

Dementia Family Caring

Developing personalised strategies to support mental health and well-being

Project Report

May 2023



'The aim of this project was to co-design, deliver and evaluate the effectiveness of a health and wellbeing programme for family carers of people living with dementia, to manage feelings of stress and anxiety.'

Background to the project – why we needed it

Family and informal carers have long made a significant contribution to the care of people living with dementia and continue to be the foundation of dementia care in Scotland. Family caring can bring positive and rewarding experiences for both care recipient and provider. However, due to the complex and progressive nature of dementia, family caring is often physically exhausting, associated with psychological harms, and loss of well-being (Alzheimer Research UK, 2015).

The number of unpaid carers of people living with dementia increased by over a third during the COVID-19 pandemic (Scottish Government 2020), with many carers doing more and experiencing increasing levels of physical and psychological distress. The disproportionate impact of the COVID-19 pandemic on both people living with dementia and on the levels of stress, trauma and anxiety experienced by family carers is likely to be long-felt. The need to create opportunities for family carers to develop personalised strategies for managing carer distress has therefore arguably never been greater.





Introduction to the project – what we did

Following a successful application to the 2022/23 Catalysts for Change project, funded by the Queen's Nursing Institute for Scotland (QNIS) and the National Lottery Community Fund, funding was received to support the testing of a six-week stress and anxiety management programme for family carers, on four occasions, over a 12 month period. The programme was co-led by Susan Holland, Alzheimer Scotland Dementia Consultant for NHS Ayrshire and Arran and Sheena Boyd, Alzheimer Scotland Dementia Advisor, East Ayrshire. Key support was provided from Project Development and Implementation Group members, which included local family carer representation. Consultancy support was also provided by the Depute Director of the Alzheimer Scotland Centre for Policy and Practice (ASCPP), University of the West of Scotland.

The programme was delivered from the Alzheimer Scotland Dementia Resource Centre in Kilmarnock, Ayrshire between April 2022 and March 2023. During each week of the six-week programmes, a 2 ½ hour programme session was facilitated, the design of which was as follows:

- 45 minute session: Decider Life Skills (Ayres and Vivyan 2020)
- 60 minute session: Practical stress and anxiety management activities including:
- 45 minute session: Reflection and peer discussion

Programme participants

Programme attendance was open to local family carers supporting relatives living with dementia, either at home or in a care home setting. Referrals were accepted from Community Mental Health Teams from across NHS Ayrshire and Arran and from the local Carers' Academy team.

Each six-week programme was able to accommodate a maximum of 6 family carers. Provision was also put in place to support the needs of the person being cared for, if this was required to support family carer participation in the programme.

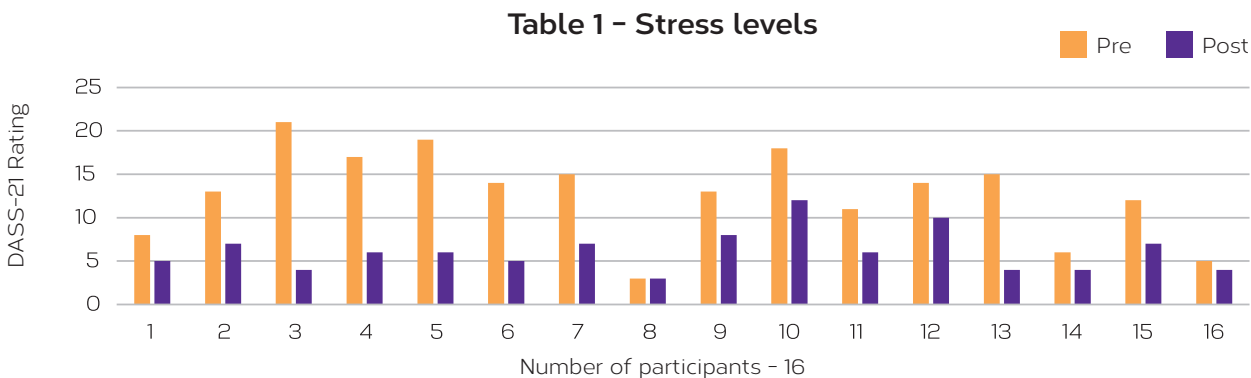
A total of 22 referrals were received during the 12 month test period. Twenty family carers accepted the opportunity to participate in the programme, although two had to withdraw due to health issues and two chose not to re-attend following attendance at Session 1 of the programme. A total of 16 people completed the programme, 5 of whom took up the offer of support for their relative with dementia during programme completion.



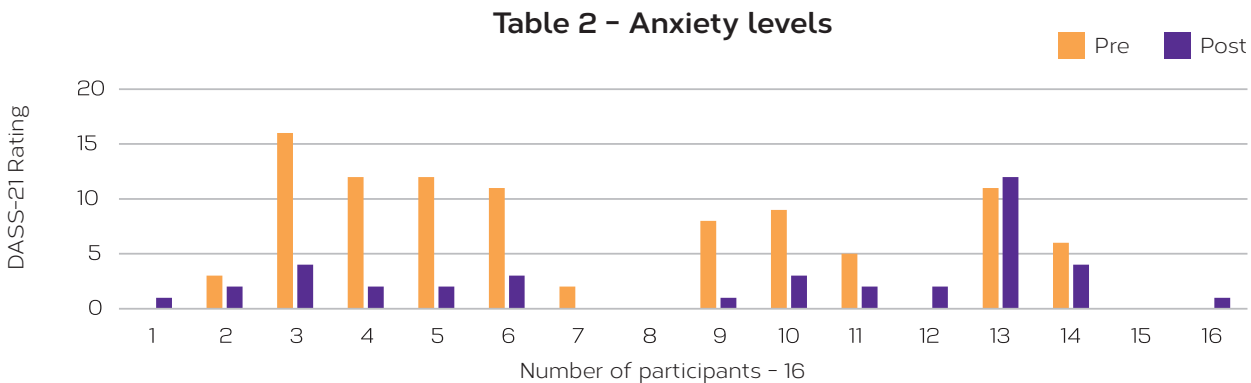
Programme evaluation

An assessment of psychological wellbeing was obtained by asking programme participants to complete the Depression, Anxiety and Stress Scale-21 Items (DASS-21) rating scale pre and post participation in the six week programme. Pre and post scores were compared upon programme completion and indicate that:

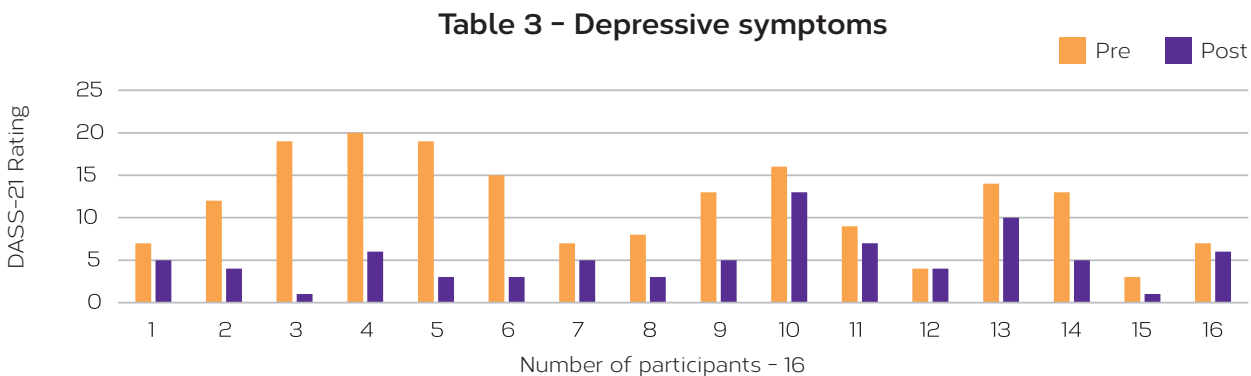
15 (97%) participants experienced a reduction in feelings of stress following programme completion. See Table 1:



10 (69%) of the 14 participants who reported experiencing feelings of anxiety experienced a reduction in anxiety symptoms following programme completion. See Table 2:



15 (97%) participants experienced a reduction in depressive symptoms following programme completion. See Table 3:

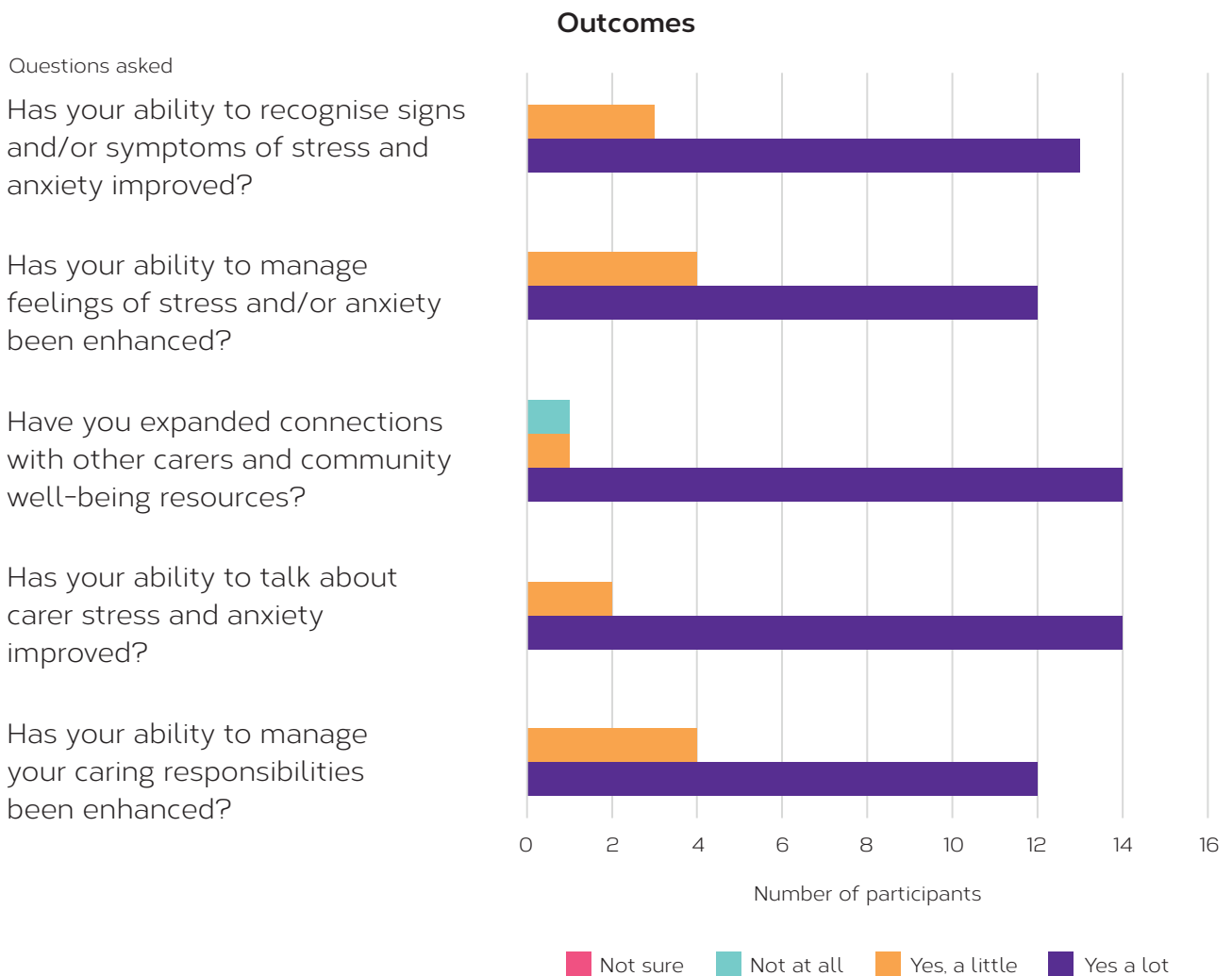


Programme outcomes

An assessment of the value and impact of each six-week programme was also obtained by asking programme participants to complete a pre-designed questionnaire at the end of each six-week programme session. Questions were designed to evaluate the success of the programme in meeting the following outcomes:

Participants will:

- Increase their ability to recognise signs and symptoms of stress and anxiety
Enhance their ability to use self-help strategies to prevent and manage feelings of stress and anxiety
- Expand connections with other family carers and community well-being resources
- Improve their ability to talk about carer stress and anxiety
- Enhance their ability to manage caring responsibilities
- 15 (97%) participants reported improvements across all 5 outcomes. See Table 4 for a summary of questionnaire findings.





Some examples of evaluation feedback from participants

Carers were able to notice warning signs of stress and anxiety and consider how they might mitigate these:

"It taught me to notice the signs of stress that I had ignored previously"

"I am more aware of the triggers and now I can stop myself and take a breath"

Stress in others was also recognised more quickly, especially when the situation was pressured or rapidly changing:

"I can now recognise signs of stress in others as well as myself when dealing with difficult situations"

The ability to empathise and respond differently to their loved one living with dementia was enhanced:

"I now try to look at things from my husband's point of view"

"It has made me able to understand and communicate with my mum so much better and as a result we are a lot happier"

We spoke to two of the participants, Linda and David who shared their thoughts with us on the course and the benefits it had for them.

Linda

I care for my husband who was diagnosed with Alzheimer's disease at 55 - he is 62 now. I worked for a while after his diagnosis but have been his full time carer for six years. The first five years were good - we had a dog and would go out walking but there has now been a decline. I do get respite through social work. I used to feel guilty, but I look forward to it now. Being a carer can be really difficult, you are always thinking of the next thing you have to do.

I heard about the project through coming to the Kilmarnock Dementia Resource Centre and through meeting Sheena (Dementia Advisor). She had said there was a course coming up that she thought I would enjoy and really benefit from. She was lovely and so supportive. I was keen as I thought it would be good to do something that would help me.

The activities were great. I never realised how much I would enjoy the painting - at the end of the day I thought 'I can paint!' I showed my daughter a picture and she

said, "you never did that!" It was a real confidence boost for me. It was good to just be part of a group where you are listening to someone and learning skills. I absolutely loved the Tai Chi. Every time we came out we all felt really uplifted, and I met some nice people that I would never have met otherwise. I've been trying to do Tai Chi for a while - there is a group on a Saturday morning, but I can't get a carer on a Saturday morning, so this was a good opportunity for me. I felt I did relax. I have tried to carry on some of the skills such as mindfulness at home when things are quite stressful, and I still do some of the Tai Chi moves. I did thoroughly enjoy the course, everyone was so supportive, and I would say to anyone else thinking of doing a similar course to just go for it.





David

I care for my mother who has vascular dementia that came on within the last four or five years. I am an only child so there's just me. It was very trying at first, but when I came to Alzheimer Scotland they explained a lot of things to me. It calmed me down a lot and helped me deal with the frustration. I was used to stress – I was a fireman for 30 plus years, but this hit me in a different way all together. When I came here, I saw I wasn't the only one experiencing these problems. I did a three week course in the Kilmarnock Dementia Resource Centre that helped with coping strategies. I then did some carer courses at the Carers' Academy at University of the West of Scotland which were great and made me understand the condition so much better. I wish I had this knowledge at the earlier stages of my mum's dementia. Really, the members of staff at the

Dementia Resource Centre have been a great support.

As I had benefited from the previous courses, I had no hesitation in signing up for the wellbeing course. I enjoyed all of the activities I took part in, like the Tai Chi, yoga, wellness and art.

Although I wasn't able to carry them on, I enjoyed them while I was here doing them. I looked forward to coming here each Tuesday to do the activities but more so to meet up with the other people on the course. I was on the first course that they did here and since then have met up with people from the group again. It was so nice to see them all! You realise that they are moving on and are able to move on, and that you are moving on and although there are still the same problems you are handling it better.



Conclusion

This project acted as a 'Catalyst for Change' at a local level, by formally bringing together health and social care staff, voluntary sector staff and education staff in a collaborative initiative to support the mental health and wellbeing of family carers of people living with dementia. To our knowledge this was also the first project at a local level which involved the use of the Decider Skills (Ayres and Vivyan, 2020) as a therapeutic intervention for family carers of people living with dementia.

The limitations of this project are recognised in terms of the limited number of people involved in the 12 month test period. Nevertheless, this project has demonstrated the potential for programmes such as these, to not only

improve outcomes for family carers of people with dementia, but also those they care for. We are delighted that the project was positively received by programme participants and that it proved to be an effective means of supporting family carers mental health and wellbeing. In sharing this report we aim to raise the profile and share learning about the mental health and support needs of family carers of people with dementia and the collaborative opportunities that exist to support these.

We would like to take this opportunity to say a special thank you to all the family carers and people living with dementia who shared this journey with us and to QNIS for supporting this project.



Reference Links for report

Scottish Government (2020) Dementia and COVID-19-National Action Plan to Continue to Support Recovery for People with Dementia and their Carers. Available: www.gov.scot/publications/dementia-covid-19-national-action-plan-continue-support-recovery-people-dementia-carers/

Alzheimer Research UK (2015). Dementia in the family: The impact on carers. Alzheimer Research UK: London. www.alzheimersresearchuk.org/wp-content/uploads/2019/09/Dementia-in-the-Family-The-impact-on-carers1.pdf

Decider Life Skills - Ayres M. and Vivyan C (2020). The Decider Life Skills Handbook 3rd Edition. www.thedecider.org.uk

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