SUDEP

What we know, what we don't know,
and how this influences how we discuss SUDEP risk with our patients

WCN Workshop, 2025

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DISCLOSURES

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None

SUDEP:

Learning Objectives

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- **Definition**
- **Classification**
- **Incidence**
- **Risk factors** and mitigating these
- Underlying **pathophysiological** mechanisms
- **Ethical** and **Legal** considerations: to inform or not to inform

EPILEPSY
Mortality

Epilepsy is associated with an overall ***two to three-fold increased mortality*** compared to the general population

Trinka, E, et al, 2023 Frontiers in Epidemiology

Causes of death in patients with epilepsy (PWE)

A significant proportion of this increased mortality is due to **epilepsy-related deaths**, which include:

- (Co-morbidities)
  (cardiac, metabolic, etc.)
- (Suicide)
- **The underlying cause of the epilepsy**
  (tumour, meningitis, encephalitis, metabolic derangement, poisoning, etc.)
- **Situational Factors**
  (drowning, road traffic accidents, etc.)
- **Refractory status epilepticus**
- **SUDEP**

Tomson T, et al, Neurology 2025; Wicks & Fountain, 2012; Duncan *et al.*, 2006; Schuele *et al.*, 2007 ; Sander & Bell, 2004

SUDEP
What we know…

Over the past two decades, we have learnt a great deal about SUDEP:

- Incidence
- Risk factors
- Underlying pathophysiological mechanisms

SUDEP

What we still don't know…

Yet, we still do not understand:

- why some seizures are fatal, while others are not
- why some succumb to SUDEP after only a few seizures, and others survive hundreds of seizures
- How to prevent SUDEP effectively

and we are **still searching for reliable, validated biomarkers to help assess SUDEP risk**

SUDEP
Definition

The first formal definition of SUDEP was made by Nashef, et al., in 1997

Epilepsia, **38**(Suppl. 11):S6–S8, 1997
Lippincott–Raven Publishers, Philadelphia

Sudden Unexpected Death in Epilepsy: Terminology and Definitions

L. Nashef

Kent and Canterbury Hospitals NHS Trust, Canterbury, Kent, England

SUDEP
Definition

"Sudden, unexpected, witnessed or unwitnessed, non-traumatic and non-drowning death in a patient with epilepsy, with or without evidence for a seizure, and excluding status epilepticus, where autopsy does not reveal any toxicological or anatomical cause of death."

Epilepsia 1997;38:S6–8. Clinics 2011;66:65–9.

SUDEP
CLASSIFICATION

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SUDEP is a diagnosis of exclusion:

- **Definite SUDEP**
  witnessed or unwitnessed with no alternative cause identified on history or at post mortem, excludes status epilepticus
- **Probable SUDEP**
  as above but no post mortem performed
- **SUDEP-Plus**
  contributory co-pathology is present, e.g. coronary artery disease, on history or at post mortem
- **Possible SUDEP**
  where a competing cause of death is present
- **Near SUDEP**
  when patient has been revived

Epilepsia 1997;38:S6–8. Clinics 2011;66:65–9.

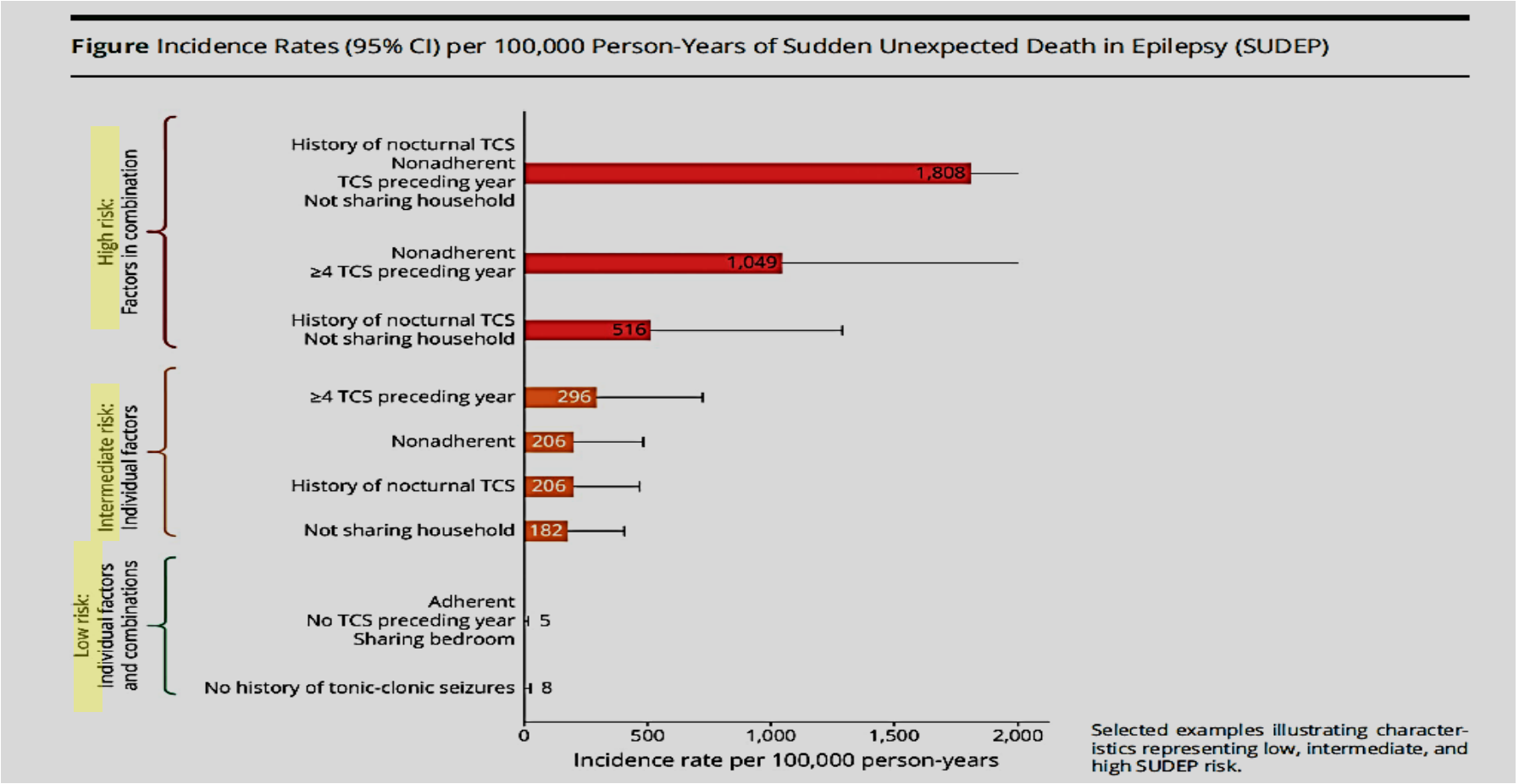
SUDEP

Incidence

- **1 in 10,000 person-years** in **all newly diagnosed epilepsy** in both adults and children
- **1 in 1,000 person-years** in adults and children with **chronic epilepsy**.
- **1 in 200-300 person-years** in **poorly controlled epilepsy** cohorts seen in specialist centres
- **1 in 100 person-years** in those with **severe, treatment-resistant epilepsy**
  (particularly high among those with uncontrolled tonic-clonic seizures)

Sveinsson O, et al, 2017;89(2):170-177; Tomson *et al*., 2005.

Depending on seizure characteristics and individual circumstances, the **risk of SUDEP may increase 300 fold** in PWE



Tomson T *et al* 2025 Neurology

RISK OF SUDDEN DEATH

In young PWE

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It is estimated that **SUDEP may be responsible for approximately 30% of all young adult epilepsy-related deaths**

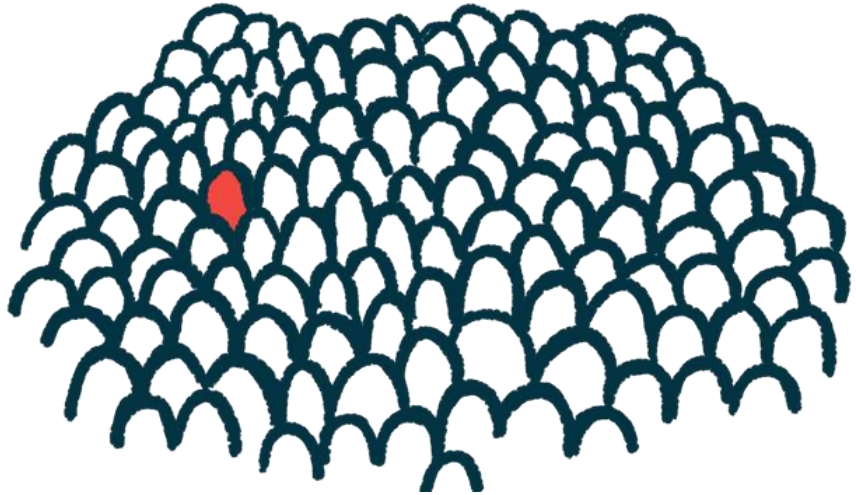
Tomson T, *et al* Neurology 2025
Trinka, E, et al, Frontiers in Epidemiology 2023
Mbizvo K, et al. 2021 Epilepsia.
Holst AG, et al Epilepsia 2013
Ficker DM, et al Neurology 1998

SUDEP INCIDENCE

Is it really that rare?

After stroke, SUDEP is the most common neurological cause of life years lost

So we need to take it seriously



Sveinsson O, et al. Neurology. 2017

BIOMARKERS FOR SUDEP RISK

What's available?

There are no validated biomarkers for SUDEP risk

- **Prolonged post-ictal EEG suppression** (PGES) has been suggested

Landmark 2010 **MORTEMUS Study** identified:

- **impaired post-ictal respiration**
- **impaired post-ictal arousal**
- **post-ictal bradycardia**

The "low" rate of SUDEP in the general epilepsy population means that any prospective study to confirm reliable biomarkers would require a very large cohort followed up for many years to be sufficiently powered.

Lhatoo SD, et al, Ann Neurol. 2010;68(6):787-796; MORTIMUS study

SUDEP
Risk factors

- **Generalised Tonic Clonic Seizures (GTCS) are by far the most important risk factor**

  But SUDEP can occur in patients with focal seizures with impaired consciousness without a history of GTCs, as and in Benign Rolandic Epilepsy with centrotemporal spikes

- **Nocturnal GTCS** (and, possibly, sleeping in the prone position)
- **Early onset age** (before the age of 16 years)
- **Long duration** (over 15 years)
- **Male gender**
- **Untreated GTCS or poor compliance**
- **Substance abuse and alcohol**
- **Low socioeconomic status**
- **Living alone**

Tomson T *et al* 2025 Neurology,; Sperling *et al.*, 1999; Langan *et al.*, 2000; Tomson *et al.*, 2008; Surges *et al.*, 2009; Tomson *et al.*, 2016; Shankar *et al.*, 2014 & 2016

SUDEP:

Modifying risk factors

There is evidence that the risk of SUDEP is reduced by:

- **Reducing the frequency of GTCS**
- **Nocturnal supervision**

There is no good evidence yet that any other interventions are effective

Tomson T, *et al* Neurology 2025

REDUCING SEIZURE FREQUENCY REDUCES SUDEP

What's the evidence?

Compared to a PWE free from GTCS:

- **1-2 GTCS per year increases the risk of SUDEP five-fold**
- **≥ 3 GTCS per year increases the risk of SUDEP fifteen-fold**

Tomson T, *et al.,* 2025 Neurology, 2025;
Hesdorffer *et al.*, 2011

REDUCING SUDEP IN DRUG-REFRACTORY EPILEPSY

Adjunctive ASM?

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Interestingly:

Treatment with an **adjunctive ASM** has been shown to **reduce the incidence of SUDEP by more than seven times compared with placebo** in a meta-analysis of placebo-controlled randomized trials in patients with refractory epilepsy.

So, should we routinely prescribe an “add-on” ASM in all our PWE with increased risk of SUDEP?

Ryvlin P, et al., Lancet Neurol. 2011;10(11):961-968.

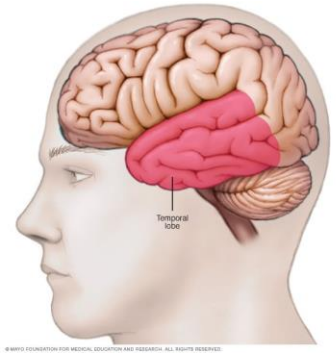
REDUCING SUDEP IN DRUG-REFRACTORY EPILEPSY

Epilepsy Surgery?

Epilepsy surgery likely reduces the risk of SUDEP by reducing seizure frequency

- **Patients with refractory epilepsy, who do not undergo surgery, have a six fold higher risk of death (including SUDEP)** compared to those who do undergo epilepsy surgery.

- **Patients with refractory epilepsy, who are rendered seizure-free after surgery, have a standardised all-cause mortality rate similar to the general population**



There is little double that

/ should be performed in appropriate patients with refractory epilepsy

Sperling MR, et al., 2016
Sperling MR, *et al.*, 2005

NOCTURNAL SUPERVISION?

Yes, it reduces the risk of SUDEP

- At least some of the risk associated with nocturnal seizures relates to lack of supervision and delayed resuscitation.
- **Sharing a room with someone competent to provide assistance has been shown to reduce risk of SUDEP**.
- Where nocturnal supervision is present, wearable seizure-detecting devices may be helpful, although there is generally limited and poor-quality evidence for their efficacy.

Co-habiting with a spouse, friend or relative is advisable if seizures are uncontrolled,
especially in PWE who also have intellectual disability.

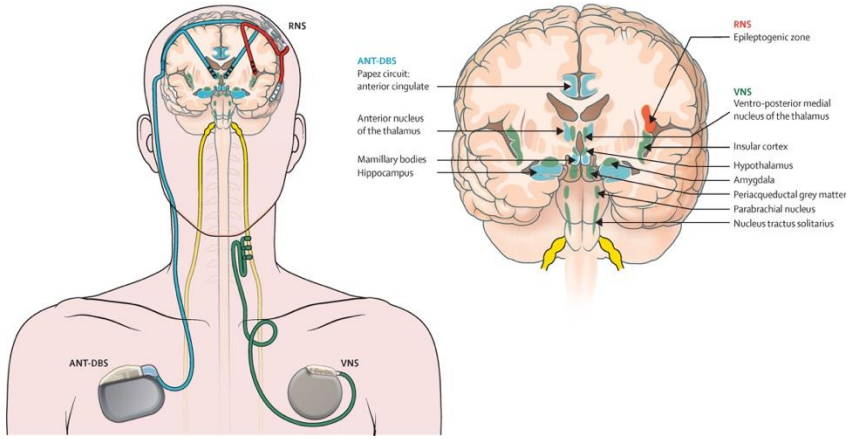
Tomson T *et al* Neurology, 2025;
Monte' C, *et al*, 2024;
Sander *et al*, 2013;
Maguire MJ et al, Cochrane, 2016.
Beniczky S, Wiebe S, et al. Clinical Neurophysiology 2021;
Langan *et al.*, 2005;
Shankar *et al.*, 2016;
Young *et al.*, 2015

REDUCING SUDEP IN DRUG-REFRACTORY EPILEPSY

What other interventions may work?

There is less evidence for:

- **Vagal nerve stimulation**
- **Automated seizure-detection devices**
- **Brain-responsive neurostimulation**



Although we lack randomized controlled evidence that these interventions prevent SUDEP,

it may be reasonable to consider advising their use in some high-risk PWE.

Ryvlin *et al*., 2011; Shankar et al., 2016;. Ryvlin et al, Neurology. 2017;89(9):878–9; Devinsky O, et al. Epilepsia. 2018;59(3):555-561; Ryvlin et al, Epilepsia. 2018;59(3):562-572

WEARABLE SEIZURE-DETECTION DEVICES

What's available?

- Smart watches that sense motion and/or electrodermal activity,
- Arm monitors that detect electromyographic activity,
- Mattress motion detectors under mattresses
- Sound detectors

Disadvantages:

- **High false positive responses.**
- **Unproven benefit** in preventing SUDEP

ILAE/IFCN Guideline Cochrane. 2020;4(4):CD011792

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Seizure-detection devices are useless in preventing SUDEP if there is no one close at hand to render first-aid and

Automated Epilepsy Detection Devices

ILAE & IFCN PRACTICAL GUIDELINES

The **2020**, **ILAE/IFCN guideline:**

Supports the use of some wearable seizure-detection devices under certain circumstances

Comment:

"Although there is good evidence for the effectiveness of wearable devices for detecting GTCS from in-patient, video-EEG monitoring studies, their clinical validation, acceptability and utility in the real-world is lacking."

https://www.ilae.org/guidelines;
Beniczky S, Wiebe S, et al. Clinical Neurophysiology 2021

AVOIDING SEIZURE TRIGGERS

Does this reduce SUDEP?

Similarly, there are no RCT studies confirming that modification of seizure triggers such as **alcohol, sleep-deprivation or emotional stress** reduce SUDEP.

Nevertheless **it is sensible to advise avoiding triggers** as this reduces seizure frequency.

Tomson *et al.*, 2016; Shankar et al., 2016

THE ETHICS OF ADVISING UNPROVEN INTERVENTIONS

What should be considered?

Always weigh **potential benefit vs. negative implications**:

- Is the intervention justified?
- Is there strong suggestive evidence of benefit, even if unproven?
- What would be the socio-economic impact?
- What are the potential side effects?

The use of an unproven intervention should be a joint decision with an informed patient

SUDEP AND GENETICS

There is growing interest in the contribution of genetic risk factors for SUDEP

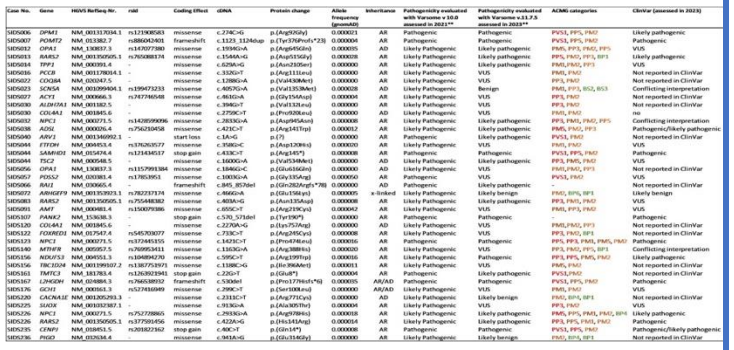
- **Numerous pathogenic gene variants have now been identified in up to 50% cases of SUDEP patients at post-mortem**.

- Most **involve cardiac-, epilepsy-, and respiratory control genes**

Polygenic risk has been postulated with the additive effect of variants in multiple genes

Buerki SE, et al. Seizure 2023 113, 66-67
Whitney R, et al European J of Epilepsy 2023

Just some of the numerous possible genes implicated in SUDEP



SUDEP AND GENETICS

Should we do predictive genetic testing for SUDEP risk?

The **Genetics Commission of the International League Against Epilepsy** (ILAE) recently published recommendations for predictive genetic testing in PWE

Should only be considered when there is a high likelihood of finding a genetic cause.

In other words:

- **early-onset epilepsy** (neonatal and infancy)
- **concomitant intellectual disability, autism, multi-system abnormalities or dysmorphic features, and**
- **refractory epilepsy without additional comorbidities**

In future, when the genotype-phenotype correlations are better defined, genetic testing may be considered in all patients with risk factors of SUDEP, regardless of aetiology, to help make informed choices about preventive measures and potentially lower SUDEP risk.

Krey I, et al Epileptic Disord 2022;24(5):765–86)

SUDEP PATHOPHYSIOLOGY

What's involved?

Anatomical structures and networks

- Cortex
- Amygdala
- Brainstem
  - Periaquaductal Grey (PAG)
  - Raphe nucleus
  - Rostral ventral lateral medulla

Physiological Mechanisms

- Respiratory depression & apnoea
- Cardiac dysrhythmia and asystole
- Failure of arousal mechanisms

Neurotransmitters

- Catecholamine storm
- Adenosine
- Serotonin

SUDEP PATHOPHYSIOLOGY

It's complicated!

The primary pathophysiological mechanism remains controversial.
Cardiac vs. Respiratory mechanisms have been hotly debated.

- **The Cardiac Theory**: chronic seizure-related cardiac fibrosis and post-ictal dysrhythmias lead to asystole and death
- **The Respiratory Theory:** post-ictal impairment of central brainstem function causes depression of respiratory responses to hypercapnoea, as well as reduced arousal, which lead to apnoea and, ultimately, asystole and death

Most researchers now believe that central respiratory failure with PROLONGED APNOEA is probably the primary mechanism.

Costiagliola et al, 2021 Ann Clin& Translat Neurol

SUDEP PATHOPHOPHYSIOLOGY

Likely combined failure of both respiratory and cardiac mechanisms

- Cardiac- and respiratory functions are closely linked physiologically.
- Central regulation of both cardiac- and respiratory function occur in the hypothalamus and brainstem
- **Seizures disrupt the function of these brainstem structures and affect both cardiac and respiratory activity, as well as arousal.**
- It is argued that suppression of central respiratory mechanisms may be more important than cardiac dysfunction because **the heart has additional intrinsic "protective" pacemaker mechanisms**.

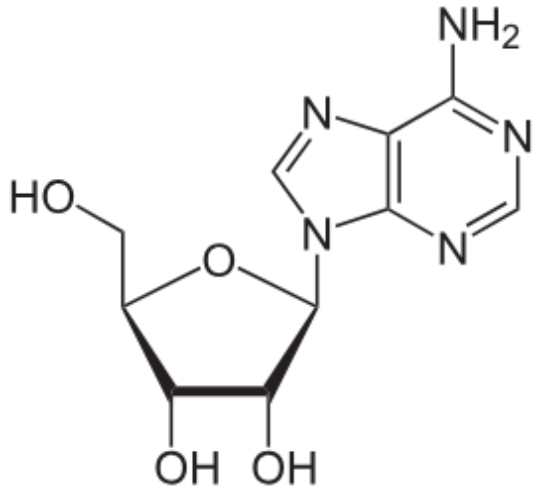
(E. Boglietti, ET AL 2025, Ryvlin et al., 2013; Sowers et al., 2013; Kennedy and Seyal, 2015; Allen LA, *Epilepsia.* 2020;61:1570–1580

SUDEP

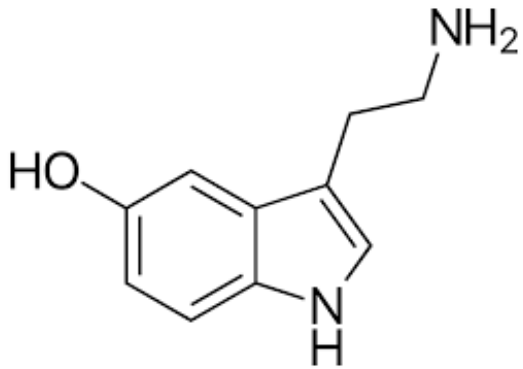
Neurotransmitters

Two neurotransmitters are considered especially important:

- **Adenosine**
- **Serotonin**

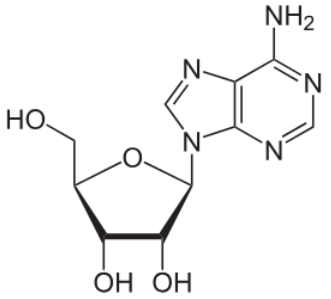


Adenosine



Serotonin

ADENOSINE HYPOTHESIS in SUDEP



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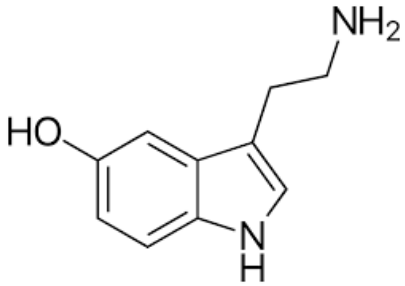
- **Seizures result in high-energy expenditure which, in turn, results in greatly elevated levels of adenosine in the plasma and brain**
- Adenosine is known to **suppress ictal activity**
- But adenosine also **inhibits central respiratory centres** in the rostroventral lateral medulla (RVLM) and is implicated in **post-ictal respiratory depression and apnoea**

Shen , et al

SEROTONIN HYPOTHESIS in SUDEP



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- The **raphe nuclei** throughout the midbrain, pons and medulla, contain serotonergic neurones, some of which **project to forebrain structures**
- These raphe neurons play **major roles in central control of respiration** and mood
- Serotonin has **potent seizure-suppressive actions**
- Serotonin also **stimulates the central brainstem respiratory centre** by increasing its sensitivity to elevated blood CO2 levels

Seizures have been shown to activate this serotonergic system

Tupal and Faingold

SUDEP

A simplified, unified pathophysiological hypothesis

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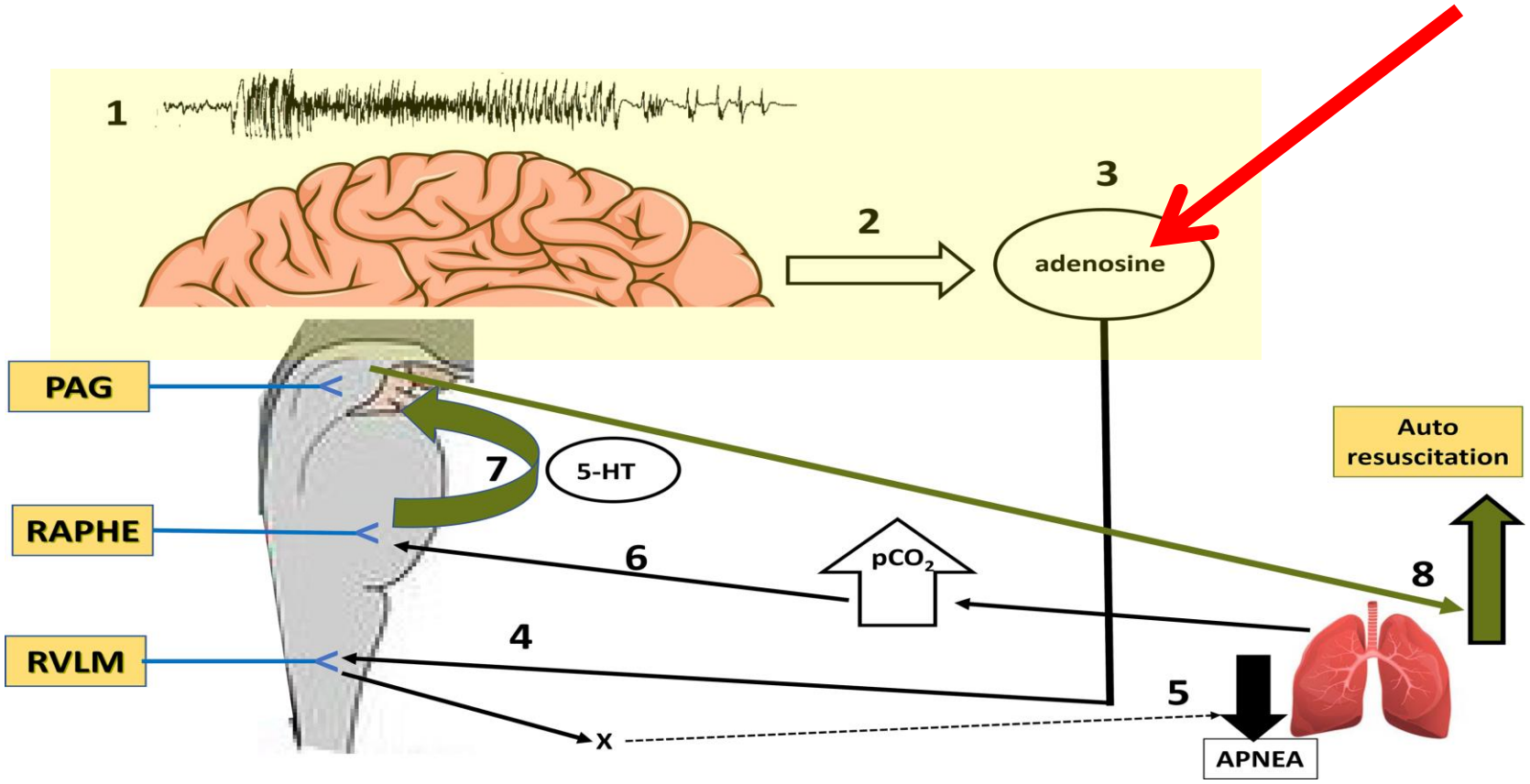
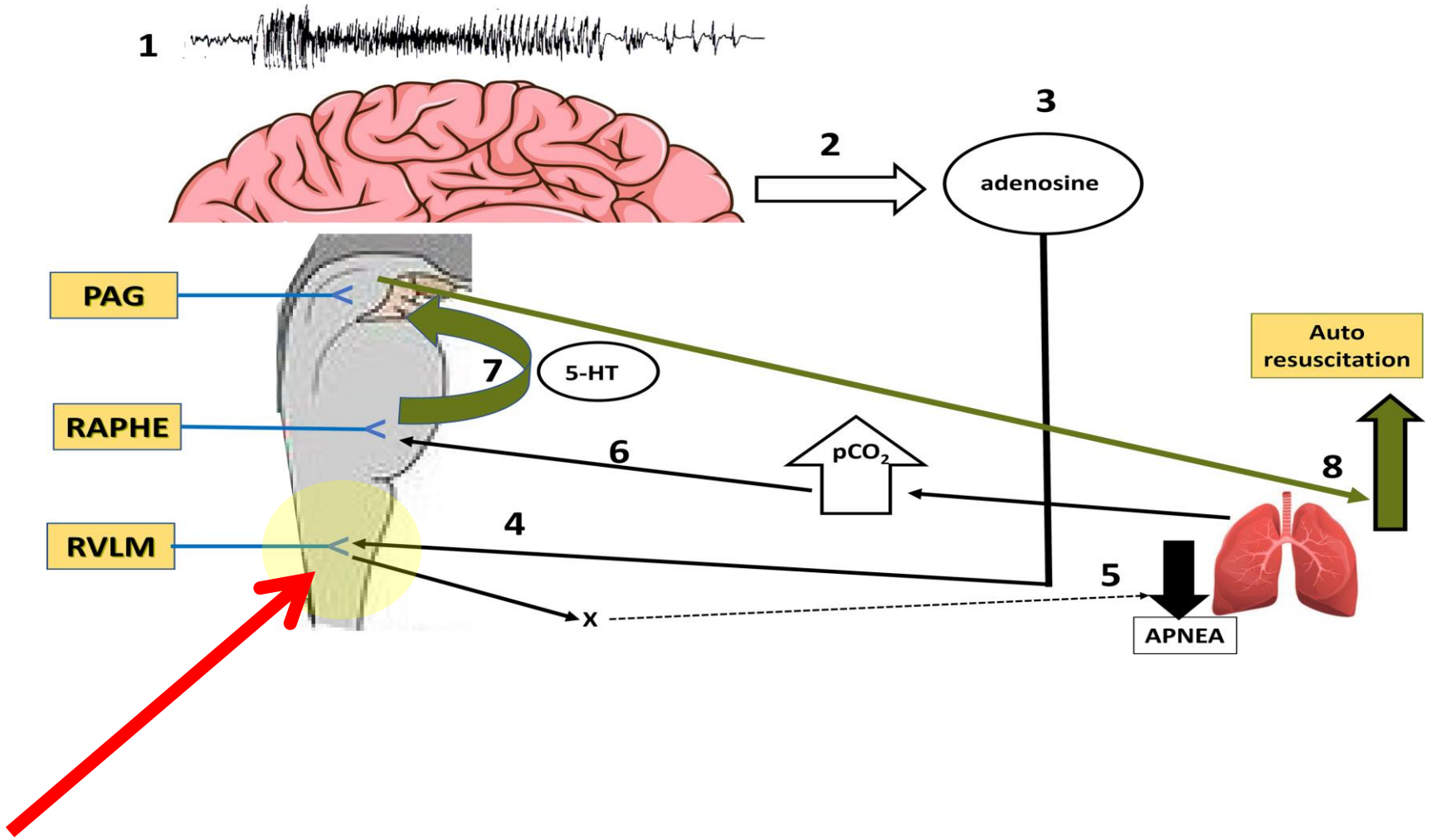
So how do we put this all together?

A GTC seizure causes release of adenosine



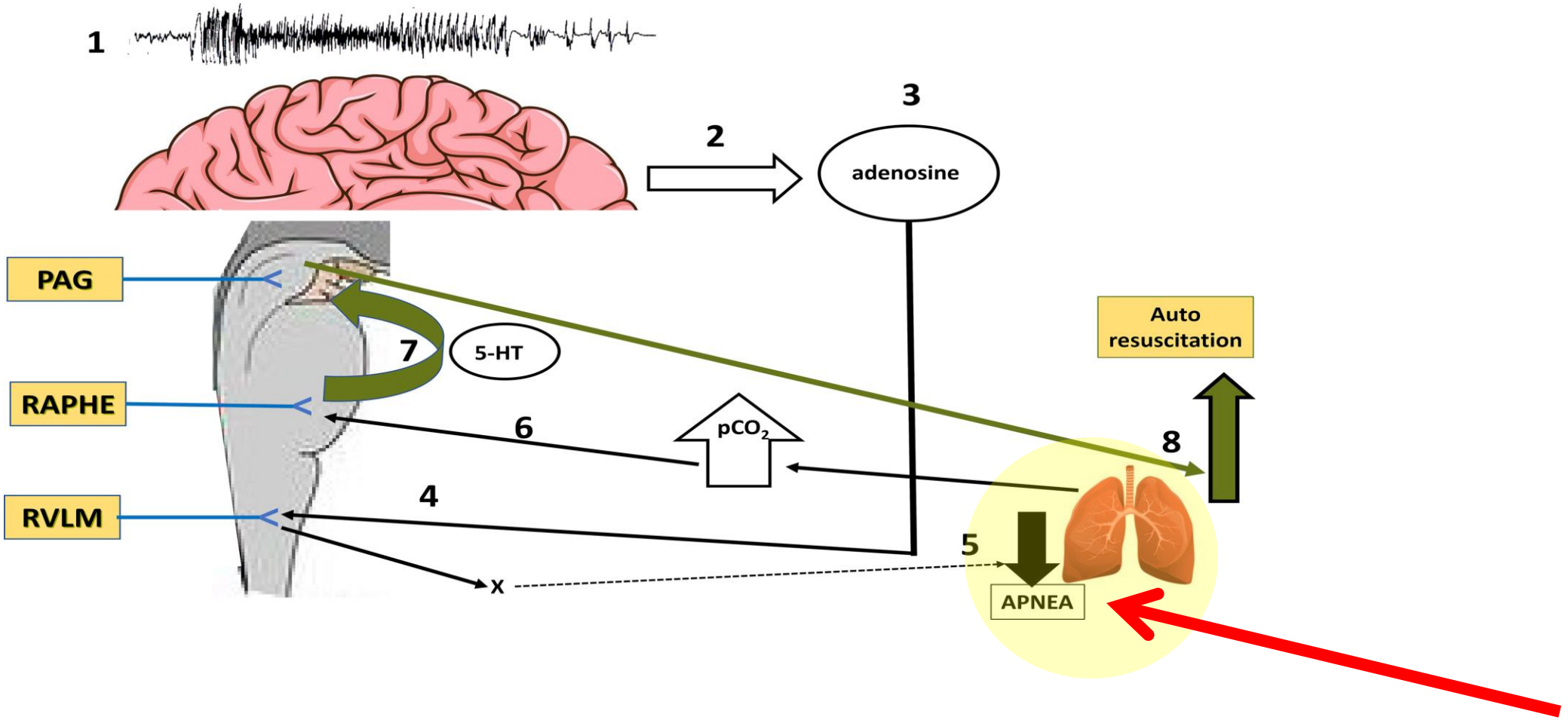
Faingold CL & Feng HJ Epilepsia, 2022

Adenosine induces respiratory depression by acting on the neurons in the rostral ventral lateral medulla (RVLM)



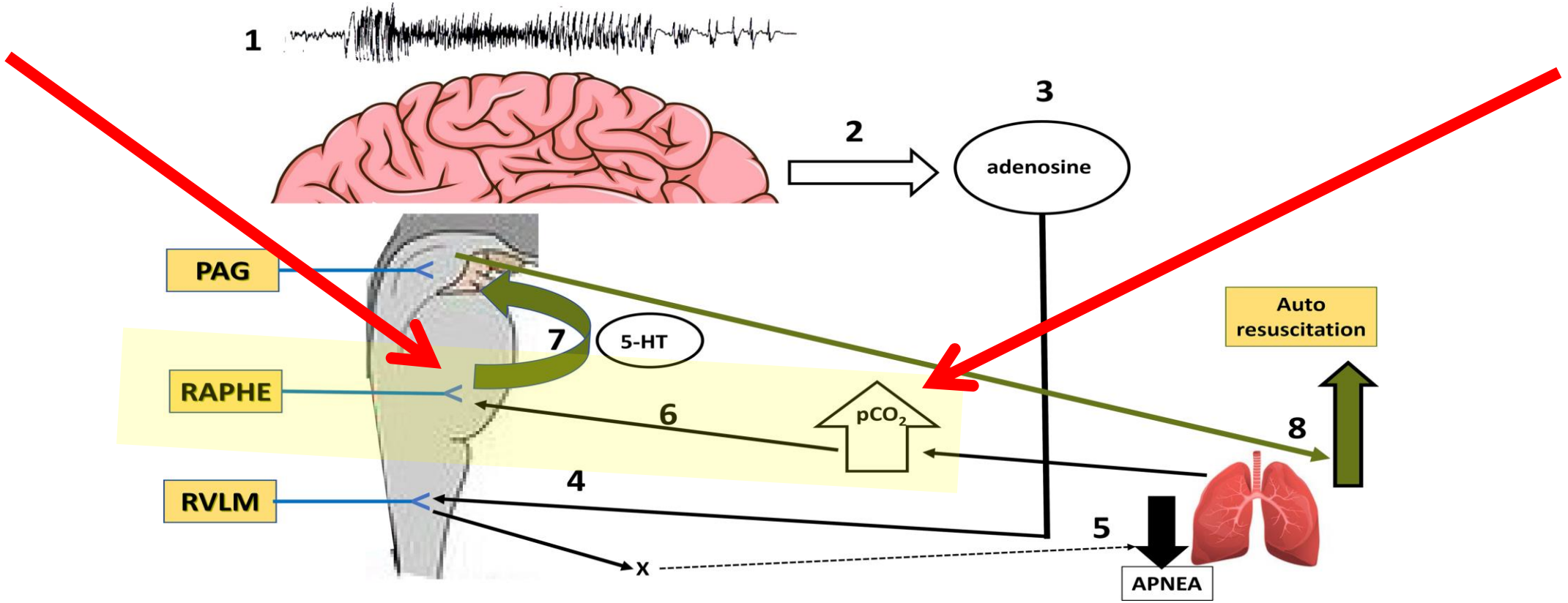
Faingold CL & Feng HJ Epilepsia, 2022

This, diminishes central drive to the lungs and causes apnoea



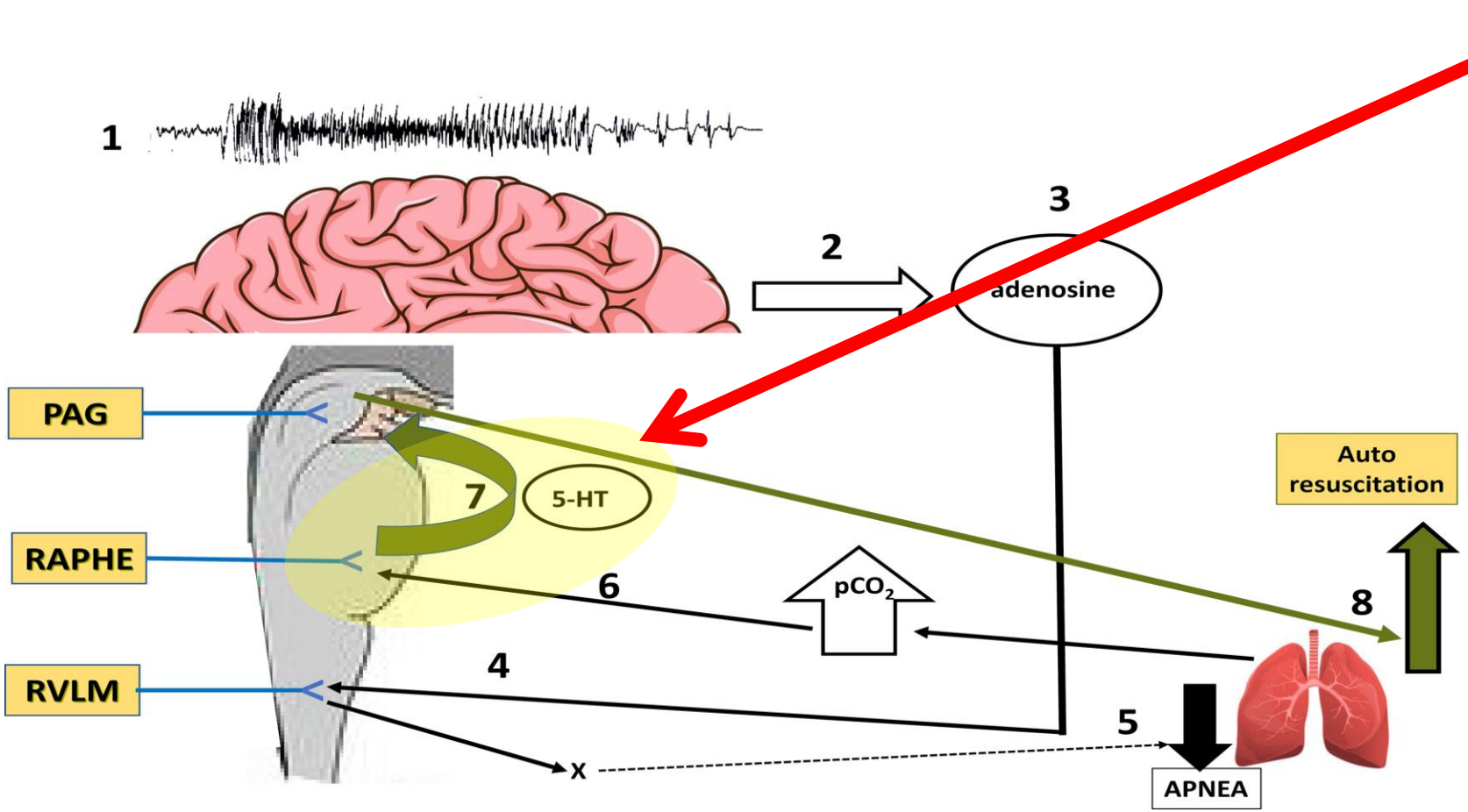
Faingold CL & Feng HJ Epilepsia, 2022

The apnoea causes hypercapnoea, which activates the serotonergic raphe neurons



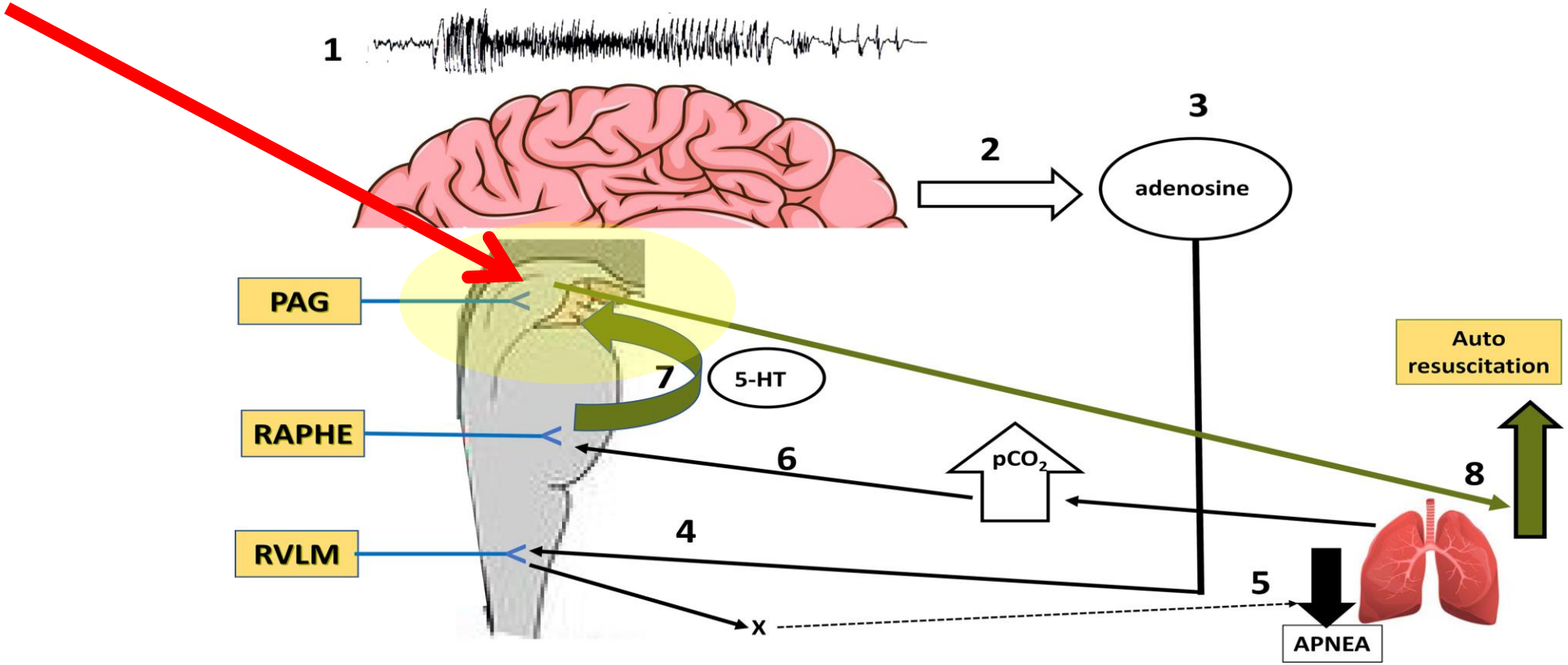
Faingold CL & Feng HJ Epilepsia, 2022

Activated raphe neurones release serotonin



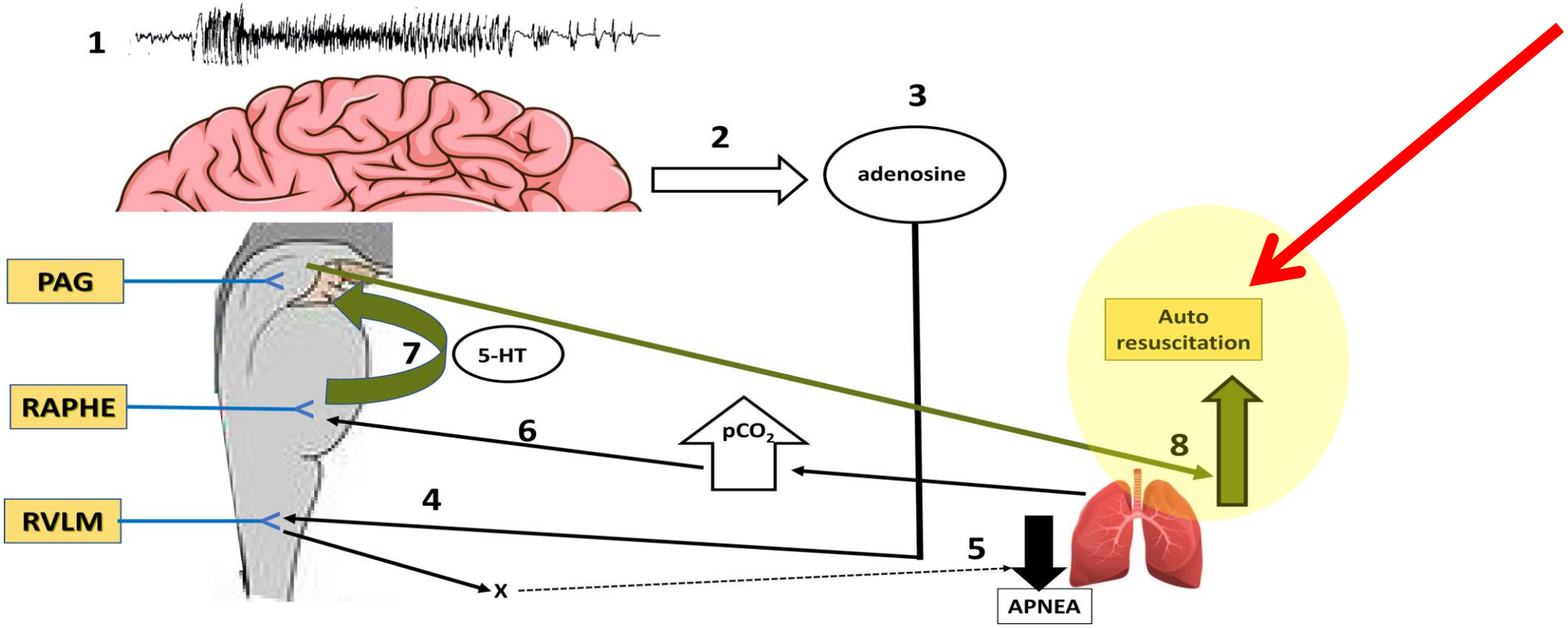
Faingold CL & Feng HJ Epilepsia, 2022

Serotonin activates neurones in the periaqueductal grey



Faingold CL & Feng HJ Epilepsia, 2022

PAG activation triggers autoresuscitation mechanisms including an increased stimulatory response of the central respiratory centres to hypercapnoea



Faingold CL & Feng HJ Epilepsia, 2022

If these serotonergic mechanisms are insufficient to overcome the apnoea,

SUDEP results

Faingold CL & Feng HJ. Epilepsia, 2022

SUDEP

Are Serotonergic drugs (SSRIs) protective?

- Unproven.
- **Retrospective and prospective studies** have concluded that **postictal respiratory depression in PWE taking SSRIs, is significantly less than in PWE not taking these drugs**.
- And, serotonergic drugs significantly reduce the susceptibility of seizure-induced sudden death in SUDEP animal models

So, should we be routinely prescribing SSRIs to our PWE at risk for SUDEP?

Lacuey N et al Epilepsy Behav. 2019;98:73–9
Bateman LM Epilepsia. 2010;51:2211–4

SUDEP

What about fenfluramine?

- Serotonin is a potent anticonvulsant
- **Enhancement of serotonin neurotransmission** plays a major role in the action of the recently approved anticonvulsant drug **fenfluramine**

So, should we be routinely prescribing fenfluramine to our patients at risk for SUDEP?

Yao Ning, et al JNNP-2022
Cross JH, et al 2021 Seizure;
Tupal S & Feingold 2019 Epilepsia
Pringsheim, et al. Neuropedics 2021

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With the basics out of the way, lets talk

SUDEP Counselling

SUDEP
2025 Sitrep

Neurologists and PWE, as well as their caregivers, have become much more familiar with SUDEP over the past 2 decades.

This has been driven, in large part, by families devastated by the condition, advocacy groups, and by neurologists feeling powerless to predict or prevent these deaths

We now know much more about the condition…

https://www.sudepglobalconversation.com/

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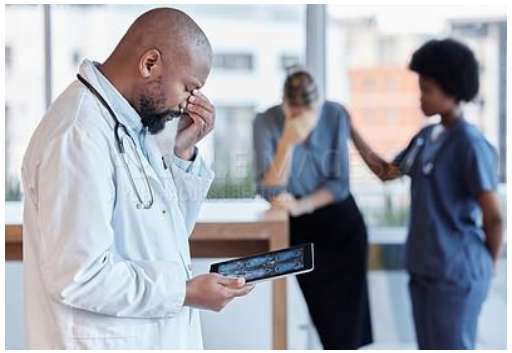
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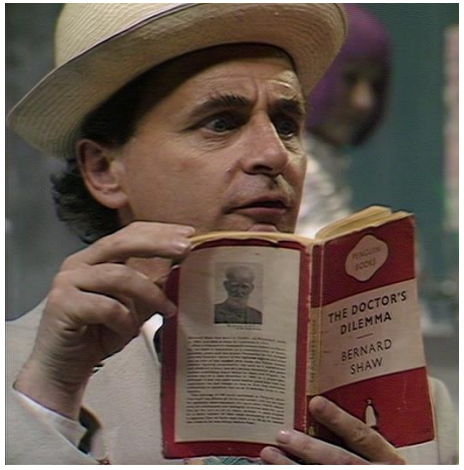
SUDEP
The Doctor's Dilemma

Despite this

- We, as neurologists, continue to struggle with, and are ambivalent about, whether, how, and when to discuss the risk of SUDEP with our patients, their families and care givers.
- Perhaps this is because we feel it is morally wrong to provide information about a serious complication that is rare, poorly understood, difficult to prevent and may cause inappropriate anxiety.



Friedman D, et al. Epilepsy Behav.2014
Ronen GM, et al, Epilepsy Behav. 2017

SUDEP

Patients and Caregivers are less conflicted

I want to know,
I want to know
I want to know,
I want to know

In contrast, PWE and their families are not ambivalent

They want to know about:

- The risks of SUDEP
- How to reduce these risks

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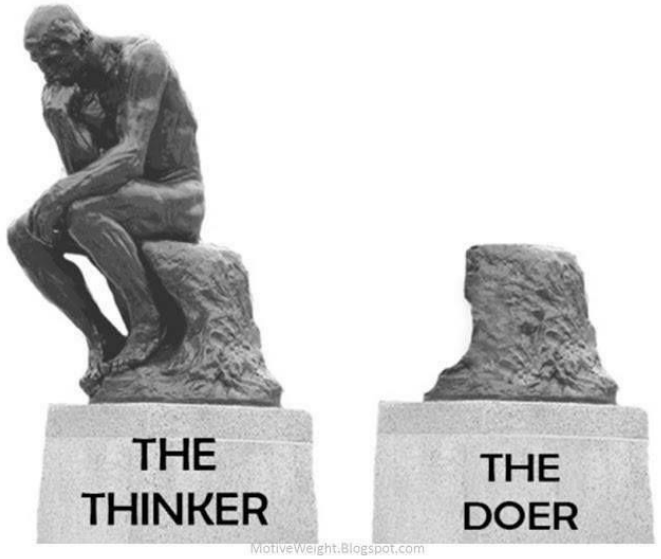
Friedman D, et al. Epilepsy Behav.2014
Ronen GM, et al, Epilepsy Behav. 2017

There is now a compelling argument that SUDEP education is not something to consider…

It is something to do for ALL patients with epilepsy



SUDEP COUNSELLING

Yet we continue to agonise…

To counsel or not to counsel?

Which PWE should be informed?

- All patients
- Only GTC seizures
- Only frequent GTC seizures
- Only refractory GTC epilepsy
- Patients with poor ASM compliance

When should we counsel them?

- At time of diagnosis
- At follow up visit
- At time of diagnosis and again at follow up visit
- Only if asked

How should we inform them?

Whitney, R et al., 2023 Epilepsia, SUDEP counseling: Where do we stand?

SUDEP COUNSELLING

In the past…

How many of us counselled PWE about SUDEP 20 years ago?

A 2006 Survey of 783 UK neurologists

- **5 % of neurologists discussed SUDEP with all their patients,**
- 26% discussed it with most of their patients,
- 61% with a few patients,
- 7.5% with none

Similar figures in:

- Italy (2010),
- USA (2014)
- Austria, Germany and Switzerland (2016)

NICE Guideline. 2004. Morton B, et al JNNP . 2006;77(2):199–202; Gayatri NA, et al Epilepsia. 2010;51(5):777–82. Waddell et al. Seizure. 2013;22(1):74–6. Ross D, et al Epilepsia; 2015;56(4):e33–5. Friedman D, et al. Epilepsy Behav.2014;35:13–8; Strzelczyk A, et al. Epilepsia. 2016;57(4):612–20; Harden C, ET AL, Neurology 2017;88:1674–80.

SUDEP COUNSELLING

How many of us do it now?

Numerous recent studies confirm that **most neurologists still do not discuss SUDEP routinely with all PWE**

2022 Global Survey of 1123 neurologists from 27 countries,

- **Only 12% discussed SUDEP with most of their epilepsy patients**
- **41.5% rarely discussed SUDEP with their patients and caregivers**

Asadi-Pooya AA, et al. Epilepsy Behav. 2022;128:108570

REASONS GIVEN FOR NOT DISCUSSING SUDEP

Is ignorance bliss?

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Reasons given for not discussing SUDEP in ALL PWE

Not True!

- SUDEP is a rare condition
  (but it is the most common neurological cause of life years lost after stroke)
- It may cause unnecessary anxiety in PWE and their caregivers
  (this appears to occur only in the minority of patients, and is typically transient)
- Unlikely to affect the occurrence of SUDEP
  (but risk factor mitigation has been shown to work, and very few PWEs believe that nothing can be done to prevent the occurrence of SUDEP)
- Unlikely to result in behavioural change
  (one-fourth of PWE indicated that they had made substantial behavioural adjustments after learning about SUDEP)

Asadi-Pooya AA, et al. Epilepsy Behav. 2022;128:108570, Wadle NE, et al Epilepsia. 2023;64(2):406–19; Keddie S, et al JRSM Open 2016;7(9):2054270416654358

DISCUSSING SUDEP

With which PWE do we do it?

This study concluded that most neurologists were still of the opinion that only PWE at highest risk of SUDEP should be informed about the condition:

For example, those with:

- Frequent GTCS,
- Poor compliance
- Refractory GTC epilepsy.

Asadi-Pooya AA, et al. Epilepsy Behav. 2022;
Wadle NE, et al, Epilepsia. 2023;
Keddie S, et al., JRSM Open 2016

SUDEP COUNSELLING

Is this similar in all countries?

This seems to be the opinion of neurologists in virtually all countries

Only a minority of neurologists worldwide think that SUDEP should be discussed with **ALL** PWE

- 18.6% Africa (13/70)
- 26.1% Middle East (71/272),
- 30.6% Asia (15/59)
- 30.9% Europe (96/311),
- 36.2% Former USSR (47/130),
- 50.3% South America (99/197),
- 63.2% North America (43/68).

Regional differences may be due to resources, education, legal frameworks, ethics, and spiritual attitudes

Asadi-Pooya AA, et al. Epilepsy Behav. 2022;128:108570

SUDEP COUNSELLING

One **exception is Scotland** where there is now a legal obligation to inform epilepsy patients about the condition

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What about

SUDEP GUIDELINES?

NATIONAL AND INTERNATIONAL SUDEP GUIDELINES

All the following guidelines advise informing ALL PWE about SUDEP at the time of, or shortly after diagnosis:

- American Academy of Neurology (AAN)
- American Epilepsy Society (AES)
- National Institute of Health and Care Excellence (NICE)
- International League Against Epilepsy (ILAE) endorses the AAN guidelines

Yet most of us still don't do it

GUIDELINES ON SUDEP COUNSELING

Are you a believer?

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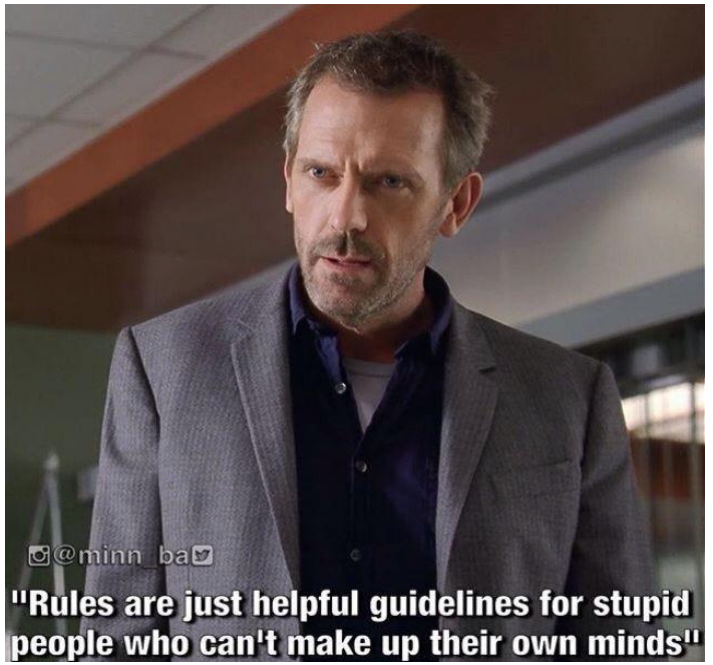
So, why don't we follow the guidelines?

Firstly, it is reasonable and sensible for us to exercise caution when applying generalised guidelines in our individual practices



- **Guidelines are often the result of consensus and are not always evidence-based.**
- **"A consensus means that everybody agrees to say collectively what no one really believes individually"** Abba Eben
- Some of us even think it is ethically wrong to discuss SUDEP in low-risk PWE

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So what is the

Ethical Perspective?

APPLYING ETHICAL PRINCIPLES WHEN MANAGEING A PATIENT WITH SUDEP

The four principles

The four principles underly modern biomedical Ethics:

- **Autonomy**
  (each person is an individual worthy of respect and of having a voice),
- **Beneficence**
  (doing good),
- **Non-maleficence**
  (doing no harm)
- **Justice**
  (fairness, regardless of a person's circumstances).

Each of these principles should be considered as equally important

APPLYING ETHICAL PRINCIPLES

Autonomy:

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Patients, caregivers and advocacy groups all share and endorse the opinion that SUDEP should be discussed with every PWE as early as possible, and preferably by the treating neurologist

We are obliged to listen to our patients regarding their overwhelming wish to be informed about SUDEP

Maguire MJ et al; Cochrane Database Syst Rev 2016;
Tonberg A et al. Epilepsy Behav 2015
;Ronen et al 2013

APPLYING ETHICAL PRINCIPLES

Beneficence and Non-maleficence

Doing more good than harm

Clinicians should always be concerned about causing unnecessary anxiety in their patients

However, the literature suggests that **potential anxiety resulting from being informed of SUDEP risk is overrated**, and most patients and family cope pretty well after receiving this information.

Also, where counselling does result in excess anxiety, this is **typically transient**

Therefore:

We should start with the assumption that patients and families are able to cope with the facts

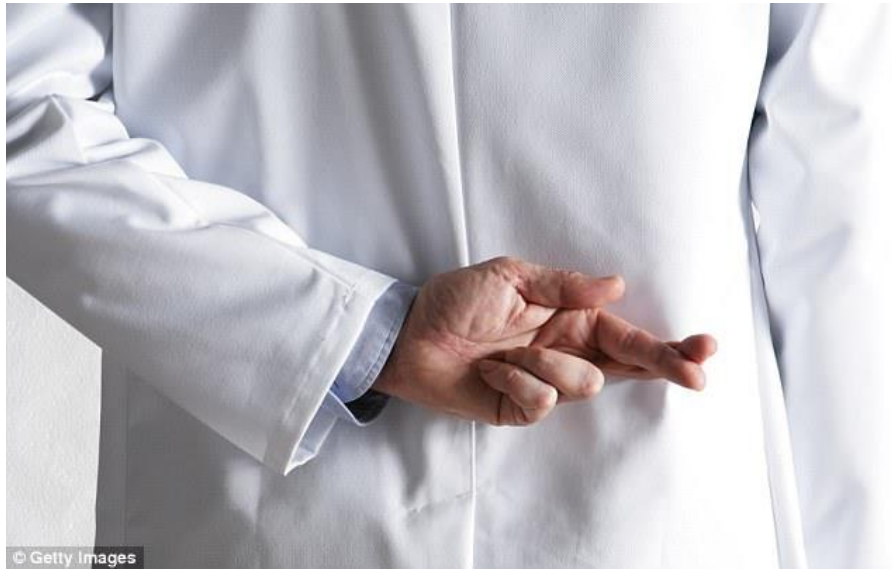
Reserve any non-disclosure for situations where harm is expected to result from telling the truth

Ronen GM, et al 2017 Curr Neurol Neurosci Rep

APPLYING ETHICAL PRINCIPLES

Justice:

Patients have the indisputable right to receive honest and comprehensive information from their clinician regarding their condition, especially if they ask for it.



Ronen GM, et al 2017 Curr Neurol Neurosci Rep
Ronen GM, et al 2017 Epilepsy & Behav

So, from an ethical perspective,

It seems that we are obliged to inform all our PWE about SUDEP

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What about

The Medicolegal Perspective?

LEGAL ASPECTS OF SUDEP COUNCELLING:

The right to know vs. the right not to tell

- As clinicians we must balance the **“right to know”** and **“right not to know”**
- **Therapeutic privilege** permits us to withhold information about material risks if we believe our patients are “unable to cope” with receiving such information.
- In the past there was a tendency to **“protect” patients against emotional distress** caused by the “breaking of bad news”.
- This has been replaced by the acknowledgment that patients have a **“right to be informed”** about their condition

Knoppers BM. Et al. J Law Med Ethics.
Edwin A. et al, 2008 Ghana Med J.
Beran RG.Seizure. 2015;27:47–50.
Ronen GM, et al 2017 Epilepsy & Behav

LEGAL ASPECTS OF SUDEP COUNSELLING

In most countries there is no legal requirement for a physician to inform patients of their medial conditions

Scotland is an exception.

Nisbet T, et al 2017 Epilepsy & Behav

LEGAL ASPECTS OF SUDEP COUNCELLING IN SCOTLAND:

The Fatal Accident Inquiry (FAI)

In 2010, a legal inquiry conducted into the SUDEP deaths of two young women in Scotland, concluded that:

- neither had been advised of the risk of SUDEP by their neurologists.
- their deaths might have been avoided had this been done

The court ruled that:

- **the 'vast majority' of patients should be informed about SUDEP when they are diagnosed with epilepsy,**
- **If not, it should be recorded why this did not occur.**

As a consequence, most patients in Scotland with newly diagnosed epilepsy are now counselled about SUDEP

Nisbet T, et al 2017 Epilepsy & Behavior

LEGAL JUDGEMENTS VS. GUIDELINES

The Scottish Fatal Accident Inquiry has shown, perhaps unsurprisingly, that **a legal ruling has a far greater effect on changing clinical practice than guidelines do.**

This is likely because of perceived medico-legal implications for clinicians.

SUDEP

Has the Fatal Accident Inquiry reduced SUDEP deaths in Scotland?

Interestingly….

There is no compelling evidence yet that the incidence of SUDEP has fallen in Scotland despite the fact that the majority of PWE are now informed about the condition in that country

Mbizvo GK, et al 2021 Epilepsia

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What about the

Doctor-Patient Relationship?

SUDEP COUNSELLING

The doctor-patient relationship

It's clear that PWE, their families and caregivers all **want to be informed** about SUDEP risk

And, ethically, they have the **"right to know"**

Discussing the risk of SUDEP:

- **Maintains trust and an honest relationship with your patient**
- **Educates and empowers patients**
- **Avoids misinformation from other sources** (social media, internet)
- **Enhances patient self-management skills** (behavioural modification)
- **Probably reduces SUDEP incidence in high-risk patients**

Whitney, R et al., 2023 Epilepsia
Ronen GM, et al 2017 Epilepsy & Behav

GUIDELINES: SUDEP COUNSELLING

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Counselling: When, how and what to say?

The **available guidelines are pretty consistent** regarding when and how to counsel patients and care givers about SUDEP

GUIDELINES: SUDEP COUNSELLING

When?

Most advise:

- Discussing SUDEP **at the time of epilepsy diagnosis, or shortly thereafter**
- Providing an **opportunity for further discussion at follow up visits**
- (Also discussing SUDEP in patients with a previous diagnosis of epilepsy, who have not been counselled in the past)

SUDEP COUNSELLING

How?

Most advise:

- **Face-to-face** discussion
- Preferably by the **treating neurologist** (or epilepsy nurse)
- **Written information** (pamphlet) or link to appropriate website
- **Caregivers should decide whether or not a child or patient with ID should be informed**.

SUDEP COUNSELLING

What to say?

Counselling should be **INDIVIDUALISED according to the patient's epilepsy type, SUDEP risk and socioeconomic circumstances and education**

In general, guidelines suggest telling patients with newly diagnosed epilepsy the following:

- If they remain seizure-free, then their risk of SUDEP is very small
- About 1 in 1000 adults and children with epilepsy will be affected per year, (then tell them 999/1000 will not)
- The better seizures are controlled, the lower will be their risk of SUDEP
- The better their compliance, the lower will be their risk of SUDEP
- Where seizures remain uncontrolled despite a variety of ASM regimes, then epilepsy surgery, vagal stimulation and other interventions may be helpful.
- Consider advising patients with frequent and/or nocturnal GTC seizures about nocturnal supervision and automated epilepsy-monitoring devices

SUDEP

So, what are the bottom lines?

Most guidelines stress that ALL PWEs should be counselled about SUDEP,

And the vast majority of patients, their families and caregivers want to be told about SUDEP at or soon after the time of diagnosis of epilepsy.

Despite this, most neurologists worldwide still believe that only those at highest risk should be informed.

From an ethical perspective, there is little justification for not informing your patients,

However, there is no legal imperative to inform your patients (Except in Scotland)

Because no two patients are the same or present the identical management problems, dogma must not dictate that every patient should be counselled in the same way.