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EPILEPSY & LIFESTYLE ISSUES

While some restrictions are necessary, adults and children with epilepsy should be encouraged to live a full life with the condition, In many instances this is achieved through the adoption of safety measures particularly in respect of activities where having a seizure would pose a risk to one's own safety or that of others.

Out & About

Carry a special identity bracelet, neck pendant or card with details of your epilepsy, your medication, first aid and a contact phone number for a relative.

If you are fortunate enough to experience a warning sign or aura (not everyone does) this may allow you tell someone you may be about to have a seizure or enable you to move to a safe place. A child can carry a card on behalf of a parent which can be given to a helper in the event of a seizure. Keep money and valuables carried to a minimum and conceal them to guard against theft or loss.

Leisure & Sport

Inform instructors, trainers or coaches of a diagnosis of epilepsy and ensure they are made aware of how to recognise and manage seizures. Supervision is advised for people with frequent seizures undertaking sporting activities which require special guidance. Some people may have seizures from strenuous physical exertion, so make sure to pace yourself and take breaks as needed.

The following activities require particular attention and in cases of uncontrolled seizures may be considered inadvisable until improved control is achieved:

Swimming

A person with epilepsy should only swim when accompanied by a competent swimmer who is capable of dealing with a seizure in the water. It is preferable to swim in a pool where an attendant can intervene as swimming in the sea may pose more risks.

It is important to inform pool attendants and lifeguards of one's epilepsy and ensure they are familiar with appropriate first aid.

Wearing a brightly coloured swimming cap will aid prompt location of any swimmer who may experience difficulty.

Cycling

A cycle helmet should always be worn and cycling in heavy traffic should be avoided where seizures are frequent.

Where seizures are controlled there may be no increased risk.

Horse Riding

Hard riding hats should always be worn. For those with controlled seizures there may be little risk but those with frequent seizures may require special facilities and close supervision.

Contact Sports

Boxing is inadvisable.

Field sports with risk of head injury need individual assessment.

High Risk & Extreme Sports

Scuba diving, sky diving, rafting, hand-gliding, bungee jumping and pot-holing should be avoided as should any activity where intervention and rescue during seizures may pose difficulty or indeed risk to oneself or others.

Climbing

With supervision climbing may be possible but individual assessment is needed.

Safety is paramount at all times and appropriate headgear must be worn at all times.

TV, Discos & Computers

There is a great deal of misinformation about epilepsy and photosensitivity. Only 3-5% of people with epilepsy are photosensitive which means that they can have a seizure on exposure to flickering lights. The diagnosis of photosensitivity is made on an EEG and persons affected are advised accordingly. Most people with a diagnosis of photosensitive epilepsy can safely use computers and watch TV if they follow certain guidelines.

Television

When watching TV ensure the TV area is well lit and sit about 10 feet from the screen using the remote control to change channels.

If approaching the screen, covering one eye with a hand reduces the effect by 50%.

Computers

When using VDU's ensure that a glare reduction filter covers the screen to reduce brightness. The rate of flicker which triggers photosensitive seizures is very low at 15-20 flashes per second on average; this is not usually found on newer machines - though where it is found the rate can possibly be adjusted to a safer range depending on the machine specifications.

When working with a VDU a person should take frequent rest breaks to avoid becoming overtired.

Discos

Persons with photosensitive epilepsy attending discos should check in advance whether strobe lighting is used and if management will switch it off.

See Epilepsy Ireland leaflet Photosensitive Epilepsy

Safety in the Home

General Principles

- (a) Always keep a well stocked first aid kit.
- (b) Keep all medicines in a secure place out of reach of children.
- (c) Avoid having trailing electrical flexes and cords. Freestanding furniture and appliances may be knocked over easily, position furniture carefully, avoiding or covering sharp edges.
- (d) Do not climb ladders and avoid use of stairs if seizures are frequent. Ground floor accommodation is preferable where possible if seizures are frequent.
- (e) Avoid freestanding heaters and exposed elements; open fires are hazardous so always use a fireguard which has been fixed securely to walls or flooring. Enclose hot pipes and use radiators with a low surface temperature.
- (f) Avoid or limit use of glass and mirrored panels in doors, coffee tables and other fixtures.
- (g) If using electrical appliances is unavoidable use cordless ones and follow all safety precautions.
- (h) Arrange a regular call system with a friend, neighbour or relative if you live alone.

In the Bathroom Domestic Bathing

- (a) Young children must be supervised at all times. Adults should shower or take a shallow bath keeping the bathroom door unlocked. Always turn taps off before getting into the bath.
- (b) Showers are preferable to baths but showers with a high sided base should be avoided. Shower chairs can prevent falls and toughened glass in shower doors can prevent injury and are safer than curtains.
- (c) To maintain privacy in the use of the bathroom an "engaged" sign is recommended. Doors should open outwards for ease of access during a seizure.
- (d) Water must not become too hot as heat can induce seizures in some people. Taps and showers left running can cause scalding - fitting a thermostat can prevent this.
- (e) Glass shelving should be avoided as should hard flooring which can be a hazard in the event of a fall.

(f) Tight spaces where a person can get wedged during a seizure should be avoided where possible.

In the Kitchen

- (a) A microwave oven is safer than a conventional oven but position it carefully to prevent dislodging it.
- (b) Where conventional ovens and cookers are used - gas heat is quicker to extinguish, uses a cooker guard rail, use the back rings/burners, turn saucepan handles away from the edge.
- (c) Grill food instead of frying - avoid chip pans.
- (d) Avoid carrying hot plates and pans; use a trolley to transfer food.
- (e) Use an automatic cut-off cordless kettle - cordless irons are preferable also.

In the Bedroom

- (a) Use special anti-smother safety pillow due to risk of smothering on a soft pillow during sleep seizures.
- (b) Use a low good-sized bed with padded headboard.
- (c) Smoking in bed is unwise for everyone especially for someone with nocturnal seizures.
- (d) Keep freestanding furniture away from beds to prevent injury during a fall. Built-in furniture is preferable.
- (e) Coarse carpets can lead to friction burns for those who fall - keep a safety mat beside the bed.
- (f) Wall mounted lamps pose fewer risks than ordinary bedside or table lamps which are easily knocked over.

In the Garden

- (a) For parents who may have seizures, safety measures must ensure that young children do not wander off or otherwise sustain injury - gates need effective locks.
- (b) Ponds are best avoided but where they exist may be covered with safety mesh.
- (c) Hard landscaping features, paths, patios, rockeries, statuary and walls may present hazards to persons with frequent seizures where falls are a feature. Grassed areas and wooden decking may be more suitable.

Local Authority Grants may be available to assist with costs of necessary house modifications.

Epilepsy, Mortality & Risks

Epilepsy is often assumed to be a benign condition with a low mortality risk. However, there is increased mortality among people with epilepsy especially those with more difficult forms and among young people. People with epilepsy are more at risk of incurring accidental injuries or even death due to lack of safety precautions and many epilepsy related accidents could be prevented.

Less easy to prevent is the phenomenon of Sudden Unexpected death in Epilepsy (SUDEP) which is a non traumatic, often unwitnessed death in a person with epilepsy who is usually young and otherwise healthy. Reasons for this occurrence are unclear but research is underway to attempt to explain it. As with other chronic conditions such as asthma and diabetes a small number of people with epilepsy will die prematurely each year.

While causes are unclear there are precautions which can reduce risks of seizures and of SUDEP, which include;

- (a) seeking prompt diagnosis and appropriate treatment of epilepsy.
- (b) taking the correct doses of medication as prescribed, avoiding sudden changes or abrupt withdrawal.
- (c) ensuring adequate rest and sleep
- (d) avoidance of alcohol
- (e) avoiding other known seizure triggers where possible
- (f) using safety pillows for those with nocturnal seizures
- (g) ensuring others are aware of proper first aid - especially dealing with prolonged seizures correctly

See also Epilepsy Ireland leaflet *"Taking Control"*