

Pediatric, Adolescent and Young Adults

Palliative Care

A holistic approach to life-limiting disease

written and edited by

Deborah Todd, Roger Holzberg, Adele Sender



“Neither palliative care nor comfort care is abandoning care. It’s actually bringing more care to a patient or to a family.”

– Nancy Iverson, M.D

Reimagine Well Learn Guide:

Pediatric, Adolescent and Young Adult

Palliative Care

A Holistic Approach to Life-Limiting Disease

Deborah Todd
Roger Holzberg
Adele Sender

“Neither palliative care nor comfort care is abandoning care. Its actually bringing more care to a patient or to a family.”

— Nancy Iverson, MD

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 journey.

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

Team Reimagine Well

Copyright 2019 © Reimagine Well

All Rights Reserved

ISBN: 978-0-9992364-8-2

TABLE OF CONTENTS

• WELCOME	1
• PALLIATIVE CARE	5
Family Life	11
Home Care	19
Pain Management	25
Child Life	29
End of Life	33
Bereavement	41
• A MESSAGE FROM TEAM REIMAGINE WELL	44
• Learn Guide Authors	45

As you use this Palliative Care Guide to educate yourself you may want to create your online patient or caregiver Support Community, which can be accessed at <http://www.reimaginewellcommunity.com/reimaginewell>.

WELCOME

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.”



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.

“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 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.”

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

– Nancy Iverson, M.D

This Learn Guide serves to provide support, education, and resources within all aspects of palliative care. With a comprehensive and holistic approach, it is designed to help and empower children, adolescents and young adults, and their families as they travel through the challenges of their life-limiting journey.



Nancy Iverson Dr. Iverson is a national expert and a pioneer in children’s 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).

The San Francisco Bay Area has served as Dr. 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.