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


**Fast Facts and Concepts** are edited by Sean Marks MD (Medical College of Wisconsin) and associate editor Drew A Rosielle MD (University of Minnesota Medical School), with the generous support of a volunteer peer-review editorial board, and are made available online by the Palliative Care Network of Wisconsin (PCNOW); the authors of each individual *Fast Fact* are solely responsible for that *Fast Fact*’s content. The full set of *Fast Facts* are available at Palliative Care Network of Wisconsin with contact information, and how to reference *Fast Facts.*

**Copyright:** All *Fast Facts and Concepts* are published under a Creative Commons Attribution-NonCommercial 4.0 International Copyright ([http://creativecommons.org/licenses/by-nc/4.0/](http://creativecommons.org/licenses/by-nc/4.0/)). *Fast Facts* can only be copied and distributed for non-commercial, educational purposes. If you adapt or distribute a *Fast Fact*, let us know!

**Disclaimer:** *Fast Facts and Concepts* provide educational information for health care professionals. This information is not medical advice. *Fast Facts* are not continually updated, and new safety information may emerge after a *Fast Fact* is published. Health care providers should always exercise their own independent clinical judgment and consult other relevant and up-to-date experts and resources. Some *Fast Facts* cite the use of a product in a dosage, for an indication, or in a manner other than that recommended in the product labeling. Accordingly, the official prescribing information should be consulted before any such product is used.