

HAND-OUT: “A GOOD DEATH”

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DOMAINS FOR THE MEASUREMENT OF QUALITY CARE:

1. *Physical and Emotional Symptoms.*
Pain, shortness of breath, fatigue, depression, fear, anxiety, nausea, skin breakdown, and other physical and emotional problems often destroy the quality of life at its end. Symptom management often is deficient. Care systems should focus upon these needs to ensure people a comfortable and meaningful end of their lives.
2. *Support of Function and Autonomy.*
Even during the inevitable and progressive decline of a fatal illness, much can be done to maintain personal dignity and self-respect. Achieving better functional outcomes and greater autonomy should be valued.
3. *Advance Care Planning.*
Often, the experience of patient and family can be improved just by planning ahead for likely problems, so that crisis decisions reflect the patient's preferences and circumstances.
4. *Aggressive Care Near Death-site of death, CPR, and Hospitalization.*
Although aggressive care often is justified, most patients prefer to avoid it when the short-term outcome of such care is death. High rates of medical intervention near death should prompt examination of provider judgement and care system design.
5. *Patient and Family Satisfaction.*
A dying patient's peace of mind and the family's perception of the patient's care and comfort are extremely important. The time at the end of life should be precious to both, not merely tolerable. We must measure both patient and family satisfaction with the decision-making process, care given, outcomes achieved, and the extent to which opportunities were provided to complete life in a meaningful way.
6. *Global Quality of Life.*
Often, a patient's assessment of his or her overall well being illuminates successes and shortcomings in care that are not apparent in more specific measures. Quality of life can be quite good despite declining physical health, and care systems that achieve this should be valued.

7. *Family Burden.*

How health care is provided affects whether families have serious financial and emotional effects from the costs of care and the challenges of direct caregiving. Current and future financial pressures on providers are likely to displace more responsibility for services and payment onto families.

8. *Survival Time.*

With pressure upon health care resources likely to increase, there is new reason to worry that death will be too readily accepted. Purchasers and patients need to know how survival times vary across plans and provider systems. In conjunction with information about symptoms, satisfaction, and other domains listed here, such measure will allow insights into the priorities and tradeoffs within each care system.

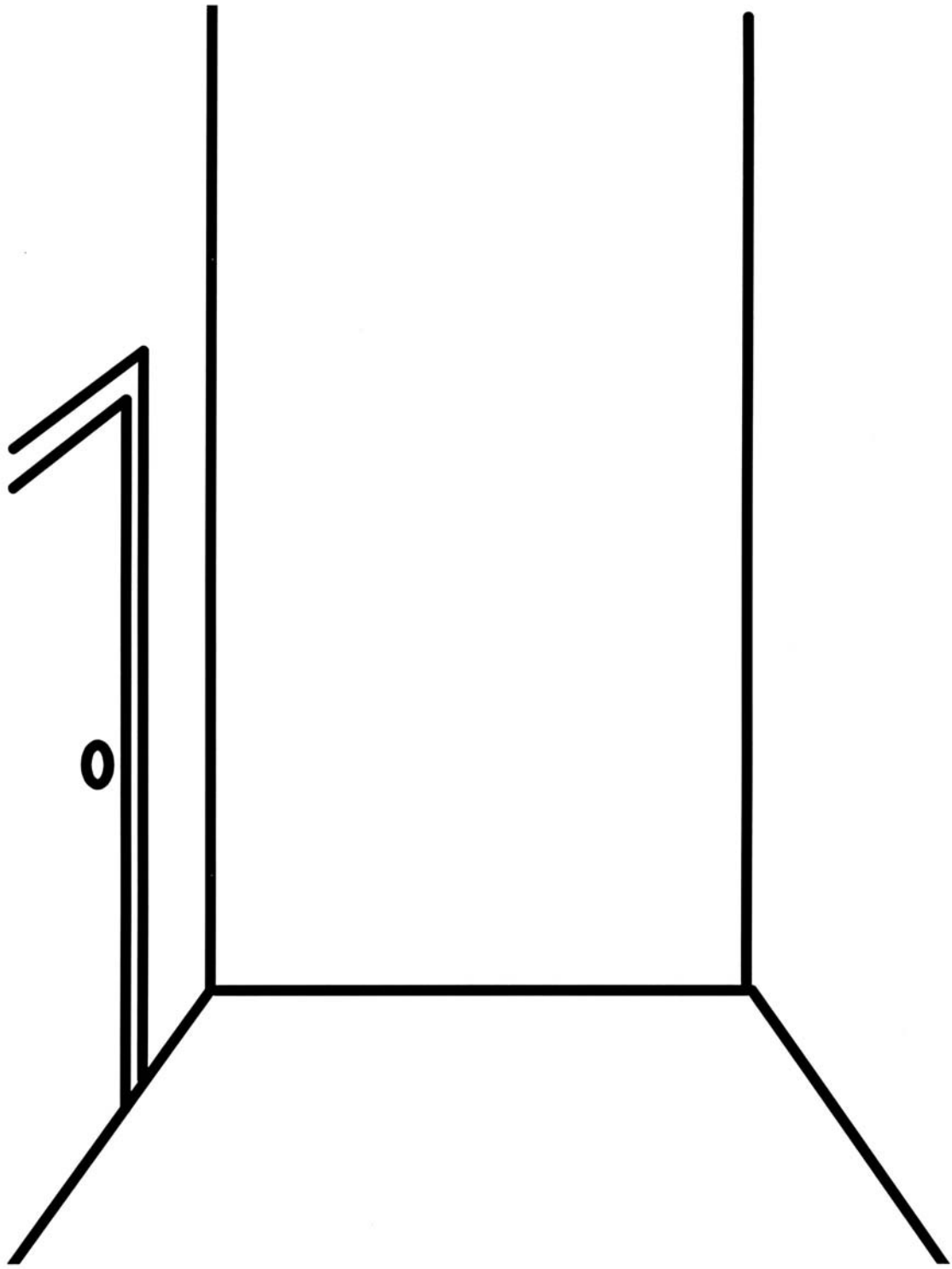
9. *Provider Continuity and Skill.*

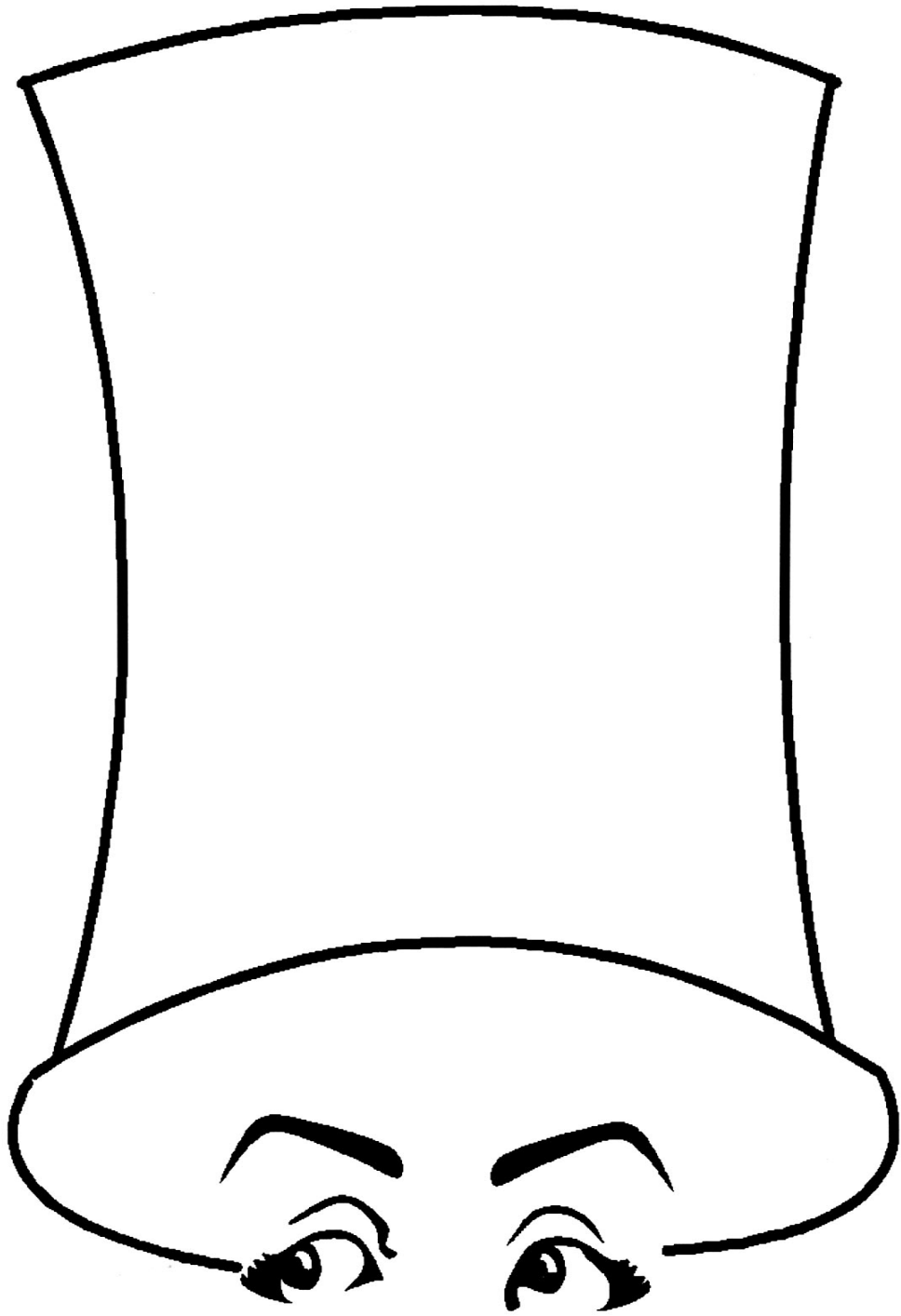
Only through enduring relationships with professional caregivers can patient and family develop trust, communicated effectively, and develop reliable plans. Providers also must have relevant skills, including rehabilitation, symptom control, and psychological support. Care systems must demonstrate continuity and provider skill.

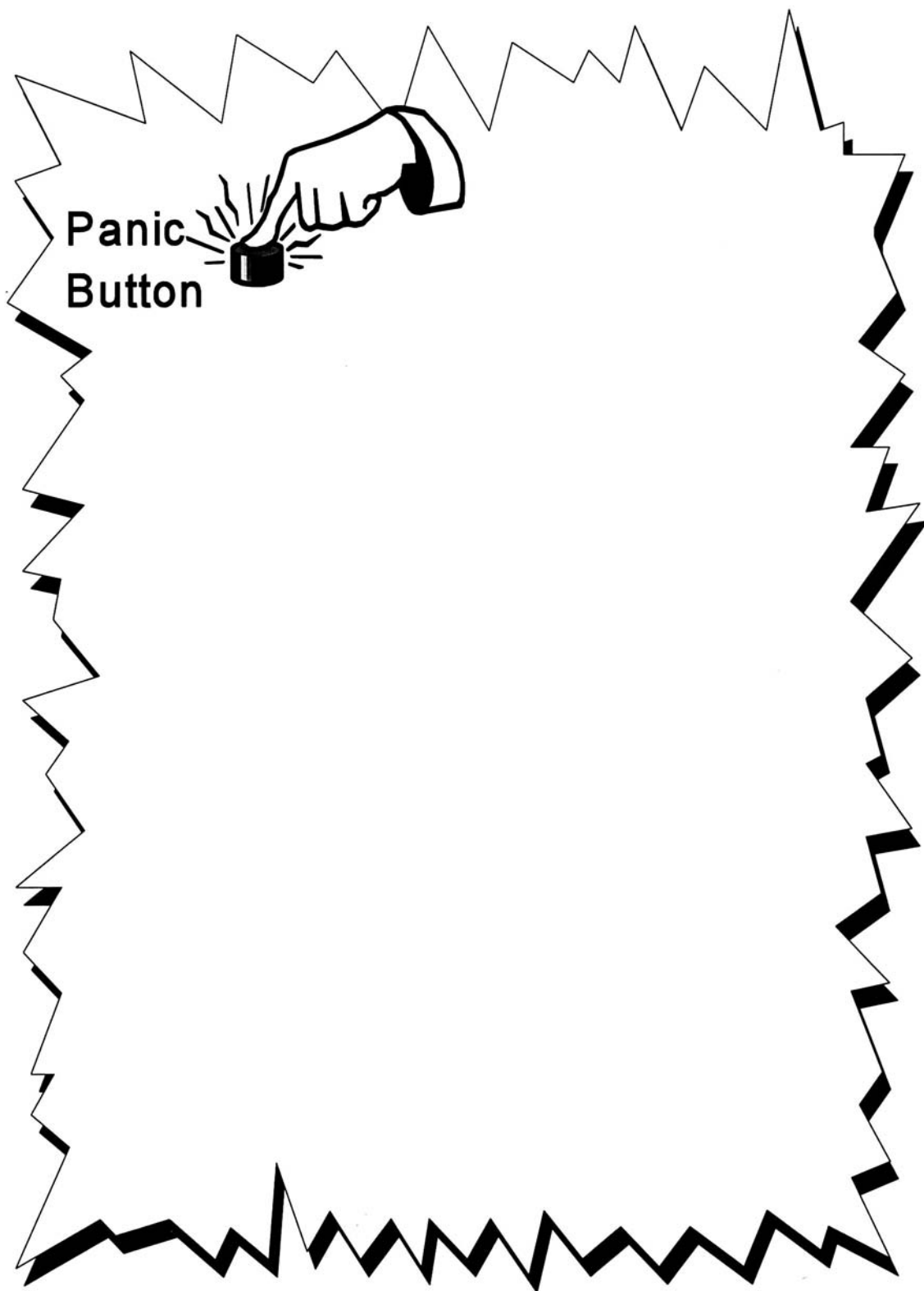
10. *Bereavement.*

Health care stops with the patient's death, but the suffering of the family goes on. Survivors may benefit from relatively modest interventions.

Ayers, E., Harrold, J., & Lynn, J. (1997). A good death: Improving care inch-by-inch. Bioethics Forum 13(1), 38-40.







The Dying Person's Bill of Rights

- I have the right to be treated as a living human being until I die.
- I have the right to maintain a sense of hopefulness, however changing its focus may be.
- I have the right to be cared for by those who can maintain a sense of hopefulness, however changing this might be.
- I have the right to express my feelings and emotions about my approaching death, in my own way.
- I have the right to participate in decisions concerning my care.
- I have the right to expect continuing medical and nursing attention even though "cure" goals must be changed to "comfort" goals.
- I have the right not to die alone.
- I have the right to be free from pain.
- I have the right to have my questions answered honestly.
- I have the right not to be deceived.
- I have the right to have help from and for my family accepting my death.
- I have the right to die in peace and dignity.
- I have the right to retain my individuality and not be judged for my decisions, which may be contrary to the beliefs of others.
- I have the right to discuss and enlarge my religious and/or spiritual experiences, regardless of what they may mean to others.
- I have the right to expect that the sanctity of the human body will be respected after death.
- I have the right to be cared for by caring, sensitive, knowledgeable people who will attempt to understand my needs and will be able to gain some satisfaction in helping me face my death.

Sorrentino, S.A. (1999). *Assisting with Patient Care*. Mosby, St. Louis. Page 843.

A GOOD DEATH

- ✓ **Free from avoidable distress and suffering for patients, families, and caregivers.**
- ✓ **In accord with patients' and families' wishes**
- ✓ **Reasonably consistent with clinical, cultural, and ethical standards.**

Dignified Death

- ✓ **Dying accompanied by respectful and skillful caregiving.**
- ✓ **Stress on autonomy.**
- ✓ **Free from dependency or physiological affronts not usually perceived as dignified.**
- ✓ **Helps people preserve their integrity while coping with unavoidable physical insults and losses.**

A BAD DEATH

- ✓ **Needless suffering.**
- ✓ **Dishonoring a patient or family wishes or values.**
- ✓ **Offending the norms of decency.**
- ✓ **Result from or accompanied by neglect, violence, or unwanted and senseless medical treatments.**

Humane Care System

One that people can trust to serve them well as they die, even if their needs and beliefs call for departures from routine practices or idealized expectations of caregivers.

Conveys by word and action that dignity resides in people, not physical attributes, and that helps people to preserve their integrity while coping with unavoidable physical insults and losses.

Palliative Care

- ✓ **Affirms life and regards dying as normal.**
- ✓ **Neither hastens nor postpones death.**
- ✓ **Provides relief from pain and other distressing symptoms.**
- ✓ **Integrates the psychological and spiritual aspects of patient care.**
- ✓ **Offers a support system. (WHO, 1994)**

Biological, moral, and ethical factors dictate that a guarantee of access to good palliative care must be regarded as a priority in our global society.