



World Water Safety

INTERNATIONAL LIFE SAVING FEDERATION

Gemeenteplein 26 – 3010 Leuven – Belgium
Tel: (32.16) 89.60.60 – E-mail: ils.hq@telenet.be - Web: www.ilsf.org

MEDICAL POSITION STATEMENT - MPS 17

SEIZURES AND EPILEPSY RISKS FOR BATHING, SWIMMING, LIFESAVING AND LIFEGUARDING

NOTE: This statement is intended for those lifeguards, acting in a professional or volunteer capacity, who are trained in the techniques of water rescue and resuscitation and who assume a duty to safeguard members of the public at aquatic sites. They may be called lifeguards, lifesavers or both. This statement is not directed at members of the public trained in water safety and rescue techniques, but without a duty to respond, who may also be known, in some areas of the world, as lifesavers.

BACKGROUND

Epilepsy is a chronic neurological disorder of the brain that affects people worldwide of both sexes and all ages. It is characterised by recurrent seizures, where there are brief episodes of involuntary movement that may involve a part of the body (partial) or the entire body (generalised). Seizure episodes are the result of excessive electrical discharges in a group of brain cells (1).

The practical clinical definition of epilepsy is the occurrence of at least two unprovoked (or reflex) seizures, occurring more than 24 hours apart (2). Epilepsy is considered to be resolved for individuals who had an age-dependent epilepsy syndrome but are now past the applicable age or those people who have remained seizure free for the last 10 years, with no seizure medications in the preceding 5 years.

With regard to causes, 60% of cases of epilepsy will have no obvious, identifiable cause and this is known as idiopathic epilepsy. In the remaining cases where there is underlying identifiable cause, then this is known as secondary or symptomatic epilepsy. Common cause of a secondary epilepsy could include brain damage from childbirth, severe head injury, stroke, infection such as meningitis, or a brain tumour, to name a few (1).

There are precipitating conditions which can assist and encourage the development of a seizure. Common precipitating factors include fever in predisposed children, alcohol and drugs, sleep deprivation, and stress. Reflex seizures are precipitated by specific sensory

stimulation. Identification of specific causative stimuli and avoidance of those stimuli is helpful. The most common are flickering light, unexpected sounds, and immersion in hot or cold water. Most specific precipitating factors are not apparent.

Individuals with a high seizure threshold can be exposed to significant epileptic stimuli but never have a seizure; those with low seizure threshold can be exposed to minimal stimulus and have a seizure.

There are many kinds of seizures. Seizures vary from a brief lapse of attention or muscle jerks to severe and prolonged convulsions. Seizures vary in frequency, from less than one a year to several per day (2).

It is challenging to balance individual and societal risks with rights of individuals to maximize their potential and quality of life. Mythology and social stigmas remain issues for individuals and families with epilepsy in some countries. The World Health Organization – CREST Project is directed at education and culture-specific reduction of stigma in developing nations (3). In the most developed countries human and workers' rights legislation are in place to minimize discrimination against individuals with disabilities (4, 5).

The prevalence of a disorder is the proportion of a population with that disorder at a given point in time. The prevalence of epilepsy is 4-8 per 1000 people in the developed world (European statistic) (6). Epilepsy prevalence is higher in developing countries and lower socioeconomic areas where etiologic factors (infectious diseases, trauma, birth injury, malnutrition) are more frequent and treatment may be less available. The incidence in Africa varies between 8-16 per 1000 people (7).

The incidence of epilepsy is the proportion of new cases of epilepsy diagnosed during a year. The annual incidence of epilepsy in the developed world ranges from 4-7 cases per 1,000 people (7). There is higher incidence in the developing world and in lower socioeconomic populations (8-15 per 1000), this is largely due to poorer perinatal care, higher burden of infectious disease and increased head trauma (7).

Standardized mortality ratio (SMR) is the ratio between the deaths observed among patients with epilepsy and the deaths expected in a reference population with a similar age distribution. In epilepsy, the SMR is 2.2 (8). Persons with epilepsy are at increased risk of death from many causes. Unintended injury and, specifically, drowning, has a higher SMR and higher risk for persons with epilepsy.

A United Kingdom population based prospective cohort study recruited 1195 patients between 1 and 90 years of age with newly diagnosed definite epilepsy, possible epilepsy or febrile convulsions from general medical practices in England and Wales between 1984 and 1987. This group was until 2010. This community-based population of persons with epilepsy had an SMR of 2.55 compared with expected all-cause mortality. Mortality from all causes was substantially higher in the first year after diagnosis. Pneumonia and ischaemic heart disease were the most frequent causes of death which had elevated SMR. Few people died from epilepsy related causes. There were seven epilepsy related deaths in the cohort- three from status epilepticus, three from accident/drowning and one from possible SUDEP

Other studies reviewing the relationship of seizures with drowning have been carried out retrospectively, with a higher proportion of individuals with multiple disabilities. The retrospective case reviews calculate a relative risk (RR) for a person with epilepsy to have submersion and/or drowning. Table 1 summarizes the findings of the retrospective case reports.

	Fatal Submersion			Nonfatal Submersion			Total RR (calc)*
	Total #	with Seizure	RR (calc)*	Total #	with Seizure	RR (calc)*	
Adams	163	4	4.9	0	0	0	4.9
Chun	347	16	9.1	0	0	0	9.1
Deitz & Baker	117	4	6.8	0	0	0	6.8
Pearn et al. 1977 (8)	25	2	16	86	4	10	10.8
Pearn 1978	31	0	0	109	4	7.3	5.7
Orlowski et al.** (9)	26	2	15	74	4	10.8	12
Kemp & Sibert (10)	149	4	5.4	157	6	7.6	6.5
Ryan & Dowling (11)	482	25	10.3	0	0	0	10.3
Quan & Cummings	709	64	18	0	0	0	18
Diekema et al. (12)	146	9	12.3	335	21	12.75	12.5
Total	2,195	130	11.9	761	39	10.2	11.4

*assume most developed population risk of epilepsy = 0.5%.

In the retrospective case review by Ryan and Dowling (11), 15 out of 25 deaths were in unsupervised bathtubs. Of the 23 drowning deaths on medication, 19 were determined to have undetectable or sub-therapeutic levels of one or more of their drugs at autopsy. Diekema, Quan and Holt (12) conducted a case review of youth under 20 involved in unintentional submersions in the US. This study found that 2 of the 21 submersions were witnessed; 18 of the 21 children submerged in bathtubs or pools. Three of the 21 submersions were in lifeguarded pools; the lifeguard did not witness the submersions. In the study analysis, after removal of the high risk disabled persons from the calculation, the relative risk for persons with epilepsy for submersion and drowning death was 10. The highest relative risk was in children with epilepsy in bathtubs.

Retrospective case reviews in the United States on injury and death rates in individuals with epilepsy are proportional to convulsive seizure frequency (13, 14). There are reports of quick, silent submersions in pool and open water settings with individuals presumed to have a convulsive seizure (15, 16, 17). In approximately half of the witnessed submersions, there is no report of seizure activity. It may not be seen or it may not be a seizure. Besag (15) described a convulsive seizure that may cause instantaneous and silent submersion. There may be some other cause of the instant incapacitation that is observed.

SUDEP or Sudden Unexpected Death in Epilepsy is defined as sudden, unexpected, nontraumatic, nondrowning death in an individual with epilepsy, witnessed or unwitnessed, in which postmortem examination does not reveal an anatomic or toxicologic cause for the death. Submersion and drowning from any cause is catastrophic. In our effort to prevent drowning, this diagnostic dilemma may be interesting but not clinically important. Immediate prevention of submersion and/or rescue is needed.

The evidence is clear that the relative risk of submersion and drowning is increased in individuals with epilepsy. Bathtubs are a source of preventable submersion and drowning deaths. The evidence also indicates that in the general population absent supervision, seizure history and child abuse are associated with increased risk of bath tub submersion. Seizure frequency of one or more seizures in a month, previous adverse drug reactions, known previous seizures whilst in the water and mental retardation are all factors which increase the risk of submersion in epilepsy (10). Individuals with frequent, unpredictable,

convulsive seizures are at greatest risk. Individuals with rare, controlled, or no seizures remain at increased risk for all-cause mortality and injury, including drowning. There is a significant variation between the risk analysis done prospectively and that done retrospectively. More research in this area would be beneficial.

Much of the available literature discusses relative risks. Absolute risk may be more important than relative risk to understand this issue and the options for risk management and water safety strategies. The absolute risk of a low-risk individual having a seizure that would put themselves or others at risk is low. The absolute risk of a person with high-risk factors is greater, and precautions are warranted to save lives from drowning. The message is clear, high seizure frequency is strongly associated with increased mortality (11).

Lifesaving training involves swimming and water activity. This is an environment of risk for all participants, and an increased risk for those with a seizure disorder (1). Individuals with epilepsy may be less fit and less active when compared to age-matched controls (12). Sporting activities were previously discouraged by many doctors and parents for people with epilepsy due to safety concerns and effects on seizures. However, evidence now shows that the vast majority of those individuals can participate in sports without negatively affecting seizure frequency (13). Only 2% of people with epilepsy have genuine exercise induced seizures (14). Positive effects of exercise can possibly include seizure prevention and decreased frequency and improved cardiovascular and psychological health (14). Individuals with seizure disorder should be encouraged to maintain control of their disorder, and then to participate in most healthy, risk-evaluated types of recreation, social, and vocational activity (13).

Many organisations, including national lifesaving federations, have made recommendations concerning swimming and bathing (15,16,17). There are no studies of the impact or safety of individuals with epilepsy taking aquatic instructional activities. The position of epilepsy-advocacy organisations is to minimize restrictions and provide evidence-based advice to high-risk individuals and high-risk activities (18,19). Common advice includes swimming in a lifeguarded pool environment, with a friend or “buddy” who is aware of person’s epilepsy history, wearing of a lifejacket if seizures are frequent or if in an open water environment (20).

Lifeguard duties may involve swimming, running, and water rescues. Lifeguard duties also require reliable responses for rescue, and support for actions of colleagues. Challenging environmental, social, psychological, and physical demands may be part of the response expectation. Sudden incapacitation cannot be accepted. There are employment standards in many countries that impact decisions about lifeguard employment, and the options for that lifeguard when they develop a seizure disorder after employment (4, 5).

There appears to be no evidence on the effects of seizure disorders in the lifeguard population. The literature from other emergency response areas, such as the military and the airline industry, was thus reviewed. There is a wide variation of restriction placed on individuals with seizure disorders in these helping professions (21,22). There has been a trend to reduce restrictions placed on individuals with seizure disorders (23).

There has been evidence-based processes to establish legal driving criteria in some countries and states (24, 25, 26, 27). In that setting, the seizure-free interval may be important. In a cohort study in the USA comparing car crash outcomes in people with seizures, there was no difference between 3 months of seizure-free interval when compared with one year of seizure-free interval (28).

The evidence indicates that risks of injury and sudden incapacity are highest in the first year after diagnosis of epilepsy and seizures of other cause. In the adult with epilepsy who is medically stable, well controlled with compliance with treatment, the risk of sudden incapacity is similar to that of the non-epilepsy population, one year after the diagnosis. This justifies a seizure-free interval of one year for lifeguard patrol duties. After a seizure event there should be a suspension of patrol duties for a period of time. There is evidence that this period should be at least 3 months. Assuming ideal conditions, compliance, and medical support. Lifesaving training and shallow still-water competition has focused supervision and intermediate risk. A seizure-free interval of at least 6 months has been recommended based on expert opinion. Deep open-water recreation or competition participation has higher drowning risk, and should have a seizure-free interval of at least one year, based on expert opinion. It is important that the increased risk of open water activities is recognised and appreciated by the lifeguard and his/her teammates, coaches etc.

STATEMENT

Persons with epilepsy have increased relative risk for all injuries including submersion and drowning. High-risk individuals with epilepsy include those with concurrent disabilities, unpredictable or frequent convulsive seizures, poor medication compliance/frequent adverse medication events. High-risk individuals should have maximum prevention, rescue, and treatment available for participation in water activities, and water activity in a non-lifeguarded or open water environment should be curtailed

There is no evidence on the risks related to lifesaving instruction, competition, or lifeguard patrol duties for individuals with epilepsy. There is no evidence on the safe seizure-free interval for aquatic activities. The evidence used for the recommendations in these areas is extrapolated from other areas of similar concern, and is low in quality for our purpose. Driving licensing correlations are available for review and comparison. These correlations may be the best evidence available for extrapolation to our setting.

KEY ASSUMPTIONS

1. Sudden incapacity in water and in some cases on water can result in drowning death.
2. Lifeguard patrol duties, deep and open water activities carry high risk to the person with a seizure disorder and to their colleagues.

RECOMMENDATIONS FOR THE PUBLIC

1. Bathtub use for children with epilepsy should have direct, close (in the room), and continuous supervision. Older children and adolescents with epilepsy should not bathe or shower with the bathroom door locked.
Recommendation Class: IIa
2. When children reach the age of independent bathing, they should shower with a maximum temperature regulation of 43°C
Recommendation Class: IIb
3. Epilepsy carries increased relative risk of submersion and drowning. Children and adults should be advised of this increased relative risk.
Recommendation Class: IIb
4. Individuals with unstable, or potentially unstable epilepsy should avoid water activity until stability is re-established.
Recommendation Class: IIb
5. Epilepsy submersion and drowning risk is greatest in an identified high-risk group that includes:

- those with frequent (more than one per year) seizures
- those with unpredictable convulsive seizures, **and/or**
- those who have other disabilities.

Extra precautions and attention are warranted. This patient group should avoid water activities, or should participate in clear, shallow, still water, with a (securely fastened) personal flotation device that will support an unconscious person, and they should be within arm's length of a capable support person.

Recommendation Class: IIb

6. Individuals with stable, controlled epilepsy and no other risk factors, who participate in recreational, instructional, and competitive water activities, should do so in supervised areas and with another capable person.

Recommendation Class: IIb

7. Individuals with chronic disabilities who are intellectually and neurologically able, and medically stable should be encouraged to undertake swimming and lifesaving training.

Recommendation Class: IIb

8. It may be helpful to provide absolute risks, so that persons with epilepsy and their advocates can make informed risk management decisions.

Recommendation Class: Indeterminate

RECOMMENDATIONS FOR LIFEGUARD PATROL DUTY AND OPEN-WATER RECREATION AND COMPETITION

1. There are no higher levels of evidence studies on lifeguard patrol duties, deep water recreation, or competition participation by persons with epilepsy. Further research in this area may be helpful.

Recommendation Class: Indeterminate

2. Lifeguard patrol duty and deep open-water recreation and competition participation for individuals with seizure disorders carries increased risk for the participant, co-workers, and the public. Sudden incapacity cannot be accepted.

Recommendation Class: Indeterminate

MINIMUM RECOMMENDED SEIZURE-FREE INTERVALS FOR PERSONS WITH A SEIZURE DISORDER TO PARTICIPATE IN SWIMMING, LIFESAVING TRAINING, WATER SPORT, AND LIFEGUARD PATROL DUTIES AS MAY BE PERMITTED BY THE LIFEGUARD ORGANISATION.

1. There is no evidence on the seizure-free interval in swimming, lifesaving, or lifeguarding. Evidence is extrapolated from lower-level studies in other areas of similar concern (police, fire, military, driving licensing, and aviation). The seizure-free intervals below are extrapolated from other areas. They should be a guide; with medical reports, they can be used to determine safe participation. Further research in this area may be helpful.

Recommendation Class: Indeterminate

2. Lifesaving training should be available to individuals with epilepsy who have confident seizure control, treatment programme compliance, knowledge of their risk, and a seizure-free period of at least 6 months. This interval may be longer if the participant has high-risk features. Proof of medical authorization, compliance, and stability may be requested. Consideration should be given to use of a safety craft to provide close supervision of the lifesaving learners with confident seizure control to assist with any unusual incidents that might arise.

Recommendation Class: IIb

3. If an organisation chooses to permit individuals with controlled epilepsy and no unexplained or unpredictable seizure activity to participate in lifeguard patrol duty or in deep-water recreation and competition activities, the organisation should require a seizure-free interval of more than one year prior to participation.

Recommendation Class: IIb

4. If an active patrol lifeguard, and/or a deep open-water recreation or competitive participant, has seizures with a clear medical cause, usual patrol and deep open-water recreation or competition activities should be suspended. If the lifesaving organisation chooses to permit resumption of activity, the organisation should require a seizure-free interval of more than one year prior to resumption.

Recommendation Class 11b

5. Medical authorization should include as a minimum:
 - a. A qualified Medical Doctor/Neurologist review, including consideration of the patient's level of knowledge of, and insight into, their medical condition; ability to self-manage the condition; compliance with physician-prescribed treatment, and willingness and ability to modify risk factors.
 - b. A qualified Medical Doctor/Neurologist review of the lifeguard's job description, the range of responsibilities the lifeguard might assume to include: extended water observation, swimming (distance and environment should be specified), oversight of large numbers of people who depend upon the lifeguard's vigilance, and any other responsibilities appropriate to the individual (local) assignment

POTENTIAL CONFLICT OF INTEREST STATEMENT

This research and writing has been undertaken voluntarily without payment or in-kind benefit from any stakeholder or agency.

None of the participants in the consensus process leading to this position statement has a conflict of interest with the stakeholder industry, technology, persons or organisations that are identified and/or impacted by the position statement.

This educational position statement is the property of International Life Saving Federation (ILS). Any reproduction or use of this material in whole or part should be fully referenced with acknowledgement being given to ILS (www.ilsf.org) and to the author(s).

LEVEL OF EVIDENCE

This document is based on expert consensus.

REFERENCES

1. Epilepsy: Aetiology, epidemiology and prognosis
World Health Organization, Fact Updated February 2016
<http://www.who.int/mediacentre/factsheets/fs999/en/>
2. A Practical Clinical Definition of Epilepsy: ILAE Official Report. International League Against Epilepsy
<http://www.ilae.org/visitors/centre/Definition-2014.cfm>
3. The CREST Study Collaborative Research on Epilepsy Stigma Project -Developing Approaches to Reducing Stigma of Epilepsy
http://www.who.int/mental_health/neurology/en/epilepsy_poster.pdf?ua=1
4. Disabilities Discrimination Act 1995- Chapter 50
http://www.legislation.gov.uk/ukpga/1995/50/pdfs/ukpga_19950050_en.pdf
5. Titles I and V of the Americans with Disabilities Act of 1990
<https://www.eeoc.gov/laws/statutes/ada.cfm>

6. EPILEPSY IN THE WHO EUROPEAN REGION: Fostering Epilepsy Care in Europe
http://www.who.int/mental_health/neurology/epilepsy/euro_report.pdf
7. EPILEPSY IN THE WHO AFRICAN REGION: Bridging the Gap
http://www.who.int/mental_health/management/epilepsy_in_African-region.pdf
8. The long-term risk of premature mortality in people with epilepsy Aidan Neligan,1,* Gail S. Bell,1,2,* Anthony L. Johnson,3 David M. Goodridge,4 Simon D. Shorvon1 and Josemir W. Sander1,2,5 -Brain – a Journal of Neurology
<http://brain.oxfordjournals.org/content/brain/134/2/388.full.pdf>
9. Sudden Unexpected Death in Epilepsy Author: Shahin Nouri, MD; Chief Editor: Selim R Benbadis, MD
<http://emedicine.medscape.com/article/1187111-overview>
10. Seizure-Related Injuries, Drowning and Vehicular Crashes – A Critical Review of the Literature. Authors: Michael Tan & Wendyl D'Souza Curr Neurol Neurosci Rep (2013) 13:361 DOI 10.1007/s11910-013-0361-4
<http://www.ncbi.nlm.nih.gov/pubmed/23690025>
11. Recognizing and preventing epilepsy-related mortality A call for action. Authors Orrin Devinsky, MD, Tanya Spruill, PhD, David Thurman, MD, PhD and Daniel Friedman, MD, MSc. Neurology February 23, 2016 vol. 86 no. 8 779-786
<http://www.neurology.org/content/86/8/779.full>
12. Epilepsy & Sport: Epilepsy Action Australia
<http://www.epilepsy.org.au/sites/default/files/Epilepsy%20and%20sport.pdf>
13. 3 Dubow JS, Kelly JP. Epilepsy in sports and recreation. Sports Med. 2003;33(7):499-516
<http://www.ncbi.nlm.nih.gov/pubmed/12762826>
14. 4 Nakken, K.O. Physical exercise in outpatients with epilepsy. Epilepsia. 1999, vol. 40, no5, pp. 643-651 (44 ref.)
<http://www.ncbi.nlm.nih.gov/pubmed/10386535>
15. Surf Life Saving Australia Policy Statement, Epilepsy 2012
<https://apps.sls.com.au/sites/sls.com.au/files/downloads/SLSA%20Governance/Current%20Supporting%20Documentation/3.06%20Seizures%20and%20Epilepsy%20-%20August%202012.pdf>
16. British Swimming Epilepsy Policy
<http://www.swimming.org/library/?search=epilepsy>
17. USA Swimming Safety/Risk Management and the Inclusion of Swimmers with Disabilities
<http://www.usaswimming.org/Rainbow/Documents/281d02ca-449e-4839-b32c-d0dba6af0327/RiskMgt.pdf>
18. Epilepsy Society UK- Swimming and Water Sports
<https://www.epilepsysociety.org.uk/swimming-and-water-sports#.V2VEOrgrLIU>
- Seizure Smart Swimming- Epilepsy Action Australia
<http://www.epilepsy.org.au/node/4821>
19. Epilepsy Foundation- Playing Sports and Other Activities
<http://www.epilepsy.com/learn/seizures-youth/about-kids/playing-sports-and-other-activities>
20. Bateman BJ, Finlay F Long term medical conditions: Career prospects. Occupational and Environmental Medicine Dec 2002 V59 (12) pg 851-2
21. McCormick TJ, Lyons TJ Medical causes of In-flight incapacitation: USAF Experience 1978-1987 Aviation, Space and Environmental Medicine Sept 1991
22. Gunderson CH Impact of the new fitness regulation for epilepsy Military Medicine, Vol 156, June 1991
23. Richards KC The risk of fatal car crashes in people with epilepsy Neurology 2004; 62:E12
24. Sillanpaa M, Shinnar S Obtaining a driver's license and seizure relapse in patients with childhood- onset epilepsy Neurology 2005, 64(4): pg 680-1
25. Drazkowski J, Fisher R, Siven J, et al Seizure-Related Motor Vehicle Crashes in Arizona Before and After Reducing the Driving Restriction From 12 to 3 Months Mayo Clinic Proceedings, 2003 78: 819-825
26. Krumholz, A, To drive or not to drive: The 3-month seizure-free interval for people with epilepsy Mayo Clin Proc Vol 78, (7) pg 817-8, July 2003
27. Sheth, SG, Krauss G, Krumholz A, Li G, Mortality in epilepsy: Driving fatalities vs other causes of death in patients with epilepsy Neurology, 2004, Vol 63 (6), pg 1002-6

Position Statement approved by the ILS Board of Directors on 21/04/2012 and 03/09/2016.