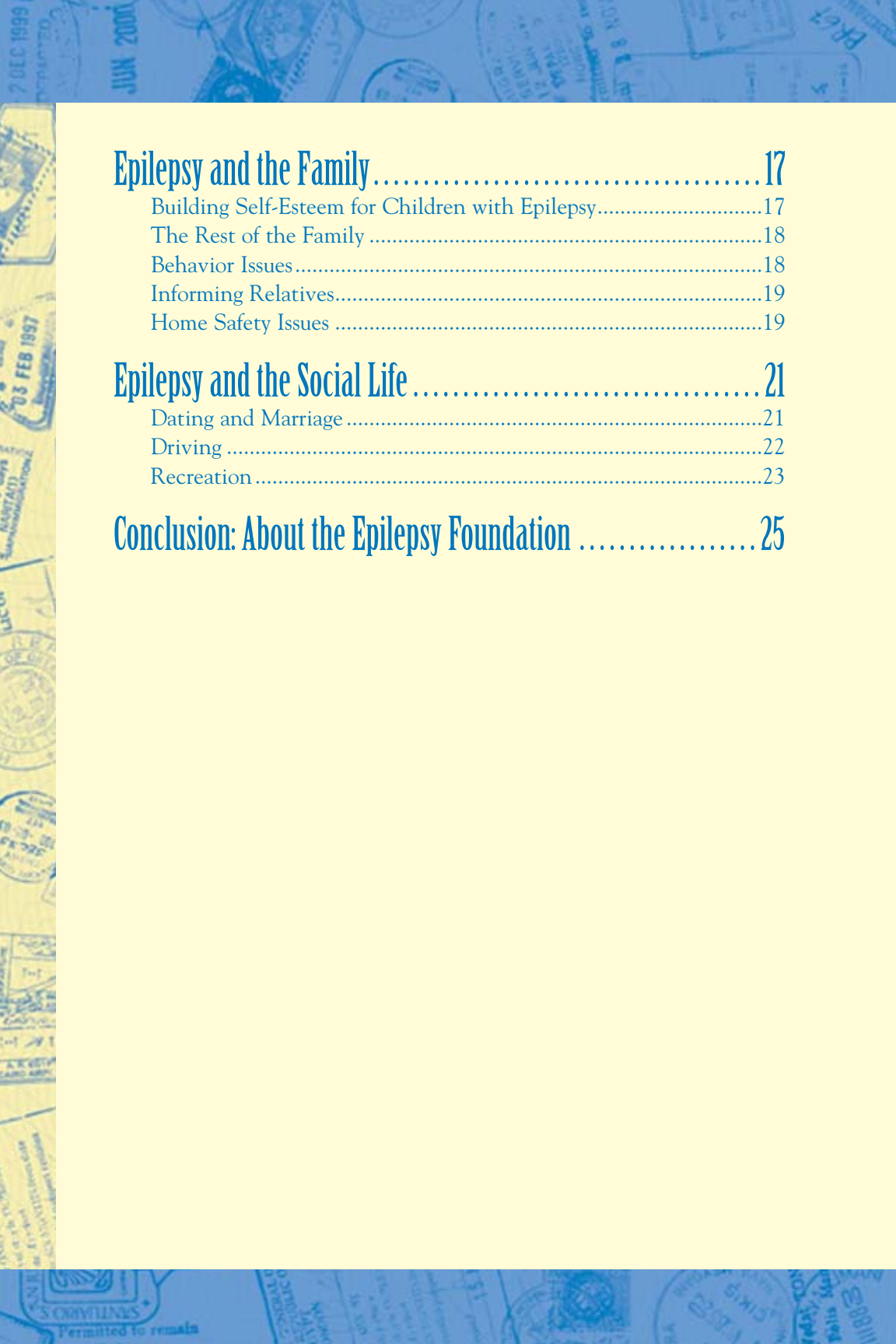


Community
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Your health care team is a key partner in your seizure treatment. The Epilepsy Foundation is also your ally.

You can turn to us for help and support while living with epilepsy. As with any health condition, knowing what to expect and how to cope is important.

Knowing about your community resources and how to use them well is important, too.

This *Community Passport* provides you with an overview of resources and information about how best to live your life – including the parts of your life involving work, family, and social activities. The Passport will also guide you to additional community allies – providing services and programs – to help you live well with epilepsy.

We based the content of this passport on the most common non-medical topics people with epilepsy and their caregivers ask of our Information and Referral staff.

After reading this passport, if you have any additional questions, please refer to the insert for your local Epilepsy Foundation or us at (800) 332-1000. You may also ask questions and find updated information about your local Epilepsy Foundation at www.epilepsyfoundation.org.



Epilepsy is one of the most common disorders of the nervous system.

- **Epilepsy affects people of all ages, races, and ethnic backgrounds.**
- **More than 2.7 million Americans of all ages are living with epilepsy.**
- **Every year, 181,000 Americans will develop seizures and epilepsy for the first time.**
- **The condition can develop at any time of life, especially in early childhood and old age.**

Epilepsy is what you have, not what you are. You are not an “epileptic.” You are a person with epilepsy. Epilepsy is part of your life. It is not your whole life.

Other people may think that having epilepsy makes you different in some obvious way. But that’s their mistake. Given the chance, you can probably live, work, and function in the world just as well as anyone else.

However, there are many areas of life in which having epilepsy can cause special difficulties. Knowing more about them may make it easier to cope.

If you have had epilepsy since childhood, you may be concerned about what it’s going to mean to you as an adult. With the best of intentions, your parents may have protected you too well from the outside world. You may wonder now

how you are going to make the change from being dependent on them to living on your own. Doing so may take some extra effort on your part.

If you have frequent seizures, you may feel you have to live less than independently. But there may be other living arrangements to help you live independently. To find out what’s available in your area, contact your local Epilepsy Foundation.

If you have recently developed epilepsy, you may wonder how much your plans for the future will have to be changed. Perhaps no changes will be required. Or perhaps you will have to re-think some of your plans, at least until your treatment has had a chance to work and your seizure control becomes stable.

epilepsy and employment

Today people with epilepsy are working at thousands of different kinds of jobs from one end of the country to the other. Many of these people have excellent seizure control, but not all of them do. Having occasional (or even fairly frequent) seizures may make your job hunt more difficult, but not impossible.

In fact, there are certain things you can do to increase your chances of getting a job. If you are just entering the job market, decide what sort of job you want and take a long look at the qualifications you'll need to reach that goal. The better qualified you are, the better your chances of success.

If your seizure control is not yet good enough for you to get a driver's license, avoid occupations that would require you to drive as part of the job, or that would place you in hazardous situations unless your seizures are of a kind that would not expose you to risk. Think about jobs that allow you to work at home, at your own pace. Keep in mind that the growth of the Internet economy has created many non-traditional job opportunities for people with computer skills.

If your seizure control is completely reliable or your seizures are of a kind that do not affect you at work, almost all jobs should be open to

you. In fact, the only thing you may want to do that other job applicants don't is to learn how to talk comfortably about epilepsy with other people so that, if you discuss your epilepsy with an employer, you can explain how much or how little impact it has on your ability to perform your job well.

If you feel you have been unfairly treated by a prospective or current employer and you want to challenge it, contact the Jeanne A. Carpenter Epilepsy Legal Defense Fund at www.epilepsylegal.org or call (800) 332-1000 Ext. 4.

You can also get further information on epilepsy and legal rights at www.epilepsyfoundation.org. Also, in many communities, the local Epilepsy Foundation offers programs that help people with epilepsy to find jobs.

Americans with Disabilities Act

People with disabilities are protected from discrimination by a variety of federal and state laws, including the Americans with Disabilities Act. The ADA was passed by Congress and signed into law on July 26, 1990. The ADA grants civil rights protections to individuals with disabilities similar to those granted

to women and minorities. The Act prohibits discrimination on the basis of an individual's disability in employment, by state and local governments and their instrumentalities, by public accommodations, in public and private transportation and in communications. The ADA grants all individuals with disabilities uniform protections regardless of which state they live in.

For comprehensive information on the ADA and on the role of Federal agencies enforcing this and other disabilities rights laws, see www.ada.gov.

Also, you may visit the website of the EEOC. In particular see the EEOC's questions and answers about epilepsy in the workplace and the ADA at www.eeoc.gov/facts/epilepsy.html.

When to Disclose Epilepsy to Your Employer

Many people chose not to discuss epilepsy with a potential employer, however. Whether you do or not is up to you. If you have excellent seizure control and the employer does not ask any health-related questions, there's no reason to start talking about epilepsy unless you want to talk. Under the Americans with Disabilities Act, employers

with more than 15 employees may not ask any health-related questions or require a medical examination until after they have offered you the job. Such inquiries or examinations for current employees are allowed only if they are job-related.

The important issue is whether you are able to do the job as described. Employers are also required to make reasonable accommodation for a disability.

You can learn more from the Job Accommodations Network:
(800) 526-7234
www.jan.wvu.edu/media/epil.htm
Email: jan@jan.wvu.edu

If you decide to talk about your epilepsy, for example, and tell coworkers what to do if you have a seizure, or if you have to tell in response to a lawful question from the employer (after a job has been offered), remember that the more confident, well-informed, and relaxed you can be, the more reassured the employer is likely to be. Employees may ask if you are safely able to perform work-related activities.

Explain how long you've had epilepsy and how well it's controlled. If you drive, say so. Say how long you've been seizure-free. Explain that research studies show the longer people are free of seizures, the

greater the likelihood they will stay that way.

If you've never had a convulsive seizure in your life, mention that as well. Remember, the average person thinks everyone with epilepsy has convulsions all the time.

If you have only occasional seizures, point that out, too. Explain that if one should occur it will only last a very short time. And always explain how this condition actually affects your ability to perform in a job. Remember, too, that studies show people who have acquired good job skills have a better chance of getting a job, whether or not they have epilepsy.

Epilepsy Foundation Career Support Center

www.epilepsyfoundation.org/programs/csc.cfm

Workplace Safety

People with epilepsy are successfully employed in a variety of jobs that might be considered high-risk: police officer, firefighter, welder, butcher, construction worker, etc. Epilepsy is a highly variable disorder and it is difficult to generalize about safety issues. Since the term “epilepsy” refers to a broad range of symptoms and underlying causes, the Epilepsy Foundation advocates individualized determinations when

epilepsy appears to be relevant to job hiring and placement decisions. Individual evaluations should take into account the type of job, the required tasks, the degree of seizure control, the type(s) of seizures, whether the person has an aura (warning), the person's reliability in taking prescribed anticonvulsant medication, any side effects of such medication, and any accommodations which would help the person do the job.

Employers often raise safety concerns and may try to exclude people with epilepsy from jobs involving public safety. It may be useful to point out to employers that most people with epilepsy can be safely licensed to drive, and the current trend is to require a three month seizure free period prior to licensing.

Under the ADA, employers may not exclude employees for safety reasons unless there is specific medical documentation, reflecting current medical knowledge, that the individual would pose a “direct threat” to health and safety. The EEOC, the federal agency implementing the private employment section of the ADA, has defined “direct threat” as a significant risk of substantial harm to the health or safety of the individual or others that cannot be eliminated or reduced by reasonable

accommodation. The determination that an individual poses a “direct threat” is to be made on a case-by-case assessment of the individual’s present ability to safely perform the essential functions of the job. The employer must identify the specific risk posed by the individual. The employer’s assessment is to be based on a reasonable medical judgment that relies on the most current medical knowledge and/or the best objective evidence.

In determining whether an individual would pose a direct threat, an employer should consider the following factors:

- Duration of the risk,
- Nature and severity of the potential harm,
- Likelihood that the potential harm will occur, and
- Imminence of the potential harm.

Courts are beginning to interpret these provisions of the law. Their decisions will provide guidance in what might and what might not be a direct threat in individual circumstances.

Missing Work

While many people with epilepsy are able to maintain regular employment without interruption, others may need to miss work because of seizures, changes in

medication, or to visit a doctor for regular monitoring. Some people fear that they will lose their jobs if they take time off, either because they will violate the employer’s attendance policy or the employer just won’t want to keep an employee on the payroll who can’t be at work 100 percent of the time. Federal laws and some state laws may, however, protect you in such a situation as long as you do some advance planning. These laws are known as the Americans with Disabilities Act (ADA) and the Family and Medical Leave Act (FMLA).

Request a Reasonable Accommodation Under the ADA

Under the Americans with Disabilities Act, employers with 15 or more employees may not discriminate against a qualified individual on the basis of disability. Employers must provide a reasonable accommodation, if necessary, as long as it does not impose an undue financial or administrative burden on the employer. One reasonable accommodation may be time off for medical reasons. This may be a reasonable accommodation even if the employer has its own attendance policy and taking the leave would normally violate the policy. While employers can continue to enforce attendance policies as long as they

apply the policy in the same way for all employees, the ADA may require the employer to make a reasonable modification to the policy if necessary to provide an individual with a disability a reasonable accommodation.

Flexible leave policies may also be considered as a reasonable accommodation when an individual with a disability may require time off due to their disability. Under the ADA, an employer is not required to provide additional paid leave as an accommodation, but should consider allowing use of accrued leave, advanced leave or leave without pay, where this will not cause an undue hardship.

To take leave as a reasonable accommodation, the employee must request it. While the request need not be in writing, it is often helpful to put it in writing. Also, the request needs to be made in advance. Employees should keep in mind that even if taking leave would be the best accommodation available; employers are not required to provide it if another effective accommodation is available or if providing the leave would impose an undue financial or administrative burden on the employer. You may also be entitled to leave as a reasonable accommodation under your state's law.

If you believe your rights have been violated you may file a complaint with the Equal Employment Opportunity Commission by calling (800) 669-4000 (voice) or (800) 669-6820 (TDD).

understanding health care plans

Don't know your PPO from your POS? Health care plan names and features can be confusing. Plans will differ in how much you have to pay and how easy it is to access the services you need. Below is a general description of the most popular types of health care plans around today.

If you are able to choose among health care plans, look for one that will help take care of your long-term needs because of your seizure disorder. Still, even if your health care choices are limited, remember one point: Health care is simply too important to live without.

Indemnity Plan

With an indemnity plan, sometimes called fee-for-service, you can use any medical provider (such as a doctor or hospital). You, or the medical provider, send the bill to the insurance company, which pays part of the bill if the service is covered by the plan, and you pay the other part of the bill.

Most indemnity plans also make you pay a “deductible.” This means you pay a certain amount, such as \$500, before the insurance company begins to pay. After you meet the deductible, most indemnity plans pay a percentage of the medical service provided. Frequently, the insurance company pays around 80 percent of the bill and you pay 20 percent.

Indemnity plans pay for medical services, medical tests, and prescriptions; however, these plans usually don't pay for preventive care, such as annual exams.

Managed Care

Most health care plans today fall under the “managed care” umbrella. In general, the doctors or hospitals you visit are somewhat restricted, but more preventive services are covered. The following describes some types of managed care plans; however, these descriptions change as health care plans compete for business.

Preferred Provider Organization (PPO).

With a PPO, you choose from a list of doctors or hospitals within a network. These health care providers have agreed to limit fees on the services they provide. If you visit health care providers within the network, your costs will be lower than if you seek care outside of the network. Often you pay the full cost of health care if you visit doctors or hospitals outside the network. You can visit any of the doctors or hospitals within the network without a referral from a primary doctor.

When you visit a PPO doctor or hospital, you usually must make a “co-payment,” which is a set amount you pay for certain services. For

example, when you visit the doctor, you may pay a \$15 or \$20 co-payment. The remainder of the bill is sent to the insurance company for payment. However, under some plans, the individual must pay the entire cost of the medical visit and then must file a claim with the insurance company for reimbursement. In addition to a co-payment, some PPO plans also make you pay a deductible (described above). The deductible is common if you visit doctors and hospitals outside the PPO network.

Health Maintenance

Organization (HMO). HMOs offer members a range of health benefits, including preventive care, for a set monthly fee. There are many kinds of HMOs. Some HMOs operate central medical facilities or clinics. Other HMOs feature a group of doctors who maintain private offices.

With an HMO, you select a primary care physician. The primary care physician coordinates your health care and you usually must contact him or her to be referred to a specialist.

When you visit an HMO doctor or hospital, you usually make a co-payment; however, you won't face a deductible. If you seek medical care from doctors or hospitals outside the HMO, you must pay the full cost of that care.

Point-of-Service (POS) Plan.

POS plans blend many of the features of an indemnity plan, PPO plan and HMO. With a POS plan, you will pay the lowest cost if you visit doctors or hospitals within the network. You select a primary care physician, but can seek care from specialists without a referral. However, if you go to specialists — inside or outside the network — without a referral from your primary doctor, your costs will be higher.

You will pay a co-payment with a POS plan which is typically less expensive if you visit doctors within the network. If you seek care outside the network, the plan will pay part of the cost, but your share will be larger. Also, if you go to doctors and hospitals outside of the network, you likely will pay a deductible.

understanding health care provisions

Pouring over your health care plan may not sound like light reading; however, everyone should understand the provisions listed in his or her health care policy. This is especially important if you're coping with a chronic condition, such as a seizure disorder. When reviewing your health care plan, pay particular attention to information about co-payments, co-insurance, deductibles, exclusion periods, lifetime maximums, and prescription drugs.

Co-payment

Many managed-care plans, such as HMOs, PPOs, and POSs, require you to pay a set amount each time you go to the doctor or hospital. For an office visit, the co-payment often is around \$20; a visit to the emergency room often has a co-payment of around \$75; and a hospital stay may have a co-payment of about \$250.

Co-insurance

Co-insurance is the portion of a health care cost you pay. For example, a health care plan may pay 80 percent of the approved cost of a treatment. You would have to pay the other 20 percent. That percent is your co-insurance amount. Plans vary as to the amount they expect you to pay.

Some plans have a “stop-loss,” “breakpoint,” or “out-of-pocket”

limit. This amount is the most you will have to spend per person each year. For example, an insurance company may have a stop-loss of \$5,000. After you have paid the \$5,000 in covered deductibles and other covered costs, the insurance company will pay 100 percent of the covered expenses for the rest of the year.

Deductible

A deductible is the amount you must pay each year before the medical plan starts paying a portion of the bill. For example, if your health care plan has a \$500 deductible, you must pay the first \$500 of covered medical costs before the health care plan begins to provide payment. Indemnity plans and some managed care plans charge a deductible.

Pre-existing Condition Exclusion Period

A pre-existing condition is a medical problem you had before you joined a health care plan. When you have a pre-existing condition, you are likely to have to wait a certain length of time before the new plan will help pay the cost of that medical problem. This length of time could be three months, six months, or one year. Employers cannot make you wait more than one year.

Read your health care plan carefully to see if you will face a pre-existing condition exclusion period. Also, keep in mind that if you have met the following, a pre-existing condition exclusion period doesn't apply to you:

- You have had medical coverage for 18 months.
- You have already met a pre-existing condition exclusion period.
- You have not been without medical coverage for more than 62 days.

Lifetime Maximum

Health care plans usually set a limit on how much they will pay for an illness or injury. This limit is called a "lifetime maximum benefit." When the limit is reached, the health care plan no longer pays for medical care.

Each plan sets its own limit, and the amount of the limit varies widely. Obviously, a health care plan with a high lifetime maximum benefit amount is particularly important for someone coping with a chronic disorder.

Prescription Drugs

Good medical plans pay the majority of the cost of approved medications. Still, you may have to pay part of the cost of medications. Your medication also must be approved

under the plan. To find out what medications are covered under your health care plan, ask to see the plan's "formulary." You may be able to appeal denial of prescription drug coverage within the plan and then to a state insurance agency.

Take a Leave of Absence Under the Family Medical Leave Act

If you need to take time off work because of your own medical condition or that of a family member, you may also be entitled to leave under FMLA or a similar state law. The FMLA allows qualified employees to take up to 12 weeks of unpaid leave during a 12 month period for medical reasons, the birth or adoption of a child, or to care for a child, spouse, or parent who has a "serious medical condition." Under the FMLA, a serious medical condition includes an illness, injury, impairment, or physical or mental condition that either requires inpatient, hospice, or residential medical care or continuing treatment by a health care provider.

To be able to take leave under FMLA, you must have worked for a particular employer with 50 or more employees, for one or more year(s) and a minimum of 1,250 hours within the previous 12-month period.

The Family and Medical Leave Act requires employers with 50 or more workers to provide up to 12 weeks of unpaid leave to eligible employees who are coping with certain family or medical situations. If you take this leave to care for a family member during a serious illness, you can take the leave in small increments or all at once.

To be eligible for the leave, an employee must have worked for:

- A covered employer (typically, a “covered” employer means a private-sector employer; most government workers are not eligible for the Family and Medical Leave Act)
- A total of 12 months
- More than 1,250 hours during the past 12 months. Again, to be covered by the Act, you need to tell your employer about your child’s seizure disorder (or that of you or your spouse).

If you qualify for leave under FMLA, you do not need to take your leave all at once. You may request a reduced work schedule with fewer hours or days as an alternative instead of a leave of absence. For example, you may request several hours off per week for medical appointments or delay the start of your workday by one hour during a change of anticonvulsant medication if you require regular medical monitoring.

Employers may request certification from your physician or the medical provider caring for your family member. The physician’s note should address the condition, duration of the condition, and in cases of family member care, for what purposes the employee is needed to provide care. Employees should specifically request FMLA leave from their employer and in cases where advance planning is possible, such as expected births or medical procedures, must give 30 days notice to the employer.

While you are on leave, your employer is not required to pay your salary. Many employers do, however, allow you to exhaust your accrued sick and vacation time so that you can continue to be paid during this absence. Depending on the terms of the policy, you may also be able to get benefits under a private short-term disability insurance policy.

Employers are, however, generally required to continue payment of employee benefits for the duration of the leave. The law also guarantees that an individual will have the opportunity to return to the same or an equivalent position with the same benefits, pay, and other conditions of employment when the leave is over, unless the employer can show that returning the individual to his old job would cause “substantial and grievous economic

injury.” Employers are also prohibited from adversely affecting seniority benefits as a result of taking FMLA leave or from terminating or otherwise discriminating against employees for requesting leave. Some employers allow employees to take more leave or provide more generous benefits than FMLA requires. State law may also offer additional protections, or more broad coverage of family medical care.

For more information about your rights under the FMLA, contact the Wage and Hour Division of the U.S.

Department of Labor (DOL) at (866) 4-USWAGE (487-9243), TTY: (866) 487-9243.

If you believe your rights under the FMLA have been violated, you should contact your local Wage and Hours Office of the U.S. Department of Labor.

Contact your state’s department of labor for information about your state’s law.

planning financially

for a Child with Epilepsy

If you have a child with a seizure disorder, it's important to consider specific issues, take certain steps, and have particular paperwork in place.

Talking with an Employer

Your child's seizure disorder may mean taking additional time off work for medical tests and visits. Your employer may question why you are gone so frequently. You may want to consider talking with your employer about your child's disorder. Also, certain programs, such as the Family and Medical Leave Act, only apply if your employer has been informed about your family's circumstances.

Keeping Records

Many companies don't mind giving you time off until your child's health is stable. Still, it's a good idea to keep careful records of all talks with your boss or people in the benefits office. Also, keep copies of your performance review. This information will come in handy if you ever feel you have been treated unfairly at work.

Health Care

If you are changing jobs, make sure your child (and your whole family) will have continuous health care coverage. If you have a child who

isn't covered under a health care plan, look into your state's Children's Health Insurance Program (CHIP). CHIP helps children, age 18 and younger, without health insurance. It was designed for children whose parents have incomes too high to qualify for Medicaid but too low to afford private health insurance. Each state runs its own CHIP and determines eligibility.

To learn more about CHIP: Centers for Medicare & Medicaid Services

(800) 267-2323
www.cms.hhs.gov/schip

U.S. Department of Health & Human Services

(202) 619-0257

**Call (877) KIDS-NOW or
(877) 543-7669
toll free or visit
www.insurekidsnow.gov.**

Life Insurance

Of course, you want to be there to watch your child turn into an adult. But, life is uncertain. That's why life insurance is important. The money from a life insurance policy can go a long way in making sure the dreams

you have for your child can be realized, even if you're not around.

If your employer provides your only life insurance coverage, consider a private policy. You probably will need more life insurance than the amount offered by your employer.

Wills

Your will directs how — and to whom — your assets will be distributed. You also use your will to name a guardian for your minor children. If you die without a will, your state will determine who will look after your children. A lawyer specializing in estates should help you write your will.

Special-Needs Trust

A special-needs or supplementary-needs trust offers a way of safeguarding your child's eligibility for government benefits while providing for additional needs not covered by the government.

A special-needs trust allows a trustee to pay for items and services beyond the bare necessities the government provides. For example, if your child's television were to break, the trustee could buy a new one. A special-needs trust can pay for everything from baseball games and movies to private rehabilitation.

To create a special-needs trust, take these steps:

- Review any paperwork where your child is listed as a beneficiary. This could include life insurance policies, retirement accounts, and savings account.
- Change the beneficiary from your child's name to the special-needs trust. This way, the trust inherits the assets and will not be counted as income when a determination is made whether your child is eligible for government benefits.
- Work with a qualified lawyer. This is a complicated area of the law and you will need an expert to draft the trust correctly.

Telling others about your seizures can be difficult, particularly when you are newly diagnosed. First, make sure you have time to find out about seizures and what to do should one occur. Ask your doctor if there is a nurse or social worker you can meet to learn more about what to do and how to talk with your family. Also, see if there is an Epilepsy Foundation affiliate in your area. It can help you get the information you need and connect you with other people who experience seizures.

Telling family members about seizures is a very important step. Your immediate family, including children, should know what a seizure is, what to do, and what not to do. They may have many questions, fears, or misperceptions that will need to be addressed along the way. Usually, people are more fearful or worried about what they don't know, than what they do know, and you may find that your family will be relieved to learn what is going on, especially what they can do to help. If you have children of different ages, you will need to think about how much information each one can handle in the beginning. And as your children grow, reassess what they know and how they feel.

The key part of talking with family members is to do so in a way that eases their concerns and addresses

the practical, safety issues, but doesn't encourage them to be overprotective of you. Sometimes well-meaning spouses or even children end up "protecting" the person with seizures to the point that roles and relationships can get very mixed up. If you find this happening, ask for help from a professional early on. It will help you keep your independence and sanity, and help your family step back, too! Remember, epilepsy is a family affair. While it may feel scary in the beginning and at different times during your life, you can learn ways to cope with these ups and downs and continue to live an active and productive life.

Building Self-Esteem for Children with Epilepsy

One of the biggest challenges for parents when a child has seizures is to help the child maintain self-esteem and self-confidence.

Studies comparing children with epilepsy with children who have other health conditions such as asthma or diabetes show that having seizures often has a more negative effect on how children feel about themselves.

It is important to encourage a positive outlook in children diagnosed with epilepsy. The following are some tips that can be

used to encourage children with epilepsy:

- Emphasize the positive and praise success.
- Build on things the child likes and can do.
- Parents should avoid describing the child's seizures or the financial burden of medical care as problems in front of the child.
- Encourage a special hobby or lessons to acquire a special skill.
- Discuss seizures and epilepsy openly with the child and answer all questions about it.
- Encourage the child to be active and to have as much social contact with other children as possible.
- Parents should try not to make the child's seizures a reason not to do things the family would otherwise do.

The Rest of the Family

It may be helpful for parents to talk with their other children about epilepsy. They can encourage siblings to ask them questions about it.

Children often have misconceptions. They may even blame themselves in some way for what has happened to a brother or sister. They may be afraid they will start to have seizures, too.

Siblings sometimes feel abandoned and lonely because the parents have

had to focus so much on the health problems of the child with epilepsy. Parents may have had to spend long hours at the hospital while the other children waited at home.

Set aside some special time for the other children in the family, and make time to answer their questions fully.

One of the most difficult questions that siblings may have is whether a child could die during a seizure. Parents and other family members worry about that, too. The answer is that it is rare for a child with epilepsy to die during a seizure.

Behavior Issues

Parents sometimes have a tendency to ignore behavior they don't like (as long as no one is likely to get hurt by it) and reward good behavior. This is as likely to work for children with epilepsy as it is for other children.

However, parents often worry that if a child is emotionally upset by discipline or a wish that is not being granted, he or she will have a seizure. Parents may be tempted to give in to unreasonable demands from a child with epilepsy because of that natural concern.

It is important for the parents of a child with epilepsy to check with

the child's health care team about the level of risk for the child and how to respond to negative behavior in a way that is safe and reasonable.

Informing Relatives

Informed, understanding relatives are a wonderful source of strength when a child has epilepsy. But the rest of the family — uncles, grandparents, aunts, cousins — may have beliefs about this condition that hail from an earlier time.

They may think it is similar to mental illness (it isn't), or someone's fault (wrong), or is related to mental retardation (usually not), or is even a sign of spiritual possession (an old myth that still lingers).

The family's commitment to helping a child with epilepsy live as normally and actively as his or her condition permits, and to treat the child as much as possible just like any other child, will shape their attitudes as well.

Home Safety Issues

The following are home safety tips for people with epilepsy:

Living Areas

- Carpet the floors in your house or apartment with heavy pile and thick under padding.
- Pad sharp corners of tables and

other furniture; look for rounded corners when you shop.

- Put guards around the fireplace or, preferably, close fireplace screens while a fire is burning.
- Don't smoke or light fires when you're by yourself.
- Don't carry hot fireplace ashes or lighted candles through the house.
- Avoid space heaters that can tip over.
- Use curling irons or clothing irons with automatic shut off switches to prevent burns.
- Select chairs with arms to prevent falling.
- Make sure motor-driven equipment, such as a lawn mower, has a "dead man's" handle that will stop the machine if your hand releases normal pressure.

Bathrooms

- Hang bathroom doors so they open outwards instead of inwards (so that if someone falls against the door, it can still be opened).
- Put extra padding under carpeting in the bathroom.
- Hang an "Occupied" sign on the outside handle of the bathroom door, instead of locking it.
- Routinely check that the bathroom drain works properly before taking a bath or shower.
- If you fall frequently during seizures, consider using a shower

- or tub seat with a safety strap.
- Keep water levels in the tub low.
- Consider using a hand held shower nozzle while seated in tub or shower.
- Set water temperature low so that you won't be scalded if you lose consciousness while hot water is running.
- Avoid using electrical appliances, such as a hair dryer or electric razor, in the bathroom or near water.

Kitchens

- Slide containers of hot food along the counter instead of picking them up, or use a cart when taking hot foods or liquids from one room to another.
- Use plastic dishes and cups with lids (commuter cups) to prevent cuts or burns from spills.
- Use a microwave oven for cooking.
- When you use the stove, try to use the back burners as much as possible.
- Remove burner controls from gas or electric stoves when not in use.
- Use long, heavy duty oven mitts or holders when reaching into a hot oven.
- Wear rubber gloves when handling knives or washing dishes and glassware in the sink.
- Use plastic rather than glass containers as much as possible.

Dating and Marriage

Men and women who have epilepsy marry and have children just like other people. However, as a group they tend to have a slightly lower marriage and reproduction rate and some men may report a lower sex drive. If you are a man with epilepsy and you are troubled by what seems to you like a reduced sex drive or inability to have sexual intercourse, check with your doctor. Medication changes or other treatment may help.

Both men and women with epilepsy are sometimes concerned that sexual activity itself might cause seizures; however, research does not support this belief except in extremely rare cases.

Close relationships usually pose another question: At what point do I explain that I have epilepsy?

There's no right answer for everybody, of course, but in general, disclosing the fact of having epilepsy seems to create the least difficulty when it happens after people have had a chance to get to know each other, rather than on the first date.

If you have frequent seizures, you may want to tell your friend about them earlier in the relationship so he or she will know what is happening and what to do if one should occur.

Although it may seem difficult at first, talking about epilepsy to other people usually becomes easier with practice. Your confidence and feelings of well-being will grow as you become more and more comfortable with what you're saying and how you're saying it.

Sometimes people with epilepsy worry about whether their tendency to have seizures will be passed on to their children. While there is a definite genetic factor in some types of epilepsy, this doesn't mean that all epilepsy is directly inherited. Epilepsy caused by injuries or illnesses that affect the brain are not thought to be genetically caused.

However, some researchers think that some people may have a greater inborn susceptibility to seizures after injury than others.

In general, there is only a slightly higher risk of epilepsy in a child when one of the parents has it (3% vs. 1%). This risk goes up when both parents are affected. It is also higher when other family members have it as well. Even so, there is a much greater chance that epilepsy will not be passed on to your children.

Driving

Can you drive an automobile if you have epilepsy? Yes, if your seizures are controlled or of a kind that do not affect consciousness or motor control that would affect driving and you meet the licensing requirements in your state.

How long you have to be free of seizures varies in different states, but it's most likely to be between three months and a year. Some states have exceptions to seizure free requirements that only take place during sleep, don't impair consciousness (commonly called auras), or are preceded by a very long warning.

When you apply for a license, some states may require that your doctor send a letter to the Department of Motor Vehicles stating that you are free of seizures and, in his or her opinion, can therefore drive safely if you meet your state's other driving requirements.

Many states also require individuals to report when they have had a seizure and the Epilepsy Foundation supports voluntary self-reporting. You may need a doctor's letter to indicate that your seizures are under control again.

A few states require doctors to report people who have lapses of

consciousness to the state. The Epilepsy Foundation opposes this regulation because it is not effective and interferes with the doctor-patient relationship. If your state has such a requirement, you may wish to ask your legislator to get it removed.

Driving is a privilege that carries serious responsibility with it. You can help protect yourself and others as follows:

- If your doctor changes your medicine, don't drive until you know how the change is going to affect you, or until your doctor says you can drive.
- If you have a seizure, don't drive yourself to the doctor's office afterwards. If you need medical attention, call a friend or take other transportation until you have been told you can drive again.
- Don't drive if your seizure control isn't good enough to get a license, or if you start having seizures again after getting a license. Insurance may not cover you in an accident if you are driving illegally when it happens and you could seriously hurt yourself or someone else. In addition, you could be charged with a crime if there are injuries to person or property.

Alternatives to driving oneself include: public transportation, car pools, taxis, and special programs

offering transportation to people whose disabilities make it impossible to drive.

There will also be times when you simply have to ask someone for a ride. If you are frequently dependent on certain people to provide transportation, see if there is some service you can perform in return so you will feel more comfortable about accepting their help.

To find the latest state-by-state driving laws, go to www.epilepsyfoundation.org.

Recreation

Leading an active life is good medicine for most people with epilepsy. If you find that getting overheated or physically tired triggers seizures, then you may want to avoid exercising when it's very hot. Take breaks when you feel you need them.

But if you are like most people with seizures, you will find that exercise is good for you in a number of ways. It makes you feel good and fights depression. It keeps your weight at reasonable levels so you look your best, and it builds self-confidence and self-esteem.

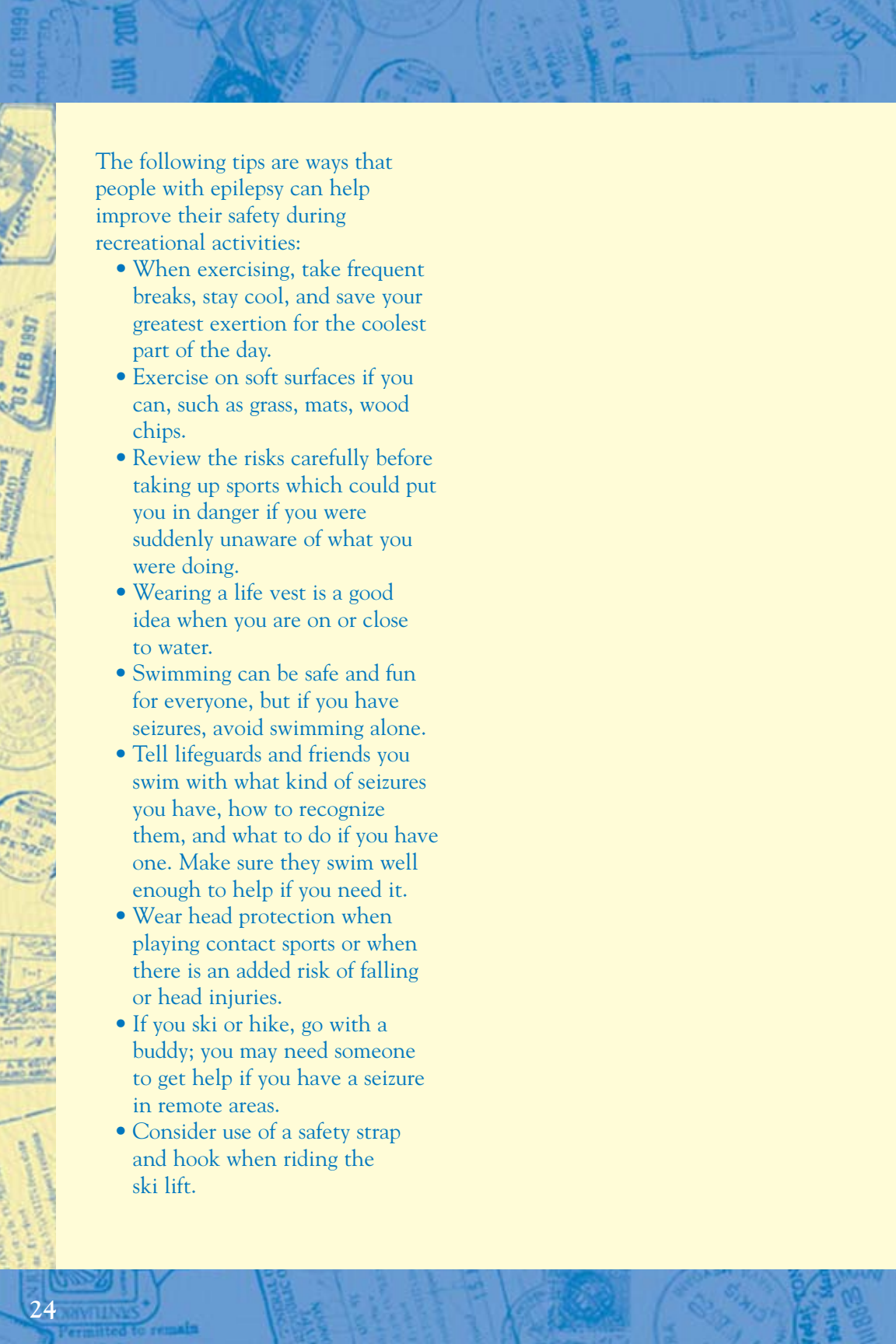
For all these reasons, the Epilepsy Foundation encourages people with epilepsy to engage in sports and recreation activities as part of a positive approach to an active life.

However, precautions are necessary for some activities.

Swimming and Other Water Sports

Swimming is a wonderful exercise. However water can be a hazard for anyone, and especially people with epilepsy. If you become unconscious while in the water, or if a seizure causes you to fall into water, you could drown. Even taking a bath in a tub with a few inches of water can be dangerous for people with epilepsy.

It is therefore advisable to review your seizure control with your doctor to see whether water sports of any kind are appropriate for you at this point in your treatment. If you are still having seizures, you should not swim unless a lifeguard or a friend who is a good swimmer is there to provide help if you need it. No one, whether or not he or she has epilepsy, should swim alone. Life jackets are a good idea for all watercraft activities and when swimming in oceans, rivers and lakes where water may not be as clear as it is in a swimming pool.



The following tips are ways that people with epilepsy can help improve their safety during recreational activities:

- When exercising, take frequent breaks, stay cool, and save your greatest exertion for the coolest part of the day.
- Exercise on soft surfaces if you can, such as grass, mats, wood chips.
- Review the risks carefully before taking up sports which could put you in danger if you were suddenly unaware of what you were doing.
- Wearing a life vest is a good idea when you are on or close to water.
- Swimming can be safe and fun for everyone, but if you have seizures, avoid swimming alone.
- Tell lifeguards and friends you swim with what kind of seizures you have, how to recognize them, and what to do if you have one. Make sure they swim well enough to help if you need it.
- Wear head protection when playing contact sports or when there is an added risk of falling or head injuries.
- If you ski or hike, go with a buddy; you may need someone to get help if you have a seizure in remote areas.
- Consider use of a safety strap and hook when riding the ski lift.

About the Epilepsy Foundation

The Epilepsy Foundation is the sole national voluntary agency dedicated to ensuring that the 2.7 million people with epilepsy in the United States are able to participate in all life experiences; and to prevent, control and cure epilepsy through research, education, advocacy and services. In addition to programs conducted at the national level, epilepsy clients throughout the United States are served by affiliated Epilepsy Foundation offices in nearly 100 communities.

Typical of the Foundation's national programs are its Jeanne A. Carpenter Epilepsy Legal Defense Fund, Epilepsy Gene Discovery Project, Employer Awareness Training, Telementoring, Women's Health Forums, H.O.P.E. (Helping Other People with Epilepsy) Mentoring Program, Speak Up Speak Out Advocacy Network, Public Policy Institute, Elderly and Women's Health Initiatives, and Research Grants Program. Services commonly provided in local communities are information and referral, counseling, patient and family advocacy, community education, and support groups.

The Epilepsy Foundation was established on January 1, 1968 as the Epilepsy Foundation of America,

culminating the merger of several regional epilepsy organizations. It began doing business as the Epilepsy Foundation on January 1, 1998, formalizing the name most often used by the public in referring to the organization. It is a 501(c)(3) tax-exempt charitable organization existing under the laws of the State of Delaware, with a national office in metropolitan Washington, DC.

The Foundation is governed by a Board of Directors composed of business leaders, healthcare professionals and client representatives, with the advice and counsel of a 50-member Professional Advisory Board whose members are among the world's leading epilepsy physicians and health experts. The Epilepsy Foundation is funded primarily through individual donations from the general public, and receives restricted grant support from the federal government, foundations and private industry. The organization is a participant in the Combined Federal Campaign, and a member of the Better Business Bureau, the National Health Council and of the International Bureau for Epilepsy.

If you wish to make a gift to the Foundation, please go to www.epilepsyfoundation.org.

To learn more about any of the topics presented in the Community Passport or to sign up to receive e-mail updates, please go to www.epilepsyfoundation.org/passport.



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This document is intended to provide basic information about epilepsy to the general public. It is not intended, nor does it, constitute medical advice. Readers are warned against changing medical schedules or life activities based on the information it contains without first consulting a physician.



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