

# NO WAY

**IT CAN'T BE!**

**a guidebook for young adults facing cancer**

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It Can't Be!**  
**a guidebook for young adults facing cancer**

written by Doug Ulman & Diana Ulman

SURVIVORSUPPORT GO!  
MISSION **FIGHT** ENCOURAGE  
POWER STRONG HOPE! **GUIDE**  
PUSH! INSPIRE  
& **SUPPORT**

## **"YOU HAVE CANCER."**

It was a total shock to hear those words. I was 19 ... so much going on ... looking to the future ... ready to go back to school ... and in that moment everything stopped. CANCER!

No way, it absolutely couldn't be! It had to be a mistake. Then it started to sink in. I had CANCER. And I had no idea what it all meant!

I'm Doug Ulman, 3-time cancer survivor. In 1996, I was diagnosed with my first malignancy—chondrosarcoma. Within a year of my first cancer diagnosis, I was diagnosed with malignant melanoma twice.

At the time of diagnosis I was a college sophomore. I studied hard, played varsity soccer, and was full of the zest and energy of an average 19-year-old. A routine x-ray revealed something suspicious, but I thought nothing of it. Further tests showed a cancerous tumor growing in my back. I will always remember the doctor telling me that I had cancer.

I used to think that a diagnosis of cancer meant there was no hope - that you were going to die.

I now know better. There are many new cancer treatments, and many breakthroughs are on the horizon. Cures are being developed in labs and people are surviving cancer and living with cancer at record rates. There is hope!

Soon after my diagnosis and surgeries, I realized that as a young adult facing cancer, I was confronted with so many unique and difficult issues. I had to deal with medical decisions, medical insurance, fertility, career and school concerns, nutrition, overwhelming emotions, relationships. There were so many questions and no clear answers. I could find no support or information for young adults affected by cancer anywhere.

To fill that void, I founded the Ulman Cancer Fund For Young Adults, {UCF} with the help of my family.

The UCF mission is to change lives by creating a community of support for young adults, and their loved ones, as they fight cancer and embrace survivorship.

This guidebook, NO WAY, It Can't Be, embodies the work of UCF. In the following pages you will find suggestions and ideas about how to navigate the challenges ahead of you as you deal with your cancer. The information in this book is information I wish I had had as I faced my cancers. I hope it helps you from the very beginning of your cancer journey, throughout the entire process.

A friend told me that he and I were lucky, because no one can have the perspective on life that a cancer survivor has. From the moment of diagnosis, you are a cancer survivor.

You're not alone. Best wishes,



Doug Ulman

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## **start with an education**

**Deciphering The Diagnosis**

**The Search For Information**

**Put Technology To Work For You**

**Useful Websites**

**What Other Resources Are Available?**

# education



What was it like to hear the doctor give you the diagnosis?

How was it handled?

How would you have liked it handled?

And what do you want to learn about the diagnosis?

You may want to obtain a journal to keep records of your thoughts and feelings.

## Deciphering The Diagnosis

Chondrosarcoma. I didn't even know what language that was. I had to have the doctor spell it out for me twice and then repeat it so I could say it. Chondrosarcoma. And, as soon as I could say it I wanted to know everything I could about it. From what I've discovered mine was not only a normal reaction but a healthy one, and something I recommend for everyone.

When the doctor shares the diagnosis with you, he or she should describe it to you as fully as possible. But you are initially shocked, confused and overwhelmed. You may have a million thoughts racing through your head and will most likely need some time to digest your thoughts before you can concentrate on understanding and researching your illness and recommended treatments. As soon as you are able, you will want to learn as much as possible about the disease.

There will be a lot of new information for you to learn, some of it very complicated. Your medical team will explain your options and the current treatment protocols for your diagnosis. You will probably have many questions, and you may need the information explained to you several times before you have a clear understanding of the situation. Your doctor should explain your situation in detail and to your satisfaction. If need be, request that he or she slow down and repeat. You may want to record what the doctor says so that you can play it back at your leisure, and when your thoughts are clear, or so that you can share the information with others, without having to trust your memory. Even if time has passed since your doctor gave you the diagnosis, when you have more questions, call the doctor's office and request that your doctor go back over the information, share with you the latest information available on the disease, and answer all of your questions. You may also wish to ask your medical team for recommendations as to where best you might research the disease yourself. It is important to research on reputable websites and in reputable books and articles.

## The Search For Information

Medical information in books, in journals and online can be confusing, depressing, troubling, and even scary. The medical language can also be difficult to comprehend. It was terribly hard to learn of the high percentage of people who die within five years of being diagnosed with the same type of sarcoma that I had, but I learned

that this information often includes statistics that are outdated, and includes differing stages of disease.

When I told my family doctor, soon after my diagnosis, that I was researching Chondrosarcoma, {the tumor on a rib in my back}, he explained to me that my tumor was a stage 1 or 2, which is often successfully surgically removed. The type he thought would be discussed in books and online would be a stage 4 tumor, which is more serious. And he was exactly correct in predicting what I found. Thanks to his warning I was prepared for what I read. Remember to research armed with information from your doctor or health care professional. As you research, compile a list of questions for your medical team. Not all information online is reliable or applicable.

Due to your emotional state of mind at this time, and the amount of stress that you are experiencing, you may find it difficult to concentrate on your research. If that is the case, enlist a friend or family member to help you with this important task. Remember, unfamiliar medical terms may be confusing and the information that you find may be frightening, misleading, or inapplicable.

## Put Technology To Work For You

Education and information are critical in the war on cancer. The more knowledge you have the more empowered you will be to make important decisions. Technology allows us access to the latest information on many different forms of cancer, treatments, research in progress, recent studies, nutrition, clinical trials and support services. If you do not have a computer, you should be able to access the internet at a school, public library, or cancer center. Staff at those institutions will be available to assist you.

## Useful Websites

When I first was diagnosed with cancer, I immediately went online to learn as much as I could. I typed "chondrosarcoma" into a search engine and found a number of sites with information. I also searched general cancer sites for basic information about facing cancer. If you are not familiar with how to use the web ask for guidance at your public library, local college or university, or at your cancer center. Both here and on the UCF website, [www.ulmancancerfund.org](http://www.ulmancancerfund.org), you will find a list of useful and reliable sites.



It is imperative that you note questions that arise from your research, and have them answered by a medical professional.

## Websites

### {General Cancer - Medical & Treatment Information}

**The Ulman Cancer Fund for Young Adults {UCF}** changes lives by creating a community of support for young adults, and their loved ones, as they fight cancer and embrace survivorship. UCF Patient Navigators give cancer survivors one-on-one guidance in dealing with all aspects of their cancer journey.

410.964.0202 @UlmanCancerFnd [www.facebook.com/ulmancancerfund](http://www.facebook.com/ulmancancerfund)

[www.ulmancancerfund.org](http://www.ulmancancerfund.org)

**LIVESTRONG** provides physical, emotional and practical support to guide people through the cancer experience, brings them together to fight cancer—and works for a world in which the fight is no longer necessary.

855.220.7777 @LIVESTRONG [www.facebook.com/livestrong](http://www.facebook.com/livestrong)

[www.livestrong.org](http://www.livestrong.org)

**National Cancer Institute** is the U.S. government's principal agency responsible for conducting and supporting cancer research. Accurate, up-to-date, comprehensive cancer information is available on the NCI website as well as information about clinical trials. Written material about specific cancers and treatments will be sent to you upon request.

800.4.CANCER{226237} @theNCI [www.facebook.com/nationalcancerinstitute](http://www.facebook.com/nationalcancerinstitute)

[www.cancer.gov](http://www.cancer.gov)

**National Cancer Institute: Adolescents & Young Adults with Cancer Section** is a section of the National Cancer Institute that focuses exclusively on young adult cancer issues. Find young adult-specific resources for treatment information, coping and support, and education.

800.4.CANCER{226237} @theNCI [www.facebook.com/nationalcancerinstitute](http://www.facebook.com/nationalcancerinstitute)

[www.cancer.gov/cancertopics/aya](http://www.cancer.gov/cancertopics/aya)

**The American Cancer Society {ACS}** is a national, community-based organization dedicated to helping people faced with a cancer diagnosis. ACS supports research, patient services, early detection, treatment and education.

800.227.2345 @americancancer [www.facebook.com/AmericanCancerSociety](http://www.facebook.com/AmericanCancerSociety)

[www.cancer.org](http://www.cancer.org)

**CancerQuest** is a website of the Emory University Winship Cancer Institute that teaches the biology of cancer. It assumes no previous knowledge on the topic and can help to inform and empower anyone who visits the site.

404.727.0308 @CancerQuest [www.facebook.com/CancerQuest](http://www.facebook.com/CancerQuest)

[www.cancerquest.org](http://www.cancerquest.org)

**Oncolink** is a site of the University of Pennsylvania Cancer Center and aims to help the public and health care professionals get accurate cancer information. This is a great educational site for both patients and their families.

215.349.8895 @OncoLinkTeam [www.facebook.com/OncoLink](http://www.facebook.com/OncoLink)

[www.oncolink.org](http://www.oncolink.org)

**American Society of Clinical Oncology {ASCO}** is a comprehensive site with information on the medical, psychosocial, and practical aspects of cancer. Particular to young adults, there is information on returning to school after cancer treatment as well as information on reentering the job market.

888.651.3038 @CancerDotNet [www.facebook.com/CancerDotNet](http://www.facebook.com/CancerDotNet)

[www.Cancer.net](http://www.Cancer.net)

**LIVESTRONG Fertility** provides cancer patients with comprehensive information about fertility preservation, the effect of treatment options on fertility, referrals to fertility preservation specialists, can help you get the answers you need to make wise and educated treatment and fertility decisions, and can also supply information about grants to help defray the cost of sperm banking and egg harvesting before treatment.

855.220.7777

[www.livestrong.org/fertility](http://www.livestrong.org/fertility)

**MyOncofertility.org** is a resource for information about fertility preservation options and nationwide referrals for physicians who can talk to you about your fertility preservation options with regard to your cancer diagnosis and treatment options.

866.708.FERT{3378} @oncofertility  
[www.facebook.com/pages/Oncofertility-Consortium/274654090671](http://www.facebook.com/pages/Oncofertility-Consortium/274654090671)

[www.myoncofertility.org](http://www.myoncofertility.org)

**Oncofertility Consortium** is a national, interdisciplinary initiative designed to explore the reproductive future of cancer survivors and provides resources that will help you navigate the complex fertility issues facing patients with cancer.

@oncofertility  
<https://www.facebook.com/pages/Oncofertility-Consortium/274654090671>

<http://oncofertility.northwestern.edu>

**Clinical Trial Matching Service** powered by EmergingMed enables people with serious illness to research Clinical Trial treatment options.

877.601.8601 @emergingmed  
<https://www.facebook.com/pages/EmergingMed/156342877715723>

[www.emergingmed.com](http://www.emergingmed.com)

[www.cancercare.org](http://www.cancercare.org)

**Cancer Care** uses professional oncology social workers to provide telephone, online, and face-to-face counseling, support groups, cancer information, and financial and co-pay assistance to anyone affected by cancer.

800.813.HOPE @cancercare www.facebook.com/cancercare

#### {Matching with Survivors}

**Imerman Angels** matches people touched by cancer with those who have fought and survived the same type of cancer. Cancer caregivers {spouses, parents, children and other family and friends of fighters} also receive one-on-one connections with other caregivers and survivors. These one-on-one relationships inspire hope and offer the chance to ask personal questions and receive support from someone who is uniquely familiar with the experience.

[www.imermanangels.org](http://www.imermanangels.org)

877.274.5529 @ImermanAngels www.facebook.com/ImermanAngels

**The Cancer Hope Network** matches cancer patients or their family members with trained volunteers who have themselves undergone and recovered from similar cancer experiences.

[www.cancerhopenetwork.org](http://www.cancerhopenetwork.org)

800.552.4366 @CancerHopeNet www.facebook.com/CancerHopeNetwork

#### {Support Organizations}

**Cancer Support Community** {formerly The Wellness Community and Gilda's Club Worldwide} optimizes patient care by providing services including support groups, counseling, education and healthy lifestyle programs for people with cancer and their loved ones in a network of 150 local affiliates and online.

[www.cancersupportcommunity.org](http://www.cancersupportcommunity.org)

888.793.9355 @CancersupportCm  
www.facebook.com/CancerSupportCommunity

**The National Coalition for Cancer Survivorship {NCCS}** raises awareness of cancer survivorship and strives to eliminate the stigma of cancer by providing public policy leadership and advocacy. NCCS also produces publications on survivorship.

877.NCCS.YES {877.622.7937} @CancerAdvocacy  
www.facebook.com/CancerSurvivorship

[www.canceradvocacy.org](http://www.canceradvocacy.org)

**National Hospice and Palliative Care Organization** provides End of Life care and support to patients and families and is committed to expanding and improving such care.

703.837.1500 @NHPCO\_NEWS www.facebook.com/NHPCO

[www.nhpco.org](http://www.nhpco.org)

**Triage Cancer** {formerly Navigating Cancer Survivorship} is dedicated to helping survivors, caregivers, and health care professionals navigate cancer survivorship issues by connecting them to experts, information, and resources.

424.258.4NAV{4628} @TriageCancer www.facebook.com/TriageCancer

[www.triagecancer.org](http://www.triagecancer.org)

#### {Legal, Insurance & Financial Help}

**Cancer And Careers** offers everything you need to know about dealing with issues in the workplace while dealing with cancer. These issues include insurance, sick leave and disability. Career coaches are available to speak with. Cancer and Careers also has comprehensive health insurance information.

646.929.8023 @cancerandcareer www.facebook.com/CancerandCareers

[www.cancerandcareers.org](http://www.cancerandcareers.org)

**Cancer Legal Resource Center {CLRC}** is a joint program of Disability Rights Legal Center and Loyola Law School, Los Angeles. CLRC provides information and education about cancer-related legal issues to the public through its national telephone assistance line.

866.THE.CLRC {866.843.2572} @DisabilityRLC  
www.facebook.com/DisabilityRightsLegalCenter

[www.disabilityrightslegalcenter.org/cancer-legal-resource-center](http://www.disabilityrightslegalcenter.org/cancer-legal-resource-center)

**Coalition of Cancer Cooperative Groups** provides links to organizations that offer financial assistance such as co-pay relief programs and medication relief programs. This site also provides information on clinical trials.

877.227.8451

[www.cancertrialshelp.org](http://www.cancertrialshelp.org)

**HealthCare.Gov** is a government-run website that provides guidance and information on federal health care laws. It has specific sections for young adults and for people with pre-existing conditions.

[www.healthcare.gov](http://www.healthcare.gov)

[www.patientadvocate.org](http://www.patientadvocate.org)

**Patient Advocate Foundation {PAF}** is a direct patient services organization with a mission to eliminate obstacles for patients trying to access quality healthcare. PAF seeks to safeguard patients through effective mediation assuring access to care, maintenance of employment and preservation of their financial stability relative to their diagnosis of life threatening or debilitating diseases.

800.532.5274

**Rise Above It {RAI}** provides consultation and financial grants to individuals and families with immediate needs in their fight against cancer. Through financial assistance and personal attention, RAI strives to instill a positive attitude within its recipients, thus allowing them to live each day with faith and a fighting spirit.

@Rise\_Above\_It

[www.facebook.com/pages/Rise-Above-It-RAI/100733823354965](http://www.facebook.com/pages/Rise-Above-It-RAI/100733823354965)

[www.raibenefit.org](http://www.raibenefit.org)

**The SAMFund** Supports young adult cancer survivors in the United States as they recover from the financial impact of cancer treatment. Through direct financial assistance, in-person and online support, The SAMFund helps young adults move forward towards their personal, professional, and educational goals.

617.938.3484

@TheSAMFund [www.facebook.com/TheSAMFund?v=wall](http://www.facebook.com/TheSAMFund?v=wall)

[www.thesamfund.org](http://www.thesamfund.org)

#### {Young Adult and Diagnosis Sites}

**Association of Cancer Online Resources {ACOR}** is a unique collection of online cancer communities designed to connect people for information sharing and support. There are communities for many specific diagnoses and others for cancer-related issues.

212.226.5525

[www.acor.org](http://www.acor.org)

**Be The Match** connects patients with life-threatening blood cancers such as leukemia and lymphoma with their donor match for a life-saving marrow or umbilical cord blood transplant.

800.627.7692

@BeTheMatch

[www.facebook.com/BeTheMatch](http://www.facebook.com/BeTheMatch)

[www.bethematch.org](http://www.bethematch.org)

**Critical Mass - The Young Adult Cancer Alliance** {formerly LIVESTRONG Young Adult Alliance} is a coalition of non-profits, patient advocacy groups, clinical and research institutions, professional societies, government agencies and dedicated individuals with a shared vision of a world where young adults with cancer have no barriers to survive and thrive. Search the many resources for young adult cancer survivors represented in The Critical Mass member list.

512.553.3556

@heycriticalmass

[www.facebook.com/CriticalMass](http://www.facebook.com/CriticalMass)

[www.criticalmass.org](http://www.criticalmass.org)

**15-40 Connection** seeks to create awareness of the fact that cancer is the #1 disease-related cause of death for 15-40 year olds, and to promote early detection of cancer through advocacy and awareness.

508.869.5200

@1540Connection

[www.facebook.com/1540connection](http://www.facebook.com/1540connection)

[www.15-40.org](http://www.15-40.org)

**Stupid Cancer** empowers young adults affected by cancer by building community, improving quality of life and advocating for the young adult cancer population.

877.735.4673

@StupidCancer

[www.facebook.com/stupidcancer](http://www.facebook.com/stupidcancer)

[www.stupidcancer.org](http://www.stupidcancer.org)

**Tamika And Friends** is dedicated to supporting and informing those with cervical cancer and to raising awareness about cervical cancer and its link to HPV {human papillomavirus}.

866.595.2448

@tandherfrenz

[www.facebook.com/TamikaandFriends](http://www.facebook.com/TamikaandFriends)

[www.tamikaandfriends.org](http://www.tamikaandfriends.org)

**Young Survival Coalition {YSC}** is a global organization dedicated to the critical issues unique to young women diagnosed with breast cancer. YSC offers resources, connections and outreach so women feel supported, empowered and hopeful.

646.257.3000

@YSCBUZZ

[www.facebook.com/youngsurvivorcoalition](http://www.facebook.com/youngsurvivorcoalition)

[www.youngsurvival.org](http://www.youngsurvival.org)

#### {Personal Patient Websites}

**Caring Bridge** provides free, private websites where folks can connect, share news, and receive support during serious health events, care, and recovery.

651.452.7940

@CaringBridge

[www.facebook.com/CaringBridge](http://www.facebook.com/CaringBridge)

[www.caringbridge.org](http://www.caringbridge.org)

**My Life Line** enables cancer patients and caregivers to create free customized websites. MyLifeLine's mission is to empower patients to build an online support community of family and friends to foster connection, inspiration, and healing.

[www.MyLifeLine.org](http://www.MyLifeLine.org)

@MyLifeLineOrg      [www.facebook.com/MyLifeLine.orgCancerFoundation](http://www.facebook.com/MyLifeLine.orgCancerFoundation)

### {Young Adult Camps, Adventure & Wish Programs}

**Athletes 4 Cancer** harnesses the healing power of the elements with the determination of the human spirit to benefit lives affected by cancer. Their programs focus on renewing, rebuilding, and restarting lives after cancer through outdoor adventure.

[www.athletes4cancer.org](http://www.athletes4cancer.org)

415.617.5678      @athletes4cancer      [www.facebook.com/Athletes4Cancer](http://www.facebook.com/Athletes4Cancer)

**Camp Mak-A-Dream** located in Montana, Camp Mak-A-Dream offers cost-free programs throughout the year to children, teens, young adults and women with cancer, as well as programs for children who have a sibling or a parent with cancer.

[www.campdream.org](http://www.campdream.org)

406.549.5987      [www.facebook.com/pages/Camp-Mak-A-Dream/37094882711](http://www.facebook.com/pages/Camp-Mak-A-Dream/37094882711)

**First Descents** offers young adult cancer fighters and survivors a free outdoor adventure experience designed to empower them to climb, paddle and surf beyond their diagnosis, defy their cancer, reclaim their lives and connect with others doing the same.

[www.firstdescents.org](http://www.firstdescents.org)

303.945.2490      @FIRSTDESCENTS      [www.facebook.com/FDAventure](http://www.facebook.com/FDAventure)

**3 Little Birds 4 Life** grants wishes for current young adult cancer patients 18-40 years of age, provides resources for young adults with cancer to find help in all aspects of the cancer journey and raises awareness in communities that it is possible for young adults to be diagnosed with cancer.

[www.3LittleBirds4Life.org](http://www.3LittleBirds4Life.org)

618.977.0519      @3LittleBirds4L  
[www.facebook.com/pages/3-Little-Birds-4-Life/165418566886226](http://www.facebook.com/pages/3-Little-Birds-4-Life/165418566886226)

### Hospitals That Help

Many of the nation's leading cancer hospitals operate useful web sites. We list two of them here. The UCF web site provides links to many other helpful ones. Find them at [www.ulmancancerfund.org](http://www.ulmancancerfund.org). During your search for information and answers, pursue all possible sources and resources.

For more information contact us at:

The Ulman Cancer Fund For Young Adults

921 E. Fort Avenue • Suite 325

Baltimore, Maryland 21230

410.964.0202 or 888.393.fund {3863}

[info@ulmancancerfund.org](mailto:info@ulmancancerfund.org)

[www.ulmancancerfund.org](http://www.ulmancancerfund.org)

**The James Comprehensive Cancer Center** of The Ohio State University is one of the largest cancer and research centers and its web site gives clear and concise information on many types of cancer and treatment programs.

800-293-5066

@osuccc\_james

[www.facebook.com/OSUCCCJames](http://www.facebook.com/OSUCCCJames)

[jamesline@osumc.edu](mailto:jamesline@osumc.edu)

[www.cancer.osu.edu](http://www.cancer.osu.edu)

**University of Maryland Greenebaum Cancer Center** is home to the first Ulman Cancer Fund For Young Adults onsite Young Adult Patient Navigator Program.

800-888-8823

@umgcc

[www.facebook.com/UMGCC](http://www.facebook.com/UMGCC)

[www.umgcc.org](http://www.umgcc.org)

### What Other Resources Are Available?

There are also many resources available in print. At The National Cancer Institute, in addition to offering a toll free phone line professionally staffed by people trained to provide accurate personalized answers to your cancer related questions, they will send you free publications that they produce on a variety of cancer related topics. Call 800.4.CANCER {800.422.6237}.

In recent years, there also have been many books written about the psychosocial issues associated with young adult cancer. An online search will lead you to many of them and some of them are listed on the UCF website as well.

## **the folks in white coats**

Dealing With Health Care Practitioners

Making Medical Decisions

Fertility

Coping With Treatment

Surgery, Radiation, Chemotherapy and Other Treatments

# health care



There is no downside to a second opinion - you either get the reassurance that you are on the right path or you find that you need to do more research - and perhaps you need a third opinion.

## Dealing With Health Care Practitioners

You've just been told that you have cancer. You are hearing some of the most important information of your life, and you're hearing it from virtual strangers — doctors, nurses, and health care practitioners of all sorts — and you hardly know anything about them.

Who are these people? What is their experience with the illness they are diagnosing? How do you know whether to trust them?

Ideally, the health care practitioners you deal with will be bright, knowledgeable, intelligent, well trained, respectful, sensitive, patient, caring, honest, and positive. You deserve to be cared for by someone with all of those traits and abilities. And there are many who meet those criteria.

However, unfortunately there are also those who do not. Even as you are overwhelmed and confused, you must be vigilant in pursuing excellent care. Keep looking until you find it. You might have to shop around for your caregivers. Just as you would when purchasing something major like a computer or smartphone, do your homework. Ask your family doctor or people you know who have had cancer for recommendations. You can meet with doctors, ask them questions and see if they communicate well with you. Also, check out their background, education and training as well as their experience in their field. This is perhaps the most important consumer decision of your life. Even in your tenuous emotional state, it is imperative that you find someone who you are comfortable with. Find a doctor that is right for you! And remember that it is OK to change doctors at any time.

Once you have found practitioners to work with, you will want to build a partnership between those practitioners, your loved ones, and yourself. You are the most important person in this partnership, and as you develop this relationship, you must clearly make your needs known. The following is a list of suggestions of what you may expect from your medical teams and how to communicate with them:

- You owe it to yourself to find medical practitioners with whom you are comfortable.
- Expect to be treated with respect and honesty.
- Be proactive and expect your practitioners to acknowledge and appreciate that as part of your role.

- Expect your health care practitioners to maintain positive attitudes – mental outlook is contagious and can certainly impact your condition.
- Expect the folks in white coats to understand your emotional state in addition to your physical state. The physical and emotional are intertwined and you need to be treated as an entire human being.
- Do not accept arrogance, negativity, condescension, or intimidation.
- Communicate in a straightforward manner, and expect the same from your caregivers. {efforts to be tactful can sometimes confuse the issue}
- Clearly communicate to your health care practitioners that even though you are a young adult, you are the patient and you would like them to speak and be responsible directly to you. {Do not allow them to play you against your parents or visa versa}
- If you are hospitalized, you are entitled to humane treatment—the caregivers are there to serve your needs.
- If you are in a teaching hospital, you may choose to allow students on rounds in your room, or you may deny them that opportunity if it is intrusive or uncomfortable for you in any way, at any time.
- Keep a running list of concerns and questions.
- Ask questions until you fully understand the answers.
- Take notes or record discussions with medical team for later review.
- Keep a journal of each appointment or medical encounter, test, treatment, and medication. In addition to helping you keep track of your progress, this journal can be shared with new practitioners who might join your team, and they can easily be brought up-to-date. {See charts in “Some Record Keeping Help” section}
- Keep a journal of your feelings and thoughts as well.
- Expect everyone to keep an open mind about complementary therapies such as acupuncture, nutrition, vitamin therapy, music for relaxation during surgery or cancer treatments.
- Investigate and consider clinical trials.
- Develop a good system of phone or e-mail communication and timely responses from your caregivers.

*"Doug,  
I want to applaud the work that you are doing, especially among young people. You are an inspiration not only to those with cancer, but for those of us who treat them. I offer you any assistance I might be able to render, please feel free to ask... know that you are in my thoughts and prayers."*

Dr. Lou  
Jemez Springs, NM

*"I was diagnosed with chroidal melanoma of my right eye at 22 and lost the eye at 24.*

*I have been cancer free for 16 years and work as an RN. This is a great site to help me educate students about cancer. I wish something like this {UCF} was available 16 years ago. Keep up the good work."*

Candace  
Potomac, MD

*"My baby, Charlie Ann, is proof that anything is possible after cancer."*

Sylvia  
Severna Park, MD

## Making Medical Decisions

You are the most important person in this process. {I know that I have said this before, but it bears repeating} As you are confronted with a great deal of new information, and you realize that the disease you have could be life-threatening, you may feel totally out of control. It is important to realize that you control the decisions about your care and treatment plan. Your feelings, questions and needs are of primary concern. The members of your partnership must work together with the purpose of obtaining, maintaining and supporting the best possible health for you. Get as many opinions as you need and can afford. There is no downside to getting a second opinion. Either the second opinion agrees with the first, and you gain assurance that you are on the correct path, or the opinions differ and you then pursue more opinions to learn more or gain consensus. Some second opinions involve seeing the second doctor and in other cases, sending records to the doctor and speaking by phone will suffice. Many people worry that they will offend their medical team if they want to get other opinions. That should never be your concern. Your focus should be on finding the best treatment plan to get you the best results. I have found that doctors are usually very comfortable with their patients seeking other opinions, and often they want to consult with other doctors as well.

## Fertility

As you discuss your treatment plan with your medical team it is critical that you address the issue of fertility preservation. Fertility can be affected by the type of cancer you are dealing with or by the required life saving cancer treatment. Facing the possibility of infertility either because of the cancer treatment or because of the location of the cancer, can be scary and overwhelming on top of the shock of the cancer diagnosis. Each disease, patient and situation is unique. It is imperative that you ask questions of your medical practitioners to learn about your treatment options and determine if and how they will affect your fertility and sexuality. For comprehensive information about fertility options please visit **LIVESTRONG** Fertility online at [www.livestrongfertility.org](http://www.livestrongfertility.org). You can also obtain fertility information by calling 855.220.7777 and speaking with a **LIVESTRONG** cancer patient navigator. Another fertility website is [MyOncofertility.org](http://MyOncofertility.org), a program of Oncofertility Consortium, Northwestern University. These resources will help you get the answers you need to make wise and educated treatment and fertility decisions. There are also

fertility preservation specialists to whom you can be referred by your medical team and/or Fertile Hope or [MyOncofertility.org](http://MyOncofertility.org). Find out what your fertility preservation options will be before, during or after treatment. Learn about harvesting egg or saving sperm before treatments begin. It is best to make decisions on fertility preservation prior to the start of treatment if at all feasible and often there is a small window of time for these discussions and preservation procedures to be accomplished. Some fertility preservation options are costly and few are covered by health insurance carriers at this time. However, there are financial assistance programs available for those who qualify. Although this topic can be difficult to deal with, there is often hope that the ability to reproduce after cancer treatment can be possible.

## Coping With Treatment...Surgery, Radiation, Chemotherapy and Other Treatments

Once you have been given a cancer diagnosis, a treatment plan will be developed by you and your medical team. A number of different treatments may be used to help control, combat, or cure the cancer. Sometimes these treatments are used alone and sometimes they are best used in combination with one another. Surgery and radiation therapy work on specific parts of the body, while chemotherapy and biological or immunotherapy work throughout the entire body. It is vital that you understand your options. Once again, communication is the important key word. Ask questions so that you fully understand what choices you have, and what to expect before, during and after your treatment.

Some of the questions that you may want to ask your treatment team:

- What do you hope to accomplish with this treatment?
- What are the chances that the treatment will work?
- Are there other ways to achieve the same goal? Do these options have reduced side effects?
- Will my treatment present a risk to my fertility?
- How can I harvest eggs or save sperm before I begin treatment?
- What side effects might occur?
- Will the treatment cause pain?
- Will I need anesthesia?
- How can I expect to feel during and after the treatment?

The treatment process is one of the most challenging aspects of surviving cancer, and perhaps one of the greatest challenges of your life.

How do you prepare for this challenge?

How have you prepared for other challenges?

How is this different?

Your doctors or medical professionals will prepare you physically for the surgery but often they do not help you prepare emotionally or mentally.

I spent the time before my surgery meditating, contemplating and thinking positive thoughts.

- Will I be able to function normally during my treatment?
- Will I be able to work during my treatment?
- Will my appearance change because of the treatment?
- How and where will the treatment be administered?
- Will I need help getting home from treatment?
- What will my treatment schedule be?
- Will my treatment cause scars or skin burns?
- If the treatment is surgery, how extensive will it be and how long will the surgery last?
- What will my recovery period be?
- When can I exercise again?
- Will there be long-term physical side effects?
- How costly is the treatment and is the treatment covered by my insurance plan?

There are many tips that can help you through your treatment. Understand that on-going emotional support is extremely helpful and important as you embark on your treatment program. Try to connect with other cancer survivors, join a support group or engage in counseling before, during and after the treatment process. Very intense relationships sometimes develop between individuals and their nurses, technicians and doctors during treatment, and there can be a feeling of emotional abandonment when the treatment ends thereby ending those relationships. On-going support mechanisms can help to fill that void.

Everyone handles treatment differently, both physically and emotionally. Some people find that the foods that appeal to them during treatment are quite different than the foods that they normally eat. In addition, some people use yoga, meditation, reading, relaxation tapes, journaling, exercise or any number of other modes to help them cope. You will find what works best for you.

Acknowledge your feelings, whatever they are. It can be very helpful to find a safe place to express them. That could include but is certainly not limited to a professional counselor, clergy, friend or family member, cancer survivor support group or medical practitioner.

It is imperative throughout the treatment process that you immediately inform your medical team of any changes in how you are feeling, mentally and physically. Those changes could indicate a need to adjust your medication or treatment plan, and doctors might be able to add medications or suggest ways to combat any adverse effects you may be having.

### Surgery

Surgeries to remove malignant tumors are the most invasive of the cancer treatments. Many cancer surgeries involve removing not only the cancer, but also a portion of tissue surrounding the malignancy to try to assure that all of the cancer cells are removed. Side effects of surgery can include discomfort and pain which can most often be controlled by medication from your doctor. Surgical side effects will depend on how extensive the surgery is, where in the body the tumor is and what surgical techniques are used. Whether or not they involve general or local anesthesia, surgeries can be an assault on the body. Give yourself plenty of time to recuperate. It is helpful to become fully aware of what to expect before you have surgery. Find out how extensive the surgery will be, about how long the procedure should take and what the recovery process will be like. Ask your medical team if physical therapy would help your recuperation and if so ask for a referral. Also, you may want to ask for recommendations for products to diminish the rigidity and appearance of any scars.

What has to be remembered with cancer treatments, no matter how bad it gets, is that you are preserving your life.

So during treatment it may help to imagine what you would rather be doing, and then plan to do it.

Go ahead and write down some of your plans for when you are finished with treatments.

What brings you pleasure?

Who do you enjoy being with?

And what do you plan to do when your treatments are completed and you are feeling better?

Not only can treatment impose upon your body but it also imposes on your time and activities. It may become very difficult to resume any normal activities and schedules during this time.

But what would you like to do?

Would you want to continue with work or school?

Would you rather be free during the whole time?

Put together a plan during your treatments, because whatever you decide is best for you will be what's best for you.

## Radiation

There are a number of different types of radiation treatments, and procedures differ from hospital to hospital. But the essence is that radiation kills multiplying cells. The most common type of radiation treatment is beam radiation. In addition, gamma knife radiation and cyber knife radiation are recommended for specific types of tumors. If your treatment plan includes radiation, it is important to know what will be required of you, how many treatments you will have, and what your schedule will be. Talk to your radiologist about setting a schedule that works for you. Many people are able to continue working while they are having radiation treatments, although some feel less energetic than they did before the radiation began. You may want to ask your medical team about the best way to protect your skin from radiation "rash" or burning during your treatment.

## Chemotherapy

Chemotherapy treatment is the use of strong medications to treat cancer. By putting these drugs into the body, doctors attempt to kill the malignant cells that multiply. Chemotherapy, which is used to either keep a cancer from spreading, shrink a tumor, slow the growth of cancer, kill off cancer cells that may be left after other treatments are completed, or cure cancer, can be used alone or in conjunction with other treatments. In addition to killing cancer cells, some chemotherapy drugs can also kill healthy cells that multiply, such as gastric cells or hair follicles. Because of this, some people experience hair loss. Before you start treatment, you might want to buy a hat or two that appeal to you so that you will have them on hand if you need or want to cover your head. Some people find that taking control by cutting short or shaving their hair is a good idea to help avoid any depression that may be brought on by losing hair gradually or in clumps. You may also wish to purchase a wig to wear until your hair grows back. Your medical team can direct you to shops that cater to oncology patients. Some insurance plans cover the cost of wigs and your medical team may also have information about organizations that help defer the cost of wigs.

Chemotherapy treatment can have short term and long lasting effects on the body. Some of those effects may include mouth sores, nausea, vomiting, fatigue and foggy thinking. There are medications that can help manage some of those conditions. Some folks find that wearing acupuncture wrist bands helps ward off nausea. It is important to investigate possible effects and make treatment decisions based on information learned.

There are many different types of chemotherapy and each drug is given in different doses and in different ways. Ask your medical oncologist exactly what you will be taking and how it will be administered. Some treatments require hospitalization. Others can be administered in an outpatient clinic while still others are taken at home. It is a good idea to keep records of the medications and dosages that are given to you. Depending on how your chemotherapy is given and how it affects you, you may be able to continue normal activities or some activities during your treatment.

## Other Treatments

There are other treatments that are recommended under certain circumstances such as Bone Marrow Transplants of different types and Immunotherapy. Your medical team will inform you if other treatments are appropriate for you and should educate you about the processes and the possible effects.

What choices do you have?

Remember, wherever you are in the process, you have choices.



**record keeping help**

Chronological Chart

Medical Records

Financial Records

Provider Information

# records



It is very important and very helpful to keep good medical and financial records. These records will be invaluable to you and to all the doctors you see, as you progress through your treatment. A binder or an accordion folder can be useful for keeping everything together. **LIVESTRONG** has developed a record keeping tool, the **LIVESTRONG** Guidebook, that can be ordered, free of charge at [www.livestrong.org](http://www.livestrong.org).

### Keep A Chronological Chart

- List all doctor visits, tests, biopsies, CT scans, treatments, MRIs, X-rays and blood work.
- Include date and any discussion notes.
- Update weekly and add in results as you receive them.

{Medical practitioners will be able to quickly become familiar with your case by reading your chronological chart}.

\* Photocopy this chart as needed.

Date	Doctor/Facility	Purpose of Visit	Tests	Notes

### Obtain And Keep A File Of All Medical Records

- Request duplicate copies of your tests and records, from each doctor and lab, for your own file.
- Include all records, tests and test results, pathology reports, and scans. Let the provider's office know in advance that you want these records.
- Each new medical provider will want to see all of your results and records, etc. This will be extremely helpful and time saving. If you don't carry the records with you, you will have to have these records sent from office to office.
- Be aware that you must sign a release each time documents are sent from one location to another. It is a good idea to have extra copies of release forms along with the phone and fax numbers of the records department of each facility you visit.

This may sound like a lot of work, but in the long run it will make your treatment go more smoothly. There will be fewer delays if you hand carry your records.

\* Photocopy this chart as needed.

### Medical Providers/Facilities

Doctor/Facility	Phone	Email	Address





## reactions and actions

In The Beginning

Focusing Your Emotions

Writing For Health

There Are Many Ways To Cope

Mind Body Connection

Exercise

Survivorship

Facing The End Of Life

How People Can Help

There Is Help

# reactions



### In The Beginning

From the day I was told that I needed a CT scan, through surgery and diagnosis, and for a long time after, I was on a virtual roller coaster. The enormous range of emotions was overwhelming and forever changing. I moved from shock to disbelief, to anger, pain, denial, optimism, confusion, fear, hopefulness, hopelessness, loneliness or depression in any given moment. It was so unpredictable. Anything could trigger a stirring of tears or a wave of anxiety. It could hit as I walked across campus, as I talked to friends, at a party, at work, in the grocery store, as I laid in bed: anywhere, any time. I would try to go about my normal activities, but I wasn't normal anymore, my life wasn't normal any more.

I knew that I had to talk to someone other than my family and friends. I needed to talk to somebody who could fully understand about the roller coaster ride that was disrupting my life.

### Focusing Your Emotions

I spoke with a family counselor who gave me a safe place in which to air my feelings and offered professional guidance. My mother tried to locate a support program for people my age who were affected by cancer. There was none to be found. She was told that I couldn't be placed with the pediatric patients, and that my issues were very different from the general adult population. I continued counseling on a one-on-one basis.

Counseling helped me focus. I learned there is always hope—no matter what the situation. I could not stay in the “why me” phase. I decided that I had to concentrate on hope. Although I continued to deal with the myriad of emotions, hope allowed me to battle all of the negative feelings as they came, and helped me strive for my recovery and survival.

I searched for someone who had been through what I was going through. About ten months after my first surgery I met a guy who had had the same surgery that I had. We talked for an hour on the phone, and then planned to meet for lunch and a game of golf. We had an instant bond. Talking to him was the single most helpful form of support that I found anywhere.

### Writing For Health

There's not always someone to talk to, and sometimes you may benefit by expressing your feelings in some other form. I recommend keeping a journal throughout your experience.

Each moment is unique. At any given moment you are prone to thoughts and feelings unlike those at any other time. Writing can be a helpful and healthy way to express your feelings and it may help you to acknowledge and deal with your emotions. You may want to use the open space in this booklet to note your changing emotions. As you read through the book, or take it to doctor appointments, try recording your thoughts. If more space is needed, get a notepad or writing journal to accompany this book.

We've also placed comments in the margins of the book to help you think about some of the issues you will encounter as you go through this process. These comments are to provoke thinking and feeling in preparation for some of the topics you might face. I hope that by answering them now or in moments of peace and contemplation, you will find that you have more strength to deal with those issues as they become real. You may prefer to record your thoughts using a smart phone, etc.

### There Are Many Ways To Cope

I discovered many different methods to deal with emotional stress. Each of these approaches can work for different people or for different situations. I tried any number of complimentary therapies, and suggest that you explore the options listed below. There are books, DVDs, and CDs available in local libraries or cancer centers to help you learn about a wide range of support mechanisms and coping skills. Some that I tried are:

- Meditation
- Relaxation Exercises
- Deep Breathing
- Visualization
- Prayer

### Dealing with emotions

In order to cope with the loss of control over my life and my changing moods I learned to take things one hour at a time.

I tried not to look too far ahead.

- Optimum Nutrition
- Support Groups
- Exercise {if possible}
- Professional Counseling
- Play Acting
- Painting / Drawing
- Watching Movies / TV
- Reading
- Visiting
- Talking - Hopefully to Someone With the Same Problem - But Talking To Someone
- Music

Remember to explore these options at your own pace despite what friends and family suggest. It's most important that you are comfortable with the decisions you make.

### Mind Body Connection

Being faced with a life-threatening illness forces you to grow up fast. It was important for me to allow myself to feel whatever feelings I had. I learned with some success to find a place in the back of my mind for the fear, the worry, the pain, and the upset, so that I could attempt to function in the anonymous world that had no idea what I was going through. I also reached a phase where I wanted to read as much as I could about the emotional side of cancer and the mind body connection as it relates to illness. I learned it was crucial that I air my concerns rather than holding them inside, as was my habit to do. My emotional growth was enormous as I traveled this path of uncertainty. I hope that what I have related about my journey will help ease your way.

### Exercise

Exercise can be important to both physical and mental well being before, during and after treatment. Many studies show that exercise can speed recovery after surgery and treatment as well. It can also counter feelings of depression or sadness. Please make sure you check with your medical team before you start exercising. Some medications can cause dizziness and might preclude certain activities, and some surgical procedures might dictate what movements should or shouldn't be started. It is a good idea to start slowly as you begin to get active again. You can even start while you are in bed, with basic breathing techniques and isometrics. Walking and simple Yoga positions will get you moving when you are up and about a bit. While exercise is important and productive, remember that rest is also very important and it is crucial to strike a balance between the two. Do what you can and listen to your body.

### Survivorship

Life never seemed so precious as it did when I was in the throws of my diagnosis. And never did a problem seem so overwhelming. But the thing that kept me going and that I believe resonates in the human spirit is the ability to hope. As I stated earlier, through counseling I came to focus on hope. This propelled me to want to get better and to do something about my situation. I focused my energy where it could best be of help and I hope that you can do the same.

I have continued to seek counseling "as needed" and I have attended support groups for young adults affected by cancer. Those groups continue to offer the appropriate venue in which all the issues that come up because of the cancer can be addressed. Reentering daily life as a cancer survivor and finding normalcy in my life again has been important and sometimes difficult. I want to and need to move on in many ways and yet being a cancer survivor is a huge part of who I am now. Finding a balance, like in all aspects of life, is crucial.

*"Doug, I joined your Columbia, MD support group in February, 1999. This was about a month after I was diagnosed with thyroid cancer. When I first found out I had cancer I was a mixture of really violent emotions, none of them productive. This group has been a key factor in helping me come to grips with being sick. The people involved are amazing human beings. The strength all of them exhibit is inspirational. They have helped me get involved with activities like Relay for Life and Camp Sunrise. Having such a strong and understanding group of supporters has enabled me to work to make a difference in the lives of other people suffering from cancer. I do not think I would have made it through this whole experience as well as I did had it not been for my friends from the Ulman Group."*

Becca  
Columbia, MD

The Ulman Cancer Fund For Young Adults, along with the National Action Plan on Cancer Survivorship, defines “cancer survivor” as anyone who is living with, through, and beyond cancer, referring to those who are diagnosed and those who are affected by that diagnosis including loved ones and caregivers. You are a survivor from the moment of diagnosis – when someone tells you – “you have cancer” – through treatment and for the rest of your life.

There was a time when curing and or treating the cancer was the sole focus of the patient and the medical team. As research has progressed and there are many treatments that are often very successful in managing and controlling cancers, there is a new focus on survivorship and quality of life throughout the entire process.

There are long term issues and side effects, both physical and psycho-social to be aware of. Many medical practitioners discharge their patients without addressing the long term effects of cancer. It is important to ask many questions of your health-care team.

- What should I expect in 5, 10 and 15 years?
- What secondary cancers and other medical problems should I watch for?
- When and how often should I be examined?
- Will I experience ongoing fatigue, pain, infertility, sexual dysfunction?
- Will I experience depression?
- Please give me a referral for mental health support?
- What resources are available to help me deal with these issues?
- Could my treatment have long term effects on my cognitive abilities?
- Who will follow me for long term care?
- What information should I be supplied?
- What are the treatments that I had, medications that I took?
- What are the long term effects of different medications and treatment plans?

{This information should be supplied before treatment decisions are made.}

- How do I deal with the fear of recurrence?
- Will I be able to be insured?

- How do I re-enter my former life?
- Will I face job discrimination?

The support services of The Ulman Cancer Fund For Young Adults may be helpful as people face survivorship. {[www.ulmancancerfund.org](http://www.ulmancancerfund.org)} Also, for more information on survivorship, check out **LIVESTRONG** at [www.livestrong.org](http://www.livestrong.org).

More attention is being given to these issues as more people are living long beyond their diagnosis. Long term clinics are being established at cancer centers. Public health policy makers are recognizing the importance of raising awareness of the issues faced by cancer survivors and finding new and better ways to speak to their needs.

### Facing The End Of Life

Each of us has a grant of time. Of course we don't have any way to predict how long our grant of time will be. Each of us eventually will face our end of life. When death approaches, whether due to cancer or other causes, we have choices.

*Choices about care*

*Choices about approach*

*Choices about attitude*

*Choices about dealing with relationships*

*Choices about pain control*

What gives you hope?

It could be something tangible like a friend or relative who survived cancer, or it could be something as abstract as a sunrise.

There are times when all available medications, treatments, trials, and options have been exhausted and it becomes clear that the cancer is not to be cured or held in check. After thoughtful consultations with the medical professionals each survivor dealing with the reality of the impending end of life will make extremely difficult decisions. It is very hard to balance the need for quantity of time and quality of time. Should one keep trying to beat the cancer or acknowledge that there are no more options and begin to plan for death? Some survivors choose palliative therapy to keep the cancer at bay for a short time. Others choose to discontinue treatment and use medication to control pain to be as comfortable as possible. There are no right or wrong decisions. Each person weighs their options and comes to the best answer for their particular set of circumstances.

Professional help is available for people facing end of life and many folks find it helpful to talk about their feelings. Often modes of relaxation, yoga, or visualization are found to be useful. There are trained mental health professionals as well as hospice personnel available to assist in facing these tremendous challenges. National Hospice and Palliative Care Organization can be reached at [www.nhpco.org](http://www.nhpco.org) or 800.658.8898 for support and care.

If time allows, there are things that some people choose to do to prepare themselves and their loved ones for their end of life. Some spend time doing things that they have always wanted to try; something new and perhaps lasting like ceramics, painting, scrapbooking, visiting a place they have wanted to see, planning or planting a garden, writing, or knitting. Many want to spend as much time as possible with loved ones. Some people choose to give gifts of their special possessions, or establish a special scholarship or memorial fund. Some want to be as physically active as they possibly can. Some choose to write to loved ones or prepare gifts for loved ones to receive from them after they have died. Some people may want to be more solitary.

There are also practical decisions that some people like to make for themselves.

- Some may want "Do Not Resuscitate" or DNR directives.
- Some may want to arrange to donate organs.
- Some may need to have a will drafted.
- Some may want a living will drafted.
- Some may want to discuss burial desires and funeral arrangements.
- Some may want to plan to die at home while others would prefer to be in a facility.

Caregivers and loved ones may also need professional help to assist them in helping their loved one through this time and to help them deal with their own feelings.

### How People Can Help

Often, people want to help those dealing with end of life, but they do not know what kind of help to offer. Here are some ideas you may want to pass on to those people.

- Speak to me about your feelings.
- Send me a note {please - not a get well card}.
- Email me, text me, just stay in touch! - If I can respond I will.
- Cry with me or just let me cry.
- Laugh with me too.
- Spend time with me.
- Remember that I might still want to do fun things and have light conversation.
- Let me talk if I want to and let me be quiet if I choose.
- Offer my caregivers a break so that they can get some much needed rest.
- Keep visiting.
- Ask me what I need.
- Bring music, movies, games or anything to relieve the tension.
- Avoid cliches and don't pretend that everything is ok.
- Be present with me.

- Perhaps you can help me complete some unfinished tasks.
- Assure me that you will take care of things for me.
- Hold my hand.
- Let's share memories.
- Let's hold on to hope - hope for peaceful and pain free end of life.

### There Is Help

Considered to be the model for quality compassionate care at the end of life, hospice care involves a team-oriented approach of expert medical care, pain management, and emotional and spiritual support expressly tailored to the patient's wishes. Emotional support also is extended to the family and loved ones. Generally, this care is provided in the patient's home or in a homelike setting operated by a hospice program.

In recent years, many hospice care programs added "palliative care" to their names to reflect the range of care and services they provide – as hospice care and palliative care share the same core values and philosophies. Defined by the World Health Organization in 1990, palliative care seeks to address not only physical pain, but also emotional, social, and spiritual pain to achieve the "best possible quality of life for patients and their families." Palliative care extends the principles of hospice care to a broader population that could benefit from receiving this type of care earlier in their illness or disease process.

To better serve individuals who have advanced illness or are terminally ill and their families, many hospice programs encourage access to care earlier in the illness or disease process. Health care professionals who specialize in hospice and palliative care work closely with staff and volunteers to address all of the symptoms of illness, with the aim of promoting comfort and dignity.

## **the people and issues in my life**

Issues Specific To Young Adults

Parents

Spouses

Significant Others

Siblings

Young Adults As Family & Friends

Friends, Co-Workers & Relationships

How People Can Help

# my voice



*"If there is anything I can share from my experience it is that it is okay! There is no script for how to lose a parent to cancer. I learned that it's okay to cry as hard as you want, for as long as you want. It's okay to not want to talk about it, or to talk about it for hours. It's okay to break something. It's okay to keep something of theirs that's special to you, I recommend it. It's okay to laugh and smile when you think of how it used to be. It's okay to get angry they're not here. They're your parent, they created you and they would want nothing more. I can't give you a script but I can promise you of all things - it's going to be okay."*

Brock Yetso,  
President & CEO  
Ulman Cancer Fund for  
Young Adults

## Issues Specific To Young Adults

While many people are diagnosed with cancer, Young Adults with cancer face very different issues from the general adult population and from pediatric cancer patients. They are at a time in their lives when they are mapping out careers, relationships and future plans. They are becoming independent and self sufficient. A major life threatening illness can turn their lives upside down. Below is a list of some of the difficult issues faced by Young Adults affected by cancer:

- Independence vs. dependence
- Living near family support vs. living near peer support
- Inexperience at making major medical decisions
- Inexperience at managing medical treatment
- Dealing with medical professionals
- Maintaining some semblance of "normalcy"
- Health insurance, life insurance and financial issues
- Job security / career planning
- Nutrition and meal preparation
- Fertility
- Dating
- Intimacy
- Relationships
- To tell or not to tell
- Long term physical and emotional ramifications

For more information on these issues read "A Parent's Perspective" on page 58.

## The People In My Life

It is said that when someone in the family has cancer, the entire family has cancer. Certainly a cancer diagnosis has a tremendous impact on everyone close to the patient. Each person deals with his or her own upheaval, fears, and emotions. The immediate and primary concern of everyone involved, however, must be the well being of the person with the illness. It is imperative that everyone pull together, support one another, communicate well, put any petty differences aside and cater to the emotional needs of the patient.

While the entire family probably feels vulnerable, it is important that each member think positively and offer love, hope, and support if possible. After the shock, research, decision-making process, and development of a treatment plan, there will be time to deal with the emotional needs of the family members and friends, but for a while, the needs of the person with cancer are paramount.

A young adult with cancer may feel isolated and unable to share feelings. Opening up to family and friends can be crucial to recovery. In order for others to provide you the much needed love and support, they need to be able to understand you, so it is important to try to communicate your feelings and thoughts.

## Parents

Young adults facing cancer often find themselves in an awkward position. They may feel great tension as they are caught in a situation of needing to rely on the help and expertise of their parents at a time in their lives when they would otherwise be reaching toward much greater independence from their parents. It is extremely useful for parents and child to talk openly in order to strike a respectful balance of power.

In most cases young adults are capable enough to make their medical decisions, however, it is wise and helpful for them to include their parents and/or others in the process. Parents often have a great deal of experience in managing health care, and can be of enormous help in navigating the maze of information and decisions that need to be dealt with. Open, honest, positive, realistic, and hopeful discussion is very important. Because the young adult has just recently come of age and has been under their parents' care for so long, it is not unusual for a parent to tend to want to

What do you want to express to your parents or guardians? How are their actions helping you or hindering you?

Would you like to ask them for more help, or more independence?

make the decisions for their child, and to protect him. Parent and child must talk openly. Help in research, keeping records, taking notes, making medicine charts and food preparation are generally appreciated and can alleviate some of the stress that the young adult is under. In addition, every person dealing with major illness, regardless of their age, needs an advocate, a buffer and a person to field questions from the many people who call expressing care and concern. Anyone close to the situation can serve in these important and useful ways. Young adults should be encouraged to express their needs and desires to those around them and let people know what they find helpful and what boundaries they want to set.

There are several websites that allow folks to post about their illness so that friends and family can follow the journey easily and you can avoid the many calls and conversations that you might not be able to handle. Check out [caringbridge.org](http://caringbridge.org) and [mylifeline.org](http://mylifeline.org)

As difficult as it may seem, try to remember humor; not to cover over feelings but to lighten the mood that prevails, and relieve the tension that everyone is living with. Intersperse the more serious conversations with lighter, more normal discussions so that the illness is not the only topic of conversation. Mostly express love often and openly.

### Spouses And Significant Others

You are working through your own concerns and needs. You are also very concerned about your loved ones. Spouses and significant others, much like parents, become caregivers, emotional supporters, advocates, and confidants for their loved ones facing cancer. Because they too are young adults, who often have not yet had to deal with or manage life threatening illness it is extremely challenging and difficult. Their personal fears have to be put aside as they help their loved one, but it is vital that they find an outlet for their own emotions. Help is available from other family members, medical practitioners, friends, caregiver support programs, or professional counselors.

#### Concerns:

- What will the future bring?
- Will I be widowed?
- Will we be able to have children?
- How will we make it financially?
- Will I be able to keep working?
- How can I help the children?

There are often concerns weighing on patients and their loved ones pertaining to the practicalities of daily life. Hospital social service departments, health departments, and advocacy groups can give assistance in these areas. Family and friends often want to help and do not know how. Ask them to help in specific ways, as in child care, meal preparation, respite relief, running errands, transportation to treatments or loans.

### Siblings

The patient who has siblings is extremely fortunate. These family members are privy to all that is going on. Being that they are also young adults, or close to it, they can more easily relate to the stresses, fears, and concerns that the young adult with cancer might be facing. Siblings play a very important role in the support process. Hopefully they are in close proximity or can communicate regularly, and can let the patient know that they are available for counsel. Siblings also must find a way to face their own feelings. Watching a brother or sister struggle with a life-threatening disease makes one face his or her own mortality. In addition, the realization that their sibling may not always be around for them can be very frightening. And while the family's focus is on the sick sibling, the others have less attention from their parents and may need to fend for themselves much more than usual. All of this upheaval can be difficult and stressful. It is imperative that family members create a support system for themselves. That support system could be a close friend, a support group, or a professional counselor.

### Young Adults As Family And Friends

Young adults who are family members or friends of cancer patients have another group of concerns to address. If they do not live near by, they often feel disconnected from the situation. They may feel responsible for helping with the care of a parent, friend, or sibling, and may feel guilty if distance precludes their involvement. It can be frightening to hear of the illness and not be able to see for one's self what is actually going on. In addition, as much as friends may try to understand what the patient is feeling and dealing with, they just can't possibly know. It is most difficult to watch this process, want to help, and yet, feel helpless. It is important to let the patient know that you are there for them, want to help them, and do not want to intrude on their privacy. Talking openly and honestly once again can help everyone involved.

*"Doug,  
I think your site is very helpful, and I think what you are doing is great. My brother was just diagnosed with cancer, and he as well as our family is trying to cope and get through the treatment process. As family, it's hard trying to stay positive all the time...your advice has been helpful. I think it would be great if my brother could get in touch with you- and talk to someone who has been there before. Thanks again for your helpful site."*

Nicole  
Denver, CO

In what instances do you tell someone that you have cancer?

How do you go about doing that?

Practice how you would want that conversation to go, and let yourself open up to some of the emotions you feel.

If you get asked often about your situation, how do you respond?

Can you come up with a standard answer that will help you get by?

## Friends, Co-Workers And Relationships

How wonderful and helpful it is to have close friends to lean on when dealing with cancer. It is, however, often necessary to put them at ease, as they might be inexperienced in dealing with a young person with a serious illness. Let them know that they can speak openly about your disease, and that you would rather they be direct with you than whisper to others.

Tell them that you are the same person that you always were and at the same time you are very different. You still need to laugh and relax. You can't focus on cancer all the time. But you have a very different perspective on life. Small inconsequential things don't matter so much any more, and life isn't as carefree as it was. Your moods can change without notice. You might be difficult to be around at times. Communicate your appreciation of their support. Acknowledge that it is hard to be a close friend to you right now.

My roommate, Andy, had an extremely challenging task in living with me right after I was told I had cancer. My moods and emotions changed from moment to moment. Sometimes I was withdrawn and quiet. He often found himself trying to anticipate my frame of mind. I hope he and all my friends know how much I appreciate their patience with me.

Co-workers can be a tremendous source of support. In addition to moral support, they can perhaps fill in the gap at work, helping to take over some of your duties while you are ill and not able to work. This can relieve a great deal of stress as you recuperate. Keeping a job while dealing with life threatening illness is a major concern.

For those looking to find new employment, there are so many issues to deal with. In addition to the normal stresses of job-hunting, there are questions of disclosure. Do I tell a prospective employer about my illness? How much detail do I give? Will my health history strongly influence my chances of being hired or how I am treated?

Am I eligible for insurance coverage at a new job? There are job counselors who could help answer some of these questions, and there are laws concerning discrimination.

Keeping a job can also be a concern as you deal with treatment. Days missed and sick leave, unpredictable side effects, job pressure, and deadlines can all be causes of enormous stress. Counseling is vital to helping you get through these difficult issues. Maintaining a positive perspective and putting energy into recuperating are the highest priorities. Don't try to go it alone. Others are dealing with the same challenges, and can help you find ways to cope with the emotional and practical aspects of balancing illness and employment.

Developing new relationships is an additional challenge. At what point do you tell new friends about your illness. When dating or in a romantic relationship how and when do you broach the subject? Will the illness or fear of recurrence or fear of infertility scare people away from a serious relationship? Will a physical relationship prove difficult? Will I feel well enough for a physical relationship and will I be self conscious about scars or disfigurement? Talking with other young people with cancer, or a professional counselor, may be helpful in determining what is best for you.

*"Doug, You are an inspiration to young adults with cancer, and the website is a great resource for sharing and inspiration. We are not alone. The similarity between our stories is amazing. I was 28 when diagnosed with a chondrosarcoma in January of 1998. I too excelled at soccer. I captained my high school team and was a member of Bowling Green State University's team in 1988. Shortly after surgery, my wife and I were blessed with a beautiful baby girl. Keep up the good work!"*

David  
Cleveland, OH

## How People Can Help

Talking about what you are facing is always helpful, and ignoring your feelings is almost always not. Find someone to talk to: a parent, a sibling, a friend, and let them help. Let your friends and loved ones know how they can make things easier for you. Here are some things you might want to tell them:

- I'm still the same person – just going through a very rough time.
- Let me know you're there for me.
- Feel free to tell me how you are feeling and I'll do the same.
- Remember, this is new for all of us.
- Speak directly to me rather than to others about me.
- Please keep calling – I'll let you know if I'm too tired to talk.
- Keep stopping by like you always have.
- Send me a card, note, email or text.
- Bring me a favorite snack.
- Bring a movie for us to watch.
- Make calls for me.
- Know that I want to keep humor in my life.
- Let me take the lead in discussing the medical details.
- You can't say "the wrong thing" – what ever you say or feel is OK.
- Please keep in touch.

You might want to add your own suggestions in this margin. Then copy this page to hand out to your family and friends.

*"Cancer was a turning point in my life. It certainly had its negative moments {and months}. However, with the help of the Ulman Cancer Fund, it has been an overwhelmingly positive part of my life. Discovering my new normal with help from UCF has been eye opening and inspirational."*

Tom  
Timonium, MD

## **a parent's perspective**

Thoughts From Diana

After The Diagnosis

Taking Action

Issues Specific to Young Adults

Dealing With Emotions

In Conclusion

# parent's perspective



### Thoughts From Diana

I remember my 19th year. It was 1968. I was a junior in college, studying fine arts, independence and life in general. Things were pretty terrific. Suddenly, everything was different! My father; my strength, my role model, and my best friend was diagnosed with leukemia, and on July 25, 1968, he died. This mysterious disease called cancer had changed my life forever.

Twenty-eight years later, I watched as my son, Doug, was diagnosed with cancer at the age of 19. Cancer is less mysterious now than it was years ago. But it is still a powerful disease that can crash down on a wonderful, hopeful, youthful life and change it forever.

In a split second, in August of 1996, everything changed for our son and our family.

### After The Diagnosis

My first reaction to the news that Doug had a tumor in his back was shock, followed very quickly by denial, fear, and desperation. I only wanted to know when I would wake up from this nightmare. As conversations with doctors and family members continued, it became clear that I was awake and that we were living this drama. Emotions ran through me in no particular order. In any given moment I felt anger, acceptance, resolve, disbelief, confusion, and hope. Depression set in, followed by determination, exhaustion, sadness, and motivation. I could be infused with energy and fight and then overwhelmed with tears and pain. This myriad of emotions, stayed with me several years into this process, in no particular order, but no longer controlling me as it originally did. I became aware of a definite, although loose, progression through which I moved, as we faced Doug's illness.

### Taking Action

After my initial reactions, I resolved to learn as much as I could about this disease. I networked for hours on the phone, and followed every lead I was given. From each conversation, I gained useful information. I searched the Internet, looking for medical explanations. I then summarized what I had learned for the rest of the family, and made lists of questions to be taken to the medical professionals for answers. I kept thorough notes on everything from research to recommendations.

We learned the hard way the importance of finding a doctor who, in addition to being highly qualified medically, is a respectful, sensitive, and caring human being. It is of utmost importance to form a partnership between patient, family and medical professionals. Some suggestions are listed below.

- Be proactive
- Do not be intimidated
- Advocate for your child and teach your child to advocate for him or herself
- Demand respect
- Do not accept negativity from health practitioners
- Do not accept arrogance from health professionals
- Ask questions until you fully understand the answers and take notes or record answers for later review
- Leave no stone unturned
- Check all medications
- Keep a journal of every treatment, medication, appointment, etc.
- Keep a journal of emotions, reactions, and feelings  
{if writing is inconvenient, record your thoughts}
- Attempt to cope with the immediate issues at hand rather than looking too far ahead
- Take one hour at a time
- Solicit friends to field inquiries about the patient's condition
- Serve as a buffer for patient while in the hospital

Writing can be a useful and therapeutic tool for anyone facing the challenges of a cancer journey. You may want to examine and express some of your own dreams, fears, and concerns in this way.

### Issues Specific To Young Adults

In the natural course of life, young adults go forth with optimism, idealism, and a belief that they are indestructible. When they are robbed of that special perspective because of a life threatening disease they have a particularly difficult adjustment to make. There are issues that are very specific to young adults dealing with cancer. Just as these young people should most likely be separating from family and becoming independent, they are pulled back into a role of dependency due to the need for family help and support. Encourage as much independence as is possible for your young adult child. Whenever possible do not hover.

Living arrangements often complicate the situation as many young adults live a distance from family either because they are away at school or working in a different community from where they grew up. Should they move home and give up school and peer support, or should they stay away from home and be far from family support? Should they travel back and forth and then need doctors in both locations? We made sure that there were medical and emotional support systems for Doug in place, both in our hometown and in the city of his university.

Most young adults do not have experience in making major medical decisions. They find themselves thrown into a situation of supreme importance. They must sign authorization forms for procedures to be done where frightening adverse affects such as paralysis and death are listed alongside headache and dizziness. They must also make very crucial treatment decisions. Clear and honest explanations are critical. Respecting the patient's decisions when they differ from your choices is extremely difficult but important.

Some medical professionals work well with the entire family. Some speak to the young adult and ignore parents while other medical professionals talk to parents, ignoring the patient. Yet others play one against the other. Furthermore, some family members have difficulty communicating with one another. It was most helpful that we were able to work through decision processes together as a family, and not be sidetracked by doctors with their own agendas, or by competition for control among ourselves. Of course the final decision is the prerogative of the patient.

Health insurance is not always in place as young people move from coverage under their families' policy to coverage by a policy of their own. Many young adults have no health insurance at all. As most young adults have not yet purchased life insurance, they may find themselves ineligible once they are diagnosed with cancer. Even those patients who have health insurance can experience financial stress as bills for co-payments, deductibles, lost wages or travel for treatment add up. Finding financial help and deciphering bills is another challenge that parents can often help with, alleviating another burden that can be overwhelming.

The decision as to whether to go public or not with the information that one has a life threatening illness is a difficult one for young adults. It is important to proceed with life in as normal a way as possible, and telling everyone about the illness can make normalcy difficult. On the other hand, support from friends and family is very helpful to recovery and survival. Friends want to help but often do not know quite how. The patient sometimes finds him or herself having to put the friends at ease about the illness rather than the other way around. In the end we found that the support of friends and the ability to talk freely about what we were going through, was more important than the loss of privacy.

Navigating medical care, medications and follow up treatment can be overwhelming, on top of trying to get back to school or work.

Assuring good nutrition and meal preparation is another burden on a young adult who perhaps has not yet become proficient in that area.

If chemical treatments are indicated, then concerns of fertility come to light. Saving sperm or eggs may be desirable, and can be another unexpected cost. There is often a small window of time in which this can be done. It is wise to speak with a fertility clinic {andrology clinic} or contact [www.livestrongfertility.org](http://www.livestrongfertility.org) to learn about your fertility preservation options early in the process while the opportunity exists. If an emergency arises or a quick turn of events should change the treatment plan the chance to save healthy sperm or egg may be lost. Speak candidly and openly about this option.

*"I could always rely on [UCF's] positivity and strengthening message to get me through my many surgeries, six rounds of chemotherapy and many weeks of radiation and on to the next soccer game or Girl Scout meeting. I am proud to say that I did not have to miss out on life as I feared, but lived life even fuller."*

Julie  
Lutherville, MD

Support groups for young adults are not always readily available, posing a problem of isolation for them as they deal with cancer. The singularly most helpful thing for Doug was to talk to someone in his age bracket who had faced cancer. The Ulman Cancer Fund For Young Adults ([www.ulmancancerfund.org](http://www.ulmancancerfund.org)) can help connect young adults affected by cancer and their loved ones with others with similar experiences for peer support and information exchange.

Dating and intimacy can also be difficult for young adults as they recover from treatment. Many worry that their cancer, the possibility of reoccurrence, or the possibility of infertility will be obstacles to serious relationships. Body image is also a concern for those who may have scars or some type of disfigurement. Sensitivity to these subjects is imperative and again support from others who are dealing with the same issues is very helpful.

### Dealing With Emotions

Once we worked through the initial research, and were on what we considered the right track for medical treatment, we began to look at the emotional side of this challenge. I believe that the mind body connection is very strong and undeniable, so I researched a multitude of approaches to healing. These approaches included meditation, visualization, nutrition, exercise, stress management, relaxation, counseling, and breathing techniques. Much of this information was available on the internet or in books on tape, which I could listen to in the car or while doing other work. I gathered a great deal of information, summarized it and presented it in such a way as not to overwhelm my son. I found it imperative that I take my cue from him as to when he was ready to pursue these subjects. My goal was to make him aware of available options. He chose what interested him when he was ready. It was extremely important for us to allow for tears, to express love openly, to maintain an atmosphere of positive energy, to communicate honestly, and to remember to rely on humor. I learned to take regular interludes during the day, during which I would find a peaceful spot either in reality or in my mind and take time to breathe deeply and renew the sense of awe that this universe stirs in me. This exercise gives me strength. Through this entire process we have learned to recognize the strength of the human spirit and to capitalize on the benefits of reaching out to others in similar circumstances.

If I were to give only one piece of advice to a family dealing with cancer, it would be to keep talking. When a family member becomes ill with cancer the entire family becomes ill with cancer. Each member of the family needs support, either from a professional, a friend, a group or an individual similarly affected by this disease. Don't try to go it alone. There are so many people who can help ease the path. The most remarkable help for me came from other mothers of cancer patients. We had an instant bond. They were the only people I found who really understood my innermost feelings. How comforting we have been to one another.

### In Conclusion

As I raised my children, I tried to teach them coping skills to help them through adversity that I knew would come, as it does to everyone. However, I never allowed myself to imagine that it would come so severely at such an early age. I tend to be a "fix-it" person so when Doug was diagnosed with cancer I found myself dealing with the ultimate frustration. I couldn't "fix" him. I couldn't make him better. I couldn't protect him from cancer. I could however offer critical support in many ways. I could offer love. I could remain hopeful. And certainly I could grow and learn from all that we were going through.

This is our journey. It is our challenge. Our perspective is changed and we have learned some very important lessons: to cherish, savor, appreciate and enjoy our time with one another and to live in awe of the wonders of life. As we went through the process of dealing with Doug's cancer I found myself writing poetry.

I leave you with the following poem.

The plan changed  
By *Diana Ulman*

The plan changed.  
The course has been diverted.  
Where are we going?  
Confused and in pain.  
More tears.

Hold on.  
We'll hold on to each other,  
to you.  
You are not alone.  
It will be all right.

That's what I've said all along.  
It will be o.k.

Now, I'm not in control.  
I don't understand.  
I can't know.

But we'll journey.  
We'll learn as we go.  
And we'll find the way.  
And we'll find the way.

the plan changed



**help & hope**

Services of the Ulman Cancer Fund For Young Adults

On To Hope

# SERVICES



*"UCF stepped in and helped create a network of support that I needed to continue being an independent, educated, and well-equipped patient. UCF, and their partners, offered guidance in financial, legal, and medical assistance, as well as practical everyday needs like hospital transportation during treatment, meals, and help around the house if necessary."*

Jessica  
Columbia, MD

## The Ulman Cancer Fund For Young Adults {UCF}

Frustrated by the lack of support programs or literature focused on the needs of young adults affected by cancer, we created The Ulman Cancer Fund For Young Adults to fill the void that existed in health care services. Since its inception in 1997, UCF has been working tirelessly to provide young adults and their families with a unique and comprehensive community of support. UCF supports, educates, connects and empowers young adult cancer survivors. Our work is guided by our mission, vision and values.

### {mission}

We change lives by creating a community of support for young adults, and their loved ones, as they fight cancer and embrace survivorship.

### {our vision}

We envision a world in which all young adults affected by cancer will have access to the resources necessary to thrive.

### {our values}

The Ulman Cancer Fund For Young Adults' work is built on the belief that every young adult diagnosed with cancer deserves hope and support.

The values that guide our daily work with young adults — as well as our long-term organizational planning — include:

- **Collaboration.** Ongoing cooperation and idea and resource sharing will lead to the best possible outcomes for young adults living with cancer — and their families. Collaborators include medical providers, the patient advocate world, nonprofit organizations and private entities, as well as government agencies, community members, and individual patients and the institutions that care for them.
- **Perseverance.** Every obstacle can be overcome with determination, hard work, and resourcefulness. UCF's organizational efforts serve as a model for young people facing the greatest challenge of their lives.
- **Integrity.** Every donation and dollar spent will be used in the most efficient and effective way.
- **Compassion.** All young adults living with cancer — and their loved ones — deserve to be treated with a concern and sensitivity that reflects the unique medical and emotional issues they face.

UCF is a leading voice in the young adult cancer community and we offer many services that you might find helpful as you navigate your cancer journey.

- **Patient Navigation** – Through our Patient Navigation Program we offer one-on-one guidance and assistance to young adults dealing with cancer. Trained UCF employees help each client navigate their cancer journey, wherever they are in the continuum. This program is tailored to the needs of each individual. We help our clients learn to effectively advocate for themselves, find the resources they need, deal with their treatment team, increase their knowledge of their disease, find information on clinical trials, obtain second opinions, find emotional, financial, and practical support, address fertility issues, connect with others in similar situations for peer support, and help them in so many other ways as needs arise. The UCF patient navigators also introduce each client to the broader UCF support community which offers friendship and social, fitness and volunteer activities in an environment of optimism, energy and understanding. Patient Navigation services can be accessed by calling 1-888-393-FUND{3863} or emailing [patientnavigation@ulmancancerfund.org](mailto:patientnavigation@ulmancancerfund.org). We also provide patient navigators in a number of cancer centers to serve the young adult patients at those facilities.
- **Support Groups** – Support groups provide a platform for young adults affected by cancer to share concerns and learn methods of coping with their cancer challenges. Studies show that young people fighting cancer benefit greatly from discussing practical and emotional concerns with similarly situated peers. Since its inception, UCF has started and modeled young adult support groups nationwide in partnership with various organizations, and currently offers a number of professionally facilitated groups.
- **College Scholarships** – UCF is committed to helping young adults continue their education after being affected by cancer through their own diagnosis or the diagnosis of a loved one. We offer many college scholarships to support the financial needs of young adults affected by cancer. Find out more about our College Scholarship program at [www.ulmancancerfund.org/scholarships](http://www.ulmancancerfund.org/scholarships).

*"Being diagnosed with melanoma at 17 made me feel so isolated and alone. Finding Ulman Cancer Fund For Young Adults made me feel part of a community that understood."*

Virginia  
Washington, DC

*"My UCF Patient Navigator is a great listener and source of support."*

Connie  
Columbia, MD

*"The other survivors in the Ulman Cancer Fund For Young Adults Cancer to 5K program inspire me. The support, knowledge, and encouragement of the coaches and volunteers is amazing. They have all had a wonderful impact on my life. They helped me take my life back from cancer – physically, mentally, and emotionally. In my case, the cancer may reoccur. If it does, I am in the best shape of my adult life and plan to keep that up...I would recommend this organization to any young adult facing the challenges that cancer brings."*

Tony  
Catonsville, MD

- **Awareness, Education, Outreach and Prevention** – Information about cancer and young adults, cancer treatments and descriptions of the types of cancers most likely to be diagnosed in young adults can be found on the UCF website. We seek to raise awareness about the young adult cancer issues and the unique concerns and obstacles faced by young adults dealing with cancer. UCF provides speakers to companies, schools, and other groups to promote awareness and prevention of cancer in the young adult community. Find out more at [www.ulmancancerfund.org](http://www.ulmancancerfund.org).
- **"No Way It Can't Be!" - A Guidebook for Young Adults Facing Cancer** – Written by Doug Ulman and Diana Ulman this is a comprehensive resource for young adults dealing with cancer from their initial diagnosis through long-term survivorship. We hope the information helps young adults and their loved ones learn about the issues surrounding a cancer diagnosis. It contains all the information we wish someone had told us along the way. The Guidebook is distributed nationwide and is available on the UCF website at [www.ulmancancerfund.org/guidebook](http://www.ulmancancerfund.org/guidebook).
- **My Way - Writings of Young Adult Cancer Survivors** - Edited by Diana Ulman, this compilation contains essays, musings, poems, songs and letters by young adult cancer survivors relaying their cancer stories. Each of us can benefit from the experiences of and knowledge gained by those who have gone down the cancer path before us and from feeling that we are not alone. This companion to the UCF Guidebook is distributed nationwide and is available on the UCF website at [www.ulmancancerfund.org/myway](http://www.ulmancancerfund.org/myway).
- **Helping Others Fight** – This program directly supports the practical needs of cancer patients and their families through a corp of dedicated volunteers helping with such tasks as yard work, home repairs, household chores, pet care, tending to errands, meal preparation and delivery, chemotherapy companionship, and delivery of Chemo Care bags. {Available in certain geographic areas.}

- **Support Through Sport** - Understanding the social, emotional and physical benefits of exercise and community, UCF has developed a group of programs, events and partnerships that combine sport and support. Through these programs, we promote fitness and exercise for survivors and supporters. At the same time we raise awareness of the young adult cancer experience. Certain of our Support through Sport programs also offer UCF an opportunity to raise funds to support the services that we provide.

**Cancer To 5K** – Cancer to 5K is a 12-week training program designed to introduce or reintroduce cancer survivors to physical activity by providing them with the engagement, guidance, and support necessary to complete a 5K-distance road race. It is free of charge and is open to cancer survivors regardless of their current treatment status. We currently offer group workout programs in a number of locations as well as an "at home" training guide online. Each participant is paired with a volunteer sherpa throughout the program. Find out more about our Cancer to 5K program at [www.ulmancancerfund.org/cancerto5k](http://www.ulmancancerfund.org/cancerto5k).

**Team Fight** - Team Fight is an endurance training program where men and women train together for specific events to raise funds and awareness through sport. Since its inception, over 3,000 people have participated in the program. Learn more at [www.ulmancancerfund.org/teamfight](http://www.ulmancancerfund.org/teamfight).

**4K For Cancer** - 4K for Cancer is a life changing program offered to college age young adults. Each year, approximately 150 participants dedicate their summer to biking or running across the United States, visiting and inspiring communities while raising awareness and funds in the fight against cancer. Learn more at [www.ulmancancerfund.org/4kforcancer](http://www.ulmancancerfund.org/4kforcancer).

Check out [www.ulmancancerfund.org](http://www.ulmancancerfund.org) for a complete listing of UCF's support programs.

Jasmine was diagnosed with acute promyelocytic leukemia at the age of 18. She found the Ulman Cancer Fund after meeting a UCF patient navigator while she was completing her chemotherapy. She signed up for UCF's Cancer to 5K program after looking for ways to get healthier after treatment and has since completed two 5K races.

*"The people at the race and those who helped run the Cancer to 5K program always made me feel as though I was more than a cancer patient. They made me feel like a person training for a race. The races also have given me my self-esteem back. They showed me I could do anything if I work hard enough."*

Jasmine  
Baltimore, MD

## On To Hope

Young adults comprise the fastest growing group of cancer survivors worldwide. As research and technology allow for more cures and better treatment it is more evident than ever that addressing issues of survivorship is crucial. So many people are living with cancer, living with the effects of cancer, living beyond cancer.

It is our hope that for each cancer survivor hope prevails.

Hope for health  
Hope for empowerment  
Hope for understanding  
and  
Hope for peace of mind

The Ulman Cancer Fund For Young Adults will continue to help young adults affected by cancer deal constructively and successfully with the physical and emotional aspects of cancer as it impacts every facet of life. We invite you to become part of our community of survivors and supporters who understand the challenges of the young adult cancer experience. Join us. There are so many ways to get involved with UCF, from volunteer opportunities to fitness activities to socializing and networking. We are here for you for the long haul: from the day of diagnosis through long term survivorship.

Cancer changes lives ... SO DO WE!

**SO DO WE!**

It is our fervent hope that this book will help ease your journey.

Many wonderful volunteers helped bring this information to you...  
to all the folks who reviewed the many drafts and added their  
insightful perspectives

we say...

**thank you!**

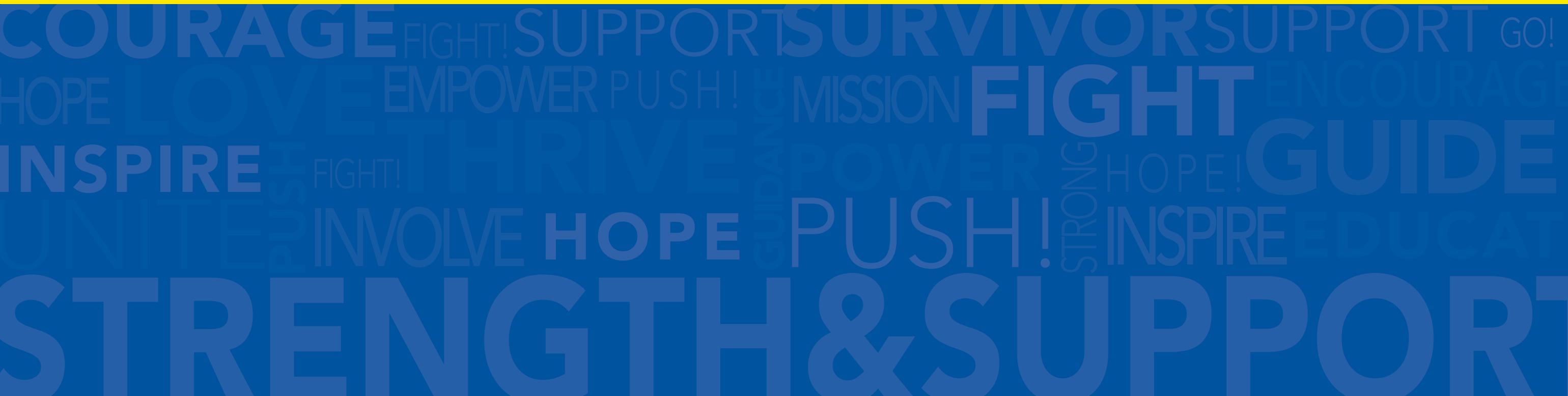
**NO WAY  
It Can't Be!**  
**a guidebook for young adults facing cancer**

written by Doug Ulman & Diana Ulman

designed by Jodi Neal {[www.ingeniumio.com](http://www.ingeniumio.com)}

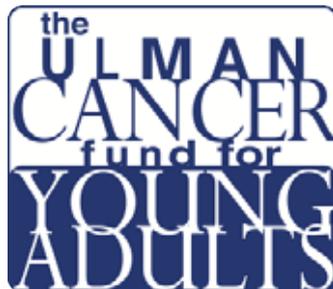
divider photos by Matt Nesbitt

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# MISSION

We change lives by creating a community of support for young adults,  
and their loved ones, as they fight cancer and embrace survivorship.



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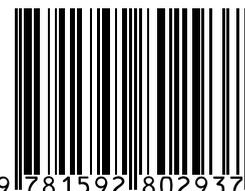
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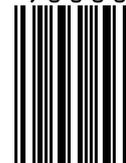
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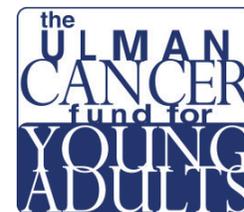
# QUESTIONS

## Questions For Your Treatment Team

Once you have found practitioners to work with, you will want to build a partnership between those practitioners, your loved ones, and yourself. You are the most important person in this partnership, and as you develop this relationship, you must clearly make your needs known. The following is a list of suggestions of what you may expect from your medical teams and how to communicate with them:

- You owe it to yourself to find medical practitioners with whom you are comfortable.
- Expect to be treated with respect and honesty.
- Be proactive and expect your practitioners to acknowledge and appreciate that as part of your role.
- Expect your health care practitioners to maintain positive attitudes – mental outlook is contagious and can certainly impact your condition.
- Expect the folks in white coats to understand your emotional state in addition to your physical state. The physical and emotional are intertwined and you need to be treated as an entire human being.
- Do not accept arrogance, negativity, condescension, or intimidation.
- Communicate in a straightforward manner, and expect the same from your caregivers. {efforts to be tactful can sometimes confuse the issue}
- Clearly communicate to your health care practitioners that even though you are a young adult, you are the patient and you would like them to speak and be responsible directly to you. {Do not allow them to play you against your parents or visa versa}
- If you are hospitalized, you are entitled to humane treatment–the caregivers are there to serve your needs.

- If you are in a teaching hospital, you may choose to allow students on rounds in your room, or you may deny them that opportunity if it is intrusive or uncomfortable for you in any way, at any time.
- Keep a running list of concerns and questions.
- Ask questions until you fully understand the answers.
- Take notes or record discussions with medical team for later review.
- Keep a journal of each appointment or medical encounter, test, treatment, and medication. In addition to helping you keep track of your progress, this journal can be shared with new practitioners who might join your team, and they can easily be brought up-to-date. {See charts in “Some Record Keeping Help” section}
- Keep a journal of your feelings and thoughts as well.
- Expect everyone to keep an open mind about complementary therapies such as acupuncture, nutrition, vitamin therapy, music for relaxation during surgery or cancer treatments.
- Investigate and consider clinical trials.
- Develop a good system of phone or e-mail communication and timely responses from your caregivers.



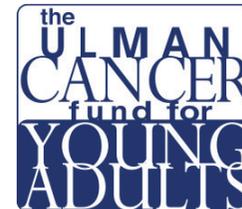
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## Issues Specific To Young Adults

# ISSUES

While many people are diagnosed with cancer, Young Adults with cancer face very different issues from the general adult population and from pediatric cancer patients. They are at a time in their lives when they are mapping out careers, relationships and future plans. They are becoming independent and self sufficient. A major life threatening illness can turn their lives upside down. Below is a list of some of the difficult issues faced by Young Adults affected by cancer:

- Independence vs. dependence.
- Living near family support vs. living near peer support.
- Inexperience at making major medical decisions.
- Inexperience at managing medical treatment.
- Dealing with medical professionals.
- Maintaining some semblance of “normalcy.”
- Health insurance, life insurance and financial issues.
- Job security / career planning.
- Nutrition and meal preparation.
- Fertility.
- Dating.
- Intimacy.
- Relationships.
- To tell or not to tell.
- Long term physical and emotional ramifications.



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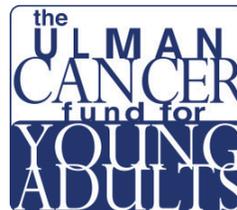
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## How People Can Help

Talking about what you are facing is always helpful, and ignoring your feelings is almost always not. Find someone to talk to: a parent, a sibling, a friend, and let them help. Let your friends and loved ones know how they can make things easier for you. Here are some things you might want to tell them:

- I'm still the same person – just going through a very rough time.
- Let me know you're there for me.
- Feel free to tell me how you are feeling and I'll do the same.
- Remember, this is new for all of us.
- Speak directly to me rather than to others about me.
- Please keep calling – I'll let you know if I'm too tired to talk.
- Keep stopping by like you always have.
- Send me a card, note, email or text.
- Bring me a favorite snack.
- Bring a movie for us to watch.
- Make calls for me.
- Know that I want to keep humor in my life.
- Let me take the lead in discussing the medical details.
- You can't say "the wrong thing" – whatever you say or feel is OK.
- Please keep in touch.



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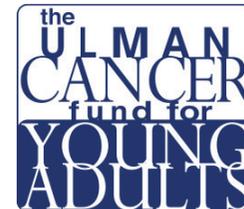
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## Advice to Patients and Parents

# ADVICE

We learned the hard way the importance of finding a doctor who, in addition to being highly qualified medically, is a respectful, sensitive, and caring human being. It is of utmost importance to form a partnership between patient, family and medical professionals. Some suggestions are listed below.

- Be proactive.
- Do not be intimidated.
- Advocate for your child and teach your child to advocate for him or herself.
- Demand respect.
- Do not accept negativity from health practitioners.
- Do not accept arrogance from health professionals.
- Ask questions until you fully understand the answers and take notes for later review.
- Leave no stone unturned.
- Check all medications.
- Keep a journal of every treatment, medication, appointment, etc.
- Keep a journal of emotions, reactions, and feelings {if writing is inconvenient, record your thoughts.}
- Attempt to cope with the immediate issues at hand rather than looking too far ahead.
- Take one hour at a time.
- Solicit friends to field inquiries about the patient's condition.
- Serve as a buffer for patient while in the hospital.



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UCF is a leading voice in the young adult cancer community and we offer many services that you might find helpful as you navigate your cancer journey.

- **Patient Navigation** – The UCF Patient Navigation Program offers one-on-one guidance and assistance to young adults dealing with cancer. Trained UCF employees help each client navigate their cancer journey, wherever they are in the continuum. This program is tailored to the needs of each individual. Patient Navigation services can be accessed by calling 1-888-393-FUND{3863} or emailing [patientnavigation@ulmancancerfund.org](mailto:patientnavigation@ulmancancerfund.org). We also provide patient navigators in a number of cancer centers to serve the young adult patients at those facilities.
- **Support Groups** – Support groups provide a platform for young adults affected by cancer to share concerns and learn methods of coping with their cancer challenges.
- **College Scholarships** – UCF is committed to helping young adults continue their education after being affected by cancer through their own diagnosis or the diagnosis of a loved one. [www.ulmancancerfund.org/scholarships](http://www.ulmancancerfund.org/scholarships).
- **Awareness, Education, Outreach and Prevention** – Information about cancer and young adults, cancer treatments and descriptions of the types of cancers most likely to be diagnosed in young adults can be found on the UCF website. We seek to raise awareness about the young adult cancer issues and the unique concerns and obstacles faced by young adults dealing with cancer. [www.ulmancancerfund.org](http://www.ulmancancerfund.org)
- **“No Way It Can’t Be!” - A Guidebook for Young Adults Facing Cancer** – Written by Doug Ulman and Diana Ulman this is a comprehensive resource for young adults dealing with cancer from their initial diagnosis through long-term survivorship. [www.ulmancancerfund.org/guidebook](http://www.ulmancancerfund.org/guidebook)
- **My Way - Writings of Young Adult Cancer Survivors** - Edited by Diana Ulman, this compilation contains essays, musings, poems, songs and letters by young adult cancer survivors relaying their cancer stories. [www.ulmancancerfund.org/myway](http://www.ulmancancerfund.org/myway).

- **Helping Others Fight** - This program supports the practical needs of cancer patients and their families through a corp of dedicated volunteers helping with such tasks as yard work, home repairs, household chores, pet care, tending to errands, meal preparation and delivery, chemotherapy companionship, and delivery of Chemo Care Bags.

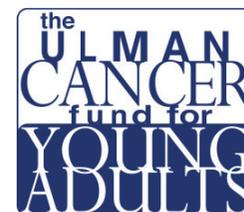
- **Support Through Sport** - Understanding the social, emotional and physical benefits of exercise and community, UCF has developed a group of programs, events and partnerships that combine sport and support. Through these programs, we promote fitness and exercise for survivors and supporters. At the same time we raise awareness of the young adult cancer experience.

- **Cancer To 5K** – Cancer to 5K is a free, 12-week training program designed to introduce or reintroduce cancer survivors to physical activity by providing them with the engagement, guidance, and support necessary to complete a 5K-distance road race or walk. [www.ulmancancerfund.org/cancerto5k](http://www.ulmancancerfund.org/cancerto5k)

- **Team Fight** - Team Fight is a training program where men and women train together for specific events to raise funds and awareness for UCF through sport. [www.ulmancancerfund.org/teamfight](http://www.ulmancancerfund.org/teamfight).

- **4K For Cancer** - 4K for Cancer is a program offered to college age young adults. Each year, approximately 150 participants dedicate their summer to biking or running across the US, visiting and inspiring communities while raising awareness and funds in the fight against cancer. [www.ulmancancerfund.org/4kforcancer](http://www.ulmancancerfund.org/4kforcancer).

Visit [www.ulmancancerfund.org](http://www.ulmancancerfund.org) for a complete listing of UCF's support programs.



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