

Adolescent and Young Adult (AYA) Cancer

From Diagnosis to Wellbeing

written and edited by
Martin Casella, Roger Holzberg, Adele Sender



“As an international AYA and Pediatric Oncologist, I am very impressed with how this guide covers important topics for patients and their families in a comprehensive and age appropriate manner. Using text, web links and videos, it gives timely, accurate access to information in different formats. I look forward to my patients having access to this Learn Guide!”

– Dr. Antoinette Anazodo, Adolescent Oncologist, Director of the Sydney Youth Cancer Service, Australia

Reimagine Well Learn Guide:

Adolescent and Young Adult (AYA) Cancer

From Diagnosis To Wellbeing

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Roger Holzberg
Adele Sender

If you, or someone you love, has been diagnosed with cancer and you are between the ages of 15 and 39, this Adolescent and Young Adult (AYA) Learn Guide will help you through the anxiety of a cancer diagnosis. Our goal is to provide you with concise, evidence-based, easily understood educational resources throughout your entire cancer journey.

With links to online resources, this book will serve to empower both patients and caregivers as you navigate from diagnosis to wellbeing. It will also provide you with a (private and safe) support community to connect with, where you can learn from the cancer survivors and families, who have gone before you.

— Team Reimagine Well

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NOTE:

Both parts of this book are designed to go hand-in-hand. We strongly encourage you read forward only to the phase you are in right at this moment:

- | | |
|-------------|-------------|
| ● Diagnosis | ● Healing |
| ● Treatment | ● Wellbeing |

As you utilize Part 1 of the Learn Guide to educate yourself, and get coached on how to become an empowered patient, you may also want to begin creating your support community. That AYA Support Community can be accessed at <http://www.reimaginewellcommunity.com/>, and the details on how to best use it are found in Part 2 of this Learn Guide.

WELCOME

A message to you newly diagnosed adolescent and young adult cancer patients... and your families. From Leonard Sender, M.D, one of the Founders of Reimagine Well.

“Information can lead to knowledge. Knowledge is power. You have to become empowered to learn, then ask the right questions and get the information you need. The best way to get the type of treatment that is right for you, that will lead to the type of outcome we want for you, is to become fully engaged in the process.”



After you download this Enhanced eBook onto your phone, tablet, computer, or print a hard copy, bring it with you to all meetings with your Healthcare Professionals.

— Team Reimagine Well

“Never believe statistics. Statistics are based on everybody else. You’re your own individual. You are your own person. I brought hope with me to the hospital. You can’t do anything without hope!”

— AYA Cancer Patient,
Age 17, Medulloblastoma Brain Cancer



“It helps to share information and hope. I totally agree that keeping positive and never giving up hope is paramount.”

— AYA Cancer Caregiver/Dad

“What an amazing opportunity to build a community and connect with people who can relate to what it feels like when you’re told you have cancer... in the end, the experience of being more transparent with my fears was cathartic and healing.”

— AYA Cancer Patient,
Age 23, Colon Cancer

CONTRIBUTING EXPERTS



Leonard Sender, M.D.

Dr. Leonard “Lennie” Sender is a pioneer in cancer care treatment, especially in adolescents and young adults, which are typically underrepresented cohorts in oncological research. Dr. Sender is Director of the Adolescent and Young Adult (AYA) Cancer Program at CHOC Children’s Hospital in Orange County, where he leads one of the nation’s largest programs considering the unique challenges faced by AYA cancer patients, such as preservation of fertility, management of the effects of treatment, and the psychosocial impact of the disease. As an innovative leader in research, Dr. Sender is conducting extensive studies to improve outcomes and quality of life for AYAs. He is Chairman Emeritus of the Stupid Cancer organization and is a founding member and chairman of SeventyK.org, an advocacy site for AYAs with cancer.

Dr. Sender received his medical education in South Africa and his pediatric internship and residency at UC Irvine Medical Center. His pediatric hematology/oncology subspecialty training included Children’s Hospital of Los Angeles.

“I’ve been involved with pediatric cancers, adolescents, and young adults for nearly 30 years. The first thing I want to say to a patient who has just completed their treatment is congratulations and, secondly, well done. What we need to talk about now is how we get you to your new normal, how we get you to adulthood, how we understand all the consequences of the therapy that you’ve been through, and how we make sure that you truly have wellbeing going forward.”



Jocelyn Harrison, MPH, RD

Jocelyn Harrison received her Master of Public Health from UCLA and completed a dietetic internship at the Los Angeles Veterans Hospital. She has developed nutrition programs and marketing for the USDA Dietary Guidelines for Americans, Choose Health LA, and the American Diabetes Association. Her Reimagine Well work includes literature reviews and helping with “immersive healing environment” patient benefit studies.

“The most important things you can do to fight cancer and prepare yourself for treatment are - eat a mostly plant-based diet, maintain a healthy weight and be physically active. Although a diagnosis can be overwhelming, you have a part to play in your own treatment. Be empowered, this is your journey.”



Jenee Areeckal, MSW, LCSW

Jenee Areeckal is a clinical social worker at UCSF Benioff Children’s Hospital. She is a three-time cancer survivor and an amputee due to osteogenic sarcoma who knows what it is like to live through and be treated for cancer as a teen and young adult. Today she uses her story to inspire her patients and families both during and after treatment. She is proof that life after cancer can be wonderful and fulfilling.

“I am a three time AYA cancer survivor. I had osteogenic sarcoma when I was 15, with two relapses, and had ovarian cancer at 38. I’ve been taking care of teens and young adults with cancer for about 10 years. It’s been my life’s passion to help them navigate through not only their treatment, but also post-cancer Survivorship. It’s also very important for me to help educate patients how to become strong survivors. I hope that by seeing me “get busy living”, patients have hope that it is possible to survive and thrive after cancer.”



Lilibeth Torno, M.D.

Dr. Lilibeth Torno serves as Assistant Division Chief of Oncology as well as Clinical Director of the Cancer Institute Outpatient Services and the ACTS (After Cancer Treatment survivorship) program at CHOC Children’s Hospital. She recently pioneered the development of a multi-institutional pediatric

and AYA cancer survivorship consortium in Southern California as a research collaboration platform for cancer survivorship.

Dr. Torno completed her fellowship training at Children's Hospital of Los Angeles. She completed her residency at CHOC. She attended medical school at University of Santo Tomas, Manila, Philippines.

“I've been involved with pediatric cancers, adolescents, and young adults for 30 years. The thing I want to say to a patient who has just completed their treatment is, firstly, congratulations and, secondly, well done. What we need to talk about now is how we get you to your new normal, how we get you to adulthood, how we understand all the consequences of the therapy that you've been through, and how we make sure that you truly have wellness going forward.”

"Cancer is rare and unexpected in the young, creating unique emotional and medical challenges. This Learn Guide offers an accessible first step in this journey. You will find reliable information and experienced peer patient veterans to help light the way. You are not alone."

– Nicolette Chun, Genetic Oncology Counsellor, Stanford Hospital Cancer Center

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Leonard Sender, MD Dr. Leonard "Lennie" Sender is a pioneer in cancer care treatment, especially in adolescents and young adults. Lennie is Director of the Adolescent and Young Adult (AYA) Cancer Program at CHOC Children's Hospital in Orange County, where he leads one of the nation's largest programs considering the unique challenges faced by AYA cancer patients.



Lilibeth Torno, MD Dr. Lilibeth Torno is the Clinical Director, Outpatient Services and the CHOC ACTS (After the Cancer Treatment Survivorship Program). She also leads the Ambulatory Care Services of The CHOC Cancer Institute and directs the CHOC Long Term Follow-up Clinic for survivors of childhood cancer.



Jocelyn Harrison, MPH, RD Jocelyn Harrison received her Master of Public Health from UCLA and completed a dietetic internship at the Los Angeles Veterans Hospital. She has developed nutrition programs and marketing for the USDA Dietary Guidelines for Americans, Choose Health LA, and the American Diabetes Association.



Jenee Areckal, MSW, LCSW Jenee Areckal is a clinical social worker at UCSF Benioff Children's Hospital. She is a three-time cancer survivor and an amputee due to osteogenic sarcoma who knows what it is like to live through and be treated for cancer as a teen and young adult.

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EVOLVING THE PATIENT JOURNEY