



Health Care Planning for Individuals with Intellectual and Developmental Disabilities

A Conversation with Elise S. Kopley, Esquire

“Every individual at 18 years old is legally emancipated, and the law recognizes that person as capable and competent to make his/her own decisions,” says Attorney Elise S. Kopley. Having the capacity or the ability to make effective health care decisions can differ widely for individuals with disabilities. Attorney Kopley offers helpful information when considering an individual’s rights and protections, whether the individual has the capacity to make effective health care decisions, has some limits to capacity, or is incapacitated and unable to make effective health care decisions.

1. What are the rights and protections of an individual who has the capacity to make effective decisions?

A person who has the capacity to make his/her own health care decisions can make a health care plan. A health care plan involves effective communication of an individual’s medical values, preferences and wishes. This plan should be discussed in consultation with medical providers and loved ones. An essential component of a plan entails preparing for the individual’s incapacity by the creation of a **Health Care Proxy**, a document in which a person identifies the person(s) to make important medical decision in the event that the individual cannot make their own health care decisions.

2. What are the rights and protections to consider for an individual who has some limits to capacity?

A person who has some limits may need help to make health care decisions with appropriate care. There are varying levels of capacity. An individual may be generally healthy to handle most aspects of their life, but require some assistance with medical matters. For instance, an individual may need assistance accessing health care, understanding medical professionals or communicating their wishes effectively. An individual’s natural support system (family, friends, service providers, etc.) may help them to meet their medical needs. In addition, some individuals may have difficulty with complex medical decisions, but appreciate what a health care proxy is and are clear about who they want to be making medical decisions on their behalf. In these instances, a health care proxy, in addition to the support mentioned, should be considered.

For those individuals who have greater difficulty with the intricacies of medical decision making, it may help to be very clear about the members of the individual’s support system in the **Health Care Proxy** document. For instance, you would name the **Health Care Agent** as the person who makes medical decisions, and also list the names of those who should be notified as part of the support system when the Health Care Proxy is activated.



If you know capacity is going to be changing and for some may progress to incapacity, it is most important for individuals to be involved in their future decisions by discussing and writing down their wishes and preferences for care in a **Personal Directive or Living Will**. A written statement creates a clear expectation for those people who will carry out the individual's wishes for care. It helps minimize any future confusion or conflict when everyone is on the same page.

Lastly, it is critical and necessary for an individual to have a **Durable Power of Attorney (DPOA)**, in which the individual chooses a trusted person to manage and protect their financial and personal matters. Some families may consider a document similar to a DPOA called "Appointment of an Advocate", where the individual appoints another person to act as their advocate in health care and related matters. You can learn more about this document and others in a guide called "Coming of Age in Massachusetts" by Attorney Frederick M, Misilo, Jr, at www.fletcherilton.com/pdf/special-needs-articles/Fred%20Misilo%20-%20CoA-lo%20res%20copy.pdf

3. What are the rights and protections to consider for an individual who is incapacitated or unable to make effective decisions?

A person who is incapacitated or unable to make effective decisions needs someone else to make health care decisions for them. Health care decisions are varied and complex, and include (but are not limited to) identifying a medical need, selection of medical providers, to weighing the advantages and disadvantages of treatment options. If an individual executed a valid health care proxy and later becomes incapacitated, due to sudden or expected illness, they would need the assistance of their health care agent to make medical decisions for them.

If an incapacitated individual never executed a valid health care proxy, either because the individual did not have capacity to execute a proxy or as a result of a failure to plan, a guardian may need to be appointed to assist with medical decisions.

Guardianship is a legal process for adults who have a clinically diagnosed medical condition and are unable to make or communicate effective decisions about their everyday self-care, health, and safety. The Massachusetts court can appoint a guardian to make some or all personal and medical decisions on the adult's behalf. A guardianship protects the individual's rights and can be limited to areas where the adult's ability is impaired. www.massguardianshipassociation.org/information/guardianship-of-an-adult-2/intellectual-disability-and-guardianship

Parents of adult children with special needs experience an added financial burden and for many, this includes the legal fees associated with a guardianship. You may be able to deduct expenses incurred for medical care from income tax. Read more at www.fletcherilton.com/pdf/special-needs-articles/Tax%20Breaks%20for%20Guardianship%20Fees.pdf

Elise S. Kopley is an Officer at the Fletcher Tilton PC. She concentrates her practice in the areas of Estate, Tax & Financial Planning, Estate & Trust Administration, Elder Law, Special Needs Law, Probate Law and Litigation, including Guardianship & Conservatorship, and Government Benefits Advocacy. Prior to joining Fletcher Tilton, Ms. Kopley served as Assistant General Counsel for the Massachusetts Department of Developmental Services.