



PARTICIPANT INFORMATION SHEET

Study title: Research to design a course on seizure first aid for people with epilepsy and their family and friends

(REC reference no: 15/NW/0225)

1. Invitation paragraph

You are being asked to take part in a research study. Before you decide whether you want to take part, it is important for you to know why the research is being done and what it will involve.

Please read this information sheet carefully. If you wish to, you can talk about it with your friends and relatives. Ask us if there is anything you do not understand or if you want more information. You can take time to decide whether you want to take part.

2. What is the reason for the study?

People with epilepsy need to know what to do when a seizure happens. They also need to be able to tell others what to do. This is also true for the friends and family of people with epilepsy.

To feel confident to do these things, some people with epilepsy and family members have said they need more information about epilepsy and seizure first aid. They said they want to know more about the effects of seizures, how to deal with different types of seizures and know when they do and do not need emergency medical help.

Therefore, together with the *Epilepsy Society*, we have made a short course on seizure first aid that people with epilepsy and their family and friends can go on. The course is called Seizure First Aid Training.

Ambulance staff, neurologists, nurses and emergency medicine doctors helped us decide what information the course should give.

We now need to run some practice courses to find out what people with epilepsy and their family and friends think of the course. This will help us know if any parts of the course need changing to make sure it is as good as it can be.

3. Why am I being invited to take part?

We are looking for people with epilepsy to come to one of our practice courses in Liverpool with a family member or friend.

To take part in our study, people with epilepsy need to be aged 16 or over. They must have been diagnosed with epilepsy for 1 or more years and be prescribed anti-epileptic medication. They also need to have visited a hospital emergency department for epilepsy at some point during the last few years. The person can have any type of epilepsy and their seizures can be of any severity. As the Seizure First Aid Training course is given in English people only take part if they can speak, read and understand English well.

You are being invited to take part because we believe you fit this description. You, or a person that you know, contacted us after seeing our advert for participants.

4. Do I have to take part?

No. It is up to you. If you want to take part, you will be given this information sheet to keep, given the opportunity to have any questions answered and asked to sign a consent form.

If you decide to take part, you are free to change your mind at any time and you will not need to give a reason. A decision to stop taking part will not affect the standard of medical care you receive. No new information would be collected on you. However, any information that had already been collected would be kept by the study team.

5. What will happen to me if I take part?

If you agree to take part, a researcher will contact you to get you to sign a consent form. They will arrange for you and one of your family members or friends to come to one of the practice courses.

The course will happen in [INSERT MONTH] of this year. They last about 3 hours and will be held at the [INSERT NAME] centre. This is a specially designed centre for those with conditions like epilepsy. It is [INSERT SUMMARY OF LOCATION].

Each course will be given by a specially trained health professional from the charity, the *Epilepsy Society*. These people are typically nurses and will be able to help should a seizure happen.

The course will be run on a weekday. For the course you will need to go to the centre just once. The courses will typically start at [INSERT TIME] and finish at [INSERT TIME], with breaks included.

The research team will speak with you to find a course that is convenient for you to come to.

About 10 people with epilepsy and their family and friends will be at each of the courses.

During the course, the health professional will give lots of information about epilepsy and show some video clips. The things that the course will cover include:

- How common epilepsy is
- Its causes and some myths about epilepsy
- The tests doctors use to diagnose it
- The different types of seizures and their effects
- How to deal with different seizures, including when to call an ambulance and how to help paramedics help you
- How to improve your confidence and tell others what to do if a person with epilepsy has a seizure.

At the course, you can ask questions. If you want to, you can also share your experiences with the other people.

Everyone taking the course is given an information pack to keep. It includes all the things talked about on the course. It also gives the details of support organisations.

As we have said, the main reason for this study is to see if any part of the Seizure First Aid Training course needs changing to make it better. To help us do this, we want to hear participants' views of the course. Therefore, straight after the course, our researcher will spend about an hour with you and the rest of the group to hear your thoughts. This group talk will be audio-recorded to give an accurate record of the conversation.

6. Expenses

We do not expect that you will have any expenses from taking part in our study. If needed, we can pay for a taxi to take you and your family member or friend to and from the course. We will also provide refreshments for you. Each participant will also receive a £10 shopping voucher to thank them for their time and effort.

If you decide to take time off work to go on the course, we will not be able to pay you or your employer.

7. Are there any benefits in taking part?

We hope you and your family member or friend will get helpful information on epilepsy and learn some things that may increase your confidence to deal with seizures. However, this cannot be guaranteed. The information we get from the study may help us better support people with epilepsy in the future.

8. Are there any risks in taking part?

There are no known risks of taking part.

Taking part in the study will not change the care you get for epilepsy. Your medicines will stay the same and you will see your usual doctors and nurses as normal.

The Seizure First Aid Training course and the group chat afterwards will involve thinking about epilepsy and feelings. For some people, this may be upsetting. You can stop taking part in the course or the group chat at any time. This would not affect your medical care.

If taking part in the study makes you worried about your feelings, you could talk to your GP. You can also ask the health professional giving your course for advice. However, they would not be able to refer you to any NHS service themselves.

9. Will my taking part in this study be kept confidential?

Yes. Anything that we publish or pass on will have your name and address and any personal information removed so that you cannot be identified. All information will be stored on password protected computers at the University of Liverpool. Your participation will not affect your medical care.

Only the research team will be able to see the information will collect on you. This includes the audio recordings.

With your permission, we would want to tell your GP about your taking part. We would also need to tell your GP if the health professional giving your course or our researcher becomes worried about your health. However, we would talk about this with you first.

The Seizure First Aid Training course is given to groups of about 10 people with epilepsy and their family and friends. Because of this, we cannot promise that other participants will not share information about one another outside of the group. To lower the chances of this happening, we will get all participants to sign a form. This will say that they agree that anything they hear about other participants should not be talked about outside of the group. The health professional giving the course will remind participants of this at the start.

10. What if something goes wrong?

The University of Liverpool has insurance cover just in case you experience a problem from taking part. If you are worried about anything to do with the study, you should contact the research team. Their details are at the end of this sheet.

11. What will happen to the results of the study?

The results from this study will be used to see if any changes to the Seizure First Aid Training course are needed. They might also be published. You will not be identified in any publication. If you would like to have a copy of the published results, you can ask for one by contacting the study team.

All information generated by this study, including the transcriptions from the focus groups, will be held on password secured computers at the University of Liverpool offices. In line with the university's policy, data will be archived at the University of Liverpool for of at least 10 years, longer if judged to be of historical significance. After this period the data will be destroyed.

12. Who is funding and organising the study?

The study is funded by the National Institute for Health Research. The study is being done by the Institute of Psychology, Health and Society, The Whelan Building, University of Liverpool, L69 3GL. The lead researcher is Dr Adam Noble.

13. Who has reviewed the study?

This study has been reviewed and approved by National Research Ethics Service Committee North West - Liverpool East (Reference: 15/NW/0225).

14. Contact for further information:

Should you need further information about the study you can contact the research team at any time:

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You will be given a copy of this information sheet and a signed copy of your consent form to keep.