



Parent or carer perspective of a fatal asthma attack Participant Information Sheet

You are being invited to take part in a research study which will involve a face to face discussion lasting about up to 2 hours. Before you decide, it is important to know why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the research about?

Each day 3 people die from asthma in the UK. Although doctors and nurses know some of the reasons why people die from an asthma attack, very few researchers have asked parents to tell their story of what happened. We would like you to tell us about your child's asthma care, what effect asthma had on your lives, about your family home and living environment and what happened during the final attack. We hope to learn from you and make changes to the way we educate patients and families about asthma and how to manage attacks. Hopefully over time this will help prevent asthma deaths.

Who is organising and funding the research?



Ann McMurray is a PhD student from the University of Edinburgh and will be leading the discussions. She has worked as an asthma nurse specialist in the NHS for the past 16 years. She will be supervised by Dr Marilyn Kendall and Professor Steve Cunningham from the University of Edinburgh and Dr Louise Fleming from Imperial College, London. Ann McMurray's PhD is funded by the University of Edinburgh and is linked to the work carried out by the Asthma UK Centre for Applied Research.

Why have I been asked to take part?

You have been asked to take part as sadly your child, who was aged between 5 years old and 24 years old, died due to an asthma attack. This attack will have taken place within the last 10 years and you were with your child when it happened. We are keen to speak to families throughout the UK. If you would like to take part our researcher will confirm these details with you before we make any further arrangements.

Do I have to take part?

No, it is up to you to decide whether or not to take part. If you think you might be interested in taking part please contact the research team using the details at the end of this leaflet. They will be happy to answer any questions you have about the study and will organise to meet you for the discussion. If you decide to take part you are still free to withdraw at any time, and without giving any reason. Please just let the research team know you do not want to take part any more. You can do this by email, text or phoning. A decision not to take part, or to withdraw at any time, will not affect the standard of care you currently receive from the Health Service.

What will happen if I take part in the research study?

If you would like to take part our researcher (Ann McMurray) will arrange a suitable time to come and talk to you, at a place that is convenient to you. This will either be at your home or a local community venue. If you need to travel to a venue we will pay for your expenses.



This will be quite informal, where you will be encouraged to talk about your experiences. You don't have to answer all the questions if you don't want to – we are keen to hear your views in your own words. The discussion may last up to 2 hours, depending on how much we have to talk about. The researcher will ask your permission to record the discussion with a digital recorder so that the research team can listen to these and write them up afterwards. Your name and any other information that you provide in the discussion which might identify you will be removed or changed so that you can't be recognised.

Are there any benefits in taking part?

The discussion will involve talking about issues that are important to you and give you the chance to share your experiences. The study may not have any direct or immediate benefit to you but we hope that the information we get from you may help us develop better care for other people with asthma. There is still a lot of research required to stop asthma deaths and this is only a small study which will not solve the problem. We would however really value your input so we can start to improve our understanding of what happens during these fatal attacks.

Are there any disadvantages or risks in taking part?

Sometimes people can become upset when they discuss personal thoughts or feelings about issues which are important to them. The researcher will ensure that your thoughts and feelings are respected at all times. The discussion may take up to two hours which can seem like a long time so we will need to take some breaks, just let the researcher know and they will stop the recorder for as long as you need, or end the discussion there. You can take as many breaks as you need. We will also make sure that you know who you can contact for any advice, if you feel you would like, because of what you discussed with the researcher. These will include contact numbers for Asthma UK Nurses helpline, Child Bereavement UK, Cruse and your GP. If you are still upset after the discussion has ended the researcher will stay with you until a family member or friend can be with you. The researcher will contact you the following day to make sure you have some support in place or answer any questions you may have.

What happens when the research study stops?

After the discussion with the researcher, your involvement in the study will end. We will write up a summary of study findings and can send you a copy if you wish. In the future the anonymised transcripts of our discussion may be used in other ethically approved studies.

Will my taking part be kept confidential?

All the information we collect during the course of the research will be kept confidential and there are strict laws which safeguard your privacy at every stage. In order to monitor and audit the study we ask your consent for responsible representatives from the sponsors and NHS Institutions to access your data collected during the study, where it is relevant to you taking part in this research. The Sponsors are responsible for overall management of the study and providing insurance and indemnity. With your consent we will inform your GP that you are taking part.

Are there times when you may need to share my information with other professionals?

What you say in the discussion is kept confidential by the research team but you may say something that the researcher thinks should be shared with another professional or service or that the researcher believes they have an obligation to report. If you do say something like this, then after the discussion has ended the researcher may talk to you about sharing



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this information, and whilst preserving your confidentiality take advice from other members of the research team.

How will my information be stored?

After the discussion the encrypted audio recording will be sent to 1st Class Secretarial, a third party contractor for transcription. Once completed the typed transcript of our discussion will be stored on a password-protected computer. The recordings will be deleted after the study is completed. The transcripts may be archived in an anonymous form (this means without any information that could be used to identify you). Your name and address will be stored on an NHS computer network and you will be given a study number. The transcripts will be stored on a University network with your study number and will be stored for 5 years after the study is complete. All data is handled in accordance with the University of Edinburgh's data handling and storage policies. Any information that you provide to the research team and everything you say in the discussion will be kept strictly confidential. Your name and address will be kept separately from your interview. Only the researcher will see this information.

What happens if I don't want to continue the study?

If you don't want to carry on with the study you can withdraw at any time even after you have met with the researcher and had a discussion. Please just let the research team know that you do not want to take part any more. You can do this by phone or by email or text (simply send us a text/email with your name and write "Stop interview".) You do not need to give a reason. Taking part in the study, or not taking part in the study, will not affect the care that you currently receive from the Health Service.

What will happen to the results of the study?

At the end of the study we will send you a summary of our findings either by email or post. Findings will be presented at conferences, training events, published in a journal and will contribute towards the submission of a Doctorate in Philosophy degree (PhD). Quotes from the discussion will be used in publications however you will not be identified in any of these

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people called a research ethics committee. A favourable ethical opinion has been obtained from A favourable ethical opinion has been obtained from West of Scotland Research Ethics Committee 3 (WoSREC3). NHS management approval has also been given.

Who will sponsor the study?

The study is sponsored by the University of Edinburgh and NHS Lothian.

For further information on the study and to take part please contact:

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If you have any concerns or questions about any part of the research, you can speak with an independent person who is not involved in the study:

Julie Westwood, NHS Lothian

Julie.Westwood@nhslothian.scot.nhs.uk

0131 536 0773

Complaints – if you wish to make a complaint about the study please contact;
resgov@accord.scot

Thank you for taking time to read this information leaflet.