
Palliative Care for Individuals with IDD

PROJECT ECHO

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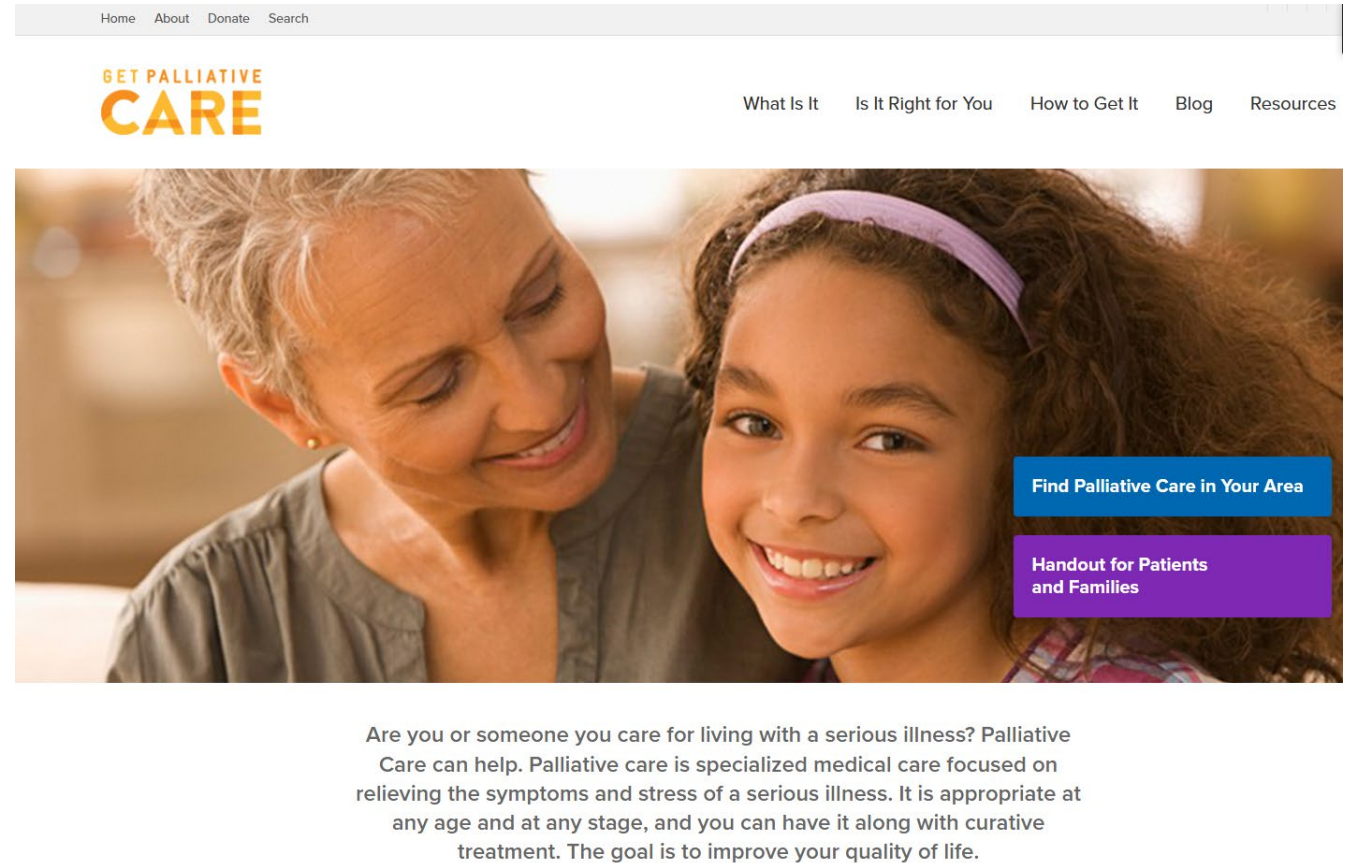
February 12, 2026

A black and white photograph of a railway track. In the foreground, a track switch is visible, with two rails curving towards the right. The rails are supported by wooden sleepers and metal fasteners. The track extends into the background, where it curves again. The ground between the tracks is covered with gravel. The lighting creates strong shadows, highlighting the textures of the rails and sleepers.

I have nothing to disclose

Palliative Care - getpalliativecare.org

- Specialized care focused on relieving the symptoms and stress of a serious illness
- Goal is to improve or maintain quality of life in whatever stage of illness
- Living as well as possible for as long as possible

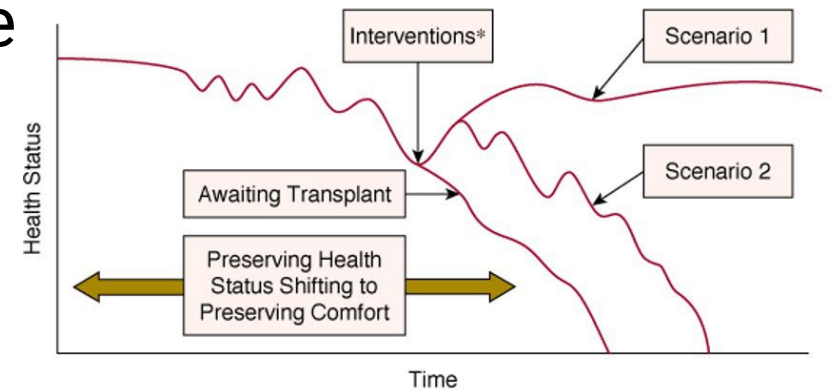


What is serious illness?

- **Life-Limiting Condition (LLC)** – there is no reasonable hope for cure, and will lead to early death (muscular dystrophy)
- **Life-Threatening Condition (LTC)** – curative treatment may be feasible but may fail and be burdensome (cancer)
- **Chronic Complex Conditions (CCC)** - condition that involves several organ systems or one organ system enough to require specialized care, often at a tertiary medical center (cerebral palsy, genetic conditions, trauma)
- Overlap with intellectual and developmental disabilities (IDD)

Predicting Prognosis and Trajectory

- Some diseases have more predictable courses than others - static vs progressive
- Diseases of childhood include the uncertainty of neurodevelopment
- New therapies may alter the course of an illness and change prognosis
- Uncertainty is very difficult for families
- Life-sustaining therapies and technologies may dramatically alter the length and quality of life



* Examples of interventions: chemotherapy, radiation therapy, organ transplantation, gastrostomy feeding tube, antireflux surgery, treatment of acute respiratory exacerbations from chronic pulmonary aspiration, medication changes for intractable epilepsy.

Source: Rudolph CD, Rudolph AM, Lister GE, First LR, Gershon AA: Rudolph's Pediatrics, 22nd Edition: www.accesspediatrics.com Copyright © The McGraw-Hill Companies, Inc. All rights reserved.



Palliative Care is...

- NOT closing the door on curative treatment
- NOT pushing for less aggressive therapy
- NOT only hospice and end of life care
- NOT taking away hope
- NOT giving up
- It is about living your best life

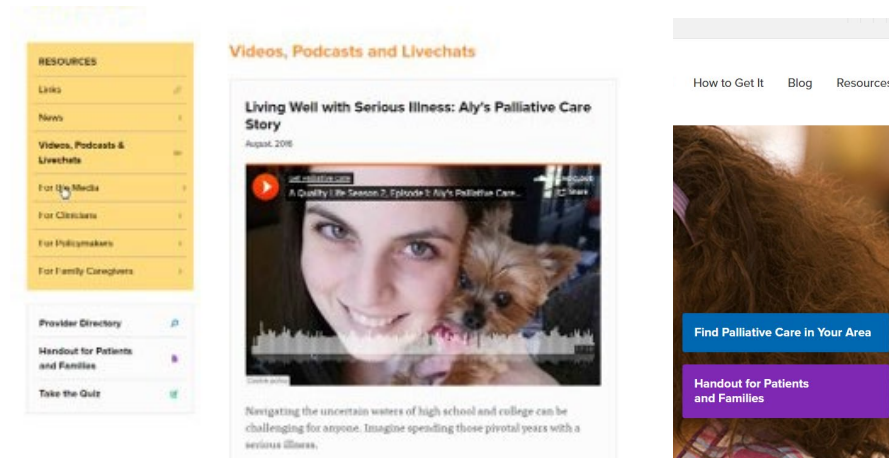


Primary vs Subspecialty Palliative Care

- Primary palliative - provided by anyone on healthcare team
 - Communication skills
 - Attention to symptoms and quality of life
 - Care coordination and collaboration between specialties
 - Help with making decisions
- Subspecialty - provided by an interdisciplinary team
 - Communication in challenging scenarios
 - Symptom management for quality of life with worsening disease
 - Psycho-social-spiritual support for “total pain”
 - Care coordination and collaboration
 - Advance care planning, tradeoffs, life and death decision-making



Palliative Care - getpalliativecare.org



Are you or someone you care for living with a serious illness? Palliative Care can help. Palliative care is specialized medical care focused on relieving the symptoms and stress of a serious illness. It is appropriate at any age and at any stage, and you can have it along with curative treatment. The goal is to improve your quality of life.

There are small teams and limited resources for specialty palliative care. ChildServe and other facilities and hospice teams also provide palliative care expertise and training.

Palliative Care Provider Directory

Search Results: 13 results found

ENTER ADDRESS, ZIP CODE OR CITY & STATE
iowa

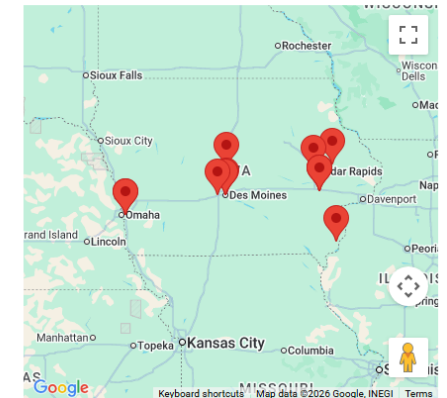
RADIUS
Closest 20 results

CHECK THE ONE THAT APPLIES:
☒ Hospital ☐ Nursing Home ☐ Office/Clinic ☐ Home

Search

The Palliative Care Provider Directory is a resource to help you or a loved one locate palliative care in your area. It includes all programs that have listed themselves with us. Please contact the palliative care program directly to confirm eligibility.

- Blank Children's Hospital
- CHI Health Mercy Council Bluffs
- Iowa Lutheran Hospital
- Iowa Methodist Medical Center
- Mary Greeley Medical Center
- Methodist Jennie Edmundson Hospital
- Methodist West Hospital
- Southeast Iowa Regional Medical Center
- UnityPoint Health - Jones Regional Medical Center
- UnityPoint Health - St Lukes Hospital
- University of Iowa Hospitals and Clinics
- University of Iowa Stead Family Childrens Hospital



Palliative Care - getpalliativecare.org

Clinic/Office-based

Palliative Care Provider Directory

Search Results: 6 results found

ENTER ADDRESS, ZIP CODE OR CITY & STATE

RADIUS

Closest 20 results

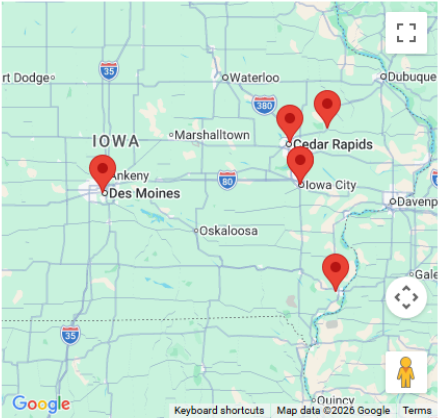
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- Blank Children's Hospital Pediatric Palliative Care Clinic
- Jones Regional Medical center
- Pediatric Specialty Clinic
- Southeast Iowa Regional Medical Center- Palliative Care
- UnityPoint Health - St. Luke's Palliative care Clinic
- University of Iowa Dance Marathon Pediatric Cancer Center



Home-based

Palliative Care Provider Directory

Search Results: 6 results found

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- Compassus Palliative Care
- Palliative Care Consulting by Hospice of Dubuque
- UnityPoint Health - St. Luke's Palliative Care
- Carelon Health Palliative Care
- Palliative/Supportive Care
- Blank Children's Hospital SHINE Perinatal and Pediatric Palliative Care Team

If you are a palliative care provider and would like to be listed in the Provider Directory, please visit [this page](#).
This directory is published as a convenient public service and is provided for informational purposes only. We regret we cannot answer questions for you as a caregiver, please contact your doctor for more information.

Special considerations in IDD care

- What distressing symptoms are likely?
 - Pain from spasticity, abdominal pain, central pain / neuro
 - Dyspnea, secretion management, nausea, fatigue
- How are distressing symptoms evaluated?
 - Patient report? Using appropriate scales?
 - Behavior tracking? FLACC
 - Caregiver report?
- What treatment options are available?
 - Pharmacological – considering side effects, med interactions
 - Non-pharmacologic – therapy, integrative
- How will treatment trials be evaluated?



Special considerations in IDD care

- What is anticipated future medically and cognitively?
 - Stable? Improvement? Decline? Fragility?
 - What future quality of life or life and death decisions are reasonably predictable?
- How are healthcare decisions made?
 - Patient with or without support?
 - Advance Directive designated by patient with capacity?
 - Legal next of kin?
- Is there consideration of appointing a legal guardian?
 - Iowa law currently requires a guardian to have additional court approval to withhold or withdraw life-sustaining treatment, which requires support from team
- Is IPOST an option to consider?
 - Portable order with CPR/DNR and other decisions

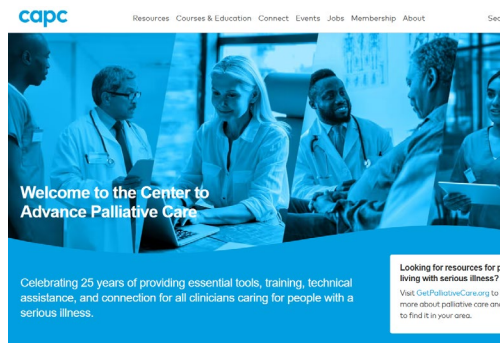


HIPAA PERMITS DISCLOSURE OF IPOST TO OTHER HEALTH CARE PROVIDERS AS NECESSARY				
Iowa Physician Orders for Scope of Treatment (IPOST)				
First follow these orders, THEN contact physician or nurse practitioner. This is a Physician order sheet based on the person's current medical condition and wishes. Any section not completed implies full treatment for that section. Everyone shall be treated with dignity and respect.				
A	Check one	CARDIOPULMONARY RESUSCITATION (CPR): <u>Person has no pulse AND is not breathing.</u> ☐ CPR/Attempt Resuscitation ☐ DNR/Do Not Attempt Resuscitation		
B	Check one	MEDICAL INTERVENTIONS: <u>Person has a pulse AND/OR is breathing.</u> ☐ COMFORT MEASURES ONLY Use medication by any route, positioning, wound care and other measures to relieve pain and suffering. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. <i>Patient prefers no transfer to hospital for life-sustaining treatment. Transfer if comfort needs cannot be met in current location.</i> ☐ LIMITED ADDITIONAL INTERVENTIONS Includes care described above. Use medical treatment, cardiac monitor, oral/IV fluids and medications as indicated. Do not use intubation, or mechanical ventilation. May consider less invasive airway support (BiPAP, CPAP). May use vasopressors. <i>Transfer to hospital if indicated, may include critical care.</i> ☐ FULL TREATMENT Includes care described above. Use intubation, advanced airway interventions, mechanical ventilation and cardioversion as indicated. <i>Transfer to hospital if indicated. Includes critical care.</i> Additional Orders: _____		
C	Check one	ARTIFICIALLY ADMINISTERED NUTRITION Always offer food by mouth if feasible. ☐ No artificial nutrition by tube. ☐ Defined trial period of artificial nutrition by tube. ☐ Long-term artificial nutrition by tube.		
D	MEDICAL DECISION MAKING			
Directed by: (listed in order of Iowa Code/Statute for Priority of Surrogates; check only one) ☐ Patient ☐ Durable Power of Attorney for Health Care ☐ Spouse ☐ Majority of Adult Children ☐ Parents ☐ Majority rule for nearest relative ☐ Other: _____		Rationale for these orders: (check all that apply) ☐ Advance Directives Year AD completed: _____ ☐ Patient's known preference ☐ Limited treatment options ☐ Poor prognosis ☐ Other: _____		
Physician/ARNP/signature (mandatory)		Print Physician/ARNP/ Name	Date	Phone Number
Patient/Resident or Legal Surrogate for Health Care Signature (mandatory)				Date
SEND FORM WITH PERSON WHENEVER TRANSFERRED OR DISCHARGED				



Iowa Physician Orders for Scope of Treatment

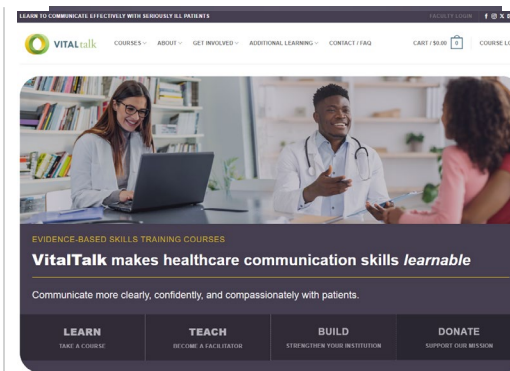
Other resources



CAPC

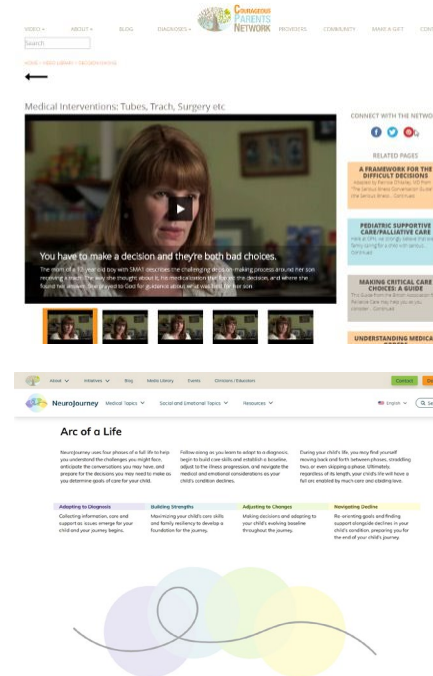
Center to Advance Palliative Care – for healthcare providers

Iowa Health Care has an institutional membership



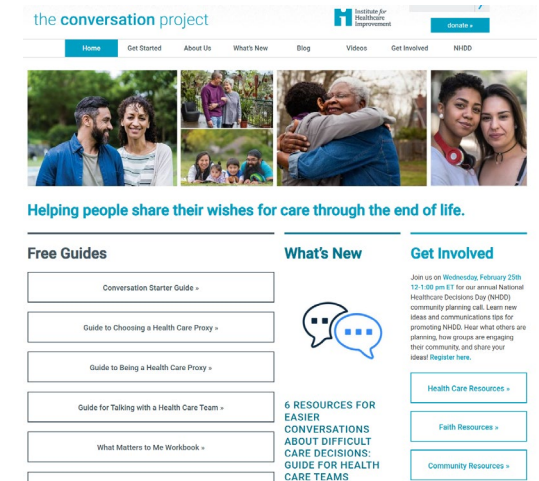
VitalTalk

Website and app with evidenced based guides for serious conversations



CPN and NeuroJourney

Courageous Parent Network – designed by parents with clinician support



The Conversation Project

Helping people share their wishes for care through the end of life

Thank you

→ uihc.org



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Getpalliativecare.org