

New York State Department of Health

Palliative Care Access Act

Questions and Answers for Patients, Families, and Surrogates

Health care consumers with serious illnesses have greater access to information about palliative care as a result of two New York State laws. The Palliative Care Information Act (PCIA) and the Palliative Care Access Act (PCAA) require health care providers to make available to patients with serious illnesses, and their families, information about their condition, their treatment options, and palliative care services. The PCIA requires physicians and nurse practitioners to offer terminally-ill patients information and counseling concerning treatment options, palliative care and end-of-life options. The PCAA imposes certain requirements on hospitals, nursing homes, home care agencies and two types of assisted living residences (enhanced and special needs) regarding palliative care. It requires these entities to make available information and counseling regarding options for palliative care and to facilitate access to palliative care to patients with advanced life limiting conditions and illnesses.

- 1) Question: What is the Palliative Care Information Act (PCIA)?
- 2) Question: What is the Palliative Care Access Act (PCAA)?
- 3) Question: What is the difference between the Palliative Care Information Act and the Palliative Care Access Act?
- 4) Question: What is palliative care and how can it help me?
- 5) Question: What will palliative care add to the care I am receiving now?
- 6) Question: Why would my health care practitioner suggest that I get palliative care?
- 7) Question: What does it mean if I ask for palliative care?
- 8) Question: What kind of questions would be good to ask my health care practitioner about palliative care if I think it might be good for me?
- 9) Question: What questions should I ask of my health care practitioner to make sure that my personal beliefs, values, and goals are considered in the palliative plan of care?
- 10) Question: If I want to have palliative care, can I keep my doctor or nurse?
- 11) Question: What happens if I change my mind and want to stop getting palliative care?
- 12) Question: If I ask for palliative care, does it mean I am "giving up"?
- 13) Question: How is palliative care different from hospice?
- 14) Question: Do I have to be in a hospital to receive palliative care?
- 15) Question: Can you explain how palliative care is paid for? Does my insurance cover palliative care?
- 16) Question: Is palliative care available for children?
- 17) Question: What makes palliative care for children different than palliative care for adults?
- 18) Question: How do I explain to my child why he/she needs palliative care services?
- 19) Question: Where can I find palliative care services for my child?
- 20) Question: Do the Palliative Care Information Act and the Palliative Care Access Act apply to children?
- 21) Question: Must children themselves be informed of their palliative care options and right to access palliative care services?

1) Question: What is the Palliative Care Information Act (PCIA)?

Answer: The Palliative Care Information Act (PCIA) requires the attending health care practitioner to offer to provide patients with a terminal illness with information and counseling regarding palliative care and end-of-life options appropriate to the patient, including:

- Prognosis;
- Range of options appropriate to the patient;
- Risks and benefits of various options;
- Patient's "legal rights to comprehensive pain and symptom management at the end of life."

Physicians and nurse practitioners are also required to offer patients with a terminal illness information regarding other appropriate treatment options, if the patient wishes to initiate or continue treatments other than, or in addition to, palliative care.

The Palliative Care Information Act focuses on patients with a medical condition that is expected to cause death within six months. However, this information and counseling is also appropriate for patients with serious illnesses who do not have a terminal condition. Patients may choose to accept or decline the offer of information and counseling.

2) Question: What is the Palliative Care Access Act (PCAA)?

Answer: The Palliative Care Access Act (PCAA) requires that hospitals, nursing homes, home care agencies, special needs assisted living residences, and enhanced assisted living residences, provide access to information and counseling regarding options for palliative care appropriate to patients with advanced life limiting conditions and illnesses. These providers and residences must also facilitate access to appropriate palliative care consultation and services, including associated pain management consultation and services, consistent with the patient needs and preferences.

3) Question: What is the difference between the Palliative Care Information Act and the Palliative Care Access Act?

Answer: The Palliative Care Access Act (PCAA) is broader than the Palliative Care Information Act (PCIA) because:

- It applies directly to hospitals, nursing homes, home care agencies, enhanced assisted living residences and special needs assisted living residences, whereas the PCIA applies to physicians and nurse practitioners in all settings including private offices and health care facilities;
- It applies to patients/residents with "advanced life-limiting conditions or illnesses who might benefit from palliative care" and not just those with a terminal illness or condition as defined by law;
- It requires, not only an offer of information and counseling, but also that the covered health care provider or residence "facilitate access to appropriate palliative care consultations and services, including associated pain management consultations and services."

4) Question: What is palliative care and how can it help me?

Answer: Palliative care is patient- and family-centered care for people with serious illnesses. It helps to relieve symptoms, pain, and stress so that you and your family can have the best possible quality of life throughout your illness. Palliative care aims to guide and assist the patient and family in making decisions that enable them to work toward their goals. Palliative care affirms life by supporting the patient and family's goals for the future, including their hopes for cure or life-prolongation, as well as their hopes for peace and dignity throughout the course of illness, the dying process and death.

You may receive palliative care by a team of professionals including doctors, nurses, social workers, and chaplains. The team's job is to anticipate and address the physical, emotional, and spiritual needs that you may face because of your illness. You and your family are also a part of the palliative care team, and you will be given all of the information that you need in order to make choices about your care.

5) Question: What will palliative care add to the care I am receiving now?

Answer: Palliative care services adds an extra layer of care and support that may be combined with the care you are already getting. Your palliative care professionals or team will work to make you comfortable by relieving your symptoms, pain and side effects of your treatment for the entire length of your illness. The team will also work with you to make sure you understand your treatment choices.

6) Question: Why would my health care practitioner suggest that I consider palliative care?

Answer: By suggesting that you consider palliative care, your health care practitioner is helping you to access a variety of resources to manage your illness. Your doctor or other health care practitioner might suggest palliative care for you for many different reasons. Some common reasons include:

- You may have an uncomfortable symptom like, pain, shortness of breath, nausea, or anxiety;
- You may need emotional, spiritual, or practical support related to your serious illness;
- You may have had many visits to the hospital or emergency room recently;
- The treatments for your illness may not be working as well as they did in the past;
- You may be faced with complicated decisions about what treatments you should choose;
- If you are unsure why your health care practitioner has suggested palliative care, you should ask him or her why he/she thinks it might help you.

7) Question: What does it mean if I ask for palliative care?

Answer: If you ask for palliative care, it means that you understand that you have a serious illness. It means that you want to make sure that any side effects of treatments for your illness are avoided or relieved as much as possible. It means that you want to have a team of professionals with different kinds of training working together to help you have the best life possible throughout your illness. It may mean that you are feeling overwhelmed and think that having help to manage your care and your stress would be a good thing.

8) Question: What kind of questions would be good to ask my health care practitioner about palliative care?

Answer: If you feel like you and your family need more help to manage your illness, you can talk with your doctor about palliative care. You might ask:

- What type of treatments will be added if I get palliative care?
- Can I pursue a cure and get palliative care?
- Will I still get the care I am receiving now if I want it?
- Can I keep my same doctor or nurse?
- Is palliative care going to make it easier for me to live my life?
- Can you explain what the palliative care team is?

9) Question: What questions should I ask of my health care practitioner to make sure that my personal beliefs, values and goals are considered in the palliative plan of care?

Answer: You should share your personal beliefs, values, and goals with your health care practitioner.

- Examples of questions you should ask your health care practitioner may include:
- How can we make sure that my medical treatments fit within my religious and cultural values, beliefs and goals?
- Can we change the treatments so there is no conflict with my spiritual or cultural practices?
- How will we make sure that my symptoms and pain are not too much for me?
- What will you do if I have pain or other uncomfortable symptoms?

10) Question: If I want to have palliative care, can I keep my doctor or nurse?

Answer: Most of the time, palliative care is an extra layer of support that you can get while you keep seeing your health care practitioners. Sometimes, if your treatment(s) become complicated, your practitioner may transfer your care to other health care practitioners who specialize in palliative care. If you are concerned, this is a good question to ask your doctor, nurse, or social worker.

11) Question: What happens if I change my mind and want to stop getting palliative care?

Answer: It is your choice to receive or stop palliative care. If you feel that you do not need the extra support provided by palliative care, you can contact your health practitioner(s). Tell them about your decision and talk about your future health care.

12) Question: If I ask for palliative care, doesn't it mean I am "giving up" on a cure or on life-prolonging treatment?

Answer: No, it does not. It means that you want the benefits of having a team of professionals with different kinds of training working together to help you have the best life possible while you are living with your illness. Rather than giving up, you are working with a team to ensure that everything will be done to make you as physically and emotionally comfortable as possible.

13) Question: How is palliative care different from hospice care?

Answer: The goal of palliative care is to relieve suffering and improve the quality of life for people of any age, and at any stage in a serious illness, whether that illness is curable, chronic or life-threatening. Palliative care can enhance your level of comfort and help you achieve the highest possible quality of life. You can receive palliative care while you are undergoing treatments that may cure or reverse the effects of your illness. In fact, palliative care can help you cope with aggressive treatments by managing your pain and symptoms. Hospice care is a type of palliative care for people who are terminally ill, if the disease runs its normal course. When medical treatments cannot offer a cure, hospice provides care, comfort, and support for persons with life-threatening illnesses and their families.

14) Question: Do I have to be in a hospital to receive palliative care?

Answer: No. Most hospitals usually provide some palliative care services but there may be other health care providers in your area with palliative care services. These may include nursing homes, assisted living facilities, or your own home by a home care agency. Some hospices also provide non end-of-life palliative care in your home. Please note that some types of palliative care services are not available in every county across New York State. You can ask your health care practitioners about the palliative care services available in your area, or search for providers using the following links: [Get Palliative Care](#) (CAPC) or [Hospice and Palliative Care Association of New York State](#) (HPCANYS).

15) Question: Can you explain how palliative care is paid for? Does my insurance cover palliative care?

Answer: Most insurance plans, including Medicare and Medicaid, cover medical services that are considered palliative care. Some plans also cover supportive services. Ask to speak with a social worker or call your health plan if you have questions about your healthcare coverage.

16) Question: Is palliative care available for children?

Answer: Yes, it is available for children. Although serious illnesses do not occur as often in children as in adults, some children develop serious, potentially life-threatening diseases. These children, like adults, can receive palliative care at any stage of their illness, whether that illness is potentially curable, chronic, or life-threatening. The approach to palliative care for children may be different than for adults, but the goal is the same: to relieve suffering in patients (and their families) throughout the course of their illness, whether or not it is curable.

17) Question: What makes palliative care for children different than palliative care for adults?

Answer: Just as medical care for children differs from such care for adults, so, too, does palliative care. The basic principles are the same: relief of physical, emotional, social and spiritual suffering. But the way that relief is provided may differ. For example, the doses and types of medications used to relieve pain and other symptoms in children may be different. Another important distinction is that children are very resilient, and even when they have a disease that cannot be cured, they are often able to handle therapies aimed at controlling the disease. Therefore, many children receive "disease-targeted" care and palliative care (that is, care aimed at keeping them comfortable) at the same time. Neither parents nor children have to choose one or the other.

Because children (and families of children) who receive palliative care have different needs than adults, these children ideally should receive that care from pediatric professionals. In addition to their pediatricians and pediatric subspecialists, they may benefit from nurses and nurse practitioners who are trained in caring for chronically ill and/or serious ill children. Child life specialists (trained professionals who focus on children's comfort) can help children to express themselves through play. Music and art therapists with pediatric experience are very effective in doing the same thing. Likewise, pediatric social workers, chaplains, school counselors, psychologists and psychiatrists can also help children and their families. All of these pediatric palliative care team members can also work with and provide comfort to siblings of ill children as well as their parents.

Perhaps the most challenging aspect of providing palliative care for children is that many people expect children to be healthy, and when a child has a serious illness, family, friends, and even doctors, nurses and other medical personnel are not quite sure what to do or say. So a big part of palliative care for children (and their families) is being able to communicate clearly and effectively with parents about what is happening, what the road ahead might hold, and perhaps most importantly, how to explain things to the child who is ill and his/her siblings.

18) Question How do I talk to my child about his/her illness and treatment?

Answer: This is certainly one of the very biggest challenges in taking care of a child with a serious illness. How much should we tell him? How do I answer her scary questions? Who can guide me? Children are like adults in that every child is different, and therefore the approach to talking to them must be individualized. As a general rule, children do best when information is shared with them. But how that information is shared and who shares it will depend on their personalities, how they handle difficult information, their actual age, their stage of development, and how much they want to know. If you are uncertain how to explain his/her illness and care to your child (and most parents are), some people who could guide you include your pediatrician, other healthcare workers involved your child's care, or perhaps a trusted teacher, clergy or family member.

19) Question: Where can I find palliative care services for my child?

Answer: Many of the larger children's hospitals in the state have pediatric palliative care teams. For those families who live in rural areas or who do not know of a nearby team, it would be wise to ask your child's pediatrician where you might find the right people to provide palliative care services. The pediatrician might know of a hospital-based team or even a home-based team. If not, sometimes home health agencies can help with children's comfort with the assistance of the pediatrician.

20) Question: Do the Palliative Care Information Act and the Palliative Care Access Act apply to children?

Answer: Yes, they do apply to children. The Department is aware that life-limiting illnesses and terminal illnesses are far less common in children than in adults. The Department also recognizes the unique challenges of discussing palliative care with parents of children with life-limiting illness as well as with the children themselves. In addition, it may be particularly challenging to predict life expectancy in children with life-limiting illnesses, and hence difficult to know just when such discussions should take place. That said, these laws do apply to children who have advanced diseases or terminal illnesses; i.e., their parents must be offered the opportunity to learn about their child's

prognosis, about the range of supportive care and treatment options available to the child, the risks and benefits of these options, and the children's "legal rights to comprehensive pain and symptom management at the end of life." Given the fact that few children in the general population have life limiting and/or terminal illnesses, some pediatric practitioners may not be comfortable conducting these difficult conversations. If that is the case, your pediatrician should consult with a pediatric palliative care subspecialist or refer you to one.

In addition, the PCAA requires that certain health care providers (including hospitals, nursing homes and home care agencies) "facilitate access to appropriate palliative care consultation and services, including associated pain management consultations and services." The Department acknowledges that pediatric palliative care services may not be as readily available as palliative care services for adults. Your pediatrician or health plan may be able to connect you with a pediatric subspecialty group.

21) Question: Must children themselves be informed of their palliative care options and right to access palliative care services?

Answer: This cannot be answered with a simple "yes" or "no," since there is such variability in children's ages and developmental stages. Clearly a 2-year-old child cannot be informed nor could a 10-year-old with a severe developmental delay. Generally a 17-year-old with normal cognitive status should be informed. The challenge is the many children in between – the normal 12-year-old child or the precocious 8-year-old child. As a general guideline, sharing information with a child about his or her diagnosis, prognosis, and treatment and palliative care options is appropriate, if the child has the ability to understand and appreciate the nature and consequences of his/her disease and trajectory of that disease and the nature and consequences of treatment and palliative care options. You should discuss with your physician your child's ability to understand these issues and how much information should be shared with him or her. If you object to your child being offered information about diagnosis, prognosis and treatment options, you should discuss your concerns with your physician and health care team.

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