

FAST FACTS AND CONCEPTS #192
PALLIATIVE CARE FOR ADULTS WITH DEVELOPMENTAL DISABILITIES

Neil M Ellison MD and Drew A Rosielle MD

Introduction The life expectancy for adults with developmental disabilities (DD) is now within 5 years of the general population. This has resulted in an increased frequency of death from age related illnesses such as cancer, heart disease, and chronic lung disease. This *Fast Fact* will review special issues in the care of developmentally disabled people with life-limiting diseases. *Fast Fact #193* will discuss decision making around life-threatening diseases for adults with DD.

Background Adults with DD may be defined as persons with impaired social functioning and decreased ability (mild to profound) to comprehend new or complex information or to learn new skills. These disabilities begin prior to age 18. Examples include people with autism, Down syndrome, and cerebral palsy associated mental retardation. During the past decades there has been a move towards decreased institutionalization with mainstreaming of persons with DD to the community. Home care is often provided by elderly parents. Community housing may be supervised by individuals with little familiarity with the patient.

Barriers to medical and palliative care for adults with DD

- Suboptimal nutrition, limited exercise, decreased utilization of health screening often negatively impact developmentally disabled people's health.
- Communication barriers can lead to more advanced illness presentation.
- Lack of clarity of goals of care and poorly defined decision-makers (see *Fast Fact #193*).
- Developmentally disabled people may not be allowed appropriate bereavement:
 - Deprived of the knowledge of death of their caregivers and loved ones.
 - Excluded from funerals, memorial services, or other bereavement activities.
- Patient lack of comprehension of their illness, its symptoms, or its treatments:
 - May interpret illness or treatments as punishment for wrong-doing.
 - May not be able to understand death and why their family/caregivers are sad around them.
- Symptom assessment may be compromised by an inability to communicate:
 - Individuals demonstrate a wide range of behaviors indicating discomfort, some of which may be subtle and only apparent to people who know them well, if at all.
 - Signs of distress may be apparent even though it is unclear what is causing the distress: pain, other somatic symptoms, anxiety/fear, sadness?

Providing effective palliative and supportive care to adults with DD

- Work closely with caregivers to maximize time in familiar surroundings, with familiar people and objects, in identifying routines and activities enjoyable to the patient, and in ways to offer emotional reassurance.
- Communicate about symptoms understandable to the patient, as opposed to abstract diseases.
- Symptom assessment and management (see also *Fast Fact #126*):
 - Research has supported the finding that symptom assessment needs to be individualized to the patient, based on the experience of a patient's closest caregivers.
 - DisDAT – a distress assessment tool – has been developed to help clinicians and caregivers identify, communicate about, and document an individual's signs of distress and contentment (3,4).
 - Symptom management should focus on careful examination of patterns of distress, a thorough physical examination, judicious use of diagnostic testing, and empiric use of comfort medications based on what is felt to be the most likely cause. Trial and error, with constant monitoring of adverse medication effects, is often necessary.

References

1. Read S. Learning Disabilities and Palliative Care: Recognizing Pitfalls and Exploring Potential. *Intl J Palliat Nurs.* 2003; 11:15-20.
2. Tuffrey-Wijne I. The palliative care needs of people with intellectual disabilities: a literature review. *Palliat Med.* 2003; 17:55-62.
3. Regnard C, Reynolds J, Watson B, et al. Understanding distress in people with severe communication difficulties: developing and assessing the Disability Distress Assessment Tool (DisDAT). *J Intellect Disability Res.* 2007;51:277-292. (Further discussion of and examples of DisDAT are available at: <http://www.disdat.co.uk>.)

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