



Pain in the Pediatric Palliative Care Context

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and Palliative Care Service

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- No financial disclaimers or conflicts of interest to declare
- Parental consent has been received to use patients' names and personal information for educational purposes

Objectives

- Identify differences & similarities between palliative care in children & adults
- Recognize the importance of symptom management in pediatric palliative context
- Learn pain assessment tools for children
- Case studies will be presented



WRHA Symptom Management & Palliative Care Service

- Established by Dr. Mike Harlos in 2006
- 1.2 FTE physician and 1.0 Clinical Nurse Specialist.
- Referrals per year: 50-80
- Deaths per year: 30-40
- Location of care
 - Children's
 - St. Boniface
 - Women's
 - St. Amant
 - Home



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Our Team

- MD coverage 24/7
 - Dr. Mike Harlos, Medical Director (Adult & Pediatric Palliative Care)
 - Dr. Dave Lambert
 - Dr. Chris Hohl
 - Dr. Bruce Martin
- Daytime contact
 - Erin Shepherd, Clinical Nurse Specialist: Mon - Fri



Palliative Care is...

- an **approach to care**
- focuses on comfort and quality of life for those affected by life-limiting/life-threatening illness
- goal is **much more than comfort in dying**; palliative care is about *living*
- meticulous attention to:
 - control of pain and other symptoms
 - supporting emotional, spiritual, and cultural needs
 - maximizing functional status

(Dr. M. Harlos)

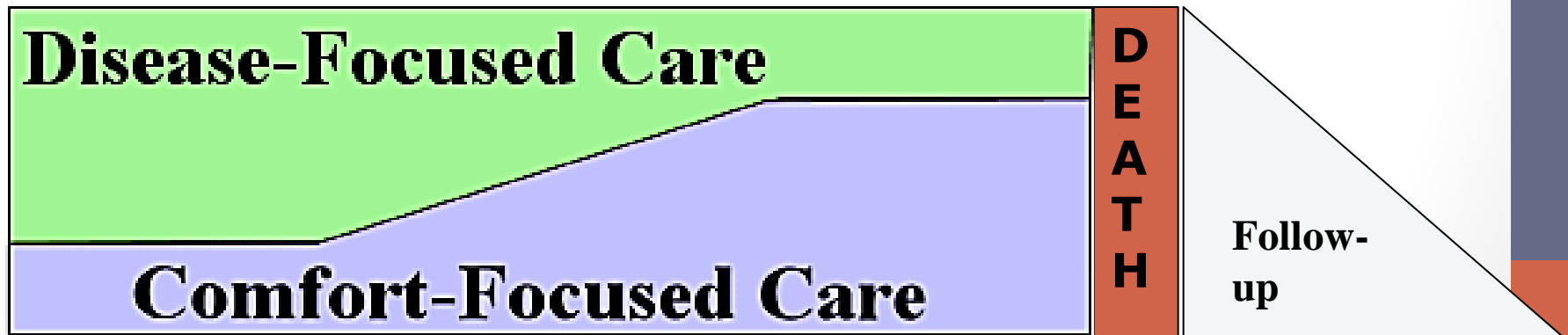
Palliative Care is...

- The spectrum of investigations and interventions consistent with a palliative approach is guided by
 - goals of patient and family
 - accepted standards of health care
 - not by preconceptions of what is or is not "palliative".

(Dr. M. Harlos)

Pediatric Palliative Care

- Palliative care for children is not exclusive of ongoing cure-focused care
- Can be involved as a parallel process, with a variable profile depending on goals of care and clinical circumstances



“Thank you for giving
me aliveness”

Jonathan – 6 yr old boy terminally ill boy

Ref: “Armfults of Time”; Barbara Sourkes



How people die remains in the memories of those who live on.

—Dame Cicely Saunders

Palliative Care for Children

- Number of children who die is small
 - Timescale/trajectory of childhood illness is different from adults
- Many conditions are rare - diagnoses specific to childhood
 - Many conditions are genetic (>1 child in the family)
- Need to consider stages of growth and development
- Prenatal disease significant in palliative care for children
- Provision of education and play when a child is seriously ill is essential

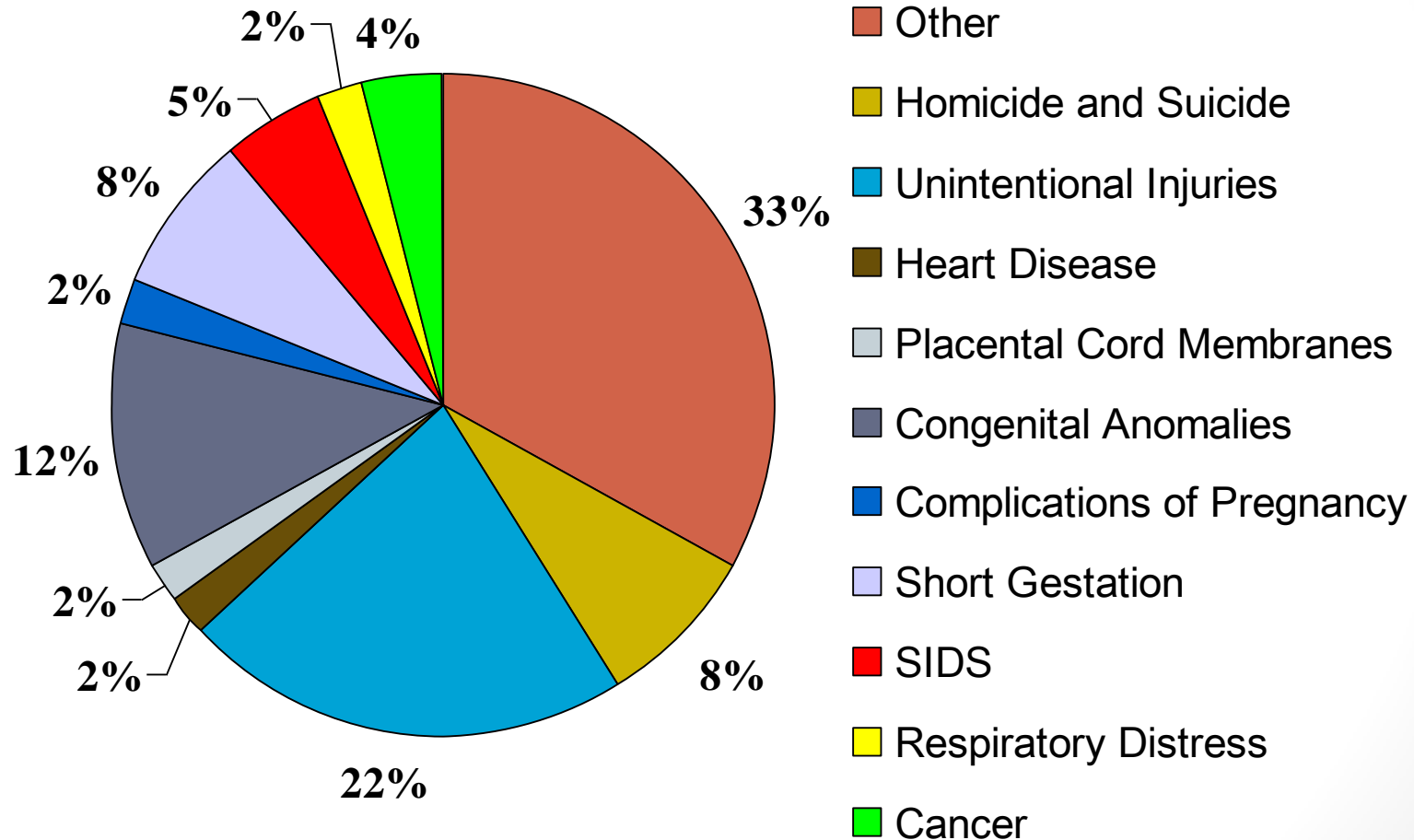
Differences Between Adult & Pediatric Palliative Care

- Order of life
- Diagnosis
- Prognosis
- Parents as decision-makers
- Society beliefs on death and dying (age)

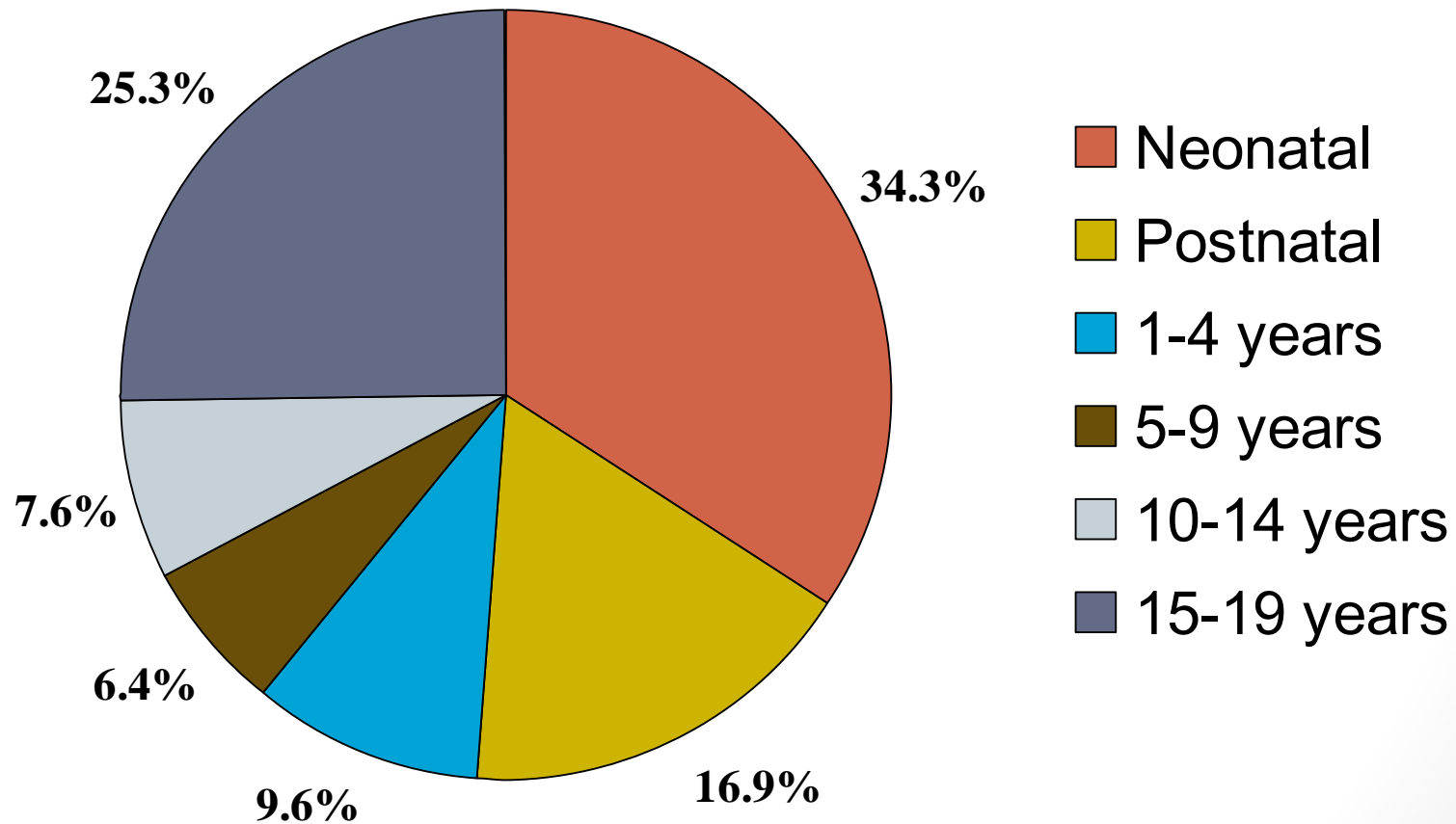
Similarities Between Adult and Pediatric Palliative Care

- Communication
- Symptom management
- Family as unit of care
- Psychosocial support
- Society beliefs on death and dying (taboo)

Major Cause of Childhood Deaths



Percentages of Deaths by Age Group



Pain Assessment in Infants & Children

- Performed routinely by child-friendly, age & developmentally appropriate methods
- Tools should elicit quantitative & qualitative data
- Child, family & health care team need to collaborate to ensure individualized care
- Pain management is based on multidimensional & contextual approach

QUESTT

- Question the child
- Use pain rating scales
- Evaluate behaviour
- Secure parents' involvement
- Take cause of pain into account
- Take action & evaluate results

Tools for Pain Assessment in Children

- FLACC – Facial expression, Legs, Activity, Crying, Consolability pain tool (Merkel et al., 1997)
- FACES pain rating scale (Wong et al., 2001)
- Numeric Scales – 0-5 or 0-10



happy



depressed



angry



pensive



excited



suicidal

How to recognize the moods of an Irish setter

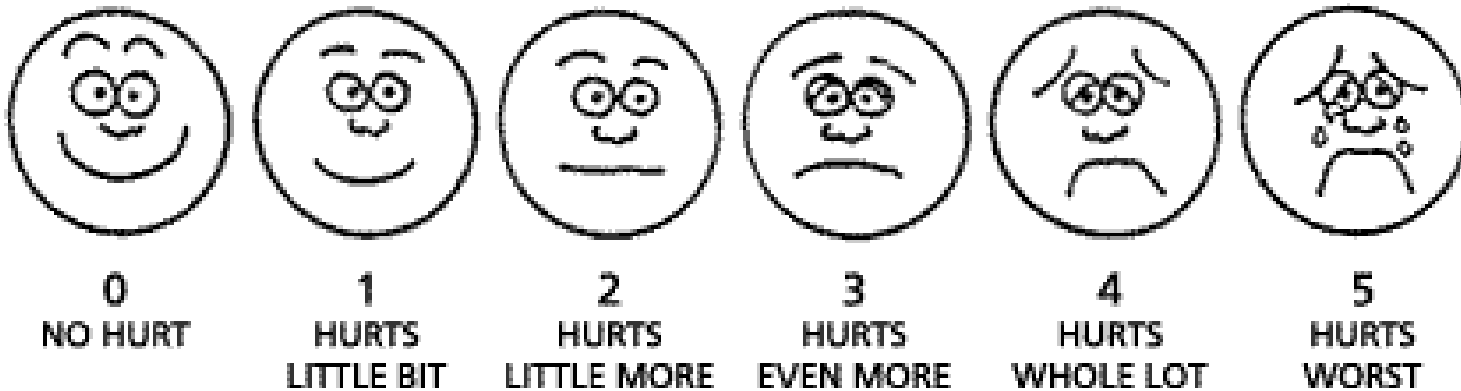
FLACC (non-verbal)

Category	Scoring		
	1	2	3
Face	No particular expression or smile	Occasional grimace or frown, withdrawn, disinterested	Frequent to constant quivering chin, clenched jaw
Legs	Normal position or relaxed	Uneasy, restless, tense	Kicking, or legs drawn up
Activity	Lying quietly, normal position, moves easily	Squirming, shifting back and forth, tense	Arched, rigid or jerking
Cry	No cry (awake or asleep)	Moans or whimpers; occasional complaint	Crying steadily, screams or sobs, frequent complaints
Consolability	Content, relaxed	Reassured by occasional touching, hugging or being talked to, distractible	Difficult to console or comfort

Each of the five categories (F) Face; (L) Legs; (A) Activity; (C) Cry; (C) Consolability is scored from 0-2, which results in a total score between zero and ten.

From *The FLACC: A behavioral scale for scoring postoperative pain in young children*, by S Merkel and others, 1997, *Pediatr Nurse* 23(3), p. 293-297. Copyright 1997 by Jannetti Co. University of Michigan Medical Center.

Wong-Baker Faces



Instructions: Point to each face using the words to describe the pain intensity. Ask the person to choose face that best describes own pain and record the appropriate number.

Recommended for children \geq 3yrs

Selecting the Right Drug

- Step 1: Mild Pain
 - Acetaminophen & NSAIDs
- Step 2: Moderate Pain
 - Codeine (weak opioid) – not used in peds
- Step 3: Moderate to Severe Pain (consider adjuvants)
 - Morphine (PO, SL, IV, SC, PR)
 - Hydromorphone (PO, SL, IV, SC, PR)
 - Oxycodone (PO)
 - Fentanyl (PO, SL, IV, IN, transdermally)
 - Methadone (PO, IV)
 - Ketamine (PO, PR, IV)



Routes

- **Oral route** is preferred for most children, most of the time
- **Alternate routes:**
 - GT
 - IV (peripheral and central)
 - **Subcutaneous**
 - **Transmucosal** (nasal, buccal, sublingual)
 - Transdermal / transcutaneous
 - Spinal: epidural, intrathecal
 - Rectal



Intranasal Fentanyl for Palliative Newborns

- Protocol initiated at St Boniface and Women's
- To be given for dyspnea &/or pain
- Use atomizer to mist the liquid for better absorption
- Based on anticipated birth weight
- Recommend having it at bedside during delivery to minimize delay if patient in symptomatic



*Wolfe Tory Medical Inc. MAD Nasal: Mucosal Atomization Device. Available at:
<http://www.wolfetory.com/nasal.php#>*



Intranasal Fentanyl for Symptom Management in Palliative Newborns

STANDARD ORDERS

DATE _____ HSC NO. _____
 PATIENT _____
 DOB _____
 PROV HC# _____
 DOCTOR _____
 CLINIC/UNIT _____ LOC'N _____

These orders are to be used as a guideline and do not replace sound clinical judgment and professional practice standards.

Patient allergy and contraindications must be considered when completing these orders.

Standard orders. *If not in agreement with an order, cross out and initial.* Requires a check (✓) for activation.

A Medication Order for pediatric patients who weigh 50 kg or less must include the dosage by weight in terms of 'milligrams per kilogram per day' or 'milligrams per kilogram per dose' OR by body surface area ('milligram per square meter per dose or day'). (WRHA Medication Order Writing Standard, March 2009)

Drug Allergies ▶	ORDER TRANSCRIBED AND ACTIVATED	DATE _____ TIME _____ Patient's Height _____ Patient's Weight _____
R MEDICATION ORDERS TO BE INITIATED OR DISCONTINUED	TEST DONE	GENERAL ORDERS PAGE 1 OF 1
DATE _____ TIME _____		
<p>Orders applicable to Labour and Delivery (L&D) and Labour, Delivery, Recovery, Postpartum Unit (LDRP) only</p> <p><input type="checkbox"/> Anticipated birth weight less than 1 kg</p> <ul style="list-style-type: none"> Fentanyl 1 mcg intranasal q 5 minutes PRN for respiratory distress (tachypnea and increased work of breathing accompanied by distress)* <p><input type="checkbox"/> Anticipated birth weight greater than 1 kg</p> <ul style="list-style-type: none"> Fentanyl 2.5 mcg intranasal q 5 minutes PRN for respiratory distress (tachypnea and increased work of breathing accompanied by distress)* <p>* If 3 doses are administered in a 30 minute period and are ineffective, physician must be notified to reassess.</p>		<p>This protocol is intended for palliative newborns who are opioid-naïve.</p>
PHYSICIAN'S SIGNATURE _____ MD		TRANSCRIBED: _____ REVIEWER: _____
PRINTED NAME _____ MD GENERIC EQUIVALENT AUTHORIZED		<input type="checkbox"/> FAXED DATE: _____ TIME: _____ INITIALS: _____

Symptom Management for Epidermylosis Bullosa

- Used oral and intranasal routes because IV/SC was not an option
- Regular medications
 - Morphine PO (pain)
 - Clonidine PO (pain & agitation)
- As needed medications
 - Fentanyl IN (for pain & pre-dressing change/bath)
 - Ketamine IN (pre-dressing change/bath)
 - Methotrimeprazine IN (pre-dressing change/bath)
- In hospital and at home

Pain Management at EOL – Case Study 1

- Marisa was a 17-yr-old young woman with CNS tumour with metastases to spinal cord
- Diagnosed with primitive neuroectodermal tumour (PNET) at age 7
 - Chemo
 - Radiation
 - Surgery
- Multiple spinal cord and brain relapses over subsequent 10 yrs
- Referred to our service in 2007 for pain management
 - Methadone (regularly)
 - Morphine (prn)
 - Gabapentin (reg)

Marisa (cont.)

- Last recurrence was in July 2009
- In Sept 2009, pain meds included:
 - Methadone (PO/GT; reg)
 - Ketamine (PO/GT; reg + prn)
 - Morphine (PO/GT; reg)
 - Hydromorphone (PO/GT; prn)
 - Gabapentin (PO/GT; reg)
- pain control options were discussed:
 - Interventions
 - Epidural
 - Nerve block
 - Medications
 - Tramacet
 - cannabinoids

Marisa (cont.)

- Final admission Jan – Mar 2010
 - In month prior to admission: ↑ pain, ↓ function, ↓ sensation to lower body & lower limbs
- Medications at EOL
 - IT bupivacaine & clonidine
 - Methadone (PO/GT; reg + prn)
 - Ketamine (PO/GT; reg + prn)
 - Gabapentin (PO/GT; reg)
 - Diazepam (PO/GT; reg + prn)
 - Baclofen (PO/GT; reg)
 - Venlafaxine (PO/GT; reg)
 - Sertraline (PO/GT; reg)
 - Hydrocortisone (PO/GT; reg)

Marisa (cont.)

- Complex pain requiring complex pain management
- Marisa died on March 23, 2010 at Children's Hospital

Pain Management at EOL – Case Study 2

- Morgan was just shy of 2 years old when she was diagnosed with a brain tumour
 - Chemo
 - Surgery
 - Weeks in PICU
- Required intubation and ventilation
- Developed severe meningitis as a complication of treatment
- Experienced tumor re-growth with grim prognosis
- Parents were given the option to withdraw life sustaining treatment and they desired to do this
- Wanted Morgan to die at home





Morgan's Pain Scale

- **S-** I am sleeping and appear comfortable my face is relaxed
- **0-** I am neutral, but I am able to smile and laugh.
- **2-** I am more quick to “say” NO by shaking my head.
- **4-** I don't want people to look at me or touch me
- **6-** I am starting to contradict myself. I push my parents and my toys away
- **8-** I am grinding my teeth
- **10-** I am in full crisis. I begin hitting myself in the head

Planning for Home Discharge from PICU

- Inter-facility transport model adapted
- Phases of transport examined: pre, during and post transport
- Roles and responsibilities discussed and documented
 - Created role clarity
 - Consistent with scope of practice
- Medical orders written (not activated)



Pediatric Palliative Care Role in Discharge Plan

- Ensuring paperwork in place
 - Letter of Anticipated Home Death
 - Advance Care Plan
 - Registration on Palliative Care Program
 - Manitoba Palliative Drug Access
- Medication administration in the home
 - Linking with community pharmacy
 - Accessing pump for community use
- Assisting with coordination of transfer plan



Medications at Home

- Midazolam and Fentanyl infusion (in same IV bag)
 - Continuous infusion
 - Bolus
- Fentanyl for IV administration by physician
- Considerations when evaluating dose and ease of administration



Transition from PICU Team to Pediatric Palliative Care Team

- The first minutes
- The first hours
- Struggle when to leave
- Connecting throughout the day and evening
- Home visit by physician when death occurred
 - Morgan died on Nov 29, 2009 at home surrounded by her family

Thank you

- To the families for allowing us to share their stories
- To you for your attention

Questions



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