

ORGANIZATION NEWS

INFORMATION/EDUCATION PAGE

Future Planning After Brain Injury: A Guide for Family Caregivers



Why plan?

Brain injury can lead to profound changes for individuals and their families. It is often the love and support of family caregivers that provide the structure, safety, and resources to manage the associated day-to-day challenges. It is critical that family caregivers and individuals with brain injury plan for future needs. As the person with brain injury ages, so do their family-member caregivers. What happens when the family caregiver is no longer able to provide this care? According to a recent national survey, more than 50% of family caregivers have not planned for how to continue their loved one's care in the future.¹ The information provided here can help you, as a family caregiver, to prepare for the best future possible. Show that you care by planning ahead.

What plans need to be made?

Record keeping

- Good documentation is essential. You typically have more knowledge of the medical history of the individual with brain injury that others do not have.
- Making sure the records can be accessed by other selected individuals is vital when you may not be able to provide the information.

- Run the information by other individuals to ensure that they can read and understand the contents.
- Tell other family members and close friends the plans and where to find any important records.
- Develop a flexible and easy system to keep information and records organized.
- Organize your records into categories, such as personal, emergency, health care, insurance, and community, as depicted below.
 - o Personal information: Full name, birth date, birthplace, social security number, marital status, immediate family, diet, hobbies, special friends, religion, education, guardians, trustees, power of attorney, and funeral arrangements.
 - o Emergency information: Contacts (eg, family members, nonfamily caregivers, neighbors), allergies, and physician telephone numbers. Make sure those listed as contacts are aware of the plan and know where to find the information.
 - o Health care information:
 - Provider information (name, address, and telephone numbers for current physicians, psychologist, eye care specialist, dentist, and therapists)
 - Allergies, current medications and dosage
 - Past hospitalizations
 - Medical records. Copies of medical records can be very helpful in communicating one's medical history to other providers. You must request a patient's medical records in writing before a medical facility can release them. Call the facility and ask them to mail you a release form. Note: Many

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health care providers charge for medical records by the page. To minimize cost, consider narrowing the request to include: physician admission History and Physical, physician discharge summaries, medication history, laboratory and imaging results, and physician clinic notes.

- Maintain documentation of all interventions and medications tried, even those that were not effective or not tolerated.
- o **Insurance information:** Copies of insurance cards, social security card, Medicare or Medicaid card, and Veterans Administration benefit card.
- o **Community information:**
 - Community provider details include: mental health programs, Department of Social Services, day hospital and similar activities, case management services, and vocational programs.
 - Community activities include: church, employment, recreation programs, support groups, or volunteer work. Maintain and frequently update a list outlining the role and contact information for each.
 - Transportation resources include: agency name and contact information, payment processes, and where services are used.

Financial and legal considerations

- It is essential that all families, not just the wealthy, carefully plan estate distribution to secure the fullest benefits for their loved one with a brain injury. Without careful planning, estate assets can make the individual with a brain injury ineligible for government benefits. Estate planning often involves getting good legal and financial advice. Select an attorney who is knowledgeable in estate planning considerations relevant to brain injury and government benefits.² A Special Needs Trust is an option used to create a trust and preserve Medicaid and Social Security Income eligibility without a penalty.³

Table 1 Planning for the future checklist

Record Information		
Done	Issues to Consider Personal Medical Insurance Community Emergency	Notes
Request Records		
Done	Issues to Consider Medical records Legal records Certificates (birth, death, divorce)	Notes
Plan		
Done	Issues to Consider Future housing Transportation Maintain involvement in important activities and community participation	Notes
Meet With an Attorney With Expertise in Brain Injury to Prepare Legal Documents		
Done	Issues to Consider Special needs trust Guardianship (if necessary) Power of attorney (if necessary) Will	Notes

- The Achieving a Better Life Experience (ABLE) Act of 2014 allows states to create tax-advantaged savings programs for eligible individuals with disabilities.⁴ Look into what your state offers regarding the ABLE Act (www.ablenrc.org).
- A guardian is needed if the individual with brain injury is unable to make financial, medical, and community decisions. There are different types of guardians.
 - o A guardian of the estate is appointed for the sole purpose of managing the individual's property, estate, and business affairs.
 - o A guardian of the individual performs duties related to the care and custody of the individual.
 - o A general guardian has responsibility for both the individual and the estate.⁵

NOTE: When individuals turn 18, they are in control of their own affairs unless guardianship is arranged.

- Power of attorney is an option when an individual may have decreased cognitive and functional abilities. In this case, the individual with the brain injury has the ability (capacity) to make decisions and appoints another individual to act for him/her in financial and legal situations.
- Each state has its own rules regarding legal documents. Consult someone with legal expertise to find out what the rules are in your state.

Living arrangements

- It is paramount to plan for the future housing needs of the individual with brain injury. Many individuals with brain injury live with family members. Others find that the best residence is a group home, supervised living arrangement, or adult foster care. Inheritance or items of monetary value willed to an individual may affect their state or federal assistance and benefits to live in a residential facility or receive other services. This should be considered when planning for the distribution of estates.

When should I begin?

Do it now! You cannot wait for more time or less stress. No one else is going to do it for you.

How do I get started?

- Record and organize all existing personal, medical, financial, legal, and emergency information.
- Learn the laws of your state to receive maximum benefits and avoid loss of services.
- Include the individual with brain injury in the planning, discussions, and decision making.
- [Table 1](#) provides a checklist of important points for the family-member caregiver and the individual with brain injury to discuss and set into action immediately.

Is help available?

- The public library and Internet provide useful information on special needs.

- Professionals and organizations that specialize in disabilities may offer help.

Where can I get more information?

- Challenges, Changes, and Choices: A Brain Injury Guide for Families and Caregivers (<https://www.biausa.org/wp-content/uploads/Guide-for-Families-and-Caregivers.pdf>)
- Family Caregiver Alliance (www.caregiver.org; e-mail: info@caregiver.org)
- Online support groups
- Government benefits: Benefit Eligibility Screening Tool (<http://ssabest.benefits.gov>)
- National Council on Independent Living: promotes the independent living philosophy and advocates for rights and services for those with disabilities. (Address: 1916 Wilson Blvd, Suite 209, Arlington, VA 22201; phone: 877-525-3400; www.NCIL.org; ncil@ncil.org)
- Commission on Disability Rights (<https://www.americanbar.org/groups/diversity/disabilityrights/>)
- Disability Law Directory: assistance in locating an attorney (<https://www.legaldirectories.com/lawyers.aspx>)
- A Family Handbook on Future Planning (<https://mha.ohio.gov/Portals/0/assets/FamiliesChildrenandAdults/Healthy%20Babies/AlcoholandPregnancy/FASD-family-handbook.pdf?ver=2019-01-15-061516-187>)
- Achieving a Better Life Experience Act (ABLE) Accounts (www.ablenrc.org)

Authorship

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