out from the caring role, even if this is only for a few minutes each day. The 'Behavioural Activation' technique looks at ways to make more time in your busy caring role to have time for yourself. 'Goal Setting' and 'Problem Solving' are also techniques that can help around difficulties making more time for yourself outside the caring role. In Part 4 we mentioned that if depression or low mood increases in the stroke survivor depression or low mood may also increase in the carer, and vice versa. It is therefore also important to remember that taking care of your own mental health is of benefit to the stroke survivor as well.

'PUSH, PUSH, PUSH'

Some carers spoke to us about difficulties with the stroke survivor they care for experiencing low levels of motivation. Carers spoke about how trying to push the stroke survivor, within their capabilities, helped overcome such difficulties. They spoke about the importance of continuing to push the stroke survivor to do exercises, or tasks around the house, or activities around self-care, helping them to strike more of a balance within the caring role. Many carers also spoke about how adopting a 'push, push, push' attitude with health care professionals was also helpful in terms of gaining adequate support.

ADAPTING GOALS

Carers spoke to us about adapting activities and goals so that they could still be achieved in their new life situation, for both themselves and the stroke survivor. You may have noticed yourself that there are activities you used to enjoy, or things you value that you feel you can no longer do now you are a carer. This is very common but many carers spoke about adapting their goals or activities to accommodate their new role as a carer and finding this a helpful way of coping. If you are interested in adapting your goals or setting new goals to work towards now you are a carer you may find the 'Goal Setting' technique helpful.

OTHER SOURCES OF SUPPORT

Many carers and relatives we have worked with to develop this programme have spoken about how it can often be really difficult to find help, support and advice around stroke and caring.

However a number of the carers we have worked with have spoken about the benefits of seeking external support, for both them and the stroke survivor they care for. We have therefore listed a number of organisations that carers and relatives of stroke survivors have found helpful in supporting day to day issues with caring for stroke survivors and practical difficulties that you might encounter.



Different Strokes

Tel: 01908 317618 or 0845 130 7172

Email: info@differentstrokes.co.uk

Website: www.differentstrokes.co.uk

Different Strokes helps stroke survivors of working age to optimise their recovery, take control of their own lives and regain as much independence as possible by offering 'rehabilitative services', information and advice.

Different Strokes currently does this by:

- Organising a national network of weekly exercise classes
- Providing practical, easy to use information for the recovering stroke survivor
- Offering a 'StrokeLine' telephone service so that younger stroke survivors can speak to other younger stroke survivors (01908 317618 or 0845 130 7172)
- Keeping stroke survivors informed, through newsletters, an interactive website and other means, of developments relevant to them



Stroke Association
Helpline: 0303 3033 100
Website: www.stroke.org.uk

Stroke Association is the UK's leading stroke charity. They campaign to improve stroke care, and support people to make their best possible recovery. The Stroke Association funds world-class research to develop new treatments and ways to prevent stroke. They are here for everyone affected by stroke. Please call their Helpline on 0303 3033 100 or visit www.stroke.org.uk for more information.



Headway
Free, confidential helpline: 0808 800 2244
Email: helpline@headway.org.uk
Website: www.headway.org.uk

Headway is a charity set up to give help and support to people affected by brain injury. A network of local Groups and Branches throughout the UK and Channel Islands offers a wide range of services, including rehabilitation programmes, carer support, social re-integration, community outreach and respite care. The services available will vary, depending on local needs and resources.

Support from Headway includes:

- A free, confidential helpline (0808 800 2244; helpline@headway.org.uk)
- A comprehensive website (www.headway.org.uk), including a section dedicated to caring for someone with a brain injury (www.headway.org.uk/caring.aspx)
- An award-winning range of publications and factsheets, including the BMA award-winning booklet Caring for someone with a brain injury
- A network of more than 100 groups and branches across the UK

OTHER SOURCES OF SUPPORT



Stroke Foundation
Website: www.strokefoundation.com

StrokeFoundation.com is dedicated to providing the most up-to-date and comprehensive information about stroke. Their mission is to educate the public and healthcare community about the serious medical condition of a stroke.

The Stroke Foundation endeavour to keep StrokeFoundation.com up to date with all the latest news and information and hope that StrokeFoundation.com acts as a spring-board from which further information, help and advice can be found.



Connect
St Alphege Church, King's Bench Street
London SE1 0QZ
Tel: 020 7367 0840
Email: info@ukconnect.org

Connect is a charity for people with aphasia (sometimes known as dysphasia). We offer counselling for people with aphasia and carers from a trained counsellor who has aphasia.

People with aphasia can get involved in a range of activities. Connect call these 'Access to Life' services because they support people to become re-connected with life again.

We offer:

- Peer-led conversation groups
- Befriending
- Training healthcare workers about aphasia
- Aphasia hubs
- Drop-in



**Carers Trust, 32–36 Loman Street
London SE1 0EH
Tel: 0844 800 4361, Fax: 0844 800 4362
Email: info@carers.org
Website: www.carers.org**

Carers Trust is the UK's largest charity for carers. With local Network Partners they work to improve support, services and recognition for carers in communities across the UK. Carers Trust offer practical help, both in and outside the home, desperately needed breaks, information and advice.

To find your nearest Network Partner, call 0844 800 4361 or visit www.carers.org. Carers Trust also helps carers through interactive websites www.carers.org and www.youngcarers.net.



**Carers Direct
Free, confidential helpline: 0808 802 0202**

Carers Direct is the official website designed to help carers get the help and support they need as a carer. Carers Direct offer all the information you should need to get the financial help you're entitled to, as well as advice on getting a break from caring, going to work and much more.

You can call Carers Direct on 0808 802 0202 for free, confidential information and advice for carers. Lines are open 9am to 8pm Monday to Friday (except bank holidays), 11am to 4pm at weekends. Calls are free from UK landlines and mobiles.

You can also visit the following website:
<http://www.nhs.uk/CarersDirect/Pages/CarersDirectHome.aspx>

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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