

Introductions

OVERVIEW

The **Pediatric, Adolescent, and Young Adult Palliative Care Learn Guide** is designed to help support children and their families -- with a comprehensive and holistic approach to care -- as they travel through the challenges of their cancer journey.

This is an interactive guide that serves to provide support, education, and resources within all aspects of palliate care, to empower patients and their caregivers.

OUR EXPERT

Meet Dr. Iverson

"My name is Nancy Iverson. I'm a pediatrician and I particularly have worked with pediatric palliative care and in-home pediatric hospice. I also do a bereavement support group for parents who are anticipating the loss of a child or have experienced the death of a child."

Dr. Iverson is considered a national expert and a pioneer in children's

The San Francisco Bay area has served as Doctor Iverson's home for more than 20 years. In that time she has been on staff at organizations that include UCSF, CPMC, and Kaiser. She helped develop the pediatric palliative care programs at UCSF, assisting the educational team as a subject matter expert.



palliative care. Living With Loss -- a support group for parents and families of children with life-threatening illnesses -- is a program Dr. Iverson developed as a board member and advisory committee member to Support for Families of Children with Disabilities. She has developed similar programs as an advisor and educator at The Institute for Health and Healing at CPMC, and Comfort for Kids (an in-home pediatric palliative care and hospice organization located in the San Francisco area).

"Having your child diagnosed with a potentially life-limiting illness is devastating for parents...your whole world is turned upside down, and what I would like to remind parents, even though it feels like there are decisions you're going to have to make that you know nothing about, that so much is out of your control, you're still the parent, and there are many resources available to help you deepen and enrich your abilities to parent your child, even through these very difficult times."

One Thing I'd Like To Say To You

"One thing I'd say to you as the parent of a newly-diagnosed child is that you're not alone in this -- there are a lot of people and a lot of resources that can help. I know it's really tough. There are a lot of decisions that you will be involved in that you never even dreamed would be possible. But you'll find lots of help and support along the way."

Do everything you can to overcome your fear and become an empowered part of your care team -- to do everything from creating art with your child to making the best possible medical decisions on behalf of your child -- to give them the best wellbeing for this journey that you can. A pediatric palliative care team can help you in a sense reclaim your parenthood and continue to be the very best advocate and the very best parent possible for your child throughout the trajectory of their illness."

Palliative Care

DEFINITIONS

Defining Palliative Care

Palliative care is a comprehensive and holistic approach to caring for someone with a serious illness. Palliative care considers the child's entire universe, from their family and friends, to their favorite activities, sports, and school. Palliative care also looks at the needs of the family, and how to best support family members during their child's illness.

Child Life specialists are part of your child's palliative care team, as are the registered dietitian, therapists, clergy, teachers, friends, family, nurses, and doctors who support your child's mental, emotional, spiritual, and physical wellbeing.

Comfort Care and Palliative Care

Comfort care and palliative care have one important element in common - they are all about "care," and making

the child's journey through their illness as comfortable as possible.

The Difference Between Palliative Care and Hospice

Many people confuse the term palliative care with hospice. While both are along the continuum of care for a sick child, they do have different meanings. Ideally, palliative care begins at the time of diagnosis to address all aspects of care for a child. Hospice care is specifically given at the end of life.

Where Can Palliative Care Be Provided?

As both a philosophy and a method of care, palliative care is integral to the treatment, healing, and wellbeing of your child. It includes everything that's part of your child's world, from siblings and friends, to school, sports, and activities, and even addresses the needs of family members who are involved with your child.

Palliative care, then, isn't limited to a single place. It happens anywhere and everywhere that affects the quality of your child's life.

"People often think that palliative care is only available in a certain room in a certain hospital...In fact, palliative care can be provided in any number of settings. From a hospital room, which can be very important, but also out in the community, and particularly in the home of the child and the family." - Dr. Iverson

GOAL

TREATMENTS

Do Other Treatments Need to Stop?

Palliative care is about providing complete and holistic care, looking at every option to contribute to a child's overall wellbeing. Treatment is only one part of the care available to a child with cancer, and it can be an important part of the overall palliative care strategy.

"In pediatric palliative care, we want to bring everything possible to bear for the wellbeing of the child." - Dr. Iverson

CARE TEAM

Who's On The Palliative Care Team?

"Who the members are of a pediatric palliative care team can vary from one institution to another, one community to another."

In keeping with the philosophy of a pediatric palliative care team, we look at what can contribute the most to the overall wellbeing of a child. So this could include physicians, nurses, social workers, child life workers, spiritual care workers, sometimes play therapists, sometimes music or art therapists." - Dr. Iverson

Family Life

FAMILY SUPPORT

Involving Your Family

Family support is one of the most integral structures of a child's cancer journey, and there are many resources available to help family members during this time.

This Learn Guide is an example of educational material that helps families understand components of their child's care. The child's entire medical team is aware of the importance of making sure that family members are supported along with the patient, under the umbrella of palliative care.

Explaining Palliative Care To Your Family

Parents can find it difficult to explain palliative care to family members, from those who want to be deeply involved in the child's care, to those who simply want to be updated about what's going on, to siblings who might

be afraid of what the diagnosis means and how it might affect them.

Helping family members, as early as possible, understand that your child has a full care team that contributes to every aspect of your child's life, can help ease your family's minds. With the help of your palliative care team, you and your family can move beyond the initial shock and uncertainty of diagnosis, to focus on finding the best way to support your child through their illness.

"...It means offering as many services as possible to the time that the child is living with this particular illness..." -

Dr. Iverson

SPIRITUAL & CULTURAL BELIEFS

Respecting Spiritual and Cultural Beliefs

Cultural and spiritual beliefs are deeply personal, and there is no "one size fits all" approach to making sure a family's beliefs are heard and understood. Your palliative care team wants to know what's important to your family as a whole, and for each individual who is involved in your child's caregiving.

"We don't make assumptions. We actually learn about what is really important both spoken and unspoken for every family member and every child." - Dr. Iverson

CUSTOMIZED CARE

Is Care Customized?

Every family member has their own individual beliefs and special way of seeing the world based on their background and personal experiences. It's important for your child's team to learn what's important to you and other involved family members, so they can provide the best care possible.

"...one of the things that we do is learn about each family member so that we can really customize how we work with, and what would help, each family member based on who they are and what they want to bring to the table..." - Dr. Iverson

TALKING TO YOUR CHILD

How Do You Talk To Your Child About Their Care?

"I really like to encourage a parent to tell me a bit about their child so that we can co-create a way to share information that would be most helpful for that child."

No one knows your child better than you do. How you talk to your child about their illness and their care is as individual as each child and family. But we all have some common ground, and topping off that list are the needs to feel safe and heard.

As an advocate for your child, listen to your intuition and trust your feelings. If something feels off in their care, speak up and have a conversation with anyone on the team about changing things.

"I like to talk with parents about learning what their child is like, so no matter what the age of the child, whether the child's a two-year-old, a six-year-old, a teenager, what are already the styles of communication that the families have? And how do their kids best respond. If their kid likes to take off a little bite and go chew on it for a while and come back, then consider that's different than a child from early on who likes to ask one question after another until a topic is thoroughly explored. So, I really like to encourage a parent to tell me a bit about their child so that

we can co-create a way to share information that would be most helpful for that child." - Dr. Iverson

RELATIONSHIPS

The Impact of Palliative Care on Relationships

"One of the ways that palliative care works beautifully is to include the family as much as possible - not to insist that family members step out of their normal way of acting to become somebody different in the child's illness, but to meet each family member where they are and help them stay in the role as a part of this family and a part of being actively engaged in this child's life." - Dr. Iverson

BURNOUT

Avoiding Burnout

Caregiver burnout is a very real danger for families who have a child with cancer. It's a topic can come up at home, with friends, in workshops and support groups, where parents and caregivers can explore the challenges they're facing.

Talk to your palliative care team and ask for help. You might want them to point you to the right place to sign up for a support group in your area. Maybe they can involve your child in a

hospital activity, so that you can take a shower without feeling guilty about being away for 10 minutes.

Try to keep something "normal" about your life outside of cancer -- going to the gym, or a weekly lunch meeting with a friend - something in your daily routine that gives you a break and helps you refresh, so you can come back to your child with more energy.

You're not going to be able to handle everything all by yourself. Let go of the things that don't matter. For the things that do matter, ask for help. Accept help. Share your responsibilities with friends or family so you have the time and energy to focus on what's most important.

"One fundamentally important part of palliative care is recognizing the impact that an illness has on everybody involved. So, again, for the child, for the parents, for siblings, also for the caregivers, both the medical team and for caregivers who are in the home, the parents, the family, the friends. And with the acknowledgement of that comes also the commitment to help ease the burden of caregiving, to help find ways to resource additional strengths, resilience -- in a sense, to allow caregivers to give everything that they want to give." - **Dr. Iverson**

ART

Using Art In Palliative Care

The importance of art in a child's life is one that can, and should, be honored during palliative care. But as Dr. Iverson points out, it's often the last thing that's considered with many families and medical professionals.

Including art throughout a child's time in palliative care can be very meaningful for the child, and as we'll discover a little later in this guide, can help create connections and lasting memories for families.

SUPPORT GROUPS

Should I Join A Support Group?

"No one that I know of can go through the illness of a child, especially a life-limiting illness or the death of a child without needing enormous support," say **Dr. Iverson**. She explains here how support comes in many different forms (including support groups).

How Do I Find A Support Group?

"It can be enormously challenging to deal with every single decision you have to make while your child has a life-limiting illness. In addition to that, how do you find the support and the accesses that both fit you and your family and your community?"

One of the best resources is other parents, so if you do have the opportunity to talk to other parents or to be a resource for other parents and it fits how you are, definitely take advantage of that. And ask and ask and ask. With your child's specialists ask them what resources they know available." - **Dr. Iverson**

Home Care

ENVIRONMENT

When Does Care Happen At Home?

Palliative care is a holistic approach to care that covers every aspect of your child's life during their illness. It's easy to see, then, that palliative care at home really starts when your child is diagnosed.

Changes in your home life happen quickly, and new accommodations have to be made to support your child and help your family continue to function. When sudden shifts like this happen in family life, overwhelm soon follows.

Your child's care team is an important resource that can help guide you and your family through overwhelm, to find your footing in your new normal, and figure out how best to continue palliative care wherever your child might be -- whether in the hospital, at school, or at home.

From the practical side of providing care, your child's oncologist will work with you to determine what is appropriate and needed for your child

in their home care. Talk to your insurance company early, and as often as necessary, so that once your child has transitioned from the hospital to home, you are clear about how much in-home care is covered.

The Partners for Children (PFC) Pediatric Palliative Care Benefit also helps eligible children receive palliative care during treatment as a Medi-Cal benefit, through the Department of Health Care services.

To Learn More:

Coalition for Compassionate Care of California (CCCC) / Children's Hospice & Palliative Care Coalition

(<https://coalitionccc.org/tools-resources/pediatric-palliative-care/>

(<https://coalitionccc.org/tools-resources/pediatric-palliative-care/>))

Partners for Children pediatric palliative care benefit

<https://coalitionccc.org/tools-resources/pediatric-palliative-care/partn...> (<https://coalitionccc.org/tools-resources/pediatric-palliative-care/partners-for-children/>)

Department of Health Care Services (DHCS) Pediatric Palliative Care (PPC) benefit

(<https://www.dhcs.ca.gov/services/ppc>

(<https://www.dhcs.ca.gov/services/ppc/Pages/d>)

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Infections And Other Illnesses

Infections and other illnesses during cancer can often lead to emergency room visits. Your hospital's team members can help you understand what you can do at home to help prevent infections, and what you must do when an infection or illness occurs.

Especially during flu season, avoid being around people who are sick, and be vigilant about your child's and family's hygiene and cleanliness at home. Methods for thoroughly washing hands, showering, and brushing teeth are taught at the hospital. Its important that these guidelines travel with you when you transition back home.

"Often parents and other family members are very overwhelmed by what they see in a hospital setting, especially things related to infection control, closed doors, hand washing, masks, gowns, all that kind of thing, and think, "It's impossible that I can take care of my child at home and bring all those institutional things into a home setting.

"A palliative care team can really help each family learn what's right for them and how they can maximally take care of their child at home and do all the right, say, infection measures, all that kind of thing, but in a home environment, where it's completely safe and helpful for the child." -

Dr. Iverson

NUTRITION

Your Child's Health Through Nutrition

"Families often feel like they can't possibly offer at home what can be offered in a hospital. Home environments have much to offer. They can offer a very familiar setting, a child's favorite blanket, favorite paintings on the walls, favorite sounds and smells. Families can also do so much to help with their child's nutrition -- having familiar meals at home, having a way to prepare food

that already fits with a child's likes and dislikes is another gain that isn't intimidating, once you have a team working with you to do that at home.

For every single person nutrition is very, very important, not just micro and macro nutrients we get, but what food is in cultures and families and communities, and one of the hardest things can be "how do I feed somebody, especially a child, who's got an illness, and what do I do?" It's a great question, and one of the things to really be aware of is that a palliative care team can also help you with that." - Dr. Iverson

COMPLIMENTARY MEDICINE

Use Of Complimentary And Alternative Medicine

Your child's treatment is a tapestry of many types of care. In addition to the curative treatments, like chemotherapy, radiation, or surgery, your child might also receive complimentary treatments like accupuncture, music or art therapy, or psychotherapy.

Nutrition is also an important part of your child's treatment, when tastebuds change and eating habits

are as up and down as a roller coaster. Be sure to check in with your team for help as you navigate your child's changes in taste.

Now that you're familiar with the meaning of palliative care and all that it entails, remember that experimenting with new diets or procedures while your child is ill can be detrimental to their treatment and even dangerous for your child. Whether it's food, supplements, or any type of therapy, always check with your care team first.

"It's so important to talk with your child's specialist...because some, especially of the nutritional therapies, actually undermine the effectiveness of chemotherapy." - Dr. Iverson

SPIRITUAL CARE

Spiritual Care At Home

"The idea of spiritual care in a time of a child's illness can be just as intimidating as all of the medical procedures, diagnostics, interventions, et cetera. Spiritual care can also become so simple.

Just being able to talk about what works in our family, what have we found to be our best resource, and how do we best gather those around us that help us stay sustained in our own spiritual well-being? With a child too, especially teenagers, they have all developed into their own ways of thinking, and their ways of developing their own belief systems.

Having a team involved that is sympathetic to that and being available to listen and support each and every patient and family as they're adapting their spiritual beliefs to fit a situation, or relying on their spiritual belief to sustain them through a difficult time, is one of the huge resources that can come from a palliative care team." - **Dr. Iverson**

PSYCHOLOGICAL CARE

Including Psychological Care

"The concept of psychological care is so built into any pediatric palliative care team that it hardly deserves mention.

In a sense just like we would take vital signs on a patient normally coming into the emergency room, we just look at psychological care as part of the fundamental building blocks of a good pediatric palliative care team."
- Dr. Iverson

Pain Management

MANAGING YOUR CHILD'S PAIN

Methods to Help You Manage Your Child's Pain

As your child's advocate, one of your most important jobs is to recognize when your child is in pain and to help alleviate it. There are many methods, beyond medication, that can help your child, through a variety of therapies, as Dr. Iverson discusses here. Your care team can help you understand the best approach at easing your child's pain.

"One thing that patients and parents can do better than anybody else is really truly acknowledge how much pain is present for a child, and one of the real strong places that a parent can show up is assessing their child's pain."

So a parent can become a very strong voice, and members of the palliative care team can help them become that strong voice in making sure that their child's pain is really acknowledged and treated properly." -

Dr. Iverson

Child Life

SCHOOL

What Do I Do About School?

School is one of the most important aspects of a child's life, and one that has to be managed for children of all ages, even during illness.

There are many resources available to help your child stay active in their school work, make sure they have any accommodations they might need, keep them on track for their grade level, and even help you plan how they can graduate on time -- whether from kindergarten, eighth grade, or high school -- and move into their next level of education.

Talk to your child's school early. Take advantage of in-hospital school resources. Accept help with tutoring or home schooling if that's what your child needs. Work with your care team for pointers that can lead you forward in managing your child's education, and help your child stay actively engaged with school.

ACTIVITIES

Which Activities Can My Child Do?

"In the keeping of the idea that every child is an individual, we realize every child has activities that they love and some activities that they're just putting up with, perhaps for their parents or for some school system.

But we really work early on to identify which activities really mean a lot to the child. And then we work to provide the best fit possible with what a child is able to do, and what best matches their interest and abilities." - **Dr. Iverson**

VISITORS

Can Friends And Family Come To Visit?

Connections with friends and family during your child's illness can have a very positive effect on their outlook and spirit. Yet there could be times when they'll have to avoid in-person visits to minimize their exposure to germs and viruses, or to make sure they're not overly fatigued and they get enough rest.

Lean on your care team to find out when friends and family can come for a visit. Sometimes, a group friends or family may be able to visit at one time, while other times one or two visitors might be the limit. To support your child and make the most of visits

from family and friends, let your care team help guide you about visiting schedules and allowances.

"...exactly how to keep and nurture those social connections that matter so much is something that's fundamentally important with pediatric palliative care." - **Dr. Iverson**

SOCIAL MEDIA

What About Social Media?

"Social media is a huge arena for a lot of conversation right now, and it can be incredibly important for how a child navigates an illness...social media now has become a big topic of conversation and probably it would be even more so during the time of diagnosis and treatment for a potentially life-limiting illness.

I like to look at how many arguments can parents spare themselves -- and with a team that's totally attuned to the wellbeing overall of a child, that discussion into how much social media to allow or give permission to, and what type of social media it is, can be a conversation that happens in more of a group setting -- so there can be help from say a child life worker, a psychologist, various people that are involved on the team, in addition to the family, so that again the best possible atmosphere is set up to be aligned for the child's wellbeing." - **Dr. Iverson**

DISCIPLINE

What About Discipline During My Child's Illness?

As Dr. Iverson stated earlier, it's important to look at *"how many arguments parents can spare themselves."* Discipline during your child's illness could very well be one of those places where arguments can occur, or with a little bit of knowledge, can be avoided.

Many factors can influence behavior during an illness, including reactions to medicine, pain, fatigue, isolation, and psychological states like depression. Much of your child's change in behavior might be completely normal, and it's important to know what's typical and what isn't before stepping in to discipline.

Your child's care team can has years of experience understanding how illness can affect behavior. With their help, you can learn what to expect and what's normal, so that, as Dr. Iverson puts it, you can approach discipline with your *"most positive parenting mode possible."*

End of Life

CONVERSATIONS

Talking About End Of Life

"Conversations about end of life care can be especially intimidating for anybody, but especially when it's a child approaching end of life, and it can be almost impossible for parents to envision happening.

With a pediatric palliative care team, there are members of a team who are experienced in what happens around end of life with a child, and also with how to have those conversations so that each family can determine how best to involve their child in decision making, in choices when those choices are possible, in what best supports their quality of life right up until the very last breath that they take." - **Dr. Iverson**

How Two Teens Approach Their Own End Of Life Decisions

Adolescents, teens, and young adults facing the possibility of end of life will often have very strong feelings about how the discussion is handled, how involved they are in details, and which family, friends, medical team and caregivers they want with them. Whatever they decide about their own level of involvement, it is most important that the child feels heard, and their wishes honored as much as possible.

Dr. Iverson shares the stories of two teens dealing with their own end of

life decisions, and the very different approaches each one takes in discussing and managing the details surrounding their end of life.

REMEMBERANCES

How Will I Be Remembered?

*"One question that comes up frequently for both children and for parents is, "How will I be remembered?" Or, "How will my child be remembered?," says **Dr. Iverson**. She offers several suggestions, particularly through art, that families can use to create memories and rememberances together.*

How One Family Created A Bond Through Writing

*"I'm remembering one home visit I did...[and] as I was leaving, the stepmother asked me about some questions she had about various relationships between family members, how people were or weren't showing up, and I just said, "Sometimes it's helpful to write together." - **Dr. Iverson***

Here, Dr. Iverson shares the story of connecting a family through writing together as they faced their son's end of life.

DIRECTIVES

What is DNR, DNAR, or AND?

"One of the questions that comes up often is, "What happens with resuscitation?" DNR is one of the terms that's used when a document is signed saying, "Do not allow resuscitation." This can be really difficult for some parents....

What it really means is that we have an option available so that parents do not have to allow their child to have ineffective but often injury-promoting techniques or resuscitation methods...so that the child will not have to be subjected to such things as chest compressions, intubation, being put on machines if there is not a chance that that's actually going to help your child survive into a recovered, healthy lifestyle. So in a sense, DNR can be protecting your child from injury that can occur at the time of an end of life.

"Instead of DNR, there is also a term called AND, "Allow Natural Death," which means that a child will be supported in every way possible, including maximal symptom management, that kind of thing, but no injurious blows will be inflicted, like chest compressions or intubation or anything like that.

"There's also another term, DNAR, "Do not attempt artificial resuscitation," which gets also into using different medical implementations, aggressive techniques, that kind of thing, to sustain life where a child's body cannot sustain that life on their own.

"Any parent that signs a DNR or an AND, actually has more empowerment as a parent in that situation. They are allowed, then, to make the decision at the time. So, if they have signed a DNR or AND, and feel like that's not the direction they want to go at that time, they can just refuse to implement that. On the other hand, if say they're at home with a child or somewhere out in public and paramedics are called, without that document signed there is the necessity that all aggressive forms of attempted resuscitation will be employed.

"One of the things that I think about, and I do like to encourage parents to think about, is that signing a DNR or a DNAR or AND, can actually allow them to continue to be protectors of their children. They can really be protecting them from unintentional but unfortunately inevitable

injury from aggressive resuscitative techniques when those won't be helpful to the child. So in a sense, it is one more way for parents to fully be empowered with their ability to love and care for their child." - **Dr. Iverson**

PLANNING

What About Organ Donation Or Autopsy?

*"Often, questions do come up. "What happens after end of life?"...And parents...don't want to grapple with that question, but they really don't even know who to turn to for that." -
Dr. Iverson*

The palliative care team is a strong support and resource to help families weigh options regarding decisions after end of life, such as organ donations and autopsy.

What About Arrangements?

"A myriad of things happen after the end of life of a child, and it can be incredibly difficult to navigate. Do we need a mortuary, do we have a service, what do we do with all those things?"

"That is one question that a pediatric palliative care team can be an enormous resource from initiating some of those first conversations, whenever it may be. Maybe at the time of a child's diagnosis, maybe a month before the end of a child's life, but the more thoughtfulness and planning and resourcing can go on with that, not only is it less intimidating, but it can also help a family find the places that are the best fit for them.

"It also really helps to have a team available as a resource, because it can be so completely overwhelming at the time of end of life and after, and to not have to explore a whole new paradigm is fundamentally important and a really strong component of pediatric palliative care."

- **Dr. Iverson**

RAINBOW ROOMS

Rainbow Rooms

Families sometimes want and need a special place to be together when their child is at the end of life. A Rainbow Room provides this private place for families, where caregivers and immediate family can stay overnight with the child. Families are encouraged to bring their child's favorite toys and possessions from home. Loved ones are encouraged to come and spend time with the child and surround them with love. The care team provides around-the-clock care, to control the child's pain, and to make the patient and family as comfortable as possible.

Bereavement

PERSONAL GRIEVING AND CHRONIC SORROW

Personal Grieving And Chronic Sorrow

"For most families, grieving starts at the time of diagnosis for a child with a potentially life-limiting illness." - Dr. Iverson

With decades of experience supporting grieving families and conducting bereavement support groups, Dr. Iverson explores grieving, chronic sorrow, and the understanding that grieving is not a linear process.

GRIEVING PARENTS AND SIBLINGS

How Grieving Manifests in Parents And Siblings

"There is an enormous amount of learning I've had in running a parent support group for 19 years now....One thing is that the grief never stops. It

becomes...woven into the texture of their lives.

"This can sound like really bad news, but it's actually quite comforting news for parents to hear that they're not the outlier, they're not the weird one, because they didn't get over their...grief in a certain amount of time." - **Dr. Iverson**

In this video, Dr. Iverson explores how grieving can manifest in parents and in siblings.

