



HELPING RELATIVES AND CARERS OF STROKE SURVIVORS OVERCOME DEPRESSION PROGRAMME



CEDArS

For Carers of Stroke Survivors

Helping You to Stay Well

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UNIVERSITY OF
EXETER





WELL DONE FOR GETTING THIS FAR

You have now completed all the steps that can help you to feel better and remain well. It is now important to try and make the strategies you have learnt in this programme part of your daily life so you can stay well in the future.

Over the last few weeks you have hopefully noticed your mood improve as you have started to engage in important and meaningful activities that can help bring your life purpose and help you to stay well. You may have started doing activities again that you had stopped doing for a while. You may have started new activities or begun working towards new goals. Hopefully you have started to regain some balance again in your life.

Helping You to Stay Well

It is important to think about what has been helpful for you during this programme so you can stay well in the future. There may be certain strategies you have learnt during the programme that have been helpful - it is really important to make these part of your daily life so that you keep well.

Experiencing setbacks, challenges and difficulties in life is normal. This can especially be the case when we are caring for someone with a stroke. Also, everyone experiences dips in their mood from time-to-time - this is perfectly normal and to be expected. However, it is important to keep an eye on your mood just in case you experience a dip and it doesn't improve on its own.

A good starting place can be to think about the signs and symptoms that may indicate you are not well, or coping as well as normal. These may be signs that you are experiencing low mood or depression again.





MY LOW MOOD WARNING SIGNS

It can be really helpful to write down the warning signs that may indicate you are experiencing low mood or depression. You can refer back to these signs if you feel you are struggling in the future.

It can be useful to think about your warning signs in terms of the 'vicious cycle' or 'downward spiral' we spoke about in the 'Introduction Booklet'. These are the changes in behaviours, thoughts and physical feelings that you experience when feeling depressed or low. Have a think about what your warning signs are and write them down. You may want to look back at the 'vicious cycle' or 'downward spiral' you put together at the beginning of the programme if you struggle with this.

Physical Feelings

Behaviours

Feelings





MY STAYING WELL TOOL KIT

Next it can be helpful to write down what activities, strategies or techniques you have found helpful in the programme with your low mood. You can then refer back to these in the future if you find your low mood or depression returning.

Remember: Simply experiencing any of these symptoms for a short time will be perfectly normal. However if you find yourself experiencing them for a while and it is beginning to have an impact on your life again then you may need to do something about it.



What activities helped me to feel better the last time I was depressed?

What techniques in this programme were particularly helpful?

What skills have I learnt during this programme?



CHECKING IN WITH YOURSELF

As you finish the programme it can be helpful to find a regular time to check in with yourself to see how you are doing.

You may find this useful to continue for a number of weeks after finishing the programme to help ensure you are keeping up the activities that have helped you to feel better and are making them part of your daily life so that you stay well.

My Check-In

- When will I check in with myself? E.g., every Monday morning
- How many weeks will I check in with myself? E.g., for the next 5 weeks
- What will I do during my check in? You may want to ask yourself the following questions.

What activities slipped?

What activities have I been able to keep up?

What has helped me to keep up these activities?





What has led to these activities slipping?

Am I experiencing any warning signs?

What could I do to help me start doing these activities again?

If so, what might it be helpful to do?





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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