Pediatric Advanced Care Team (PACT) CODE CARD

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What is Pediatric Palliative Care (PPC)?

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

Core PACT Members

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

Requesting 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 PACT visit with your family. PACT is a team that works with us, and they specialize in optimizing your child's quality of life by helping to manage symptoms and by providing additional support to your child and your family. They can also help you clarify your goals of care, and help you 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: Inpatient (617-355-4158), clinic (781-216-3700)
- Make-A-Wish Foundation: (800) 722-WISH

Non-Pharmacologic Symptom Management

- Limit non-essential painful procedures
- Address coincident depression and anxiety
- For fatigue: consider contributing factors (anemia, depression, drug effects), address sleep hygiene, encourage gentle exercise
- For dyspnea: consider suctioning, repositioning, loose clothing, a fan, limitation of IV fluids, breathing and relaxation exercises
- For nausea/vomiting: consider dietary modifications (bland or soft foods, adjust timing or volume of feeds), aromatherapy (peppermint, lavender), acupuncture or acupressure

WHO Pain Ladder

Pain Level	Drug Class	Specific Agent
Step 1: Mild to mod	Non-opioid ± adjuvant	acetaminophen or NSAID
Step 2: Mod, or uncontrolled after Step 1	Non-opioid around the clock (ATC) + immediate-release (IR) opioid PRN ± adjuvant	Acetaminophen or NSAID, + PRN morphine, oxycodone, or hydromorphone
Step 3: Mod to severe, or uncontrolled after Step 2	Sustained-release (SR) opioid ATC or continuous infusion, + IR/IV opioid PRN ± non-opioid ± adjuvant	SR oxycodone, morphine, or transdermal fentanyl

KEY TIPS for Prescribing Opioids

- Any patient on opioids must be on a bowel regimen that includes a stool softener AND laxative *("mush and push!")*
- When speaking with patients and families, use the term "opioid" rather than "narcotic," and reassure families that their child will not become a "drug addict" on the appropriate opioid regimen.
- Increase opioid dose based on clinical response; the "right dose" is the dose that best controls 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, and 100% increase for severe pain.

Key Tips for Managing Breakthrough Pain (BTP)

- BTP is a transitory flare of moderate to severe pain that occurs on a background of otherwise adequately controlled pain.
- BTP is different from end-of-dose failure (EDF). EDF is pain at the end of a dosing interval of an ATC analgesic.
- To manage BTP: increase daily dose of opioid by 50-100% of the total amount of breakthrough medication given in past 24 hrs.
- Each subsequent dose of the breakthrough opioid should equal 10-15% of the total daily opioid requirement.

Standard Opioid Starting Doses and Intervals

Opioid	Enteral (PO)	Parenteral (IV)
Morphine	0.2-0.3 mg/kg (10-15 mg) Q3-4h	0.1 mg/kg (5 mg) Q2-4h or 0.03 mg/kg/h (1.5 mg/h)
Oxy-codone	0.1-0.2 mg/kg (5-10 mg) Q3-4h	n/a
Hydro-Morphine	0.04-0.08 mg/kg (2-4 mg) Q3-4h	0.015-0.02 mg/kg (0.75-1 mg) Q2-4h or 0.0006 mg/kg/h (0.3 mg/h)
Fentanyl	n/a	0.5-1 mcg/kg (25-50 mcg) Q60min, or 0.5-1 mcg/kg/h (25-100 mcg/h)

** Doses in parenthesis are for children > 50 kg.*
** For infants <6 months, initial per-kg doses should begin at 25% of the above per-kg doses.*
** All doses are approximate, and should be adjusted according to clinical circumstances.*

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)

Sample Equianalgesic Calculations

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

- Opioid antagonists can reverse opioid-induced respiratory depression; however, they also may reverse analgesic effects.
- Naloxone should *NOT* be administered for a depressed RR without concomitant hypoxia, or for a patient who is arousable.
- In either of those cases, 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 give IV in 1-2 ml increments at 2-3 min intervals until response.

Adjuvant Agents: The primary purpose is not analgesic, yet they may 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

Communication Tips

Instead of Saying:	*Try Saying:*
Our hypoplast	The child with hypoplastic left heart disease
Your child failed the 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 to write a "Do Not Attempt Resuscitation" (DNAR) order for your child?
We are going to withdraw support, or we will be pulling the ventilator now	We will stop mechanical ventilation, but will continue to provide maximal supportive care

Discussing Goals of Care

• Goals of care are different for everyone. The only way to understand a child/family's goals of care is to ***ASK***.
• Goals of care may include: physical and psychological comfort; attending prom, graduation, 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 health care providers fully understand the wishes of the patient and family.
• Forecast the medical possibilities, and explain the role of life-sustaining treatments (see below).
• Offer a medical recommendation based on the medical situation and the goals of care of the patient and family
• Offer resources to help the family think about difficult decisions (social worker, chaplain, families who faced similar decisions).
• Lay out the plan, including a time to meet again.
• Document the discussion.

Tips for Discussing Life-Sustaining Therapies (LST)

• Avoid mechanical descriptions of CPR, such as "starting the heart" or "putting on a breathing machine."
• Use neutral, non-judgmental language to describe options; for instance, avoid describing cardiac resuscitation in terms of broken ribs and painful electroshock.
• Avoid saying, "Do you want us to do everything?"
• 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 a Child's Death

☐ 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 history by speaking with the child's nurse and/or other caregivers.
☐ Involve chaplaincy, child life, and other supportive services based on family preferences.
☐ Determine whether autopsy and 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 during the past 5 years, no history of lymphoma or leukemia.
• Donation is not limited to whole organs; families may choose to donate specific 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 to determine eligibility and discuss procurement logistics.

Tasks to Complete AT the Time of Death

☐ If you did not know the child prior to death, familiarize yourself with the child's history before speaking with the family.
☐ Consider asking the child's nurse or chaplain 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 and feel for the absence of heart sounds and of pulse.
☐ Look and listen for the absence of spontaneous respirations.
☐ Note the position of the pupils and the absence of pupillary light reflex.

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):** Massachusetts 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 Massachusetts Medical Examiner (ME):** Call **1-617-267-6767.** This is legally mandated for all deaths of children <18 years, including anticipated home deaths +/- hospice.
☐ **Notify the attending physician** regarding the child's death.
☐ **Chart Documentation:** *Date/time of death; presence of family at time of death; physical exam 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.*
☐ **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.*
• Note those special qualities or characteristics that you appreciated about the person.
• Recall a memory about the person, and capture what it was about the person in the story that you admired. Humor is ok – funny stories are often appreciated.
• Remind the bereaved of their personal strengths (patience, optimism, faith, 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

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Created by Erica Kaye MD & Christina Ullrich MD, MPH