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COMPASSION & CHOICES
IMPROVES CARE,
EXPANDS OPTIONS,
AND EMPOWERS
EVERYONE TO
CHART THEIR
END-OF-LIFE JOURNEY.
NASW Standards for Palliative & End of Life Care (2000)

“Introduction: All social workers, regardless of practice settings, will inevitably work with clients facing acute or long-term situations involving life-limiting illness, dying, death, grief, and bereavement. Using their expertise in working with populations from varying cultures, ages, socioeconomic status, and nontraditional families, social workers help families across the life span in coping with trauma, suicide, and death, and must be prepared to assess such needs and intervene appropriately.”
NASW Standards for Palliative & End of Life Care (2000)

Standard #5. Attitude/Self-Awareness: Social workers in palliative and end of life care shall demonstrate an attitude of compassion and sensitivity to clients, respecting clients' rights to self-determination and dignity. Social workers shall be aware of their own beliefs, values, and feelings and how their personal self may influence their practice.

Standard #6. Empowerment and Advocacy: The social worker shall advocate for the needs, decisions, and rights of clients in palliative and end of life care. The social worker shall engage in social and political action that seeks to ensure that people have equal access to resources to meet their biopsychosocial needs in palliative and end of life care.
I. Psycho/Social Barriers to talking about Death
II. Medical Landscape of End-Of-Life Options
III. How to Talk to Clients about Preparing for Death
IV. Basic FREE Paperwork for Everyone
V. Resources FREE for YOU and your Clients

I. Psycho/social barriers to talking about death
What are YOUR thoughts on Death?
Please take a moment to consider....

● What are your experiences with death?
● What messages have you incorporated from your family, culture, religion, experiences?
● Have you prepared for the inevitable?
● What would it be like for your loved ones if you were to die unexpectedly?
Provisional number and rate of total deaths by demographic characteristic National Vital Statistics System, United States, 2022

<table>
<thead>
<tr>
<th>AGE</th>
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<td>15-24</td>
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<td>75-84</td>
<td>823,908</td>
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<td>Over 85</td>
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Who dies without a will:

“Two-thirds of U.S. adults have no will, and their dying intestate has serious implications for grieving family members and other potential heirs looking to settle the deceased’s affairs”. Oct 29, 2022 CNBC
We plan for other anticipated events in our lives:
Births, Graduations, Weddings, Anniversaries,
Bar/Bas Mitzvahs, Retirements, etc.

What did COVID teach us?
Unexpected deaths
Isolation
Non-traditional ways to say goodbye or
hold death ceremonies

II. Medical Landscape
Dying In America

Care Options at the End-Of-Life

- Pursuing curative treatment
- Refusing curative treatment
- Discontinuing curative treatment
- Palliative care
- Hospice
- Voluntarily Stopping Eating and Drinking (VSED)
- Continuous Deep Sedation
- Medical Aid-In-Dying
Definition of Palliative Care

Palliative care focuses on pain and symptom management for people living with serious illness as well as coordination of care and quality of life.

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Definition of Hospice

Hospice provides comprehensive, holistic support for terminally ill people and those close to them including comfort care and the relief of physical, psychological and spiritual suffering.

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Definition of Voluntary Stopping Eating and Drinking (VSED)

VSED is when a mentally capable individual decides to control their own dying by making a conscious decision to refuse foods and fluids of any kind, including artificial nutrition and/or hydration, in order to advance the time of their death.

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Definition of Continuous Deep Sedation

Continuous palliative sedation therapy is the use of ongoing sedation for symptom management, considered during the end of life when a patient is close to death and continued until the patient's death.
Definition of Medical Aid In Dying

Medical aid in dying allows terminally ill adults to request and receive a prescription for medication that they may choose to take to bring about a peaceful death. To qualify, one must be mentally capable, able to self-ingest the medication and have a prognosis of six months or less to live.
11 jurisdictions representing ... 1 in 5 Americans

OREGON  WASHINGTON  HAWAI'I  DISTRICT OF COLUMBIA
MONTANA  NEW JERSEY  MAINE  CALIFORNIA
VERMONT  NEW MEXICO  COLORADO

A unifying issue in partisan times

Source: Susquehanna Polling & Research telephone survey of 951 voters, Nov. 2-10, 2021
Remember: It is the illness that is ending the person’s life.

What populations would NOT be eligible for Medical Aid In Dying?

- If you are not eligible for hospice (6 months)
- If you cannot make cognitive choices
- If you cannot self-administer

- Parkinson’s
- ALS
- Dementia
Engaging Diverse Communities

III. How to introduce the topic to all clients over 18 years of age
● Ask what are their thoughts/fears about death
● Review familial and/or cultural/religious messages
● Planning can AVOID family conflict (especially with dysfunctional family systems)
● Empower underrepresented populations who often:
  ○ Have less in writing
  ○ Spend more money at the time of crisis
  ○ Access less medical support
  ○ Spend less time in hospice

How to talk to clients about EOL Options

● For all clients, discuss end-of-life options and refer to resources for planning and preparing paperwork. Having an Advance Directive is important for persons over the age of 18 years.
● When a client or their loved one is ill, review end-of-life options and share resources for better understanding of their options. Discuss how to have the conversation with loved ones and Healthcare Representative. Consider the Compassion & Choices End-of-Life Options Consulting Service.
How to Advocate for your clients

- Educate yourself and others about end-of-life options
- Know your resources for referring clients
- Empower them with education, options, resources
- Practice this with yourself and your family and loved ones
- Encourage completion of documentation of care wishes (Advance Directives including dementia planning)

Scenarios to consider:

a) A patient/client’s religious identification does not, as a body, support the end-of-life option they are considering
b) A family member does not agree with current end-of-life options the patient/client is choosing
c) Your patient/client has a doctor who does not support their legal end-of-life options in Illinois
d) Medical Aid In Dying is authorized in your state of practice and you work at a healthcare facility that does not support this option
IV. Basic Paperwork

Wishes Booklet

My End-of-Life Decisions

Compassion & Choices
Components in the Planning Guide and Toolkit:

- Values Worksheet about your Priorities and Wishes
- Advance Directive Descriptions and Choosing Representation
- Decisions About Life-Sustaining Measures
- How to Talk to Loved Ones
- How to Talk to Your Medical Team, Filing Paperwork
- Dementia Provisions
- Other Documents

Advance Directives by state

- Advance directives include:
  - A living will ("what you want")
  - A power of attorney ("who will speak for you")
  - Practitioner Order for Life Sustaining Treatment (POLST)
  - Addendums that further clarify your wishes

- Everyone over 18 should have an advance directive.

- Choose Your State
Why an Advance Directive is Critical

- You specify in advance what kind of medical care you would want if you become incapacitated.
- You can identify another person (as well as alternative people should the first person be unavailable) as your health care representative to make healthcare decisions on your behalf when you are unable to do so.
- In most states, you do not need a lawyer or a notary. In Illinois, you need a witness to sign the form.
- Everyone over 18 should have an advance directive.
- Each State Department of Public Health offers FREE forms.

Practitioner Order for Life-Sustaining Treatment (POLST)

- Particularly useful for:
  - Frail elderly
  - Patients with progressive diseases
  - Anyone whose death within the next year would not be a surprise.
The writer can keep it as simple as they want.

The document can be edited at any time.

The document only requires 2 witnesses, no lawyer and no notary

Sections include:
  - Declarations
  - Executor Provisions
  - Pet Care Directives
  - Gifts at Death (items)
  - Gifts of Residue (finances)

There are opportunities for:
  - Funeral Wishes
  - Personal Statement

V. Resources for you and your clients
Ways to Take Action

- Set and Share Your End-of-Life Priorities
- Contact Your Legislators
- Complete and File Advanced Directives
- Donate
- Share Your Story
- Volunteer

Consider Donating Organs at: LifeGoesOn.org
Will YOU follow up for yourself and loved ones first?
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