

Palliative Care Glossary

This glossary was created by the Haslinger Family Pediatric Palliative Care Center at the Akron's Children's Hospital in Akron, OH. To learn more about the Haslinger Center, visit:

<https://www.akronchildrens.org/cms/subsite/e72d31b7552f899a/index.html>

Acute care - Hospital care given to patients who generally require a stay of several days and that focuses on a physical or mental condition requiring immediate intervention and constant medical attention, equipment and personnel. The term acute is used for a sudden onset and short duration.

Addiction - Addiction is a primary, chronic, neurobiologic disease, with genetic, psychosocial, and environmental factors influencing its development and manifestations. It is characterized by behaviors that include one or more of the following: impaired control over drug use, compulsive use, continued use despite harm, and craving.

Advance Medical Directives - Advance directives are used to give other people, including health care providers, information about your wishes for medical care. Advance directives are important in case there is ever a time when you are not physically or mentally able to speak for yourself and make your wishes known. The most common types of advance directives are the living will and the durable power of attorney for health care.

Allodynia - When pain is caused by something that does not normally cause pain (such as clothing touching the skin); hypersensitivity usually caused by nerve disruption.

Alternative Medicine - Treatment procedures that are not generally prescribed by Western medicine practitioners, often because of lack of supporting peer-reviewed experimental data. Examples include acupuncture and herbal therapies.

Ambulatory care - Care given to patients who do not require overnight hospitalization.

Analgesic Medications - Medications used to prevent or treat pain.

AND (Allow Natural Death) - Refers to the order at Akron Children's Hospital that allows a natural course of events to occur in an acute care setting. It is an active, positive position embodying the hope that dying will occur peacefully and naturally as possible, surrounded by

loved ones. The AND order codifies the spirit of ongoing communication between the patient and legal decision-maker(s) and the health care team. Its completion should not be viewed as an end in itself, but rather as a tool to document preferences while facilitating further advanced care planning.

Anti-depressant - Medications used to treat depression, and also used to treat chronic pain. Anti-depressants can also be helpful for pain-related symptoms, like sleep problems and muscle spasms.

Anxiolytic - Medications used to treat anxiety, and also used to treat chronic pain. Anxiolytics reduce pain-related anxiety, help relax muscles and help people cope with pain.

Artificial Nutrition/Hydration - Fluid and nutritional supplements provided through an IV or a feeding tube to patients who are unable to eat or drink by mouth, or those who are dehydrated or malnourished.

Assent - A child's affirmative agreement to participate in his or her own medical care. In order to give meaningful assent, the child must understand that procedures will be performed, voluntarily choose to undergo procedures, and communicate this choice.

Autonomic (or neurologic) storming - A sudden and temporary increase of symptoms in the course of a disease. This is an uncontrolled and unpredictable mental state. Symptoms can include alterations in level of consciousness, agitation, increased posturing, dystonia, hypertension, hyperthermia, tachycardia, tachypnea, and diaphoresis.

Bereavement - The process of grieving someone's death.

BiPAP Machine (Bilevel positive airway pressure) - BiPAP is a form of non-invasive ventilation which uses an electronic circuit to monitor the patient's breathing; attempts to restore circulation of the blood and prevent death or brain damage due to lack of oxygen. Composed of two parts: compressing the chest to force blood to circulate and pushing air into the lungs to give oxygen; this can be done by mouth or mask.

Cardiopulmonary Resuscitation (CPR) - An emergency procedure consisting of external cardiac massage and artificial respiration; the first treatment for a person who has collapsed and has no pulse and has stopped breathing; attempts to restore circulation of the blood and prevent death or brain damage due to lack of oxygen. Composed of two parts; compressing the chest to force blood to circulate and pushing air into the lungs to give oxygen; this can be done by mouth or mask.

Caregiver - Any person who provides care for the physical and emotional needs of a family member or friend.

Causalgia (Complex Regional Pain Syndrome II) - Pain, usually burning, that is associated with

autonomic changes - change in color of the skin, change in temperature, change in sweating, swelling. Causalgia occurs after a nerve injury.

Central Nervous System - The brain and the spinal cord.

Chronic Pain - Pain that occurs for more than one month after healing of an injury, that occurs repeatedly over months, or is caused by a lesion that is not expected to heal.

Clinical Trials - Carefully planned and monitored experiments to test a new drug or treatment.

Complementary Medicine - Approaches to medical treatment that are outside of mainstream medical training. Complementary medicine treatments used for pain include acupuncture, low-level laser therapy, meditation, aroma therapy, Chinese medicine, dance therapy, music therapy, massage, herbalism, therapeutic touch, yoga, reiki, osteopathy, chiropractic treatments, naturopathy, and homeopathy.

Computed Tomography (CT/CAT) Scanning - A painless technique used to produce a picture of a cross-section, or "slice," of a part of the body. X-rays are used to produce this picture.

Constipation - Difficulty having a bowel movement, or having fewer bowel movements than normal.

Coordination of Care - An approach where all members of the medical team work together to plan the care in the hospital, for discharge, and at home.

CPAP Machine (Continuous positive airway pressure) - A form of non-invasive ventilation used for the treatment of obstructive sleep apnea. Through a mask, a CPAP machine increases air pressure in the throat so that the airway does not collapse when breathing in. Obstructive sleep apnea occurs when the patient's airway becomes restricted as the muscles relax naturally during sleep. This restricts breathing and causes arousal from sleep

Critical Illness - A disease that may lead to death.

Delirium - A disturbance of brain function that causes confusion and changes in alertness, attention, thinking and reasoning, memory, emotions, sleeping patterns and coordination. These symptoms may start suddenly, are often due to some type of medication or medical problem, and may get worse or better multiple times.

Dependence - A state of adaptation to a drug that is manifested by specific withdrawal syndrome. Can be produced by abrupt cessation, rapid dose reduction, decreasing blood level of the drug, and/or administration of an antagonist. Not the same as addiction.

Do-Not-Resuscitate (DNR) Orders - Instructions written by a doctor telling other healthcare providers to not try to restart a patient's heart, using CPR or other related treatments, if his or

her heart stops beating. Usually, DNR orders are written after a discussion between a doctor and the patient and/or family members. DNR orders are written for people who are very unlikely to have a successful result from CPR -- those who are terminally ill or those who are elderly and frail.

Durable Power of Attorney for Health Care - A legal document that specifies one or more individuals (called a healthcare proxy) you would like to make medical decisions for you if you are unable to do so yourself.

Dyspnea - Difficulty in breathing, or subjective sensation of having trouble getting enough air.

Emancipated Minor - A legal mechanism through which a person below the age of majority gains certain civil rights, generally identical to those of adults. Emancipated minors are free of any authority from their parents or other legal guardians. The extensions of these rights, as well as the remaining prohibitions, vary according to the jurisdiction. Not a legal status in Ohio.

End-of-Life Care - Doctors and caregivers provide care to patients approaching the end of life, which is focused on comfort, respect for decisions, support for the family, and treatments to help psychological and spiritual concerns.

Entitlement - A federal program (such as Social Security or unemployment benefits) that guarantees a certain level of benefits to those who meet requirements set by law.

EPEC (Education for Physicians on End-of-Life Care)/ELNEC (End-of-Life Nursing Education Curriculum) - A project designed to educate providers across the United States about providing good end-of-life care for patients. EPEC includes a curriculum used to train doctors in clinical knowledge and skills they need to care for dying patients.

Ethics - A system of moral principles and rules that are used as standards for professional conduct. Many hospitals and other healthcare facilities have ethics committees that can help doctors, other healthcare providers, patients and family members in making difficult decisions regarding medical care.

Euthanasia - The practice of terminating the life of a person in a painless or minimally painful way in order to stop suffering or other undesired conditions in life. This may be voluntary or involuntary, and carried out with or without a physician. In a medical environment, this can be carried out by oral, IV or intramuscular drug administration.

Fatigue - A feeling of becoming tired easily, being unable to complete usual activity, feeling weak, and having difficulty concentrating.

Fibromyalgia - A pain disorder in which a person feels widespread pain and stiffness in the muscles, fatigue, and other symptoms.

Gastrostomy Tube (G-tube or Mickey button) - A feeding tube placed surgically into the stomach to allow provision of artificial nutrition/hydration or administration of medications.

Grief - The reaction to loss. It encompasses thoughts and feelings, as well as physical, behavioral, and spiritual responses. These reactions may appear immediately after someone experiences a death, or they may be delayed; they may even be absent. No particular survivor will necessarily experience all of them, nor must all be present. Grief is highly variable and unique for each person. It is an evolving process with multiple dimensions.

Guardian - An individual who is authorized under applicable State or local law to consent on behalf of a child to general medical care.

Home Care - Services provided in the home such as nursing and physical therapy.

Hospice - A special philosophy (not a place) of caring for people with terminal illnesses and their families by meeting the physical, emotional, social, and spiritual needs. The goals of hospice are to keep the patient as comfortable as possible by relieving pain and other symptoms; to prepare for a death that follows the wishes and needs of the patient; and to reassure both the patient and family members by helping them understand and manage what is happening. Entrance into a hospice program does not require a DNR or abandonment of cure-directed therapy.

Hospice Home Care - Most hospice patients receive care while living in their homes. Home hospice patients have family members or friends who provide most of their care, with help and support from the trained hospice team. The hospice team visits at the house to provide medical and nursing care, emotional support, counseling, information, instruction and practical help. A home care aide may also be available to help with daily care, if needed. Patients can usually continue to receive disease-directed therapy, including transfusions, chemotherapy, radiation therapy and clinic/doctor visits.

Hyperalgesia - Extreme sensitivity to pain.

Hyperpathia - An exaggerated response to something that causes pain, with continued pain after the cause of the pain is no longer present.

Informed Consent - The process of making decisions about medical care that are based on open, honest communication between the healthcare provider and the patient and/or the patient's family members.

Interdisciplinary Team - A group of people who perform tasks independent of one another, with individual expertise, but who coordinate their efforts with one another to maximize the benefits for the client/family/child and minimize the duplication of procedures/services. Coordination usually takes the form of "staffings" and/or meetings, which generally include the family. The core members of a clinical interdisciplinary team typically include physicians,

nurses, social workers, and chaplains. Other disciplines may also be members of the team, according to the needs of the patient and family, such as ethicists, pharmacists, volunteers, psychologists, psychiatrists, pain specialists, nutritionists, physical therapists, occupational therapists, music therapists, art therapists, and bereavement counselors.

Intractable Pain- Intractable pain is chronic pain that cannot be treated or removed by usual medical treatments or by natural healing. Intractable pain is debilitating, constant, and incurable even after efforts to relieve this pain made by physicians and surgeons that specialize in treating the part of the body acting as the source of the pain. This type of pain can cause elevations of pulse, blood pressure, and adrenal gland hormones, but vital signs can also be normal in children experiencing chronic, intractable pain. Untreated pain has severe long-term consequences and multi-system effects on ability to heal, sleep patterns, appetite/nutritional status, social engagement, coping skills, emotional stability, and life enjoyment, to name only a few. Early untreated pain that becomes intractable in young children interferes with normal nervous system development and can cause long-term problems with pain management throughout life.

Intubation - The process of inserting a breathing tube into a patient's airway to help with breathing; usually requires a ventilator to provide breathing support.

Life-Sustaining Medical Treatment (LSMT) - Encompasses all interventions that may prolong the life of patients. Although LSMT includes the dramatic measures of contemporary practice such as organ transplantation, respirators, kidney (dialysis) machines, and vasoactive drugs, it also includes less technically demanding measures such as antibiotics, insulin, chemotherapy, and nutrition and hydration provided intravenously or by tube.

Living Will - A legal document that outlines the kinds of medical care a patient wants and doesn't want. The living will is used only if the patient becomes unable to make decisions for himself.

Long-Term Care - Care that is provided in nursing facilities, at home, or in the community that supports patients with chronic impairment for an indefinite period of time.

Magnetic Resonance Imaging (MRI) - A painless technique that uses magnetic fields and radio waves (without radiation) to create clear cross-sectional pictures of the body.

Mourning - Culturally and socially sanctioned ways that individuals convey feelings of grief and loss.

Myofascial Pain - Muscle pain and tenderness.

Nasogastric Tube - A tube placed into the stomach or small intestine through the nose to allow provision of artificial nutrition/hydration or administration of medication.

Nerve Blocks - Injections of anesthetic (or numbing) substances into nerves in order to reduce pain.

Neuropathic Pain - A complex, chronic pain state that usually is accompanied by tissue injury. With neuropathic pain, the nerve fibers themselves may be damaged, dysfunctional or injured. These damaged nerve fibers send incorrect signals to other pain centers. The impact of nerve fiber injury includes a change in nerve function both at the site of injury and areas around the injury.

Opioid - A type of medication chemically related to opium. Opioids are strong analgesics. Opioids include morphine, codeine, and a large number of synthetic (man-made) drugs like methadone and fentanyl.

Pain - An unpleasant feeling that may or may not be related to an injury, illness, or other bodily trauma. Pain is complex and differs from person to person. **Acute Pain** has a known cause and occurs for a limited time. It usually responds to treatment with analgesic medications and treatment of the cause of the pain. **Chronic Pain** occurs for more than one month after healing of an injury, occurs repeatedly over months, or is due to a lesion that is not expected to heal. **Pain Due to Nerve Injury** is caused by an injury or other problem in the nervous system.

Palliate - To relieve the symptoms of a disease or disorder; to provide comfort.

Palliative Care - The total care of patients with life-threatening illness. In palliative care, the focus of care is on quality of life. Control of pain and other physical symptoms, and treatment of psychological, social and spiritual problems are considered most important. Care is provided by a multi-disciplinary team of caregivers who focus on care coordination, help with informed decision making, and aggressive symptom management.

Palliative Sedation - The continuous administration of medication that sedates a person to unconsciousness. Used for the imminently dying to relieve intractable symptoms when all other interventions have been unsuccessful. Requires informed consent of the patient and/or family.

Patient-Controlled Analgesia (PCA) - Pain medication given through an IV or epidural catheter. Patients control the dose of medication they take, depending on how much is needed to control the pain. PCA is usually used for patients recovering from intra-abdominal, major orthopedic, or thoracic surgery, and for chronic pain states, such as those due to cancer.

Peripheral Nervous System - The nerves throughout the body that send messages to the central nervous system.

Peripheral Neuropathy - Pain caused by an injury or other problem with the peripheral nervous system.

Phantom Pain - Pain that develops after an amputation. To the patient, the pain feels like it is

coming from the missing body part.

Pharmacotherapy - The treatment of diseases and symptoms with medications.

Physician Assisted Suicide - Actions by a doctor that help a patient commit suicide. Though the doctor may provide medication, a prescription, or take other steps, the patient takes her own life (for instance, by swallowing the pills that are expected to bring about death). Illegal in Ohio.

Postherpetic Neuralgia (PHN) - Painful condition following shingles (herpes zoster).

Preventive Care - Comprehensive care emphasizing priorities for prevention, early detection and early treatment of conditions, generally including routine physical examination and immunizations.

Prognosis - The description of the path a disease is likely to take.

Psychological Approaches - Techniques used to help patients cope with pain and deal with emotional factors that can increase pain. Such strategies include biofeedback, imagery, hypnosis, relaxation training, stress management, cognitive-behavioral therapy, and family counseling.

Reflex Sympathetic Dystrophy (Complex Regional Pain Syndrome I) - Pain, usually burning, that is associated with "autonomic changes" - change in color of the skin, change in temperature, change in sweating, swelling. Reflex sympathetic dystrophy is caused by injury to bone, joint, or soft tissues.

Rehabilitation - Treatment for an injury, illness, or pain with the goal of restoring function.

Respite Care - Temporary care given by another in place of the primary caregiver so the primary caregiver can take a break. Can occur in the patient's home, in the hospital, or in another facility.

Skilled Nursing Facility - A facility, either freestanding or part of a hospital, that accepts patients in need of rehabilitation and medical care that is of a lesser intensity than that received in the acute care setting of a hospital.

Sub Acute Care - A term used to describe short-term care in a nursing facility usually for physical therapy.

Surrogate Decision Maker - Competent adults may formulate, in advance, preferences regarding a course of treatment in the event that injury or illness causes severe impairment or loss of decision-making capacity. These preferences should be followed by the healthcare team out of respect for patient autonomy. Patients may establish an advance directive by documenting their treatment preferences and goals or by designating a proxy to make

healthcare decisions on their behalf. For children, who are not legally competent, surrogate decision makers (usually parents) act in their best interests.

Terminal Condition - An irreversible, incurable, and untreatable condition caused by disease, illness, or injury from which, to a reasonable degree of medical certainty as determined in accordance with reasonable medical standards.

Tolerance - A state of adaption in which exposure to a drug induces changes that result in a diminution of one or more of the drug's effects over time.

Tracheostomy- A tracheostomy, or tracheotomy, is a surgical procedure that creates an opening in both the neck and trachea of the child in order to aid in getting air into the child's lungs. A hollow tube, the tracheostomy tube, is inserted into the incision and allows for an artificial airway and normal respiration. This procedure is used when an obstruction is present in the upper respiratory tract, which is the area between the nose and the larynx. Obstruction can be a result of an actual physical blockage or be due to hypotonia (floppiness) of the airway. The term tracheostomy can refer the opening created by the procedure as well as the procedure itself. Tracheostomy tubes can be connected to oxygen delivery systems or to ventilators (respirators), or the child can breathe regular room air through the tube if supplemental oxygen is not needed.

Transdisciplinary Team - A group of people who performs tasks collaboratively by sharing not only information, but roles. Mutually agreed upon priority goals are developed and information, knowledge, and skills are transferred across disciplinary boundaries. Periodic staffings/meetings and frequent consultations (monthly at least) provide opportunities for exchange of information and training as various members assume a primary facilitator role for addressing the goals. All team members are considered 'active' and must be available to meet with others on the team at least monthly and to deliver service directly as needed. Direct service by other members can continue but less frequently, if the primary facilitator(s) is/are capable of addressing those discipline-related needs.

Trigeminal Neuralgia - A disorder of the trigeminal nerve that causes brief attacks of severe pain in the lips, cheeks, gums, or chin on one side of the face.

Ventilator - A machine that helps a patient to breathe; mechanically assists patients in the exchange of oxygen and carbon dioxide (sometimes referred to as artificial respiration). Patients are usually placed on a ventilator because of a medical condition that makes it hard for them to breathe well on their own.

Withdrawal - A syndrome that might occur when a medication that has been used regularly to treat pain is no longer used, or when the dose is decreased. Showing symptoms of withdrawal does not mean a patient is addicted to his pain medication.

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