



Campaigning for SUDEP Action



There are many ways you can help make a difference and raise awareness in your local area and beyond on behalf of SUDEP Action.

Here are some general ideas about how you can get involved:

Writing letters

Writing a letter is a great way to start engaging with one of our campaigns as it helps you set out the campaign issues, ideas and actions in a focused way.

Some of our campaigns will have a specific focus or audience in mind and may come with a template you can tweak to suit your local area, but sometimes you might want to write your own for a specific local issue.



What makes a powerful letter?

- Use 2 or 3 main points to keep it focused and short – use facts & statistics if relevant to support your main points
- Use a personal story or experience if you feel you can
- Use language that you find natural, find alternative phrases to suit you if you are using a template letter
- Use standard letter writing conventions & check your letter carefully before sending.
Visit <http://www.goodletterwriting.com/formal-letters.html> for further information
- Ask for a reply within a reasonable timeframe

Arranging a private meeting

Some campaigns will involve a specific audience or person, who it may be possible to organise a meeting with to discuss the campaign and your ideas to get them involved.

Meetings can be a good follow up if you have previously written a letter as it allows you to go into more detail and add a personalised element to the campaign. Make sure you organise the meeting with a specific person and that they are aware of the purpose of your meeting beforehand.



What makes a memorable meeting?

- Plan what you want to say – use the campaign notes to make clear, focused points
 - o What is the issue?
 - o What are your concerns?
 - o What action do you want moving forward?
 - o What is the ideal outcome of the meeting/in the future?
- Send any useful leaflets or background information (keep it short) to the person you are meeting so they can read it beforehand
- Take notes during the meeting (if you can) so you have a record of what was said and any actions agreed
- Contact them either by phone or letter soon after the meeting to thank them for their time & remind them of any actions agreed upon

Information stands

Running an information stand is a great way to get key ideas and information about our current campaigns out to the general public or specific groups.

Both need careful planning though to make sure it is a success:



Steps to holding an information stand

1. Organising your stand

- Choose a date – it could be a specific day eg: SUDEP Awareness Day or a day chosen to suit your target audience. Consider the time of day you will run the stand to best suit your target audience
- Find a suitable venue and get written permission to use it eg: from the Council, Owner, Surgery Manager – this is crucial! Try to be somewhere publically accessible & easy to get to without interrupting normal business
- Organise a table & chairs either with the venue or source your own (make sure the venue knows)
- Let SUDEP Action know when and where your information stand will be. We can then send you the relevant leaflets & information. We can also send you a banner so you can make sure you stand out!
- Publicise, publicise, publicise! Ask SUDEP Action, the venue & your friends & family to spread the word about your information stand

2. The day before

- Write some short key points about the campaign to jog your memory on the day
- Pack your car with everything you need or see if the venue can store it overnight for you – then you won't have to rush
- Speak to the venue to confirm & go over your plans
- Check the weather – especially if your stand will be outside! You may need to dress appropriately, change the date/location/set up of your stand slightly to suit

4. After the event

- Contact the venue to thank them for letting you hold your stand & telling them how it went
- Let SUDEP Action know how you got on – we'd love to hear how it went & see any pictures!
- Return any spare leaflets and banners back to SUDEP Action for others to use

3. On the day

- Get there early to set up – make your stand eye-catching but not too information heavy.
- Consider your first impression – how are you standing? What is your facial expression? What are you wearing? You want to come across as friendly and helpful
- A positive attitude, smile & some small talk are great first steps to catching someone's attention.
- Speak clearly and stay focused when people come over – give them enough detail to inform without talking too much
- Remember not everyone will want to or have time to stop & talk – this is fine & won't be the case for everyone, so don't let it dishearten you

Tips:

- Either bring a packed lunch or ask someone to fill in for you at lunchtime if your stand lasts all day. If you can't, leave a sign to say they can help themselves to information & somewhere for them to leave their contact details
- Remind people of the charity's website if they need more information or you get low on leaflets. You can also point them there, or ask them to email us if they ask a question you are unsure of
- Take a picture of the stand & send it to SUDEP Action – we can promote your campaigning during the day & use your campaigning as an example for other supporters in future

Joining a health group or committee

Many hospitals, GP surgeries and Clinical Commissioning Groups (CCGs – groups which decide on & allocate services to GPs in a specific location) have groups their patients can be part of. They allow you to have a say in the services and care plans provided in your area.

They are useful places to raise awareness of epilepsy, epilepsy risk and how standards of care can be improved & better supported for people with epilepsy.

You can find details of your local groups by visiting the website of the hospital, surgery or CCG. If you are not sure how to find your CCG visit: <http://www.nhs.uk/Service-Search/>



Tips:

- Each healthcare centre may use a different name for the patient group so you may need to spend some time looking at their website or contact them directly
- Some centres may also offer the option to take part in surveys as well or instead of a patient group – these are great if you are unable to commit to regularly attending meetings & can be quickly completed and shared with others in your local area

For more information about SUDEP Action and our current campaigns visit:
www.sudep.org

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).