



EPILEPSY - make your risks smaller



A support guide for Parents & Carers

This guide is the companion guide to the 'Epilepsy – Make your risk smaller' easy read leaflet. Please read this leaflet yourself before going through the easy read with the person who has epilepsy.

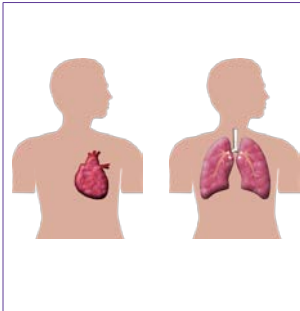

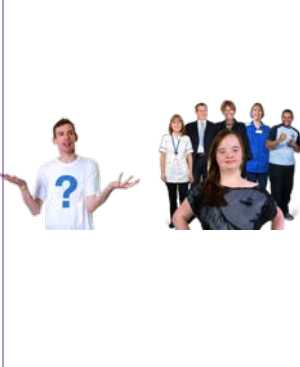

When going through the easy read leaflet with them, make sure you are able to do so at their pace and during a period of uninterrupted time.

They may have questions which you can discuss as you read through the easy read leaflet. You may find the answers in the extra information provided in this leaflet but if you are unsure of the answer, it may be useful to write a list of questions and ask their GP or Epilepsy Healthcare Professional.




Note: There is additional information provided below to help you explain the easy read leaflet in more detail should you need to. It has been written so the information is ready to be said to the person with epilepsy.




	Information in easy read leaflet	Additional information you can give as a carer
	Sometimes when you have a fit (seizure) things can go wrong	You normally recover from a seizure well. But sometimes seizures may last longer than usual or you may get hurt during the seizure. The people who look after you should have an emergency care plan to tell them what to do if this happens.
	You may want to use a medical alert bracelet which includes information about your care plan	You may want to speak to your Doctor, Nurse or Carer about this if you don't have one already.






	When you have a fit (seizure), your heart beat or breathing might slow down or stop	Seizures can affect the heart and breathing, but in most people this returns to normal after a short period of time.
	You could be very ill. Sometimes people can die suddenly. This is called <u>S</u> udden <u>U</u> nexpected <u>D</u> eath in <u>E</u> pilepsy (SUDEP)	The people who care for you will know if / when to call an ambulance as they will know if your seizure is 'mild' or 'severe'. SUDEP is when a person with epilepsy dies suddenly. Although SUDEP can happen, there are things you can do that may make your risks of SUDEP smaller.
	We don't know why SUDEP happens, but we are trying to find out	Researchers are looking at what might cause SUDEP and think it is to do with the heart or brain going wrong, but are not sure yet exactly why it happens. Charities are working with Researchers around the world to find answers.
	We do know what you can do to help keep yourself safe from SUDEP	There are ways you can work with the people who care for you which may help lower your risks of SUDEP. They may also be able to help you lower the number of seizures you have and make you feel healthier too.



Things you should do

	<p>Eat well</p>	<p>Having a healthy diet and eating regularly is recommended to help you stay healthy. Not eating for a long time (fasting) may make your seizures get worse.</p>
	<p>Sleep well</p>	<p>Not getting enough sleep or not sleeping well can make your seizures worse. Your Doctor can give you some ideas on how to sleep better if this is a problem.</p> <p>If possible avoid sleeping on your stomach as this may be more risky for people with epilepsy.</p>
	<p>Take your tablets at the right time</p>	<p>Your Doctor will have said when to take your epilepsy tablets (and how many). It is important to take the right amount at the same time each day so they work properly. The people who care for you can help you with this.</p>



	<p>Keep appointments with your Doctor or Nurse</p>	<p>It is really important to go to your Doctor, Nurse or Hospital appointments as they can make sure your epilepsy isn't getting worse and you can ask them any questions you have.</p> <p>If you can't go to one of your appointments you should ask for it to be changed to another day soon after.</p> <p>It can be useful to have your Carer go to the appointments with you. They can help you give information to the Doctor & remember what they say at the appointment.</p>
	<p>Keep taking your medication until your Doctor tells you to stop</p>	<p>Stopping medication suddenly without speaking to your Doctor can make your seizures get worse and put you at risk. It is important you take them as the Doctor has told you to.</p> <p>You may need extra information and help. Ask your Carer to ask for this.</p>
	<p>Tell your Doctor or Nurse if you often feel sad</p>	<p>Everybody feels sad from time to time, this is normal. But if you feel like this very often, you may have something called 'depression', which may increase your risk of seizures and SUDEP. You should speak to the people who care for you and your Doctor about it as they can help.</p>

Things you should do - continued

	<p>Have a Carer to look after you at night to check for fits (seizures)</p>	<p>Some people have seizures at night while asleep. If you do, your Carers should be close by and be able to regularly check you are ok and breathing normally.</p>
	<p>Have a seizure alarm at night so your Carers will know if you have a fit (seizure)</p>	<p>Some people who have seizures at night have alarms in their bedroom that go off when they have a seizure. They can make you feel safer as they tell your Carers you are having a seizure & they can come and check you are ok. But they can sometimes go off when you aren't having a seizure, which can be annoying.</p> <p>There are lots of alarms available and your Doctor or Nurse will be able to tell you more about them and how they can be used as part of your night-time care plan.</p>
	<p>Keep a fit (seizure) diary - this is a record of your fits (seizures) so that you can show this to your Doctor or Nurse</p>	<p>There are lots of examples of seizure diaries; your Carer can help you find the best one for you. They can also help you fill it out (or do it for you).</p> <p>A seizure diary is very useful to show what your epilepsy has been like and if it has changed since your last appointment with the Doctor or Nurse.</p>

	<p>Tell your friends you have epilepsy</p>	<p>The more people around you who are aware of your epilepsy, the more they can help you stay safe and reduce your risks. Your Carer should make sure those around you know what to do if you have a seizure.</p>
	<p>Have a shower instead of a bath</p>	<p>It is important to keep yourself safe in water as you could have a seizure and drown.</p>

Make sure you don't do

	<p>Don't drink too much alcohol</p>	<p>Alcohol stops your tablets working well. This can make your seizures increase. It can also make any side-effects from your epilepsy tablets worse. If you are worried about the amount of alcohol you drink, speak to your Carer, Doctor or Nurse and they can help.</p>
	<p>Don't take illegal drugs</p>	<p>Illegal drugs can be dangerous for people with epilepsy and can lead to seizures getting worse. If you are worried about illegal drugs, speak to your Carer, Doctor or Nurse and they can help.</p>



Remember, if you are worried about anything at all speak to your Doctor or Nurse.

You can also look at our website:

www.sudep.org

Further information can be found in our 'Be Smart, Be Safe' & 'SUDEP - Reducing your risk' leaflets which can be downloaded from our website.

Pictures taken from Photosymbols

Online www.photosymbols.com



This leaflet has been developed from information provided by the

Leicestershire Partnership NHS Trust. Leicestershire Partnership 
NHS Trust

Please contact us for further information, details of helplines for people with epilepsy, and details of helplines that can help you improve or maintain your mental wellbeing:

Head Office:
01235 772850
info@sudep.org

SUDEP Action Scotland:
0131 516 7987
www.sudep.org

Support (direct line):
01235 772852
support@sudep.org
SUDEP.ORG

SUDEP Action 2015. SUDEP Action & SUDEP Action Scotland are the working names of Epilepsy Bereaved.
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