



*Thank you for your interest in this research and taking time to consider participating.*

*Please read this information sheet carefully before deciding whether or not to take part.*

### **What is the Healthy Parent Carers programme?**

The Healthy Parent Carers programme aims to promote better health and wellbeing of parents of children with special educational needs or disability. The programme provides information about small steps that parent carers can take every day and that have been shown to be associated with better health and wellbeing. These are called CLANGERS – Connect, Learn, be Active, Notice, Give, Eat well, Relax, and Sleep;

The programme has been designed together with parent carers in the PenCRU Family Faculty, who are a group of families of disabled children interested in and involved in our research.

Please note that the *Healthy Parent Carers* programme focuses on valuing parent carer health and wellbeing and it is **not** a treatment for any specific health issues.

### **What is the aim of the study?**

This research will compare two ways to improve the health and wellbeing of parent carers, either by accessing a group programme or using online resources.

We will use the findings from this study to decide whether to run a larger study of the programme, which would evaluate whether it improves parent carers' health and wellbeing.

### Who can take part in this study?

In this project we are seeking:

- Primary carers of a child or young person aged up to 25 years with special educational needs or disability who want to do something to improve their own health and wellbeing.
- Participants willing and able to attend group meetings at specific venues in Devon, Cornwall, or Somerset on scheduled dates and be able to access information online.
- Participants who can communicate in English.
- Participants who can access online materials.

### What will participants be asked to do?

If you decide to take part, we will ask you to provide some details about yourself and fill in a questionnaire about your health and wellbeing.

You will be randomly allocated to receive either **the Healthy Parent Carers online materials** or to participate in a **Group programme**. We will send you a letter to let you know which programme you have been allocated to.

If you are allocated to the group programme, you will receive a phone call from your group facilitator before the programme begins. The group programme may be six weekly daytime sessions (4 hours each) or twelve weekly evening sessions (2 hours each). Participants will only be permitted to attend on their own; we cannot include children or partners at the group sessions.

If you are allocated to the online materials, you will receive a link and password to access online resources containing information and videos about health and wellbeing.

The questionnaire will be repeated at the end of the programme and six months later. This can be completed at home online. After completing the programme we may invite you to participate in a telephone interview to provide more detailed feedback.

### How much time will it involve?

**All participants:** Participants will be asked to commit to:

- completion of online questionnaire (approximately 1 hour) with a researcher present for support if needed
- completion of online questionnaire (one hour) at the end of the programme
- telephone interview (30 minutes) after completion of programme (optional)
- completion of online questionnaire (one hour) after 6 months

**Group programme:** Participants in the group programme will also be asked to commit to:

- six weekly sessions (10:00am to 2:00pm) or twelve weekly sessions (6:00pm-8:00pm) during the school term at a specific venue.

**Online resources:** Participants accessing the online resources will also be asked to:

- access online written resources (approximately 3 pages per module) and follow links to video and audio files (up to 15 minutes each) for 12 modules about health and wellbeing.

### Will I receive reimbursement for my time?

All participants in both groups will receive shopping vouchers as a thank you for your time completing the questionnaires. A £25 shopping voucher will be sent to you after completing the questionnaire at each of the three time points in the study and an additional £25 voucher will be provided for people participating in an interview. We are not able to reimburse travel, parking or childcare expenses as part of this research.

### What happens next?

If you wish to take part in the study, we will meet you and ensure you understand what is involved and check you are available to attend one of the programme groups and can access information online. We will ask you to sign a consent form. You will complete the first set of questionnaires. At a later date we will send you a letter to let you know whether you have been allocated to the group intervention or to access the online materials.

### What will happen to the results of this study?

We will write up the results of the study for an academic publication and plain language summaries to share on the PenCRU website. If you consent to the research team keeping your contact details until the results of the study are available, we will send you a summary of the results. We also plan to share the results at conferences and meetings with service providers or community groups. We will also use the results to plan a larger nationwide study to evaluate the Healthy Parent Carers programme across the UK.

### What data or information will be collected and what use will be made of it?

- 1) We will keep a record of your contact details in order to keep in touch with you about the study, send you reminders and study information, send you shopping vouchers, and to send you a summary of the results.
- 2) We will audio-record the group programme sessions. Your participation or engagement will not be judged in any way. Researchers will evaluate the delivery of the programme by the facilitator and think about whether the programme needs to be changed in the future.
- 3) We will collect data through questionnaires, and we will use it to understand the delivery of the programme and to plan a future study. Responses will be anonymised for the analysis meaning that they will be linked to an ID number, not your name. Nobody will be identified in any reports.
- 4) Some participants will be invited to take part in interviews, which will be audio-recorded. The recordings will be transcribed and analysed to help us understand how the programme and study worked, what was good about it and how we could improve it. False names will replace any real names mentioned.

Interviews will use questions that have not all been determined in advance, but will depend on the way in which the interview develops. The Medical School Research Ethics Committee is therefore aware of the general topics to be explored in the interview, but has not been able to review the precise questions to be used. In the event that the line of questioning does develop in such a way that you feel uncomfortable, you may decline to answer any particular question(s).

- 5) We may use extracts or quotes from the feedback forms or the interviews in published reports and articles, but these will not include any personal details or information that might be used to identify you.
- 6) All data, including your contact details, will be stored on password protected computers or in locked filing cabinets. Only the members of the research team at the University of Exeter Medical School will be able to access the data and your personal information. If you are allocated to the group intervention, the intervention facilitators will also have access to your contact details and personal information relevant to delivering the programme, such as accessibility requirements. Facilitators will not see responses to questionnaires.
- 7) After the project is finished, all paper copies of records will be scanned and destroyed at the end of the project. Your contact details, group session and interview recordings, transcripts, and any identifiable data will be kept for 5 years after the end of the study, and then will be destroyed. Anonymised data will then be stored in an online repository at the University of Exeter and may be analysed by other researchers in the future.

The University of Exeter processes personal data for the purposes of carrying out research in the public interest. The University will endeavour to be transparent about its processing of your personal data and this information sheet should provide a clear explanation of this. If you do have any queries about the University's processing of your personal data that cannot be resolved by the research team, further information may be obtained from the University's Data Protection Officer by emailing [dataprotection@exeter.ac.uk](mailto:dataprotection@exeter.ac.uk) or at [www.exeter.ac.uk/dataprotection](http://www.exeter.ac.uk/dataprotection)

### **How will my information be kept confidential?**

Your participation in the study and all data collected will be kept confidential unless there are any safeguarding concerns about which we are duty-bound to respond.

The questionnaires will be anonymised for the analysis, and what is said in the interviews will be typed out with any names and other personal information replaced with false details. This means that your name, your child's name, and any other personal details cannot be identified by anyone reading the published findings.

If you are allocated to join a group intervention, we will use the Chatham House Rule, "When a meeting, or part thereof, is held under the Chatham House Rule, participants are free to use the information received, but neither the identity nor the affiliation of the speaker(s), nor that of any other participant, may be revealed", to provide anonymity to speakers and encourage openness and the sharing of information. However, you will need to bear in mind when sharing personal information that there is always a risk that group members may breach these rules.

If you are allocated to attend group sessions, some venues will require participants to sign in for security and fire safety purposes. Venues will also have their own staff on site when group sessions are held, but they will not be present in the rooms during sessions.

### **What are the possible disadvantages and risks of taking part?**

We will ask you to complete questionnaires and may ask you to take part in interviews. If any of the questions that we ask make you feel uncomfortable, you may decline to answer any particular question(s).

Taking part in the programme involves thinking about your experiences and challenges as a parent carer. If during the course of this project we become concerned about your wellbeing we will discuss this with you. If we have any safeguarding concerns then we will be duty bound to contact a medical professional or our safeguarding officer.

### **Can participants change their mind and withdraw from the study?**

Participants may withdraw from the study at any time without giving a reason. You can decline filling in the questionnaires or taking part in the interview. However, feedback is

crucial in this study, so we will encourage everyone to participate fully. If you choose to withdraw from the study, you can request that your personal details and data be deleted. We will be able to delete all of your personal and contact details. We will only be able to delete your anonymised data up until the point when the analysis has been conducted (February 2020). We will also be unable to delete recordings or transcripts of group sessions that you were a part of as these will include data from other participants as well.

### What if I have any questions?

If you have any questions about the study, either now or in the future, please contact:

Chris Morris  
Peninsula Cerebra Research Unit (PenCRU)  
University of Exeter Medical School  
St. Luke's Campus, Magdalen Road, Exeter, EX1 2LU  
  
Tel.: 01392 722968, Email: [pencru@exeter.ac.uk](mailto:pencru@exeter.ac.uk)

### What if I have any complaints?

If you have any complaints about the way in which this study has been carried out, please contact the Chair of the University of Exeter Medical School Research Ethics Committee:

Ruth Garside, PhD  
Chair of the UEMS Research Ethics Committee  
Email: [uemsethics@exeter.ac.uk](mailto:uemsethics@exeter.ac.uk)

**This project has been reviewed and approved by the University of Exeter Medical School Research Ethics Committee. UEMS REC REFERENCE NUMBER: 18/06/174.**