

National Epilepsy Week 2015 - Stay Smart

How
you can get involved

17-23
May

Our STAY SMART campaign is launching during National Epilepsy Week. This campaign focuses on raising awareness of the risks associated with epilepsy and providing people with the tools to monitor and take steps to lower the risks.

Launching this week is our SUDEP and Seizure Safety Check List - part of the latest stage of work on the Epilepsy Life Project. It aims to provide an easy reference, practical, evidence based tool that is quickly completed in clinic by doctors and patients. This helps to support prioritisation of clinical activity, give a baseline to compare change of risk factors and focuses meaningful communication between doctor and patient. The Check List is based on evidence of risk factors for SUDEP, and includes the major risk factors known to be associated with fatality in epilepsy.

On the horizon we also have EpSMon - a smartphone app for use by adults who experience seizures. It contains an assessment tool which supports the user to assess their risk every three months and take action where possible to help lower the risk factor. EpSMon uses evidence based on work completed for the 'Epilepsy Safety Check List' as part of the Epilepsy Life Project.



GPs & CCGs

Contact your local GP surgery or Clinical Commissioning Group (CCG) to raise awareness of the SUDEP and Seizure Safety Check List & EpSMon.



- 1 Use the template letter to write to your GP Surgery informing them of the Check List & App - don't forget to include our EpSMon poster & leaflet.
- 2 Visit your local Surgery - ask them to hand out our leaflets &/or create a display table of them during National Epilepsy Week.
- 3 Tweak the template letter to write to your local CCG about the Check List & App - encouraging them to use it in their GP surgeries.
- 4 Arrange to meet with your local GPs / Nurses / CCG to inform them of the Check List & App - showing why it is vital they use & promote them.

See the 'Campaigning for SUDEP Action' sheet for more information

See the 'Getting your MP involved' sheet for more information

Raise awareness via social media - use the hashtags #epilepsyweek #StaySafe #safetychecklist and #EpSMon

Don't forget to tweet, facebook & email your pictures to us too!



MPs

Now the General Election is over, use this time to reconnect with them & remind them of how & why they should be involved.

- 1 Write to your local MP using the template letter to inform them of National Epilepsy Week & how they can get involved in raising awareness of the SUDEP and Seizure Safety Check List and EpSMon.

The letter mentions a few key asks - they can commit to some or all of them!
- 2 Meet with your local MP to share your story and explain why their support of the SUDEP and Seizure Safety Check List and EpSMon App is important. (The template letter for MPs can help give you the information you need)



Local Ideas

It is also important during National Epilepsy Week to continue raising awareness locally of Epilepsy risks and the work of SUDEP Action. You could do this by:

- 1** Inform your local newspaper / radio station / news channel of National Epilepsy Week, EpSMon, the SUDEP and Seizure Safety Check List & why it is important people with epilepsy understand and manage their risks. Contact us asap at juliet.tumeo@sudep.org if you would like a Press Release.
- 2** Holding a fundraising event too? Make sure you have our current leaflets available on the day to help raise awareness.
- 3** Are there any events happening locally for National Epilepsy Week? If so, see if you can go along and represent SUDEP Action in some way.



Don't forget to let us know how you are getting involved in the Stay Smart campaign for National Epilepsy Week 2015



Remember to take pictures to show how you are getting involved - we'd love to see them (& share them if you don't mind)



SUDEP Action
Making every epilepsy death count

SUDEP Action
SCOTLAND



SUDEP Action & SUDEP Action Scotland are the working names of Epilepsy Bereaved.
Registered charity 1050459 (England & Wales), SC045208 (Scotland).