Seizure Related Deaths

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“Approximately 30% of children with epilepsy have other developmental disabilities. In one study, children with mental retardation and cerebral palsy had a 35% chance of developing epilepsy, children with mental retardation alone had an 8% chance, and children with a brain injury occurring after birth had a 75% chance. In general, the risk of a child with a developmental disability experiencing an unprovoked seizure by age 5 is about 4 times greater than in the general population.” (2013 Epilepsy Foundation of Metropolitan New York) The occurrence of seizures has been reported to be as high as 50% during the lifetime of individuals with disabilities.

“Overall, epilepsy increases the risk of dying by a factor ranging between 1.6 and 3 times that of the background population (Forsgren et al. 2005). How much does epilepsy shorten life, on the average? It depends upon the type of epilepsy. A study in the UK of 564 people with epilepsy followed for 15 years (Gaitatzis et al. 2004) showed that people with epilepsy of unknown cause died an average of two years earlier, but those with a known underlying serious disease causing the epilepsy died an average of 10 years earlier.” One study which followed 245 children with persistent epilepsy for 40 years found that during that period 32 individuals died of causes related to epilepsy. (Web-MD Epilepsy Health Center)

Epilepsy-related causes of death include

- Deaths related to the underlying illness causing the epilepsy
- Deaths from conditions related to seizures, such as depression (suicide)
- Trauma or drowning as the result of seizure activity
- Sudden Unexplained Death in Epilepsy (SUDEP)
- Status epilepticus
  (Epilepsy.com Spotlight Newsletter, August, 2010)

Of the over 40 different seizure types that have been identified, many are due to conditions such as brain tumors or degenerative neurological conditions which may ultimately lead to the death of the individual. Death can also occur due to co-morbid conditions, which exist as part of the same issue or syndrome but do not directly cause seizure activity.

Traumatic deaths related to epilepsy include those from drowning, injuries related to falls and other accidents, such as automobile accidents.
Sudden Unexplained Death in Epilepsy, or SUDEP, is most common in young adults ages 20 to 50. Death occurs from cardiac or respiratory failure due to unknown causes and is most likely to be seen in individuals with poorly controlled generalized tonic clonic seizures and seizures which occur during sleep. Young age when seizure activity began, poor compliance with anti-epileptic medications and use of alcohol are other common factors in these deaths. SUDEP does not necessarily occur during a seizure or in conjunction with recent seizure activity.

Status epilepticus is generally defined as prolonged seizure activity (for 30 minutes or longer) but can also include seizures that occur back-to-back with no post-ictal recovery or seizures with a markedly prolonged post-ictal period. Status epilepticus can occur with any seizure type but is most dangerous with generalized tonic clonic seizures due to swelling that can occur at the base of the brain. In the U.S. there are approximately 50,000 deaths due to status epileptics each year. Death frequently occurs due to fatal disruption of brain physiology or disruption of normal cardiac rhythm. During their lifetime approximately 15% of individuals with epilepsy will experience status epilepticus.

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Seizure Rating Information for HRST Users

The HRST assigns enhanced risk to individuals with seizure activity based on the frequency and/or severity of seizures. As a screening instrument the HRST does not differentiate between types of seizures, instead giving equal scrutiny to all seizure types and allowing the individual’s support team and physicians to make final decisions regarding necessary support and treatment.

We do, however, make several recommendations in the Evaluations /Service and Training Considerations for addressing many of the factors which may lead to deaths due to seizures. These include making sure that the individual has access to the services of a Neurologist at appropriate intervals and that their primary care provider is informed of the extent to which seizure activity disrupts their lives. Pharmacists’ services are also often sought related to safety issues and potential side effects of medications.
Many causes of seizure-related deaths are issues that could be reduced or eliminated by enhanced support in the home and work environments. All care providers, whether they are paid personnel or family members, should have basic instruction on seizure types and how to identify and document seizure activity as well as information about safe and appropriate medication administration. Training should also include information about identifying signs that seizure activity is worsening. These include increased seizure intensity, change in seizure signs and prolonged seizure times, even when they do not qualify as status epilepticus. Finally, instruction is needed about how to recognize and respond to seizures and seizure emergency and unwanted effects of medications and how and to whom to report problems.