



There Is Something More We Can Do For You!

Moving From Curing to Caring



Huntington's Disease Society of America

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Presenter Disclosures

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The following personal financial relationships with commercial interests relevant to this presentation existed during the past 12 months:

No relationships to disclose
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When do I start planning for the future?

The best time is now when not facing a crisis.

What kind of help is out there?

Where do I start?

How do I get services to help me?

How are services paid for?

How do I know when it is time to call palliative care or hospice?

What can palliative care and hospice do for me?

Advance Care Planning

- Living Will or Advance Directives
- Power of Attorney for Health Care
- Durable Power of Attorney
- Documents available at your doctor's office, on line, state website, websites i.e. Five Wishes.
- Should be free or have a minimal cost associated.
- State specific—must have the right document.

Advance Directive

- Allows you to document your wishes concerning end of life care.
- Copies should be filed with your physicians and hospital and at home.
- EMS staff can't honor these so use what your state allows to prevent them from doing what you don't want.
- Should cover resuscitation, hospitalization, feeding tubes, mechanical ventilation, IV fluid, other treatments.
- Update the document as needed.

Health Care Power of Attorney

- Used when you can no longer make decisions for yourself as determined by 2 physicians.
- Make sure that it is someone who will act as you have directed, in your best interest.
- Can be a relative, a friend, a person you do business with, who ever you direct. Get their consent first.

How Will I Know?

- You have an advanced chronic illness characterized by worsening of a disease that is not responsive to curative measures.
- Poor quality of life; suffering.
- Increasing worry on the part of the caregiver.
- Needing support and someone to talk to about the many issues.

What is Available?

- Palliative Care
- Hospice Care

Palliative Care

- Provided in a variety of settings hospitals, offices, homes, nursing homes and assisted living centers.
- Care directed at treating symptoms such as pain, anxiety, nausea, delirium, etc using a team approach with nursing, social workers, chaplains involved.
- No stipulation regarding life expectancy. Can still be pursuing active treatment of illness.
- Goal is to improve quality of life by providing pt/family support, managing symptoms.

Palliative Care cont'd

- Less focus on the disease, more of a focus on comfort.
- Holistic approach that focuses on physical, psychological, spiritual and social aspects.
- Assist with family conflicts regarding care.
- Care provided by MDs, NPs, PAs and the rest of the team.
- Paid for by Medicare Part B, like regular doctor's visits.

Hospice Care

- Must have an end-of-life diagnosis and an attending that predicts the patient has 6 months or less to live. Can self refer.
- Hospice is a team approach to end of life care involving nursing care, social workers, aids, spiritual care personnel, volunteers and physicians.
- No further curative care is planned
- Goals of care are control of symptoms such as pain and nausea, assisting the patient and family and easing the transition from this life.

Hospice Care Cont'd

- Assist with decision making, allay fears, navigate with experienced, caring staff.
- Hospice is not just for cancer patients but anyone with a life-limiting illness.
- Covered 100% by Medicare Part A.

QUESTIONS????

