I can do no other than be reverent
Before everything that is called life.
I can do no other than to have compassion
For all that is called life.
That is the beginning
And the foundation
of all ethics.
DISCLOSURES

• No disclosures
OBJECTIVES

• Participant will understand framework for focused nursing care in the hospital setting, utilizing values to meet the challenges of care for the developmentally disabled individual.

• Participant will describe and recognize behaviors and clinical indicators that manifest with acute illness or disease processes.

• Participant will define “Palliative Care” concept and goals, utilizing short and long term framework for care team discussion.
SPECIAL NEEDS PROGRAM ORIGIN

- Funded through private grant through hospital Foundation

- Developed (officially) in 2008 to coordinate care of DD/IDD population *(wrote business plan to support goals)*

- Provide staff education

- Individualize Care Planning and accommodation for patients, families, caregivers
GOALS

• Educate and support nursing staff
• Facilitate care
• Address issues of legality
• Safety
• Advocacy
• Demonstrate importance of establishing baseline information for appropriate and effective care
• Serve the medically fragile DD/IDD community on the lifelong care continuum
INDIVIDUALIZE CARE PLANNING

- Personify the values EXCELLENCE, DIGNITY, JUSTICE, COLLABORATION and STEWARDSHIP – Care for me
- Gather Baseline information – Know me
- Be attentive to non verbal cues – Listen to me
- Provide approaches to support Safety, Comfort and Compassion – Keep me safe
- Provide accommodation, assistive language and mobility supports – Empower me
- Support the Health Care Team – Work together
STAFF EDUCATION

• Provide in service and annual updates
• Personal guidance with bedside nurse
• Document in health record and list recommendations
• Provide understanding of baseline receptive understanding, behaviors, routines, communication type, non verbal cues, innovative care requirements, disability type and associated chronic issues with a focus on acute illness
• Collaborate on appropriate discharge plan
• Received referral for patient who has history of Cerebral Palsy. Awake, alert and nonverbal, as baseline. Communicates using eye gaze upward for “yes” and downward for “no”. Good receptive skills. Nickname is “Charger”. Small beanbags placed in palms for positioning, as he tends to clench fists. C-pillow provided for head alignment while in bed. Typically eats pureed diet. Edentulous. Pain evidenced by tears. Wears diapers for incontinence. He is NOT conserved. He is a consumer of Valley Mountain Regional Center case management services and his service coordinator is Sandy Aygo #555-955-5555. Medical Consents are obtained from VMRC Clinical Director per W&I code 4655. No known family. Resides at Qualcomm Board and Care and attends an adult Program at Mission Bay, where he enjoys outings and Elvis music. Custom wheelchair is not at hospital. He is used to being up in his chair during day. Recommend OOB in Special Needs wheelchair with tray, for meals. He likes baseball caps, watching football and coloring activities.
Special tilt in space wheelchair
CHALLENGES

Coping skills inadequate

We’ve got a runner!
MORE CHALLENGES

• Exacerbation of pre existing maladaptive behavior

• Continual stressors

• Social rejection and stereotyping

• Overloading information

• False reassurance given
RESPONSIBILITIES OF HEALTHCARE PROVIDERS

You’ve got to know the territory

- Clue into the baseline medical problem while treating the new issue
- Seek further information about the individual
- Utilize available resources to further this understanding

We already have the medical support. We need to provide better understanding and recognition of what is typical for the disability, the individual. Then, plan around that
RESPONSIBILITIES continued

DETERMINE PAIN

➢ Observe facial expressions, mood and behavior, moaning

➢ Level of comprehension – receptive

➢ Ability to communicate – expressive

➢ Clinical indicators (ie: HR, BP, spasticity, diaphoresis)

➢ Current medications and reconciliation of home medications

➢ What is comforting for the individual?
PET THERAPY
PET THERAPY
COLLABORATE WITH COMMUNITY PARTNERS

- Family Resource Network/Support groups
- Regional Centers
- United Cerebral Palsy
- The ARC
- DRAIL
- Community Center for the Blind
- U.C. Davis M.I.N.D. Institute
- Shriner’s Hospital for Children

Support care needs across a continuum of care
Community Resources
COMMUNICATION DEVICE
ACCOMMODATION

• Interpreter (language phones or ASL)
• Communication pictures, phrase board or home devices
• Soft call light
• C pillow for neck alignment
• Care staff/family to stay with patient- sleep beds
• Special chairs with tilt in space capability/seizure precautions
• Bariatric equipment
• Beanbags to support contractures (OT consult)
• Meditation room (quiet place for Autistic patients/families)
• Special cups with handles
INNOVATIONS/THERAPEUTIC NURSING INTERVENTIONS

- Colorful cups over oxygen/nebulizer treatments
- Party blowers to promote deep breaths
- Stuffed animals/pet therapy
- Music/DVD’s/computer at desk
- Activity aprons/coloring books
- Promote familiar use of direction or prompting
- Up in chair with tray, during day and for meals
- Picture boards/dry erase boards
- Warmed blankets
- Sing your instructions
Micah
GOAL ORIENTED CARE

• Care has historically evolved from custodial care to goal oriented care

• Understand that severe impaired immobility is not a cause of death

• Individuals may be “perceived” as having poor quality of life

• Follow physician direction and Core measures (interventions from order sets)

• Decision to avoid aggressive intervention based on irreversibility and unrelenting progression of a degenerative illness
LEGAL RESPONSIBILITIES

• Recognize rights, act as an advocate and protect those rights

• Maintain confidentiality in accordance with professional standards, guidelines, state and federal law

• Laws that prevent discriminatory practice: ADA Title III Americans with Disabilities Act; Title VI of Civil Rights Act of 1964; Section 504 of the Rehabilitation Act of 1973; California Welfare and Institutions Code Section 4640-4659; Code 4655 W&I VMRC (Regional Center established 1965, funded under a contract with the state) designated representative authorized to provide medical consent; California Health and Safety Code, etc.

• Conservator vs. non-conserved

• Laws set up to end discrimination and abuse
SPEAKING UP FOR THOSE WHO CAN’T

• Recognize that behaviors may appear maladaptive and disruptive, usually serve some function for the individual and in most cases the function is COMMUNICATION

• Inability to use language for coping skills

• Inability to analyze situations or use strategies to control emotions, feelings or symptoms

• Behaviors, such as aggression misdiagnosed and incorrectly treated with restraint or pharmacotherapy
"feeling sick" and not being able to tell anybody is exhibited by common clues

- Drooling/not opening mouth (sore throat, nausea, mouth pain or infection, toothache, thrush, inability to manage secretions)
- Refusing food (nausea, general malaise, unfamiliar textures, abdominal pain, constipation, fear)
- Seizures (provoked by acute events including infection/sepsis, head injury, chemical imbalance-drinking too much water decreases sodium, brain tumor, severe constipation, inadequate drug levels of anti seizure meds)
BOWEL CARE

History
Home regimen
Hydration

Untreated leads to worsening conditions: bowel obstruction or ileus
May see an increase in seizure activity as a first clue to a more serious issue

Seek further information about the individual’s typical duration and type of seizures
SYMPTOMS OF DISTRESS

• Self injurious behaviors
• Aggression
• Agitation
• Self stimulation
• Sleep disturbance
• Regression/loss of skills
• Regression in toileting
• Hyperactivity or poor attention/lethargy
• Excessive eating or poor eating
• Weight fluctuation
Examples of behaviors related to medical condition

- Face slapping: unrecognized dental problem
- Masturbation: urethritis/prostatitis/vaginitis, pinworms, UTI (may push on lower abdomen or rocking motions)
- Agitation or screaming at night: esophagitis secondary to reflux
- Staring, eye blinking, mouth movements: atypical seizure
- High activity level: general pain or discomfort, dehydration, constipation, hernia, intestinal obstruction, sepsis, trauma, electrolyte abnormality
- Sudden sitting: cardiac problems, dizziness, orthostasis (low BP), seizures, atlanto-axial dislocation
CONTINUED BEHAVIORS

- Unwillingness to sit or uneven sitting: back pain, hip pain, rectal/vaginal/prostate discomfort.
- Breathing difficulty: aspiration, CHF, reflux, pneumonia, bowel obstruction, FBO, apnea.
- Change in LOC: hydrocephalus, seizures, hypoxia, head injury, stroke, medications, metabolic condition.
- Hand/fingers in mouth: asthma, dental pathology, middle ear problems, GE reflux, nausea, sinus problem.
- General scratching: Prader-Willi, eczema, lice, renal disorder, pancreatitis, gastritis, dermatitis, medication side effect.
CONTINUED BEHAVIORS

- Hand flapping/pacing: stimulation or calming measures

- Pica: under stimulating environment, iron deficiency, lead poisoning, psych disorder, hypothalamic problems

Recognize that developmentally delayed people may not be able to describe, localize or understand what is wrong.
Sepsis is defined as the presence or presumed presence of an infection accompanied by evidence of a systemic response called the systemic inflammatory response (SIRS).

SIRS is defined as the presence of 2 or more of the following:

- Temperature > 38 degrees or < 36 degrees C.
- Pulse > 90 beats/minute
- Respiratory Rate > 20 breaths/minute
- WBC > 12,000 or < 4000, or > 10% bands
Severe sepsis is defined as the presence of sepsis and dysfunction of one or more organs.

Organ dysfunction is defined as acute lung injury, coagulation abnormalities, thrombocytopenia, ALOC, renal, liver, or cardiac failure or hypo perfusion with lactic acidosis.

*Lactic acidosis is a physiological condition characterized by low pH in body tissues and blood. Lactic acid is produced when oxygen levels in blood drop.*
Septic shock is defined as the presence of Severe sepsis and refractory hypotension

Systolic BP < 90mmHg
MAP < 65 mmHg unresponsive to a crystalloid fluid challenge of 20-40 ml/kg.

MAP = (CO x SVR) + CVP

Based on relationship between flow, pressure & resistance
The Society of Critical Care Medicine publishes evidence based recommendations every year.


Bundle completed within first 6 hours of presentation:
- Serum lactate
- Blood cultures prior to antibiotics
- Broad spectrum antibiotic in first hour / every hour antibiotics are delayed, the risk of death from sepsis goes up by 6-10%
• Help to decrease oxygen consumption

There is increased O2 demand with respiratory muscle use.

Decrease the work of breathing and redistribute blood flow to vital vascular beds by intubation/mechanical ventilation/sedation.
RISK FACTORS FOR SEPSIS

• ASPIRATION

- CNS impairments contribute to dysphagia & GE reflux
- wheezing, coughing, respiratory distress
- tolerance over time leads to “silent aspiration”
- severe episodes of aspiration may lead to pneumonia
RISK FACTORS FOR SEPSIS

• Urinary Tract Infection

  – Anatomic abnormalities – incomplete emptying or bacterial colonization, neurogenic bladder, urethral stricture, indwelling catheter
  – Non anatomic conditions – voiding dysfunction, chronic constipation, poor perineal hygiene, chronic vaginitis
  – Joint contractures of hip, chronic constipation, abnormal voiding patterns

Most common organism is Escherichia Coli
INFECTION PREVENTION

• Swallow study / evaluation for dysphagia / speech therapy

• Good dental hygiene

• Supervised feedings / enteral feedings

• Toileting routine / control constipation

• Good perineal hygiene / treat chronic vaginitis
Infection sources

• Empyema/abcess (collection of pus) or effusions (escape of fluid between tissues that line the lungs and chest) - pneumonia
• Surgical site infections
• Necrotizing skin (Group A strep infection common)
• Intravascular catheters, urinary catheters
• G tube sites
• endocarditis
• VP shunts

*Source control is a vital part of treatment*

*Mortality decreases with early intervention*
Sepsis

Think sepsis in a person with

Altered LOC
Low BP
Worsening hypoxia
Decreased urine output
“Baby boy NICU”
Physical Therapy
Cerebral Palsy: Reduce pain and spasms, facilitate brace use, improve posture, minimize contractures, facilitate mobility, improve patient ease of self-care.

Few medical professionals are familiar with CP and it’s related conditions

Pain may go unrecognized and not treated
REFERRALS

Swallow evaluation

Recommendations for diet (reference home diet)

Assist with feeding

Assist with oral motor exercises

*Speech Therapy may recommend NPO and alternative feeding*
Medical situations that affect Discharge plan

- New tracheostomy
- Need for supplemental oxygen
- Need for wound care management
- Change in ambulatory status
- New G-tube
- Need for long term I.V. antibiotics
- New Insulin requirement
- Dialysis or Cancer treatment
- Hospice care
Goals of care are to maximize quality of life by improving daily function & reducing extent of disability. Achieved by symptom management.

-Rose Hernandez, Pharm.D.
Common Medications

- Phenytoin (Dilantin)
- Divalproex (Depakote)
- Carbamazepine (Tegretol)
- Topiramate (Topamax)
- Oxcarbazepine (Trileptal)
- Levetiracetam (Keppra)
- Neurontin (Gabapentin)
- Phenobarbital
- Lamotrigine (Lamictal)
- Pregabalin (Lyrica)
- Primidone
- Baclofen
- Diazepam (Valium)
So many medications ??

- Ask for a Pharmacy review of medications
- Rule out any side effects causing problems
- Rule out any med combinations causing problems
- Check drug levels for anti seizure meds
- Liver and kidney function routine testing
Palliative Care aims to relieve suffering and improve quality of life for patients who have a serious, life-threatening or chronic illness that cannot be cured.
Comfort Care

*rather than*

Treatment and Cure
PALLIATIVE CARE

Interdisciplinary Team Approach

Core Team at every meeting includes:

- M.D. consultant
- Palliative Care R.N.
- Social Worker from unit
- Chaplain

Participation from other disciplines are included as needed:

- Special Needs nurse, P.T., R.T., S.T., care home staff
Advance Care Planning

Discussion with patients, families, caregivers includes:

- Education about the illness including prognosis specifically for those with chronic illness who may not be at end of life
- Current options for treatment
- Future options for treatment
- Possible consequences to decisions
- Code status clarification
- Discussion focused on the PATIENT

*Care team never goes in with personal agenda*

*Biases are left at the door*
Palliative Care Goals

- Prevent and relieve suffering
- Support quality of life
- Address all comfort needs
- Current legalities and ethics
Instead of:

“There is nothing more that we can do”

Substitute:

“We can always provide support and comfort”
Physiological Processes at End of Life

• Dying involves a series of irreversible events that leads to cell destruction and death.

• Respiratory System

  Cheyne-Stokes sign of pulmonary system failure:
  1. alternate hyperpneic and apneic phases
  2. these phases alter concentration of body’s CO2, reducing the level
  3. sensors within body prevent body from breathing in order to increase level of carbon dioxide
  4. never able to reach adequate balance and ultimately respirations cease
Physiological Processes at End of Life

• Cardiovascular System: heart and vessels

1. Heart unable to pump strongly enough to keep blood moving
2. Blood backs up first throughout heart
3. Ultimately backs up into the lungs and liver, causing congestion
4. Decreased blood causes decreased circulation to body
Physiologic changes continued

• Skin cool to touch
• Appear cyanotic, possibly mottled
• Failure of peripheral circulation can result in drenching sweat

WHEN IS A PERSON SUFFERING?
Critical Medical Interventions

- Mechanical Ventilation

- CPR

- Artificial Nutrition: TPN, Nasogastric tube feeding, new G-tube

- Hemodialysis
Mechanical Ventilation/Respirator

• May be LIFE SAVING

• Uncomfortable/require restraint

• Unable to communicate/bed confinement

• May need tracheostomy/subacute living facility

• May not change underlying disease (CHF, COPD)
Artificial Nutrition

- Reduces septic complications
- Improves wound healing
- Preserves GI integrity
- Preserves immunologic defense
- Improves nutrition
- Won’t prevent malnutrition
- Won’t prevent skin breakdown
- Won’t prevent aspiration pneumonia
- Risks with bleeding and infection
- May increase discomfort and SOB
- May decrease contact with caregiver
NOT Comfort measures, typically

- Intravenous antibiotics
- Hydration
- CPAP
Palliative Care

Is the type of care aimed at alleviating pain and other symptoms of disease, with the understanding that the treatment is not curative

*May include chemotherapy, radiation therapy, seizure medications*
Structured Discussion

VALUES ASSESSMENT

What makes life worth living?
What is important to the patient?
What is the patient’s perception?

“your motive’s noble, but now I pray
You’ll read in my eyes
What my lips can’t say”

-J.P. Rooney M.D.
BIBLIOGRAPHY


St. Joseph’s Medical Center Job Description & Competency-Special Needs Nurse

St. Joseph’s Medical Center Core measures

Lippincott, Williams & Wilkins, Critical Care Oct-Dec 2011 p. 367,376.


BIBLIOGRAPHY

Rubin, I. Leslie M.D.; Crocker, Allen C. M.D., Medical Care for Children and Adults with Developmental Disabilities. 2nd Ed. 2006. p 33-36 and p 510-516.


National Patient Safety Goals 2015
BIBLIOGRAPHY


Shreve, Marilyn Standifer. HEALTH NOTES California State Board of Pharmacy. Care of Children & Adults with Developmental Disabilities. p 7-44.

St. Joseph’s Medical Center Palliative Care Services

U.C. Davis M.I.N.D. Institute
Thank You