

Talking about SUDEP

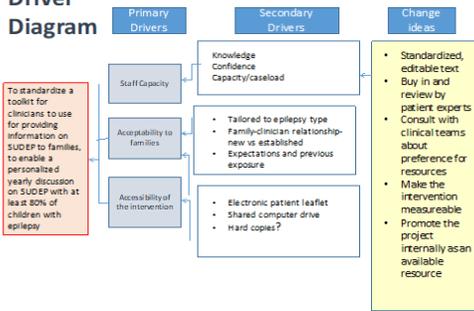
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Aim/purpose: To standardize a toolkit for clinicians to use for providing information on SUDEP to families, to enable a personalized yearly discussion on SUDEP with at least 80% of children with epilepsy

What is the problem: Evidence of planning of care that encompasses provision of SUDEP (EPILEPSY12 standard 9.2) was below national average (21% vs 41%) and had deteriorated in 2020 compared to previously (29% vs 40%) We also recognized a need for **cultural shift** away from anxiety and avoidance of SUDEP, toward confidence and integration into usual practice.

Driver Diagram

Driver Diagram



What our tests revealed

We are still very much at a stage dealing with *qualitative information*
Consultation with Regional Epilepsy Network

Most agreed an **EPR smartphrase** would be useful

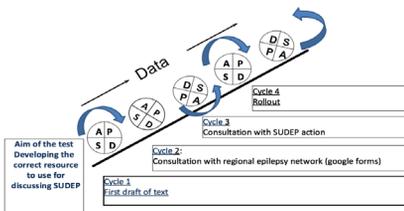
Themes

Individualised risk discussions → shorter, punchier paragraphs easy to omit/include

Centralised on shared drive → yet to create 'smartphrases' for electronic patient record.

Keep building the resource

PDSA cycles



Qualitative Results

FOCUS GROUP RESULTS

Content

Approach

Three major categories

1) New diagnosis 2) Follow up, well controlled 3) Follow up, drug resistant

Patient and Stakeholder engagement

Useful insights into level of detail/ parental and patient expectations- they wanted *more*
More signposting to monitoring devices

SUDEP Action
Making every epilepsy death count

EXAMPLE OF EPR RESOURCE:
We discussed the risk of Sudden Unexpected Death in Epilepsy (SUDEP). Here are some key points:

SUDEP is when someone with epilepsy dies suddenly and prematurely & no cause of death can be found. It is not a condition itself, but a way to categorise these sudden deaths.

Overall, people living with epilepsy are at a 1 in a 1000 risk of SUDEP per year, but risk is specific to each individual and ways to reduce risks are person-centred too. People with learning disability, other physical conditions or rare epilepsies may be at higher risks. Different types of epilepsy carry their own level of risk, some higher, some lower.

Epilepsy with generalised tonic-clonic seizures has a higher risk. This is especially if these happen at night or when asleep.

Increased number of seizures also increases the risk.

People with absence or myoclonic seizures are not known to have an increased risk for SUDEP.

Epilepsy risks (linked to dying prematurely) can change over time. However steps can be taken to reduce some of these risks.

We discussed things we can do to help reduce the risk of SUDEP. These could include:
Getting better control of your epilepsy, to reduce number of seizures where possible
Taking your epilepsy medication regularly and as prescribed
Following safety advice and lifestyle measures
Using epilepsy monitors, that may help to better detect night-time seizures – however these should be one part of a wider safety plan to reduce epilepsy/SUDEP risks.
How girls of child bearing age will need to have pre-conception counselling to help understand the risks related to this, and how if you take certain medications they may need to be reviewed/changed as you get older.
That the EpSMon app can help people 16+ to monitor and manage their epilepsy risks (www.sudep.org/epsmon)
Additional helpful information is available below.

<https://sudep.org/sudden-unexpected-death-epilepsy-sudep>
<https://sudep.org/childhood-adolescence-and-ni> (Free leaflets from SUDEP Action on reducing Epilepsy risks and SUDEP for children with epilepsy are available here: <https://sudep.org/leaflets-and-downloadable-information>)
<https://www.epilepsy.org.uk/info/daily-life/safety/practical-guidance>
<https://www.epilepsy.org.uk/info/daily-life/safety-aids-equipment/smart-monitors>

Team personal learning/Team highlights

- ✓ Making even small changes takes time
- ✓ There is value in qualitative data driving change
- ✓ Even though we strayed from our original SMART objective, the QI principles gained on this programme have informed a really useful local resource for SUDEP information sharing and we will continue to hone it

Next steps

- ✓ Launched on shared drive
- ✓ Link to EPR resource is planned
- ✓ Continue qualitative feedback
- ✓ Present to paediatric governance with results
- ✓ Paediatric SUDEP checklist with SUDEP Action

Successes/challenges

Successes

Buy in from service users, staff using the resource

The qualitative feedback shows our attitude toward discussing SUDEP in the trust is shifting

Challenges/Limitations

Lack of quantitative data so far- hope to see impact in EPILEPSY 12 next round

Need to launch as **smartphrase**
Aiming to discuss at every consultation is not always possible. This needs to be worthwhile for the patient and family not just 'tick box.'