Code Lavender Resource Guide

Take Care of You While You Care for Someone in the Hospital

May, 2020

This pastoral ministry offers guidance and short-term (six weeks or less) support for family members with a loved one in the hospital, whether a planned or an emergency visit. To receive care from Code Lavender, please contact a member of the clergy, emergency pastoral care 980-819-1225, or Code Lavender Coordinator Suzan Becker: suzanbecker@yahoo.com. You will hear from a member of the ministry to discuss what form of support would be most helpful at this time. That ministry member will continue as your point of contact and serve as the coordinator for efforts such as meals, lawn care, or regular check-ins to see how you are doing.

- Checklist for patient on "What to pack" and "Whom to contact" when preparing for hospitalization
- Helpful Information for Navigating the Hospital System
- Information on Advanced Directives and Hospice/Palliative Care
- Ideas for How to Support the Patient
- Ideas for How to Support the Family
- Do's and Don'ts of Hospital Visits by John Cox, Episcopal Church Hospital Lay Chaplain
- Best practices for Pastoral Support
- A Care Network for Caregivers

WHAT TO PACK

- Phone and phone charger
- Other devices (iPads, Kindle, laptops, and their chargers
- Reading glasses, prescription glasses and/or contact lenses
- Pillow, pajamas, favorite stuffed animal, blanket
- Medications and vitamins or a list of them
- Advanced Directives paperwork
- Book of Common Prayer (also available online, www.bcponline.org)

WHOM TO CONTACT

Holy Comforter Emergency Pastoral Care Phone number: 980-819-1225

Parish Care Coordinator: in this time of clergy transition Father Greg, Deacon Gene and Jessica Dunlap are all direct contacts for pastoral care

Code Lavender Coordinator: Suzan Becker, suzanbecker@yahoo.com.

Phone number for the Chaplain and Spiritual Care Department at area hospitals:

Carolinas Medical Center and Levine Children's Hospital Atrium Health : 704-355-2218

Mercy Hospital Atrium Health: 704-304-5000

Presbyterian Hospital Novant Health: 704-384-4168

Huntersville Medical Center Novant Health: 704-316-6718

Matthews Medical Center Novant Health: 704-384-6360

Pineville Atrium Health: 704-667-2730

Union Atrium Health: 980-993-3478

University City Atrium Health: 704-863-6589

Possible reasons for contacting chaplains:

- Pastoral visitation when outsider visitors are limited or not allowed, or the need is immediate
- Help and counseling with confusing feelings
- Prayer
- Assistance with communication with loved ones at a distance and Holy Comforter
- Weekly worship if you are confined with the hospital
- Counseling and nonjudgmental guidance regarding end-of-life concerns

RECOMMENDED PRAYERS

O God, the strength of the weak and the comfort of sufferers: Mercifully accept our prayers, and grant to your servant the help of your power, that his sickness may be turned into health, and our sorrow into joy; through Jesus Christ our Lord. Amen. (Collect for Recovery from Sickness, BCP page 458)

Heavenly Father, giver of life and health: Comfort and relieve your sick servants, and give your power of healing to those who minister to their needs, that they may be strengthened in their weakness and have confidence in your loving care; through Jesus Christ our Lord. Amen. (Collect for Strength and Confidence, BCP page 459)

This is another day, O Lord. I know not what it will bring forth, but make me ready, Lord, for whatever it may be. If I am to stand up, help me to stand bravely. If I am to sit still, help me to sit quietly. If I am to lie low, help me to do it patiently. And if I am to do nothing, let me do it gallantly. Make these words more than words, and give me the Spirit of Jesus. Amen. (Collect for Use by a Sick Person in the Morning, BCP page 461)

NAVIGATING THE HOSPITAL SYSTEM

Navigating the healthcare system for adult inpatients is like visiting a foreign country where you kind of understand the language and some of the customs. Like any trip, it will be much easier if the admission is planned. If unplanned, it is much more like an emergency landing, but you can figure all this out on the fly. These tips will make the whole experience much easier.

Family communications

- Identify a family spokesperson. Ideally this would be the closest relative because he or she can speak for the patient if he or she is unable.
- The family spokesperson may want to have another person to help take notes and keep track of what was said. It can be hard to process what is said when your loved one is ill. This person can also explain everything to the rest of the family. This role would be especially important if the closest relative is overwhelmed
- Make notes about what was said, including who, what, and when
- Keep a list of personnel involved with the patient; they may change periodically

Hospital personnel

These are some of the personnel you may see, their role in the patient's care, and what to expect of them.

Doctors

There are doctors for each service or type of medicine. For example, a cardiologist focuses on the heart and a neurologist focuses on the brain, spinal cord, and nervous system. To make it more complicated, surgeons get specialized names too: a cardiac surgeon does heart surgery and a neurosurgeon does brain surgery. You may be admitted for surgery (with a surgeon in charge or "attending") but if you develop another problem,

the attending doctor may request the advice of a specialist. This is called a "consult" (short for consultation). These doctors will be part of the "consulting service" and are referred to as "consulting doctors." They may make "recommendations." You may have several of these consultants if you have several conditions, but the admitting/attending doctor has the last say and coordinates it all.

Within each group there is a hierarchy.

- Attending doctor or "attending"- most educated, most experienced doctor who oversees all of the patient's care
- Fellow - doctor who is already a practicing doctor but is taking more training to learn a specialty
- Resident - doctor who has graduated from medical school but who is gaining supervised experience over a course of three years
- NP or nurse practitioner - a registered nurse who with a doctor; can do almost anything a doctor can do; more independent than a PA but has a similar role (called "advanced practice providers" or APPs)
- PA or physician's assistant- person who works under the supervision of a doctor; can do almost anything a doctor can do (also called "advanced practice providers" or APPs)
- Intern - medical school student who can perform some supervised doctor functions such as asking about your condition, drawing blood, etc

Nurses

Nurses specialize as well, usually depending on the type of patients they work with, e.g. an ICU nurse vs. a labor and delivery nurse vs. a pediatric nurse. Educational levels vary according to role.

Within this group there is a "chain of command." If you have a concern about your bedside nurse, ask to speak to the charge nurse. If that does not resolve the issue, ask to speak to the nurse manager/head nurse during daytime hours or the nursing supervisor at night or on weekends. You can escalate nursing concerns up the ladder to a nursing director, vice president, or chief of nursing services.

- **Nurse executive or administrator**, e.g. vice president, director, house supervisor (RN with masters or doctorate education after bachelor's degree) oversees the function of a whole division or the whole hospital
- **Nurse manager or head nurse** (RN with 4-year bachelor's degree or higher) is in charge of the smooth function of the nursing unit 24/7, 365 days per year
- **Clinical supervisor or assistant nurse manager** (RN with 4-year bachelor's degree or higher) assists the nurse manager in all functions and also serves as charge nurse
- **Charge nurse** (RN with 2-year associate's degree or higher) supervises all nurses working during a particular shift; may also have their own set of patients
- **Bedside nurse or direct-care nurse** (RN with 2-year associate's degree or higher, or LPN with 1 year of education) gives medications, starts IVs, monitors vital signs and lab results; coordinates the patient's care for the shift
- **Nursing assistant (CNA), nurse technician, or healthcare technician** (usually less than 6 months of training) assists with walking,baths,toileting, brings food trays, provides water and other comforts

Therapists

The patient may or may not see these people, depending on their condition. Therapists may come to the patient's bedside to do therapy or the patient may be taken to them for use of specialized equipment. They include:

- **Physical therapists** (PT) and PT Assistants help the patient develop strength and balance for activities like walking, waving arms, holding head upright
- **Occupational therapists** (OT) and OT Assistants help the patient develop dexterity for activities like brushing teeth, combing hair, writing, dialing a phone
- **Speech therapists** are often called after the patient has a stroke. They usually work on swallowing reflexes. They can and do help people (especially children) learn to speak clearly
- **Art and/or music therapists** provide guided diversion and relaxation to ease the patient's stress
- **Pet therapists** use specially trained dogs to soothe, calm, or brighten the day for patients. Everyone else seems to benefit too.
- **Child Life Therapists** are pediatric developmental specialists who use play to help children understand and cope with illness, injury, or hospitalization. They can also work with a patients children to help them if a parent is ill
- **Hospital School Teachers** are available to children who are missing classes

Support

These professionals do not see all patients but are available as needed; ask for them if the patient or family member needs their services.

- Chaplains can provide spiritual support when your priest cannot be with you. They are specially trained to help anyone of any religion (or none) to cope with the strains of hospitalization for the patient, family, and healthcare team
- Social workers assess a patient 's needs; they can connect patients and families with community resources and can also serve as counselors
- Discharge planners are nurses or social workers whose focus is to get the patient home; they are often focused on logistics such as getting a hospital bed or home oxygen and making sure the patient has all needs met at home
- Palliative Care and Hospice are both services offered to those who are suffering. Palliative Care doctors, nurses, and social workers focus on chronic, life-changing conditions; Hospice doctors, nurses, and social workers focus on end-of-life

Others

These professionals provide specific services only when needed; the patient may only have brief, intermittent interactions with them

- Pharmacists review medications and their doses, dispense the medication to the nursing unit, and serve as an expert for any medication related concernDietary personnelLab personnel
- Radiology personnel work with X-rays, CT scans, MRIs, and many other diagnostic tests involving radiation. They may also be involved in radiation therapy to treat cancer
- Lab personnel draw blood, but they also run all the diagnostic tests based on the patient's blood, urine, or other body fluids

- Interpreters provide what we usually think of as translation, They can be the mouthpiece of the patient and the medical team because of their language abilities
- Transport personnel will take a patient to and from the many locations in the hospital, such as radiology or therapy; they assist with the patient's transfer between units and when going home
- Registrars will make sure the patient is registered appropriately and that all information is correct
- Cleaning personnel are critically important: keeping the environment clean prevents spread of hospital-acquired conditions

These "patient-facing" personnel are supported by an even larger group of professionals who work behind the scenes, e.g. maintenance, biomedical engineering, information services (computers), equipment and supply specialists, etc. A hospital runs like a small city! No wonder you need a notebook to keep track of those who enter a patient's room.

A day in the hospital starts early.

- 4:00 am Vital signs (VS) checked; patient awakened for X ray
- 4:30 am Patient reawakened for lab draws
- 5:30 am Resident wakes up patient for physical exam
- 6:15 am Night nurses finish up tasks for their shift
- 7:00 am Report off from night nurse to day nurse
- 7:15 am Day nurse does full assessment
- 7:30 am Breakfast delivered
- 8:00 am Attending doctor and team examine patient; review chart, VS, medications, labs, and Xrays; discussion of plan for the day
- 8:15 am Nurse changes IV fluids, gives medications, changes dressing
- 9:00 am CNA assists with bath and linen change, assists to chair
- 10:30 am Consulting doctor and team examine patient; review chart, VS, medications, labs, and Xrays; discussion of further needs
- 10:45 am Physical therapist comes to assist patient walking in hall
- 12:00 N Nurse brings medications;
- 12:10 pm CNA obtains vital signs
- 12:15 pm Lunch delivered
- 1:00 pm Quiet time begins
- 3:00 pm Quiet time ends
- 3:30 pm CNA assists patient to chair
- 4:00 pm CNA obtains vital signs
- 4:15 pm Discharge planner makes a visit
- 4:30 pm Nurse gives medications
- 5:30 pm Supper delivered
- 6:15 pm Day nurse finishes up the tasks
- 7:00 pm Report off from day nurse to night nurse
- 7:15 pm Night nurse does full assessment
- 8:00 pm CNA obtains vital signs; assist patient in preparing for bed
- 8:30 pm Night nurse gives medications
- 9:00 pm Lights out
- 12:00 MN CNA obtains VS; night nurse gives medications
- 12:30 am Period of less interrupted sleep; patient must be checked every hour
- 4:00 am Begin again

If you evaluate this typical schedule, the patient has the chance for rest/sleep from 1:00 pm to 3:00 pm, 9:00 pm to 12:00 MN, and 12:30 am to 4:00 am- a total of 8.5 non-consecutive hours. Better not to visit so the patient can get some rest.

Discharge plans: Getting the patient home

- Set up a time for one contact person to speak to the nurse or physician each day for a daily update. You may have to call the unit and then ask to be transferred to the nurse caring for the patient.
- Ask them what they think the hospitalized individual will need when the patient comes home
- Given that list, explore creative ways a plan can be developed and set in motion. Involve the patient and the nurse; many places have a specified discharge planner. That's another thing hospitals love: proactive discharge plans
- Post a calendar with expected discharge "Countdown" (4 days to discharge, 3 days to discharge, etc.

INFORMATION ON ADVANCED DIRECTIVES

- Diocesan resource on end-of-life planning and care, https://vimeo.com/channels/1628261
- Free North Carolina Living Will | Advance Directive - PDF | eForms – Free Fillable Forms
- https://www.sosnc.gov/documents/forms/advance_healthcare_directives/organ_tissue_donor_card.pdf
- North Carolina Secretary of State Advance Health Care Directives Organ Donation and the NC DMV
- NC Organ Donor Registration | Donate Life NC

IDEAS FOR HOW TO SUPPORT AN ADULT PATIENT

Using technology

- Make daily phone calls or Facetime at a regular, specified time that works for everyone
- Speak to nurse to find out when NOT to do this. Many doctors' rounds are early in the am, therapies and tests are done in mornings, most have a quiet afternoon time for rest. About 4 pm may be the ideal "visit" time and for those with some dementia, it is before they "sundown". It might even help diminish the confusion with sundowning. They may have to find someone to hold the phone to the patient's ear and that time often works for nurses. It could be anyone though-the nursing assistant, etc.
- Make sure the patient has access to glasses and hearing aids and that someone will put them on/in if the patient is unable
- Ask the nurse or chaplain if technology is available, e.g. iPad for Facetime
- Chaplains may be better able to assist with technology than nurses who have other pressing responsibilities

Provide visual reminders that the patient is loved

- Send cards or photographs daily, either digitally or by mail, with updates, e.g. "Here is Fluffy the cat, sitting on top of the refrigerator. Scared me to death when I looked up! Don't ask me how she got there." or "My tomatoes are coming in nicely; I can't wait to share a tomato sandwich with you."
- Involve young children or grandchildren in making cards or drawing pictures
- Ask hospital staff to post them in the patient's room where the patient can easily see them, e.g. taped to bedrail.

- Provide a poster board and tape for the staff; ask staff to save these photos (as they are replaced by new ones and tape the old ones to the poster board to create a visual representation of a "visit" OR tape them to a wall or window (Hospitals sometimes have regulations about this- fire hazard, wall damage, only emergency warnings allowed, etc.)
- Have a larger photo of family, pet or home enlarged and signed by everyone

Provide audible reminders that the patient is loved

- Send recordings of friends and family that the patient can replay
- Messages from friends and family
- Voice of a beloved child or grandchildren
- A family member reading a book or articles of interest from a favorite newspaper or magazine, e.g. "Listen to this article in the Charlotte Observer, 'Walking Tours of Historic Charlotte'

Provide concrete reminders from home that the patient is loved

- Ask if the patient can have items from home at the bedside and/or if they are allowed to receive food, e.g. a fruit basket or home-made treat, e.g. your famous cheese straws.
- Can they wear their own pajamas or clothes? If so, get them theirs or give them some as a gift. Be careful about slippers though because some actually increase falls in a hospital environment.
- Send a favorite pillow or washable quilt to place on the patient's bed
- Send small but replaceable items from home, e.g. a framed picture of a garden
- Ask the chaplain's services to make sure the patient is connected to our weekly Facebook service, Thursday Blast, Zoom meetings, and anything else offered by the church (remember asking about an iPad?)
- Send the bulletin and highlight the patient's name on the prayer list
- Send a Book of Common Prayer (contact the church, 704-332-4171, for a copy or bcponline.org and Sunday and midweek worship on Facebook Live)

IDEAS FOR HOW TO SUPPORT THE FAMILY

These are other great ideas can be found in the book If There's Anything I Can Do: What You Can Do When Serious Illness Strikes by Josephine Hicks

- Meals (disposable, eco-friendly containers to eliminate need to wash dishes)
- Text messages (calls can be overwhelming; indicate early and often that there is no need to respond)
- Errands
- Pet Needs
- Lawn care or exterior "spruce up" (e.g. pressure wash their sidewalk/driveway)
- Help arrange for childcare
- Sit (socially distanced & masked) with them while they wait in hospital parking lots
- Offer to meet them for sitting quiet/praying/coffee time in our peaceful Memorial Garden space
- Remind them to pay bills on time
- Surprise "Thinking of You Gifts" (e.g. $5 Starbucks card, Hand Lotion, lavender essential oil and cotton balls)
- Set up a drive-by caravan to wave to family to cheer them up and on
- Give a free gift mask in a cheerful fabric made from our Masketeers!
- Offer goodie bags with things they can have in the hospital (magazines, cans Starbucks, snacks)
- Show up and change their sheets, dust, vacuum (with permission)

- Ask if they are keeping up with their daily meds
- Give families a printed handout of resources, contacts, phone numbers (see below)
- Offer to help set up CaringBridge site www.caringbridge.org
- Ask family members if they would like company during patient's surgery/procedures
- Offer to sit with patient, if visitors are allowed, while they go home rest/refresh

BEST PRACTICES FOR WHEN YOU OFFER PASTORAL SUPPORT

- Keep efforts simple, focused and practical
- The ministry of presence is very powerful
- Be prepared that stress may lead family members to react less patiently than they typically would
- Honor confidentiality; clergy are available to support you as your offer support to the caregiver
- Don't open-endedly ask, "What can we do?" "What do you need?" Instead offer specific ideas for help
- Coordination of our resources and efforts is critical to our success
- Recognize that families "crash" after initial adrenaline of crisis
- Be a listener & leave space for families to vent
- Validate their experience and sit with their pain and discomfort, avoid attempts to fix
- Divide our work according to our individual gifts we bring to this ministry
- Communicate with clergy, we work as a team

MORE RESOURCES

How Not to Say the Wrong Thing by Susan Silk and Barry Goldman, LA Times, April 7, 2013 describes the Ring Theory which places the patient at the center with concentric circles/rings of support. The counsel is to "Comfort IN, dump OUT". Seek those in the circle beyond yours to support and comfort you.

A CARE NETWORK STRUCTURE FOR CAREGIVERS