Issues for You and Your Patient Advocate to Discuss

Setting up your Patient Advocate and Living Will is the first step to making your wishes known. Because situations and circumstances in our life change, it may be important to revisit our health care wishes. Many experts say that you should revisit your decisions 1) at the start of a new decade; 2) when you experience the death of a loved one; 3) when you experience a divorce or major family change; 4) when you are diagnosed with a serious health condition, a decline or deterioration in your health. Should you experience one of these above changes, not only should you revisit the decisions you have made in your medical advocate, but below are some of the questions that you may want to discuss with your patient advocate as well:

Any time you sign a Designation of Patient Advocate and Living Will (many individuals refer to this same document as a Health Care Power of Attorney or Advance Medical Directive) you should make sure you give a copy to your patient advocate, your physician, any medical specialist that you work with and you should keep a copy readily available for your own use. In addition to the steps provided above, below are some questions you may want to review with your patient advocate so they have a better understanding of how you feel about medical care and/or life support issues. To make sound moral decisions, patients and/or their patient advocates must receive all relevant information about their condition including the proposed treatment and its benefits, possible risks, side-effects, and costs.

When choosing the person best suited to serve as your patient advocate, some of the things you should consider are as follows:

1. Someone who would be able to act on your behalf and separate his or her own personal or religious feelings from yours.
2. Someone who lives close or could travel to be at your side immediately.
3. Someone who you trust with your life.
4. Someone that you talk with now about sensitive issues and will listen to your wishes and concerns.
5. Someone who would be a strong advocate in the face of an unresponsive doctor or institution.
6. Someone who is confident enough to handle conflicting opinions between family members.
7. Someone who will likely be available in the future.

Before answering the questions below, it is important to make a distinction between some basic terminology we use regularly when discussing end of life issues. **Brain dead** should not be confused with **persistent vegetative state** or **coma**. In brain death, the entire brain irreversibly ceases to function. Everything shuts down; the cerebral cortex, which controls higher functions, as well as the brain stem, which regulates automatic actions like heart beat and breathing. In a persistent vegetative state, the cerebral cortex has been destroyed, leaving the person incapable of thought or memory, but the brain stem remains intact and functional. A person in a persistent vegetative state can live for years without a mechanical ventilator or other technological support. A coma is just a general term for lack of unresponsiveness and can occur for any number of reasons. The coma can be temporary, as it is used during general anaesthesia, or permanent, as sometimes happens following an injury. With a coma only detailed neurological testing can determine the extent of the brain injury

or its prognosis. With a better understanding of above, the confusion between each of these and the emotional distress it can cause can be avoided.

For the following questions, in some situations only one answer will apply and in some circumstances you may circle more than one response:

1. If I can no longer recognize or interact with family or friends:

   a. I definitely want treatment that might keep me alive.
   b. I probably would not want treatment that might keep me alive.
   c. I am unsure of what I want.

COMMENTS:

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2. I can no longer walk, but I can get around in a wheelchair:

   a. I definitely want treatment that might keep me alive.
   b. Probably would not treatment that might keep me alive.
   c. Unsure of what I want.

COMMENTS:

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3. If I am in severe, un-treatable pain most of the time:

   a. I definitely want treatment that might keep me alive.
   b. I probably would not want treatment that might keep me alive.
   c. I am unsure of what I want.

COMMENTS:

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4. If I am on a feeding tube that keeps me alive:

   a. I definitely want treatment that might keep me alive.
   b. I probably would not want treatment that might keep me alive.
   c. I am unsure of what I want.

COMMENTS:

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5. If I am on a kidney dialysis machine that keeps me alive:

   a. I definitely want treatment that might keep me alive.
   b. I probably would not want treatment that might keep me alive.
   c. I am unsure of what I want.

COMMENTS:

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6. If I am on a breathing machine to keep me alive:

a. I definitely want treatment that might keep me alive.
b. I probably would not want treatment that might keep me alive.
c. I am unsure of what I want.

COMMENTS:

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7. If I need someone to take care of me 24 hours a day:

a. I definitely want treatment that might keep me alive.
b. I probably would not want treatment that might keep me alive.
c. I am unsure of what I want.

COMMENTS:

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8. If I have to live in a nursing home permanently:

a. I definitely want treatment that might keep me alive.
b. I probably would not want treatment that might keep me alive.
c. I am unsure of what I want.

COMMENTS:

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9. If the doctors are recommending treatment to your patient advocate, but the treatments will have a severe side-effect, such as severe pain, nausea, vomiting or weakness that could last for several months:

a. I would be willing to endure such side effects if the chances of regaining my current health was less than 70%.
b. I would be willing to endure such side effects if the chances of regaining my current health was less than 50%.

c. I would be willing to endure such side effects if the chances of regaining my current health was less than 20%.

COMMENTS:

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10. If you were suffering from Alzheimer's disease and it had progressed to the point where you could no longer recognize or converse with your family and spoon feeding was no longer possible, would you want to be fed by a tube?

a. Yes
b. No
c. Uncertain

COMMENTS:

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11. Which of the following situations do you fear the most:

    a. Being in pain.
    b. Losing the ability to think.
    c. Being a financial burden on family.

COMMENTS:

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12. If a doctor advised you that your condition was terminal, but treatment such as chemotherapy might give you an additional six months of your life would you want chemotherapy or a rigorous treatment plan even if it had sever side affects such as constant pain, nausea, vomiting, weakness?

    a. Yes
    b. No
    c. Uncertain

COMMENTS:

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13. If you were terminally ill with a condition that caused you a considerable amount of pain, would you want to be sedated even to the point of unconsciousness if it would control the pain?

    a. Yes
    b. No
    c. Uncertain

COMMENTS:

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14. Is it more important for you at end of life care that your wishes be followed or that friends and family are comfortable with the decision that you have made.

    a. My decisions are more important.
    b. Having family and friends agree is more important.
    c. Uncertain.

COMMENTS:

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15. Assume that you are physically frail and are unable to perform some of the most basic tasks such as dressing, bathing, eating and going to the toilet. Assume that you live at a nursing home and although your mind is fairly clear each time that you come down with an illness such as flu or pneumonia, you are hospitalized for several days and given antibiotics through and IV tube. The next time you get pneumonia do you want

aggressive antibiotic treatment again or just kept comfortable until death occurs.

a. I would like antibiotic treatment.
b. Keep me comfortable.
c. Uncertain.

COMMENTS:

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16. If your heart, kidneys, pancreas, lungs, liver or any other vital organs could all be used in a transplant operation to save lives, would you want your family to donate them at your death?

a. Yes
b. No
c. Uncertain

COMMENTS:

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17. If there is a presumption in favor of continuing to provide food and water to a patient, but there is a stage in the dying process when even food and water may no longer obligatory because they provide no benefit. If the doctor has determined that food and water is providing no benefit:

a. I still want to be provided with food and water
b. I would want food and water discontinued immediately
c. I am unsure of what I want

COMMENTS:

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18. If I am suffering from extreme and/or unreasonable pain, it is my wish that:

a. I be kept as comfortable as possible but remain in a conscious state
b. I request that I be given the maximum amount of medication to relieve any and all pain even though it may bring about disorientation or produce unconsciousness
c. I am unsure of what I want

COMMENTS:

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