

Brain Injury Association of America

Policy Statement on Individuals with Impaired Consciousness

Brain injuries are a significant public health problem in the United States. According to the Centers for Disease Control and Prevention, at least 5.3 million Americans are living with long-term disability as a result of a traumatic brain injury. For thousands of individuals who sustain a severe brain injury, the resulting disability is a prolonged state of impaired consciousness. The terminology currently used to define the varied states of impaired consciousness includes “coma,” “vegetative state” and “minimally conscious state.” Some object to the term ‘vegetative’, finding it demeaning and derogatory. Alternate terms, such as “wakeful unconsciousness” have been suggested to avoid the negative connotations of this word. Current science is just beginning to develop the tools to understand, to treat and to predict accurately recovery from impaired consciousness.

The American Congress of Rehabilitation Medicine (ACRM), a multidisciplinary group of rehabilitation professionals involved in clinical care and research, has provided the following guidance:

“After severe brain injury, some individuals remain unconscious for long periods of time. In true coma, the person’s eyes remain closed and there is little or no spontaneous movement. Individuals either recover consciousness or evolve into the vegetative state within 4 weeks. In the vegetative state, the eyes are open and there is some degree of spontaneous movement, but there is no evidence that this movement is purposefully related to the surrounding environment. In the minimally conscious state, there is inconsistent but definite behavioral evidence of conscious awareness. Critical decisions in this context typically revolve around the individual’s current state of consciousness and their potential for further recovery. In order to clarify these issues, it is imperative that the individual be carefully assessed by professionals skilled in distinguishing between the vegetative and minimally conscious states and evaluating prognosis.”

The Brain Injury Association of America (BIAA) strongly endorses the recommendation of the ACRM that individuals with impaired consciousness receive “repeated assessments designed specifically for individuals who are unable to communicate independently and that these assessments should be conducted by specialists skilled in this process.” The Brain Injury Association of America maintains that all persons should have access to the best, most recent, most accurate information about the diagnosis, treatment and prognosis of severe brain injury.

When individuals with brain injury are severely disabled as a result of impaired consciousness, families and friends can be confronted with difficult treatment decisions. Individuals can best avoid these emotional conflicts by executing an advanced directive in anticipation of situations when the individual no longer has the ability to communicate his or her wishes. The two most common forms of advanced directives are a “living will” or a “durable power of attorney for health care” (a health care proxy). The laws for advanced directives vary from state to state

The process of developing an advanced directive can provide a forum for critical discussions with family and professionals that otherwise might not occur. Individuals are encouraged to be specific and explicit as to end of life decision making in order to ensure their expressed wishes are established and to minimize stress, conflict and guilt that may emerge in family members due to vague or ambiguous instructions.

In the event that an individual has not executed an advanced directive, the Brain Injury Association of America supports the notion that all decisions of a surrogate decision maker should be consistent with the best interests and expressed wishes of the individual with the disability. Difficult decisions, including those involving the discontinuation of life sustaining treatments in persons with terminal illnesses or with no reasonable prospect of regaining conscious awareness, should be consistent with the governing laws and made with the counsel of well-informed professionals, loved ones and any needed spiritual guidance. Use of the court to assist in the determination of end of life decision making is an option if involved parties are in conflict; however, such venues may create additional emotional burden on all who are involved.

The Brain Injury Association of America believes it is imperative that such critical end of life decisions should be in the context of accurate diagnosis and prognosis by skilled specialists, expert in the area of impaired consciousness

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