EPILEPSY FIRST AID TRAINER MANUAL

Seizure 1st Aid Training for People with Epilepsy and their Significant Others

This manual provides a script for trainers to follow. The purpose of this narrative framework is to promote consistency across trainers in course delivery

Contents

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Seizure First Aid Training Course

Introduction:

- It important to standardise what is said to participants and ensure that roughly the same things are covered with participants regardless of who the trainer is leading their session. This way we can ensure quality for all patients and carers.
- This manual provides a rough script for those delivering the course to follow. The course will work best if the participants interact and ask questions and so the script should not necessarily be strictly adhered to. There is certainly room for you to put your own impression onto the course's delivery.
- The script is presented in line with the slides that you should show and is also shown in the speaker's section of the PowerPoint slides.

Main purpose of session:

- To provide people with epilepsy and those who support them with a practical view of how to manage seizures, including what to do and what not to when seizures occur.

Materials required for delivery:

- Course computer, projector and speakers for videos
- Electronic copy of PowerPoint slides
- Participant information packs (~20) and additional leaflets
- Flip chart and pen for recording participant expectations of course
- Laminated activity sheets and cards for patient story activity
- Kindness Questionnaires sufficient in number for participants (~20)
- Course mobile phone so participants who are lost can contact trainer if needed and in case of emergency
- Participant register
- Participant feedback sheets

Slide 1: Epilepsy Seizure First Aid Training

(0 / 0 mins)

[Script – N/A]. Simply have this slide showing on the screen as participants arrive so they know they are in the correct location.

Slide 2: Welcome

(5 / 5 mins)

- Welcome everybody and many thanks for coming today. I hope everyone has had a chance to get refreshment and to sign the register of attendance.

- Before we start today's training session on epilepsy seizure first aid, there are a few housekeeping things I need to mention:

  - This session will run from X [insert time] to Y [insert time]. We shall have two coffee breaks through the course for about 10 minutes each.

  - Now should you need a break at all during the course or have any questions do please feel free to ask. In case you have not seen them, the toilets are located at X [insert].

  - Finally, [we are/ are not] expecting a fire alarm test today and so if you hear an alarm we shall need to leave this room and go to X [insert].

- Now you might have epilepsy yourself, or know someone who does. Either way, we hope that you will find this training session helpful.

- As you may already know there are lots of different types of epilepsy and everyone is individual. This means that some of things we say today will be important to you, but some things may not.

- Today’s course is designed to give you information about epilepsy first aid. This means you should feel free to ask questions and share your opinions.

- Because today’s session will work best if everyone feels comfortable to share their opinion and sometimes personal experiences, it is important that we agree from the start that any personal details people speak about during this session are respected by us all and kept confidential by not sharing any personal information about anybody else outside of this room. Does this sound okay to everyone? ...

Slide 3: Taking on what is said today

(10 / 15 mins)

- Now today’s session will involve me giving you lots of information. Some you might know already, but some may be new to you.

- Don’t worry about the possibility of not remembering things…in order to help you take on what is said today we are going to give you paper copies of everything that is talked about. You will also be given a website address where you can see everything that will be shown to you today.
- Now we tend to remember things best when we are in a positive frame of mind. Therefore, to further help you take on what is said today we are going to individually, each do a little task to help us get into a positive frame of mind.

- This involves completing a short [kindness] questionnaire **[Hand out COPIES OF KINDNESS QUESTIONNIARE]** It only takes a couple of minutes to do and asks you to think about some nice things you might have done in the past.

- I would like you to have a go at completing the task. After you have done it, we shall then start the training sessions.

- Don’t worry about your hand writing or anything like that as the answers you give are just for your eyes and we shall be talking about them and you will get to take the paper home with you.

- *(Note to trainer: We do not need to collect the completed questionnaires. It is the act, rather than the questionnaire answers that is important. If person refuses to do it, then there is nothing that can be done about this.)*

Slide 4: Goals of this course

(2 / 17 mins)

By the end of the session we hope you will:

- Feel more confident to manage your seizures/ the seizures of someone you know
- Know how to tell others how to help
- Know some things that may reduce the chances of a seizure
- Know some things that may reduce the chances of injury from a seizure
- Manage your epilepsy and reduce the chance of having a seizure

- You will also be given an information pack. This will include copies of everything you hear today so you can remind yourself of what was talked about, as well as some further information on other topics

- As part of today's course I am going to run through lots of things with you. However, we want today's session to be quite interactive and meaningful to you so…please feel free to ask questions if you have any

- The course will be most helpful and work best if people feel relaxed and able to share their thoughts and experiences of living with or being affected by epilepsy. Because of this is it is important we agree from the start that anything people say during this course should remain confidential and that we should not share it with other people outside this group

- Now you might be here today because you yourself have epilepsy or because you know someone who does. Either way some of the information you hear today will be relevant to you, whilst some may not. This is because people's epilepsy and personal situation can be different from someone else's

Slide 5: What would you like from today?

(5 / 22 mins)

- In order to try to help me make sure we cover the things you might be interested in hearing about, I would like to hear from each of you if there is anything in particular you want to get from this course

- I shall go around the room. As we go around it would be nice if you could each tell us your name, whether you have epilepsy yourself or know someone who does, and tell us anything you would like to get from today. We shall then note down these things and come back to them later

(Note to trainer: Establish expectations of participants, note these down, confirm whether they will be met during the session to some extent, and then at 'main message from today slides' relate back to these expectations to see if patients / others need directing elsewhere).

Slide 6: True or false quiz

(2 / 24 mins)

- To get us started, let's have a quick quiz…

- There are lots of myths and truths out there about epilepsy. Some things that are talked about are right, but some are wrong

- I am going to put some sentences up on the screen. I would like you to tell me whether you think it is true or if it is a myth – so false

- Don't think about it too much, just tell me the first thing that comes to mind. Don't be worried if you don't know the answer.

- The first statement is:

Slide 7: True /false (1) - Not many people have epilepsy

(2 / 26 mins)

- **"Not many people have epilepsy."**

- What do you all think? Please put your hand up if you think this is true? Now, who thinks it is a myth – so **false**

- The answer is that this it is False… Epilepsy is actually one of the most common health problems. In fact, about 50 million people around the world have epilepsy

- In the UK alone there are around 600, 000 people. Roughly speaking, this means that for every 100 people in the UK, 1 will have epilepsy

Slide 8: True /false (2) - Anyone can develop epilepsy

(2 / 28 mins)

- So what about this one: **"Anyone can develop epilepsy."**

- Please could you put your hand up if you think this is true?

- It is actually **True**.

- Epilepsy can affect people of both sexes, and all of ages, races, social classes and religions. Epilepsy is, however, most commonly diagnosed in children and older people.

- Because epilepsy can affect anyone, it is important to remember that there are also lots and lots of people with epilepsy who have done really special things for the world. Does anyone know of any famous people who also have epilepsy?

- Some include:

    - Julius Caesar, Roman statesman
    - Napoleon, French emperor

    - Alfred Nobel, founder of the Nobel Peace Prize
    - Dai Green, the British Olympic hurdler

Slide 9: True /false (3) - Epilepsy is caused by evil spirits

(2 / 30 mins)

- **"Epilepsy is caused by evil spirits"** Who thinks this is false?
- **It is False – This is a myth.**
- Epilepsy is nothing more than a problem caused by brief disturbances in the brain
- It is what we call a neurological disorder. Some people used to believe that epilepsy is caused by evil spirits, curses or possession. None of this is true at all
- One reason people think this is that seizures can be dramatic and scary to see and sometimes people's imaginations have got the better of them
- It is also impossible to "catch" epilepsy from someone else as epilepsy is not contagious. Epilepsy is also not a sign of madness

Slide 10: Epilepsy, sz's & how the brain works /video

(10 / 40 mins)

- As we have heard epilepsy is a neurological condition – meaning it is a health condition that involves the brain and the nervous system
- We are now going to watch a short video that tells us a little more about epilepsy. It also shows the main types of seizures and says what can be done to help. The video is presented by a neurologist who is from the Epilepsy Society

- After the video we are going to have some tasks based on what should be done to help someone who is having a seizure, so please try to watch as carefully as you can.

- The video lasts about 10 minutes and so try to get yourselves comfortable and make sure you can see the screen.

Slide 11: First aid for convulsive seizures

(10 / 50 mins)

- So, we have seen some examples of the main types of epilepsy and we have also heard about how we can help someone who is having these different kinds of seizures.
- Now when people think about epilepsy, it is usually convulsive seizures that come to mind. These are the ones when the person will lose consciousness, fall to the floor and shake. When the shaking has stopped, the seizure has usually stopped.

- I would like us to now talk some more about how to help someone who is having a convulsive.

- When we think about how we can help someone who is having a seizure, we can think about:

1. Firstly, what one should to help whilst the person is having the seizure
2. Secondly, about what we should NOT do when the person is having a seizure, and

3. Finally, we can think about what we can do once the person's seizure has stopped

- I am going to split you into 3 smaller groups and I am going to give each group a different thing to think about

- Group 1 – will be from [*identify the people to be included in G1*] -. I would like your group to have a think for a few minutes (~5 mins) about what you think someone should do to help a person when the seizure is happening. I am going to give you this blank page and a bunch of sentences. I would like you to choose the sentences which you think are the things someone should do if they saw someone having a seizure.

- Group 2 – will be from [*identify the people to be included in G2*]. I would like you to think in you group for a few minutes about the things a person should definitely NOT do if they saw someone having a seizure. I am going to give you this blank page and a bunch of printed sentences or statements. I would like you to choose those which you think are the things someone should NOT do if they saw someone having a seizure.

- Group 3 – will be from [*identify the people to be included in G3*]. I would like you to think in your group about what a person should do to help a person after the person's seizure has finished. I am going to give you this blank page and some statements. I would like you to choose those which you think are the things someone should AFTER the seizure has finished.

- If each group can talk amongst themselves and choose the sentences which they think are right for the question their group have been set.

- After about 5 minutes I will ask your group to tell everyone else what answers you came up with and we can see how well your answers come up with what is recommended by doctors and nurses.

- *(Note to trainer: Group work now happens. This might require facilitation, clarification and encouragement from you. The main idea is to try to elicit their views and when the group as a whole comes back together for any incorrect views to be challenged, delicately).*

- Thank you everyone. So now I want to go around the different groups and hear what ideas you have come up with and see if they match the right answers which doctors give. We can also then talk about differences and why doctors recommend what they do.

Slide 12: What can you do to help someone during a seizure?

(5 / 55 mins)

- So Group 1 – you were asked to think about what someone should do to help a person who is having a convulsive seizure whilst the seizure is happening.

- So what statements did you come up with?..... *[ask for spokes-person or does everyone want to pitch in?] …*Ok thank you.

- Let’s see if your answers match what health professionals say. Doctors and nurses say that you:

1. **Stay calm**; it can be upsetting and scary to watch someone have a seizure, particular a relative or friend, but remember that this person is unconscious and not in pain. Many people will not remember what happened during their seizure.

During tonic-clonic seizure the person will go stiff, lose consciousness and then fall to the ground. This is followed by jerking movements. A blue tinge around the mouth may occur. This is due to irregular breathing.

Stay with them until they have woken up again and are speaking and breathing normally.

2. **Allow the seizure to happen**

3. **Look around** - is the person in a dangerous place? If so, move them away from anything that could cause injury – such as a busy road or hot cooker. If they are not in danger, don't move them. Move objects like furniture away from them. If they don't collapse but seem blank or confused, gently guide them away from any danger. Speak quietly and calmly

4. **Note the time the seizure starts**. Do this by looking at your watch, a clock or phone. Do not simply try to guess. Watching a seizure can be upsetting and this can make us often think a seizure has lasted longer than it has. Most seizures will stop by themselves and most people’s seizures usually last the same length of time

If a convulsive (shaking) seizure doesn't stop after 5 minutes, call for an ambulance (dial 999). If they have emergency medication and you know their care plan, you could administer this

5. **Cushion their head** with something soft if they have collapsed to the ground – such a coat, a blanket. You could even “cup” their head with your hands

6. **Loosen any tight clothing around their neck** – such as a collar or tie, to aid breathing

7. **Look for an epilepsy identity card or identity jewellery** – This could tell you what sort of epilepsy they have, what sort of seizures are normal for them and the telephone number of a relative or friend to call if they have a seizure. Some mobile phones have an 'Emergency ID' section where you can store details about your epilepsy and contact details to be used in an emergency (& can be accessed even if the phone is password protected). Not everyone will know about these schemes, so it is recommended to have other methods also in place to help keep your safe

8. **Stop people crowding around.** If the person has a seizure in a public place, people will often stop and stare. Some may want to help and want to know if they can do anything. If you can, ask these people to move along. Try saying something like "He/ she is just having a seizure, please could you give us some room and move along". When the person has had the seizure it is much nicer to know that everyone has not been staring at them

Slide 13: What not to do during a seizure

(5 / 60 mins)

- So Group 2 – you were asked to think about what someone should **not do** if they saw someone having a convulsive seizure.

- So what statements did you come up with?..... Ok thank you.

- Lets see if your answers match what doctors and nurses say:

1. **Don't hold them down**. Restraining them may cause injury to the person having the seizure or the person holding them. A seizure is caused by a disruption in the brain and so cannot be stopped by holding the person. Holding someone down may also make the person more confused and upset. People are not usually aggressive on purpose during a seizure, but holding them down may make things worse. If a person tries to walk around, let them walk in a safe, enclosed area if possible.

2. **Don't put anything in their mouth** or try to do anything to their mouth or tongue. People often try to do this because of the incorrect belief that people can swallow their tongue during the seizure. The truth is that the bottom of our tongue is attached to our mouth and so this is impossible. Putting something in someone's mouth could seriously harm their teeth and gums, or it may block their airway and can cause them breathing difficulties. In fact, you might even be bitten. Jaw and face muscles may tighten during a seizure, causing the person to bite down. The person might

sometimes bite their tongue or the inside of their cheeks during the seizure, but this will heal. Putting an object in their mouth could cause more damage.

3. **Don't try to move them** unless they are in danger

4. **Don't give them anything to eat or drink** until they are fully recovered; If a person is not fully awake or aware of what is going on, they might not swallow correctly. Food, liquid or pills could go into the lungs instead of the stomach if they try to drink or eat at this time.

5. **Don't attempt to bring them round.**

Slide 14: What to do after the seizure has stopped

(5 / 65 mins)

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- So Group 3 – Most seizures are short and stop by themselves.

- You were asked to think about what someone should do after the seizure has stopped to help the person with epilepsy.

- By stopped, I mean once the shaking or convulsing has finished. For most people the shaking will stop by itself and last only 1 or 2 minutes. The person will then begin to slowly return to consciousness. They may fall asleep.

- So what statements did you come up with?..... Ok thank you.

- Lets see if your answers match what doctors and nurses say:

1. **Checking breathing** – Usually, once the person has stopped shaking, their breathing goes back to normal. If after the shaking has stopped the person's breathing sounds difficult or noisy, gently check their mouth to see that nothing is blocking their airway, such as food or false teeth. If there is something blocking their airway try to gently remove it if it is safe to do so. You could also wipe away any spit around their mouth. If their breathing continues to sound difficult or has stopped, call 999 immediately for an ambulance.

2. If their breathing has returned to normal and you do not think that the person may has damaged their neck, back or any part of the spine, gently put the person in the **recovery position**. At this point they will usually be very dozy and fairly easy to move. We shall talk about the recovery positon some more in a moment. In short, it means rolling the person onto their side to help make their breathing easier.

3. **Minimise embarrassment** – When they have a seizure some people may wet themselves or lose control of their bowel. If this happens, try to minimise embarrassment by placing a coat or a jumper over the person's lower half

4. **Stay with the person until they have recovered**. As the person is coming round, they may be confused, so try to comfort them. The person may feel embarrassed or confused about what happened. Keep this in mind as the person wakes up. Reassure them that they are safe. Once they are alert and able to communicate, tell them what happened in very simple terms. Offer to stay with the person until they are ready to go back to normal activity or call someone to stay with them.

5. **Check they have not injured themselves**

6. In most cases a seizure will be short, stop by itself and **the person will NOT usually need to go to hospital.** Most people will usually only need reassurance and the chance to sleep and recover. In such situations the person will not receive any different care at hospital than they would at home. Most people prefer to recover at home, rather than having to go to a busy, noisy hospital, waiting around and having to have lots of tests and answer lots of questions.

7. **Make a note of what happened during the seizure**, as this may be useful for the person or their doctor and also of what they're like afterwards (e.g. sleepy, confused, or aggressive), and record how long the seizure lasts.

Slide 15: When to call an ambulance?

(10 / 75 mins)

- After most seizures, a person with epilepsy does not need emergency medical attention. However, sometimes it is entirely right to call for emergency medical attention when someone is having or has had a seizure.

- The following are medical emergencies and medical attention is needed. 999 should be called and the person taken to the hospital emergency department.

1. **When the seizure doesn't stop after 5 minutes –** Seizures lasting longer than 5 minutes do not tend to stop by themselves and the person will need to receive medication to make the seizure stop. Seizures that do not stop by themselves are a medical emergency and potentially life-threatening. If the person receives medical attention, most can be successfully treated and the person can recover well. Some of you might have had a seizure like this. It has a special name – status epilepticus.

2. **When one seizure follows another with no recovery in between –** sometimes these are called "cluster seizures". Here the person will have one convulsive seizure after another, with no recovery in between. What we mean by there being no recovery in between is that the person will not get a chance to return to their normal self before they go on to have another.

[Note to trainer: Response to the question - What is status epilepticus?

Sometimes a seizure does not stop by itself. When a seizure is very long or one seizure happens after another without the person recovering in between this is called status epilepticus (or 'status'). If a seizure carries on for more than 5 minutes then this is considered to be a medical emergency and you should call an ambulance. Emergency medication may need to be given to stop the seizure. If the seizure doesn't stop it could cause lasting damage to the brain, or even death… If you are concerned about 'status' you might like to talk to your neurologist about what the possible risks of 'status' mean for you]

- If you have experienced a seizure that lasts longer than 5 minutes or you have seizures that tend to happen one after the other without a chance for you to recovery in between, you might have been prescribed a special emergency medication that you can be given if this happened again. Research shows that emergency medicines, given when a seizure has lasted five minutes, can stop seizures turning into status epilepticus.

- There are 2 types. The older one is Diazepam which is given to the person via the rectal/ back passage. The newer one is midazolam and this is given by placing squirting the medication inside their cheek or nose. If somebody uses a wheelchair, then they will probably have been prescribed midazolam as this is easier to administer

- If you not been prescribed emergency medication, but you do have a history of having seizures that last more than 5 minutes or seizures that tend to happen one after the other without a chance for you to recover, you might like to speak to your epilepsy doctor or nurse to see if it might be suitable for you. If you are, you will need to receive a prescription and you will need to get some training in the use of the medication. In your packs there are two leaflets that provide you with more information about the two types of emergency medication

3. **When someone has any difficulty in breathing after the seizure**

4. **When someone has injured themselves badly during or following a seizure –** such as having burnt themselves, dislocated something, cut themselves. People will often experience small bumps and bruises and these typically do not need medical attention

5. **If the seizure has happened in water**

6. **If it is their first ever seizure –** An ambulance should also be called if it is the persons first ever seizure. This situation does not however apply to anyone in this room as you have all already been diagnosed with epilepsy

7. **If you feel they need medical attention**

Slide 16: Questions or comments?

(5 / 80 mins)

- In a moment we shall talk some more about the recovery position. Before we do this, does anyone have any questions about how to manage different seizure types or comments that they would like to make. Was there anything on the cards that you disagreed with or felt was missing?

Also, does anyone have any concerns about managing seizures or fears that they would like to raise?

[Note to trainer: Scripted responses to two potential important questions that might arise, but which we shall not routinely cover unless prompted to do so by a particpiant on the day:

Q1: Can seizures cause brain damage? *As we get older we all experience some brain cell loss. The potential for seizures to increase extra loss of brain cells is not clear and may depend on the type and length of* *seizure(s) an individual has. Quite often memory can be affected during or after a seizure. This can be because the brain cells in parts of the brain responsible for memory can be sensitive to the effect of seizures. Recovering one's memory can vary from one person to another, and even after fully recovering from a seizure, some people's memory might be permanently affected…* ***talk to your neurologist or doctor if you are concerned about how your epilepsy might affect you****.*

Q2: Can seizures cause death? *Epilepsy, <u>as with many other medical conditions</u>, carries a risk of dying for some people. In the UK there are around 1,000 deaths related to epilepsy a year. The cause of these deaths varies and may be due to complications during or after a seizure, as a result of accidents, suicide or the underlying medical reasons for someone's epilepsy… talk* ***to your neurologist or doctor if you are concerned about how your epilepsy might affect you****.]*

Slide 17: Refreshment

(10 / 90 mins)

- Duration - 10 minutes

Slide 18: Recovery position

(2 / 92 mins)

- If a person is unconscious or asleep but is breathing after a seizure and you do not think that the person has damaged their neck or their back, they should be placed in the recovery position

- The reason we do this is it will help their airway remain clear and open. It also ensures that any fluid will not cause them to choke

- The main aim is to gently roll the person onto their side

- We are going to first watch a video of the recovery position. I shall then ask for volunteers so that we can go through this process using some slides on the screen to help us do it step by step

Slide 19: Recovery position - video

(2 / 94 mins)

- Play video: Duration 2 minutes

Slide 20: Let's practice the recovery position (1)

(2 / 96 mins)

- In the video we heard about the recovery position. The recovery position can help someone recover after a convulsive seizure. You should put the person in the recovery positon if their breathing is normal and after the shaking or convulsing has stopped, not during

[Note to trainer: you may first need to move the tables to make some room...]

- Ask for 2 volunteers for the practice demonstration of the recovery position

- I shall talk you through the steps one by one. I shall also show you some photos on the screen to help you

- Please feel free to ask any questions you may have during the demonstration as it is important that you can feel confident doing this and also know how to teach other people who are not here today – like friends and family

Slide 21: Let's practice the recovery position (2)

(8 / 104 mins)

- There are 6 steps and we shall do these together. They are on the slide now

- So Step 1: Please Kneel on the floor to one side of the person who is on the floor and pretending to be unconscious

- Step 2: Place the person's arm that is nearest you at a right angle to their body, so it is bent at the elbow with the hand pointing upwards. This will keep it out of the way when you roll them over

- Step 3: Gently pick up their other hand with your palm against theirs (palm to palm). Now place the back of their hand onto their opposite cheek (for example, against their left cheek if it is their right hand). Keep your hand there to guide and support their head as you roll them

- Step 4: Use your other arm to reach across to the person's knee that is furthest from you, and pull it up so that their leg is bent and their foot is flat on the floor

- Step 5: Gently pull their knee towards you so they roll over onto their side, facing you. Their body weight should help them to roll over quite easily

- Step 6: Gently raise their chin to tilt their head back slightly, as this will open up their airway and help them to breathe. Check that nothing is blocking their airway. If there is an obstruction, such as food in their mouth, remove this if you can do so safely

- Stay with them, giving reassurance, until they have fully recovered

- Ok great. Well done!

Slide 22: Questions or comments?

(5 / 109 mins)

- Before we move on to talk about other things, does anyone have any questions or comments?

Slide 23: Who needs to know how to help?

(3 / 112 mins)

- When someone has a seizure they may lose consciousness or become less aware of things

- This means it is those around the person who are most able to help make sure the person having the seizure is okay and safe

- It is important therefore to have a think about whose company you are mostly in. We can make sure we know who we need to tell and how they can help if we have a seizure

- So, if we imagine this person in the middle is you, what people might we need to tell how to help? Any suggestions?...

- Thank you. Yes these mostly match what we have come up with ourselves:

1. Family
2. Friends
3. Boyfriend/ girlfriend / partner
4. Work colleagues
5. Members of the public
6. Health workers – such as ambulance staff, doctors and nurses

Slide 24: What do they need to know and why?

(5 / 117 mins)

- It is often said that knowledge is power. It is also true in this case, the more those around you know the more power they will likely have to help you

- So, what do these people need to know in order to help you?

1. **Firstly, they need to know that you have epilepsy.** Why? This helps them understand why you may have collapsed. People can collapse and have funny turns for lots of different reasons, not just epilepsy. This includes strokes and heart attacks. Knowing that you have epilepsy will help them understand why you have collapsed and what help you should be given. Unless they know you have epilepsy, paramedics and doctors will be very concerned and would want to get you to hospital straightaway

2. **They need to know what sort of seizures are normal for you.** Why? This is so that they know what to expect and this will help them to be able to judge if the seizure you are having is usual or whether you need emergency medical help

3. **They need to know how you can be helped**. There are lots of myths surrounding epilepsy and how someone who is having a seizure can be helped. Those around you need to be told what to do and what not to do if you have a seizure. We learnt these things earlier

4. **They need to know how you would like to be cared for**, such as if you would like a particular person to be called and asked to come if you have a seizure

Slide 25: How to get this information to them – significant others

(5 / 122 mins)

- So, how can we get this information to them? (Family, friends, boyfriends, girlfriends & work colleagues)

- Well l<u>et's talk about family, friends, and work colleagues first. We shall talk about the public and health professionals later on</u>

- These are our suggestions as to how we can get the information we need to family friends and so on.

1. Firstly, by coming to this course you have all been given some important information. You now need to pass this information onto those who are around you

2. Your family, friends and work colleagues may actually have some false beliefs about epilepsy and about how to help you when you have a seizure. To help you to tell them what is right and correct, we are giving you copies of the slides from today's training course. You can show them to your family, friends and colleagues

3. The information from today's course is also going to be on a free website for you so that you can send the website address to your friends, family and colleagues. On the website they will be able to watch the video that you have seen today

4. In your information packs there are also lots of leaflets and wallet sized first aid cards that you pass on

5. If the person would like more information you can also point out the websites, helplines of the Epilepsy Society and Epilepsy Action. They might also like to download one of the free apps that are out there and which provide first aid advice that people can look to when a seizure happens to help remind them of what to do

- One issue that is worth pointing out is that you might not want to tell everyone at work or all your friends and family about your epilepsy. This is a personal choice. One way around this might be just to tell those close to you and those who you know you will always be near, such as your line manager or just a few key people that you know will be around. You can then work out a plan so that they have the information they need and know what to do if a seizure occurs

Slide 26: How to get this information to them - strangers

(5 / 127 mins)

(Members of the public and health workers)

- Obviously seizures can happen at any time and in any place. This means you might have a seizure in public when you are alone. How can we help to get information to members of the public and health workers about how to help?

- The easiest way is by carrying some form of medical identification with you. There are 3 main ways to do this. None of them are completely fool-proof, but they could help:

1. An '*I have epilepsy*' card. The idea is that this is a card which you carry with you in your bag or your wallet. When called to help, paramedics will often look for your ID in your bag or wallet to find out who you are.

On an '*I have epilepsy* card you can write your name and some key information about your seizures and also the contact number of someone who could be called to give more information about you. There is a free copy of one of these cards in your information pack.

One of the reasons it can be good have the contact details of someone else on you is that they might be able to be called to come and take you home. It is often not possible for paramedics to just leave you as you might be very sleepy or wet yourself. If there is not someone who can come to take care of you and keep an eye on you, the ambulances are often forced to take you to hospital.

2. Mobile phones. On many modern so-called Smart phones we can put 'In case of emergency information' on them for free. Paramedics are now trained to look at your phone to find this information which they do not need your password to see.

On the Iphone for example you can you enter this information via the 'health' icon on the homescreen. You can include all the key information, such as that you have epilepsy, what your seizures are like and the contact number of a relative or friend.

On the screen you can see a picture of what this 'In case of emergency information' looks like on the ipone.

In your folders you will find basic instructions on how to add ICE contacts and information to your mobile phone?

If you do not have a so-called modern Smartphone, it might be possible to on your mobile phone contact list simply enter the word 'ICE' in front of the name of the person you would like to be contacted. ICE stands for In Case of Emergency.

3. Medical jewellery. You can obtain lots of different types, such as bracelets and necklaces. These are liked by some people as they give details of your diagnosis and the contact details of someone who might be able to help. The problem for some people is that they do cost money.

Slide 27: Questions or comments?

(5 / 132 mins)

- Before we move on to talk about other things, does anyone have any questions or comments?

Slide 28: Refreshment

(10 / 142 mins)

- Duration – 10 minutes

Slide 29: Personal stories - introduction

(2 / 144 mins)

- What I would now like us to do is to hear some personal stories the names have been changed but relate to the facts which people have told us

- These stories describe different situations in which a person with epilepsy has had a seizure. Each of the stories ends in a way that is disrupting for the patient and their life

- I would like you as a group to hear the story and then try to come up with some suggestions as to what they might have done differently so that things turned out better

Slide 30: Ben's story (1)

(1.5 / 145.5 mins)

The first story is about someone called Ben. Ben is:

- 17 years old. Lives at home
- Epilepsy for a few years. Takes medication
- Still has convulsive seizures, usually when is tired
- They last about 2 minutes
- He did not sleep well last night
- However, Ben is excited as he has a 'date' later on
- His mum asks him to walk to the shops to get some milk

Slide 31: Ben's story (2)

(1.5 / 147 mins)

- On the way to the shops, Ben has one of his usual seizures

- A stranger sees Ben fall and calls for an ambulance
- When it arrives, Ben’s seizure has finished
- Ben is sleepy and cannot answer questions
- The paramedic is worried about Ben. She doesn’t know why Ben collapsed
- Ben has no ID on him

Slide 32: Ben’s story (3)

(2 / 149 mins)

- The paramedic decides the safest option is to take Ben to hospital
- Ben wakes up in a noisy and busy hospital
- In the end, Ben goes home 4 hours later after his mum has been called
- By the time Ben gets home, he has missed his ‘date’

Slide 33: How to change what happened to Ben

(5 / 154 mins)

- Hopefully it is clear that Ben did not need to go to the hospital as the type of seizure he had was normal for him and he just needed to ‘sleep it off’. Actually, going to the hospital was the last thing he wanted as he ended up having to stay in hospital and had to have lots of tests he did not need and he ended up missing his date!

- But, what things could Ben have done differently?

- Does anyone have any thoughts on what Ben could have done to avoid the situation?

- Yes.... These match what we came up with ourselves:

1. Carrying medical ID. If he had a I have epilepsy ID card in his pocket and emergency medical information on his phone it might have been possible to avoid the trip to hospital because the

paramedics would have known that he has epilepsy and what his usual seizures look like. This would have meant they would have been less worried about his health. They would also have know a telephone number of his family who they could have called to come and take him home

2. Paying attention to and dealing with his triggers – Ben was aware that he was tired and hadn't got a good night's sleep. He also knows that lack of sleep is a trigger for his seizures. Perhaps he should have paid more attention to this. He could have for example explained to his mum why he was feeling sleepy and rested some more, rather than having gone to the shops

3. Whilst Ben was too sleepy to do so, it is worth noting that if you are with someone who knows you and your epilepsy and an ambulance has been called, you are within your rights to speak with the ambulance crew and explain why you feel it is not necessary to go to hospital. You might be asked to sign a form

Slide 34: Triggers

(5 / 159 mins)

- For some people certain things can make having a seizure more likely. These things are often called 'triggers'. The things that trigger one person's seizures might not affect other people with epilepsy in the same way.

- In the story we heard that for Ben was more likely to have seizures when he was tired and didn't get enough sleep.

- Here are some of the seizure triggers that are commonly reported by people with epilepsy.

1. Not taking your epilepsy medicine as prescribed: There are two main reasons why people sometimes say they do this. Ones is forgetting to and the other is deciding not to, often because of side-effects

2. Feeling tired and not getting enough sleep is one of the other common things that people with epilepsy say trigger their seizures.

3. Flashing or flickering lights: Some people have seizures which are triggered by flashing or flickering lights, or some patterns. This is called photosensitive epilepsy.

4. Hormonal. Some women with epilepsy find that they are more likely to have seizures at certain times of their menstrual cycle (periods). This is called catamenial epilepsy.

5. Missing meals: Some people with epilepsy say that if they skip meals, they are more likely to have a seizure

6. Alcohol: Drinking more than modest amounts of alcohol in 24 hours can increase the risk of having seizures. For most people, the risk is highest several hours later when the alcohol is leaving their body. If you have a history of heavy drinking, even small amounts of alcohol can increase the number of seizures you have

7. Stress: It’s not known exactly why stress might trigger seizures. But many people with epilepsy say that if they are feeling stressed, they are more likely to have a seizure.

Slide 35: Knowing your triggers

(5 / 164 mins)

- The reason it can be helpful to find out if you have any triggers is that this means we can possibly take some control over when our seizures happen and reduce how many one has
- Keeping a seizure diary is a good way to try and find out what might trigger your seizures
- Every time you have a seizure, record it and make a note of what you were doing and how you were feeling. If you do this over time, you might see a pattern emerging
- You should have all been given a diary as part of this study. There are also free smartphone apps which contains seizure management tools, including a seizure diary to help you monitor your triggers. The Epilepsy Society has one. It is available on both iPhone and Android phones

Slide 36: Some ways of dealing with triggers

(10 / 174 mins)

- If you know you have a trigger you may be able to change how you go about things so that you do not come across the trigger and so have less seizures.
- The way you can choose to manage them is a personal choice.
- What I would like to do now is bring up just a few of the triggers we have talked about so we can how one can often go about dealing with them. You can use this same way of thinking for all types of triggers.
- So one of the main triggers to forgetting to take ones medication or not taking it because of side effects. If this was a trigger what sort of thing could we do to try to avoid it?

- Yes thank you. … These are what we came up with.

1. The first is if you have trouble remembering to take your tablets you could use some memory aids –

It can be helpful to take your medication at the same time as another regular activity, to help remind you to take them. For example, taking them before you brush your teeth or when you eat breakfast and dinner

Using a pill box, that has a section for each day of the week, may also help you to keep track of when you have taken your medication

There are also free smartphone apps, such as the one from the Epilepsy Society, that can be set-up to be used a medication reminder function which you can use with the phone's alarm. It is available on both iPhone and Android phones

2. One of the reasons people may not take the medications is because of side effects

If you feel that you are experiencing side-effects that mean you do not want to take your tablets you should talk to your GP (family doctor) or epilepsy specialist. **Don't stop** or change them yourself.

Everyone with epilepsy is entitled to a regular review by either your GP or a specialist depending on how your epilepsy is. The review should an opportunity for you to discuss any issues that are important to you at that time. If you are not being offered one – there is a letter in your pack to remind your health professional of your entitlement

If you are still unhappy, talk to your GP (family doctor) about your concerns and ask about other options for your treatment. This may include getting an opinion from a different epilepsy specialist. Your GP can arrange this if they feel it is in your best interest

Time is often short in medical appointments, so it is useful to think about what you want to say beforehand. The Epilepsy Society's form 'Your appointment' may help you to think about what is most important to you. You can fill it in to show your doctor or nurse, or keep it to remind yourself of what you would like to happen at your next appointment

- What about hormonal changes for women? Well the first thing to do is to keep a diary to make sure there is a pattern:

    1. This will help you and your doctor see the pattern

    2. Your doctor can discuss possible treatments with you. One possible treatment is to receive an additional drug called Clobazam (Frisium) that you take on the days when you are at a higher risk of having seizures

- And finally, what about flashing lights or patterns? What can be done here?

1. Well firstly it is important to remember that this is not that common. Only about 1 in 20 people with epilepsy have it

2. You should have also already been tested for it photosensitive epilepsy when you were diagnosed

3. If you are not sure whether you may be photosensitive, you can ask your GP or specialist whether you've had the test for it

4. If you are photosensitive you will usually have the seizure pretty much straightaway

5. If someone with photosensitive epilepsy finds themselves facing any photosensitive trigger, covering one eye with their hand immediately reduces the risk, as for the trigger to work it needs to hit both eyes. Closing both eyes will not stop a photosensitive effect and may even worsen the effect

6. Other things can be done include using flat screen TVs and computer monitors, taking regular breaks from screens, sitting well back from the screen and using a remote control to change channels

7. Also, regulations require that TV programmes and news stories have a warning if there is going to be a high level of flashes in the programme. Listen out for these and stop watching at these points

Slide 37: Questions or comments?

(5 / 179 mins)

Before we move on to talk about other things, does anyone have any questions or comments?

Slide 38: Sandra’s story (1)

(1.5 / 180.5 mins)

- I am now going to tell you another patient story

- After you have heard it I would like you as a group to try to come up with some suggestions as to what they might have done differently so that things turned out better

- The story is about a lady called Sandra. She is:
- 70 years old. Lives with husband
- Epilepsy since a stroke
- Usually gets an ‘aura’ or warning sign before she has convulsive seizure
- Warning is a rising feeling in stomach
- Sandra’s family are coming around for lunch later
- She is busy cooking. Her husband is reading the newspaper in the kitchen
- Sandra starts to get one of her auras

Slide 39: Sandra’s story (2)

(1.5 / 182 mins)

- Sandra feels under pressure to cook the meal for her family
- She decides to ignore the aura and hope it doesn’t turn into a big seizure
- She goes over to her gas cooking hob and stirs some vegetable boiling in water on it
- Sandra then has a convulsive seizure

Slide 40: Sandra’s story (3)

(3 / 185 mins)

- She burns herself on the gas hob and tips the hot water on her leg
- The burns are quite serious and painful
- Sandra’s husband has to take her to the hospital
- She stays in for a few days and also has go to see a doctor later on to make sure the burns were healing

Slide 41: How to change what happened to Sandra

(5 / 190 mins)

- What things could Sandra have done differently to avoid getting burnt?

- Does anyone have any thoughts?

- Yes, there are two main things:

Paying attention to her warning signs (aura)

- Before having a generalised seizure, some people experience a warning sign.

- This is actually a seizure itself. It is sometimes called an aura.

- The feeling or warning that you get depends on the area of the brain that that is affected.

- Auras can be hard to describe. The person may:

- Get a rising feeling in their stomach.
- Have an unusual smell or taste
- their vision may begin to change
- They may get a feeling like you've 'been here before‘ – something called de ja vu
- There are lots of others as well.

- If they always or usually happen, auras can be very useful. They might give you time to get to safe place or let someone else know that you are going to have a seizure.

- Sandra really should have not ignored her aura and stopped cooking. Her husband could have taken over the cooking responsibilities.

- Is there anyone here who has aura’s and who is able to use them to get safe?

Home safety:

- Like many people with epilepsy and their families, you may have concerns about your safety when you have a seizure. Seizures can put you at risk of accidents and injury such as burns, scalds, bruises, cuts, fractures, and head injuries

- It is important to be aware of what the main risks are within the home when you have seizures. This is because many of them can be prevented or reduced with often a few simple steps

  - Not all the suggestions will be right for everyone. Some safety issues may not be relevant to you. Some people may not want to put safety measures in place; however it can be important to get a balance between making situations safer and freedom of choice

  - Some safety changes may be expensive or unacceptable for you to put in place. You may be able to get some help with making your home safer from your local authority, if they believe that you need it

  - In your packs you will find an epilepsy risk assessment form. These are designed to be used by individuals. The forms focus on what the individual risks may be because of someone's seizures, risks associated with living conditions around home and risks associated with activities outside the home. **You might like to have a look at the Risk Assessment Safety at Home FORM IN YOUR PACKS when you get home to help you identify your own risks**

Slide 42: Main points to remember – people with epilepsy

(5 / 195 mins)

- OK, we are now reaching the end of today's training session.

- What I would like to do now is highlight the main things that we have talked about today and that we would like you to have in your mind.

- When doing this, I am going to bring over the list of things you each said that you hoped to have got from today. I can then see if I have covered the things you wanted to hear about and if there is anything I have missed.

- I am actually going to separate the points and first talk about the main points that we would like those of you with epilepsy to take away from today's session.

- These are as follows:

  - Epilepsy is nothing more than a common medical condition. It is not something to be ashamed of

  - Seizures can be frightening to know you will have, but most seizures are short and will stop by themselves

  - Usually, you will not need emergency medical attention after you have had a seizure

  - You can help those around you be able to help

  - Tell friends and family how to deal safely with seizures. Show them the slides from today, send them the website address for this course and given them a seizure first aid card for their wallets

  - Carry a medical ID to tell strangers how to help and who they should call if you have a seizure

  - You may be able to reduce seizures and injury. We have talked a little bit today about triggers, auras and home safety. There is more in your information packs as well

Slide 43: Main points to remember – people without epilepsy

(5 / 200 mins)

- Now these are the main points we would like those of you who know someone with epilepsy to take away from today
- These are as follows:
  - Seizures can be upsetting to see, but try to stay calm
  - You have the power to help when seizures happen
  - The person is usually not in pain and won't remember
  - Most seizures are short and will stop by themselves
  - Don't restrain the person or put anything in their mouth
  - Usually the person will not need medical help, just comforting and putting in the recovery position – which you now know

  - Time the seizure. If shaking lasts longer than 5 minutes, one seizure follows another, or the person has badly injured themselves call for an ambulance

Slide 44: Sources of further information

(5 / 205 mins)

- It is best when looking online to try to stick to reputable, well-known organisations as they only show information that has been checked by health workers and those giving advice have been trained to do so
- Remember there is a lot more information in your packs, including a copy of everything that has been said today. There is also a website where you can go to see the information and show your friends and family the video that you saw today
- In your pack you will also find the contact details for other organisations that can provide you with more information
- Most of these organisations, such as the Epilepsy Society and Epilepsy Action, have YouTube channels, websites and helplines which you can telephone

Slide 45: Final questions /comments / debrief

(10 / 215 mins)

- Thanks for time
- Participant Feedback sheets
- Certificates of attendance

Trainer notes and reflections

Date	Comments	Action
