

Information Sheet for Website

What is the aim of this study?

This study is being conducted as part of a doctoral qualification in Clinical Psychology at the University of Essex -Tavistock training programme

The aim of this study is to better understand how parents of children with congenital heart conditions make sense of difficult and distressing experiences during their child's treatment. We would like to find out how this affects them and how they cope.

Before you decide whether or not to take part it is important for you to understand what this study is about and what taking part will mean for you. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear. For further information on this study please contact Emily Tan on the contact details below.

Why have I been invited to take part?

We are inviting you to take part in this study because we understand from the Children's Heart Federation that you might be interested in this topic. We are looking for parents of children with a diagnosis of a congenital heart condition.

How do I get involved?

This is a two part study. The first part is open to all parents of children with a diagnosis of a congenital heart condition without any other diagnosed developmental disorders. This part of the study involves answering four quick questionnaires accessible only through an online link.

The second part of the study involves participating in an online discussion group. We are looking to hear from parents with a range of different experiences. We will select parents from those who have completed the questionnaires and are interested in sharing their experiences to form small online discussion groups. If you are interested in taking part in this part of the study you will be asked to leave an email contact address through the online link. It is possible not everyone will be selected to participate in an online discussion group. The discussion groups will be conducted through closed Facebook forums. You do not have to participate in the online discussion group if you do not want to.

How does the link to the questionnaires work?

The link will take you to an online dedicated survey page. Your responses will be kept secure and will only be accessible to the researchers. Only the information you enter into the survey page will be accessible to the researchers.

How do the Facebook forums work?

The discussion forums are closed groups so only other members of the same forum group and the researchers will be able to identify you from your posts. Please note that no names will be given out to anyone. This type of group is known as a "secret" group on Facebook. This means that only members of the group have access to the group and can see the group. The group will not be visible on your Facebook profile to other people on Facebook.

What will happen if I join the Facebook discussion forums?

If you would like to join the discussion forum on Facebook you will need to have a Facebook account. You will be asked to accept the Facebook administrator as a friend on Facebook. You will then be given access to the group and can begin posting in the discussion.

A new question is posed on the forum each week for 6 weeks and you will have a week to respond to the question. There is no right or wrong answers to these questions. We are interested in your perspective and thoughts on each question. You should also feel free to discuss the question with other people in the forum or comment on similarities or differences in perspective or experience.

The discussion forums will be moderated by Emily Tan and participants will be asked to adhere to the rules of the forum. Posts to the forum which break these rules may be removed and participants who repeatedly disregard the rules may be asked to leave the group.

After the discussion has been analysed the themes from the discussion will be posed back to the group for group members to comment on. After this the group will be closed. This means all the content of the group will be removed from Facebook by the group administrator. Then all members including the group administrator will be removed from the group. The group will no longer appear visible to you on Facebook. Facebook automatically deletes groups with no members.

Who is the study open to?

We would like to hear from parents over the age of 18, who are raising or have experienced raising a child diagnosed with a congenital heart condition.

What if I change my mind and I don't want to carry on with the study (I want to withdraw)?

If you choose to take part and then decide you would prefer to withdraw, then you can tell Emily Tan. You can leave the study at any time. You do not have to explain why and you do not have to give us any more information. This will not affect the support you receive from the Children's Heart Federation or any other services in any way.

If you do not wish us to use the information you have given us, we will destroy the information. If you wish to withdraw your questionnaire responses you can contact Emily Tan who will ensure that your data is removed from the study. You can also leave the Facebook discussion forum at any time. If you wish your posts to be removed from the forum and excluded from the study you can do this by contacting Emily Tan who will ensure that your posts are removed. You will also be removed from the group and will not have access to the group discussion posts.

How will the information be used?

The results of this study will be reported in a doctoral thesis. The findings will be used to develop better ways of providing parents with information about potentially distressing events and what they might feel. The findings may be presented through Children's Heart Federation website, in the media and in scientific reports and papers. We may use direct quotes in an anonymised form when reporting the results of the study in publications and presentations. A summary of the research findings will be sent to all the participants who wish to receive this at the end of the study.

Who has reviewed the study?

This study has been reviewed by The University of Essex Ethics Board (Ref. 14029)

What are the possible benefits of taking part?

There may not be any direct benefit to you of taking part but we hope that the results from this study will be used to develop better ways of providing parents with information about distressing events and what other parents have experienced. Some parents may find discussing their experiences with others in a similar situation helpful; however this is not the primary aim of the discussion group.

What are the possible disadvantages and risks of taking part?

There are no real risks or disadvantages to taking part. We should note that it is possible that important information relevant to this topic could come from bereaved parents. As such, some discussions may touch upon sensitive issues for some families. If you should feel uncomfortable talking about or reading other parent's experience of distressing events related to their child, or do not want to continue taking part you are free to stop at any time.

If you are affected by any of the discussions on the forum and would like to talk to someone you can contact the Children's Heart Federation Helpline 0808 808 5000 or email info@chfed.org.uk who will also be able to direct you to further sources of support if you wish.

What if there is a problem?

If in the event that there is evidence to suggest that you might be experiencing levels of distress which might pose a risk to your future wellbeing you will be contacted by the researcher by email and advised to seek professional medical consultation.

If you have concerns about the study, then you can speak or write to Emily Tan or her academic supervisors, details below.

Will my General Practitioner (GP) know I am taking part?

We do not propose to inform your GP about your participation.

Will my taking part in the study be kept confidential?

Your identity and participation in the study will be kept confidential. If you accidentally post personally identifying information to the Facebook discussion forum the moderator will remove the identifying information to protect your identity.

How will you store my data?

Your information will be anonymised and kept secure in an encrypted electronic format.

Further information and contact details

The study team are based at Essex University. If you would like to have further information about the study or wish to write or speak to someone about it, then please contact us:

Emily Tan, Trainee Clinical Psychologist

Email: ectan@essex.ac.uk

Dr Leanne Andrews, Academic supervisor

Email: landre@essex.ac.uk

Dr Fran Davies, Academic supervisor
Email: fdavies@essex.ac.uk

The School of Health and Human Sciences
University of Essex
Wivenhoe Park
Colchester, CO4 3SQ
Telephone: +44(0)1206 873910

What to do now

Please read through the information and talk about the study with family members, friends or colleagues if you wish. It is your choice whether to take part and you may contact Emily Tan on 0793 489 8789 or email ectan@essex.ac.uk if you need more information or would like to ask questions of talk to someone about the study before deciding.

If you have decided you want to take part...

If you wish to take part, then please click on the link to the questionnaires below

[Link to Questionnaires](#)

Thank you for taking the time to read this information