

FAST FACTS AND CONCEPTS #193
DECISION MAKING FOR ADULTS WITH DEVELOPMENTAL DISABILITIES NEAR THE END OF LIFE

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Background This *Fast Fact* will address medical decision making for adults with developmental disabilities (DD) who are facing terminal or life-limiting diseases such as cancer, end-stage organ failure, or progressive debility. See *Fast Fact* #192 for barriers to care and symptom assessment issues for persons with DD.

Advance Care Planning Clinicians should elicit individual preferences regarding end of life care from adults with DD or their guardians early in the course of a disease. Early discussions of a disease's likely course, as well as concerns such as cardiopulmonary resuscitation, mechanical ventilation, artificial nutrition, spiritual values, and place and circumstances of death may be helpful.

Who decides? Many patients will have legal guardians (often, but not always, family members) who have decision-making responsibility. However, some adults with DD will be able to express their values and wishes which should be accommodated as much as possible by surrogates and clinicians. Non-guardian family members and caregivers often provide valuable insight and decisions should ideally be made by consensus of all interested parties. Guardians are obliged to act in the patient's best interests; in the rare instance that clinicians suspect they are not doing so adult protective services or the courts need to be involved.

On what grounds? Treatment decisions need to be made based on reasonable estimates of benefits vs. risks, with attention always to effects on the patient's quality of life (QOL).

- Clinicians should be aware of their own biases in assessing a patient's QOL. People with profound disabilities can lead rich lives, considered precious to them and those who love them. Surrogate decisions should be made by caregivers who know the patient well and attempt to view the QOL from the patient's perspective.
- Define the risks/burdens of treatments for the patient:
 - Will treatments be understood? Can the patient readily comply with the therapy or will restraints or sedation be necessary (e.g. to receive chemotherapy or undergo diagnostic studies)?
 - Will treatments result in undue pain, suffering, or fear (hospitalization, IVs, nausea, vomiting, mucositis, diarrhea, or other side effects)?
 - How will QOL be different after treatment (e.g. post-chemotherapy neuropathy, new functional deficits, change in place of residence due to health status)?
 - Will remission or benefit be sustained long enough to warrant the duration of therapy?
- In emergency situations or in the absence of a decision maker, life-sustaining care should be the initial approach. However withdrawal or withholding of life-prolonging care is ethically appropriate if outcomes are either inconsistent with a patient's values or goals (such as maintaining or improving QOL) or the burdens of treatment clearly outweigh any medical benefit. Clinicians should be aware of local regulations governing such decisions.

Communication

- Find out as much about the patient as possible: *"What is a normal day like for her?" "What sorts of activities seem to be enjoyable or meaningful for him?" "What disturbs her?"*
- Focus on goals: *"If he could no longer enjoy X, what do you think he would want?" "Sounds like being at home – in familiar surroundings – is very important for her happiness. Is removing her from home frequently going to be worthwhile, even if she does live somewhat longer?"*
- Make recommendations on your best understanding of the situation and likely outcomes.
- Avoid use of the term "futility" or language that otherwise seems to undervalue the patient's life. Recognize that trust may need to be built with families due to prior incorrect predictions such as *"Your baby will never live to be an adult," "You will never be able to care for this child by yourself,"* or *"They will never have a meaningful life."*

References

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