

ESRD Network # 12 Patient Newsletter

Providing kidney patients and their families information on diet, health, and kidney disease.

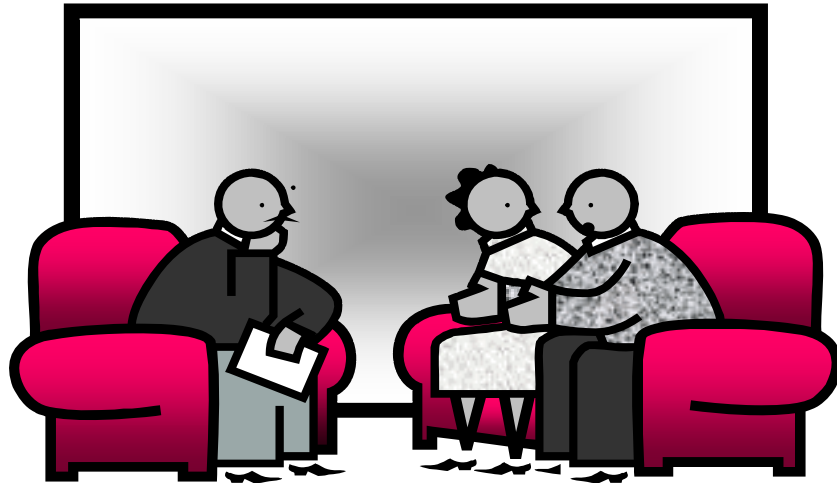
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Discussing Death & Dying



End-of-Life Planning

Death can be a frightening concept, leading to a sense of denial for the inevitable. Often times, the concept of our own mortality is difficult to accept, far less consider planning. Unforeseen events happen and planning ahead is not losing hope or faith, rather advocating your values, wishes and desires. We encourage you to approach your family and dialysis staff regarding your preferences in the hope that they understand and advocate for **your** choices in the event that you are not able to make decisions for yourself. Advanced Directives are a means of communicating the above, in the event you are unable. They are typically addressed any time someone is hospitalized. Advanced Directives are for everyone, not just dialysis patients. Study after study show patients (89 – 93%) want Advanced Directives, yet only a mere 18% have actually done them.¹ Studies have also shown that dialysis patients desire Advanced Directives², however the topic may not have been approached by the renal care team. This newsletter will provide information on Advanced Directives and planning for end-of-life care. After reading the newsletter, consider speaking with your loved ones about Advance Directives for yourself and them in the event that either one of you are no longer able to advocate for yourselves. Know their end-of-life wishes and be sure to share yours.

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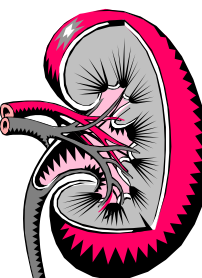
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The History Behind the Patient Self-Determination Act

The History Behind the Patient Self-Determination Act

Nancy left her parent's home on January 11, 1983, telling her sister "I will call you." Unfortunately, that call never came. On her way home, Nancy lost control of her car on an icy road in Missouri. The vehicle overturned and Nancy was found face down in a ditch, deprived of oxygen for at least 12-14 minutes. Paramedics resuscitated her, however she arrived at the hospital unconscious. (Lack of oxygen for more than 4 to 6 minutes can result in irreversible brain damage or death ³).

Her family was contacted and on February 5th, a decision was made by her husband and parents to have a feeding tube surgically placed. The family was told to "wait and see" if Nancy's condition would change. Unfortunately they were not told how long to 'wait to see' if a change would occur. Nancy was transferred to a rehabilitation center later that month, and transferred to another, (state-run) rehabilitation center several months later – all the while the family continued to "wait and see."

In January the following year, Nancy's parents, Joe and Joyce Cruzan obtained guardianship and eight months later, after Nancy's husband's visits decreased and he withdrew from the family and filed for divorce. The family continued to "wait and see," but knowing how much Nancy loved Christmas, opted to bring her home for the holidays to see if it would cause a change in her condition. Unfortunately the change did not occur.

July 1986, Joe read about persistent vegetative state in a medical journal. Convinced that the symptoms described reflect what the family observed in Nancy, they decided several months later to stop the tube feedings. During the same time period, the rehabilitation center diagnosed Nancy as in a "persistent vegetative state". However, the family could not just simply request the tube feedings be stopped.

Desiring some legal assistance, Joe contacted the American Civil Liberties Union (ACLU) in February 1987. Little help was available because the Supreme Court was unwilling to review such a case in the past, so little could be done. However with dogged persistence, Joe was able to convince the ACLU about the plight of his daughter and a referral was made to an attorney, Bill Colby of Shook, Hardy & Bacon, in Kansas City, Missouri.

The family spoke with Mr. Colby in May of 1987 and a formal request was hand delivered to the rehab center to stop Nancy's tube feedings. The rehabilitation center could not stop the tube feedings without a court order, therefore Mr. Colby filed a motion and a three-day hearing began in March 1988.

Originally, the judge ruled in the family's favor, however the State of Missouri appealed the ruling. In September 1988, arguments began before the Missouri Supreme Court. The Supreme Court overturned the judges' ruling in November by a 4-3 decision.

The family continued to fight on behalf of Nancy, as they believed she would not want to exist in such a state. July 1989, the United States Supreme Court decided to review the case. Later that year, oral arguments began and the following June a decision was rendered; it upheld the Missouri Supreme Court ruling 5-4. However, it did specify that "discovery of new evidence regarding the patient's intent" could turn the case around.

Nancy had once worked at a school for handicapped children and two women approached the family to insure them they were doing what Nancy would have wanted. Unaware that Nancy had ever had these conversations, a new hearing was requested in the Missouri probate court on August 30, 1990. Within the next month, the Missouri Attorney General had requested to be dismissed from the case. In October, the judge granted a new hearing and allowed the State to withdraw. This new information possibly offered "new evidence regarding the patient's intent."

The following month, November 1990, the women were called to testify regarding Nancy's wishes. Six weeks later the judge found that the new testimony was "clear and convincing evidence" and orders the feeding tube to be removed. Four days later, protestors arrived at the rehabilitation center where Nancy resided, carrying signs and attempting to persuade the family to continue the tube feedings. The family believed that their beloved sister, aunt and daughter would not want to have existed like in her current state. As described by the family, "Nancy was freed from the bondage of a body that no longer served her, rather imprisoned her December 26th, 1990, a mere 16 days shy of an eight year ordeal." Chris Cruzan, sister of Nancy.

Special thanks are extended to Chris Cruzan for sharing her sister and family's fight, the battle was difficult, but the doors to patient rights were opened.

The Patient Self-Determination Act

Due to the outcome and attention drawn by the Nancy Cruzan case, Congress passed the Patient Self-Determination Act (PSDA) in 1990 and implemented the law in 1991. The law

“encourages all people to make choices and decisions now about the types and extent of medical care they want to accept or refuse should they become unable to make those decisions due to illness. The PSDA requires all health care agencies (hospitals, long-term care facilities, and home health agencies) receiving Medicare and Medicaid reimbursement to recognize the living will and power of attorney for health care as advance directives. The PSDA does not create new rights for patients but reaffirms the common-law right of self-determination as guaranteed by the Fourteenth Amendment. Under the PSDA, health care agencies must ask you whether you have advance directives and must provide you with educational materials about your rights under state law.”⁴

¹ Emanuel LL, Barry MJ, et. Al., 1991

² Swartz RD, Perry E, 1993

³<http://www.merck.com/pubs/mmanual/section16/chapter206/206c.htm>

⁴http://www.cancer.org/docroot/MIT/content/MIT_3_2X_The_Patient_Self-Determination_Act.asp?sitearea=MIT

⁵<http://www.partnershipforcaring.org/HomePage/>

Under the current law, dialysis facilities are NOT required to offer Advanced Directives. The laws differ state to state.

The following pages outline the basic legislative requirements in each state in the Network #12 area. The documents included in this newsletter are reprinted with Permission of Partnership for Caring, Inc., 1620 Eye Street, NW, Washington, DC 20006. Partnership for Caring (PfC) is a nonprofit organization that offers help to people dealing with health care decisions and end-of-life medical care. Advance directives for the Network #12 area were prepared by Partnership for Caring. If you live outside the Network #12 area or desire more information on these topics it can be found on their website at www.partnershipforcaring.org, or you can call their free hotline (1-800-989-9455) for help dealing with specific end-of-life situations. PfC's hotline is open seven days a week, 24 hours a day for people having a crisis involving end-of-life care or decisions. If you live in a state other than Missouri, Iowa, Kansas or Nebraska, Partnership for Caring can additionally assist you with the documents needed in other states. All state forms are available and can easily be downloaded.

Two-Types of Advanced Directives

Two-Types of Advanced Directives



Living Wills:

Living Wills specify in writing the wishes and desires for treatment in the event you are unable to specify them for your self. They can be general or specific. The biggest drawback to Living Wills is the vagueness with which most are written. Due to the vague content and inability to specify all illnesses and situations, some difficulties can be found when interpreting them.

Durable Power of Attorney for Health Care:

This type designates a “proxy.” This is a person that you elect to make you health care decisions for you in the event that you are no longer able to make them for yourself. The proxy is appointed while the patient is competent and fully able to discuss their desires with the proxy. The drawbacks to this directive can be: poor communication between patient and proxy; the proxy’s ability to understand your choices and follow them even if they are at odds with the proxy’s beliefs/desires; the availability of a proxy; and reliance upon the proxy acting in your best interests. However, there are also advantages, which include flexibility in the time of need and the fact that the proxy can advocate and communicate your desires to the health care team, providing that your proxy is fully informed.

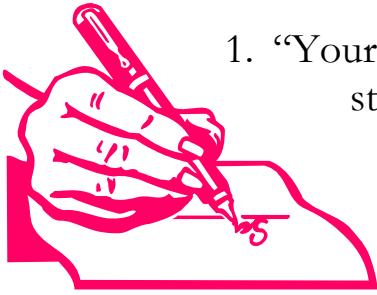
Once you have decided which type would work best for you, there are many questions to consider answering to assist those making the decisions for you. Below are just a few examples:

- Do I want to live on a machine (can include or exclude dialysis)?**
- Do I want artificial breathing if I cannot breathe on my own?**
- Do I want artificial feedings through a tube in my stomach, or possibly an IV in my vein?**
- What beliefs do I have that would assist and guide those making my decisions?**



Other Considerations...

Other Considerations...



1. “Your Durable Power of Attorney for Health Care and / or your state declaration are important legal documents. Consider keeping the original in a safe, secure place. It is not recommended to place the documents in a safety deposit box as it may prevent your proxy from gaining access to them.
2. After you have signed your Durable Power of Attorney for Health Care and / or your state declaration, make at least five copies of each and distribute them to your physician, nursing home, dialysis facility, friends and family. Ask that the copies be placed in your medical record.
3. Share your feelings regarding your wishes for care and medical treatment often. Do not hesitate to discuss your desires in the event your medical condition changes.
4. If you desire to change information in either your Durable Power of Attorney for Health Care, or your state’s declaration, you **MUST** complete new documents.
5. You can revoke or withdraw these documents at any time.
6. Ambulance personnel are required to provide cardiopulmonary resuscitation (CPR) unless they are given separate doctor orders to not perform these measures. CPR involves chest compressions in an attempt to restart your heart and/or artificial breathing. People in poor health can opt to request “no CPR” by asking their physician to write the orders that instruct ambulance personnel not to perform CPR. Not all states have laws authorizing outpatient do-not-resuscitate orders.”⁵ For further information, feel free to speak with your physician or phone our Network office at 1-800-444-9965.



The following questions can assist you in further evaluating values, beliefs and preferences to assist your loved ones in understanding your wishes. These questions come from Midwest Bioethics Center's Booklet – “Caring ConversationsSM – making your wishes know for end-of-life care.”

With whom do you want to have a caring conversation?

What do you most want to say to them?

When and where will you have your caring conversation?

What life events have given you the most joy?

What life events have saddened you the most?

What beliefs do you hold that influence your thoughts about life and your thinking about dying?

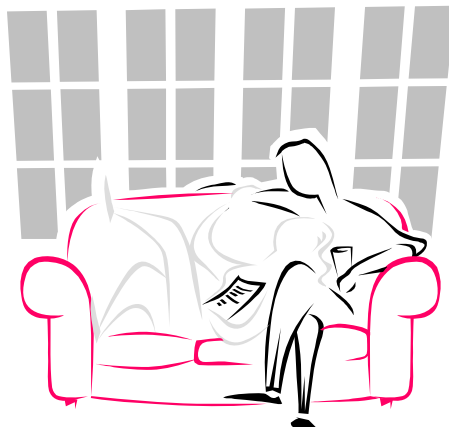
What concerns do you have about your health or future healthcare?

What are your fears regarding the end of your life?

What do you value most about your physical or mental well being? (Do you love to be outdoors? Does being able to read or listen to music bring you pleasure? How important is it to be aware of your surroundings and the people with you? How important is seeing, tasting, touching?)

Are there circumstances under which you would refuse or discontinue treatment that might prolong your life? If so, describe those circumstances.

If you could plan it today, what would the last day of your life be like? (Where would you be? What would you be doing? What would you eat? What music would you listen to? What would be your final words and last acts?)



How do you want to be remembered?

If you wrote your own epitaph or obituary, what would it say?



Nebraska Advanced Directives

“Nebraska’s legislation provides for two documents to protect your rights to refuse medical treatment and/or request specific treatment in the event you are not able to make decisions for yourself. **The documents are only legally binding if completed by a competent adult (at least 19 years old) or someone who is or has been married.**

Durable Power of Attorney for Health Care

“This legal document lets you name someone to make decisions about your medical care – including decisions about life support – if you can no longer speak for yourself. The Durable Power of Attorney for Health Care is especially useful because it appoints someone to speak for you any time you are unable to make your own medical decisions, not only at the end of life. It goes into effect when your doctor, or a consulting physician certifies in writing that you are incapable of making health care decisions. The doctor must also document the cause and nature of your incapacity.”⁵

You may appoint a family member or close friend whom you trust to make serious decisions on your behalf. The person you appoint should have a clear understanding of your wishes and desires and be willing to accept the responsibility for having to make medical decisions for you. This appointed person might also be called your ‘attorney-in-fact’, ‘proxy’, or ‘agent’. You may not appoint your doctor or other health care professionals involved in your care, or an employee of your health care provider unless they are related to you by blood, marriage or adoption, an owner or operator of your healthcare treating team, or a person unrelated to you by blood, marriage or adoption that is a proxy for ten or more people. You may also appoint a second ‘agent’ in the event that your first is unavailable to act for you.

Your Durable Power of Attorney for Health Care becomes a LEGAL document only if it is:

1. notarized by a public notary, or
2. signed in the presence of two witnesses

Your witnesses must be at least 19 years old and not be any of the following:

1. your doctor or other healthcare provider,
2. an employee of your healthcare team or insurance provider,
3. the person appointed as your ‘agent’
4. your spouse, parent, child, grandchild, sibling or heir to your estate.”⁵

Nebraska Advanced Directives

Nebraska Advanced Directives

The Nebraska Declaration

“The Nebraska declaration is the state’s living will. It lets you state your wishes about medical care in the event that you develop a terminal condition and can no longer make your own medical decisions. The Declaration becomes effective if your death would occur without the use of life-sustaining medical care. (One other doctor must agree with your attending physician’s opinion of your medical condition.)

You can add personal instructions in the area of the document called ‘additional, specific directions’. For example, you may want to emphasize pain control but refuse artificial feedings. If you have a Durable Power of Attorney for Health Care, you can also consider writing information in your Declaration that states ‘for questions about the interpretation of my desires, please consult with my agent’.

Your Nebraska Declaration becomes a LEGAL document only if:

1. Your signature is witnessed by a notary, or
2. You sign it in the presence of two witnesses.

Your witnesses must be at least 19 years old, may not be employees of your health or life insurance companies and at least one of them may not be an administrator or employee of your health care team.

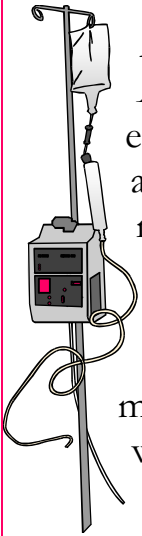
What if I change my mind?

Your Declaration may be revoked at any time and in any manner, regardless of your mental or physical state. Your revocation is effective as soon as you inform your doctor. Your doctor is then required to make this a part of your medical record.

Other Important Facts...

Due to specific restrictions in the state law, a pregnant patient’s Declaration will not be honored if the baby has developed to the point of living outside the womb with or without life sustaining procedures. .”⁵

UNDERSTANDING COMMONLY USED LIFE-SUPPORT MEASURES:

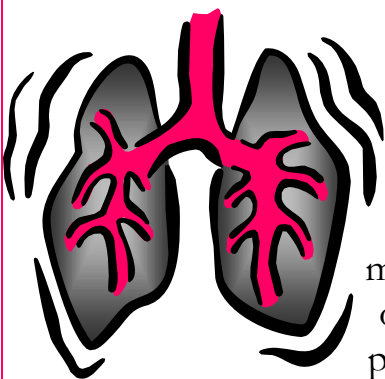


Artificial nutrition and hydration:

Artificial nutrition and hydration (or tube feeding) supplements or replaces ordinary eating and drinking by giving a chemically balanced mix of nutrients and fluids through a tube placed directly into the stomach, the upper intestine or a vein. Artificial nutrition and hydration can save lives when used until the body heals. Long-term artificial nutrition and hydration may be given to people with serious intestinal disorders that impair their ability to digest food, thereby helping them to enjoy a quality of life that is important to them. Some health care facilities and physicians may not agree with stopping or withdrawing tube feeding. Therefore, explore this issue with your loved ones and physician and clearly state your wishes about artificial nutrition and hydration in your advance directive.

Cardiopulmonary resuscitation:

Cardiopulmonary resuscitation (**CPR**) is a group of treatments used when someone's heart and/or breathing stops. CPR is an attempt to restart the heart and breathing. It may consist only of mouth-to-mouth breathing or it can include pressing on the chest to mimic the heart's beating and cause blood to circulate. Electric shock and drugs can also be used to encourage the heart to beat. When used quickly in response to a sudden event like a heart attack or drowning, CPR can be life saving. However, the success rate is low for patients at the end of a terminal illness. If you do not wish to receive CPR under certain circumstances, clearly state your wishes about CPR in your advanced directives.



Mechanical ventilation:

Mechanical ventilation is used to support or replace the function of the lungs. A machine called a ventilator (or respirator) forces air into the lungs. The ventilator is attached to a tube inserted in the nose or mouth and down into the windpipe (or trachea). Mechanical ventilation often is used to assist a person through a short-term problem or for prolonged periods in which irreversible respiratory failure exists due to injuries to the upper spinal cord or a progressive neurological disease. Some people on long-term mechanical ventilation are able to enjoy themselves and live a quality of life that is important to them. For the dying patient, however, mechanical ventilation often merely prolongs the dying process until some other body system fails. It may supply oxygen, but it cannot improve the underlying condition. When discussing end-of-life wishes, make clear to loved ones and your physician whether you would want mechanical ventilation if you would never regain the ability to breathe on your own or return to a quality of life acceptable to you.

INSTRUCTIONS

NEBRASKA POWER OF ATTORNEY FOR HEALTH CARE

**PRINT THE
NAME,
ADDRESS, AND
TELEPHONE
NUMBER OF
YOUR
ATTORNEY IN
FACT**

I appoint _____,
whose address is _____,
and whose telephone number is _____,
as my attorney in fact for health care.

**PRINT THE
NAME,
ADDRESS AND
TELEPHONE
NUMBER OF
YOUR
ALTERNATE
ATTORNEY IN
FACT**

I appoint _____,
whose address is _____,
and whose telephone number is _____,
as my successor attorney in fact for health care.

**ADD GENERAL
INSTRUCTIONS
(IF ANY)**

I authorize my attorney in fact appointed by this document to make health care decisions for me when I am determined to be incapable of making my own health care decisions. I have read the warning, which accompanies this document, and understand the consequences of executing a power of attorney for health care. I direct that my attorney in fact comply with the following instructions or limitations: *(optional)*

**STATE YOUR
DIRECTIONS
FOR THE USE
OF LIFE
SUSTAINING
TREATMENT
(IF ANY)**

I direct that my attorney in fact comply with the following instructions on life-sustaining treatment: *(optional)*

I direct that my attorney in fact comply with the following instructions on artificially administered nutrition and hydration: *(optional)*

STATE YOUR DIRECTIONS FOR THE USE OF ARTIFICIAL NUTRITION AND HYDRATION (IF ANY)

I HAVE READ THIS POWER OF ATTORNEY FOR HEALTH CARE. I UNDERSTAND THAT IT ALLOWS ANOTHER PERSON TO MAKE LIFE AND DEATH DECISIONS FOR ME IF I AM INCAPABLE OF MAKING SUCH DECISIONS. I ALSO UNDERSTAND THAT I CAN REVOKE THIS POWER OF ATTORNEY FOR HEALTH CARE AT ANY TIME BY NOTIFYING MY ATTORNEY IN FACT, MY PHYSICIAN, OR THE FACILITY IN WHICH I AM A PATIENT OR RESIDENT. I ALSO UNDERSTAND THAT I CAN REQUIRE IN THIS POWER OF ATTORNEY FOR HEALTH CARE THAT THE FACT OF MY INCAPACITY IN THE FUTURE BE CONFIRMED BY A SECOND PHYSICIAN.

SIGN AND DATE YOUR DOCUMENT

(signature of person making designation)

(date)

DECLARATION OF WITNESSES

WITNESSING PROCEDURE

We declare that the principal is personally known to us, that the principal signed or acknowledged his or her signature on this power of attorney for health care in our presence, that the principal appears to be of sound mind and not under duress or undue influence, and that neither of us nor the principal's attending physician is the person appointed as attorney in fact by this document.

YOUR WITNESSES MUST PRINT THEIR NAMES AND SIGN AND DATE YOUR DOCUMENT
WITNESS #1

Witnessed by:

(signature of witness #1)

(date)

(printed name of witness)

WITNESS #2

(signature of witness #2)

(date)

(printed name of witness)

OR

NOTARY

**A NOTARY
PUBLIC
SHOULD
COMPLETE
THIS
SECTION OF
YOUR
DOCUMENT**

The state of Nebraska)
) ss.
The County of _____)

On this _____ day of _____ 20_____, before
me, _____, a notary
public in and for _____ County,
personally came _____,
personally to me known to be the identical person whose name is affixed to
the above power of attorney for health care as principal, and I declare that
he or she appears in sound mind and not under duress or undue influence,
that he or she acknowledges the execution of the same to be his or her
voluntary act and deed, and that I am not the attorney in fact or successor
attorney in fact designated by this power of attorney for health care.

Witness my hand and notarial seal at _____
in such county the day and year last above written.

(SEAL)

(signature of notary public)

INSTRUCTIONS

NEBRASKA DECLARATION

If I should lapse into a persistent vegetative state or have an incurable and irreversible condition that, without the administration of life-sustaining treatment, will, in the opinion of my attending physician, cause my death within a relatively short time and I am no longer able to make decisions regarding my medical treatment, I direct my attending physician, pursuant to the Rights of the Terminally Ill Act, to withhold or withdraw life-sustaining treatment that is not necessary for my comfort or to alleviate pain.

Other directions:

**ADD PERSONAL
INSTRUCTIONS
(IF ANY)**

**SIGN AND
DATE
YOUR
DOCUMENT
PRINT YOUR
ADDRESS
TURN TO THE
NEXT PAGE
TO
HAVE YOUR
DOCUMENT
WITNESSED**

Signed this _____ day of _____

Signature _____

Address _____

