

The logo for Epilepsy Action features a large blue letter 'E' on the left. A white horizontal bar with rounded ends is positioned across the middle of the 'E'. Overlapping this bar are two rectangular boxes: a blue one on the left containing the word 'epilepsy' in white lowercase letters, and a red one on the right containing the word 'action' in white lowercase italicized letters.

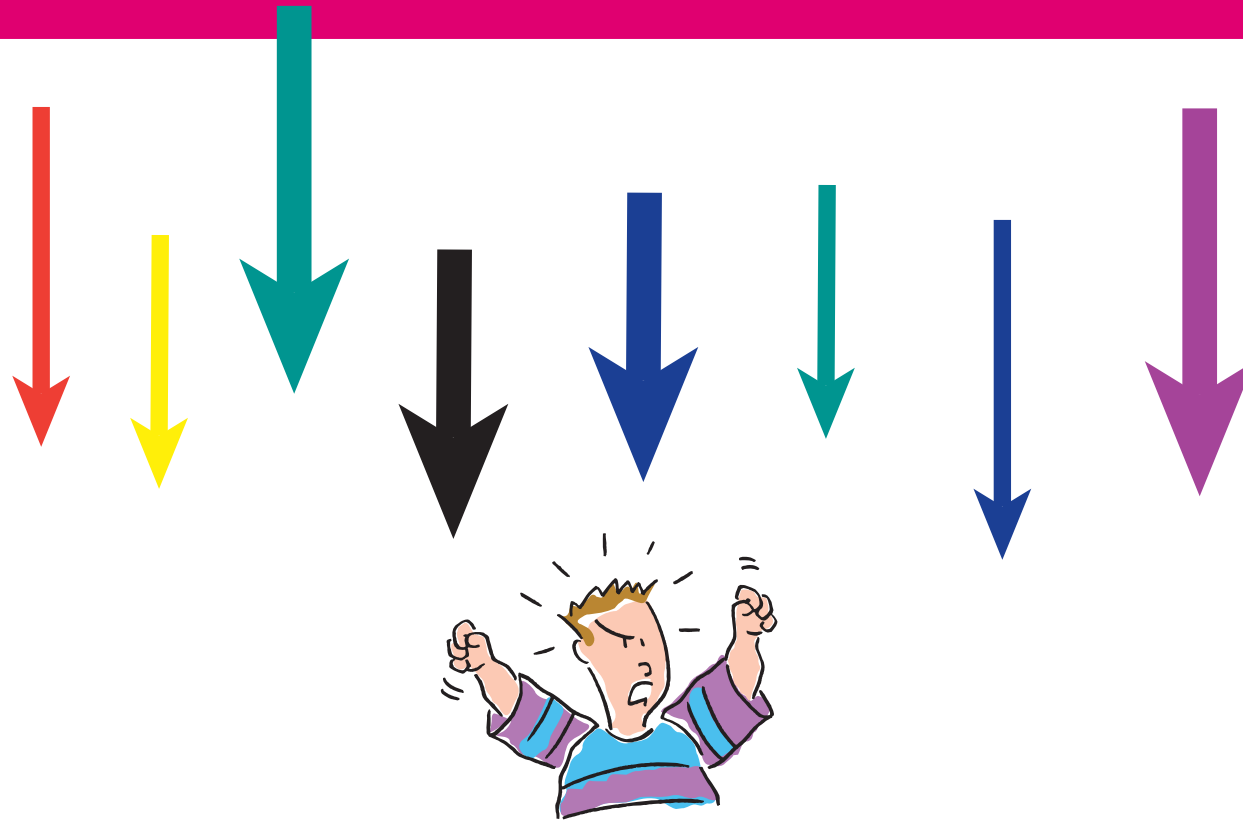
epilepsy *action*

Sue Mitchell

**Being an effective gateway
for information**

A solid red horizontal bar with rounded ends, positioned below the text.

The information problem



Our role

Reliable, respected and trusted providers of information on epilepsy

- Provide accurate, up-to-date information
- Provide balanced and responsible information
- Provide information in the way people need it
- Give people all relevant information, so that they can make the best choices for their own lives

Why are we needed?

- Far too much information
- Not all information can be trusted
- Some information can be difficult to understand
- Some information can be biased or promotional
- Some information can give a wrong impression
- Good information can get lost

Good and bad information sources

- Professional journals
- Medical professionals
- People living with epilepsy
- Websites
- Online forums and blogs
- News media

Some good and bad from all sources

A difficult task

- Collecting information
- Filtering out the bad and keeping the good
- Re-writing and 'translating'
- Passing high quality information on

This takes time and effort - and a process agreed and backed by the whole organisation



Setting standards

Epilepsy Action's process

- Set an agreed quality standard
 - Part one - epilepsy facts
 - Part two - language, presentation and legal issues
- Train staff in how to use the standard
- All materials must follow the standard

An effective quality standard

- Suitable for the audience
- Relevant to epilepsy
- Avoid discrimination
- No jargon
- References
- Non-promotional
- Disclaimer
- Feedback opportunity
- Legal requirements (charity details, address, contact information)
- Reflect diversity
- Non-judgmental
- Warm tone

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- No abbreviations
 - Easy to read and grammatically correct. Check spelling!
 - Acknowledge source
 - Not worrying or wrongly reassuring
 - Correct facts. Check statistics!
 - Follow copyright law - and copyright your own material
 - Images suitable for people with photosensitive epilepsy
 - Balanced opinion - or clear it is the author's own opinion and others may disagree
 - Data protection information on all feedback options and forms
 - Information dated and author named

The UK situation

- Quality of patient information has become a government priority
- A new standard is being introduced
- If your organisation has not passed the standard, the health services may not use or recommend your information
- A quality standard process must be in place to pass the standard

Being a trusted information source

- The quality and style of information is consistent
- Easy for the user to find the original information and other evidence
- Easy ways for the user to feedback to you
- Quick response to change and new information
- Easy to find and access

The information solution

