

Research Summary

Healthy Parent Carers: a peer-led programme to improve health and wellbeing

This research summary was written by PenCRU and members of the PenCRU Family Faculty

Key findings

- Parent carers of disabled children are at greater risk of poor mental and physical health.
- Researchers and parents of disabled children co-developed a group-based health promotion programme for parent carers. It is purposely designed as a group activity led by parent carers.
- The programme aims to improve health and wellbeing by encouraging parent carers to take some time for themselves and engaging with activities associated with better health and wellbeing called CLANGERS: Connect, Learn, be Active, Notice, Give, Eat well, Relax, and Sleep.
- We tested the programme with an initial group of parent carers over six weekly sessions. Participants in the group felt the programme was valuable in building resilience and identifying specific strategies to deal with the challenges that parent carers commonly face.
- This study was too small to determine whether it is effective for improving health and wellbeing, but the results showed the programme could be delivered, appeared to be well received.

Who carried out this research and why?

The research was led by researchers at the University of Exeter Medical School and parent carers from the PenCRU Family Faculty public involvement group.

Why is this topic important?

Parent carers of disabled children tend to have poorer mental and physical health than parents of children without disabilities. They may experience high levels of stress and depression. They can find it difficult to look after their own health and take part in healthy activities or programmes.

Although many health promotion programmes exist, few are designed specifically for parent carers. Parent carers may find it hard to engage

with a programme if the activities or content are not perceived to be relevant, accessible, or if the facilitators and other participants do not share or understand their experiences and challenges. A bespoke programme tailored to parent carers' specific needs and circumstances is needed.

What was the purpose of the research?

The purpose of this research was to develop a programme to improve the health and wellbeing of parent carers, and find out whether it can be delivered and is acceptable to parent carers. This summary explains how the programme was developed and tested.

How were families involved as researchers?

Parent carers from the [PenCRU Family Faculty](#) proposed the idea for the project based on their

own needs and experiences. It built on our evaluation of peer support for parent carers. Thirty-nine parent carers joined a working group for the study, which met on 11 occasions, with some members contributing by phone or email. They were involved in the design of the programme, tested activities, and provided feedback on programme content, activities and materials, such as a printed guide for participants and video resources. They were also involved in refining the programme throughout the project.

What did we do?

We followed a systematic process called Intervention Mapping to design the programme. This involved clarifying the aims of the programme to meet parent carers' needs, and working out target behaviours and how these might be changed, programme content, and how to deliver the messages. The process also ensures that the sustainability and implementation of the programme is considered early on.

We followed the six steps below:



What were the aims of the programme?

The Healthy Parent Carers programme aims to improve the health and wellbeing of parent carers. It does this through:

- promoting behaviours or activities associated with health and wellbeing called CLANGERS: Connect, Learn, be Active, Notice, Give, Eat well, Relax, and Sleep;
- developing knowledge, skills, and strategies to take up these health-promoting activities and to overcome perceived barriers;
- providing peer support and opportunities for parent carers to share challenges and advice;
- promoting resilience, confidence, and empowerment of parent carers.

C	CONNECT: Take time to connect with people around you; take care of important relationships; renew old, and develop new, relationships that enrich your life.
L	LEARN: Keep learning; try something new; re-discover an old interest; set yourself challenges that you will enjoy achieving; notice your personal growth.
A	Be ACTIVE: Be active as a part of your daily routines; discover physical activity that you enjoy doing and one that suits you; try to sit less and walk more; be active with the family.
N	NOTICE: Take notice of the world around you; be mindful of what you are doing and how you feel; savour the moment; appreciate the beautiful; reflect on your experiences.
G	GIVE: Do something for someone; smile; say thank you; feel gratitude; give also to yourself – acceptance, care and a permission to do what is important to you.
E	EAT well: Choose and share food that is good for you; eat mindfully: notice the different smells, textures and tastes; understand your relationship with what and why you eat.
R	RELAX: Take time to relax and rest; do something nice; write down your tasks and worries; reflect on your day; feel grateful for the good things and let go of the negative ones.
S	SLEEP: Learn about sleep hygiene; identify reasons for any sleep problems; learn about and use strategies to improve the quality of your and your child's sleep.

How was the programme delivered?

The programme had 12 “modules” delivered in six group sessions. The Healthy Parent Carers programme has the following features:

- It is delivered in groups by two parent carers and involves individual and group activities.
- It is accompanied by resources including a printed guide and video clips.
- The content is organised into three parts:
 1. Understanding health and wellbeing and setting goals
 2. Taking steps to better health and wellbeing (i.e. CLANGERS)
 3. Planning for the long term

A manual has been produced which provides the facilitators with instructions for how to deliver each session of the programme. It also includes strategies for setting up the group, helping the participants feel comfortable, and encouraging group discussion and mutual support.

Seven parent carers not involved in developing the programme volunteered to take part in a study to test the programme. Six group sessions were held weekly at the university, led by two parent carers experienced in peer support.

What did parent carers think of the programme?

All participants completed questionnaires measuring their health and wellbeing before the programme, at the end, and two months after the programme was completed.

They were invited to provide feedback and suggestions after each session using an anonymous form.

A focus group was held with participants after the programme to discuss what they thought about the programme and how it could be improved.

Overall, participant feedback was very positive:

“It was really good. I came in not expecting much, to be honest. Not knowing what it would entail. I learnt a lot.”

“It’s brilliant, for so many different reasons, not just awareness, but the coming together of people.”

“There were times in my life when this [course] would have been a life-saver.”

The main benefits that parent carers mentioned were:

- developing confidence;
- realising the importance of taking care of themselves;
- becoming aware of CLANGERS;
- benefiting from peer support, including from supportive and understanding peer facilitators.

Participants liked the activities, but struggled with setting goals each week. They suggested that we train participants to set more easily achievable goals earlier in the programme.

Participants said that the six weekly sessions were acceptable to them, but would have welcomed further sessions as well. They suggested that the programme could be delivered to existing groups of parent carers.

Overall, there was a small increase in health and wellbeing scores and a small decrease in depression scores. However, it is not possible to draw conclusions from this small study about the effectiveness of the programme.

At least half of the parents found the sessions helpful and most were willing to make some changes. Two months after the end of the programme, four out of five participants reported making lifestyle changes and keeping in touch with fellow group members. However one participant said that she did not find that the group helped her to make changes.

What does the study tell us?

The academic paper describes the development and testing of the programme with one group of parent carers. The study showed that the programme could be delivered and was well received by parent carers. This study does not provide evidence that the programme improves parent carers' health and wellbeing.

What's next?

We have used the feedback from the participants in this study to make improvements to the Healthy Parent Carers programme.

The next stage of the research will investigate whether the programme can be delivered in the community through organisations that have links with parent carers. We also want to find out whether we can test the programme to see whether it improves health and wellbeing and whether it is good value for money.

Who reviewed our research?

The research paper is published in an academic journal called BMC Public Health. Before the journal accepted the paper to be published it asked independent experts to look at it and decide whether the research had been carried out properly and reported clearly, and whether it was important enough to publish. We revised the academic paper using their feedback.

Signposts to information

The NHS Choices website provides information about carers' assessments and eligibility for care and support services from the local authority:

<https://www.nhs.uk/conditions/social-care-and-support/carers-assessment/>

Contact's website provides information about other sources of local support for families with disabled children including parent support groups and parent carer forums: <https://contact.org.uk/advice-and-support/local-support-services/>

Carers Club includes a support guide and advice on healthy eating, physical activity, mental health, and relaxation for carers: <http://www.carersclub.org/>

Carers UK's website includes advice about health and nutrition for carers: <https://www.carersuk.org/help-and-advice/health>

The full version of the study is published in the journal [BMC Public Health](#).

If you would like a copy please contact us at pencru@exeter.ac.uk

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