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## Introduction



(https://vimeo.com

/194301527)

## Adolescent and Young Adult (AYA) Cancer Survival Guide

We suggest that you bring your ebook of this guide to meetings with Healthcare Professionals. You can get the ebook from the "Request this Ebook" button above and will then be able to use it on your phone, tablet, computer, or print it out on paper.

Introducing Dr. Sender



**Dr. Leonard Sender, M.D.** is board certified both in Pediatrics and Pediatric Hematology/Oncology with professional interests strongly centered on diagnosis, treatment, and epidemiology of Adolescent and Young Adult (AYA) cancer (patients aged 15 to 39). He is Medical Director of the Adolescent and Young Adult Cancer Program in the Hyundai Cancer Institute at CHOC Children's and UC Irvine's Chao Family Comprehensive Cancer Center.

*"AYA cancer is cancer that affects adolescents and young adults (age 15-39). A positive attitude is crucial in dealing with AYA cancer. Know that there is great research going on currently that helps more and more people survive everyday."*

### MY MESSAGE TO YOU AS A NEWLY DIAGNOSED CANCER PATIENT

*Dr. Sender, "Information can lead to knowledge and knowledge is power. You have to become empowered to ask the right questions and to find the right questions to get the information you need. The only way to get the type of treatment that is right for you that leads to the type of outcome we want for you is to become fully engaged in the process."*

Lifestyle & Prevention

- Young women need to have the HPV vaccine and regular pap smears
- Exercise
- The right diet
- Self-examinations: Breast, Testicular, and Melanoma
- If you notice anything unusual, bring it to your doctor's attention immediately. Don't be afraid or embarrassed to bring anything up with your doctor. Your doctor is on your side and wants to help you prevent cancer and other diseases.

#### National Cancer Institute on Physical Activity:

<http://www.cancer.gov/cancertopics/factsheet/>

(<http://www.cancer.gov/about-cancer/causes-prevention/risk/obesity/physical-activity-fact-sheet>)

#### NCI Breast Screening:

<http://www.cancer.gov/cancertopics/pdq/>

(<http://www.cancer.gov/types/breast/hp/breast-screening-pdq#section/all>)

#### NCI Skin Screening:

<http://www.cancer.gov/cancertopics/> (<https://www.cancer.gov/types/skin/patient/skin-screening-pdq>)

#### NCI Testicular Self-Exam:

<http://www.cancer.org/cancer/testicularcancer/>

(<http://www.cancer.org/cancer/testicularcancer/do-i-have-testicular-cancer>)

#### NCI Breast Self-Exam:

<http://www.cancer.org/cancer/breastcancer/>

(<http://www.cancer.org/cancer/breastcancer/moreinformation/breastcancerlyearlydetection/index>)

What is AYA Cancer?

**70,000 AMERICANS AGED 15-39 ARE DIAGNOSED WITH ADOLESCENT AND YOUNG ADULT CANCER EACH YEAR.**

**The most common AYA cancers are:**

Cancer in adolescents and young adults (AYAs) can

behave like a different disease than cancer in children or in older adults. While significantly more research is needed to better AYA cancer outcomes, here you will find links to current research and articles on the most common AYA cancers including AYA issues regarding fertility preservation, survivorship, psychosocial and palliative care.

•Breast cancer	•Leukemia
•Brain tumors	•Liver cancer
•Cervical cancer	•Lymphoma
•Colorectal cancer	•Melanoma
•Germ Cell tumors	•Sarcoma

**To Learn More:**

- A Snapshot of Adolescent and Young Adult Cancers

(<http://www.cancer.gov/research/progress/snapshots/adolescent-young-adult>)

- Types of Children's Cancer (<https://childrensoncologygroup.org/index.php/typescancer>)

## Diagnosis

### The Diagnosis Phase

**SeventyK** created the Stop A Doc campaign to give patients an empowered way to engage with their doctors while providing a set of guideposts for healthcare professionals treating adolescents and young adults (AYAs). An extensive survey of AYA patients, caregivers and healthcare professionals resulted in five questions that every healthcare professional should be asked before they treat a 15 to 39 year old cancer patient. These questions ensure that healthcare professionals are aware of the unique needs and can provide resources and support to AYA patients.

Patients, join the campaign to "Stop A Doc" and make sure your doc can answer yes to all five questions.

Healthcare professionals, help improve the survival rates of AYAs with cancer by partaking in our campaign.



(<https://vimeo.com>)

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## WHAT'S THE FIRST THING THAT I SHOULD DO?

- Stop your Doc! This campaign helps you ask the right questions so that you make sure you get the right doctor and right treatment for you
- Interested in having children? Talk to your doctor about fertility preservation and ask your doctor about the impact of your treatment on your reproductive chances
- Make sure the treatment you are about to undergo won't harm your reproductive chances unless you've already discussed fertility preservation

### To Learn More:

- (<http://www.cancer.org/cancer/cancerbasics/thehistoryofcancer/the-history-of-cancer-cancer-treatment-radiation>) Stop A Doc (<http://seventyk.org/get-involved/stop-a-doc>)
- SeventyK Fertility Preservation (<http://seventyk.org/get-educated/fertility-preservation>)



## WHAT ARE THE MAIN DIFFERENCES BETWEEN PRACTITIONERS?

- The **oncologist** tends to the medical side of treatment, and will take care of your whole body and health during chemotherapy and radiation treatment.
- The **surgeon** is the one who will operate on you if you need to have a tumor removed.
- The **radiation oncologist** will be the one to perform any radiation needed to kill cancer cells.
- The **radiologist** performs and reviews the scans needed to determine where the cancer is and how it's growing or changing.

## WHAT TREATMENT OPTIONS DO I HAVE?

- To start, the surgeon will remove any tumors that the oncologist decides are necessary and pertinent to remove.
  - More Info on Surgery (<https://childrensoncologygroup.org/index.php/treatmentoptions/surgery>)
- The radiation oncologist would begin treating you with radiation therapy in combination with hormone therapy if that is needed as well.
  - More Info on Radiation Therapy (<https://childrensoncologygroup.org/index.php/treatmentoptions/radiationtherapy>)
- Sometimes, you may need all three treatment options: a surgeon to remove tumors, an oncologist to treat your whole body, and a radiation oncologist to treat you with radiation therapy and chemotherapy.
  - More Info on Chemotherapy (<https://childrensoncologygroup.org/index.php/treatmentoptions/chemotherapy>)

### To Learn More:

- Definition of Radiation (<http://www.cancer.org/cancer/cancerbasics/thehistoryofcancer/the-history-of-cancer-cancer-treatment-radiation>)
- Definition of Chemotherapy (<http://www.cancer.org/cancer>)

/cancerbasics/thehistoryofcancer/the-history-of-cancer-cancer-treatment-chemo)

What Should I Think About Prognosis?



- You need to understand the exact cancer you have and the exact stage you are in.
- Get a statistic based prognosis based on your current stage.
- Ask your doctor not to "Dumb it Down." You want the facts!

Not all data will apply to you, but it can give you a guideline for what will happen if you choose different options during your treatment.

**To Learn More:**

- Understanding Cancer Prognosis (<http://www.cancer.gov/about-cancer/diagnosis-staging/prognosis>)

**Health Goals for the Diagnosis Phase:**

- Get the best Healthcare Team possible
- Find the right Hospital or Cancer Center for me
- Learn as much as possible so I can have informed and empowered discussions
- Consider "active observation" (**ONLY** if appropriate and decided upon in consultation with your Dr.)
- Consider fertility preservation and discuss it before treatment

## Treatment

### The Treatment Phase

"Cancer" is not a single disease with a one-size-fits-all approach to treatment. If possible, it's important to be treated at a cancer center or medical center that specializes in treating the type of cancer you have. Adolescents or young adults with certain kinds of cancer may do better if treated with regimens tailored to younger children rather than those designed for older adults. Talk with your doctor about getting a second opinion and whether being treated on a clinical trial is a possibility.

The following topics are some items that you will want to discuss with your doctor. Write down questions before each appointment and meeting with your healthcare providers so you can be prepared.



([https://vimeo.com](https://vimeo.com/183398957)

/183398957)

### What is Cancer Treatment Like?

#### IF YOU START WITH SURGERY...

- Important to talk about how you will heal after surgery.
- If you have drains in an incision site, how do you take care of them?
- If you have a catheter for IV medication, how do you take care of that?

#### To Learn More:

- NCI's Adolescent and Young Adult Treatment and Clinical Trials  
(<http://www.cancer.gov/types/aya>)

#### HELP DEFINING THE NEW WORDS YOU'LL BE HEARING A LOT:

An entire new vocabulary of words that you've never heard is about to become a part of your everyday language.

#### To Learn More:

- NCI's Adolescent and Young Adult Treatment and Clinical Trials  
(<http://www.cancer.gov/types/aya>)  
- COG's Glossary of Cancer Terminology  
(<https://childrenoncologygroup.org/index.php/glossary>)

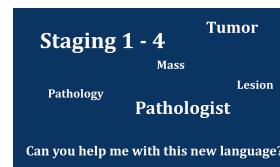
#### IF YOU START WITH CHEMOTHERAPY...

- How bad will the nausea and vomiting be and what can I take to mitigate those effects?
- Will I lose my hair and how soon will that happen?
- What should I be eating during the chemotherapy?
- Can I be exercising? Having sex?

## SOME KEY TERMS YOU WILL NEED TO KNOW:

**Pathology:** The understanding of what your actual cancer looks like. The words tumor, mass, and lesion all mean the same thing: a group of abnormal cells. To find pathology a pathologist looks at the cells under a microscope to determine the type of cancer you have.

**Staging:** To determine if a cancer is just in the one spot where it was found, or has it moved to other body parts and organs? The staging classifications in the United States are the AJCC staging standards. This allows for continuity when discussing the stage of cancer across the States. Staging also helps define your treatment and your prognosis.



#### To Learn More:

- NCI Pathology (<http://www.cancer.gov/about-cancer/diagnosis-staging/diagnosis/pathology-reports-fact-sheet>)  
- NCI Staging (<http://www.cancer.gov/about-cancer/diagnosis-staging/staging>)



#### WHAT IF I HAVE TO HAVE SURGERY?

- Ask your doctor about pain management options.
- How long will you have to stay in the hospital?
- What type of dressing will you have and how often should you change it?
- What can you expect in the first day or two?

## WHAT IF I START WITH CHEMOTHERAPY?

- There are over 80 types of chemotherapy.
- How long do the infusions take?
- Ask about premedication to stop the nausea and vomiting.
- Always ask for a list of pros and cons to make the right decision for you about chemotherapy.

### What are Clinical Trials?

Clinical trials are an important treatment option for cancer patients of all ages since they provide the most up-to-date treatments. Currently, only about 2 percent of patients 20 to 39 years old are treated in clinical trials, compared with more than 60 percent of children under the age of 15. Survival rates for pediatric cancer have increased dramatically in the last few decades. Participation of more adolescents and young adults in clinical trials will help improve treatment, survival, and understanding of the types of cancers that occur in patients in this age group.

Chemotherapy works by stopping or slowing the growth of cancer cells, which grow and divide quickly. But it can also harm healthy cells that divide quickly, such as those that line your mouth and intestines or cause your hair to grow. Damage to healthy cells may cause side effects. Often, side effects get better or go away after chemotherapy is over.

- Clinical trials are important for discovering what types of treatment work and we can't find that without people willing to participate in clinical trials.

- All the advances we have today have come from results discovered during a clinical trial.

- No drug in the U.S. is available without going through three rounds of clinical trials.

#### To Learn More:

- NCI Clinical Trials (<http://www.cancer.gov/about-cancer/treatment/clinical-trials>)
- What Is a Clinical Trial? (<https://childrencygroup.org/index.php/what-is-a-clinical-trial>)

#### Health Goals for the Treatment Phase:

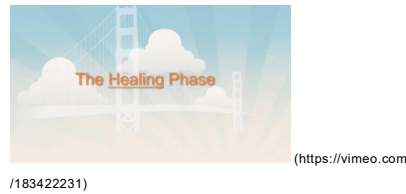
- To make arrangements for necessary in-hospital and at home post treatment care
- To get a roadmap for the Treatment Phase of my journey
- Get informed about possible post treatment side effects and how they should be reported to my healthcare team
- Develop more goals on your own

## Healing

### The Healing Phase

## WHAT WILL MY FOLLOW-UP CARE BE LIKE IN THIS PHASE?

- Keeping your physician apprised of any unusual symptoms you're having.
- CT and PET scans to make sure the cancer is gone.
- Blood tests to make sure your organs have recovered from the effects of chemotherapy.



**Dr. Sender,** *"During cancer treatment, adolescents and young adults may focus all of their energy on getting through treatment. Some may not have spent much time talking or thinking about life after cancer treatment. It's normal to have questions about returning to work or school and managing relationships. Life after treatment often presents a new set of challenges."*

- Think about resting your body.
- Engage your body in the healing process.
- Think about the type of healthy exercise and diet you need.
- Think about sleep, meditation, and anything to have less stress.
- Heal your mind, you've been through a lot of trauma!

### Health Goals for the Healing Phase:

- Plan ahead for any school or work issues - allow time
- Speak to my Dr. about any issues in being sexually active
- Develop a healthy diet (whole organic foods, less animal protein, with greens and fresh fruit)
- Create an appropriate exercise program
- Develop more goals on your own

## Wellbeing

### The Wellbeing Phase

**Dr. Sender,** "Going forward, it's important to have follow-up care visits, which can help prevent or detect any problems due to cancer or its treatment. Follow-up care can help assure that emotional issues and concerns are addressed. Talk with your doctor to learn more. Learn how others have handled life after treatment is completed."



(<https://vimeo.com/194304088>)

- It's all about looking at the rest of your body and thinking about PREVENTION! Dr. Sender believes the single most important thing you can do to prevent recurrence of cancer is to maintain a healthy body weight by eating a balanced diet and regularly exercising.
- Make a detailed recording of what your treatment was so you can talk to other doctors about it if you need to, it is important to understand what you had done.
- Depending on the type of cancer you had, you may need rescans to make sure the cancer is gone for up to 5 years after your last treatment.
- Focus on healthy living.
- Your new normal can be more fulfilling than ever before!

/194304088)



### Health Goals for the Wellbeing Phase:

- Develop a healthy "anti-cancer" diet (whole organic foods, less animal protein, with greens and fresh fruit)
- Develop and maintain a proper exercise program
- Consider giving back to AYA patients following in your footsteps
- Consider participation in post treatment studies
- Develop more goals on your own

### Difficult Questions

## CAN WELLBEING BE A STATE OF MIND?

**Dr. Sender,** "Absolutely, wellbeing is really how you think of yourself in the context of your life. What your spiritual life, what your physical life, what your emotional life is like. Get a lot of friends around you. Give back to society. Find meaningful employment, find meaning in your life. I think wellness is meaningful."



## WHAT IS PALLIATIVE OR COMFORT CARE?

Many people who have cancer or who have been treated for cancer develop symptoms or side effects that affect their quality of life. Care given to help patients cope with these symptoms or side effects is called palliative care, comfort care, supportive care, or symptom management.

### Some Online Support Communities

The **SeventyK Wellness Network** is a place **To Learn More:**



for Adolescent and Young Adult (AYA) cancer patients to go from Diagnosis to Wellbeing. It is a place for caregivers and healthcare professionals to share their knowledge.

- Join the SeventyK AYA Wellness Network

(<https://www.mybridge4life.com/seventyk>)

- SeventyK Overview Video (<http://www.seventyk.org/get-involved/seventyk-wellness-network>)

**Tips 4 Life** is a curated database of real world wisdom segmented by phase (diagnosis, treatment, healing, wellbeing), cancer type, age, location and more.



## Closing

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Closing



(<https://vimeo.com>

/172964995)

*"The most important thing I can say to you as an AYA cancer patient is to be positive. Every patient is unique. Surround yourself with your friends, and be positive. There is a lot of great research going on with more and more survivors every day."*

– Leonard Sender, M.D.



