



GLOSSARY OF TERMS

Diagnosis - The process of determining the nature of a medical condition.

DNR - A Do Not Resuscitate order is a physician's order; it is prepared by a physician or an advanced practice nurse. This means that cardiopulmonary resuscitation (CPR) would not be started if the heart or lungs stopped working.

End of life care - This helps patients with advanced, progressive, incurable illnesses live as well as possible until they die. It focuses on preparing for an anticipated death and managing the end stage of a terminal medical condition. This includes care near the time of death and immediately afterwards. It enables the supportive and palliative care needs of both child and their family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support, as well as bereavement support.

Gastrostomy tube (G-tube) - Some children cannot get adequate nutrition orally. In these cases, G-tube is inserted through the belly that brings nutrition directly to the stomach. It's one of the ways doctors ensure patients get the fluid and calories they need. G-tubes are inserted through a short procedure called a gastrostomy and can stay in place for as long as a child needs it.

Goals of Care Discussion - Goals of Care discussions ensure parents understand the serious nature of their child's illness, while helping healthcare providers to understand the family's values and goals they have for their child's care. These discussions center should help parents understand options for treatment given the current clinical context, and ensures the child/family is better supported throughout the care journey. Importantly, Goals of Care discussions provide the basis for treatment decisions and informed consent.

Palliative Care - Palliative care for children with life-limiting conditions is an active and collaborative approach that starts at the point of diagnosis. Palliative care embraces physical, emotional, social and spiritual needs. It focuses on enhancement of quality of life for the child and support for the family, including the management of distressing symptoms, provision of short breaks, and care through death and bereavement. Palliative Care can also allow for better communication among a child's caregivers, which can help

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families make better choices. Ideally, palliative care works hand-in-hand with the patient's medical (curative) team, working best when offered together.

Philosophy of Care - This is a framework of care goals and values to help parents make the best choices for their child and family. Philosophies occur along a spectrum from less intervention to a more technical approach. There are no right or wrong choices; only the ones that work best for your situation.

Plan of Care - The types of health services and items you need, how often you will receive services and the predicted outcomes of treatment.

Prognosis - A doctor's prediction of the course a particular condition or disease will take.

Symptom Management - This term is often used to refer to how common physical symptoms are handled, but in palliative care, symptom management also includes attention to psychosocial and spiritual aspects of symptoms where appropriate. Symptoms may be treated with medication or other methods.

Respite Care - This is a term for a short-term break for caregivers. Looking after a sick or disabled child is a 24-hour job. You need a break from time to time to look after your own needs. Respite care breaks can be as long or short as you need them to be. You can set up respite care for a few hours, a day, a few days or a few weeks.

Tracheostomy - This is a small, surgical opening through the skin into the windpipe (trachea). There are many reasons why children may need a tracheostomy. The most common is to relieve severe breathing difficulties due to an obstruction (blockage) or narrowing in the upper airway. Other reasons include a child needing to be connected to a machine (ventilator) that helps with their breathing, or they need to have frequent suctioning of their airway if they can't swallow their saliva properly. While a child is under general anesthetic, a curved plastic tube is inserted into their windpipe through a cut in their throat, and secured. Your child will breathe through this tube instead of their nose and mouth. The tube doesn't go into the lungs.