

## What you should know about severe brain injuries

The purpose of this publication is to provide you with information about severe brain injuries. Such injuries are among the most misunderstood and troubling of all serious medical conditions. Although treatment of brain disorders has rapidly progressed in the past few decades, many severe brain injuries, especially those that lead a patient to be placed in the ICU, remain difficult to resolve.

Miscommunication and misunderstanding about severe brain injuries is common and can be emotionally difficult for families of those who are ill. We hope that the following information will supplement what the doctors and nurses treating your loved one tell you and will thus help improve your understanding of severe brain injuries.

### WHAT ARE THE CAUSES OF SEVERE BRAIN INJURIES?

There are many causes of severe brain injuries. It is sometimes useful to think of broad categories of injury, each of which has several specific causes. Among the most common are:

- Trauma – such as injuries caused by auto accidents or assaults
- Stroke – conditions that cause bleeding into the brain or lack of blood flow
- Anoxic brain injury – a lack of oxygen getting to the brain, such as when the heart and/or lungs stop working in a cardiac arrest
- Toxic or metabolic disorders – such as low blood sugar, other chemical imbalances or drug overdoses
- Infections – either in the brain itself (encephalitis) or in the space around the brain (meningitis)

No matter what the cause is, the most severe brain injuries usually present with the patient in a coma.

## What is a coma?

Coma is best understood as an eyes-closed unconsciousness. The patient appears asleep, but unlike normal sleep, the patient cannot be awakened and the eyes remain closed. The body may be motionless or there may be various reflex body movements, but there is no purposeful body movement. The patient cannot communicate and has no awareness of self or the environment around them.

### MY LOVED ONE IS IN A COMA. DOES THAT MEAN THEY ARE BRAIN DEAD?

No. Coma is not the same as brain death. Coma is also not the same as another condition with which it is sometimes confused known as the vegetative state.

### HOW IS COMA TREATED?

Patients in a coma are treated with supportive care such as breathing machines, body positioning, and artificial nutrition and hydration. They also receive specific treatments for the underlying cause of the injury when possible. Such treatments might include surgery for some traumatic brain injuries or medications for specific metabolic or infectious conditions. Additional treatments depend on other disorders the patient may have such as diabetes, heart problems or blood pressure problems.

### HOW LONG DOES A COMA LAST? CAN MY LOVED ONE EVER RECOVER FROM A COMA?

The duration of coma is variable and depends on a number of features, including both the cause and associated medical conditions. Coma is rarely permanent. Some patients may show dramatic recovery from coma and may eventually appear completely normal. Other comatose patients may have a partial recovery and be left with problems such as seizures, paralysis or mental impairments. Still other patients may regain wakefulness but not awareness of themselves or their surroundings (the vegetative state). Some patients may regain partial consciousness (the minimally conscious state). Finally, some comatose patients may become brain dead.

## What is brain death?

Brain death is defined as the permanent loss of function of all parts of the brain. The standard criteria were first published in medical literature in 1968.<sup>1</sup>

When a patient is declared brain dead, they are legally dead. In brain death, the entire brain has died, both the upper parts of the brain (cerebrum) and the lower parts of the brain (brain stem). The cerebrum or upper brain is responsible for voluntary movement, thinking, hearing, seeing, feeling emotions and more. It is responsible for what you are doing as you read this information. The brain stem or lower brain is responsible for the vegetative functions such as breathing or sleeping and waking up (sleep-wake cycles). If you use your upper brain and think about it for a moment, you will quickly realize you don't have to tell yourself to breathe. Breathing is a basic vegetative function that happens automatically.

### HOW CAN THE DOCTORS SAY MY LOVED ONE IS BRAIN DEAD WHEN I SEE THEM BREATHING AND THEIR HEART IS STILL BEATING?

In brain death, a mechanical ventilator or "breathing machine" breathes for the patient. When the breathing machine is turned off, a patient who is brain dead will not breathe. The heart will beat for some time after the brain dies as long as breathing is artificially maintained because heart function is not entirely dependant on the brain.

### IS THERE ANY TREATMENT TO REVERSE BRAIN DEATH?

No. Medical science has not developed the ability to grow new brain tissue.

### WHO MAKES A DECISION TO STOP SUCH TREATMENTS?

Only a physician can make this decision. Remember that when a patient is declared brain dead, they are legally dead. Therefore, "life-sustaining" treatments are really not "life-sustaining" at all for a brain dead patient. However, the treatment team will normally continue organ-sustaining support such as artificial breathing or IV fluids for a brief time to give the patient's family and friends time to adjust to their loss. During this time the family is also offered the opportunity to make the "gift of life"—to donate the organs of their loved one when possible so that others might live.

## The doctors say my loved one is in the vegetative state. What does this mean?

The vegetative state is best understood as an eyes- open unconsciousness. It was first described in medical literature in 1972.<sup>2</sup> As with comatose patients, the vegetative patient has no awareness of self or the environment. Unlike coma patients, the vegetative patient has open eyes at times and has sleep-wake cycles. Although the vegetative patient has sleep-wake cycles, the patient is not conscious of their surroundings when their eyes are open. There is no comprehension or expression of language. Reflex movements may occur but there is no sustained, purposeful and voluntary response to unpleasant stimuli. The eyes may roam about the room aimlessly. The patient may appear to be looking at you or to briefly track an object, but cannot track the object consistently. The patient may have variable facial expressions such as grimaces or smiles but the patient does not follow commands.<sup>3</sup> Because the patient's eyes are open and some body movements exist, families may often be given false hope that their loved one is returning to normal when they are not.

### HOW LONG DOES THE VEGETATIVE STATE LAST? IS THERE ANY TREATMENT TO REVERSE THE VEGETATIVE STATE AND MAKE IT GO AWAY?

Comatose patients may pass through a vegetative state on the way to recovery, or the patient may remain in a vegetative state for prolonged periods of time. When the vegetative state lasts for more than a month, it is said to be persistent. Patients in the persistent vegetative state (PVS) may live in that condition for months, years, or even decades, never regaining consciousness and are sometimes referred to as being in the permanent vegetative state. The longer a patient remains vegetative, the less likely they are to recover and when they do have some recovery, it is typically only a partial recovery, leaving the patient with profound chronic impairments. Traumatic brain injury patients have a better chance of regaining brain function than do anoxic brain injury patients (brain injury due to a loss of oxygen to the brain). Once brain cells die, they cannot be replaced. Perhaps stem cell research will help solve this problem in the distant future, but at this time, treatment for the vegetative state is supportive rather

than curative. Such treatment includes artificial nutrition and hydration and continuous repositioning of the body.

These treatments may be initiated in the hospital, but ultimately must be provided in a chronic care setting if the patient is to be kept alive. If the family is able to provide continuous treatment around the clock, this may be provided at home. More often, such treatment is provided in a nursing home. Vegetative patients do not need long-term mechanical ventilation (breathing machines) unless they have significant underlying heart or lung disease.

## The doctors say my loved one is in the minimally conscious state. What does that mean?

This means the patient is similar to a vegetative patient with sleep-wake cycles, but the minimally conscious patient may intermittently follow simple commands and have some purposeful movements, including emotional responses to both pleasurable and painful stimuli.<sup>4</sup> They may even use a few simple words.

## How do doctors know what type of brain problem my loved one has?

A diagnosis such as coma, brain death, the vegetative state or other related conditions is primarily made based upon the medical history and a careful clinical examination. Remember that coma is an eyes-closed unconsciousness. This is a bedside diagnosis. Also, remember as explained above that patients rarely stay in a coma forever. The patient may have variable degrees of recovery or they may become brain dead, vegetative or minimally conscious. Careful clinical examinations over time and additional tests such as brain scans (CT, MRI or perfusion scans), brain wave tests (EEG – electroencephalogram), spinal taps and more may be ordered to assist in making a diagnosis.<sup>5</sup>

## How do doctors know if there is any chance of recovery?

Most families will want to know if the condition can be reversed. As noted above, medical science has

little to offer in the case of profound brain injury beyond supportive treatments. Physicians and nurses may keep patients with serious brain injuries alive for prolonged periods of time without curing the patient or making the patient well. Physicians often speak of the chance for the patient to have a meaningful recovery. The chance of such a recovery is dependent on a number of factors, including the cause of the brain injury, the patient's age and associated medical conditions. For example, an elderly patient with multiple other medical problems will have little chance of meaningful recovery, and if even kept alive in a vegetative or minimally conscious condition, will typically have a short life expectancy. On the other hand, a young patient, although they also will typically have little chance of recovery from a vegetative state, may be kept alive for decades.

## MEANINGFUL RECOVERY SOUNDS LIKE A LOADED TERM. WHO IS TO SAY WHAT IS MEANINGFUL?

Brain injuries and diseases are among the most troubling of all illnesses in modern medicine. They affect the very essence of who the patient is and what the patient may become. It is no accident that many of the most important medical ethics cases of the past several decades, including some you may have heard about such as the Quinlan, Cruzan and Schiavo cases, have involved patients with profound brain injuries. In those cases and others, well-meaning families and physicians disagreed over whether or not it was ethically appropriate to keep patients alive who were vegetative. Decisions about patients with profound brain injuries are often as much about ethics as they are about medical science.

## What are the ethical issues involved?

Deciding what is ethically right or wrong is a complicated endeavor and individual beliefs certainly play a role in this process. We would like to share a few of our beliefs based upon years of study and reflection upon the ethical aspects of modern medicine. At Baylor Scott & White, we pride ourselves on delivering modern, quality treatment while at the same time accepting the classic goals of medicine dating back over 2,500 years to the time of Hippocrates.

These goals in modern language are:

1. cure whenever possible
2. relieve suffering always
3. never prolong the dying process

In our attempts to cure patients and follow the other goals of medicine, physicians and nurses strive to follow sound medical science and clinical judgment based on experience. We acknowledge, as should patients, that scientifically based treatments intended to have only benefits are inevitably accompanied by burdens and risks. Technically correct treatments may themselves cause more problems than they solve in some cases and in other cases may not work at all. We also recognize that even the best science is accompanied by uncertainty that varies with the unique clinical circumstances of each patient. These unique circumstances are not only biological, but also psychological, social and even spiritual. Thus, we endorse “patient-centered decision making.” Competent patients able to communicate their preferences may make their own treatment decisions, accepting or rejecting any offered therapy. However, when patients are no longer able to communicate, as in the case of brain-injured patients, we believe that decisions should be made based upon a combination of what the patient would want if they could know all of the medical facts about their condition, and/or what is in the best interest of the patient. In circumstances in which patients are no longer able to directly make their wishes known, we turn to advance directives such as living wills. We also turn to families or others close to the patient, asking them to serve not so much as the final decision maker for the patient, but as a “messenger” for the patient.

We respect different cultural and religious traditions and acknowledge that persons of good will may disagree with each other about what is ethically right or wrong in any particular case. Individual religious leaders may express a variety of opinions and each patient or family may wish to consult their own religious adviser. In general, the major religious traditions consider life-sustaining treatments appropriate only when the benefits for the patient significantly outweigh the burdens on the patient. There is no state or federal law that prohibits the

removal or withholding of life-sustaining treatments when medically appropriate, and in the case of brain death, the patient is legally dead, meaning that organ-sustaining treatments will be withdrawn as explained above.

Given the complexity of medical science, the uncertainty of clinical practice and the psychological, spiritual, cultural and legal aspects of ethical decisions, it can be difficult to decide what is right or wrong in a particular circumstance. At Baylor Scott & White we have a skilled multidisciplinary ethics consultation process available to advise all parties and even help resolve ethical disagreements when they arise. We also provide Palliative Care services designed to assist the primary treatment team in meeting the comfort needs for patients who are in the “last chapter” of their life.

In closing, although modern science has created treatments unimaginable to the ancient healers, their moral insights remain relevant today. The biblical wisdom that there is, “a time to be born and a time to die”, remains true. When we can no longer meet the first goal of medicine by cure or temporary remission, or return the patient to a quality of life that the patient can enjoy, we believe the most appropriate goal of medicine becomes comfort, allowing the patient to pass away as peacefully as possible, surrounded by a caring family and community.

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## References

- <sup>1</sup> A definition of irreversible coma: report of the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death. *JAMA*. 1968;205:337-340.
- <sup>2</sup> Jennet B, Plum F. Persistent vegetative state after brain damage. *Lancet* 1972;1:734-737
- <sup>3</sup> Multi-society Task Force on PVS. Statement on medical aspects of the persistent vegetative state. *NEJM* 1994;330: 1499-1508, 1572-1579.
- <sup>4</sup> Giacino JT, Ashwal S, Childs N, et. al. The minimally conscious state: definition and diagnostic criteria. *Neurology* 2002;58:349-353.
- <sup>5</sup> Practice parameters for determining brain death in adults: summary statement. Report of the Quality Standards Subcommittee of the American Academy of Neurology. In: Practice Handbook: American Academy of Neurology. St Paul, Minn: American Academy of Neurology; 1994.