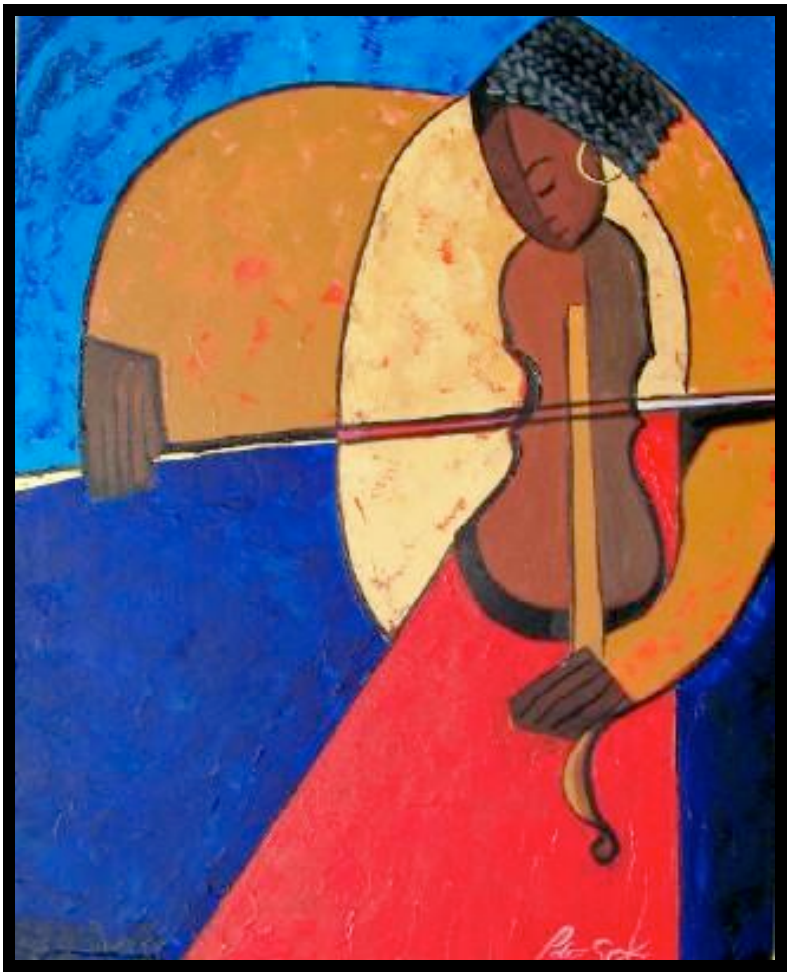
PALLIATIVE CARE IN NEW YORK STATE



Collaborative for Palliative Care

In collaboration with its partners

End of Life Choices New York

Finger Lakes Geriatric Center at the University of Rochester

PALLIATIVE CARE IN NEW YORK STATE

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PALLIATIVE CARE IN NEW YORK STATE

INTRODUCTION

The COLLABORATIVE FOR PALLIATIVE CARE, END OF LIFE CHOICES NEW YORK and FINGER LAKES GERIATRIC EDUCATION CENTER AT THE UNIVERSITY OF ROCHESTER are pleased to share this important information with you and your loved ones about palliative and end-of-life care and advance care planning. This information is based upon New York State law and Department of Health guidance.

In New York State, individuals and patients with chronic or serious illness have many rights to ensure that their health care wishes are honored and that they get the care and treatment that they want, and do not get unwanted care and treatment. Some of these rights, including those granted to us in laws governing palliative care, are described below as answers to questions.

GENERAL HEALTH CARE RIGHTS

What rights do I have as a patient?

There are numerous rights patients have. Among the rights concerning the provision of health care are the rights to:

- Receive emergency treatment;
- Receive complete information about your diagnosis, treatment and prognosis;
- Receive all the information you need to give informed consent for any procedure or treatment; this information shall include the possible risks and benefits of the procedure or treatment;
- Refuse or stop treatment at any time and be told what effect this may have on your health;
- Receive all the information you need to give informed consent to an order not to be resuscitated under very specific circumstances; and
- Designate an individual called a health care agent to give consent if you are too ill to do so.

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PALLIATIVE CARE

What is palliative care?

Most people have never been told what palliative care is, but it is very important to know about.

A definition of palliative care adopted by the Center to Advance Palliative Care (www.capc.org) is as follows:

- Palliative care is specialized medical care for people with serious chronic or acute life-threatening illnesses. This type of care is focused on providing patients with relief from the symptoms, including the pain and stress of a serious illness, assisting with medical decisions and establishing goals of care – whatever the diagnosis and regardless of prognosis
- The goal of palliative care is to improve quality of life for the patient, and family and caregivers. Palliative care is provided by doctors, nurse practitioners, nurses, social workers and other specialists who work with a patient's other doctors to provide an extra layer of support.
- Palliative care is appropriate at any age and at any stage in a serious illness, and can be provided together with curative treatment.

What are the three main pillars of palliative care?

Palliative care has three main areas of focus, as follows:

- Advance care planning;
- Improved care coordination and communication; and
- Improved pain and other symptom management.

Are there differences between palliative care and hospice?

Yes, palliative care is appropriately offered at any time during a serious illness. It is not limited to end-of-life care.

One difference between palliative care and hospice care is that hospice care is a formal system of care specific to end of life care and is provided by certified hospice agencies. Palliative care is delivered throughout the course of an illness along with curative or life-prolonging care regardless of prognosis. Palliative care is therefore provided by many different types of providers in various settings

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including: hospitals, nursing homes, home health agencies, and concludes with hospice care when life expectancy is limited.

When should I be offered palliative care?

When you are told that you have a chronic or serious illness that may be long term and debilitating or you are diagnosed with an illness which might be life threatening, you should be offered palliative care. Examples of serious illnesses include heart disease, congestive heart failure, cancer, diabetes, kidney failure, respiratory disease such as COPD, HIV/AIDS, Alzheimer's disease, Parkinson's disease, amyotrophic lateral sclerosis (ALS) and multiple sclerosis (MS). Individuals may and often do have more than one of these illnesses. In this way, palliative care can be in the form of information and counseling provided by your primary attending health care practitioner, or from a specialist including a specialist in palliative care.

There are many symptoms that people have during the course of a serious illness that might indicate a need for palliative care whether or not it has yet been offered These include pain, shortness of breath, diarrhea, nausea, loss of appetite, depression, anxiety, constipation, fatigue, or difficulty sleeping. Patients may also have emotional distress or spiritual issues their medical providers have not addressed.

Is palliative care something that I should ask for if I or a loved one were to have a serious illness and it was not offered?

Yes. You should not hesitate to ask for palliative care. Because palliative care is a relatively new field of medicine, it is sometimes not offered to many patients who might benefit from it.

New York State has passed laws which provide that all patients with a life-limiting illness be offered both information on palliative care as well as access to palliative care services as needed to control symptoms associated with their illness or its treatments

Will palliative care help me?

Palliative care, early in a disease course, has been demonstrated to be effective in improving the quality of life of patients. This is achieved by focusing on prevention and relief of suffering through detailed management of pain and other problems – physical, emotional or spiritual. In some cases, palliative care has been

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shown to extend life, reduce hospital stays, reduce visits to the emergency room, and improve patient and family satisfaction.

How does palliative care work with my own doctor?

The palliative care team, which includes doctors, nurses, social workers and other health professionals, as stated above, should also include access to and / or information on the role of chaplains, massage and other holistic therapists, pharmacists, nutritionists, who will work with your own doctor to provide more support for you and your family.

Who pays for palliative care?

Palliative care is covered by Medicare and Medicaid and commercial insurance plans similar to how your cardiologist, pulmonologist or other specialist is reimbursed. Access to a social worker or financial consultant through your palliative care provider should help you to understand your benefit coverage.

If you qualify for hospice care, the Medicare Hospice Benefit covers nursing care, durable medical equipment, some home health aide services, social work visits, pastoral care and other supportive services for you and your family. The Medicare Hospice Benefit also provides bereavement support for 18 months after their usual services have ended.

Will treatments prolong my life?

Some medical treatments aim to cure or cause reemission of disease, and prolong life. Palliative care interventions are not intended to hasten death nor prolong life, but aim to support quality of life and to relieve pain, suffering, and other distressing symptoms of illness or its treatments. In some instances, palliative care when provided at the same time as disease-modifying treatment may actually prolong life.

You will want to know whether the treatment you are considering is intended to prolong life, treat symptoms or both. Then based on your own needs, values and goals, you can decide if that is a treatment you want to pursue. Palliative care providers focus on helping you access the best information and evidence about treatment options so that you can make the best possible decisions based on your quality of life. Even if you were to decide to stop a particular treatment, the care you receive from the palliative care team never ceases.

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What are the chances that a particular treatment will be effective?

Some disease specific treatments are standard and very effective. If standard treatments have lost their effectiveness or have not worked at all, your doctor may suggest a clinical trial. Regardless of whether treatment is standard or as part of a clinical trial, knowing the risks and benefits are important.

Risks and benefits are weighed in forming decisions about the worth of treatment associated with its expected or unexpected side effects and burdens. Only the patient (and the patient's family, caregivers, health care agents or surrogates in appropriate circumstances) can say if the likely benefits outweigh the burdens and risks, but you must make sure that your doctor and medical team share with you their knowledge and understanding, and the best evidence available so that you can make an informed decision about a particular treatment.

PALLIATIVE CARE ACCESS ACT

Is there a law that enables me to get information and counseling about and receive palliative care?

Yes, the Palliative Care Access Act, Public Health Law Section 2997-d (effective 2011; See link to NYS Department of Health web site at end of booklet). If you are a patient in a hospital, nursing home, home care or a special needs or enhanced assisted living residence, and you have an advanced life limiting illness or condition, you have the right to receive information and counseling regarding palliative care, including associated pain management and access to appropriate palliative care consultations and services, including pain management consultations and services.

How is palliative care defined under this law?

'"Palliative care" means health care treatment including interdisciplinary end-of-life care, and consultation with patients and family members, to prevent or relieve pain and suffering and to enhance the patient's quality of life, including hospice..."

What is an advanced life-limiting illness or condition?

It is generally a medical condition that causes significant functional and quality of life impairment, that is not likely to be reversed by curative therapies and that is likely to progress over time to dying.

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When is palliative care offered?

According to the New York State Department of Health, "A palliative care assessment should be conducted on admission, when the patient's/resident's condition changes, and upon discharge. Palliative care should be offered based on assessment as appropriate."

What if I or my loved one who is a patient does not have the capacity to make medical decisions?

In such a situation a person legally authorized to make medical decisions such as your appointed health care agent, or if you have not appointed a health care agent, a surrogate selected from a priority list shall be provided with the information and counseling.

PALLIATIVE CARE INFORMATION ACT

Is there a law that enables me to receive information and counseling about palliative care if I am terminally ill?

Yes, the Palliative Care Information Act, Public Health Law Section 2997-c (effective 2011; See link to NYS Department of Health web site at end of booklet). It requires that attending health care practitioners, i.e., a physician or nurse practitioner, offer patients who have been determined to be terminally ill and are reasonably expected to die within six months, information and counseling appropriate to the patient regarding palliative and end-of-life options, or about any other appropriate treatments. However, earlier introduction of palliative care is often appropriate both to improve quality of life and to enable you to prepare for and make decisions about your treatment as your disease or illness progresses. Therefore, if you are seriously ill, you should ask your attending health care practitioner for this information.

How is palliative care defined under this law?

It is defined the same way as under the Palliative Care Access Act. '"Palliative care" means health care treatment including interdisciplinary end-of-life care, and consultation with patients and family members, to prevent or relieve pain and suffering and to enhance the patient's quality of life, including hospice..."

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QUESTIONS AND ANSWERS APPLICABLE TO BOTH THE PALLIATIVE CARE ACCESS ACT AND PALLIATIVE CARE INFORMATION ACT

What must be included in the information and counseling?

You have the right to receive information and counseling including but not limited to: the range of options appropriate to you, the prognosis, risk and benefits of the various options, and your legal right to comprehensive pain and symptom management.

How should I as a patient interact with my health care practitioner?

Your health care practitioner should be sensitive both to your medical condition and your emotional and spiritual needs, and to your ability to understand the information and counseling provided. There should be ongoing discussions so that you may give careful consideration to your options. There should be sensitivity to cultural and religious considerations. You should not hesitate to ask questions, raise concerns, and to let the health care practitioner know if there are things you do not understand so that they may be repeated or explained differently. You should ask, if you have a concern, that the health care practitioner be completely honest with you. You should ask if you are not told of the risks and benefits of any options offered to you.

Who should or may be present when the information and counseling are given to me?

You should be able to decide who you may wish, if any person other than yourself, to be present when the information and counseling are provided. If you are not asked, you should tell the health care practitioner who if anyone you want to be present. If you decide to receive the information and counseling alone, you can later ask to have another person or persons participate at subsequent counseling.

What if my loved ones or I do not want the information and counseling?

You have a right to refuse to accept the information and counseling but if you do decline it, you may be treated in a way that is not consistent with your goals of care and health care wishes. Even if you do refuse the information and counseling when first offered, it is appropriate for the attending health care practitioner to ask you again at a later stage of your illness. At any time, if you change your mind, you may ask for the information and counseling.

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If I have received information and counseling once is that enough?

When you are at a different stage of your illness, different information and counseling and different options may be appropriate. So you should be offered information and counseling at different times as your condition changes and your illness progresses in order to make informed decisions consistent with your goals of care as your illness progresses.

What if my loved one, who is a patient, does not have the capacity to reasonably understand and make informed choices relating to palliative care?

In such a situation, a person who has legal authority to make health care decisions for the patient, including a health care agent (proxy) or surrogate, shall be provided with the information and counseling.

May the attending health care practitioner arrange to have the information and counseling provided by another qualified health care professional?

Yes, and that person might be another physician, nurse practitioner or social worker.

What if the attending health care practitioner is not willing to provide the information or counseling?

The attending health care practitioner must arrange for another physician or nurse practitioner to do so or transfer the patient to another physician or nurse practitioner willing to do so.

What are appropriate palliative care and end-of-life options?

Depending on your circumstances including your medical diagnosis, prognosis and symptoms, your doctor should be able to help you understand your circumstances. Usually palliative care and end-of-life care includes pain management, treatment to control various symptoms such as described above, and hospice care.

A palliative care plan might be developed to address pain and other symptoms, spiritual issues, family disruption and caregiver stress, psychiatric or psychological concerns, coordination of care among health care professionals, advance care planning to ensure your goals of care are honored, and communication issues with health care professionals or family members.

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- Information and counseling may and usually should cover your right to receive or reject any treatments offered at any time including the withholding or withdrawal of life-sustaining treatments such as artificial nutrition and hydration, cardio-pulmonary resuscitation (CPR), electroshock, artificial/mechanical ventilation, dialysis, and antibiotics.

The information and counseling provided at first will often be different than information and counseling provided later. So it is important for information and counseling to be provided on an ongoing basis.

What do I need to know if I am experiencing pain and need to access good pain care and management?

Patients who have an advanced life-limiting or acute life-threatening illness may experience pain – either acute episodes of pain or sometimes chronic pain. Tell your health care practitioner or a loved one if you are suffering with pain during the course of your illness. Most pain can be controlled. Your health care practitioner may ask you to describe the pain and its intensity, and should rely on your self-report of pain.

If you are unable to communicate, there are ways that your pain can be assessed through observation. Your loved ones may also communicate with your health care practitioner about their observations about your pain, especially if they know you well and are familiar with your experiences. They themselves may experience pain also during your illness.

It may be useful to discuss the topic of pain and an appropriate plan for managing it with your health care provider in advance. This will allow time to discuss the available options including the range of over-the-counter to prescribed medications including opioids, their effectiveness, and their various risks and benefits (See section of this booklet on advance care planning).

Management of pain may be complicated and not always best managed by doctors or other clinical providers not specifically trained in pain. Ask your provider if he or she will refer you to a pain specialist if you feel your pain is not well controlled or if he or she is not willing to prescribe opioid drugs even if indicated for your pain. Pain that is left untreated or undertreated my lead to suffering; sometimes suffering that becomes intolerable and resistant to current treatment. Palliative care providers are well trained in a full range of approaches to relieving patients' pain and suffering.

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Make sure you are heard if you feel you are not receiving enough attention for your pain and other needs.

What should I know about the risks of a particular palliative treatment?

Almost all treatments may have some kind of undesired consequence or side effect but these are sometimes not fully discussed by physicians. You should ask for more information, in writing, if you do not feel well informed about your treatment plan. Depending upon your disease, prognosis, symptoms and your goals of care, particular side effects or burdens and suffering that might be experienced may not be worth the potential benefit of the treatment. For example, if the treatment will likely make you feel nauseated, weak, and tired but not prolong or improve the quality of your life, you might decide to decline it and focus on managing pain and symptom control and improving your comfort and well-being. An example of a medical decision that may call for weighing your options about whether to accept or decline treatment is chemotherapy.

Will I be referred to hospice care if it seems appropriate for me?

Hospice is appropriate for most people who are terminally ill and usually provides excellent quality medical and psychosocial care at the end-of-life to improve and maintain the best quality of life for patients. However, in New York State, compared to many other states, some patients who might benefit from hospice care may not be referred to hospice at the right time or even at all.

If you think you or a loved one might benefit from hospice and it has not been offered or discussed with you, then you should ask about information and a possible referral. If your health care practitioner is unwilling to refer you to a hospice and you think it might be beneficial, contact a hospice directly.

Is there a document that might be helpful to me when having discussions with my physician about my goals of care and to hopefully ensure that my health care wishes will be honored?

Yes. There are two important documents that can be completed – the New York State Health Care Proxy (HCP) (see more under Advance Care Planning) and the Medical Orders for Life Sustaining Treatment (MOLST).

- The New York State HCP is a document that allows you to identify a health care agent who is able to speak on your behalf if and when you are unable to do so regarding your medical care. Your agent should be aware of your

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medical decisions, choices, values and quality of life factors so that may be incorporated into your medical care. Everyone who is 18 years and older should complete a health care proxy.

- The MOLST is a medical order documented in a specific format –usually on bright pink paper, that is completed by you (or your health care agent or surrogate) and your doctor. It documents your wishes regarding life sustaining treatment, such as cardio-pulmonary resuscitation (CPR), intubation and mechanical ventilation, feeding tubes, intravenous fluids, and antibiotics and makes those decisions actual medical orders that will travel with you from home, to hospital and any other medical settings.

When should I have a MOLST?

You should ask your doctor if the MOLST might be right for you. Consider it if you reside in a long term care facility, reside in the community and need long term care services, want to avoid or receive all or some life sustaining treatment, or you have a limited life expectancy.

Will health care professionals who have responsibility under the Palliative Care Access Act and Palliative Care Information Act know of these laws and my rights under them?

They should know of your rights, but they may not. You may have to be an advocate for yourself, or a loved one may have to be your advocate if you no longer have decision-making capacity.

Are there health care professionals within the institutions covered by the Palliative Care Access Act or Palliative Care Access Act who may be especially helpful?

There are resources to help you with these laws. Ask if there is a palliative care team in the hospital or nursing home. If not, social workers can often be helpful with regard to providing certain information and counseling, and may be able to act as an advocate for you or your loved one.
Another source of information and support is the Patient Advocate or Ombudsman; most hospitals will have such a resource for all patients and families.

What if the rights I have under the Palliative Care Access Act or Palliative Care Information Act are violated?

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There are a number of things which you can consider doing including:

- Asking for an ethics consultation;
- Asking to speak to someone in charge, a medical director or nursing director or administrator;
- Asking to speak with the institution ombudsperson or patient advocate;
- Contacting organizations which advocate for patients such as the Westchester End-of-Life Coalition or End of Life Choices New York; or
- Filing a complaint with the New York State Department of Health.

Where can I get more information on palliative care, the Palliative Care Access Act and Palliative Care Information Act?

The Internet can provide further information on these subjects. New York State has a web site, http://www.health.ny.gov that discusses the PCAA, PCIA and palliative care. The website for the Center to Advance Palliative Care (www.capc.org) is also a good source of current information regarding palliative care. Some of these resources and others are listed at the end of the booklet.

HOSPICE

What is hospice?

Hospice is a system of care for individuals who have a life-limiting illness that is no longer responsive to curative treatment and life expectancy is approximately 6 months or less. Hospice is covered by most commercial insurance and is fully covered under the Medicare Hospice Benefit. Hospice care provides an interdisciplinary team of professionals and volunteers who are experts in end-of-life care, and focuses on symptom management needs and the quality of life of the patient. Hospice is not a specific place. Although hospice facilities or hospice homes may be in your community, hospice care is routinely provided at home, in nursing homes, and in hospitals – wherever the patient may be located the hospice can be there. If you or a loved one has been determined to be terminally ill, then hospice care may be appropriate and should be part of the important discussions about goals of care.

Who is on the team?

The hospice team will have physicians, nurses, social workers, chaplains, therapists, etc, all of who have been trained to work with people who have terminal illnesses.

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What is the goal of hospice?

The goal of hospice is to provide high quality services, care and support to the patient while working with the patient and family to improve quality of life and to ease suffering.

Where is hospice provided?

Most people receive hospice care in their homes but it can be provided in nursing homes, assisted living facilities, hospice residences and hospitals.

What specific services does hospice provide?

The many services that hospice provides include:

- Patient support and comfort including pain and other symptom control;
- Medical and social assessment;
- Nursing visits;
- Individual, family and group psycho-social and spiritual counseling;
- The provision of necessary equipment and supplies;
- Support for caregivers;
- Physical, occupational, speech or other types of therapy which might include pet or music therapy as appropriate;
- Dietary and nutritional advice;
- Homemaking and home health aide assistance; and
- Grief and bereavement support up to a year (or longer) for family members following the death of the patient.

How can I receive hospice care?

If a patient chooses to elect hospice care under the Medicare Hospice Benefit (MHB), then a physician and the hospice medical director must certify the patient is eligible under the MHB as explained above (i.e., physician certifies that death is likely to occur within 6 months or less if the disease runs its natural course). If a patient is enrolling under some other form of payment or benefit, physician referral and certification requirements may be different. Patients have to consent to hospice enrollment, and if they lack capacity then agents and surrogates can step in to make the decision.

Can my own doctor continue to treat me?

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Yes, if that is what you want. The interdisciplinary team will work with your doctor and develop an individualized plan of care.

Am I giving up on hope if I am in hospice?

No, not at all, you are not giving up on hope if you enroll in hospice. The time when hospice care is appropriate is usually the time when hope turns from curative goals to goals of maintaining or having quality of life, time with family and loved ones, comfort care and finding dignity in each day.

Do I have to stay in hospice once I am enrolled?

No. Most patients and family members are very satisfied with hospice. However, you can leave hospice or switch to another hospice. You may also sign yourself out of a hospice program and return to various other forms of medical care if you believe that it would be beneficial for you. It is your choice. If your disease stabilizes and you are no longer expected to have a limited prognosis, you can be discharged from hospice care and have the option to elect it again later when needed if your health condition changes.

Is hospice covered by insurance?

Hospice is generally covered by Medicare, Medicaid and most private insurance.

ADVANCE CARE PLANNING

Introduction

The vast majority of us will at some point lose the ability to make our own health care decisions. This means that someone else will have to make health care decisions for us, including decisions about end-of-life care. If you want to ensure that your goals, values, and your health care wishes are honored, there are things that you can and should do.

What is the most important thing to do to so that my health care wishes will be respected both while I have capacity and when I am no longer able to make health care decisions?

Communication is key to having your health care wishes honored. While you have the ability to do so, you should discuss your goals of care and communicate your health care preferences to loved ones and to your health care providers, explaining

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what your goals of care are and what treatments you would want, not want, or want on a trial basis in various situations. Your wishes will be appropriately documented by your health care practitioners in your health records (see HCP or MOLST section).

You should also consider appointing a trusted person as your health care agent to make health care decisions for you when you are no longer able to do so. This health care agent appointment or designation may be made by completing a health care proxy form (See Appendix). You may also have your wishes documented through the MOLST Program. (Please note that a MOLST form does not take the place of appointing a health care agent.) Both documents alone or together are a gift to you and your loved ones.

When should I do this?

You should have these conversations preferably when you are young and healthy because anything can happen to you that might put at risk your ability to make health care decisions. The leading cases involving loss of decision making capacity, which you may have heard of, involve young people including the *Cruzan, Schiavo* and *Quinlan* cases.

Why is it so important that I appoint a health care agent?

When people know your wishes and understand the reasons behind them, it is more likely that your wishes will be honored; communication between loved ones and doctors will be facilitated; serious and sometimes never-ending conflicts, which often arise between and among family members, will be avoided; and you may feel good about having had these discussions. Failure to appoint a health care agent and have appropriate conversations about your health care wishes makes it much more likely that when you can no longer make decisions for yourself, these decisions may be made by someone you would not have chosen to make them. (See Appendix for NYS Health Care Proxy.)

What specifically should be discussed?

Consider discussing your values, religious and otherwise, about what makes life worthwhile, what gives life meaning. Decisions concerning life-sustaining treatment are the most difficult for people to make and so you might discuss different scenarios to help guide the person making decisions for you as well as other family members. A few short examples of situations that might arise and that might be considered for discussion are:

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- You have advanced dementia, are 90 years old, have been bedridden for years and no longer recognize your loved ones. You now cannot eat or even be hand-fed. Would you want a feeding tube?
- If you are seriously ill and in great pain, what types of analgesics would be appropriate to control your pain, and what are their risks and side effects?
- If you are permanently unconscious, would you want a feeding tube? Artificial nutrition and hydration? Antibiotics?

Is it difficult to complete the health care proxy?

Completing the simple two-page health care proxy form, for which a lawyer is not needed (two witnesses are needed, neither of whom can be the agent who is appointed), is easy to do. It may require thought and reflection on your part to decide who you choose to be your health care agent. You may not want to choose your spouse, for example, if you are not confident that your spouse could honor your wishes. The person appointed as your agent (an alternate agent should also be appointed) should be willing to speak on your behalf, be able to act on your wishes even if different from his/hers, be a strong advocate whom you trust, be someone who knows you well and understands what is important to you and who would be able to handle conflict if it arises.

What should I do after having discussions and completing the health care proxy?

After discussions have been had with loved ones and your doctors and the health care proxy form is completed, copies should be made for everyone involved. Continue to have discussions about end-of-life preferences through the years as your thinking may change and you want to be sure that your loved ones continue to understand you and your current preferences. By having conversations about health care and end-of-life decisions and appointing a health care agent, a significant gift will be given to those who most matter to you — as well as to you. Do it today.

What if my loved ones do not want to discuss these things?

If there is reluctance on the part of family members and/or others to have these discussions, you can explain to them the importance of having conversations and how it might benefit both you and them. Most people are happy and even relieved to have these discussions and once started they usually go well. Another suggestion is to discuss end-of-life issues and requests with your health care provider who knows you well. Ask them to keep a copy of your requests and decisions if there is no one in your life at present who is willing or available to act as your agent.

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RESOURCES

There are a number of resources that include, among others:

- Center to Advance Palliative Care, http://www.capc.org/
- Collaborative for Palliative Care, http://www.cpcwestchester.org/
- End of Life Choices New York, http://www.endoflifechoicesny.org/
- Compassion and Support, http://www.compassionandsupport.org/
- Get Palliative Care, http://www.getpalliativecare.org /
- Hospice & Palliative Care Association of New York State, http://www.hpcanys.org/about/palliative-care/
- New York State Health Care Proxy: http://www.health.ny.gov/forms/doh-1430.pdf
- New York State Department of Health - Palliative Care: https://www.health.ny.gov/professionals/patients/patient_rights/palliative_care/
- Westchester End-of-Life Coalition, http://westchesterendoflife.org/

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