Dance In The Rain: A Journal for Teens with Cancer

Author: Ruth I Hoffman MPH
Doodles: Trevor Romain
Graphic Layout and Design: Ruth I Hoffman MPH

Copyright © 2014 American Childhood Cancer Organization

Published by the American Childhood Cancer Organization
Second Printing: June, 2020

ISBN: 978-0-9854593-1-4

The American Childhood Cancer Organization’s name and logo are registered trademarks of the National office of the American Childhood Cancer Organization.

For More information about the American Childhood Cancer Organization and our affiliates, please visit us on the web at:

www.acco.org

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

SERVIER
“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
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
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 ☐ OR a in big city metropolis ☐
I’d rather live on the moon ☐ OR live at the bottom of the sea ☐
I’d rather be saved by Superman ☐ OR Spiderman ☐
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!
WRITE OR DRAW
ANYTHING HERE
...SO YOU DON'T FORGET IT!
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 and who you are.
"IT DRIVES ME CRAZY WHEN MY FAMILY ..."

"I LOVE IT WHEN MY FAMILY ..."
MY SYMPTOMS THAT LED TO BEING DIAGNOSED WITH CANCER WERE ...
THE PERSON WHO TOLD ME I HAD CANCER WAS ...
BEFORE I WAS DIAGNOSED WITH CANCER, I...
AFTER I WAS DIAGNOSED WITH CANCER, I ...
I SAID WHAT?!!

My favorite color is ____________________________________________________

My favorite time of year is ______________________________________________

I escape by watching TV ☐ listening to music ☐ reading a book ☐ sleeping ☐
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 _________________________________
_____________________________________________________________________
WRITE OR DRAW
ANYTHING HERE
...SO YOU DON'T FORGET IT!
After being diagnosed with cancer, did you ever ask yourself "Why me?"

How did you answer that question?
Your innermost thoughts

Who do you share them with? Why that person?
“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 DANCING WHEN...”

“I FEEL LIKE SCREAMING WHEN...”
When you look in the mirror, what do you see? Draw or describe how you see yourself.
WHAT PHYSICALLY CHANGED AFTER YOU WERE DIAGNOSED WITH CANCER AND HOW DID YOU 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 ...”
LIST 10 **FUN** THINGS TO DO IN THE HOSPITAL TO HELP WHEN HAVING A BAD DAY.
Describe or draw the perfect hospital room! How can your friends and family create that perfect room?
WRITE OR DRAW

ANYTHING HERE

...SO YOU DON'T FORGET IT!
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 ...
WRITE OR DRAW ANYTHING HERE
...SO YOU DON'T FORGET IT!
RELATIONSHIPS!

PARENTS, FRIENDS, TEACHERS ... WHAT HAS CHANGED?
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 ☐ or never talked about at all. ☐
I’d RATHER have a big group of friends ☐ or ONE special friend. ☐
I’d RATHER be known for my intelligence ☐ or for my good looks. ☐
I’d RATHER have super powers to read someone’s thoughts ☐ or the power to make someone fall in love with me. ☐
I’d RATHER live without music ☐ or live without video games. ☐
I’d RATHER end poverty ☐ or CURE cancer ☐

Why? ____________________________________________________________
_________________________________________________________________
_________________________________________________________________
_________________________________________________________________
_________________________________________________________________
_________________________________________________________________
_________________________________________________________________
_________________________________________________________________
WRITE OR DRAW
ANYTHING HERE
...SO YOU DON'T FORGET IT!
“IT WAS SO FUNNY WHEN...”

“IT WAS SO GROSS WHEN...”

“IT WAS SO THOUGHTFUL WHEN...”

“IT WAS SO EMBARRASSING WHEN...”
PAIN

WHAT DO YOU DO TO COPE WITH A PAINFUL PROCEDURE?
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
LIST WAYS THAT YOUR FRIENDS COULD HELP YOU DURING THIS DIFFICULT TIME.
I’d rather have my tongue stuck on a popsicle □ OR on fire from hot sauce. □
My favorite part of a cake is icing □ OR filling □ OR cake. □
My favorite condiment is ketchup □ OR mustard □ OR relish. □
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:
WRITE OR DRAW ANYTHING HERE...
...SO YOU DON'T FORGET IT!
TODAY, TOMORROW...
DREAMS, HOPES, DREAMS, HOPES, DREAMS, HOPES...
“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?
GOLD 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?
WRITE OR DRAW
ANYTHING HERE
...SO YOU DON'T FORGET IT!
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.
**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.
**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 Parenteral 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.
**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:**
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](http://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](http://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](http://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](http://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](http://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/ya](http://www.livestrong.org/ya)  
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](http://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.
NOTES AND MORE THOUGHTS...
NOTES AND MORE THOUGHTS...
IN APPRECIATION FOR THE SUPPORT FROM