CONSIDERATIONS/PUBLIC ASSISTANCE FOLLOWING BRAIN INJURY
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Once a Loved One has an accident or stroke

If you are the parent, or responsible adult, of an adult with brain injury, whether it be traumatic or acquired, this fact sheet has been written for you. It contains information that might be helpful for you as you go through each stage of the person's care and recovery.

The initial news of your loved one sustaining a brain injury can come as an immense shock and cause a wide range of emotions such as anxiety and fear. Unfortunately, this is common and unavoidable. You might, however, also feel relieved if, for instance, they have survived an accident. Many people do not even know how to feel at this stage, and struggle with making sense of their emotions. This is okay, as there is no right or wrong way to feel during such a difficult time.

By instinct, you will likely want to spend most, if not all, your time by your loved one's bedside. However, this will leave you feeling exhausted at an already emotionally demanding time. It is therefore very important that you take time for yourself, rest regularly and eat healthily. Do not hesitate to seek support from family members and close friends. They can provide not only comfort but can assist in providing you time for your own rest.

Early on, your loved one might be in a coma or reduced state of consciousness. There might be various machines attached to them, and their physical appearance might be changed. You will likely have many questions, but hospital staff might not be able to give you answers at this stage as it can be difficult to make an early prediction about recovery.

Even if your loved one is conscious, they might initially display unusual or uncharacteristic behavior such as swearing, shouting, or being confused; this is known as post-traumatic amnesia (PTA). Although this can be upsetting, be assured that it is a normal stage of the recovery process and does usually get better over time.

As time may permit, learn about brain injury and hospital systems so that you are prepared for what stages might come next.

Introduction to The Recovery Team

The licensed professionals involved in the care of your family member during recovery may include:

- Neurosurgeon: A surgeon expert in diseases and conditions of the nervous system. Often the attending physician who manages the case.
- Neurologist: A physician who specializes in the nervous system and its disorders.
- Pulmonologist: A physician who manages problems with respiration and lung disorders.
- Physiatrist: A physician who specializes in physical medication and rehabilitation. **
- Orthopedic Surgeon: A surgeon who specializes in diseases of the bones and treats injuries to the limbs and back.
- Neuropsychologist: A psychologist with specialized training in relationships between the brain and behavior.

- Nurses: Nursing staff provides direct patient care in all phases of the recovery process including administering oral and intravenous medications, positioning patients, and carrying out physicians' orders.
- Physical Therapist: Evaluates components of movement, including muscle strength, tone, posture, coordination, endurance, and general mobility.
- Occupational Therapist: Focuses on reestablishing the activities of daily living, self care, and upper body motor skills.
- Speech/Language Pathologist: Responsible for evaluating and assisting with swallowing problems, communication difficulties, and cognitive deficits.
- Respiratory Therapist: A person skilled in operating machines to aid breathing and keep the airway open.
- Social Worker/Case Manager: A liaison between the professional team and other parties concerned with the patient.

** Although one of the most difficult physicians to get on board, keep trying. They are very important with overall recovery and setting a game plan.

Private Health Insurance

When a traumatic event occurs, obviously the first place medical providers and you, the care provider, will look is for health insurance, either privately held, or through work.

Private insurance gives you more options in selecting and paying for services, but policies offer different benefits. Even when hospitalization and rehabilitation are covered, there are usually caps on dollars, days, and units of service.

Fortunately, as of January 2014, all individual and small group insurance plans are required to meet or exceed the Essential Benefits Package prescribed by the Affordable Care Act (ACA). The benefits package includes several key categories of health services, such as hospitalization, physician services, prescription drugs, rehabilitative and habilitative services and devices, vision and oral services for children, mental health services, and chronic disease management services, among others.

An insurance policy is a binding contract between an insurance provider and an individual or his/her sponsor (e.g., an employer, union, or membership association). Most policies contain legal language and industry jargon that may be difficult for consumers to read and understand. Taking the time to become familiar with key terms now will make your advocacy efforts easier and more successful later.

Start by obtaining a copy of the insurance policy as well as its "Certificate of Coverage" - a document that outlines the plan's provisions and benefits. The certificate tends to be more straightforward and easier to read. It is the document most coverage decisions are based on.

If involved with a group policy, send a written request to the insurance company for a copy of the policy and a written request to the plan administrator (usually an employer's human relations department) for the Certificate of Coverage.

Most insurance companies view brain injury as a medical condition. You are most likely to find coverage for the treatment and services needed after brain injury under the medical plan benefits. Be aware, however, that some benefits, especially those relating to behavioral health, may be available under the plan's mental health benefits.

Most health plans provide case management services to insureds with high-cost medical conditions. A case manager's goal is to assure the continuity and quality of care while controlling costs. Case managers may be responsible for:

- Checking available benefits
- Negotiating rates with providers who are not part of the plan's network
- Recommending coverage exceptions where appropriate
- Coordinating referrals to specialists
- Arranging for special services
- Coordinating plan benefits with available community services

Request a case manager as soon as possible after an injury if one is not assigned. You have the right to request a change in case managers if he/she does not have the training or experience needed to handle a patient with brain injury.

It would be impossible to state here all the possible problems that may arise when it comes to insurance coverage decisions by a company. Bottom line, be a strong advocate for your loved one. Do not always accept denials as the company may be misinterpreting coverage or its application.

Always retain copies of any correspondence with an insurance company, especially involving coverage issues. Document calls with times, dates, and names. This may all become important if a coverage fight were to ensue.

If you believe coverage has been wrongfully denied, speak first with your medical provider. They may have experience and know how to resolve the issue. Do not be afraid to consult an attorney knowledgeable in the subject of insurance, or even brain injury. They may be able to quickly resolve an issue, even without the need for litigation.

Care Once Released from Hospital

Studies show that caregivers of people who have suffered a brain injury may experience feelings of burden, distress, anxiety, anger, and depression. If you are caring for a partner, spouse, child, relative, or close friend with TBI, it is important to recognize how stressful this situation can be and to seek support services.

Services that may be most helpful to you include in-home assistance (home health aides or personal care assistants), respite care to provide breaks from caregiving, brain injury support groups, and ongoing or short-term counseling to adjust to all the life changes post-injury. You also may need to ask your support system of family, friends, and community members for help with your loved one's care, so that you don't get burned out.

In your role as a caregiver, you will probably find that it can be difficult to get appropriate and adequate services for your loved one. It is important to know that you will most likely need to advocate for your loved one and be persistent in your search for assistance. You should use your network of family and friends, as well as professionals, to get tips about available resources and provide support.

Begin collecting information you will need to manage insurance, determine eligibility for various governmental benefits, and preserve evidence for possible litigation. Have available as many of the following items as possible:

- Social Security card (application for Social Security programs should begin as soon as possible. (Later is a discussion of various benefits that may be available.)
- Insurance card(s) (a copy of all policies in force, if possible)
- Driver's license
- Birth certificate
- Work records (when filing for Worker's Compensation)
- Tax return for at least the past year
- Information about assets owned by the person with a brain injury.
- Information about family assets (important when applying for various governmental funds)
- Accident reports (if applicable)

Do not hesitate to speak with hospital social workers, insurance case managers, rehabilitation evaluators, and representatives from state agencies or trust funds about benefits and payment of claims, eligibility for state-provided programs, legal issues, and discharge options.

Authority to Act on Person's Behalf

If a person is under 18, then it is axiomatic the parents, or legal guardians, have the authority to make decisions on the child's behalf. It is different, however, if the person is over 18 at the time of the incident.

If an adult is mentally incapable during an emergency to make health care decisions, there is a presumption of informed consent. An emergency exists where there is an unanticipated condition in which immediate action is necessary for preservation of life or the prevention of serious bodily harm or to alleviate severe physical pain. In this circumstance, a physician may treat a person if there is no other authorized person available to provide informed consent.

After an "emergency" ends then the issue of authority to make decisions, both for health and financial purposes, come into play.

Initially, the question is whether the person is mentally capable to make decisions on their own. Often this question will require the opinion of medical experts. If they lack capacity, then there must be an acceptable alternative in existence. In California, this means there must either be a person acting under a valid power of attorney or a "conservator" who has been appointed by a court.

Powers of Attorney (POA)

If a valid power of attorney exists, prior to the person's incapacitation, then the agent has full authority to make decisions on the person's behalf, to the extent they were granted in the power of attorney document.

There are two primary powers of attorney one should have for California – an "Advanced Healthcare Directive" (for medical decisions) and a "Durable Financial POA" (for financial purposes.

Advanced Healthcare Directive (commonly referred to as a "living will.")

The document will not only appoint person(s) to act on your behalf, but will explain your personal desires concerning medical treatment, relief from pain and even donation of organs.

An excellent source for the document itself is on the California Attorney General's website. (oag.gov and search "advanced directive")

Frankly every person over 18 should execute both powers of attorney (before any accident or medical emergency) and provide copies to the person(s) they appoint. This will go a long way to saving a family the expense of having to apply for a conservator order (discussed below) and the accompanying expenses that will be incurred while the conservatorship exists. Note also, the document is fully revocable at any time.

Durable Financial POA

This document provides authority to the appointed person(s) to make decisions and conduct financial matters on your behalf. Again, it must have been executed before the person became mentally incapable of making decisions. When executing the document, you can limit or broadly authorize the person's authority.

In choosing a form there is a very important decision required; should it take effect immediately or only when a person becomes incapacitated? If effective immediately then the appointed person has authority to act on your financial matters even while you still have capacity. Therefore, one should consider the "effective" choice carefully. Note, however, like the Advanced Directive, it is also revocable at any time.

This document is readily available through many sources online. One recommended source is (https://stanlaw.org/forms.htm)

Conservatorship

If one becomes incapacitated and does not have a durable power of attorney document executed, then any interested party (typically parents) can petition the court for a Conservatorship (California name, as opposed to other states referencing it as "Guardianship.") Conservatorship provides the appointed person control over the "Person" (health decisions)

and/or over the "Estate" (financial decisions). Once a person is appointed as a conservator, they will be issued "Letters of Conservatorship," which will serve as the person's authority to act.

The application process requires the filing of numerous court documents and payment of fees. It also takes time, but temporary orders may be issued in extraordinary circumstances. Almost every county court website will have either discussion or instructions on how to apply. Nevertheless, representing oneself is not recommended and the hiring of an attorney knowledgeable in the area is wise.

There is both good news and bad news about conservatorship. Good is that the person is monitored by and accountable to the court for their actions. Bad because the monitoring can be extensive and expensive. Also, depending on the size of the "estate" there may be imposed a requirement for a "surety bond" to be posted. This again removes much needed funds from the estate to the court system.

Disability Benefits (for both individuals and family care providers)

A. Workers' Compensation

Work-related disabilities are covered by workers' compensation laws. Nevertheless, disability benefits may also be paid for work-related illness or injuries under certain circumstances. This is an issue you might discuss with experienced attorneys.

Workers' comp insurance should cover the cost of any medical treatment reasonably necessary to treat your injury. It also allows you to collect temporary disability payments (usually equal to two-thirds of your regular wages) and/or permanent disability payments, if applicable. If your injuries force one to pursue a new line of work, workers' comp may help cover the cost of training in a new vocation.

If the injury is not work-related, then there are numerous government programs that aid, both regarding disability payments and the right to take leave from work (more importantly applicable to persons providing care for the individual).

B. California State Disability Insurance

California is one of just a few states to offer a separate and publicly funded short-term disability program. Run by California's Employment Development Department (EDD), California's state disability insurance program pays benefits to *eligible* employees who cannot work for a short period due to unexpected, debilitating injuries. California employees pay into the program via a small tax on every paycheck.

If one is eligible, they can receive about 60 to 70 percent (depending on income) of wages that were earned five to eighteen months before your claim start date. This is called the Base Period. Note: A claim start date is the date disability begins.

Eligible workers can receive benefits each week until they return to work or until benefits expire. Benefits can be paid for a maximum of 52 weeks.

To be eligible for California short-term disability insurance, one must show that:

- They are unable to do their regular work for at least eight days due to a sudden disability or medical condition.
- They have lost wages due to the disability.
- They received at least $300 in wages during the previous twelve months.
- They sought medical care from a doctor within eight days of their disability.
- They are currently under a doctor's care.
- The doctor certifies that they cannot work until they recover.

The medical provider should be told of an intent to file an SDI application. This is important because a treating physician will play an important role in the application process. The EDD will require a doctor complete the Physician/Practitioner Certification form.

Citizenship and immigration status do not affect your eligibility for short-term disability benefits.

One may still be eligible for benefits if working part time during the disability period. If part-time wages and benefits combined exceed one's regular weekly wages, the weekly benefit amount (WBA) may be reduced.

Disability Insurance Offices. (Call to find your local office)

English: 1-800-480-3287
Spanish: 1-866-658-8846
TTY: 1-800-563-2441

C. Employer's Short-Term Disability Insurance

As part of a comprehensive benefits package, many employers will include short-term disability insurance, which replaces an employee's income if they become temporarily disabled after an event unrelated to work.

An employer's private insurance company—not the government—provides these benefits. To find out if a company has short-term disability insurance coverage, one needs to review the benefits package or speak with an HR department.

D. Financial Assistance for Those Providing Care:

California's Paid Family Leave Act (PFL) provides benefits to ***eligible*** workers who need to take time off work to care for a seriously ill:

- Child
- Parent
- Parent-in-law
- Grandparent
- Grandchild
- Sibling

- Spouse or registered domestic partner

PFL defines a serious health condition as an illness, injury, impairment, or physical or mental condition of a patient that requires:

- At-home care or in-patient care in a hospital, hospice, or residential medical care facility.
- Continuing treatment by a physician or health care practitioner.

If eligible, a care provider can receive benefit payments for up to eight weeks. Payments are about 60 to 70 percent of weekly wages earned 5 to 18 months before the claim's start date.

To be eligible for PFL benefits, one must:

- Be unable to do their regular or customary work.
- Have lost wages due to the need to provide care for a seriously ill family member.
- Be employed or actively looking for work at the time the family leave begins.
- Have earned at least $300 from which State Disability Insurance (SDI) deductions were withheld during your base period.
- Complete and submit a claim form no earlier than the first day a family leave begins, but no later than 41 days after a family leave begins or you may lose benefits.
- Provide supporting documentation as required:
    - A medical certificate on your care claim for the seriously ill family member. The certificate must be completed by the care recipient's physician/practitioner. A nurse practitioner or physician assistant may certify to the need for care within their scope of practice; however, they must perform a physical examination and collaborate with a physician or surgeon.

The program is administered through California's Employment Development Depart (EDD). Claims may be filed online or submitted by mail. EDD provides an excellent discussion of the benefit and procedures online.

E. Job Protection for Those Taking Family Leave

The California Family Rights Act (CFRA) requires employers of 5 or more employees to provide an eligible employee with job-protected leave to care for a child, spouse, domestic partner, parent, grandparent, grandchild, or sibling with a serious health condition, and for the employee's own serious health condition.

Note, this law is different than the Paid Family Leave Act (PFL). The PFL provides for wage support whereas the CFRA provides job protection.

There is also a federal law providing job protection, but not wage assistance. The Family and Medical Leave Act (FMLA) entitles eligible employees of covered employers to take unpaid, job-protected leave for specified family and medical reasons with continuation of group health insurance coverage under the same terms and conditions as if the employee had not taken leave.

Eligible employees are entitled to twelve workweeks of leave in a 12-month period to care for the employee's spouse, child, or parent who has a serious health condition.

Note that California is far more generous than the federal law. Leave for grandparents, grandchildren and siblings are included under California law.

Social Security Disability Income (SSDI)

Perhaps one of the most important and long lasting programs, SSDI is for workers disabled before the age of retirement. To be considered disabled a worker must (1) be unable to do any work and (2) have a disability expected to last for at least one year. A worker must have worked a certain number of quarters (periods of three months)—eligibility is based on a formula of age plus quarters worked. The monthly SSDI payment is based on wages earned at the time the worker was injured.

If one believes a disability will last at least 12 months, they should start applying for Social Security Disability Income (SSDI). Receiving short-term disability benefits from a state (or company insurance) does not impact eligibility for SSDI benefits. The Social Security Administration (SSA) allows you to receive both SSDI benefits and short-term disability benefits at the same time. Note, however, the SSA may reduce your SSDI benefits for the time that you are eligible for both benefits if the combined amount of your SSDI and short-term disability benefits is above 80% of your pre-disability earnings.

It is common for an initial application to be denied, usually for lack of supporting evidence. Do not be discouraged. An initial appeal is easy, and more often successful.

If there is a second denial, you should consider contacting an attorney specializing in Social Security law. At that point, a third attempt will take the form of an administrative hearing before a judge. If your application is approved, you will receive back payments retroactive to the date of the original application. A standard attorney's fee is 25% of the recovered funds, usually paid directly by SSA.

Supplemental Security Income (SSI)

SSI stands for Supplemental Security Income. It is a disability payment program different than SSDI (Disability Income). They are often confused. Note also, the Social Security Retirement program (Social Security) is not to be confused with either the SSDI or SSI benefits. Social security is the benefit a person may receive after a certain age and has nothing to do with disability.The Social Security Administration (SSA) administers all three programs.

Under the SSI program, the SSA will pay monthly benefits to people with *limited income and resources* who are blind, age 65 or older, or have a *qualifying disability*.

The most notable difference between SSDI and SSI is how benefit eligibility is determined. Specifically, SSI is based on need. To qualify for SSI benefits, one's income and resources must be below a certain amount. You may be eligible for SSI regardless of whether you worked and paid into the Social Security system.

SSI has its own qualifications and application procedures. SSI qualification is based on a person's resources. Specifically, if resources (the things one owns) are worth more than $2,000 for an individual or $3,000 for a couple, one is considered ineligible. This amount includes most personal property, but excludes certain items, such as one's primary home.

Generally, the maximum Federal SSI benefit amount changes yearly. As an example of the amount, in 2023 the Federal benefit rate was $914 for an individual and $1,371 for a couple.

Some States supplement the Federal SSI benefit with additional payments. California is one of those states. If a disabled person is receiving "Non-Medical Out-of-Home" care (living in a licensed care facility) then a State Supplementary Payment (SSP) is added to the amount, bringing the total amount to as much as $1492.82 (2023).

This SSP payment is extremely relevant if a person is qualifying for the ALW program (to be discussed later).

Medicare (Health Insurance)

The federal government provides Medicare coverage to persons under 65 who are severely disabled. It follows the receipt of SSDI, Social Security Disability Income. Twenty-four months after approval for SSDI, the disabled person is usually automatically enrolled in the Medicare insurance program.

The person should not have to contact anyone. They should receive a package in the mail three months before coverage starts with their new Medicare card. There will also be a letter explaining how Medicare works and that the person was automatically enrolled in both Parts A and B. The letter should also explain that the monthly Part B premium will be automatically deducted from the SSDI check beginning the month coverage begins.

Generally, one should not turn down Part B unless they have insurance based on their own or their spouse's current work (job-based insurance). If one does not have job-based insurance and they turn down Part B, they may incur a premium penalty if they need to sign up for Medicare coverage in the future. Also, if the job-based insurance will pay secondary after one becomes eligible for Medicare, they should consider enrolling in Medicare in order to have primary coverage and pay less for their care.

If one were not automatically enrolled or has other enrollment questions, they should contact their local Social Security office

Medi-Cal (California)

California's Medi-Cal provides health care coverage to those in California who have a low income, while Medicare is a nationwide program that covers seniors and those with certain disabilities (as we have seen). California administers the federal program called Medicaid. In effect, the federal government provides funds for certain programs it has approved. Each state, if participating, administers the money under a program name unique to itself – hence Medi-Cal.

As a Medicaid program, Medi-Cal serves as a health care safety net, paying the medical expenses for beneficiaries who have low incomes. This can include individuals, families, children, and those who are pregnant, as well as seniors and *people who have disabilities*.

With Medi-Cal, one must meet certain income requirements, a condition not required by Medicare. In most circumstances, one will qualify for Medi-Cal's free coverage if they're an individual earning $20,120 or less a year or a family of four making $41,400 or less annually. Note, if you earn more, you may still qualify and can have a small monthly cost.

Medicare has no income or state residency requirements. One qualifies when they turn 65 or if they have a qualifying disability. If you meet the eligibility requirements for both programs — for example, having a disability and having a low income — you can be dually enrolled in both Medi-Cal and Medicare. This is commonly referred to as "Medi-Medi."

For those enrolled in both programs, Medi-Cal and Medicare work together in coordinating and providing care. With this type of arrangement, Medi-Cal wraps around Medicare coverage, helping to pay for Medicare premiums, copayments, and deductibles.

Please note that if one is receiving SSDI benefits and is in a 24-month waiting period before getting Medicare, they may be able to get Medi-Cal coverage while they wait. If eligible the Medi-Cal eligibility will usually continue even after one enrolls in Medicare.

Medi-Cal also provides additional benefits beyond what's usually included with Medicare Parts A and B, covering prescription drugs, dental, vision care, extended stays in skilled nursing facilities and long-term care in nursing homes.

A very important and notable coverage difference between Medicare and Medi-Cal is that only Medi-Cal covers long-term care such as nursing homes. This may be a critical difference if your loved one requires in home care or resides in an independent care facility.

A note about "Covered California." California's Medi-Cal program provides free and low-cost health care coverage to those who have a low income. Covered California is the state's health insurance marketplace under the Affordable Care Act, where residents can shop for insurance and qualify for subsidies to get lower premium assistance.

California Programs Providing Assistance with Long-term Care

The state of California, through its Department of Social Service (CDSS), has made available some financial assistance for adults who have a disability to the extent they require care with their "activities of daily living" (ADL's). Examples are bathing, toileting, walking, dressing, feeding, and transferring.

In-Home Supportive Services (IHSS)

The IHSS Program will help pay for services provided to a disabled individual so that they can remain safely in their own home. This allows a person to remain home with their loved ones or reside in a private home of their choosing. This is an alternative to out-of-home care, such as

nursing homes or board and care facilities. Funding for this latter type of care is made possible through the CDSS "Assisted Living Waiver" program (ALW). [This benefit described below].

The types of services which can be authorized through IHSS are house cleaning, meal preparation, laundry, grocery shopping, personal care services (such as bowel and bladder care, bathing, grooming and paramedical services), accompaniment to medical appointments, and protective supervision.

If approved, then a determined number of hours will be paid by the state for the supportive services. If approved for this benefit, the state will pay the designated caregiver(s) directly for the hours they performed. Oftentimes family members themselves, if providing care, will qualify for the payment.

To qualify, one must be a disabled California resident eligible for SSI or Medi-Cal. They must be living in a home, apartment, or abode of their choosing (not including a hospital, nursing home, assisted living or licensed care facility), and be unable to live safely at home without care.

Application is made through a county Office of Social Services. After receipt of an application, a social worker will perform an evaluation and determine how many hours will be approved. As part of the application process, one will need to have their health care provider fill out a medical certification form, attesting to their need for ADL assistance.

Assisted Living Waiver (ALW)

If eligible for Medi-Cal, and one desires or needs to reside in a hospital, nursing home, assisted living or licensed care facility, then the CDSS administers a program commonly referred to as the ALW. If one is approved, then the state will pay a daily amount to an approved care facility; the amount depending on what level of care is required after evaluation. The levels of care run from Tier 1 though Tier 5. (Most brain injury survivors are classified as Tier 5, providing the most financial assistance.)

To apply for this benefit, one must contact a "Care Coordinator" agency approved by the CDSS. This agency takes the application, conducts an evaluation, and then submits a report to CDSS with their request for ranking. If approved, the Care Coordinator will assist in placing the person in a home and will also regularly monitor their care and treatment.

There are some unfortunate aspects to this program. One, it is applicable only to fifteen California counties. Two, there are very few homes dedicated to care for brain injury survivors. This unfortunately results in a person having to live in a home licensed for the care of the elderly. Three, historically there has been quite a delay (waitlist) for the benefit. As such, it is recommended one apply early if they foresee the need for residing in a care facility.

For a thorough explanation please visit:

https://www.dhcs.ca.gov/services/ltc/Pages/AssistedLivingWaiver.aspx