

It
Can't
Be!



a guidebook for
young adults facing cancer



What a shock! A young adult - living life - planning for the future - looking forward to new experiences - and then everything stops. **CANCER!**

It is almost too much to take. **This absolutely can't be!** It must be a mistake. But it starts to sink in. I have CANCER. What does it all mean?

I'm Doug Ulman, **3-time cancer survivor**. When I was 19 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 played varsity soccer, studied hard, and lived life with all the zest and excitement normally granted a 19-year-old. And then a routine x-ray revealed something suspicious. **I thought nothing of it.** But further tests showed a cancerous tumor growing in my back. I still remember the doctor telling me that I had cancer.

For me, cancer used to mean death. I used to think if someone had cancer there was no hope. But I now know better. There are many new treatments for cancer, and many breakthroughs on the horizon. Cures are being developed in labs. People are surviving at record rates. There is hope! **This can be dealt with.**

Since my diagnosis and surgeries, I founded the **Ulman Cancer Fund For Young Adults**. Our mission is to provide support programs, education and resources, free of charge, to young adults, their families and friends, who are affected by cancer and to promote awareness and prevention of cancer.

The Ulman Cancer Fund Guidebook symbolizes our work. In the following pages you will find suggestions and ideas about how to proceed, **how to face the challenges ahead**. This information is information I wish I had had as I faced my cancers. I hope it helps you in whatever situation you find yourself.

A good friend of mine 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**. Good health and peace to you.

Sincerely,

Doug Ulman



START WITH AN EDUCATION

Deciphering The Diagnosis.....	4
The Search For Information	4
Put Technology To Work For You.....	5
Useful Sites On The Internet.....	6
Hospitals & Other Resources	9

THE FOLKS IN WHITE COATS

Dealing With Health Care Practitioners.....	14
Making Medical Decisions	16
Coping With Treatment	16
Surgery, Radiation, and Chemotherapy	19

SOME RECORD KEEPING HELP.....24-27

REACTIONS AND ACTIONS

In the Beginning.....	30
Focusing Your Emotions.....	30
Writing For Health	31
There Are Many Ways To Cope.....	32
Mind Body Connection	32
Survivorship	33
Facing End of Life	36
There is Help	38

THE PEOPLE AND ISSUES IN MY LIFE

Parents, Spouses, Significant Others.....	43
Siblings, Young Adults As Family And Friends, Friends & Co-Workers.....	45
How People Can Help	48
Issues Specific To Young Adults.....	49

A PARENT'S PERSPECTIVE

Thoughts From Diana	52
Issues Specific To Young Adults.....	53
Dealing With Emotions	57

HOPE AND HELP

On To Hope.....	62
Services of the Ulman Cancer Fund For Young Adults	63



Start with an Education

Deciphering The Diagnosis

The Search For Information

Put Technology To Work For You

Useful Sites On The Internet

What Other Resources Are Available?

Writing Exercise

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?

Take the space provided to answer these questions, or obtain a journal to keep records of your thoughts and feelings.

Please elaborate as much as possible.

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 when the doctor gives you this diagnosis. You will probably need to digest your thoughts and then try to learn about the disease when you're ready.

Know that you are entitled to expect the doctor to explain your situation in detail. If need be, request that he or she slow down and repeat sentences. Even if time has passed since your doctor gave you the diagnosis, call the doctor's office and request that your **doctor share with you the latest information** available on the disease. Also, ask for recommendations so that you can research the disease yourself.

The Search For Information

The information in medical books and journals can be confusing, depressing, troubling, and even scary. The 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 this information often includes statistics that are outdated, and includes **differing levels of diagnosis**. (I learned that modern medicine and technology have improved these statistics.)

When I told my family doctor, soon after my diagnosis, that I was researching my 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 on the Internet 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.

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. Be cautioned that 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. Modern technology allows us **access to the latest information** on many different forms of cancer, treatments, research in progress, recent studies, nutrition, and support services. If you do not have a computer available, you should be able to **access the internet** at a school, public library, or cancer center.



Research

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

Please use this space to list questions.

"Doug,

This website is awesome!
Finally someone is addressing
the needs of a population
which seems to be overlooked.

I have recently completed
treatment for Leukemia.

At 22 when I was diagnosed,
I realized there are virtually no
programs available for young
adults. So I thank you, and
applaud you. Stay well."

Kiersta
Aston, PA

www.ulmancancerfund.org

www.livestrong.org

www.cancer.gov

Useful Sites On The Internet

When I first was diagnosed with cancer, I surfed the Internet for information. I went to one of the major search engines and typed in Chronodosarcoma. There I found several sites that started me on my search. **I recommend the Internet** for researching your type of 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.

Websites

The Ulman Cancer Fund For Young Adults provides support programs, education and resources, free of charge, to benefit young adults, their family and friends, who are affected by cancer, and promotes awareness and prevention of cancer.

www.ulmancancerfund.org 888.393.FUND(3863)

The Lance Armstrong Foundation homepage was founded by world-class cyclist and cancer survivor Lance Armstrong, and deals with education and research for those interested in cancer. www.livestrong.org 866.235.7205

The National Cancer Institute is the U.S. government agency responsible for conducting and supporting research on cancer. Access information on clinical trials and more. www.cancer.gov 800.4.CANCER(226237)

Planet Cancer is a community of young adults with cancer, providing support and educational services. www.planetcancer.org

www.planetcancer.org

Fertile Hope is a comprehensive fertility preservation resource for patients whose medical treatments present the risk of infertility. www.fertilehope.org
888.994.HOPE (4673)

www.fertilehope.org

The American Cancer Society is a nationwide community-based health organization dedicated to eliminating cancer as a major health problem by preventing cancer, saving lives and diminishing suffering from cancer, through research, education, advocacy and service. www.cancer.org **888.ACS(227).2345**

www.cancer.org

OncoLink is run by the University of Pennsylvania Cancer Center. This is a great educational site for both patients and their families. www.oncolink.upenn.edu

www.oncolink.upenn.edu

The Testicular Cancer Resource Center is an organization that provides invaluable information about testicular cancer. www.tcrc.acor.org

www.tcrc.acor.org

The National Coalition for Cancer Survivorship raises awareness of cancer survivorship and strives to eliminate the stigma of cancer by providing public policy leadership on legislative, regulatory and financial matters. It promotes advocacy among national cancer organizations for insurance, employment and legal rights for people with cancer. NCCS produces several excellent publications for survivors. www.cansearch.org **877.622.7937**

www.cansearch.org

www.cancercare.org

Cancer Care, Inc. provides free professional counseling, education and information, including referrals for patients. www.cancercare.org **800.813.HOPE (4673)**

www.candlelighters.org

The Candlelighters is a group that provides support to adult survivors of childhood cancers. www.candlelighters.org **800.366.2223**

www.cancerhopenetwork.org

The Cancer Hope Network is an organization that offers one-on-one support for cancer patients and their families by trained volunteer survivors.
www.cancerhopenetwork.org **877.HOPENET (4673638)**

<http://www.curesearch.org>

CureSearch supports the Children's Oncology Group research centers as well as advocates for children, teenagers, and young adults with cancer. www.curesearch.org **800.458.6223**

www.patientadvocate.org

Patient Advocate Foundation is a national non-profit organization that serves as an active liaison between the patient and their insurer, employer and/or creditors to resolve insurance, job discrimination and/or debt crisis matters relative to their diagnosis through case managers, doctors and attorneys. www.patientadvocate.org **800.532.5274**

www.nhpco.org

National Hospice and Palliative Care is a leader in providing end of life care and support. www.nhpco.org **800.658.8898**

Gilda's Club provide free of charge support and networking groups, workshops and social events in home-like settings. www.gildasclub.org

888.GILDA4U(4453248)

www.gildasclub.org

The Wellness Community is a free program of emotional support, education and hope for people with cancer and their loved ones.

www.wellness-community.org **888.793.WELL(9355)**

www.wellness-community.org

Hospitals That Help

Many of the nation's leading cancer hospitals operate web sites. While there are too many sites to list, our web site provides links to many helpful ones. Find them at 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
PMB 505
4725 Dorsey Hall Drive Suite A
Ellicott City, Maryland 21042
410.964.0202 888.393.fund (3863)
info@ulmancancerfund.org
www.ulmancancerfund.org

What Other Resources Are Available?

There are also **many resources available in print**. The National Cancer Institute offers a toll free phone line professionally staffed by people trained to provide accurate personalized answers to your cancer related questions. They will also send **free publications** to you. Call 800.4.CANCER(226237).

Also, consider the **American Cancer Society** as a resource. They can answer cancer-related questions, send free publications and make referrals for related services. Call 888.ACS(227).2345.

The Folks in White Coats

Dealing With Health Care Practitioners

Making Treatment Decisions

Coping With Treatment

Surgery, Radiation, And Chemotherapy



Dealing With Health Care Practitioners

You're in the midst of devastation, shock, and confusion. You've 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? Where do they get their information? What are they thinking?

Ideally, the health care practitioners you deal with will be bright, intelligent, well trained, respectful, sensitive, patient, caring, honest, and positive. **You deserve all of that.** And there are many who meet those criteria.

Unfortunately, there are those who do not. Even as you are upset and confused, you must **be vigilant in demanding 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 stereo, do your homework. This is perhaps the most important consumer encounter of your life. Even in your tenuous emotional state, it is imperative that you find someone that you are comfortable with. Get as many opinions as you need and can afford, and remember that not every physician is the best, the smartest, or the kindest. It is OK to change doctors at any time. **Find one that is right for you!**

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 **make your needs clearly known**. The following list is a suggestion of your rights:

- You must receive respect and honesty.
- You must be proactive and deal with practitioners who acknowledge and appreciate that as part of your role.
- You must demand that your health care practitioners maintain positive attitudes—mental outlook is contagious and can certainly impact your condition.
- Do not accept arrogance, negativity, condescension, or intimidation.
- Communicate in a straightforward manner, and demand the same from your caregivers—Do not let efforts to be tactful confuse the issue.
- Make it clear to your health care practitioners that even though you are a young adult, *you* are the patient. *You* are the person that they are responsible to. Do not allow them to play you against your parents or visa versa.
- You owe it to yourself to find medical practitioners with whom you are comfortable.
- 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 tape record answers for later review.
- Keep a journal of each appointment or medical encounter, test, treatment, and medication. (See charts in “Some Record Keeping Help” section) 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.
- Keep a journal of your feelings and thoughts as well.

"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

"Doug,
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 was available 16 years ago. Keep up the good work."

Candace
Potomac, MD

- Demand that everyone 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.
- 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.

Making Medical Decisions

I said it before but it bears repeating: **You are the most important person** in this process, and the partnerships that are formed. 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. Everyone needs to know that your feelings and needs are the only ones that count right now. The members of this partnership must work together with only one purpose—to obtain, maintain and support the best possible health for you.

Coping With Treatment...Surgery, Radiation, Or Chemotherapy

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 are:

- 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?
- 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?
- 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?
- Will my treatment present a risk to my fertility?
- How can I harvest egg or save sperm before I begin 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?

Writing Exercise

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?

Writing Exercise

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.

What will get you in the right mood for surgery?

What do you anticipate cancer surgery being like?

Can you picture the cancer in your body?

Describe it, and describe it being removed.

Writing Exercise

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.

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 **network 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.

Some people experience hair loss as some types of treatment can kill off hair follicles. Before you start treatment, 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 in clumps or more gradually.

Everyone handles treatment differently both physically and emotionally. Some folks find that wearing acupressure wrist-bands helps ward off nausea. Others 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, novels, relaxation tapes, or any number of other modes to help them cope. **You will find what works best for you.**

Acknowledge your feelings, whatever they are. Find a **safe place** to express them.

Surgery

Surgeries are the most invasive of the treatments. Because many cancer surgeries involve removing not only the cancer, but also a significant portion of tissue surrounding the malignancy, **they can be long and tedious procedures**. Whether or not it involves general anesthesia, surgery is a major shock to the body. Be fully aware of what to expect before you have the surgery. It may help to know:

How extensive the surgery will be.

About how long it should last.

What the recovery process will be like.

Radiation

There are a number of different types of radiation, and procedures differ from hospital to hospital. But the essence is that you are **killing off the multiplying cells** through radiation. The most common type of radiation treatment is beam radiation. It is important to know what will be required of you if you are having beam radiation. It often means that you're going to be on a regular schedule and limited in your activities.

Chemotherapy

Often with cancer treatments you might feel worse before you get better. That's sometimes the case with chemotherapy. By **putting strong medications into the body**, doctors attempt to kill the malignant cells that multiply. This means that the chemotherapy can also kill other cells that multiply, like hair follicles. It also means

Writing Exercise

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 you're treatments are completed and you are feeling better?

Writing Exercise

What choices do you have? For where ever you are in the process, you have a choice. Consider what that choice is and what the possible outcome is.

that the patient may become ill during the treatments. In addition, chemotherapy can have short term and long lasting effects on the body. It is important to investigate those possible effects and make treatment decisions based on the information learned.

There are a number of 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.

Fertility

Cancer treatments can have a wide variety of long and short term side effects on reproductive organs. 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 fertileHOPE online at www.fertilehope.org or call 888.994.HOPE(4673). This resource 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. Find out what your fertility preserving options will be before, during and after treatment. Find out about harvesting and saving sperm or egg before treatments begin. Unfortunately, some of these options are costly and few are covered by health insurance carriers at this time, but there are

financial assistance programs available for those who qualify. New fertility preservation choices are being researched and developed constantly so there is hope for many going through cancer treatments that they will be able to become parents.

Record Keeping Help

Chronological Chart

Medical Records

Financial Records

Provider Information



A young woman in our Survivors'/Loved Ones network sent us the following guide for record keeping. It is very **important 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. The Lance Armstrong Foundation has developed a record keeping tool, the Livestrong notebook, that can be ordered at www.livestrong.org.

Keep A Chronological Chart

- List all doctor visits, tests, biopsies, CT scans, treatments, MRI's, X-rays and blood work.
- Include date and any discussion notes.
- Update weekly.

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

Date	Doctor/Facility	Purpose of Visit	Tests	Notes

* Photocopy this chart as needed.

Obtain And Keep A File Of All Medical Records

- Request from each doctor and lab, duplicate copies of your tests and records 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 diagnosis, etc.
- 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.

Medical Providers/Facilities

Doctor/Facility	Phone	Fax	Address

* Photocopy this chart as needed.

Keep A List Of All Medications

Medication	Dosage/Directions	Purpose	Prescribed By	Reactions

Keep A Complete Financial Record

Keeping meticulous financial records is of utmost importance. This is a very challenging task. Make sure you **keep a copy of every bill, statement, and payment**, whether payments come from you or an insurance provider. On a regular basis, compare and check off each individual charge with each payment. Medical bills can be very confusing and often are incorrect. Check every bill that you get and be careful not to pay bills more than once. It is important to know that **everything is billed separately**. For instance you may get separate bills from the doctor and the hospital. You may also get separate bills for a CT scan and from the doctor who reads it. The records pile up quickly.

These headings might be helpful to keep track of medical bills:

- Provider Claim/Control Number
- Date of Service
- Co-pay paid
- Contact
- Amount Billed
- Amount Paid
- My Check #

Whenever you call any office about a bill or any medical information, write down the name of the person you speak with and the date of the call. If you are calling about a bill, have your billing information in front of you to facilitate your transaction.

Billing Inquiries

Date	Company/Facility Called	Reason for Calling	Outcome	Spoke With

Insurance Provider Information

Have in one safe place all the information you need about your providers.

Use the chart below to keep that information.

Provider Name	Policy #	Address	Phone	Fax

Reactions and Actions

In The Beginning

Focusing Your Emotions

Writing For Health and Preparation

There Are Many Ways To Cope

Mind Body Connection

Survivorship

Facing The End Of Life

There Is Help



Today I felt:

I thought:

I learned:

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, 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 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 time you are prone to thoughts and feelings unlike those at any other time. **Writing is a healthy way to express your feelings** and it allows you to come in contact with your emotions. You may want to use the open space in this booklet to get in touch with 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.

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 never looked too far ahead.

There are books, tapes, and videos available in your local library or cancer center to help you learn about the wide range of support mechanisms and coping skills.

Some that I tried are:

Meditation

Relaxation Exercises

Deep Breathing

Visualization

Prayer

Optimum Nutrition

Support Groups

Exercise (if possible)

Professional Counseling

Play Acting

Painting/Drawing

Watching TV/Movies

Reading

Visiting

Talking—hopefully to someone with the same problem—but talking to someone

We've also placed questions 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 questions are to **provoke thinking and feeling** in preparation for some of the more difficult issues you will 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 dictating machine.

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 to the left.

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.

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 necessary 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

"Doug,
After having read the articles and information from your website, I can absolutely say that it was eye-opening and incredibly touching. I am 26 and a huge part of me has always felt that tanning was essential...the darker the better. My friends and I would laugh and ignore the warnings we would hear about skin cancer, especially. It took me reading about your experiences to really grasp the concept that tanning can be deadly. Thank you so much."

Kristine
Owings Mills, 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.**

- What should I expect in 5, 10 and 15 years?
- What secondary cancers and other medical problems should I watch for?
- When should I be examined?
- Will I experience ongoing fatigue, pain, infertility, sexual dysfunction?
- Will I experience depression?
- Can I have 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 have face job discrimination?

The **support services** of The Ulman Cancer Fund For Young Adults may be helpful as people face survivorship. (www.ulmancancerfund.org) Also, for more information on survivorship, check out The Lance Armstrong Foundation at www.livestrong.org *Take Control, Survivorship Topics*.

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.

Writing exercise

What gives you hope?
It could be something tangible like a friend or relative that survived cancer, or it could be something as abstract as a sunrise.

Whatever it is, put it down on paper and explain it. Let the writing help hope resonate from within.

Facing The End Of Life

Each of us has a grant of time. The length of that time is unknown. Each of us eventually faces 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

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 accept and 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 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, scrape booking, visiting a place they have wanted to see, planning or planting a garden, writing, or knitting. Many want to spend time 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.

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

- Some may want-do not resuscitate-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.

"Doug,
I didn't think of myself as an official cancer survivor before I connected with the UCF, but after reading through the resources on the website and learning about other people's personal experiences I identified with this group for the first time. I feel very lucky just to be in the same category with such an impressive group of people and I decided to run a marathon as a fundraiser for the UCF to give a little back to a group of people who have given me a lot."

Leigh
Philadelphia, PA

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 for those people.

- Speak to me about your feelings.
- Send me a note (please: not a get well card).
- 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 care givers a break so that they can get some much needed rest.
- Keep visiting.

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 home-like 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 & Issues in my **LIFE**

Parents

Spouses

Significant Others

Siblings

**Young Adults As
Family & Friends**

Friends And Co-Workers

How People Can Help

**Issues Specific To
Young Adults**



Writing exercise

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?

It is said that when someone in the family has cancer, the entire family has cancer. Certainly a cancer diagnosis **greatly impacts 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, each member must **stay positive and offer love, hope, and support**. After the shock, research, decision-making process, and development of a treatment plan, there will be time to deal with the 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 alone and unable to share feelings. **Opening up to family and friends** can be crucial to recovery. In order for others to provide 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 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.

Writing exercise

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? Why?

Do you remember anything as being humorous in this process?

And is there a way for you to express your gratitude to your parents?

"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

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 talked about. **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 care givers, 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.

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.

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?

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 by phone, 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 live can be very frightening. 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 ones 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 possible 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,

"Dear Mr. Ulman,
I think that what you are doing is so great. I am 15 and a sophomore from San Domenico School, and my friends and I have started a club called T.H.T.C. (Teens Helping Teens With Cancer.) So far we have been successful in getting the club approved...and have penpals from across the country. We want to find more ways to get involved and reach out to people who have been diagnosed with cancer. ... How can we help?"

Theresa
San Francisco, CA

"Doug,
Today...was the first time that
I have encountered another
individual who has
battled cancer three times.

When I was five I was
diagnosed with Leukemia,
when I was 13 I was
diagnosed with cancer of the
thyroid, and now I am 26
and I was diagnosed with
endometrial stromal sarcoma.

I am looking for others my
age who have had experiences
with cancer. Especially the
later of the three. I am
also willing to share my
experiences to help others."

Pamela
Elgin, IL

and do not want to intrude on their privacy. **Talking openly and honestly** once again can help everyone involved.

Friends And Co-Workers

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. I was often withdrawn and quiet and he had 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

"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

difficult? Will I feel well enough for a physical relationship and will I be self-conscious about unsightly scars or disfigurement? Talking with other young people with cancer, or a professional counselor, may be helpful in determining what is best for you.

How People Can Help

Talking 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 be a friend to you. Let your friends and loved ones know how they can help you.

- 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 or note.
- 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.

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

Issues Specific To Young Adults

- 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 53.

A Parent's Perspective

Thoughts From Diana

After The Diagnosis

Taking Action

Issues Specific To Young Adults



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 to the right.

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

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 tape 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,
use a dictating machine)

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

as these young people should most likely be separating from family and becoming independent, they are pulled back into a dependent role 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 college.

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 side effects 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 talk only 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 competition for control among ourselves. Of course the final decision is the prerogative of the patient.

Health insurance is often not in place as young people move from coverage under their families' policy to one of their own. And most young adults have not yet purchased life insurance, and 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.fertilehope.org** to learn about your fertility storing 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.

Support groups for young adults are generally not 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 Survivors'/Loved Ones Network and Discussion Forum on line at www.ulmancancerfund.org serve to fill that void for many young adults affected by cancer.

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.

“Facing cancer can be overwhelming for anyone and particularly for someone new to managing his or her own health care.”

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 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. **Making him aware of options was my goal**. He choose 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 have learned to take regular interludes during the day, during which I find a peaceful spot either in reality or in my mind and take a time to deep breathe 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**

**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.

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 that 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 I found myself dealing with the ultimate frustration and pain after Doug’s diagnosis. **I couldn’t “fix” his 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.



Hope & Help

On To Hope

**Services of the Ulman Cancer
Fund For Young Adults**

On To Hope

Young adults comprise the fastest growing group of cancer survivors world wide. 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

It is the mission of The Ulman Cancer Fund For Young Adults is to provide **support programs, education and resources**, free of charge, to benefit young adults, their families and friends, who are affected by cancer, and to promote **awareness** and prevention of cancer.

It is our goal to continue to help young adults affected by cancer deal constructively and successfully with the physical and emotional aftermath of cancer as it impacts every aspect of **life**.

Services of The Ulman Cancer Fund For Young Adults (UCF)

Frustrated by the lack of support programs or literature directed at 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 1997, The Fund has been working to provide young adults and their families with a unique and comprehensive system of support. Its mission is to provide **support** programs, **education** and **resources**, free of charge, to benefit young adults, their families and friends, who are affected by cancer, and to promote awareness and prevention of cancer.

We have grown to become one of the leading voices in the young adult cancer community and we offer many services that you might find helpful as you navigate your cancer journey.

- **Survivors'/Loved Ones Network** - Through our website survivors are connected with one another for peer support and information exchange. The network allows us to put people with similar experiences and diagnoses in touch without geographical limitations.
- **Support Groups** - We currently maintain professionally facilitated support groups in communities across the country. These groups provide a safe place for young adults to talk openly about their concerns, feelings, and emotions with others who are dealing with the same issues.
- **Patient Navigator Program** - "What's Next" - Our patient navigator program offers survivors advocacy assistance, resource guidance, and a friendly voice. The navigator builds social, educational, and emotional support through personal experiences and resources of UCF.
- **College Scholarships** - To encourage and support young adults affected by cancer, the Matt Stauffer and Marilyn Yetso Memorial Scholarships support the financial needs of young adult survivors and those who have or have had a parent affected by cancer, respectively.
- **Discussion Forum** - Also found on the UCF website, our discussion forum offers young survivors and their friends and family an opportunity to discuss issues of concern on an on-going, 24-hour basis. The issues are pre-selected, young adult-specific topics, such as dating, fertility, and interruption of education, which elicit real, candid responses.

- **Education and Prevention** - Located on the UCF website, this section raises cancer awareness by conveying the message that education and behavioral changes can help protect everyone from cancer, and provides educational materials for use at home and in the classroom on the college, high school and middle school levels.
- **Community Outreach** - The Ulman Cancer Fund For Young Adults provides speakers to groups and schools to promote awareness and prevention of cancer.
- **Voice of Survivorship Stories** - Survivors can post their stories on the UCF web-site so that they may share their experiences with others.
- **Guidebook** - "No Way It Can't Be!" - A Guidebook for Young Adults Facing Cancer Written by Doug and Diana Ulman, this book is a great resource for any individual dealing with cancer from the initial diagnosis through long-term survivorship. The information helps young adults and their families deal with the issues surrounding a cancer diagnosis. The guide is distributed nationwide and is available on the fund's website.

Visit www.ulmancancerfund.org *Services and Education* for a complete listing of the support programs we offer.

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

Many wonderful volunteers helped
us bring this information to you...

to Jodi Ceglia for her amazing talent,
boundless energy and infinite patience
in designing the guidebook

to John Meitl for his expertise in
developing, conducting and evaluating
a focus group of thoughtful survivors

to Jeannine Abbinanti, Robert Christine,
Sheri Cohen, and Eden Stotsky, for
adding their valuable and personal
perspectives through their participation
in the focus group

to Josh Isaac for his skillful editing

and

to all the folks who reviewed the
many drafts and added their
insightful perspectives

we say...

thank you

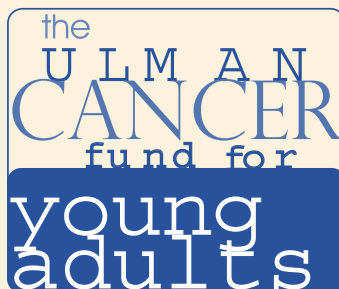
**NO WAY
It Can't Be!**
a guidebook for young adults facing cancer

written by Doug & Diana Ulman

designed by Jodi Ceglia (www.think3design.com)

© copyright 2006 by The Ulman Cancer Fund For Young Adults, Inc.

IT IS OUR MISSION TO PROVIDE SUPPORT PROGRAMS, EDUCATION AND RESOURCES, FREE OF CHARGE,
TO BENEFIT YOUNG ADULTS, THEIR FAMILIES AND FRIENDS, WHO ARE AFFECTED BY CANCER,
AND TO PROMOTE AWARENESS AND PREVENTION OF CANCER.



Support • Educate • Connect

410.964.0202 or 888.393.FUND (3863)
410.964.0402 fax

info@ulmancancerfund.org

www.ulmancancerfund.org

PMB 505
4725 Dorsey Hall Drive
Suite A
Ellicott City, Maryland 21042

ISBN 1-59280-293-1



9 781592 1802937

9 0000



LIVESTRONG
LANCE ARMSTRONG FOUNDATION

The production of
NO WAY, IT CAN'T BE,
A Guidebook for Young Adults Affected By Cancer
was made possible in part by a
Lance Armstrong Foundation Community Grant