

# Support of Hospices in Caring for Pediatric Patients in Washington State and the NWPPCC Region

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In the State of Washington, the hospice certificate of need program requires hospices to serve all hospice-eligible people in their service area, including all ages: from newborns to the elderly. In urban areas like the Seattle/Tacoma and Spokane areas, there are pediatric hospice and palliative care teams that follow pediatric patients at home. They have dedicated pediatric teams that include RN, MSW, Spiritual Care, and Pediatric Medical Director. As community providers or inpatient teams look for a hospice team who can serve a pediatric patient outside the urban hub, it can be a challenge. Rural hospices may only occasionally be asked to provide care for a child. As palliative care teams reach out with a referral, hospices are often reluctant to take on the responsibility to care for a child, as staff changes may mean that their previous "pediatric champion" is no longer there.

The Washington State Hospice and Palliative Care Organization (WSHPCO) Board prioritizes the care of children in our state. There is a monthly pediatric palliative care virtual networking meeting of stakeholders that has been meeting since the ACA first passed the provision for hospice concurrent care for pediatric patients. This group facilitated a major change in the state regulatory language which initially read: "treatments to achieve a disease-free state" to "life prolonging or curative treatments" while also receiving hospice care. The Pediatric Palliative Care networking group continues to meet monthly to problem solve access concerns and to address other pediatric palliative care issues. At the WSHPCO annual clinical conference each fall, presentations around pediatric palliative care and hospice continue to position this issue as a priority for education and discussion.

WSHPCO and the Oregon Hospice and Palliative Care Association (OHPCA), along with Seattle Children's Hospital and Oregon Health Sciences University's Doernbecher Children's Hospital, collaborated to found the Northwest Pediatric Palliative Care Coalition (NWPPCC) for the States of Alaska, Idaho, Montana, Oregon, and Washington. Through the NWPPCC, a monthly newsletter and twice annual meetings help provide education, advocacy, and peer support throughout the region for pediatric palliative care and hospice.

Over the past five years, Seattle Children's Hospital has prioritized the support of hospices in Washington State. Pre-pandemic this support included on-site visits to hospices to provide education. Since the pandemic began, virtual educational offerings have been provided which are tailored to a specific hospice's needs. Some rural

hospices have had three or four presentations, for new staff, and for ongoing education and support around hospice concurrent care. In addition, hospice medical directors have access to a pediatric palliative care trained pediatrician 24/7 to problem solve symptom management issues. Staff have access to the pediatric palliative care team including a nurse coordinator for questions and advice.

This outreach education has emphasized the similarities in caring for adults and children, as opposed to focusing on the differences between adult and pediatric care. Seattle Children's Hospital staff have found that pediatric and adult families have the same concerns around comfort and quality of life, and that hospice personnel are experts in these areas. And yet, we also know that the prospect of caring for pediatric patients can be intimidating to staff who seldom provide this care, so we try to demystify the work, with practical tips, resources, and by allowing ample time for questions.

One of the most important lessons we have learned is that relationships are important. Hospices need to know that the referring hospital or palliative care team will share as much information about the patient and family as possible, and that you will be available to help support them as they get to know the family and build rapport. When a referral is sent, we make sure to include contact for all of the key players at the children's hospital (providers, social worker, clinic nurse coordinators, etc.) so that hospices know who they can reach out to with disease specific concerns in addition to the palliative care team.

One example of a successful relationship with a hospice that primarily serves adults, is between Seattle Children's Hospital Palliative Care team and Hospice of the Northwest. This hospice serves a large geographic area with patients in Skagit and San Juan counties, as well as Whidbey Island in Island County. Many features make this service area unique for Hospice of the Northwest. They serve a rural area that is known for farming and recreation, with an area of over 2,000 square miles—some of which is only accessible by ferry. They creatively manage this area with staff that live both on and off the islands, many of whom have sheds in their back yards to store extra medical supplies and equipment. This group of hospice professionals have to navigate between islands via ferries that don't run 24 hours a day. None of the islands have pharmacies open seven days a week, which means that they must also be experts in anticipating what might be needed. This frontier-type situation in their service area, has helped to foster the initiative to navigate the frontier of serving pediatrics well.

Why is this hospice, with an average daily census like many other hospices, so well respected in their care of pediatric patients? As one of their referral sources, they have staff and physicians who are motivated and actively involved in getting to really know the kids they follow: what brings them joy, what quality of life looks like to them, and they accept the child and family's goals of care, without trying to fit them into the box of how adult hospice "works." This hospice has gone all in with pediatric care and by embracing it, they take a sense of pride in a job well done. That pride is apparent in all, from the people who answer the phone, their amazing staff, their medical directors, and executive director. They have cared for a child with heart failure from complex congenital heart disease, a teen receiving dialysis, a child who needed frequent blood transfusions because of liver disease, kids with cancer diagnoses, and kids with severe neurologic impairment. They have asked the Seattle Children's Hospital Palliative Care team to visit their hospice in person or via zoom several times to keep them current with training. They know they can call any time 24/7 with questions. They are great partners who communicate well with their referral sources, including when a child may need to be seen in an Emergency Department.

When two of their medical directors, Dr Anita Meyer and Dr Leslie Estep, were asked to share their thoughts about caring for pediatric patients, they provided wonderful insight. The following quotes capture how to serve pediatric patients successfully and respectfully within an adult-focused hospice.

"Adore the child. Interact with the child. It means everything to these families to be home. It is such an honor to be able to help with that."

"Don't become the hearse driving through the living room every visit."

Here are additional suggestions and advice from Dr Estep and Dr Meyer:

- Make/find a dose reference sheet for comfort meds for pediatric dosing. It makes clinicians feel more secure to see it in writing in readily found location.
- Help parents with their other children too. Offer more Social Work services and more spiritual care. Offer Art therapy, games, resources.
- Figure out activities that build memories.
- Our hospice team also brings so many skills in making memory mementos for the future...thumbprint pendants, etc.
- Provide more MD visits for these patients. Both to support the RNs who might be working at new skills and to improve your own skills/rapport/effectiveness.
- Try to find a local pediatrician or family doc who will support you for routine peds issues that may come up.
- Have a pediatric palliative care doctor for support.
- Keep a growth chart on kids with slowly advancing (neurodevelopmental disease) to help understand prognosis, demonstrate eligibility.
- Consider having two POLST forms, parents can decide which one it's time for.
- Have a relationship with a compounding pharmacy.
- Have a regular update for all RNs/MDs who may be covering for the patient to reduce their stress and improve quality/adherence to POC.
- If there's a change in condition or plan, communicate it to all staff who might be involved promptly.
- Prepare for the patient by reading about their rare disease AND know that the parent is likely more expert than you'll ever be. Be ready to say "I don't know." Be ready to be more collaborative. Be ready to flex around what may seem like unconventional or unproven medical beliefs.
- Expect slow movement from curative toward palliative.
- Ask about which specialty care clinics are helping families most...the children's nutritionist may be making care more burdensome with heavy emphasis on growth/calories. This can create so much guilt. Honoring how much parents know about what their child needs most is a good way to enter visits.
- These patients are both very rewarding to take care of and very difficult.
- Recognize the added stress of caring for a child with your staff in terms of both the clinical skills needed AND the emotional strain and provide support along the way. Consider having two nurses assigned to complex peds patients for extra back up. Consider having a peds patient count for 2 or 3 patients on the nurse's panel count.

We have worked closely with these physicians for many years, and so appreciate the great care they provide and their willingness to ask questions.

Additional recommendations we share with hospices in the NWPPCC region.

- <https://www.nhpco.org/pediatrics>
- Concurrent Care Medication Coverage
- <https://www.nhpco.org/wp-content/uploads/NHPCO-Medication-Flow-Chart- Apr-2020vFinal.pdf?msclkid=c95488eacfc911ec8819d2d7dbd12997>
- Pediatric End-of-Life Care Research | The University of Tennessee, Knoxville ([utk.edu](http://utk.edu))
- <https://courageousparentsnetwork.org/guided-pathways/pediatric-palliative-care-for-the-uninitiated/>
- Series of short videos created by an adult physician who had a child that received pediatric palliative care. Excellent for adult hospices caring for a child.
- [blueBook.pdf \(dfci.org\)](#) Pediatric pain and symptom management resource out of Dana Farber/Boston Children's Hospital.
- CPN | Courageous Parents Network. Great resource for parents and anyone working with children.
- Pediatric E-Journal | NHPCO Journal published four times a year with contributions from professionals and parents
- PPC Webinars Monthly webinars on various pediatric palliative care topics
- Pediatric track | Palliative Care Training Center ([uw.edu](http://uw.edu)) UW PPC certificate program
- <https://www.seattlechildrens.org/clinics/palliative-care-consultation/nwppcc/> NWPPCC website with many resources for the NWPPCC region.