



Office of Developmental Primary Care

Improving health outcomes for people with developmental disabilities

Supporting People with Loss of Function from Terminal Illness

People with terminal illnesses often lose functional abilities over the course of their disease. However, with the right accommodations, adaptive equipment, services and supports, people can live meaningful lives at every stage. Everyone can continue to participate in their home and communities, no matter what their functional ability. You can help patients who are experiencing existential distress by assisting them in adapting to functional loss. While the resources available vary, once the needs are clearly defined, you can work with your patient, health plan and medical center care coordinators, chaplain services, and community agencies to find resources and problem solve.

Respect Autonomy

Continue to speak directly to your patient, even if they are unable to respond. Include them in meetings where issues that concern them are discussed. Seek consent before talking to supporters. Ask if they have a trusted supporter who can help them make decisions. Reassure your patient that you will continue to respect their decisions, even if they need support to make them. Help your patients develop Supported Decision-Making agreements that can work in conjunction with a Power of Attorney. Sample agreements can be found in the Supported Decision-Making Resource Library on the ACLU website: <https://www.aclu.org/other/supported-decision-making-resource-library>.

Connect People to Role Models and Social Support

The best people to advise patients on how to adapt to loss of function are people who live with disabilities. Connect patients and families to support groups, patient advocates, blogs, and community organizations where they can meet people who face similar challenges. Vet the resources before referring to make sure they are positive and affirming.

Ensure Adequate Personal Assistance

Everybody deserves support for their activities of daily living. Support can come from direct support professionals, nurses, family or friends. Family or friends may be eligible to receive financial support for their important role through self-directed programs such as the In-Home Supportive Services program for Medi-Cal members, or programs such as San Francisco's Support at Home program. Self- paid assistance is available through home healthcare agencies or families can hire their own assistants. Volunteer assistance can often be found through religious or community organizations. Some neighborhoods have developed cooperatives to help each other with care. People with developmental disabilities can make requests to their regional center case coordinator.

Assess the Needs of Caregivers and Supporters

The needs of people with terminal illness are important. So are the needs of their caregivers. Assess caregiver needs outside of your patient appointments or at a separate appointment where the focus is solely on the caregiver. This will enable the caregiver to speak candidly. Caregivers may need information

and training, respite, assistance navigating health care systems, financial assistance, adaptive equipment, social support, and more. Sometimes the best solution is to relieve a caregiver of some or all of their responsibilities.

Offer In-home Care

If patients have significant weakness, fatigue, or logistical challenges, offering home visits can help relieve stress, support caregivers, and improve care. Many health plans have home care programs for people with complex needs.