PACT CODE CARD

What is Pediatric Palliative Care (PPC)?

PPC provides physical, psychological, spiritual, and psychosocial support to children with life-threatening illness and their families, despite prognostic uncertainty. PPC focuses on comfort and quality of life, *without precluding continuation of disease-directed treatment.*

Core PACT Team Members:

- Joanne Wolfe, MD, MPH (PACT Medical Director)
- Tamara Vesel, MD (Fellowship Director)
- Rick Goldstein, MD (PACT Physician)
- Christina Ullrich, MD, MPH (BCRP Rotation Director)
- Janet Duncan, CPNP (Nursing Director)
- Marsha Joselow, LiCSW (Social Work Director)
- Rita Fountain (PACT Coordinator)

Requesting a PACT Consultation:

- Introduce the concept of PACT to the child and family. If you are not sure how to do this, PACT can help you.
- Page the PACT clinician on call via the CHB paging system, and provide the following information: ***reason for*** and ***urgency*** of the referral, and the requesting ***attending physician.***

Introducing PACT: Example Conversation:

"To best meet these goals that we have been discussing, we believe it would be helpful to have the PACT team visit with your family. They are a team that works with us, and they specialize in optimizing your child's quality of life by helping to manage symptoms and provide support to your child and your family. They can also help you clarify your goals of care, and help think through any decisions as they might arise. Our goal is for all of the teams to work together to provide your child with the best care possible."

Enhancement of Quality of Life (QOL):

- Integrated Therapies Team (617-355-7684): Offers Massage Therapy, Guided Imagery, Reiki, Yoga, Meditation
- Expressive Art Therapy: Child Life (617-355-6551)
- Pet Therapy: Center for Families (617-355-6279)
- Acupuncture: For inpatient consultations, call 617-355-4158. For outpatient appointments, call 781-216-3700.
- Make-A-Wish Foundation: (800) 722-WISH

Non-Pharmacologic Symptom Management:

- Limit non-essential painful procedures
- Address coincident depression and anxiety
- Consider alternative therapies: relaxation, meditation, breathing exercises, hypnosis, guided imagery, Reiki, biofeedback, yoga, massage, acupuncture/acupressure, or art/pet/play/music therapy
- For fatigue: consider contributing factors (anemia, depression, drug effects), address sleep hygiene, encourage gentle exercise

More Non-Pharmacologic Symptom Management:

- For dyspnea: consider suctioning, repositioning, comfortable loose clothing, a fan to blow cool air towards the face, limitation of IV fluids, breathing and relaxation exercises
- For nausea/vomiting: dietary modifications (bland/soft, adjust timing/volume of feeds), aromatherapy (peppermint, lavender), acupuncture/acupressure

WHO Pain Ladder:

Pain Level	Drug Class	Specific Agent
Step 1: Mild-Mod Pain	Non-opioid ± Adjuvant	Acetaminophen or NSAID
Step 2: Mod Pain, or Pain Uncontrolled after Step 1	Non-opioid around the clock (ATC) + Short-acting PRN opioid ± Adjuvant	Acetaminophen or NSAID, + PRN morphine, oxycodone, or hydromorphone
Step 3: Mod to Severe Pain, or Pain Uncontrolled after Step 2	Sustained-release (SR) opioid ATC or continuous infusion, + PRN short-acting opioid ± non-opioid ± adjuvant	SR oxycodone, morphine, or transdermal fentanyl

KEY TIPS for Dosing/Escalating Opioids:

- Any patient on opioids must be on a bowel regimen that consists of more than just a stool softener!
- When speaking with patients and families, use the term "opioid" rather than "narcotic."
- Reassure families that their child will not become a "drug addict" on the appropriate opioid regimen.
- Increase the dose of opioid based on clinical response; the "right opioid dose" is the dose that best controls the child's pain with the fewest side effects.
- Dose increases are based on a percentage of the current dose:
  - → 30% increase for mild pain
  - → 50% increase for moderate pain,
  - → 100% increase for severe pain.

Key Tips for Managing Breakthrough Pain:

- Breakthrough pain (BTP) is a transitory flare of moderate to severe pain that occurs on a background of otherwise adequately controlled pain.
- Remember that BTP is different from end-of-dose failure (EDF). EDF refers to pain at the end of a dosing interval of around-the-clock (ATC) opioid medication.
- Increase the daily dose of sustained-release (SR) opioid by an amount equal to 50-100% of the total amount of breakthrough medication that the child required during the past 24 hours.
- Each subsequent dose of the breakthrough opioid should equal 10-15% of the total daily requirement of SR opioid.

Performing Equianalgesic Conversions:

Opioid Agent	PO/PR (mg)	IV/SQ (mg)
Morphine	30	10
Oxycodone	20	n/a
Hydromorphone	7.5	1.5
Fentanyl	n/a	0.1 (100 mcg)

Keeping the Same Opioid, but Changing the Route:

Ex: 90 mg q12 SR morphine PO → morphine IV infusion

- Calculate 24 hr dose: 90 mg q12 * 2 = 180 mg PO/24 hrs
- Use PO to IV equianalgesic ratio: 30 mg PO = 10 mg IV
- Use ratios to calculate new dose: 180/x = 30/10; x= (180*10)/30 = 60 mg IV/24hr = 2.5 mg IV/hr infusion

Changing the Opioid, but Keeping the Same Route:

Ex: 90 mg q12 SR morphine PO → hydromorphone PO

- Calculate 24 hr dose: 90 mg q12 * 2 = 180 mg PO/24 hrs
- Use equianalgesic ratio: 30 mg morphine PO = 7.5 mg hydromorphone PO
- Use ratios to calculate new dose: 180/x = 30/7.5; x = (180*7.5)/30 = 45 mg hydromorphone PO/24 hr
- Reduce dose by 25-50% to account for cross-tolerance: 45 * 0.5 = 22 mg/24 hr (or 4 mg q4h)

Appropriate Use of Naloxone (Narcan):

- Opioid antagonists can reverse opioid-induced respiratory depression, but they also may reverse analgesic effects.
- Naloxone should *NOT* be administered for a depressed respiratory rate with normal O2 saturation, or for a patient who is arousable.
- In this case, simply reduce the opioid dose, provide physical stimulation, and continue to monitor the patient closely.
- If naloxone is needed: dilute 0.4 mg (1 ml) in 9 ml of NS, and administer IV in 1-2 ml increments at 2-3 min intervals until response.

Adjuvant Agents: The primary purpose of these medications is not analgesic, however they may be used to relieve pain in conjunction with other analgesics.

Adjuvants	Comments
Tricyclics: *Nortriptyline*	May cause constipation, dry mouth, postural hypotension, prolonged QT
Anticonvulsants: *Gabapentin* *Pregabalin*	Titrate up gradually to prevent dizziness or drowsiness
Sedatives: *Diazepam* *Clonidine*	Synergistic sedative and respiratory effects with opioids; clonidine acts as an opioid sensitizer
Antispasmodics: *Baclofen*	May cause anticholinergic symptoms; lowers seizure threshold
Salicylates: *Trilisate*	Trilisate has decreased risk for bleeding as compared to other salicylates

Tips for Improving Communication Skills:

Instead of Saying:	*Try Saying:*
Our hypoplast	The child with hypoplastic left heart disease
Your child failed induction (or other treatment plan)	Our treatments were not successful in curing your child
I know how you feel, or I know how difficult this situation is for you	I can only imagine how difficult this situation is for you
Do you want us to do everything to keep your child alive?	What is your understanding of the decision to attempt life-sustaining interventions?
Are you ready to sign the "Do Not Resuscitate" (DNR) orders?	Do you agree with the medical recommendation for "Do Not Attempt Resuscitation" (DNAR)?
We are going to withdraw support now, or We will be pulling the ventilator at this time	We will stop mechanical ventilation as it is no longer clinically indicated, but we will continue to provide maximal supportive care

Clarifying Goals of Care:

- Goals of care are different for everyone. The only way to truly identify and understand your patient's goals of care is to ***ASK***.
- Some examples of goals of care might include: physical and psychological comfort, attending prom or other important events, speaking, eating favorite foods, sleeping in own bed at home.
- **Important questions to ask:** *What do you expect in the future? What are the most important things that you are hoping for your child right now? What are you most worried about?*

Sharing Bad News:

- Acknowledge the difficulty inherent in this discussion.
- Establish a shared agenda before the meeting begins.
- Ask the patient/family to explain their hopes and goals.
- Restate these hopes and goals to ensure that all heath care providers fully understand the wishes of the patient and family.
- Explain the role and impact of life-sustaining therapies
- Forecast the medical possibilities and offer a medical opinion.
- Offer resources to help the family think about difficult decisions (social worker, chaplain, families who faced similar decisions).
- Plan a time to meet again.
- Document the discussion.

Tips for Discussing Life-Sustaining Therapies (LST):

- Avoid mechanical descriptions of CPR ("starting the heart" or "putting on a breathing machine").
- Use neutral, non-judgmental language to describe options. If you are describing cardiac resuscitation in terms of broken ribs and painful electroshock, you may want to reflect on your word choice; consider sharing your reflections with the family.
- Using the word "die" often helps to clarify the fact that CPR is a treatment that attempts to reverse death.

Example Conversation about LST:

We all share the hope that your child will live as long as possible. But that is usually not the only goal. We also want your child to live as well as he possibly can, and some of the treatments that we use to extend life may alter his quality of life in ways that may not be what you want for him. If the time comes when critical decisions need to be made, you will have more control over the situation if we all understand and agree about what is most important for you and your child. Talking about these possibilities does not mean that we are giving up – we think of this strategy as hoping for the best, but planning for the worst. In case your child does not get better, what are you hoping for?

Tasks to Complete BEFORE the Death of a Child:

☐ If there is a possibility that a child may die during your shift, introduce yourself to the child and family as soon as you arrive.
☐ Familiarize yourself with the child's story by speaking with the child's nurse and/or other caregivers.
☐ Involve chaplaincy, child life, and other supportive services.
☐ Determine whether autopsy or organ donation have been discussed with the family. If not, address these issues with the family. If they agree, obtain informed consent.

KEY TIPS About Organ Donation:

- In most cases, the donor must be >36 weeks gestation; HIV, HepB, and HepC negative; no IV drug use in past 5 yrs, no history of lymphoma or leukemia.
- Donation is not limited to whole organs; families may choose to donate tissues such as corneas, heart valves, aortoiliac grafts, pericardium, bone, saphenous and femoral veins, or skin.
- Call the New England Organ Bank (NEOB) at 1-800-446-6362 in order to speak with a representative who can help you determine eligibility and arrange the logistics of procurement.

Tasks to Complete AT the Time of Death:

☐ Familiarize yourself with the child's history before entering the child's room.
☐ Consider asking the child's nurse or chaplain to come with you to introduce you to the family and provide additional support.

In the Room:

☐ Introduce yourself to the family, including your role and your relationship to the deceased child.
☐ Express your sympathy and allow the family to express their emotions before beginning.
☐ Explain that you are going to examine their child. Reassure the family that they may stay if they wish.

Pronouncement of Death:

☐ Identify the patient by his or her hospital ID tag.
☐ Ensure that the patient does not rouse to verbal or tactile stimuli. *Avoid painful and unnecessary stimuli.*
☐ Listen/feel for the absence of heart sounds and of pulse.
☐ Look/listen for the absence of spontaneous respirations.
☐ Note the position of the pupils and the absence of pupillary light reflex.

Chart Documentation of the Death of a Child:

☐ Document all findings in the medical record, including: *Date/time of death; Presence of family at time of death; Physical examination findings; Date/time of physical assessment of patient; Family and attending physician notified; Family accepts/declines autopsy and/or organ donation; New England Organ Bank notified; Medical Examiner notified.*
☐ Notify the attending physician regarding the child's death.

Tasks to Complete AFTER the Death of a Child:

☐ **Autopsy and Organ Donation Conversation/Consent** (If not discussed prior to the child's death)
☐ **Notify the New England Organ Bank (NEOB):** MA mandates that the NEOB be notified for all hospital deaths. Call **1-800-446-6362** within 1 hour of death to inform the NEOB of the family's wishes regarding donation.
☐ **Notify the Massachusetts Medical Examiner (ME):** Call the ME at **1-617-267-6767.** This call is legally mandated for all deaths of children <18 years, including planned home deaths and deaths that occur +/- hospice.
☐ **Note in Chart:** See prior section for details.
☐ **Report of Death:** The physician who pronounced the patient must complete the "Report of Death" form and bring it to the Admitting Department (or the Emergency Dept during off-hours).
☐ **Sign the Typed Certificate:** Provide your pager number, so that you may be reached later to sign the typed Death Certificate.

Writing a Condolence Letter:

- Name the deceased and acknowledge the loss.
- Express your sympathy, using words that remind the bereaved that they are not alone in their feelings of sadness and loss.
- Avoid statements such as *I know how you feel*, unless you truly empathize from prior personal experience.
- Note those special qualities or characteristics that you most cherished or appreciated about the deceased person.
- Recall a memory about the deceased, and try to capture what it was about the person in the story that you admired. You may use humor – funny stories are often very appreciated by the bereaved.
- Remind the bereaved of their personal strengths (patience, optimism, religious belief, resilience) that will help them to cope.
- Offer help during this difficult time, and be specific about your offer. *Never* make an offer that you cannot fulfill.
- End your letter with a phrase of sympathy: "You are in my thoughts" or "My fond respects to you and yours."

Online Resources for Pediatric Palliative Care:

- End of Life/Palliative Care Education Resource Center (EPERC): http://www.eperc.mcw.edu/
- Fast Facts: http://www.eperc.mcw.edu/EPERC/FastFactsIndex
- Children's Project on Palliative/Hospice Services (ChiPPS): www.hhpco.org/pediatrics.
- The Initiative for Pediatric Palliative Care: www.ippcweb.org
- Children's Hospice International: http://www.chionline.org/
- AAP Section on Hospice and Palliative Medicine: http://www.aap.org/sections/palliative/

Return to Table of Contents