



SUNCOAST
SteppingStones

Stepping Stones Program

5771 Roosevelt Boulevard, Suite 625
Clearwater, FL 33760
727/523-3458

**KID FRIENDLY
MEDICAL TERMS
AND DIAGNOSIS
DEFINED**

Introduction

**By Kathy Quance, MS., CCLS &
Eric Schleich, LCSW, CCLS**

From a child's perspective, having an illness, having a loved one with an illness or being involved with Hospice or another healthcare agency can feel very overwhelming. As the adults/caregivers in the family are given information about the loved ones health, children can also benefit from being included in this process.

How do we tell the children? What do we say?

This guide was developed to give the user (i.e., parent, healthcare provider, etc.) a starting point when having difficult conversations with children about common hospice/medical terminology. These terms are not meant to tell the "whole story" about a diagnosis or procedure, but rather to give caregivers an opportunity to provide basic information in order to promote ongoing communication with the child.

The user may need to simplify or elaborate upon the definition given based on age, cognitive understanding, and prior experience with medical situations.

In this booklet you will find the following three sections:

- a) Definitions of general body systems
- b) Definitions of common life limiting diagnoses
- c) Definitions of common medical procedures and equipment often utilized when a loved one is under hospice care.

GLOSSARY

MEDICAL TERMS DEFINED

Anesthesia	Page
Bleed Out	Page
Central Line	Page
Chemotherapy	Page
Cheyne Stokes	Page
Dialysis	Page
Discontinue Life Support	Page
DNR (Do Not Resuscitate)	Page
EEG (Electroencephalogram)	Page
Failure to Thrive	Page
G Tube	Page
Gurney	Page
Hospice	Page
Hospice House	Page
IV	Page
Living Will/Advanced Directives	Page
Mediport	Page
MRI/X-Ray/PET Scan/CT Scan	Page
Nasal Cannula	Page
Nebulizer	Page
Orthopedic Boots	Page
Oxygen Concentrator	Page
Oxygen Tank	Page
PCA Pump	Page
Radiation	Page
Soft Restraints	Page
Suction	Page
Terminal Restlessness	Page
Trach	Page
Ventilator	Page

DIAGNOSIS DEFINED

AIDS	Page
Alzheimer	Page
Aneurism	Page
Cancer	Page
Chronic Obstructive Pulmonary Disease (COPD)	Page
Coma	Page
Congestive Heart Failure (CHF)	Page
Dementia	Page
Diabetes (Type 1)	Page
Heart Attack	Page
Heart Disease	Page
HIV	Page
Miscarriage/Still Birth	Page
Multiple Sclerosis	Page
Seizure	Page
SIDS	Page
Stroke	Page
Tumor	Page

GENERAL BODY SYSTEM DEFINITIONS

Blood	Page
Bones	Page
Brain	Page
Cells	Page
Colon/Intestines	Page
Heart	Page
Kidneys	Page
Liver	Page
Lymph Node	Page
Muscle	Page
Organ	Page
Ovaries	Page
Skin	Page
Stomach	Page
Testes	Page
Uterus	Page
Veins/Arteries	Page

COMMON MEDICAL PROCEDURES

Colostomy	Page
Biopsy	Page
Blood Transfusion	Page
Ultrasound	Page
Health Care Surrogate	Page
Living Will	Page
Stent	Page
Urine Catheter	Page

DEFINITIONS OF COMMON LIFE LIMITING DIAGNOSIS

Cerebral Palsy	Page
Cystic Fibrosis	Page
Muscular Dystrophy	Page
Sickle Cell Disease	Page

MEDICAL TERMS DEFINED

Anesthesia

Anesthesia is a special medicine given by a “sleepy medicine” doctor to help the sick person go into a special sleep during surgery. This makes it so the person does not feel, hear, or see anything during the surgery. They cannot wake up until after the surgery is finished. After the surgery, the “sleepy medicine” doctor helps them wake up.

Bleed Out

When a person’s body is very sick and close to dying, their blood may come out of a part of their body like their mouth, nose, ear, or bottom. It may come out slow or fast. Most of the time, it does not hurt the person. The family or nurse may have special red towels ready to help clean up the blood.

Central Line

A skinny tube a person wears on their chest or arm that is used to give strong medicine or liquid food when they can’t eat.

Chemotherapy (Chemo)

Chemotherapy is also called “Chemo”. Chemo is a special medicine that someone takes to try to make cancer better. Most people get Chemo in an IV (in their veins) or sometimes in a pill.

Chemo can make someone’s stomach feel sick. They can also feel tired. Some Chemo can make a person’s hair fall out.

Cheyne-Stokes (Death Rattle/Death Rales)

When a person is close to dying, their breathing may sound different. They make take short breaths, or take longer to take the next breath. The doctor can give medicine to help them be more comfortable while this is happening.

Dialysis

A kidney is an organ that keeps your blood clean. If a person’s kidneys stop working, a dialysis machine cleans the blood for them.

The sick person has to go to the hospital several times a week to have their blood cleaned. It does not hurt the person to get dialysis, but it can make them feel tired.

Discontinue Life Support

When a person is very sick and needs special machines to stay alive. The only reason they are alive is because of the machines.

The doctors will do special tests to see if the person’s body can live without the machines. If they can not live without the machines, the family may choose to stop using the machines and let the person’s body stop working. A doctor will make the person comfortable. This is a very hard decision for a family to make.

DNR (Do Not Resuscitate Order)

A colored piece of paper that a family and doctor sign when there is no chance a person will get better. The paper tells doctors, nurses, and paramedics not to try and make a person’s heart start again if it stops. A family may keep the colored paper in an important place where everyone can see it.

EEG (Electroencephalogram)

A test used to see how a person’s brain is working. This is used to help doctors see if a person’s brain is very sick or has stopped working.

Failure to Thrive

A term used when a baby or person’s body gets weak and loses weight, even though they are trying their best to eat healthy food and stay healthy. Doctors try and help by giving them special drinks or food with extra vitamins to help them stay strong. The person may need their special food through a straw.

G Tube

A G Tube is a soft tube that goes into a person's belly to give them liquid food when they are too sick to eat like they used to. It can also be used to give medicine. It usually does not hurt to have this tube, but it might be sore for a few days after the doctor puts it in.

Gurney

A special bed with wheels that a person uses to get somewhere (ambulance, hospital, funeral home) when they cannot walk or use a wheel chair.

Hospice

Hospice is a place with workers that help people who are very sick or that might not get better. Hospice has many people like nurses, counselors, doctors, chaplains, volunteers and office workers that work together to help sick people and their families. Hospice workers may visit a sick person at home, in the hospital or a nursing home.

Hospice House -

These are places where people go when they are too sick for a hospital. Some of the reasons people go to them is to help their pain get better, to give their family a break from taking care of the person, or if the person may not live much longer.

IV

An IV is a very skinny, short straw that goes into a person's skin. It is usually put in their arm or leg by a doctor or nurse. The straw is used to give the person medicine. A needle is used to put the straw in, but the needle does not stay in the skin, only the straw does.

Living Will/Advanced Directives

A very sick person will use this paper to tell their family and doctors things that they want or do not want if they can't ever get better. They may choose not to have special machines or tubes to keep them alive if they can not ever get better.

Medi Port

This is a small, round disc put under the person's skin, usually in their chest, by a doctor. It is used to get medicine into the body. The person may need to use this for a long time. If they stop needing this, the doctor can take it out.

MRI/X-Ray/PET Scan/CT Scan

These are machines used to take pictures inside a person's body. These pictures help doctors see how a person is doing. It does not hurt to have these pictures taken.

Nasal Cannula

A soft plastic tube a person wears on their nose to breathe in extra oxygen/air. This can help the person to breathe a little easier.

Nebulizer/Breathing Treatment

This is a special medicine that looks like mist or smoke and helps a person breathe better. A person breathes the medicine in through a mask or "a pipe".

Orthopedic Boots

These are furry boots a person needs to wear if they stay in bed for a long time. They help keep the person's feet from getting weak or sore.

Oxygen Concentrator

An Oxygen Concentrator is a machine that takes regular oxygen from the air and makes it stronger. The strong oxygen is breathed in by the sick person through their nose and this can help them breathe a little easier. The machine makes a loud, humming noise.

Oxygen Tank

A heavy container used to hold oxygen. A sick person uses the oxygen to breathe a little easier. They may take the oxygen with them if they need to leave the house.

PCA Pump

This is a special machine that has pain medicine in it. The sick person gives themselves the medicine by pushing a button. This helps them not feel as much pain.

Radiation

If a person has cancer, a doctor uses radiation to get medicine into the body. It looks like a laser or a light. Radiation may help the cancer get smaller. It doesn't hurt, but it can make red marks on the skin. It can also make a person feel tired.

Soft Restraints

Soft Restraints are used to help keep a person safe. They may be used on someone's arms or legs to help keep them still. This can help keep a person from accidentally hurting themselves.

Suction

A special vacuum straw a nurse or grown up uses to suck germs and fluids out of a persons lungs when they are unable to cough them up. It can sound a little funny and make the person cough.

Terminal Restlessness

When a person's body is close to dying, they may have a hard time getting comfortable. The person may moan, wiggle, or breathe different. A doctor may give medicine to help the person relax and be more comfortable.

Tracheostomy (Trach)

A special breathing hole a doctor makes in a sick persons throat or neck if the person can't breathe like they used to from their mouth.

It may be hard for them to talk, cough, and eat when they have a Trach.

Ventilator (Life Support)

A machine that helps someone breathe when their lungs can't breathe by themselves.

DIAGNOSIS DEFINED

AIDS (see HIV definition)

When the HIV germ has gotten stronger and bigger and makes the person sicker.

Alzheimer Disease

When a person's brain gets sick and doesn't work like it used to. This disease can make them act different, say strange things, or forget who a person is.

Aneurysm

When a vein has a weak spot in it, and it breaks. This causes blood to leak out of the vein into places it shouldn't be. When the blood leaks out, it can cause parts of the body to not work right, or to stop working.

Cancer

When a group of cells start to grow too fast in a part of the body, making that part of the body sick. Cancer can happen in lots of different parts of the body like the lungs, brain, stomach, blood, or breast. You can not catch cancer like a cold. Most of the time doctors don't know why a person gets cancer.

A lot of people with cancer take medicine called "Chemo" which tries to make the cancer cells go away or get smaller. Also, some people have radiation or an operation to help the cancer go away or get smaller.

Cirrhosis

When a person's liver gets very sick and does not work like it used to. This can cause the person's skin and eyes to look yellow and their belly look bigger.

Chronic Obstructive Pulmonary Disease - COPD

When a person's lungs are sick in a way that makes it hard to breathe. The lungs don't open and close as well as they used to.

Sometimes they need extra oxygen to make breathing easier. They may also need special breathing medicine to make their lungs breathe better.

Coma

After an illness or an accident, a person's body doesn't work like it used to. The person may look like they are asleep, but you cannot wake them up. Sometimes they can hear you if you talk to them, but they can't talk back.

Congestive Heart Failure – CHF

CHF happens when a person's heart is too weak to pump enough blood and oxygen around the body. This can make the person very tired. There are medicines that can help the person feel better. They may also need to be careful about the things they eat.

Dementia

Dementia is when a person's brain starts to work differently. They may not recognize people, or not make sense when they talk. They need people to help remind them of things they forget. (Also see Alzheimer's Disease)

Diabetes

In a healthy person needs sugar and other foods for energy. In a healthy person the body can use sugar to make enough energy to play.

Diabetes happens when the body forgets what to do with the sugar. The person gets sick when the body has too much sugar that the body forgot to use. The person needs special medicine in a pill or shot that helps the body remember how to use sugar.

The person has to check their blood with a special machine every day to make sure there is not too much sugar in it. They have to be very careful with the kind of food they eat.

You can't catch diabetes like you can catch a cold.

Heart Attack

This happens when a person's heart does not beat the right way. It may even stop beating. Sometimes, doctors or nurses can help the heart beat again, and sometimes they can not. Sometimes it happens very suddenly.

Heart Disease

When a person's heart is sick and may not work like it used to. The person may take special medicine and be careful with what they eat.

HIV

HIV is when a person has a strong germ in their blood. This can cause the person to get sick easier. The germ cannot go away, but medicine can help keep it from growing. It is very hard to catch this germ. You can not catch it from a hug, kiss, or by touching the person with HIV.

Miscarriage/Still Birth

When a mother is pregnant, but the baby inside had something wrong with it, and it stops living. The baby comes out of mommy, but it is not alive. The mommy and the family will be very sad this happened.

Multiple Sclerosis (MS)

Nerves in our body carry messages from our brain to our muscles, telling them what to do. When someone has MS, their nerves are not working right. The messages do not get to the muscles. Without these messages the person is not able to move like they used to.

Seizure

When a person's brain sends mixed up messages to other parts of the body. This can make a person fall down or lose control of how their body moves. They cannot talk or hear during a seizure. After a seizure, the person can feel sleepy and weak. Special medicine can help the person stop having a seizure, or have less of them.

SIDS

When a baby stops breathing and its heart stops beating, it makes the body stop working and die. The baby does not feel any pain when this happens. Doctors do not know why this happens to some babies. It was not anybody's fault this happened.

Stroke

A stroke is when a blood vessel or vein gets clogged and blood can not pass through it. The part of the body where blood can not get to does not get the vitamins and oxygen it needs. This causes the person's body to work differently. They may not walk, talk, or be able to think the same as they used to. Some people get better after having a stroke, and some do not.

Tumor

When a group of unhealthy cells stick together and grow fast. Sometimes you can see the tumor or feel it under a person's skin. Other times it can't be seen or felt. A doctor may try and take the tumor out, or use special medicine to shrink it, but some tumors can't be fixed

GENERAL BODY SYSTEM DEFINITIONS

Blood

The red liquid that the heart pumps all through the body. Blood carries cells and oxygen through the body so the person can stay healthy.

Bones

Hard parts of the body under your skin that helps hold the body together. They help the body stand up, move and walk.

Brain

This organ is the body's "computer". It tells the body how to do everything, such as walk, talk and think.

Cells

A part of the body that is so tiny it can only be seen under a microscope. A cell is like a block that builds something. Some may build skin, and others may build bones or blood. There are cells in every part of our body.

Colon/Intestines

An organ that helps the body get rid of a person's poop.

Heart

An organ made of muscle that pumps or moves a person's blood all through their body.

Kidneys

An organ in the back of the body that is like a filter that helps keep a person's blood clean. Most people have two of these.

Liver

A large organ in the middle of the body. Its job is to help digest food and keep the person's blood clean.

Lymph Node

Many small organs in different parts of the body that help get rid of germs inside the body.

Muscle

Parts of the body that make the person move and be able to stand up, walk, and move.

Organ

A certain part of the body that has a special job to keep the body working, such as the stomach, heart, or brain.

Ovaries

Two tiny organs inside a girl's body that make eggs so she can have a baby.

Skin

This organ's job is to cover and protect the body's insides.

Stomach

This organ takes the food that a person swallows. It helps the body use the food to stay strong, grow, or have energy to do things.

Testes

A part of a boy's body that makes sperm that can help a woman make a baby.

Uterus

An organ inside the mommy's tummy where a baby can grow until it is born.

Veins/Arteries

Skinny tubes a person has inside their body. They carry blood to different parts of the body to help it work right. Sometimes you can see these through your skin.

COMMON MEDICAL PROCEDURES

Colostomy

A special hole a doctor makes outside of the stomach to help the person poop if they can't poop like they used to. The poop goes into a special plastic bag that gets changed when it is full. The hole may need to stay forever or just while the person gets better.

Biopsy

When a doctor needs to take out a very tiny piece of the body to see if the person is sick. The person's body will still work without this piece. The doctor gives the person some special medicine before they take out the little piece. This helps the person not feel pain when the piece is taken out.

Blood Transfusion

If a person feels weak or has been hurt badly, the doctor will give them new blood to try and help them feel better.

Ultrasound

A doctor uses a special camera to see inside a person's body. The camera touches the person's skin and can see if there is anything wrong inside their body. This usually does not hurt.

Health Care Surrogate

When a person chooses someone to help the doctors decide what to do for them if they cannot talk or think like they used to.

Living Will

A piece of paper that a sick person uses to tell their family what they choose to have done if their body stops working. Some people would like to let the doctors try and make them live again, while others would want doctors to just let their body stop working.

Stent

A small, soft tube that is used to keep a vein open so blood can keep moving through it.

Urine Catheter

A skinny, soft tube that helps a person pee if they need help going to the bathroom. The pee goes into a special bag.

DEFINITIONS OF COMMON LIFE LIMITING DIAGNOSES

Cerebral Palsy

A person who is born with a brain that works differently. This can make some parts of the body work different. They may walk, talk, or think different. One person may need just a little help and another person may need help with everything they do.

Cystic Fibrosis

A person is born with this disease. It makes their lungs get sick easily, making it hard for them to breathe. The person may also cough a lot. They take special medicine and may use special machines to help them breathe better, but the person may still cough a lot. The person needs to eat healthy food, take extra vitamins, and take medicine to help them grow and stay strong. This is important because they may have problems with their liver or pancreas, which causes them to grow slower. The person may look skinny or have a bigger chest or belly.

Muscular Dystrophy

A person is born with this disease. This disease makes a person's muscles slowly get weaker and weaker, making it hard for them to move. This person may need to use a wheelchair or machines to help them breathe.

Sickle Cell Disease

A person gets sick because the cells in their blood get stuck together inside their veins. The cells in this person's blood are shaped differently which is why they get stuck together. This stops the person's blood from moving through the veins like it is supposed to. This can cause the person pain, fever, or to feel weak.



**SUNCOAST
HOSPICE**

Licensed to serve since 1981

Your life. Our life's work.™

**Suncoast Hospice
Stepping Stones Program
5771 Roosevelt Boulevard,
Suite 625
Clearwater, FL 33760
727/523-3458**