As part of The Community-Wide End of Life/Palliative Care Initiative, we are pleased to produce this updated Advance Care Planning Booklet.

This initiative of the Rochester Health Care Forum, co-sponsored by Excellus Health Plan, Inc. and the Rochester Health Commission, involves more than 150 community volunteers. It is co-led by Dr. Patricia Bomba, Corporate Medical Director, Geriatrics, Excellus BlueCross BlueShield, Mary Jane Milano, Director, Forum Initiatives, Rochester Health Commission, Rochester, NY and Jeanne Chirico, Director of Family Life Services and the CompassionNet program, Genesee Region Home Care.

For further information about this initiative, contact Dr. Patricia Bomba at (585) 238-4514 or Patricia.Bomba@lifethc.com or visit www.compassionandsupport.org.

For additional copies, contact your Excellus BlueCross BlueShield regional office or download from www.excellusbcbs.com or www.compassionandsupport.org.

March 2003
**Advance Care Planning: What is it?**

Advance Care Planning is a process of planning for future medical care in case you are unable to make your own decisions. It is a continual process and not merely a document or isolated event. Advance Care Planning assists you in preparing for a sudden unexpected illness from which you expect to recover, as well as the dying process and ultimately death.

**Advance Care Planning is a gift to you and your family. It is an important step in assuring that your wishes are honored if you are unable to speak for yourself.**

The Advance Care Planning process involves the following:

- Becoming educated about the topic
- Exploring, clarifying, and documenting your values, beliefs and goals
- Choosing a **Spokesperson** (the “Agent” identified in the “Health Care Proxy”) and an **Alternate** (the “Alternate Agent” identified in the “Health Care Proxy”) to work with doctors to make decisions on your behalf in case you are unable to speak for yourself
- Reviewing your wishes and expectations about death and dying with your Spokesperson (“Agent”), Alternate, and the people you trust and/or those whose decisions will impact the manner in which you die, e.g., family, spiritual advisor, doctors, lawyers
- Completing the New York Health Care Proxy and Living Will forms (also known as Advance Care Directives, or Directives) that identify your Spokesperson (“Agent”) and Alternate and specify your desires and wishes
- Reviewing and updating these forms periodically or after major life-altering events
- Conducting ongoing discussions and updates about your wishes and expectations about death with your Spokesperson (“Agent”), Alternate, those you trust and/or those who may care for you when you are approaching death

Advance Care Planning begins with conversations among families and other trusted individuals, such as friends, doctors, etc. The process builds trust and establishes relationships among family, close friends, health care professionals and others who will care for you or be with you as you approach death. **Advance Care Planning permits peace of mind for you and your family by reducing uncertainty and helping to avoid confusion and conflict over your care.**

**Remember:**

Directives apply **only** when the need arises and you are unable to speak for yourself.

Please visit us at: [www.compassionandsupport.org](http://www.compassionandsupport.org)

Portions of this booklet have been adapted with permission from materials originally published by Partnership for Caring, Inc., 1620 Eye Street, NW, Suite 202, Washington, DC 20006 1-800-989-9455

Excellus Health Plan, Inc., is responsible for the content.

© 2002 Excellus Health Plan, Inc.
How to Clarify Your Values and Beliefs

Many people have strong opinions about what would be important to them at the very end of their lives. Others want to make sure that certain things they dislike or fear will be avoided. Therefore, it is important for you to take some time to explore your own values and beliefs.

After investigating your values and beliefs, it is important that your Spokesperson (“Agent”) and Alternate, family, friends, spiritual advisor, physicians, and lawyer understand your specific values and beliefs. Below are some questions for you to think about and discuss with your Spokesperson (“Agent”) and Alternate in order to make sure that he/she understands you and can act on your behalf.

**Exploratory Questions/Your Feelings about End of Life Care**

*Instructions: For each row, check one answer to express how important these issues would be to you if you were dying.*

<table>
<thead>
<tr>
<th></th>
<th>Not Important</th>
<th>Moderately Important</th>
<th>Very Important</th>
<th>Extremely Important</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Avoiding pain/suffering, even if it means that I might not live as long</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b. Being alert, even if it means I might be in pain</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>c. Being around my family and close friends</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>d. Being able to feel someone touching me</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>e. Having religious or spiritual advisors at my side when I die</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>f. Being able to tell my life story and leave good memories for others</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>g. Reconciling differences and saying &quot;good-bye&quot; to my family and friends</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>h. Being at home when I die</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>i. Being in a hospital when I die</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>j. Being kept alive long enough for my family to get to my bedside to see me before I die, even if I'm unconscious</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

What are some of the things that you would hope for that could make your last weeks, days, or hours the most peaceful?

What are your biggest hopes about the end of your life?

What are your biggest fears about the end of life?

The information contained within this page is from the ©EPEC Project, The Robert Wood Johnson Foundation, 1999.
Choosing a Health Care Spokesperson

It is important to choose a Health Care Spokesperson (the “Agent” identified in the “Health Care Proxy”) because this person will assure that your wishes are carried out based on your previously expressed and discussed values and beliefs. In addition, you should also choose an Alternate (the “Alternate Agent” identified in the Health Care Proxy”) to substitute if your primary Spokesperson (“Agent”) is unable or unavailable.

You indicate your Spokesperson (“Agent”) and Alternate using a legal document called the New York Health Care Proxy form. This form identifies your Spokesperson (“Agent”) – the individual you have designated to make decisions about your medical care – including decisions about life support – if you can no longer speak for yourself.

What to Keep in Mind When Choosing a Spokesperson

This person must:

- Meet legal criteria (competent adult, at least 18 years old)
- Be willing to speak on your behalf
- Be willing to act on your wishes
- Be able to separate his/her own feelings from yours
- Live close by or be willing to come
- Know you well
- Understand what is important to you
- Be willing to talk with you now about sensitive wishes
- Be willing to listen to your wishes
- Be able to work with those providing your care to carry out your wishes
- Be available in the future
- Be able to handle potential conflicts between your family, friends
- Be able to handle responsibility

Questions for the Person That You Might Designate as Your Spokesperson

Your Spokesperson (“Agent”) may be required to speak for you in a variety of circumstances. These situations might include those in which your desires may not mesh with the opinions and beliefs of either your Spokesperson (“Agent”) or others concerned about your welfare. Below are questions to discuss with the individual(s) you may be considering choosing as your Spokesperson (“Agent”). Discussing these questions with a potential Spokesperson (“Agent”) beforehand will help you feel confident that the person chosen for this function is the best one to speak for you when you cannot do so.

1. Will you respect my wants and needs, even if they are different from what they used to be, or if you think they are unusual or foolish?
2. If I cannot communicate for myself, will you make sure that what I have asked for is done, even if you would make different choices yourself?
3. Will you talk with me openly and lovingly about any unfinished business between us and listen if I need to apologize or ask for forgiveness for anything that has hurt you in the past?
4. Will you talk with me about my coming death – my fears, my sorrows, my joys and gratitude?
5. Will you care for yourself so that you are not drained by my illness?
6. Will you stay with me even if the going gets rough?
7. Will you seek out information about my disease and what to expect as I get sicker and near the end of life?
Discussing Your Wishes with Your Doctor

Your doctor and the other health care professionals that are caring for you when you are seriously ill or dying may play an important part in helping to assure that your wishes and desires are understood and met. It is helpful to speak to your doctor and other key health care professionals ahead of time about what is important to you. At that time, ask them questions about the kind of support you think you may need and whether they think that they could provide this support to you.

You have a right to participate in the planning of your health care even if you lose the capacity to make decisions. An Advance Care Directive gives you the ability to exercise this right. Physicians have a legal, moral, and professional responsibility to assure this right is honored.

Below are the types of questions some individuals have asked their doctors and other health care professionals.

1. Will you acquaint yourself with the social norms of my culture and religion and respect these?
2. Will you talk openly with me and/or my family about my illness?
3. What will you do if I have a lot of pain or other uncomfortable symptoms?
4. Will you let me know if treatment stops working so that my family and I can make appropriate decisions?
5. Will you support me in having my pain properly managed and in getting hospice care?
6. What will you do to make sure that you always listen to me and/or my family?
7. If I reach a point where I am too sick to speak for myself, how will you make decisions about my care?
8. Will you still be available to me even when I'm sick and close to the end of my life?
**Information about Forms**

This booklet contains two types of **Advance Care Directives** that protect your right to request treatments **you want** and to refuse medical treatments **you do not want** in case you lose the ability to make decisions yourself:

1. The **New York Health Care Proxy** is a legal document that 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 Health Care Proxy form appoints someone to speak for you **any time you are unable to make your own medical decisions, not only at the end of life**.

2. The **New York Living Will** lets you state your wishes about medical care in the event that you develop an **irreversible** condition that prevents you from making your own medical decisions. The Living Will becomes effective if you become terminally ill, permanently unconscious or minimally conscious due to brain damage and will never regain the ability to make decisions. Persons who want to indicate under what set of circumstances they favor or object to receiving any specific treatments use the New York Living Will.

| You do not need to notarize your New York Health Care Proxy form or New York Living Will. You do not need a lawyer to fill out these forms. These documents will be legally binding only if the person completing them is a competent adult (at least 18 years old), the signing of the documents are properly witnessed, and the documents are available when needed. |

**Frequently Asked Questions**

1) **Do I need to complete both of these documents?**

Completing both documents helps to ensure that you receive the medical care you desire. However, you should continue to have ongoing discussions with your Spokesperson (“Agent”) to assure that that person knows your values and wishes and can speak on your behalf regardless of what your circumstances may be.

In addition, it is beneficial to have completed both documents in case you suffer an injury, or acute medical episode, while traveling and are unable to make decisions for yourself. Completing both documents increases the likelihood that at least one of the documents will be legally recognized in another state.

2) **How can I be sure that my New York Health Care Proxy will be honored?**

To be legally valid, you must sign and date your Health Care Proxy form in the presence of **two** adult witnesses. The witnesses must sign a statement in your Health Care Proxy to confirm that you signed the document willingly and free from duress. Your Spokesperson (“Agent”) and Alternate cannot act as witnesses.

3) **How do I make sure that my New York Living Will is going to be honored?**

Unlike most states, **New York does not have a specific law recognizing living wills** but relies upon **“clear and convincing evidence”** of your wishes. Documenting your wishes in a Living Will may help to show the required level of **“clear and convincing evidence.”** You should follow the witnessing procedures established in the Health Care Proxy Act and sign your Living Will in the presence of two adult witnesses. Indicate the presence of your Living Will under the Optional Instructions section of the New York Health Care Proxy form.

4) **Can I list more than one Alternate Agent?**

Yes, you may list as many as you would like. However, each Alternate must meet the criteria listed on page 3 (see “What to Keep in Mind When Choosing a Spokesperson”).

---

5
5) Do I need to add personal instructions to my New York Health Care Proxy?
You do not need to add personal instructions to your Health Care Proxy except regarding artificial nutrition and hydration. One of the strongest reasons for naming a Spokesperson (“Agent”) is to have someone who can respond flexibly to changes in your medical situation. Adding personal instructions to the New York Health Care Proxy may unintentionally restrict your Spokesperson’s (“Agent’s”) power to act in your best interest.

6) Can I add personal instructions to my Living Will?
Yes. Personal instructions may be added to the section titled “Other Directions.” If there are specific treatments you wish to refuse that are not already listed on the document, you may list them here. Also, instructions such as “I want maximal pain medications, even if it hastens my death,” “I do not want to be placed in a nursing home,” or “I want to die at home” can be added to this section. If you have appointed a Spokesperson (“Agent”), it is a good idea to include a statement such as, “Any questions about how to interpret or when to apply my Living Will are to be decided by my Spokesperson, my ‘Agent.’”

7) What are Life-Sustaining Treatments such as Cardiopulmonary Resuscitation (CPR), Mechanical Ventilation, and artificial nutrition and hydration?
See Appendix I of this booklet for a detailed explanation of life-sustaining treatments.

8) What if I change my mind about my New York Health Care Proxy or Living Will?
You may revoke your New York Health Care Proxy or Living Will by notifying your health care provider or Spokesperson (“Agent”) orally or in writing of your revocation, or by any other act that clearly shows your intent to revoke the document. Once informed, your physician must record the revocation in your medical record and notify your Spokesperson (“Agent”) and any medical staff responsible for your care. Additionally, an updated form voids any previous forms.

9) If I spend extended periods of time in another state, will my New York Advance Care Planning Forms be honored in that state?
Each state has its own laws governing Advance Care Planning and the use of Health Care Proxy forms, Living Wills and DNR Orders. Therefore, it is important that you investigate that state’s laws on Advance Care Planning. You may want to begin by checking out the state’s Department of Health Web site or going to www.partnershipforcaring.org.

10) Are there any restrictions on who can be my Spokesperson (“Agent”)?
Your Spokesperson (“Agent”) cannot be:
   a. An operator, administrator or employee of a health care facility in which you are a resident or patient, or to which you have applied for admission, at the time you sign your proxy, unless that person is a relative by blood, marriage or adoption;
   b. A physician, if that person also acts as your attending physician.

11) What do I do if I am a resident in a facility licensed or operated by the Office of Mental Health or the Office of Mental Retardation and Developmental Disabilities?
Special witnessing requirements exist for residents of facilities operated or licensed by the Office of Mental Health or the Office of Mental Retardation and Developmental Disabilities. For more information, contact Partnership for Caring, a non-profit organization dedicated to ensuring excellent end-of-life care, at www.partnershipforcaring.org, or call (800)-989-9455.
Practical Issues to Consider after Completing Your Documents

1. **Guarantee accessibility** to your New York Health Care Proxy and Living Will. Keep a copy for yourself in a secure but accessible place. Do not put the documents in a safe deposit box or any other security box that would keep others from having access to them.

2. **Give a copy** to your Health Care Spokesperson (“Agent”) and Alternate. Your primary care physician, all specialist physicians that participate in your care and the primary hospital where you receive care should also have copies. You may also wish to give a copy to your spiritual advisor. A copy should be shared with the central community repository, if one exists. If you enter a nursing home or hospital, have photocopies of your documents placed in your medical records.

3. **Review and update your forms** periodically. Review after major life events like divorce, birth of a child, death of a spouse, as you may wish or need to choose a new Spokesperson (“Agent”). It is also important to reevaluate your wishes if new life-threatening or chronic illnesses develop, as these chronic illnesses progress, and after complicated life-sustaining treatments. Your wishes and desires may change after these events.

4. **Problems may arise** if you fail to plan or fail to share your wishes with your Health Care Spokesperson (“Agent”), your family or your doctor. Problems may arise if your goals for care or treatment change but these wishes are not reflected in your documented forms. At times, an individual’s preferences may be unclear or the focus may be too narrow. As a Spokesperson (“Agent”), it is important to avoid making assumptions and to clarify wishes ahead of time.

5. **Be sure to talk** to your Health Care Spokesperson (“Agent”), Alternate(s), doctor(s), spiritual advisor, family and friends about your wishes concerning medical treatment. Discuss your wishes with them often, particularly if your medical condition changes.

6. **If your wishes change** after your documents have been completed, an entirely new set of documents reflecting your new wishes must be written, signed, and witnessed.

7. **It is important to keep in mind that you can always revoke your New York Health Care Proxy and/or New York Living Will documents at any time.**

8. **Be aware that your New York documents will not be effective in the event of a medical emergency.** Ambulance personnel are required to provide cardiopulmonary resuscitation (CPR) unless they are given a separate order that is called a "Nonhospital DNR Order." Please see Appendix II of this booklet or visit www.health.state.ny for further information about the Nonhospital Order Not to Resuscitate (DNR Order) form.
Checklist for Action

Using the simple checklist provided below will ensure that you do not miss a step while creating a comprehensive Advance Care Plan.

☐ I have thought about what is important to me and shared that with my family

☐ I have chosen my Spokesperson ("Agent") and Alternate

➤ I have discussed my wishes with my:
  ☐ Spokesperson ("Agent")
  ☐ Alternate
  ☐ Family
  ☐ Doctors
  ☐ Spiritual Advisor
  ☐ Attorney

☐ I have discussed my wishes regarding artificial nutrition and hydration with my Spokesperson ("Agent") and Alternate

☐ I have completed my New York Health Care Proxy form

☐ I have documented on my Health Care Proxy form that my Spokesperson ("Agent") knows my wishes regarding artificial nutrition and hydration

☐ I have documented my wishes about Organ Donation on my Health Care Proxy, New York State Driver’s License (or other New York State issued identification), and/or official Organ Donor Card.

☐ I have completed my New York Living Will

➤ I have given copies of both my New York Health Care Proxy and Living Will to my:
  ☐ Spokesperson ("Agent")
  ☐ Alternate
  ☐ Family members
  ☐ Doctors
  ☐ Hospital
  ☐ Attorney

☐ I have filled out the wallet card enclosed in this booklet according to the directions, and I carry the wallet card with my state-issued identification and insurance card

☐ I have reviewed and updated my forms as needed
NEW YORK HEALTH CARE PROXY
---------------------------------------

(1) I, ___________________________________________, hereby appoint:

(name)

_______________________________________________________________

(name, home address and telephone number of agent)

_________________________________________________________________

as my health care agent to make any and all health care decisions for me, except to the extent that I state otherwise. My agent does know my wishes regarding artificial nutrition and hydration.

This Health Care Proxy shall take effect in the event I become unable to make my own health care decisions.

(2) Optional instructions: I direct my agent to make health care decisions in accord with my wishes and limitations as stated below, or as he or she otherwise knows.

_________________________________________________________________

(3) Name of substitute or fill-in agent if the person I appoint above is unable, unwilling or unavailable to act as my health care agent.

_________________________________________________________________

(name, home address and telephone number of alternate agent)

_________________________________________________________________

(4) Donation of Organs at Death:

[ ] I do not wish to donate my organs, tissues or parts.
[ ] I do wish to be an organ donor and upon my death I wish to donate:

(Continued)
[ ] (a) Any needed organs, tissues, or parts; **OR**

[ ] (b) The following organs, tissues, or parts

[ ] (c) My gift is for the following purposes:
   (put a line through any of the following you do not want)
   (i) Transplant
   (ii) Therapy
   (iii) Research
   (iv) Education

(5) Unless I revoke it, this proxy shall remain in effect indefinitely, or until the date or condition I have stated below. This proxy shall expire
   (specific date or conditions, if desired):

(6) Signature _________________________________  Date _______________

Address   ______________________________________________________

**Statement by Witnesses** (must be 18 or older)

I declare that the person who signed this document appeared to execute the proxy willingly and free from duress. He or she signed (or asked another to sign for him or her) this document in my presence. I am not the person appointed as proxy by this document

Witness 1  ______________________________________________________

Address________________________________________________________

Witness 2  ______________________________________________________

Address   _______________________________________________________
NEW YORK LIVING WILL

This Living Will has been prepared to conform to the law in the State of New York, as set forth in the case In re Westchester County Medical Center, 72 N.Y.2d 517 (1988). In that case the Court established the need for “clear and convincing” evidence of a patient’s wishes and stated that “the ‘ideal situation is one in which the patient’s wishes were expressed in some form of writing, perhaps a ‘living will.’”

I, ________________________________________________________, being of sound mind, make this statement as a directive to be followed if I become permanently unable to participate in decisions regarding my medical care. These instructions reflect my firm and settled commitment to decline medical treatment under the circumstances indicated below:

I direct my attending physician to withhold or withdraw treatment that merely prolongs my dying, if I should be in an incurable or irreversible mental or physical condition with no reasonable expectation of recovery, including but not limited to: (a) a terminal condition; (b) a permanently unconscious condition; or (c) a minimally conscious condition in which I am permanently unable to make decisions or express my wishes.

I direct that my treatment be limited to measures to keep me comfortable and to relieve pain, including any pain that might occur by withholding or withdrawing treatment.

While I understand that I am not legally required to be specific about future treatments if I am in the condition(s) described above I feel especially strongly about the following forms of treatment:

I do not want cardiac resuscitation.
I do not want mechanical respiration.
I do not want artificial nutrition and hydration.
I do not want antibiotics.

However, I do want maximum pain relief, even if it may hasten my death.
Other directions:

These directions express my legal right to refuse treatment, under the law of New York. I intend my instructions to be carried out, unless I have rescinded them in a new writing or by clearly indicating that I have changed my mind.

Signed ______________________________________ Date ____________

Address  ______________________________________________________

I declare that the person who signed this document appeared to execute the living will willingly and free from duress. He or she signed (or asked another to sign for him or her) this document in my presence.

Witness 1 _____________________________________________________

Address  ______________________________________________________

Witness 2 _____________________________________________________

Address  ______________________________________________________
APPENDIX I

Life Sustaining orLife Support Treatments

Note: In New York State, it is essential for your Spokesperson (“Agent”) to know your wishes about artificial hydration and nutrition. Documentation of these wishes is vital.

According to New York State Law, if you fail to include your wishes on artificial hydration and nutrition, your Spokesperson (“Agent”) cannot make these decisions.

The statement “My agent does know my wishes regarding artificial hydration and nutrition” as noted in the New York Health Care Proxy form included in this booklet is sufficient to allow your Spokesperson (“Agent”) to make these decisions.

Life support replaces or supports ailing bodily function. When patients have curable or treatable conditions, life support is used temporarily until the illness or disease can be stabilized and the body can resume normal functioning. At times, the body never regains the ability to function without life support.

When making decisions about specific forms of life support, gather the facts you need to make informed decisions. In particular, understand the benefit as well as the burdens that the treatment will offer you or your loved one. A treatment may be beneficial if it relieves suffering, restores functioning, or enhances the quality of life. The same treatment can be considered burdensome if it causes pain, prolongs the dying process without offering benefit, or detracts from a person’s quality of life. When gathering information about specific treatments, understand why the treatment is being offered and how it will benefit your care.

Given the rapid advances in medicine and technology, it is difficult to know all of the possible treatment choices in advance. This is why taking the time to clarify values, beliefs, and personal goals of medical care is so important.

When making decisions about life support, it is important to consider the following questions:

- Will the treatment make a difference?
- Do the burdens of treatment outweigh the benefits?
- Is there hope for recovery? If so, what will life be like afterward?
- What do I value?

Difficulty in decision-making arises when recovery cannot be predicted. In this case, a short-term trial of life support may be desired. These trials must begin with clarifying the patient’s goals of care and require active discussions between your doctor and your Spokesperson (“Agent”) about the most appropriate course of treatment.
Commonly used life-support measures include:

- **Artificial nutrition and hydration**: Artificial nutrition ("tube-feeding") and hydration (fluid replacement) 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. Long-term use of tube feeding is frequently given to people with irreversible and end-stage conditions. Often, the treatment will not reverse the course of the disease itself or improve the quality of life.

- **Cardiopulmonary resuscitation**: Cardiopulmonary resuscitation (CPR) is a group of treatments used when someone’s heart and/or breathing cease. CPR attempts to restart the heart and breathing. It may consist of mouth-to-mouth breathing, pressing on the chest to circulate the blood, electric shock and/or drugs to stimulate the heart. When used quickly in response to a sudden event like a heart attack or drowning, CPR can be life saving. The success rate, however, is extremely low for people who are at the end of a terminal disease process. Critically ill patients who receive CPR have a small chance of recovering.

- **Mechanical ventilation**: Mechanical ventilation is used to support or replace the function of the lungs. A ventilator (or respirator), a machine that is attached to a tube inserted through the nose or mouth and into the windpipe, forces air into the lungs. Mechanical ventilation is often used to assist a person through a short-term problem or for prolonged periods in which irreversible respiratory failure exists. Some people on long-term mechanical ventilation are able to enjoy themselves and live a quality of life that is important for 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.

The distinction often is made between not starting treatment and stopping treatment. **However, no legal or ethical difference exists between withholding and withdrawing a medical treatment in accordance with a patient’s wishes.** If such a distinction existed in the clinical setting, a patient might refuse treatment that could be beneficial out of fear that once started it could not be stopped.

| It is legally and ethically appropriate to discontinue medical treatments that are no longer beneficial. It is the underlying disease, not the act of withdrawing treatment, which causes death. |

The booklet “Hard Choices” is an excellent reference and can be found at www.hardchoices.com. A Spanish version of this booklet is also available.
APPENDIX II

About the Do Not Resuscitate (DNR) Order*

The Do Not Resuscitate Order documents that you do not want to have cardiopulmonary resuscitation (CPR) efforts started if your heart and/or breathing stops.

What is CPR?
CPR, cardiopulmonary resuscitation, refers to the medical procedures used to restart a patient’s heart and/or breathing after the patient’s heart and/or breathing have stopped.

What is a DNR Order?
A DNR order is an order written by a physician at the request of the patient or his/her family that instructs medical professionals not to perform CPR. This means doctors, nurses, and/or emergency medical personnel will not attempt emergency CPR if the individual’s breathing or heartbeat stops.

A DNR Order requires the signature of a physician to be legally valid.

In New York State, to ensure that your wishes are honored at home or any place outside of a hospital, a completed, signed, and dated “Nonhospital Order Not to Resuscitate (DNR Order) Form” is required.

This Nonhospital DNR Order must be visible and available in the event of an emergency. It is often kept near the phone, along with other emergency information.

Why are DNR orders issued?
CPR, when successful, restores heartbeat and breathing and allows patients to resume their previous lifestyle. The success of CPR depends on the patient’s overall medical condition. Age alone does not determine whether CPR will be successful, although illnesses and frailties that go along with age often make CPR less successful.

When people are seriously ill or terminally ill, CPR may not work or may only partially work, leaving the individual brain-damaged or in a worse medical state than before the heart stopped. In these cases, some patients prefer to be cared for without efforts at resuscitation.

Can I request a DNR order?
Yes. All adult patients can request a DNR order. If you are sick and unable to tell your doctor that you want a DNR order written, your spokesperson, a family member or close friend can decide for you.

Is my right to request or receive other treatments affected by a DNR order?
No. A DNR order is only a decision about CPR and does not relate to any other treatment.
Nonhospital Order Not to Resuscitate (DNR Order)

How can I make my wishes about a Nonhospital DNR Order known?
An adult may consent to a Nonhospital DNR order by informing a physician orally or in writing, such as a Living Will, if two witnesses are present.

Before deciding about CPR, you should speak with your doctor about your overall health and the benefits and burdens of CPR. A full and early discussion between you and your doctor will assure that your wishes will be known.

If I request a DNR Order, must my doctor honor my wishes?
If you do not want CPR and request a DNR order, your doctor must follow your wishes or:
- transfer your care to another doctor who will follow your wishes; or
- begin a process to settle the dispute if you are in a hospital or nursing home.

If the dispute is not resolved within 72 hours, your doctor must enter the order or transfer you to the care of another doctor.

If I am at home with a Nonhospital DNR order, what happens if a family member or friend panics and calls an ambulance to resuscitate me?
If you have a Nonhospital DNR order and family members show it to emergency personnel, they will not attempt to resuscitate you or transport you to a hospital emergency room for CPR.

What happens to my DNR order if I am transferred from a hospital or nursing home to home care?
The order issued for you in a hospital or nursing home will not apply at home. You, your Health Care Spokesperson ("Agent") or a family member must specifically consent to a Nonhospital DNR order. If you leave a hospital or nursing home without a Nonhospital DNR order, a doctor can issue the DNR order for you while you are at home.

What happens if I change my mind after a DNR order has been written?
You or anyone who consents to a DNR order for you can remove the order by telling your doctor, nurses, or others of the decision.

Who decides on a DNR Order for a child?
A DNR order can be written for a child with the consent of the child's parent or guardian. If the child is old enough to understand and decide about CPR, the child's consent is also required for a DNR order.

For more information regarding DNR Orders in New York State, please visit www.health.state.ny.us

© 2002 Excellus Health Plan, Inc.
State of New York
Department of Health
Nonhospital Order Not to Resuscitate
(DNR Order)

Person's Name:__________________________________________________

Date of Birth: _____/_____/_____

Do not resuscitate the person named above.

Physician's Signature _______________________________

Print Name _______________________________________

License Number ___________________________________

Date _____/_____/_____  

It is the responsibility of the physician to determine, at least every 90 days, whether this order continues to be appropriate, and to indicate this by a note in the person's medical chart.

The issuance of a new form is NOT required, and under the law this order should be considered valid unless it is known that it has been revoked. This order remains valid and must be followed, even if it has not been reviewed within the 90-day period.
Instructions for Wallet Card:

In case of emergency, this wallet card alerts medical personnel to the presence of a Health Care Proxy and directs them to your Spokesperson (Agent).

To be most effective, the wallet card should be carried on you along with your state-issued identification and insurance card.

To use this Wallet Card:

1. Simply remove the card by tearing along the perforations and fold.
2. Fill out the card so that the card includes the identical information contained within your New York Health Care Proxy form.
3. Follow the same witnessing procedures as the New York Health Care Proxy form by having the card properly witnessed by two individuals.
4. Carry this wallet card along with your state issued identification and insurance card.
5. Enjoy the peace of mind knowing that your Spokesperson (Agent) can be contacted and your wishes discussed even if something happens to you while you are not near any copies of your completed New York Health Care Proxy form.
Advance Care Planning

For Me, For You

How to maintain control, achieve peace of mind, and assure your wishes are honored

Advance Care Planning

Compassion and Support
at the End of Life

As part of The Community-Wide End of Life/Palliative Care Initiative, we are pleased to produce this updated Advance Care Planning Booklet.

This initiative of the Rochester Health Care Forum, co-sponsored by Excellus Health Plan, Inc. and the Rochester Health Commission, involves more than 150 community volunteers.

It is co-led by Dr. Patricia Bomba, Corporate Medical Director, Geriatrics, Excellus BlueCross BlueShield, Mary Jane Milano, Director, Forum Initiatives, Rochester Health Commission, Rochester, NY and Jeanne Chirico, Director of Family Life Services and the CompassionNet program, Genesee Region Home Care.

For further information about this initiative, contact Dr. Patricia Bomba at (585) 238-4514 or Patricia.Bomba@lifethc.com
or visit www.compassionandsupport.org.

For additional copies, contact your Excellus BlueCross BlueShield regional office or download from www.excellusbcbs.com or www.compassionandsupport.org.

March 2003