DANCE IN THE RAIN

A JOURNAL FOR TEENS WITH CANCER



By Ruth I. Hoffman MPH & Trevor Romain

Dance In The Rain: A Journal for Teens with Cancer

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BE ADVISED

This book is written to provide information about adolescent cancer and should not be used as an alternative to seeking professional advice. It is important to always seek the expertise of a medical professional.

IN APPRECIATION FOR THE SUPPORT FROM





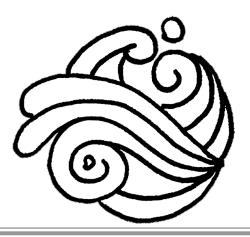
"YOU'VE GOTTA DANCE
LIKE THERE'S NOBODY WATCHING,
LOVE LIKE YOU'LL NEVER BE HURT,
SING LIKE THERE'S NOBODY LISTENING,
AND LIVE LIKE IT'S HEAVEN ON EARTH."

WILLIAM W. PURKEY



THIS JOURNAL BELONGS TO

Date I was diagnosed with cancer:
Hospital I was diagnosed at:
My cancer diagnosis:
Date I started writing in my journal:





WHY IS IT GOOD TO JOURNAL?

Being diagnosed with cancer can be very scary. This might be the first time that anyone in your family has had cancer. Most of your friends will never have experienced something like this before. You might feel different than before your cancer diagnosis. You might find it more difficult to concentrate. You might look different. You might not be able to participate in the things that were previously part of your everyday routine.

All of these changes can make you feel different and make it difficult to know who you can relate to and who you can talk to about what you are going through. You might wonder who you can trust with your deepest thoughts and feelings about what is happening in your life.

For many people with cancer, keeping a journal helps them cope with their emotions and helps them see things more clearly. Writing down your thoughts can help you better understand the emotions you are experiencing, as well as help you identify questions to ask your healthcare team. Some cancer patients who regularly journal say that they have fewer cancer symptoms and less unscheduled doctor's visits! That's definitely an 'awesome' reason to keep a journal!

This journal is your own private place to dive into those innermost thoughts and feelings. It is a safe place to express your feelings regardless of what they are. It's a place to vent, scream, reflect, hope, and dream and on those days when you feel tired and your brain feels 'chemo-fuzzy' then you can just 'doodle.'

Remember to keep in mind—there will come a time when you will be able to read your completed journal and reflect on how far you've come.



HELPFUL JOURNALING TIPS

- Remember to include a date for each journal entry.
- Find a time and place that allows you to express yourself honestly and try to
 write on a regular basis. You'll be glad that you did when you re-read your completed journal.
- Include drawings and doodles as these can also expresses your thoughts and feelings.
- Don't censor your writing. Your thoughts and feelings are very real to you. There
 are no right or wrong feelings!
- Use the writing prompts if you wish. They can be used in any order, at any time.

So explore your thoughts, listen to your feelings and

DANCE IN THE RAIN!



"LIFE IS NOT ABOUT WAITING FOR THE STORM TO PASS. IT'S ABOUT LEARNING TO DANCE IN THE RAIN."

VIVIAN GREENE

Name:	
	Height:
Weight:	
Shoe size:	Grade:
Favorite junk food:	
Favorite video game: _	
Favorite sports team: _	
Favorite book:	
Favorite movie:	

FIVE **RANDOM** THINGS ABOUT ME!

AND THERE'S MORE!	

THE MOST **AWESOME** THING I'VE EVER DONE!

I SAID WHAT?!!

I'd rather have a dog □ than a boyfriend/girlfriend □
I'd rather live on a deserted island \square OR a in big city metropolis \square
I'd rather live on the moon \square OR live at the bottom of the sea \square
I'd rather be saved by Superman \square OR Spiderman \square
If I was a super hero, my name would be
If I were a dog, I'd be a
Under my bed there's
If I could travel anywhere in the world I would go
I'd rather lose my
than my cell phone!



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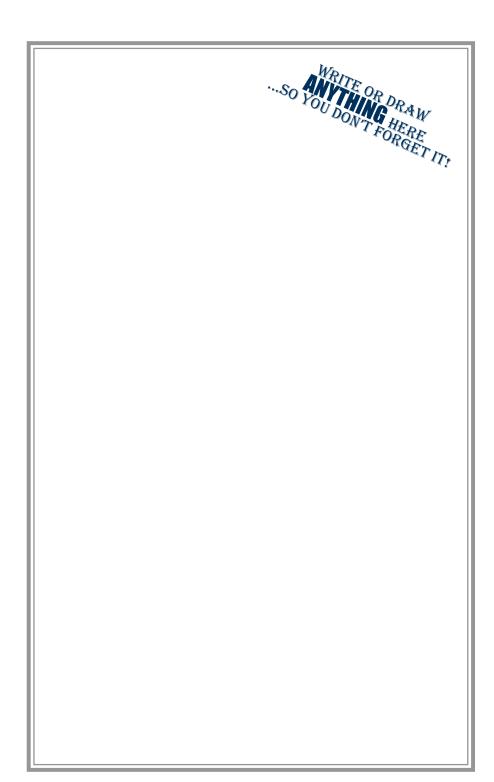
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My three favorite BANDS

1/	
2/	
3/	
My five favorite SONGS	
1/	
2/	
3/	
4/	
5/	
If I was a famous musician I would:	

DESCRIBE YOU HOW YOU LOOK	
DESCRIBE YOU AND WHO YOU ARE.	
AND	



WHEN MY FAMILY..."

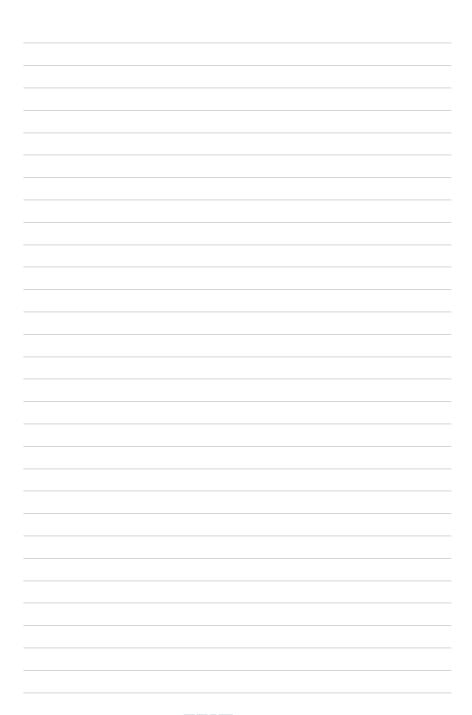
MY FAMILY AND ME



MY **SYMPTOMS** THAT LED TO BEING DIAGNOSED WITH CANCER WERE ...



THE PERSON **WHO TOLD ME** I HAD CANCER WAS ... O



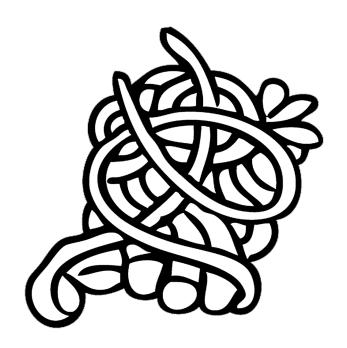


BEFORE I WAS DIAGNOSED WITH CANCER, I ...

AFTER I WAS DIAGNOSED WITH CANCER, I ...



My favorite color is
My favorite time of year is
I escape by watching TV \square listening to music \square reading a book \square sleeping \square
Other
The funniest person I know is
The magical power I would most like to have is
I wish my family had a
My most cherished possessions are
The movie character I'd most like to be is



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AFTER BEING DIAGNOSED WITH CANCER,
DID YOU EVER ASK YOURSELF "WHY ME?"

HOW DID YOU ANSWER THAT QUESTION?

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YOUR INNERMOST THOUGHTS	
YOUR INNERMOST THOUGHTS	
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"I MEAN A LITTLE FISHY TOLD ME, JUST KEEP SWIMMING, JUST KEEP SWIMMING...!"

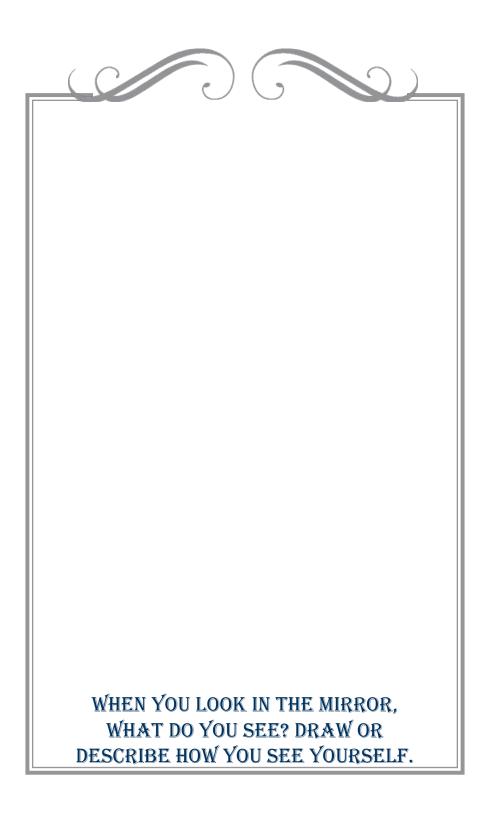
TALIA CASTELLANO

"I FEEL LIKE LAUGHING WHEN..."

"I FEEL LIKE CRYING WHEN..."

"I FEEL LIKE DANGING WHEN..."





WHAT PHYSICALLY **CHANGED**AFTER YOU WERE DIAGNOSED WITH CANCER AND HOW DID YOU FEEL?

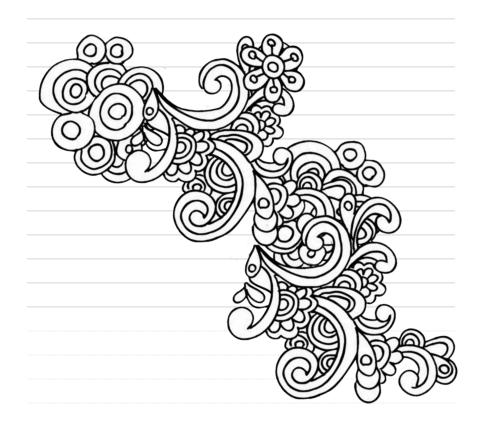
AND HOW DID TOO FEEL!

LIST THE PEOPLE WHO HAVE COME TO VISIT YOU IN THE HOSPITAL (KEEP ADDING TO THE LIST).

LIST THE THINGS THAT PEOPLE HAVE GIVEN YOU
WHILE IN THE HOSPITAL (KEEP ADDING TO THE LIST).

"MY FAVORITE THING TO DO WITH

MY **FAMILY** IS ..."

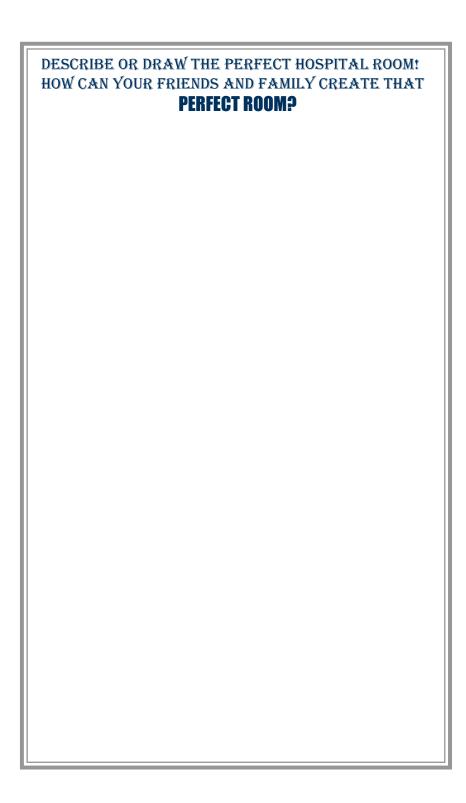


"MY FAVORITE THING TO DO WITH

MY FRIENDS IS ..."



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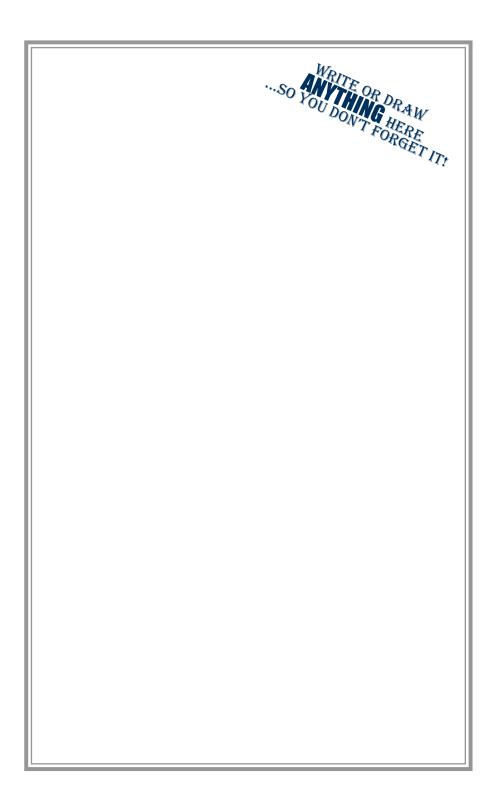
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YOUR INNER STRENGTHS

WHAT DO YOU DO TO MAKE YOURSELF FEEL STRONGER?



"STRENGTH DOES NOT COME FROM PHYSICAL CAPACITY. IT COMES FROM AN INDOMITABLE WILL." MAHATMA GANDHI





I WANT MY DOCTORS TO KNOW THIS ABOUT ME!



I WANT MY NURSES TO KNOW

THIS ABOUT ME!										

THE **HARDEST** THING ABOUT HAVING CANCER IS ...

THE **OK** THING ABOUT HAVING CANCER IS ...

A DAY IN MY LIFE **BEFORE**

CANCER ...



A DAY IN MY LIFE **AFTER**CANCER ...

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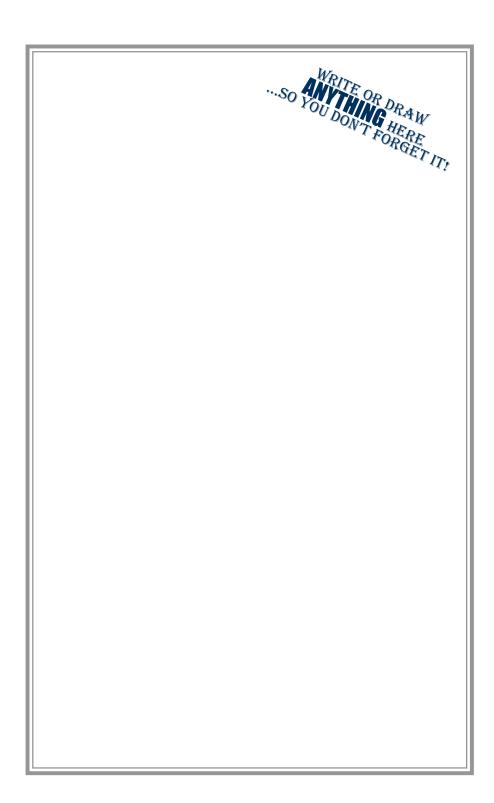
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DADENTS FOIFURS TEACHEDS WHAT HAS CHANGERS RELATIONSHIPS!

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LIST WAYS THAT YOUR SCHOOL COULD HELP YOU DURING THIS DIFFICULT TIME.



"PEACE BEGINS WITH A SMILE" MOTHER THERESA



WHO IS THE ONE PERSON THAT CAN ALWAYS MAKE YOU **SMILE**? WHY?

WHICH FRIEND HAS BEEN THERE FOR YOU? WHAT DO YOU LIKE ABOUT THAT PERSON?

WHICH **TEACHER** HAS BEEN THERE FOR YOU? WHAT DO YOU LIKE ABOUT THAT PERSON?

WHO IS YOUR **HERO**? WHY?

LIST WAYS THAT SHOW HOW YOU ARE A HERO!

WRITE ABOUT SOME TEENS OR KIDS WITH CANCER WHO HAVE BECOME YOUR

FRIEND.



"WALKING WITH A FRIEND IN THE DARK IS BETTER THAN WALKING ALONE IN THE LIGHT."

HELEN KELLER



I SAID WHAT?!!

I'd RATHER be gossiped about \square or never talked about at all. \square
I'd RATHER have a big group of friends \square or ONE special friend. \square
I'd RATHER be known for my intelligence \square or for my good looks. \square
I'd RATHER have super powers to read someone's thoughts \square or the power to
make someone fall in love with me. \square
I'd RATHER live without music \square or live without video games. \square
I'd RATHER end poverty \square or CURE cancer \square
Why?



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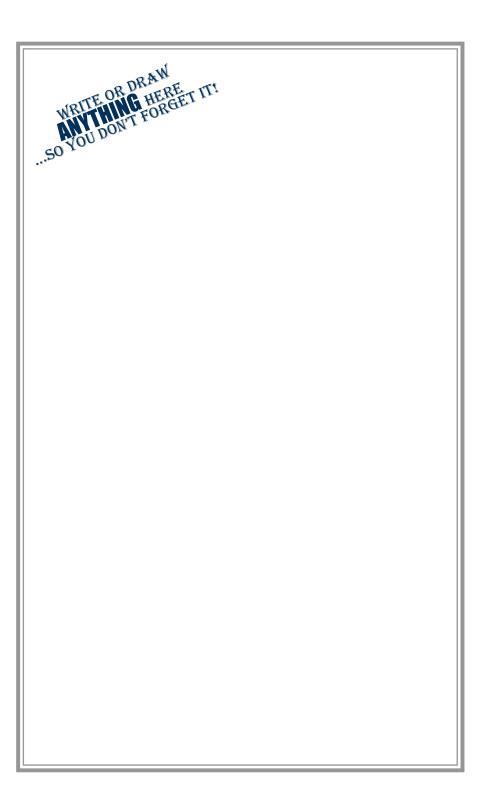
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"IT WAS SO GROSS WHEN..."

"IT WAS SO FUNNY WHEN..."

"IT WAS SO THOUGHTFUL WHEN..."

"IT WAS SO EMBARRASSING WHEN..."

WHAT DO YOU DO TO COPE WITH A PAINFUL PROCEDURE? PAIN

DRAW FIVE FACES THAT ILLUSTRATE YOUR IDEA OF A PAIN SCALE—FROM NO PAIN TO SEVERE PAIN. BE CREATIVE!

GIVE NICK NAMES TO YOUR TREATMENTS. BE CREATIVE!

GIVE NICK NAMES TO YOUR **MEDICINES.** BE CREATIVE!

HOW HAS CANCER **CHANGED**THE WAY YOU LOOK AT LIFE?



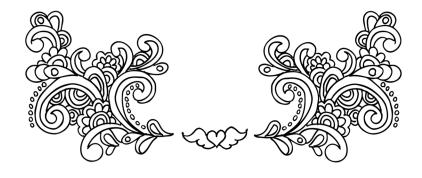
"MY MOMMA ALWAYS TOLD ME THAT MIRACLES HAPPEN EVERY DAY." FOREST GUMP



L	IST WAYS THAT YOUR FRIENDS COULD HELP YOU DURING THIS DIFFICULT TIME.

I SAID WHAT?!!

I'd rather have my tongue stuck on a popsicle \square OR on fire from hot sauce. \square
My favorite part of a cake is icing \square OR filling \square OR cake. \square
My favorite condiment is ketchup \square OR mustard \square OR relish. \square
My favorite food when it's cold outside is
My favorite food when it's hot outside is
My favorite hospital foods are
Foods I wish were on the hospital menu are:
Healthy foods I'll actually eat are:
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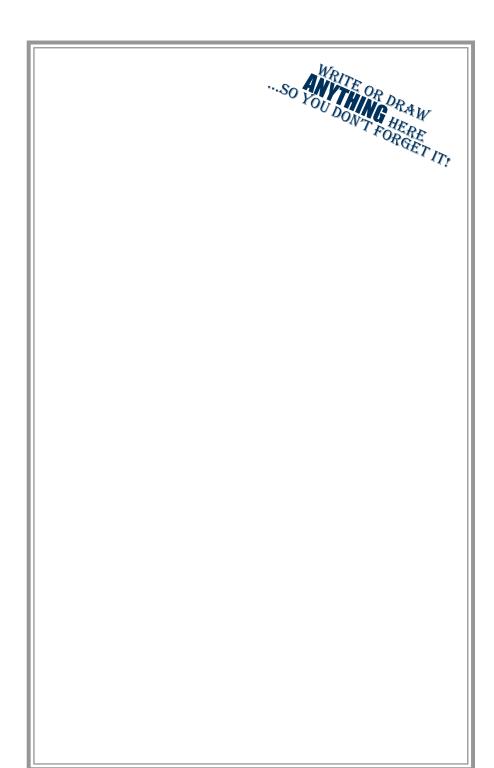
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DREAMS, HOPES, DREAMS, HOPES, DREAMS, HOPES... TOD&Y, TOMORROW ...



"THE BEST THING ABOUT THE FUTURE IS THAT IT COMES ONE DAY AT A TIME." ABRAHAM LINCOLN



WHAT WILL YOUR LIFE BE LIKE **FIVE** YEARS FROM NOW?

WHAT WILL YOUR LIFE BE LIKE TWENTY FIVE YEARS FROM NOW?

LIST 10 THINGS YOU WOULD LIKE TO DO IN YOUR LIFE!

IF YOU WERE THE DOCTOR, WHAT WOULD YOU TELL A TEEN WHO WAS JUST DIAGNOSED WITH CANCER?

FOLD IS THE SYMBOLIC COLOR FOR CHILDHOOD CANCER. LIST WAYS YOU AND YOUR FRIENDS CAN "GO GOLD" TO INCREASE AWARENESS THAT KIDS AND TEENS GET CANCER TOO?!

LIST 10 WAYS YOU CAN STAND UP TO CANCER!

IF YOU COULD CHOOSE ANY PLACE TO LIVE IN THE WORLD, WHERE WOULD IT BE? WHY?

IF YOU COULD CHOOSE ANYONE TO LIVE WITH IN THE WORLD, WHO WOULD IT BE? WHY?

WHAT DO YOU **DREAM** OF WHEN LYING AWAKE AT NIGHT?



WHAT DO YOU **HOPE** FOR?



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WHAT'S WHAT!?!

Understanding the procedures that you will go through can help to reduce fear and anxiety. Prior to any procedure being done, it's ok to ask the five 'W's.'

- WHO will be doing the procedure?
- WHAT will be done and WHAT are the side-effects?
- WHEN will it be done?
- WHERE will it be done?
- WHY is it being done?

The following are common procedures that are used to treat child and adolescent cancer. The procedures you receive will depend upon your diagnosis and the treatment required, so you will experience some but not all of the following.

Angiogram: Special x-ray procedure using sedation or general anesthesia to determine the blood supply and circulation in the area surrounding the tumor.

Audiogram: Painless test to measures potential hearing loss. Test is performed in a soundproof room and the results are displayed in the form of a graph and compared with a normal hearing graph.

Auditory Brainstem Response (ABR): Painless test using a 'click' signal delivered through earphones to determine the evoked auditory pathway and brainstem function.

Blood draws: Blood taken from using either finger poke, the large vein found on the inside of the elbow, or through your port. The blood sample is used to determine the CBC (complete blood count), blood chemistries or test for infection.

Biopsy: Surgical removal of cells or tissue from the cancer to determine diagnosis and staging of disease. The tissue can also be used for research purposes.

Blood Transfusion: Process of infusing donated blood/blood products to replenish your red blood cells (whole blood transfusions) or platelets (platelet transfusions) that have been depleted as a result of the cancer or the treatment.

WHAT'S WHAT!?!!

Bone Density: Painless x-ray scan of your non-dominant hand and wrist with results used to determine age appropriate growth (bone-age).

Bone Marrow Aspirate: Needle removal of semi-liquid bone marrow usually from the back of the hipbone (iliac crest). The resulting cells are used to determine the presence and/or type of cancer.

Bone Marrow Biopsy: Surgical removal of small piece of bone to obtain bone marrow.

Bone Scan: Painless nuclear medicine scan using a gamma camera and an IV injection of radioactive material that travels to the bone. Resulting imaging is used to determine the presence of cancer in the bone.

Computed Tomography Scan (CT): Painless x-ray type scan that gives three-dimensional (3D) picture of your body. Procedure may take up to one hour.

Creatinine Clearance: Urine collection in addition to IV blood draw to measure and compare creatinine levels in the blood and urine as a measurement of kidney function.

Echocardiogram (ECHO): Painless sonogram of the heart, using sound waves to create a picture which measures strength and function.

Electrocardiogram/ECG or EKG: Painless measurement of the electrical activity of the heart using electrodes that are placed on the skin of the chest and sometimes legs, with recordings transmitted to a monitor.

Electroencephalogram/EEG: Painless measurement of the electrical activity of the brain using electrodes that are placed on the scalp, with recordings transmitted to a monitor.

Electromyogram (EMG): Test using electrodes to determine the electrical activity of skeletal muscles. Can be done on the surface of the skin or intramuscular (needle and fine wire).

Finger Poke: Small blood drawn from pricking the fingertip with a sharp instrument. Applying Emla cream correctly one hour prior to the procedure can help to reduce pain.

WHAT'S WHAT!?!

Gallium Scan (Gallium 67): Type of nuclear medicine imaging requiring venous injection of radioactive gallium citrate 24 to 48 hours prior to the scan.

Gastrostomy: Surgical incision into the stomach and placement of a GI tube to provide direct nutritional support—Total Perenteral Nutrition (TPN).

Glomerular Filtration Rate (GFR): Intravenous injection of a contrast dye to measure the rate of filtration through the kidneys.

Intravenous Pyelogram (IVP): Intravenous injection of a contrast dye visible by x-rays to identify urinary tract abnormalities including the ureters, bladder, and kidneys.

Lumbar Puncture (LP or Spinal Tap): Spinal needle inserted between lumbar vertebrae L3/L4 or L4/L5 for the purpose of collecting cerebrospinal fluid (CNS) for diagnostic purposes, or administration of intrathecal chemotherapy or pain management medication.

Magnetic Resonance Imaging (MRI): Medical scan using magnetic field technology to create two-dimensional image of the brain or spinal cord. Scan may take up to an hour and the machine is loud and tunnel like.

131 I-meta-iodobenzylguanidine (MIBG): Nuclear medicine imaging technique sometimes used to treat neuroblastoma. Involves IV injection of radioactive material 48 hours prior to the scan, and lengthy scan often requiring sedation to reveal tumor 'hot spots'.

Multi Gated Acquisition Scan (MUGA Scan): Nuclear medicine imaging test used to evaluate the pumping function of the heart ventricles. Procedure requires you to remain still for approximately 20 minutes so sedation might be given. More accurate than an ECHO, and often used if ECHO shows abnormality.

Neuropsychological Test: Battery of written, performance and oral tests to determine cognitive functioning.

Positron Emission Tomography (PET) Scan: Nuclear medicine imaging technique using minimal radiation dose.

WHAT'S WHAT!?!

Pulmonary Function Test: Painless test consisting of blowing air into a tube to determine lung capacity and respiratory functioning.

Venous (External Catheter) Access: Needle injection and/or blood draws into an external catheter previously surgically placed into the right atrium of the heart or the large vein leading to the heart.

Single Photon Emission Tomography (SPECT) Scan: Nuclear medicine imaging test using gamma rays. Multiple two dimensional slices (2D) are combined to provide three-dimensional (3D) information about localized function in internal organs. Similar to PET scans but less expensive.

Subcutaneous Injections: Injections made under the skin. Correctly applying Emla cream or rubbing ice over the site prior to injection can reduce pain and swelling.

Surgery: An operation often used as primary treatment to remove cancerous tissue/tumor and/or take a biopsy specimen to determine a cancer diagnosis.

Temperature Monitoring: Use of a thermometer to detect fever during cancer treatment. Thermometer can be placed under the arm or tongue, or by using a special ear thermometer.

Ultrasound Imaging: Portable medical imaging technique using ultrasonography instead of radiation to view muscles, and internal organs.

Urine Sample: Collection of urine either directly into a catch basin (cup, toilet seat hat) or through catheterization if unable to urinate.

Wada Test: Also known as "intracarotid sodium amobarbital procedure (ISAP). Used prior to brain surgery to identify speech and memory centers.

X-Ray: Painless imaging technique using electromagnetic radiation.

Notes:

WHO'S WHO!?!

Understanding WHO everyone is during your treatment will also greatly help. The following is a list of some of the hospital team members who you might get to know.

Attending: Board certified doctor who specializes in cancer and has supervisory responsibilities but might not be your primary doctor.

Anesthesiologist: A physician who did additional training in anesthesiology.

Child Life Specialist: Health care worker who assists with the practical needs of helping a family whose child has been hospitalized.

Fellow: A board certified doctor who has completed residency and who is in the process of receiving further training in a specialized field such as oncology (cancer).

Intern: A board certified doctor who is in his/her first year of training after graduating from medical school.

Neurologist: A board certified doctor who has done additional training in the nervous system and the diseases that impact it.

Nurse Practitioner: A nurse who has done additional training allowing her to do some medical procedures without the supervision of a doctor.

Oncologist: A board certified doctor who has done additional training and been certified in the diagnosis and treatment of cancer.

Psychologist: A healthcare team member who studies and assists with development and behavior.

Radiologist: A doctor who has been trained in the use of radiation to diagnose and treat disease.

Resident: A board certified doctor who is doing medical training (residency) after graduating from medical school. This could be their first, second, third year of training, as opposed to an intern who is in the first year of training after graduating from medical school.

American Childhood Cancer Organization

www.acco.org

Support, education and advocacy for children and adolescents with cancer, survivors of childhood/adolescent cancer, their families and the professionals who care for them.

Camp Mak-A-Dream

www.campdream.org

A camp in Montana that provides a medically-supervised, cost-free experience for children, young adults and families affected by cancer.

Cancer and Careers

www.cancerandcareers.org

Professional support for those who are working during cancer treatment. This is also a useful resource for those returning to work after cancer treatment.

CancerCare

www.cancercare.org

Professional counseling, facilitated peer support groups, creative workshops and financial assistance. See young adult section.

Cancer Climber

www.cancerclimber.org

Offering experiential and motivational adventures and excursions such as extreme mountain climbing and summit tours.

Cancer 101

www.cancer101.org

Cancer resources that empower patients, survivors and caregivers through individualized organizational tools.

Fertile Hope

www.livestrong.org/we-can-help/livestrong-fertility

Provides reproductive health information, support and hope to cancer patients whose medical treatments present the risk of infertility.

First Descents

www.firstdescents.org

A free, one week residential camp experience for young adults with cancer and young adult survivors of cancer. The camp offers kayaking, extreme sports and professional athletics and is held in Montana or Colorado. Young adults from all states are welcome to apply.

For Pete's Sake

www.takeabreakfromcancer.org

Provides young adults and their families with a retreat from the unyielding physical and emotional demands of cancer by providing a one week, expense paid excursion in a comfortable, secure environment.

Group Loop

www.grouploop.org

A ground-breaking program providing interactive online support along with valuable survivorship resources for adolescents with cancer and their parents.

Hope Lab

www.hopelab.org

Combines rigorous research with innovative solutions to improve the health and quality of life of young people with chronic illness.

I'm Too Young For This!

www.i2y.org

i[2]y exists to ensure that every young adult affected by cancer is given access to the best age-appropriate support they are entitled to in order to get busy living at every stage of their survivorship.

LIVESTRONG Young Adult Alliance

www.livestrong.org/yaa

A coalition and leadership community of key voices in cancer advocacy and public health determined to bring about positive results for young adults with cancer.

Look Good, Feel Better for Teens

www.lookgoodfeelbetter.org

A free program that provides useful tips for adolescents dealing with the appearance and sociological side-effects related to cancer and its treatment.

Lotsa Helping Hands

www.lotsahelpinghands.com

Free, private, web-based communities to organize family, friends, colleagues during times of need via intuitive group calendar.

Making Headway Foundation

www.makingheadway.org

Improving treatment, quality of life and survivorship for children and adolescents with brain and spinal cord tumors through research, support, education and advocacy.

MaleCare

www.malecare.com

Comprehensive online support resource portal primarily for young men living with, through or beyond prostate and/or testicular cancer.

My Oncofertility

www.myoncofertility.org

A patient education resource offering easy-to-understand videos and animations, the latest information from experts, stories and advice from others who have gone through the process and more.

Next Step

www.nextstepnet.org

Provides retreats and workshops that help young adults with cancer by providing a place to feel safe enough to laugh, share experiences, and create a sense of community with peers who truly understand their challenges.

Re-Mission

www.re-mission.net

A free 3D shooter video game designed for adolescents and young adults with cancer. Players control a nanobot who battles cancer and bacterial infections, and manages realistic, life-threatening side effects associated with the disease.

Rise Above It

www.raibenefit.org

Provides grants and scholarships to young adult survivors and care providers who face financial, emotional and spiritual challenges.

River Discovery

www.riverdiscovery.org

Adventure programs for teenage cancer survivors on the Salmon River: 6 days of rafting, camping, hiking and exploring.

Stephen T. Marchello Scholarship Foundation

www.stmfoundation.org

Post secondary scholarship monies to survivors of child and adolescent cancer, focussed on current year high school graduates.

The SAMFund

www.thesamfund.org

Offering financial support through grants and scholarships to young adults as they transition into their post-treatment lives.

True North Treks

www.truenorthtreks.org

Dedicated to enriching the lives of adolescent and young adult cancer survivors through contemplative and outdoor-based activities.

Ulman Cancer Fund For Young Adults

www.ulmanfund.org

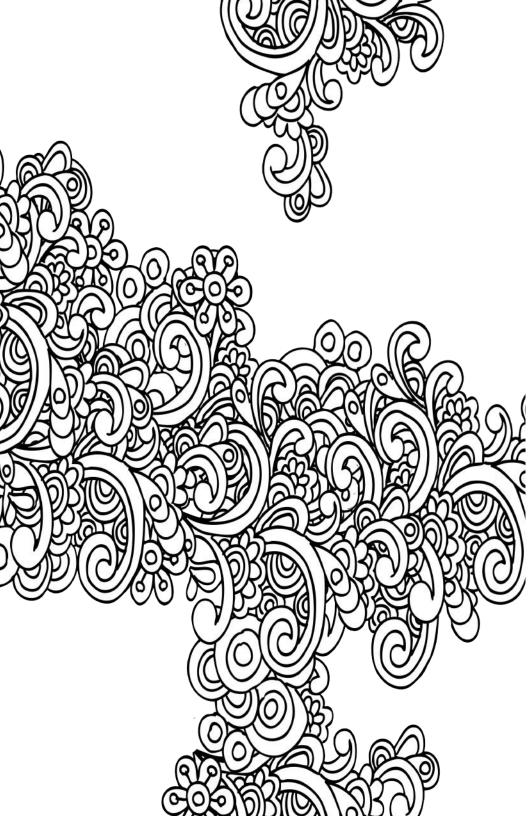
Supporting, educating and connecting young adults affected by cancer through on-line resources, college scholarships and advocacy.

Smith Center for Healing and the Arts

www.smithcenter.org

Hosts young adult cancer survivor monthly meetings with creative and relevant topics ranging from integrative health and fertility choices to coping strategies, relationship issues and everything in between.

MY WEBLINKS





IN APPRECIATION FOR THE SUPPORT FROM



