

Brain Injury & Disability Resources

ABIN-PA InfoLine 800.516.8052
Abuse Reports—Age 0-18 800-932-0313
Abuse Reports—Age 18+ 800.490.8505
Aging/Disability Referrals 866.286.3636
Area Agency on Aging (blue pages)
BIAPA Resource Line 800.444.6443
BrainSTEPS (Local Intermediate Unit)
CareerLink (blue pages)
ChildrensHealthInsurance 800.986.5437
Consumer Protection 800.441.2555
Crime Victim's Benefits 800.233.2339
Defense & Veterans BIC 866.966.1020
Disability Rights Network 800.692.7443
DomesticViolence Hotline 800.799.7233
Elks Nurses (care plans) 814.781.7860
Epilepsy Foundation 800.887.7165
Head Injury Program 717.772.2762
(1 year of rehab, \$100,000 max)
Health Insurance www.healthcare.gov
or 800.318.2596
Health Law Project 800.274.3258
Independent Living Ctrs 717.364.1732
Legal Aid (PA) 800.322.7572
Legal Clinic for Disabled 215.587.3350
Meals on Wheels www.mealcall.org
Medical Assistance 800.537.8862
Medicare Coverage 800.633.4227
(Part A & B have in-home services)
Medicare Complaints 800.783.7067
Office of Vocational Rehab (blue pages)
OVR Complaints 888.745.2357
Social Security 800.772.1213
Special Ed Consult Line 800.879.2301
Special Kids Network 800.986.4550
Waiver Enrollment 877.550.4227
Waiver HelpLine 800.757.5042
Women's Law Project 215.928.9801

ABIN-PA Services

"Empowering Survivors & Families to Rebuild Their Lives."

InfoLine

Resources. Problem-solving. Support.

Advocacy

Individual. Government Affairs.
Nonprofit Coalitions & Collaboratives.

Education

Conferences. Presentations.
Staff Training.

Literature

Free Monthly Newsletter.
Brochures.
Booklets.
PowerPoints.

Website

Newsletter Archives & Sign-Up.
Print Literature.
"Our Stories."
Print Resource List by Birthdate.
Rehab Facility Search by Type.
Videos.

Brochure Categories

General
Children <21
Adults 18+
Families & Caregivers
Rehabilitation
Dual Diagnosis
Justice System

Brain Injury Advisory:
Families & Caregivers

CAREGIVERS: TIPS & STRATEGIES



ABIN-PA is dedicated to increasing public awareness about acquired brain injury and to providing support, education, information, advocacy and other services for individuals with acquired brain injury and their families.

ACQUIRED BRAIN INJURY
NETWORK OF PENNSYLVANIA
InfoLine: 215.699.2139
Toll-Free: 1.800.516.8052
info@abin-pa.org
www.abin-pa.org

Choosing to care

If family members choose to become caregivers, their attitudes will be important for best recovery. At first, caregivers must make a lot of decisions for those with brain injury but recovery requires that people do more and more for themselves—not so easy to watch.

In the hospital

In formal settings, authority figures are in control but caregivers have a role to play. Caregivers are the only familiar faces, know the life history and preferences of the patient, and can create a feeling of hope, family warmth and joy despite outward reality. Those emerging from a coma, report conversations they overheard, so be positive!

Hospital discharge

Discharge to home, a parent's home, a rehabilitation provider or a nursing home is based on progress and funding. Whatever the location, the caregiver must fill in the gaps and require the person to be accountable for whatever tasks they are able to perform. Abilities are never clearly evident and change from day to day. Interest and safety are the guides.

Emergency Room

Discharge from a hospital emergency room is generally to home. While further medical care was not required, the caregiver must watch for the immediate signs of trouble listed on the hospital discharge sheet and for changes in cognitive, emotional, behavioral and physical function that may require rehabilitation.

Possible changes...

COGNITIVE: memory, speed, word finding, concentration, judgment, spatial awareness, multi-tasking, organization, planning, reasoning, predicting, reacting, processing, attention, reading, writing and math.

PHYSICAL: seizures, balance, gait, spasticity, weakness, paralysis, vision, hearing, speech, headache, fatigue, smell, taste, swallowing, nausea, salt balance, appetite, thirst, dizziness and one sided neglect.

BEHAVIORAL: anxiety, depression, mood swings, impulsivity, agitation, egocentricity, unaware of others, apathy, inertia, perseveration, unable to multi-task, frustration, rage, loss of self and anosognosia.

Seek brain injury rehabilitation for these problems.

Emotions

Caregivers experience a roller coaster of emotions every day, depending on the loved one's level of function at the moment. Fear, gratitude, despair, grief, anger and humor may keep the caregiver off balance and exhausted. You may be mourning the person you knew and the future you imagined. At the same time, you may be angry that no one is helping or the person isn't kind or doesn't try hard enough.

Constant adjustments

As recovery proceeds, the caregiver will be reacting to constant change. Two steps forward and several steps back. Go to the homepage Beginners Box for an overview.

Protect yourself

Make sure to get enough rest, eat well and attend to medical, dental and vision care. You must also maintain your car and home, pay the bills and have a life. You need a circle of support, whatever financial benefits are available, paid help if needed, and changes in your other priorities. The welfare and progress of the individual you assist will benefit if you take care of yourself.