ARDS (Adult Respiratory Distress Syndrome), Suggestions for Family and Friends

While your family member or friend is in the hospital being treated for ARDS, you may feel a lot of stress. One day the patient may seem to be recovering, and the next day things may take a turn for the worse. It can be a scary experience to see someone you care about on a breathing machine.

Several caregivers work together to give care to your family member. These caregivers are often specialists who are treating different concerns of the patient. For example, an infectious disease specialist might be involved to help make sure that the initial infection or an infectious complication is properly treated. A lung specialist may be adjusting the settings on the breathing machine and a kidney specialist may be required if kidney failure occurs. These caregivers talk to each other regularly to make sure that care is given in a coordinated manner.

There are some things you can do to help, even though you may feel very helpless:

- Talk to the caregivers, nurses, and other health care providers. Ask questions about the patient's condition and care, and ask how you can support your loved one.
- Talk to the patient, even if he or she is in a drug-induced sleep. Talk about fun things you did together and laugh with them about silly things that you did. Many survivors say they were, at some level, aware of the people and things around them. They also recall dreams they had while in the sleep-induced state. The dreams can be calming or frightening. Talking to the patient about happy and fun things may help make the dreams more positive.
- Ask the hospital staff if you can put family photos near the patient, play music at low volume, or rub lotion into the patient's feet and hands. Many survivors are aware of people and things around them. This may help to trigger their senses of hearing, touch, and seeing.
- Leave fears and worries at the door. Always go outside the patient's room to talk with the doctor or nurse about the patient's condition. Make sure everyone is encouraging and hopeful while with the patient. The patient may sense stress in their presence.
- Keep a journal or record of events for the patient to read after leaving the hospital. ARDS survivors want to know every detail of what happened while they were asleep.
- Remember to take care of yourself, too. Try to get enough rest and sleep, eat well, and get some exercise. Call on other family members and friends to sit with the patient so you can have a break. Your very sick loved one will need your strength and support over what may be a long recovery period.
- The family members and friends of people who have had ARDS often are deeply affected by the experience. The "roller-coaster" ride of emotions while the ARDS patient is in the hospital is exhausting and stressful. Caring for the ARDS survivor at home can also be stressful and tiring. Ask for help from others or your health care providers if you need it. Most hospitals have individuals such as social workers who can help family member cope with these issues.

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