

Thoughts from Families

Family members who have a loved one in a minimally conscious or vegetative state have identified a number of important issues:

1. *Communicating with healthcare providers*

Be sure to ask questions, share your observations and express your opinions.

2. *Managing medical equipment and supplies*

It is important to be knowledgeable about your loved one's equipment and supplies. You should know how to communicate with the companies who provide these items.

3. *Providing care*

Family members often provide some of the care for their loved ones. The amount of care you provide will depend on your role in providing care (this can range from providing most of the care yourself to simply directing the care provided by others); the people, such as sitters, attendants, nurses and family members, who are available to help you with providing care; the setting (this could be your home or a skilled nursing facility); and the guidance you receive from health care providers. It is desirable to obtain as much training as possible to provide whatever elements of care you choose to provide and are able to manage. These might include bathing, grooming, bowel and bladder management, mobility, range of motion and other medical issues your loved one may have.

4. *Learning about financial resources*

You may initially feel overwhelmed when you start to learn about various financial resources that may be appropriate for your loved one. However, with patience, persistence and some help from others, you will be able to figure out which programs apply and find your way through the application processes.

Programs you will want to learn about include:

- Healthcare programs such as Medicare and Medicaid.
- Income replacement or financial assistance programs such as SSDI (Social Security Disability Insurance), SSI (Supplemental Security Income), or possibility disability insurance policies that your loved one may have had through work.
- Services to help with community living, such as state agencies that assist people in these areas.

It might not be possible to find someone who knows everything about how to access these various services and programs. The key is to keep asking questions and following up to make sure you and your loved one get all the benefits that are available. People who may be helpful to you are social workers, therapists, case managers, the local Social Security office, your state brain injury association chapter, family members or

Thoughts from Families



friends who are disabled or who have family who are disabled, or the human resources (personnel) department at your loved one's employer.

5. Guardianship

Because your loved one is not able to fully make decisions for himself or herself, it may be helpful for you, or someone else, to be appointed guardian. This may make it easier to handle medical decision-making or management of your loved one's financial matters. If you think your loved one may need to have a guardian appointed, you will need to contact an attorney to get assistance. Guardianship can be reversed when it is no longer needed.

How to interact with your loved one who is unconsciousness or at a low level of responsiveness:

The most natural way of interacting is to talk to your loved one, even though he or she may not respond or understand. Simple things like telling him or her about recent events in your life, what is going on in your family or neighborhood, or the latest news might make you feel a sense of connection. Talking with your loved one about what you are doing as you provide care can increase your comfort with the process of caregiving. For example, telling your loved one you are going to move his or her arms and legs to help prevent joint tightness might make you feel more comfortable with this task. Only do this "range of motion" type activity if you have been instructed to do so by the doctor, nurse or therapist.

Physical touch is another way of having a sense of connection. Some family members have said the act of giving a massage or applying lotion to the hands or face helps them feel close to their loved one. It is also important to avoid the risk of overstimulation as this may result in rapid breathing, tightening of the muscles, grinding of the teeth, restlessness and fatigue.

Taking care of yourself and other family members:

Family members of a person in a vegetative or minimally conscious state often feel a sense of loss or grief for the relationship they had before the injury. There can be a number of ways to cope with these feelings. A person in a minimally conscious or vegetative state may make very slow progress or go for periods of time with no apparent progress. Sometimes keeping a journal of the changes you have observed may be comforting. This may give you a chance to look back and see ways in which he or she is more able to respond than he or she was at an earlier point in time.

Having a loved one who is in a vegetative or minimally conscious state can be physically and emotionally draining. Managing this alone can be too much to ask of one person. It is important to rely on support from others, looking to existing supports and developing new ones. You might find help from supports you have relied on in the past, such as family, friends and religious groups.

Other resources to consider include support groups, support agencies and the Internet. A good way to learn more about these possible supports is to make a contact with the Brain Injury Association of America's National Brain Injury Information Center (www.biausa.org, 1-800-444-6443) and obtain contact information

Thoughts from Families

for the closest state brain injury association (BIAA) chapter. Healthcare providers such as doctors, therapists, social workers and others can be good sources of information about supports available to you.

Even the most committed caregiver needs to have some private time. If your loved one is at home, this can range from having a friend or family member give you a two-hour break to go do something for yourself to having full-time caregivers for a week or having your loved one spend a brief time in a nursing care facility or hospital. If your loved one is still in the hospital or living in a nursing care facility, having a rotating visitation schedule can give you some breaks while giving other friends and family a chance to spend time with him or her.

When your loved one was first injured, you were likely to be in crisis mode, focusing on the problems and putting the rest of life on hold. As time goes by, you will need to shift from crisis management mode and begin to take care of the concerns of everyday life, such as paying bills, maintaining relationships with other family members, and taking care of your own physical and mental health. While it is natural to focus on your injured loved one, other members of your family will have needs, too. For some people, formal counseling with a therapist or member of the clergy can be an important part of making adjustments to life changes that have occurred because of your loved one's injury.

While caring for a person in a vegetative or minimally conscious state is an enormous challenge, use of appropriate resources, as described above, can be a big help. Each person will respond differently to this challenge, but almost everyone can cope and move forward. Many family members have a deep sense of personal satisfaction in making life as comfortable and pleasant as possible for a loved one who has sustained a severe injury.

Courtesy of:

Sherer, M., Vaccaro, M., Whyte, J., Giacino, J.T., & the Consciousness Consortium. *Facts about the Vegetative and Minimally Conscious States after Severe Brain Injury* 2007. Houston: The Consciousness Consortium