December 4 - 8 ■ Philadelphia, PA
69TH ANNUAL MEETING

Pediatric State of the Art Symposium
Death in Children with Epilepsy:
A Different Tragedy Than in Adults

Symposium Co-Chairs:
Carol Camfield, M.D.

and

Elizabeth Donner, M.D.

Monday, December 7, 2015
Convention Center – Grand Ballroom AB

5:30 – 8:00 p.m.

GENERAL INFORMATION

Accreditation

The American Epilepsy Society is accredited by the Accreditation Council for Continuing Medical Education (ACCME) to provide continuing medical education for physicians.

Credit Designation

Physicians

The American Epilepsy Society designates this live activity for a maximum of 30.75 *AMA PRA Category 1 Credits*™. Physicians should claim only the credit commensurate with the extent of their participation in the activity.

Physician Assistant

AAPA accepts certificates of participation for educational activities certified for *AMA PRA Category 1 Credit*™ from organizations accredited by ACCME or a recognized state medical society. Physician assistants may receive a maximum of 30.75 hours of Category 1 credit for completing this program.

Jointly provided by AKH Inc., Advancing Knowledge in Healthcare and the American Epilepsy Society.

Nursing

AKH Inc., Advancing Knowledge in Healthcare is accredited as a provider of continuing nursing education by the American Nurses Credentialing Center's Commission on Accreditation.

This activity is awarded 30.75 contact hours.

Nurse Practitioners

AKH Inc., Advancing Knowledge in Healthcare is accredited by the American Association of Nurse Practitioners as an approved provider of nurse practitioner continuing education. Provider Number: 030803. This program is accredited for 30.75 contact hours which includes 8 hours of pharmacology. Program ID #21547

This program was planned in accordance with AANP CE Standards and Policies and AANP Commercial Support Standards.

Pharmacy

AKH Inc., Advancing Knowledge in Healthcare is accredited by the Accreditation Council for Pharmacy Education as a provider of continuing pharmacy education.

Select portions of this Annual Meeting are approved for pharmacy CE credit. Specific hours of credit for approved presentations and Universal Activity Numbers assigned to those presentations are found in the educational schedules. Criteria for success: nursing and pharmacy credit is based on program attendance and online completion of a program evaluation/assessment.

If you have any questions about this CE activity, please contact AKH Inc. at service@akhcme.com.

International Credits

The American Medical Association has determined that non-U.S. licensed physicians who participate in this CME activity are eligible for *AMA PRA Category 1 Credits*™.

CME/CE Certificates

For those attendees who wish to claim CME or CE, there is an additional fee. Registrants can pay this fee as part of the registration process. Those who do not pre-purchase the credit will also have the ability to pay this fee at the time they attempt to claim credit. Fees for CME increase after January 16 and are a one-time charge per annual meeting.

The evaluation system will remain open through Friday, February 26, 2016. Evaluations must be completed by this date in order to record and receive your CME/CE certificate.

Member Fees:	$50 through January 15, 2016 $75 January 16 – February 26, 2016
Non-member Fees:	$75 through January 15, 2016 $100 January 16 – February 26, 2016

Attendance Certificate/International Attendees

A meeting attendance certificate will be available at the registration desk for international meeting attendees on Tuesday, December 8.

Policy on Commercial Support and Conflict of Interest

The AES maintains a policy on the use of commercial support, which assures that all educational activities sponsored by the AES provide in-depth presentations that are fair, balanced, independent and scientifically rigorous. All faculty, planning committee members, moderators, panel members, editors, and other individuals who are in a position to control content are required to disclose relevant relationships with commercial interests whose products relate to the content of the educational activity. All educational materials are reviewed for fair balance, scientific objectivity and levels of evidence. Disclosure of these relationships to the learners will be made through syllabus materials and the meeting app.

Disclosure of Unlabeled/Unapproved Uses

This educational program may include references to the use of products for indications not approved by the FDA. Faculty have been instructed to disclose to the learners when discussing the off-label, experimental or investigational use of a product. Opinions expressed with regard to unapproved uses of products are solely those of the faculty and are not endorsed by the AES.

OVERVIEW
This symposium will present a detailed review of mortality in children with epilepsy with emphasis on what is currently fact. A discussion of SUDEP will outline why this catastrophe is different in children than adults and the quality of evidence for prevention. There will be a careful discussion of what to tell patients and families about the risk of death and how to assist families should their child die.

LEARNING OBJECTIVES
Following participation in this symposium, learners should be able to:

- Discuss the risk of death with families and children with epilepsy
- Provide critical guidance about appropriate evidence-based preventative strategies
- Counsel families effectively in the event of a death
- Counsel families about the low risk of death and guide appropriate evidence-based preventative strategies
- Encourage patients to be very compliant with medication, a key way to prevent seizures and a key to preventing sudden unexplained death in children with epilepsy

TARGET AUDIENCE
Basic: Those new to epilepsy treatment or whose background in the specialty is limited, e.g., students, residents, general physicians, general neurologists and neurosurgeons, other professionals in epilepsy care, administrators.

Intermediate: Epilepsy fellows, epileptologists, epilepsy neurosurgeons, and other providers with experience in epilepsy care (e.g., advanced practice nurses, nurses, physician assistants), neuropsychologists, psychiatrists, basic and translational researchers.

Agenda
Co-Chairs: Carol Camfield, M.D. and Elizabeth Donner, M.D.

Introduction and Case Presentations
Carol Camfield, M.D. and Elizabeth Donner, M.D.

What Are the Epidemiological Facts?
Elaine Wirrell, M.D.

Leading Theories about the Cause of SUDEP in Children and Prevention
Tobias Loddenkemper, M.D.

Why Is the Data So Different for Children Than Adults?
Peter Camfield, M.D.

What Should We Say to Parents about Death Related to Epilepsy and When?
Jeffrey Buchhalter, M.D., Ph.D.

Dealing with Grief after Expected and Unexpected Death in Children
Linda Coughlin-Brooks, RN, BSN, CT

Conclusions
Elizabeth Donner, M.D.

Education Credit
2.5 CME Credits

Nurses may claim up to 2.5 contact hours for this session.

Pharmacy Credit
AKH Inc., Advancing Knowledge in Healthcare approves this knowledge-based activity for 2.5 contact hours (0.25 CEUs). UAN 0077-9999-15-034-L01-P. Initial Release Date: 12/7/2015.

The American Board of Psychiatry and Neurology has reviewed the Death in Children with Epilepsy: A Different Tragedy than in Adults Symposium and has approved this program as part of a comprehensive program, which is mandated by the ABMS as a necessary component of maintenance of certification.

Commercial Support Acknowledgement
Supported in part by an educational grant from Eisai Inc. and LivaNova.

FACULTY/PLANNER DISCLOSURES
It is the policy of the AES to make disclosures of financial relationships of faculty, planners and staff involved in the development of educational content transparent to learners. All faculty participating in continuing medical education activities are expected to disclose to the program audience (1) any real or apparent conflict(s) of interest related to the content of their presentation and (2) discussions of unlabeled or unapproved uses of drugs or medical devices. AES carefully reviews reported conflicts of interest (COI) and resolves those conflicts by having an independent reviewer from the Council on Education validate the content of all presentations for fair balance, scientific objectivity, and the absence of commercial bias. The American Epilepsy Society adheres to the ACCME's Essential Areas and Elements regarding industry support of continuing medical education; disclosure by faculty of commercial relationships, if any, and discussions of unlabeled or unapproved uses will be made.

FACULTY / PLANNER BIO AND DISCLOSURES
Carol Camfield, M.D. (Co-Chair)
Carol Camfield MD, Professor Emeritus Pediatrics, Dalhousie University, Halifax Nova Scotia

Dr. Camfield has indicated she has no financial relationships with commercial interests to disclose.

Elizabeth Donner, M.D. (Co-Chair)
Dr. Elizabeth Donner is the Director of the Comprehensive Epilepsy Program at the Hospital for Sick Children in Toronto and an Associate Professor in the Faculty of Medicine at University of Toronto. She is a graduate of the University of Pennsylvania and McMaster University, and completed post graduate training The Hospital for Sick Children and Children's Hospital Boston. Dr. Donner is a leader in SUDEP advocacy, and co-founded SUDEP Aware in 2008. She is PI of the Canadian Pediatric SUDEP Registry, a member of the Executive of the North American SUDEP Registry, Chair of the AES SUDEP Task Force and a member of the Steering Committee of the Epilepsy Foundation SUDEP Institute.

Dr. Donner has indicated she has no financial relationships with commercial interests to disclose.

Jeffrey Buchhalter, M.D., Ph.D., FAAN
Dr. Buchhalter is Director of the Comprehensive Children's Epilepsy Centre at Alberta Children's Hospital. He received his MD and PhD in Neurosciences from UCLA. He did his neurology residency at the Harvard-Longwood Neurology program in Boston, where he completed fellowships in basic and clinical neurophysiology. His main research/clinical interests are: informatics approaches to epilepsy outcome measures quality improvement and seizure/epilepsy ontologies, ketogenic diet, trials of new

antiepileptic drugs, and sudden unexpected death in epilepsy (SUDEP). He participates in several committees including: AAN Medical Economics & Management, Coding Sub-committee, the Practice Committee and the CNS Practice Committee (chair).

Dr. Buchhalter discloses receiving support for Consulting from Lundbeck, Eisai and Upsher-Smith; for Contract Research from Use of AEDs Quality Improvment Project- Alberta Health Service, indirect. Epilepsy-Informatics Outcomes Project- Alberta Children's Hospital Foundation, indirect; for Honoraria from Honoraria for speaking at the AAN Annual Meeting and practice webinars; as Other Service (with or without compensation) from Chair of the Child Neurology Society Practice Committee; member of the AAN Medical Economics and Mangement Committee, coding sub-committee; member of the AAN Practice Committee; co-director of the Partners Against Mortality in Epilepsy conference; editorial advisory board for Clinical Neurology News; editorial board for the journal Pediatric Neurology. No compensation is received for any of these activities.

Peter Camfield, M.D., FRCP(C)
MD Harvard University; Pediatric residency University of Michigan; Child Neurology residency McGill University; Entire faculty career at Dalhousie University, Halifax, Nova Scotia Currently Professor Emeritus, Department of Pediatrics, Dalhousie University, Halifax In Halifax, with Dr. Carol Camfield, we have identified and followed a large population-based cohort of children with epilepsy for the past 30+ years. Based on this cohort we have produced many publications describing the natural history of childhood epilepsy, management and treatment and long-term social outcomes. A special focus has been mortality in children with epilepsy.

Dr. Camfield discloses receiving support for Honoraria from Biocodex.

Linda Coughlin Brooks, RN, B.S.N., CT
Linda Coughlin Brooks is a registered Nurse, Certified in Thanatology. She has written numerous articles on death related to SUDEP, started the first SUDEP Task Force in Colorado, is a speaker, educator, published researcher, and advocate for epilepsy deaths. Along with a private Grief Counseling Practice in Greenwood Village, CO she is a Consultant to the National Epilepsy Foundation as the Bereavement Support Coordinator for the SUDEP Institute. Linda lost her 17 year old daughter to Sudden Unexplained Death in Epilepsy (SUDEP) in 1997.

Ms. Coughlin-Brooks has indicated she has no financial relationships with commercial interests to disclose.

Tobias Loddenkemper, M.D.
Tobias Loddenkemper is a pediatric epileptologist and director of clinical research at the Epilepsy Center at Boston Children’s Hospital and serves as an Associate Professor at Harvard Medical School. Dr. Loddenkemper received several awards, including the Early Career Physician Scientist Award by the American Epilepsy Society and the Dreifuss Penry Award by the American Academy of Neurology. He published over 160 articles, and serves as associate editor of Wyllie's treatment of Epilepsy and of Seizure. His research focuses on the study of SUDEP, status epilepticus and difficult to treat seizures in an attempt to discover a relationship to biomarkers and ultimately novel processes that set the stage for epilepsy in the developing brain.

Dr. Loddenkemper discloses receiving support for for Royalty from Serves as an associate editor for Seizure, editor reimbursement payed to Neurology Foundation in Boston, no direct income.; as Receipt Of Intellectual Property Rights/Patent Holder from Pending patents for seizure detection, epilepsy diagnosis, and seizure prediction, no royalties or income as patents are pending, patents held by Boston Children's Hospital; for Consulting from Advisory boards USL and Lundbeck; for Contract Research from Investigator initiated research/pharmaceutical research trials for Eisai, Lundbeck,

Pfizer, Upsher Smith, Accorda (all payments indirectly to institution); research support from the American Epilepsy Society, the Epilepsy Research Foundation, the Epilepsy Foundation of America, the Epilepsy Therapy Project, PCORI, the Pediatric Epilepsy Research Foundation, Cure, Danny-Did Foundation, HHV-6 Foundation; for Ownership (i.e. stocks, stock options or other ownership) from May hold health care stocks in retirement funds; for Honoraria from Speaker honoraria for grand round presentations at academic centers nationally and abroad, and by academic societies including AES, AAN and ACNS; for Other Services from spouse, Dr Karen Stannard, is a pediatric epileptologist, sees patients, reads electrophysiological studies and bills for these procedures through an academic center where she works.; as Service (with or without compensation) as an officer, director, or trustee of any other professional or advocay organization relating to science or healthcare from serves on the Laboratory Accreditation Board for Long Term (Epilepsy and Intensive Care Unit) Monitoring, on the Council of the American Clinical Neurophysiology Society (Officer/Treasurer), on the American Board of Clinical Neurophysiology, all for no compensation. Associate Editor for Wyllie's Treatment of Epilepsy 6th edition, no compensation received.

Dr. Loddenkemeper does intend to reference unlabeled/unapproved uses of drugs or products – May mention various unapproved epilepsy monitoring options and treatments in a broad context, no brand names.

Elaine Wirrell, M.D.
MD (Honours) from the University of British Columbia Pediatric Neurology Training at Dalhousie University, Halifax NS, Canada Currently am the Director of Pediatric Epilepsy and Professor of Neurology at Mayo Clinic, Rochester MN Cofounder and member of the Steering Committee for the Pediatric Epilepsy Research Consortium Research interests: epidemiology, predictors of outcome in pediatric epilepsy, epilepsy comorbidities.

Dr. Wirrell discloses receiving support for Contract Research from Clobazam in Dravet Syndrome Study Epidiolex in Dravet Syndrome and Epidiolex in Lennox-Gastaut study for all of these studies, I have received no personal compensation - all monies have been received by my employer, Mayo Clinic.

CME Reviewer
Sucheta Joshi, M.D.
I am trained as a Pediatric Neurologist and Epileptologist, and have a Masters in Clinical Research Design and Statistical Analysis. My clinical interests include caring for infants and children with difficult to treat epilepsy, and to improve access to care for underserved children. I am the Clinical Lead for the Pediatric Epilepsy Telemedicine Program in Michigan, which aims to improve access to care for children with epilepsy, using a medical home model. I am the Medical Director for the National Co-ordinating Center of the American Academy of Pediatrics for Children and Youth with Epilepsy. I am a co-investigator in the Pediatric Epilepsy Research Consortium (PERC), a multicenter group to study the rare pediatric epilepsies.

Dr. Joshi has indicated she has no financial relationships with commercial interests to disclose.

Gaston Baslet, M.D.
Dr. Baslet is an associate neuropsychiatrist at Brigham and Women's Hospital in Boston, MA, where he is the liaison psychiatrist for the Epilepsy Service, and assistant professor of Psychiatry at Harvard Medical School. Dr. Baslet is also the Associate Director of Medical Student Education at Brigham and Women's Hospital. He received his medical degree in Argentina and completed his post-graduate training in Psychiatry and Neuropsychiatry at the University of Illinois at Chicago. Dr. Baslet has been involved in the development of clinical services for PNES patients. He has published articles about

PNES in peer-reviewed journals and gives lectures to healthcare providers nationally and internationally on this health condition.

Dr. Baslet has indicated he has no financial relationships with commercial interests to disclose.

Coutrney Wusthoff, M.D.
Dr. Wusthoff is Assistant Professor of Child Neurology and by courtesy, Pediatrics (Neonatal and Developmental Medicine) at the Stanford University School of Medicine. She is also Neurology Director for the Lucile Packard Children's Hospital Stanford Neuro-NICU. She conducts clinical research in neonatal neurology, focusing on neonatal seizures, critical care EEG monitoring, and early onset epilepsies. Her clinical work includes inpatient and outpatient neonatal neurology, clinical neurophysiology, and pediatric epilepsy care.

Dr. Wusthoff has indicated she has no financial relationships with commercial interests to disclose.

Paul Levisohn, M.D. (Medical Content Specialist, AES)
Dr. Levisohn is a member of the faculty of the section of Pediatric Neurology at The University of Colorado School of Medicine and Children's Hospital Colorado Neuroscience Institute, having joined the faculty over 15 years ago following a similar period of time in the private practice of pediatric neurology. His academic career has focused on clinical care for children with epilepsy with particular interest in clinical trials and on the psychosocial impact of epilepsy. Dr. Levisohn is currently a consultant on medical content for CME activities to staff of AES. He is a member of the national Advisory Board of EF and has been chair of the advisory committee for the National Center of Project Access through EF.

Dr. Levisohn has indicated he has no financial relationships with commercial interests to disclose.

AKH STAFF / REVIEWERS
Dorothy Caputo, MA, BSN, RN (Lead Nurse Planner) has indicated she has no financial relationships with commercial interests to disclose.

Bernadette Marie Makar, MSN, NP-C, APRN-C (Nurse Planner) has indicated she has no financial relationships with commercial interests to disclose.

John P. Duffy, RPh, B.S. Pharmacy (Pharmacy Reviewer) has indicated he has no financial relationships with commercial interests to disclose.

AKH staff and planners have nothing to disclose.

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NURSING & PHARMACY

PLEASE NOTE: Providing your NABP e-profile # is required.
The National Association of Boards of Pharmacy (NABP) requires that all pharmacists and pharmacy technicians seeking CE credit have an ID number issued by NABP. Pharmacy CE providers, such as AKH Inc., Advancing Knowledge in Healthcare, are required to submit participant completion information directly to NABP with your ID number and birth information to include month and date (not year) as a validation to this ID number. If you do not have an ID number (this is not your license #), go to: www.MyCPEmonitor.net

Nursing and Pharmacy credit (per session) is based on attendance as well as completion of an online evaluation form available at:

WWW.AKHCME.COM/2015AES

THIS MUST BE DONE BY JANUARY 15, 2016 TO RECEIVE YOUR CE CREDIT.
We cannot submit credit to NABP after this date.
If you have any questions, please contact AKH at service@akhcme.com.

DISCLAIMER
Opinions expressed with regard to unapproved uses of products are solely those of the faculty and are not endorsed by the American Epilepsy Society or any manufacturers of pharmaceuticals.

Death in Children with Epilepsy – A Different Tragedy

Elizabeth Donner, MD, MSc, FRCPC
University of Toronto, Hospital for Sick Children

December 7, 2015

Disclosure

No financial disclosures.

Children with epilepsy have a 5 – 10 times increased risk of death compared to the general population.

1. What are the facts? Elaine Wirrell
2. How do deaths occur; how can we prevent them? Tobias Loddenkemper
3. Why is it different in children? Peter Camfield
4. How should we talk to parents? Jeff Buchhalter
5. How can we support families? Linda Couglin-Brooks

Mortality in epilepsy has many different faces

Case histories from Carol Camfield

#AESmtg15

3 cases of death in children with epilepsy

Carol Camfield
Dalhousie University, Halifax, NS

December, 2015

1

Disclosure

None

2

Jake
Cerebral palsy, intellectual disability and epilepsy

3

Born in rural Nova Scotia

- 42 w gestation, toxemia, C/S, no neonatal encephalopathy
- 9 lb 12oz, HC 95%ile
- Quiet, easy infant

9 months: pediatrician noted markedly delayed milestones

- No interest in surroundings
- No grasp or holding of objects
- Unable to sit

4

2 years: cortically blind.
Brief staring spells.
EEG: Bilateral multifocal spikes with diffuse background disturbance
CT: cerebral atrophy (HC 75%ile), dysgenesis of cerebellum vermis
Rx phenobarbital - good initial control

3 ½ years: GTC, daytime tonic seizures myoclonic jerks
Valproate

5

5 years: blind and non-verbal

- Blended food only due to GER
- Persistent myoclonic jerks only
- No other sz x 3 years on valproate
- Hip adductor release. No scoliosis.
- Severe osteopenia

10 years:

- Obstructive sleep apnea requires tracheostomy
- Scoliosis develops

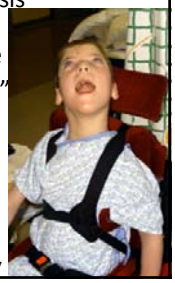
6

12 years

- GER persists
- Seizure-free x 10 yrs on valproate, except for myoclonus
- Luque rod placement for 70° scoliosis

12½ yrs fell from wheelchair at home
4 cm abrasion and "cracked patella"

- Sepsis developed 3 days later
- Death in hospital
- Autopsy: sepsis, CP and epilepsy



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Kathy - SUDEP

7 years: Previously healthy, talkative child

- Sudden onset, brief LOC with cessation of activities, 3-15 second staring spells, lip smacking, and eyelid flutter
- Normal PE and no myoclonic jerks or GTC. Does well in Grade 2 but teacher complains of inattentiveness
- EEG: nl background, freq 3hz spikes with both hyperventilation and photic stimulation
- Dx: Childhood absence epilepsy.
- Treated with Valproate x 3 years. Seizure-free after sputtering along for a year and then 2 yrs seizure freedom and discontinued.

School psychological testing: IQ 92, inattentive compatible with ADHD

Excellent gymnast

Popular with friends

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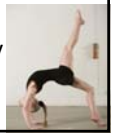
14 years

- Several brief, early morning GTC seizures. No recent myoclonic jerks or absence seizures
- Sleep deprived EEG: 1-3 sec of gen s-w 3-6Hzs
- Photic → gen. polyspikes and myoclonic jerks. Mother now recognizes jerks present at breakfast time for several months
- School difficult and gymnastics a passion

- Dx: Juvenile Myoclonic Epilepsy



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- VPA 250/500 mg
- Instructions about importance of adherence for multiple years and lifestyle counseling (avoidance of sleep deprivation and alcohol)
- Seizure-free x 4 months
- VPA doses missed on vacation resulted in myoclonic jerk crescendo→GTC x 2. Further counselling on adherence.
- Travel to gymnastics competitions, ↑school difficult, and demands of parents for independence and "freedom"

- Over next 4 years, 8-10 more GTCs associated with poor adherence

- https://www.google.ca/search?q=gymnastics+and+images&biw=735&bih=393&v&sa=X&ved=0CBwQsARqFQoTCLiFusHg8scCFQsVkgodINMEoA

- Entrance to community college lead to sleep deprivation - with exams and paper deadlines and missed doses of VPA. Several GTCs follow.

- Last seen at 3am studying on her bed for March midterm exams

- Found prone and lifeless in morning, under covers in bed.
- Autopsy and toxicology studies unremarkable except no found VPA in her blood
- Diagnosis: SUDEP

Nona – Batten's disease

Photos from family

1

Normal birth and development in pre-school and early grade school years

14 months

2

8 years: learning, behavior and visual difficulties began.
School phobia lead to home schooling

3

11 years: an "avid reader." Referrals begin:

- Child psychiatry: "mind wandering and conversation inappropriate" and visual hallucinations.
- Ophthalmology: small amplitude nystagmus, limited vision (6/9), pale disks: retinitis pigmentosa
- Neurology: anorexia and progressive dementia. Buffy coat of white cells showed changes typical of Juvenile Batten's disease (ceroid lipofuscinosis, a degenerative, autosomal recessive disorder).

4

14 years moves to near-by nursing home. Mother brings lunch daily in Nona's "Tickle Trunk"

- Mother with Nona attend the first of many international Batten's Disease Support Assoc. meetings
- GTC with incontinence begin of 2-3 minutes. Post-ictal 3-4 hours. Rx Valproate, Ca, Vit. D.
- Less spontaneous activity helping with ADLs and no reading interest
- Behavior acceptable on chlorpromazine and sleep problems with choral hydrate

5

21 years:

- Responds to light and voice with a smile. Fed by caretakers. Picks up head from chest if asked. Sings one song but otherwise mute.
- Uses wheelchair for mobility, prevention of injury, and behavior corralled.
- Mother active in Batten's group, her "lifeline."
- GTC, some occasionally prolonged stopped with nasal midazolam.

6

29 years:

Death occurred at Nursing Home

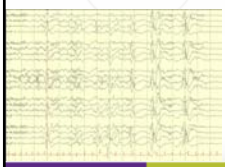
Family present

No autopsy

7

What are the Epidemiological Facts?

Elaine Wirrell MD
Mayo Clinic



AMERICAN EPILEPSY SOCIETY 69TH ANNUAL MEETING DECEMBER 4 - 8, 2015 PHILADELPHIA, PA

Disclosures

- Investigator: Epidiolex in Lennox-Gastaut and Dravet Syndrome (GW Pharma)

Learning Objectives

- How much higher is the risk of death in children with epilepsy?
- Why are the major causes of death?
- What factors increase the risk of death?
- Are these deaths preventable?
- What do I tell families?

How Common Is Death in Pediatric Epilepsy?

How Good is the Evidence? Population-Based studies

Study	Design	Incidence (I) vs Prevalence (P)	N	Mean FU (mean age at FU) in yrs
Camfield et al. 2002	Prospective	I	686	13.0 (19.2)
Nickels et al. 2012	Retrospective	I	467	13.6 (16.7)
Sillanpaa and Shinnar 2010, 2013	Prospective	I and P	245	40.0 (43.0)

How Good is the Evidence? Regional or Community or Clinic Based

Study	Design	Incidence (I) vs Prevalence (P)	N	Mean FU (mean age at FU) in yrs
Geerts et al. 2010, Callenbach et al. 2001	Prospective regional	I	472	14.4 (20.7)
Berg et al. 2004, 2013	Prospective community based	I	613	16.5 (23.3)
Gronborg and Uldall 2014	Retrospective, tertiary care clinic	I and P	1974	5.7 (15)

How Good is the Evidence? Population-Based Reviews of Pediatric Deaths

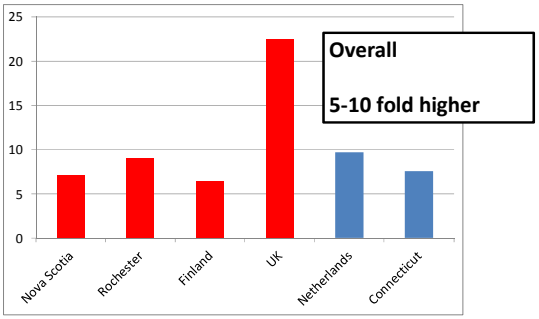
Study	Design	Incidence (I) vs Prevalence (P)	N	Mean FU (mean age at FU) in yrs
Harvey et al. 1993	Retrospective,	I and P	1095 deaths, 93 epilepsy	NA
Ackers et al. 2011	Retrospective	P	6190	4.3 yrs

- Pediatrics 2013;132:124-131
- Combined experience of 4 large pediatric cohorts of newly diagnosed children with epilepsy
- 2239 subjects followed for >30,000 person-years

Standardized Mortality Ratio (SMR)

- How much higher is the death rate in children with epilepsy compared to the general population?
- Ratio of observed deaths in the study population to expected deaths in the general population, corrected for age and sex

SMR for Pediatric Epilepsy



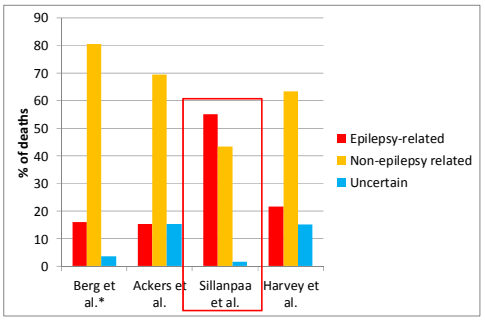
Why and When Do Children With Epilepsy Die?

Mortality in Children with Epilepsy

Epilepsy-Related:
- Complication of Seizure: SUDEP, Status epilepticus, Aspiration
- Complication of Treatment

Non Epilepsy Related:
- Natural causes:
  - Associated with epilepsy - ie brain tumors, neurometabolic disease
  - Related to underlying neurological disability – ie pneumonia in child with severe CP
  - Other
- Non-natural causes:
  - Accidental death
  - Suicide or homicide

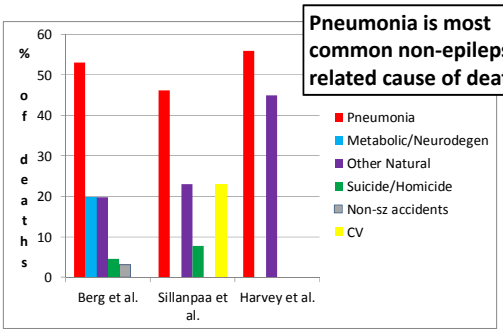
Most deaths are NOT epilepsy-related!



*modified to include metabolic/neurodegenerative conditions

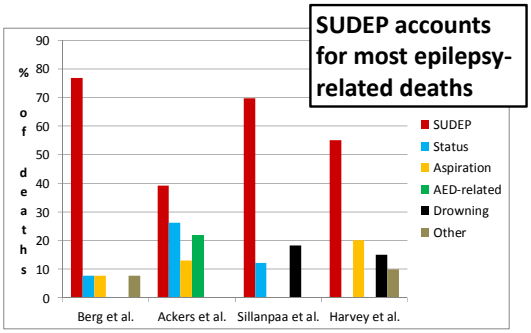
Non-Epilepsy Related Deaths

Pneumonia is most common non-epilepsy related cause of death

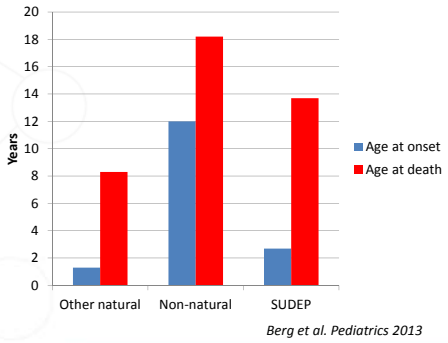


Epilepsy-Related Deaths (<25%)

SUDEP accounts for most epilepsy-related deaths



When Do They Die?



Berg et al. Pediatrics 2013

When Do They Die?

Sillanpaa and Shinnar 2010

- Deaths in childhood occurred primarily in those with complicated epilepsy, and were most often not seizure-related but due to underlying neurological disability
- Deaths due to epilepsy-related causes in subjects with uncomplicated epilepsy occurred primarily in adolescence and adulthood

Why and When Do They Die?

- Most studies suggest epilepsy related deaths are rare (≤25% of all deaths).
- Most common causes are related to severe underlying neurological disability (aspiration pneumonia) and metabolic/neurodegenerative disorder. These are more common in childhood.
- Among epilepsy-related deaths, SUDEP is most common factor. These are more common in adolescents and adults.

What are the Risk Factors for Increased Mortality?

Epilepsy Type

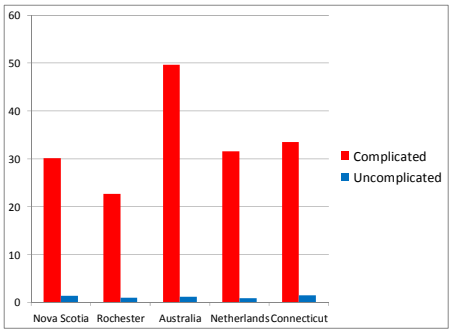
Complicated

- Known structural cause
- Significant intellectual disability
- Abnormal neurological exam

Uncomplicated

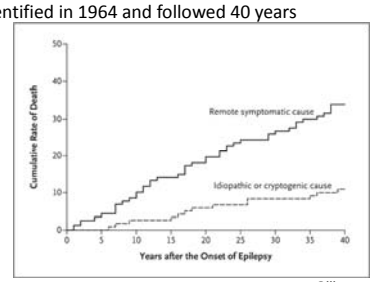
Epilepsy Type Matters!

SMR compared to General Popl'n



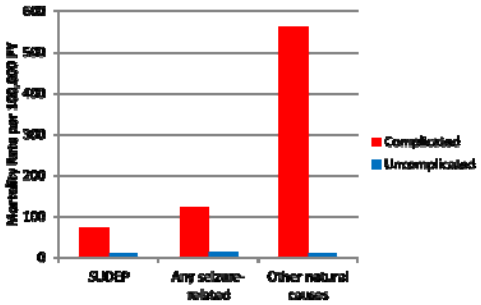
Long-term, prospective follow-up study from Finland

- 245 children with epilepsy (incident and prevalent cases) identified in 1964 and followed 40 years



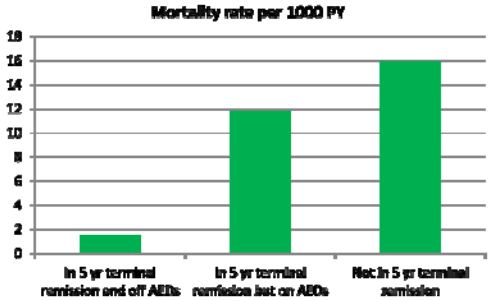
Sillanpaa et al. 2010

This is true for both non-epilepsy and epilepsy-related mortality!



Berg et al. 2013

Lack of Terminal Remission



Sillanpaa & Shinnar 2010

Lack of Terminal Remission – Other Studies

- Berg et al. 2013:
  - Seizures in the preceding year were present in:
    - 74% of patients who died of any cause
    - 92% who died of epilepsy-related causes
    - 70% who died of non epilepsy-related causes
  - Drug resistance was present in:
    - 57% of patients who died of any cause
    - 69% who died of epilepsy-related causes
    - 57% who died of non epilepsy-related causes
- Gronberg and Uldall 2014
  - 95% of children who died had refractory seizures

History of Status Epilepticus

- Sillanpaa and Shinnar 2010:
  - Prior SE was a significant predictor of death on univariable but not multivariable analysis for:
    - All deaths: Hazard ratio 1.9 (95% CI 1.2-3.2), p=0.01
    - Epilepsy-related deaths: HR 2.1 (95% CI 1.1-4.2), p=0.03
- Berg et al. 2013:
  - Prior SE occurred in:
    - 48% of children dying of all causes
    - 62% of those dying from epilepsy-related causes
    - 47% of those dying from non epilepsy-related causes

What are the Risk Factors?

- 2 Biggest Factors:
  - Complicated epilepsy
  - Lack of terminal remission
- Neurologically normal children without known cause have a similar mortality rate to the general population

Is the Mortality Preventable?

Non Epilepsy-Related Deaths

- Predominantly due to serious underlying neurological disability
  - Improved pre/perinatal care
  - Prenatal screening for rare genetic conditions
  - Improved longitudinal care of persons with neurological disability

BUT MOSTLY NOT PREVENTABLE

Epilepsy-Related Deaths

- Most are due to SUDEP
  - Reduce risk ntrol (improved compliance ressive managemer eration of surgery if refractory a
  - ?improved
  - ?more vigor nt postictally

Epilepsy-Related Deaths

- Less frequently, mortality is due to:
  - Status epilepticus or aspiration
    - Education re: positioning to reduce aspiration
    - Home rescue therapy and Status protocols for children at risk
    - Improved seizure control
  - Drowning
    - Showers rather than baths
    - Supervision when swimming (other than lifeguard)

AMERICAN EPILEPSY SOCIETY 69TH ANNUAL MEETING

What Do I Tell Families?

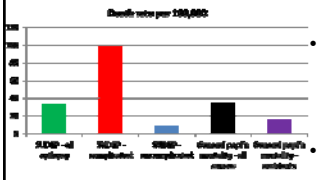
AMERICAN EPILEPSY SOCIETY 69TH ANNUAL MEETING

What To Tell Families

- Disclosure is important – families need to understand the risk
- Children with epilepsy have mortality rates 5-10x higher than the general population
  - Most deaths occur in children with "complicated" epilepsy
  - Those with uncomplicated epilepsy have mortality rates similar to the general population
- Most deaths are not seizure related but due to severe underlying neurological disability - generally NOT preventable
- SUDEP is the most common epilepsy-related cause of death and may be preventable with more aggressive treatment of seizures

AMERICAN EPILEPSY SOCIETY 69TH ANNUAL MEETING

What to Tell Families - SUDEP



- In all epilepsies – similar to overall mortality rate for all causes in age-matched population
- In complicated epilepsy – 3-fold higher than the overall mortality rate for all causes in age-matched population
- In uncomplicated epilepsy – similar to most common cause of death (accidents) in general population

Berg et al. 2013

THANK YOU

Pediatric State of the Art Symposium
Leading Theories about the Cause of SUDEP in Children and Prevention

Tobias Loddenkemper, M.D.

Slides not available

Why is the Data so Different for Children Than Adults?

Peter Camfield MD
Dalhousie University, Halifax

December 7, 2015

AMERICAN EPILEPSY SOCIETY 69TH ANNUAL MEETING DECEMBER 4 - 8, 2015 PHILADELPHIA, PA

Disclosure

Honorarium Biocodex

Learning Objectives

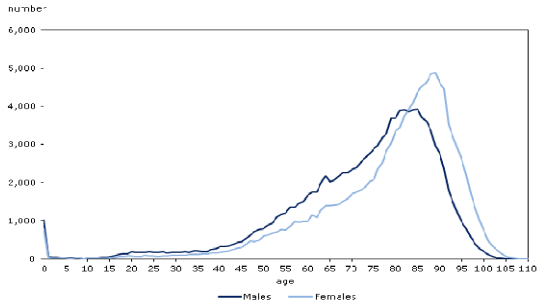
1. Death in adults is common
   Death in children is rare and particularly poignant.
2. Death in adults with epilepsy is nearly always from the normal things that adults die from. SUDEP is rare.
3. Death in children with epilepsy is nearly always from comorbid conditions. SUDEP is very rare.
4. Epilepsy may be a progressive disorder with increasing risk of SUDEP with many seizures. Complete control of seizures in childhood is desirable.

Concept 1

Children rarely die.
Nearly all deaths in children with epilepsy are from co-morbid neurological conditions.
Any death stands out. There is no background noise.

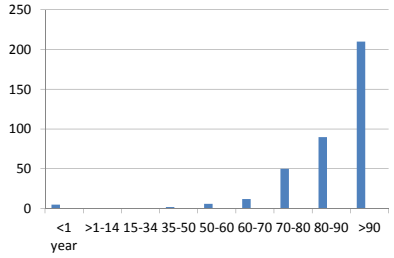
Most deaths in adults with epilepsy- the normal things that people die from.
There is a lot of background noise.

Figure 3
Number of deaths by age and sex, Canada, 2011

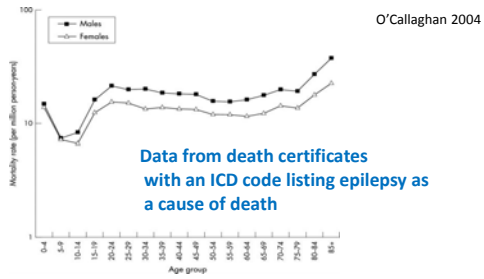


Notes: Deaths for which the province or age of death was unknown were prorated using the observed distribution.
Source: Statistics Canada, Canadian Vital Statistics, Deaths Database, 2011, Survey 3233.

Annual mortality/1000 population by age

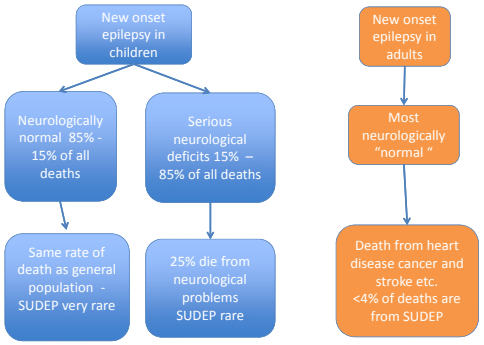


Statistics Canada 2009



O'Callaghan 2004

Epilepsy mortality rates 1950–94 England and Wales

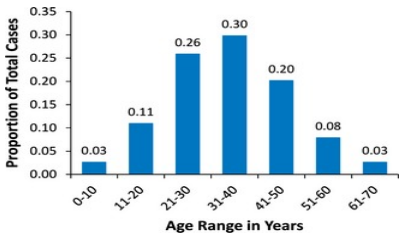


Christensen 2015, Camfield 2002, Benn 2009

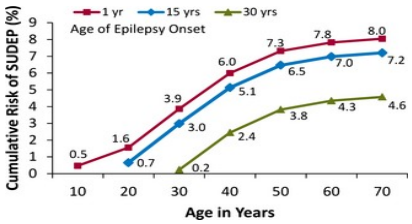
Concept 2

SUDEP can occur at any age but is strongly related to long standing, chronic epilepsy.

SUDEP is uncommon in childhood. If epilepsy persists into adulthood, the rate of SUDEP may rise.

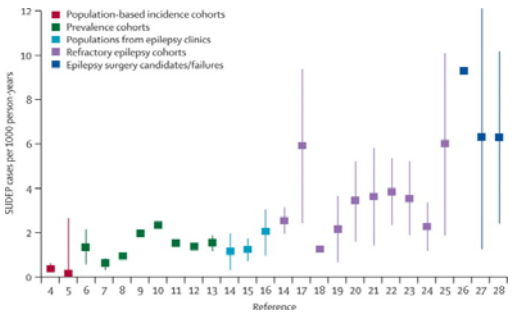


Thurman Epilepsia 2014 – based on "systematic" review
87% of SUDEP in adults >20
13% <20 years of age



Estimated cumulative risk SUDEP among people with epilepsy by age, assuming age of onset at 1, 15, and 30 years and **no remission**.

Thurman Epilepsia 2014



Tomson Lancet 2008 26 studies

SUDEP is rare in children (Berg 2013)

- 4 prospective population-based cohorts, new onset childhood epilepsy: Nova Scotia, Connecticut, Rochester, Netherlands 2239 children, >30,000 patient years follow up to ~20 years
- 10 definite or probable SUDEP
- **Overall SUDEP 0.33/1000 person years**
  "Uncomplicated epilepsy" 0.09/100,000
- **Median interval between epilepsy onset and SUDEP 9.2 years (5 mos-16 years)**
- Problem: The risk of SUDEP increases with duration of epilepsy. A large study of incidence cases with a relatively short follow up will find few cases/1000. How long is good?

>50% of children with epilepsy have a prompt and lasting remission essentially taking away risk of SUDEP

Dutch study n=413 with 15 year follow up (Arts 2013)
45% Favourable = continuous, stable long-lasting remission from the first year of treatment
26% Improving = late but then stable remission of ≥5 years after an initial poor or variable course
19% Deteriorating or variable = remissions and relapses <5 year remission
10% Poor = continuing seizures

Only 29% of children with epilepsy are at risk for SUDEP

Duration of epilepsy and risk of SUDEP
Walczak et al. 2001

- 4578 patients from EMU, 46% <19 years old
- 16,463 patient years of follow up
- 10 definite, 10 probable SUDEP (4 controls/SUDEP)
- 0 SUDEP in 0-19 year olds

Duration of epilepsy	SUDEP	OR
0 - <15 years	5	1
15-<30 years	5	1.5
>30 years	8	13.9

SUDEP is rare in childhood.

Is SUDEP rare in childhood onset epilepsy if the epilepsy persists?

Sillanpaa and Shinnar NEJM 2010

- 245 children with epilepsy
  150 incidence cases, 95 prevalence cases
  Follow up until death or median of 40 years

- 123 (50%) remote symptomatic = "epilepsy associated with a major neurologic abnormality or insult" (15% in Nova Scotia study)

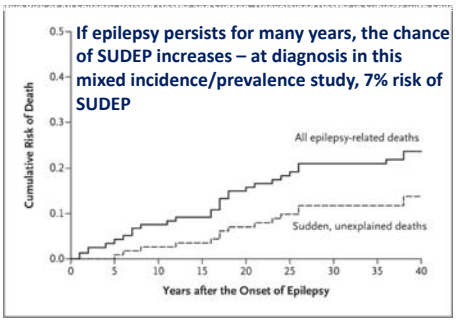
- Overall, 60 died (25%)
  Death: incidence cases = 5.3 per 1000 person years
  prevalence cases = 9.6 per 1000 person-years

Sillanpaa and Shinnar NEJM 2010

Deaths:
3/103 (3%) in ≥ 5 year terminal remission off AEDs
51/107 (48%) not in ≥ 5 year terminal remission

- Number with SUDEP = 18
  Median age at death 25 years (range, 4 to 49)

If your epilepsy remits early, you are very unlikely to die !



Sillanpaa 2010

Conclusions – secure

1. Deaths in children with epilepsy are nearly all from co-morbid conditions. Any death stands out.
2. Death in adults with epilepsy is mainly from cancer heart disease and stroke.
3. In childhood onset epilepsy SUDEP occurs but is very rare during the childhood years.
4. SUDEP appears to increase if childhood onset epilepsy is chronic and persists into adulthood.

Conclusions – speculative

- Whatever causes SUDEP may, in part, be related to multiple seizures – many seizures may alter the brain to allow SUDEP to occur. Most children with epilepsy have a shorter course.
- Children/parents may be more compliant with AEDs and night time supervision may be greater.
- Children may tougher than adults

Let's stop epilepsy in children before they grow up to be adults with epilepsy

What Should We Say to Parents of Children with Epilepsy and When (and Why?)

Jeffrey Buchhalter MD, PhD
Alberta Children's Hospital
Section of Pediatric Neurology
University of Calgary, Cumming School of Medicine

December 7, 2015

AMERICAN EPILEPSY SOCIETY 69TH ANNUAL MEETING DECEMBER 4 - 8, 2015 PHILADELPHIA, PA

Disclosure

Co-director, Partner's Against Mortality Conference, 2016

North American SUDEP Registry Executive Committee

Learning Objectives

- Learn the reasons for discussing premature mortality
- Understand what parents want based upon the literature
- Understand that the discussion of premature mortality is patient specific

Impact on Clinical Care and Practice

- Premature mortality should be discussed with most patients/families with epilepsy
  - Empowers patients/families participation in care
  - Establishes a truth telling relationship
- The conversation is tailored to the patient/family
  - Based on factors specific to the patient (e.g. etiology)
  - Modified by epilepsy related risk factors
  - Goals different depending upon the situation

Context

- 3 individuals with epilepsy who died prematurely from different causes related to epilepsy
- All had know seizures that were refractory to treatment or had an underlying neurological disorder
- What about children who have normal development, no underlying neurological disorder and seizure-free?

The What (or If)

- A logical possible answer to the 'what' question is 'nothing' (and probably the rule rather than the exception)

Reasons to disclose the possibility of mortality

- Professional
  - Truth telling
  - Share in treatment goal
  - Adherence
- Ethical
  - 'Right to know'
  - Full disclosure
- Family/Patient oriented care

Hirsch et al, 2011

AMERICAN EPILEPSY SOCIETY 69TH ANNUAL MEETING

Parental and physician beliefs regarding the provision and content of written sudden unexpected death in epilepsy (SUDEP) information

- Regional pediatric epilepsy clinic
- 100 consecutive parents/legal guardians
- Parent questionnaires
  - Provided immediately after discussing SUDEP and at 3 mos
- Physician questionnaire
  - Mailed
  - 7 questions

Gayatri et al. Epilepsia 51(5):777-782, 2010

Parent Results

- 67% completed first, 47% second questionnaire
- 91% of parents expected the pediatric neurologist to provide SUDEP risk information
- 67% of parents wanted the information at the time of dx

Gayatri et al. Epilepsia 51(5):777-782, 2010

Results:

"The majority (74%) of pediatric neurologists provided SUDEP information only to a select group of children with epilepsy and were uncertain about the effect such information would have upon the parent and child.

Conversely, 91% of parents expected the pediatric neurologist to provide SUDEP risk information. The provision of this information did not have a significant immediate and longer-term negative impact."

67% of parents wanted the information at the time of dx

Gayatri et al. Epilepsia 51(5):777-782, 2010

SUDEP: What Do Parents Want to Know?

- Stratified sampling of parents who have
  - lost a child to SUDEP
    - One on one interview, N = 6
  - children with Moderate to severe epilepsy
    - Focus group, N = 7
  - children with Mild epilepsy
    - Focus group, N = 9
  - children with New onset epilepsy
    - Focus group, N = 5

RR Nair et al, Epilepsy & Behavior 2013;29:560-4

SUDEP: What Do Parents Want to Know?

Table 1
Semiquantitative response from participants.

Question/opinion	Mothers (groups ii, iii, and iv) #21	Fathers (groups ii, iii, and iv) #15	Parents of children who had SUDEP #6
Heard about SUDEP before study	16	7	All
Risk of SUDEP overestimated	Around a third	Nearly half	None
Felt anxious/stressed on hearing about SUDEP	Nearly two-thirds	Nearly half	5
SUDEP should be discussed with parents	All	All	All
Prefers discussion at first visit	Nearly half	Nearly two-thirds	3
SUDEP should be discussed by the pediatric neurologist	All	All	All
Method of discussion: prefers face to face	All	All	All
Parents to decide whether child should be informed about SUDEP	All	All	All
Knowledge of SUDEP will change the interaction with children	None	None	None

Some small differences between mothers & fathers

CONSENSUS
- Discussion should take place & soon after diagnosis (1st or 2nd visit)
- Risk commonly overestimated
- Face to face discussion preferred
- Parents should decide if & when discussed with child
- No resultant change in interaction with child

RR Nair et al, Epilepsy & Behavior 2013;29:560-4

SUDEP: Knowledge & Experience Among US and Canadian Neurologists

- Electronic survey sent to 17,588 US & Canadian neurologists
- 1200 (9%) returned
- ~76% adult, 20% pediatric
- 93% USA
- 37% academic practice

Friedman et al, Epilepsy & Behavior 35 (2014) 13–18

SUDEP: Knowledge & Experience Among US and Canadian Neurologists

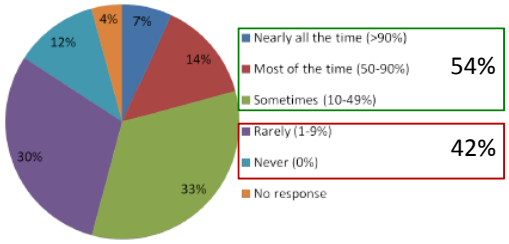


Figure 2. Frequency of discussion of SUDEP among respondents

Friedman et al, Epilepsy & Behavior 35 (2014) 13–18

So what should parents be told? Different discussions for different situations

- Seizures + respiratory issues: emphasize pulmonary toilet & early treatment of pneumonia
- Seizures + impairment of consciousness: counsel regarding water safety
- Seizures + risk factors for SUDEP

Considerations for High Risk Group

- Discuss as part of general education
- **Specific intent**: compliance (medication, surgery, device, diet)
- **Timing**: at the first office visit
- **Repetition**: PRN compliance & seizure control

Considerations for Low Risk Group

- Discuss as part of general education
- **Specific intent**: reassurance
- **Timing**: at the first office visit if time allows
- **Repetition**: none unless requested
- Be aware of the “not asked question”

Considerations for Low Risk Group

- Discuss as part of general education
- **Specific intent**: reassurance
- **Timing**: at the first office visit if time allows
- **Repetition**: none unless requested
- Be aware of the “not asked question”

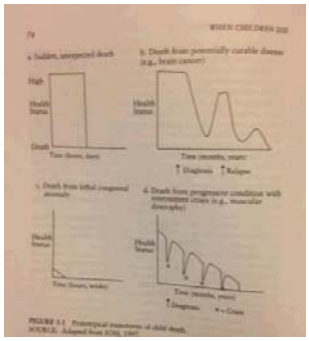
The individual in the context of epidemiology

With permission Gardiner Lapham

Henry Lapham

- 3 years old: simple febrile seizures
- 4 years old: 5 – 6 afebrile convulsive seizures in sleep or upon awakening.
- Seen by a pediatric epileptologist & started on oxcarbazepine
- Died 5 weeks after first afebrile seizure, before MRI or target AED dose reached
- Autopsy- unrevealing

When Children Die (an IOM report)

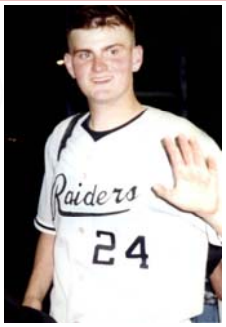


2003

Why Talk to Parents/Patients About Mortality

- Part of full disclosure in the transfer of knowledge
- Allows the possibility of intervention
- They want to know (at least the parents do)
- They have the opportunity to advocate for epilepsy services & research funding
- Reduced anxiety if risk low in an age of media exposure
- They never recover from not being told if the tragedy occurs

Chris Donalty



With permission Jeanne Donalty

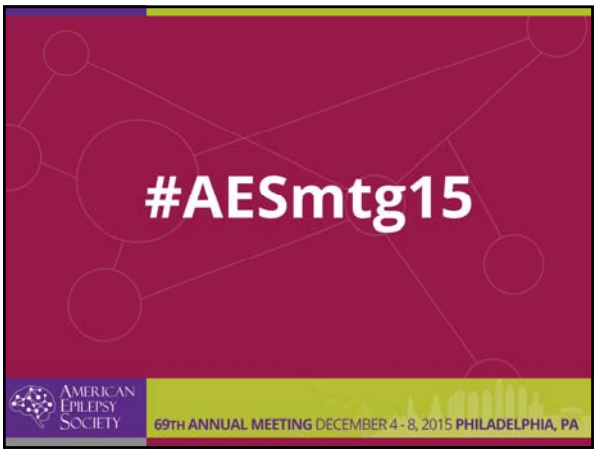
Chris Donalty

- Onset as senior in HS, ...re free"
- Died 4 yrs later in colle...

"There is nothing…nothing worse than losing a child, no matter the age or cause. But a sudden death, out of the blue, something that you were never told could happen, somehow makes it particularly cruel. All the unanswered questions….the what ifs.." Jeanne Donalty

With permission Jeanne Donalty


Save the Dates!
pame
partners against mortality in epilepsy
June 24-26, 2016
Washington, DC


#AESmtg15
American Epilepsy Society
69TH ANNUAL MEETING DECEMBER 4 - 8, 2015 PHILADELPHIA, PA

Dealing with Grief After Epected and Unexpected Death in Children

Linda Coughlin Brooks RN BSN CT

December 7, 2015

AMERICAN EPILEPSY SOCIETY 69TH ANNUAL MEETING DECEMBER 4 - 8, 2015 PHILADELPHIA, PA

Disclosure

Consultant to the National Epilepsy Foundation SUDEP Institute

Learning Objectives

- Identify the differences in grief from sudden death and expected death in children.
- Understand the basic differences between complicated and normal grief.
- Identify when and if a referral for grief counseling is needed.

DEATH OF A CHILD

Raymond, Laurel (September 4, 2015) The Powerful Psychology Of The Photo Of A Dead Child That Rocketed Around The World Retrieve from http://thinkprogress.org/world/2015/09/04/3698698

Definitions

- Sudden Death (unexpected)
- Anticipatory death (expected) Grief
- Mourning
- Bereavement
- Grief work
- Secondary loss

Rando, T. A. ed . 1988. How to go on living when someone you love dies, Lexington Books

Sudden death of child

- Shock
- No known cause of death
- Anxiety
- Self reproach
- Depression
- Unable to continue normal life
- Loss does not make sense
- Loss of security
- Loss of confidence
- No time for good-bye
- Painful

Lord J. No Time for Good-byes coping with sorrow, anger and injustice Pathfinder Publ.,1986

Doka, Kenneth J. Living with Grief after Sudden Loss, Hospice Foundation of America, 1996

Anticipatory death of a child

- Period of anticipation
- Events predictable
- Cause of death known
- Time to complete unfinished business
- Coping capacity directed toward expected end
- Loss makes sense
- Support systems provided along the journey
- Mourn with the person who dies
- Painful

Rando, T. A. ed . 1988. How to go on living when someone you love dies, Lexington Books

Impact on the Survivor

Not the amount of pain the survivor suffers
but
the impact it has on the person's ability to cope
and
go about the rest of his or her life

Coping with Loss

- Mental health history
- Resiliency skills
- Social support
- Gender
- Cause of death
- Personal death history
- Cultural and religious background
- Financial and social position

Rubin SS"The Death of a child is forever: The life course impact of child loss in Stroebe W.Hansson RO,eds.Handbook of bereavement research: Theory, Research and Intervention. New York: Cambridge University Press 1993

Normal Grief

- Majority of survivors
- Individually unique
- Severity of feelings
- Physical symptoms
- Recovery
- Self-limited
- Progression in grief

Reproduced with permission from American Psychiatric Association (28):Diagnostic and statistical Manual of mental disorders, fifth edition. Arlington, VA American Psychiatric Association, 2013

Complicated Grief

- Incapacitated by grief
- Yearning and searching
- Anhedonia
- Excessive avoidance of people places or things related to the death
- Inability to adjust to the world without deceased
- somatic symptoms

Reproduced with permission from American Psychiatric Association (28):Diagnostic and statistical Manual of mental disorders, fifth edition. Arlington, VA American Psychiatric Association, 2013

When does Grief begin?

- Death notification
- Transition of family to Victim
- Next Step

Omega Journal of Death and Dying 2004;48(2):149-164
Kenneth V Iserson, Director, Professor of Surgery Notifying survivors about sudden, unexpected deaths, www.ncbi.nlm.nih.gov PubMed Central (PMC)

What's in your Doctor's bag?

What You as the Care Provider can do:

- Assess
- Debrief
- Facts
- Information
- Resources
- Referrals
- Educate
- Validate

"The Friend who can be silent with us in a moment of despair or confusion, who can stay with us in an hour of grief and bereavement, who can tolerate not knowing, not caring, not healing and face with us the reality of our powerlessness, that is a friend who cares."

_Henri Nouwen (1932-1996)

https://www.goodreads.com/author/.../4837.Henri_J_M_Nouwen

What can parents expect to experience in bereavement?

- Length of grief
- Stages
- Grief work
- Self help
- Family reorganization
- Support

Doka, Kenneth J. (Ed.) Living with Grief After Sudden Loss: Suicide, Homicide, accident, Heart Attack, Stroke
Rando, Theresa A., Treatment of Complicated Mourning, Champaign, IL 1 Research Press, 1993

Resources

The Compassionate Friends
Bereaved parents USA
The American Foundation of Suicide Prevention
National Epilepsy Foundation SUDEP Institute
North American SUDEP Registry NASR
PAME Partners Against Mortality in Epilepsy (PAME)
SUDEP AWARE (Canada)
SUDEP Action (UK)
Mothers in Support and Sympathy (MISS Foundation)
Sudden Unexplained Death in Children Program (SUDC)
Griefnet.org
Association of Death Education and Counseling ADEC

Tools for your Doctor's Bag

- Referral list
- Resiliency/Risk Assessment Checklist
- Physical Evaluation Checklist
- Community Resource List

prc.coh.org/BereavGuidelines.pdf

What type of practitioner are you?

https://www.goodreads.com/author/quotes/3503.**Maya_Angelo**

AMERICAN EPILEPSY SOCIETY 69TH ANNUAL MEETING

Carei Ann Coughlin
Death from SUDEP
4-7-80-----12-19-98

#AESmtg15

AMERICAN EPILEPSY SOCIETY

69TH ANNUAL MEETING DECEMBER 4 - 8, 2015 PHILADELPHIA, PA

Death in Children with Epilepsy – A Different Tragedy

Elizabeth Donner, MD, MSc, FRCPC
University of Toronto, Hospital for Sick Children

December 7, 2015

AMERICAN EPILEPSY SOCIETY 69TH ANNUAL MEETING DECEMBER 4 - 8, 2015 PHILADELPHIA, PA

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Impact on Clinical Care and Practice

1. Mortality is increased in children with epilepsy
   - Most deaths are not epilepsy-related
   - SUDEP is most common cause of epilepsy-related death
2. Risk should be discussed with families
   - They want to know
   - Informed patients make informed decisions
   - Honesty and trust are foundations of the patient-provider relationship