Speaking with Professionals on the immediate and enduring impact of epilepsy deaths

Tracy Cowdry (Dip. Couns) & Julia Stirling
May 18th 2019
TIME TO LISTEN

Supporting traumatic grief in the aftermath of sudden epilepsy deaths

Tracy Cowdry & Julia Stirling
November 2\textsuperscript{nd} 2018

SUDEP Action, registered charity 1164250 (England & Wales), SC047223 (Scotland).
Epilepsy Bereaved (founded 1995) is part of SUDEP Action.
The Impact

Epilepsy Related Death

Immediate Family

Extended Family

Social Networks

Wider Community

TIME TO LISTEN  SUDEP Action’s Prevent21 Summit on Tackling Epilepsy Deaths – 2/3rd November 2018

sudep.org
Devastation
• Police
• Mortuary visit
• Contact with coroner
• Contact with NHS Trust investigator
• Post-mortem (funeral)
• Coroner’s investigation
• Hospital investigation
• Inquest
“Everyone is carrying on as usual, but everything has stopped for me”
"...the Chief Coroner maintains as central to his thinking the essential concept that bereaved families must at all times be at the heart of the coroner process”

Report of the Chief Coroner to the Lord Chancellor
Third Annual Report 2015-2016
The coroner may not know about epilepsy or SUDEP

The post-mortem report may not mention either

*and so:*

- inquest can happen without epilepsy or SUDEP in the picture, *or*
- post-mortem happens, but no inquest, *or*
- there is no post-mortem and no inquest
- risk that knowledge about that death is lost
Everyone wants answers to the same questions:

HOW did this death happen?

HOW do we prevent deaths in future?
What is helpful to a bereaved family after a death?

- finding answers to questions 88%
- someone to talk to 83%
- learning more about epilepsy-related death 72%
- understanding investigations of death 69%

Epilepsy Deaths Register
Get to us early

• we know about epilepsy deaths and SUDEP
• and about what happens after sudden death
• we support with advocacy and advice and emotional support

All the way through
Theory into Practice
“Everything can be taken from a man but one thing: the last of the human freedoms—to choose one's attitude in any given set of circumstances, to choose one's own way.”

Viktor E. Frankl  (Man's Search for Meaning)
Key Learnings and Recommendations

• Families bereaved by epilepsy need early support and intervention –
  • Signpost to us as soon as possible;
  • We are the specialists

Thank you

Tracy Cowdry & Julia Stirling
November 2nd 2018
The Royal College of Pathologists will:

✓ Use our information and expertise to train medical examiners
✓ Include our guidance on SUDEP in their e-learning for their members, clinicians and medical students
✓ Partner with us on joint initiatives

Professor Jo Martin President

Images from Twitter & rcpath.org
✓ New guide to inquests for families with signposting to SUDEP Action

✓ New specialist information for families on SUDEP and epilepsy deaths

✓ Chief Coroner to give information on SUDEP and epilepsy to all coroners and signpost to SUDEP Action
“Tell me the facts and I’ll learn. Tell me the truth and I’ll believe. But tell me a story and it will live in my heart forever.”

Native American Proverb
THANK YOU
to all of our bereaved families who have made this possible

Tracy Cowdry & Julia Stirling
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