



• Elizabeth J. Clark, PhD, MSW •

YOU HAVE
THE RIGHT TO BE
HOPEFUL

A publication of the



NATIONAL COALITION
FOR CANCER SURVIVORSHIP

The power of survivorship. The promise of quality care.

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This publication has been created by the National Coalition for Cancer Survivorship (NCCS) to provide general information and to serve as a resource for people experiencing a diagnosis of cancer. This resource represents the opinions of NCCS and is not designed to provide individual advice nor to substitute for professional counsel.

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ABOUT THE NATIONAL COALITION FOR CANCER SURVIVORSHIP

The National Coalition for Cancer Survivorship (NCCS) is the oldest survivor-led cancer advocacy organization and a highly respected authentic voice at the federal level, advocating for quality cancer care for all Americans and empowering cancer survivors. NCCS focuses on advancing public policy issues that affect cancer survivors on the federal level and providing tools and publications to individuals that address many important survivorship issues, especially the role of advocating for oneself.

In 2004, NCCS launched a legislative grassroots advocacy network, *Cancer Advocacy Now!*[™], to assure that cancer survivors, their families, friends, and caregivers have a voice in advocating for quality cancer care in Washington, D.C. and in forums where health-care policy is decided.

To learn more about NCCS or to join the *Cancer Advocacy Now!* network, visit www.canceradvocacy.org.

TABLE OF CONTENTS

	<i>Page</i>
CANCER IS A CRISIS	1
CANCER AND FEAR	2
FEAR OF DEATH	2
FEAR OF RECURRENCE	3
FEAR OF STIGMA	4
REMAINING POSITIVE	4
HOPE AND OPTIMISM	5
THE CHANGING MOSAIC OF HOPE	6
HOPE AND DENIAL	6
HOPE AND DEPRESSION	7
THE THREAT OF HOPELESSNESS	7
FAMILY HOPE	8
SUMMARY POINTS ABOUT HOW PEOPLE HOPE	9
A NOTE ABOUT HOPING FOR HEALTH CARE PROFESSIONALS	10
HOPE AND CONFIDENTIALITY	11
MAINTAINING PROFESSIONAL HOPE	11
MAINTAINING A COMMUNITY OF HOPE	12
REFERENCES AND RESOURCES	13
PUBLICATIONS ON OTHER SURVIVORSHIP ISSUES	14
HOPE WORKSHEETS	15
UNDERSTANDING THE SIGNIFICANCE OF HOPE IN YOUR LIFE	15
HOPING IS COPING	17
A JOURNAL OF HOPE	19
RANDOM THOUGHTS ON HOPE	20

*Dedicated with love to my sister Eleanor,
a twelve-year survivor of multiple myeloma.
She well understood the importance of hope.*

“Cancer Survivor” is defined by the National Coalition for Cancer Survivorship as anyone with a history of cancer, from the time of diagnosis and for the remainder of life, whether that is days or decades.

Survivorship is the challenge faced daily by millions of Americans who have a history of cancer. Current statistics note that nearly 10 million people are cancer survivors. Today, over 62 percent of all persons with cancer are living 5 years after diagnosis. Survivorship, however, is not just about long-term survival. Instead, it is about one’s quality of life from diagnosis onward. It is living with, through and beyond cancer.¹

As detection and treatments have improved, many types of cancers have shifted from acute to chronic diseases, and some cancers are now highly curable. The statistics are positive, but numbers do not really tell very much about how persons with cancer survive—physically, psychologically, socially, economically or spiritually. They do not tell us how people with a cancer diagnosis learn to live with fear and uncertainty or how they manage to be hopeful.

CANCER IS A CRISIS

A diagnosis of cancer will create a state of crisis of some intensity in nearly all individuals. The reason for this crisis is that most persons have no habitual, problem-solving mechanisms for cancer-related crises, and there ensues what is called a state of cognitive confusion wherein you literally do not know how to think about the problem, how to evaluate reality, or how to formulate an outcome to the crisis. Information is needed, but due to the shock and unfamiliarity of the situation, it is hard to accept, and even harder to understand, the broad implications of the information you do receive. In short, a crisis generally throws a person into a normless situation, and a state of panic results.



AT BOTTOM,
EVERYTHING DEPENDS
UPON THE PRESENCE
OR ABSENCE OF ONE
SINGLE ELEMENT
IN THE SOUL—
HOPE.

Henri Frederic Amiel

Sequence of Crises

To make it even more difficult, for most persons diagnosed with cancer, cancer is not just one crisis, but a sequence of crises. There is the crisis of the diagnosis, or perhaps even earlier there was the crisis of finding a symptom that you feared might be cancer. There is the crisis during the initial, intensive treatment, whether it is surgery, chemotherapy, radiation therapy or a combination of therapies.

Often there is a crisis after finishing intensive treatment. The end of intensive treatment begins the waiting period to see whether or not the therapy has been effective. Some persons with cancer feel more secure about the potential of cure or about controlling their cancer when they are undergoing therapy, and are a little frightened when no treatment is being given. ²

For persons on treatment protocols, each treatment cycle may create a crisis. There also may be crisis periods related to side effects. If there is a recurrence of the disease, new crises will occur. A common factor of each of these crisis periods is that the crisis usually is accompanied by fear and uncertainty. Fear is a part of the disease of cancer. Fear is normal. It is a basic human emotion. Cancer-related fear can be managed.

.....

COURAGE IS LIKE LOVE;

IT MUST HAVE HOPE

FOR NOURISHMENT.

Napoleon Bonaparte
.....

CANCER AND FEAR

There are three major cancer-related fears described in the research literature. These are fear of death, fear of recurrence and fear of stigma, which is fear of being thought about or treated differently.

Fear of Death

While almost all researchers in psychosocial oncology acknowledge fear of death as a problem for persons diagnosed with cancer, the findings about how and when this fear diminishes are split. Some researchers report that fear of death diminished the further away from the diagnosis period a person gets. Other researchers report that fear of death may persist for years after cancer therapy is complete. Still other researchers have noted that even after what may be considered a definitive cure, survivors are less certain about living a long life.

The experience of having cancer produces emotional scars, and it may take years before cancer is no longer the major focal point of life, until a rebalancing of life issues and problems occurs. One cancer survivor noted that it took her almost eight years before cancer receded in emphasis:

*My life is a quilt, and one of those patches is cancer. It's never not there, it just doesn't hurt anymore.*³

Resuming life-oriented or life-focused thought processes after living with an acute fear of death may be a difficult transition, and the ability to make long-range plans can take months or even years.

Fear of Recurrence

Research has indicated that reactions related to the fear of recurrence of cancer range from worry and anger in the middle of the night, to panic and thoughts of suicide. We know that insufficient knowledge (being unable to know) if or when symptoms will recur can significantly affect an individual's overall sense of control.

Acute uncertainty can persist for as long as three years after the completion of cancer therapy, and uncertainty becomes a permanent companion of the cancer experience. It often is reactivated at critical times—for example, the anniversary of your cancer diagnosis may trigger survivor reactions that parallel those present in post-traumatic stress syndrome. These anniversary reactions include re-experiencing the diagnosis and nightmares or flashbacks about the cancer experience which stimulate anxiety.

A widely held assumption about recurrence is that an individual's response to recurrence is worse (more distressing and disabling) than the shock of the initial diagnosis of cancer. Many researchers, however, have not found this to be the case because those persons with a history of cancer already have developed some cancer-related coping mechanisms. In fact, most persons with cancer become expert about their own illness and treatment. They know, more or less, what to expect medically, and they learn how to navigate the health care system. They develop the language and the needed skills to manage crisis periods such as the recurrence of disease. In short, cancer survivors learn how to live with cancer.⁴

Eventually, cancer takes on a normal—perhaps a better term would be a “new normal”—rhythm that incorporates all of the changes brought about by the cancer experience. Persons without a personal history of cancer wonder how it is possible to live normally despite cancer, and this attitude is one of the challenges that must be faced.⁵



A MERE DREAM,

A VAGUE HOPE

MAY BE MORE POTENT

THAN CERTAINTY

IN A LESSER MANNER.

Mark Rutherford

Fear of Stigma

The disease of cancer still carries a stigma. Despite treatment advances and extended survival rates for many cancers, cancer remains a stigmatized disease, and persons with cancer must contend with societal attitudes, prejudices and discrimination solely on the basis of their cancer history.

The stress of a diagnosis of cancer and its subsequent treatment requires many personal and interpersonal changes. For example, during the treatment phase, there may have been a redistribution of tasks within your family unit and these functions may need to be renegotiated. There also may be significant changes in your relationships with friends and acquaintances. Now that you have been diagnosed with cancer, people you know may respond to you differently. They may negatively stereotype you as a “cancer victim” or believe that your cancer is an automatic death sentence.

Returning to work also may create various stresses. There may be a difference in the way coworkers treat a person who has been absent, even briefly, due to cancer. They may avoid you or isolate you. Also, due to a lack of understanding, ignorance or fear about cancer, many individuals with a cancer history experience some form of employment discrimination such as dismissal, demotion, or failure to get a promotion or new job.

The challenges and tasks of living with cancer are many. Perhaps most important of all these tasks is learning to live with uncertainty while maintaining a functional and optimal level of hope.



CANCER PATIENTS CRAVE

FEELING NORMAL,

AND INCORPORATE THE

GRAY AREAS OF LIVING

WITH UNCERTAINTY

INTO DAILY LIVING.

IT BECOMES NORMAL

TO LIVE WITH THE

STRESS OF CANCER

SURVIVORSHIP.

Anne A. Burt

Cancer Survivor

REMAINING POSITIVE

For the individual and for the family, cancer has a profound negative impact, yet hopefulness and a positive future orientation are important components for quality of life in cancer survivorship.

What is hope? Is there such a thing? How can it be defined? Is it helpful or harmful? Is it necessary?

Hope is a complex concept, one that often is misunderstood by many people including health care professionals. Part of the confusion is that people define hope differently. Another reason is that health care professionals tend to think in terms of therapeutic hope which is hope that is based on therapy and is related to a cure or remission of disease.⁶ There also is generalized hope, such as the hope to maintain a high-quality of life

despite a cancer diagnosis, and there is particularized hope which is hope for something specific such as being strong enough to walk without crutches at a child's wedding.

Hope and Optimism

Many people tend to interchange the terms of hope, wishing and optimism, but there are significant differences. Wishing is usually specific; you wish for something you desire. It almost always refers to a positive outcome and generally it is passive in nature.⁷ Optimism primarily emphasizes the positive aspects of a situation, and most people think of optimism as a positive trait. While optimism may be specific in nature, the individual does not necessarily have clear plans for where he or she wishes to go. Sometimes we refer to an overly optimistic person as a "Pollyanna," a concept based on a children's book written in 1913 where the main character, Pollyanna, sees only the good side of the bad things that happened to her.⁸ Optimism, then, may close off any painful feelings and it may be inflexible because it only focuses on a positive outcome.

Wishing and optimism both have places in our lives, but to live with a disease like cancer, to get through the rigors of treatment, to navigate the complex health care system, and to fend off society's negative views about cancer as a death sentence, you have to have a strong sense of hope. Therefore, it is important to understand the meanings and functions of hope.

In his book *Anatomy of Hope*, Groopman states that there is an authentic biology of hope, and that belief and expectation are key elements of hope.⁹ Others define hope in various ways.

Hope constitutes an essential experience of the human condition. It functions as a way of feeling, a way of thinking, a way of behaving and a way of relating to oneself and one's world.⁷

Hope means desirability of personal survival and the ability of the individual to exert a degree of influence on the surrounding world.¹⁰

Hope is necessary for healthy coping, its key purposes being the avoidance of despair and the desire to make life under stress bearable.¹¹

Hope is a cognitive-affective resource that is a psychological asset. The importance of this asset becomes greater in times of threat.¹²

Hope is "mental willpower plus waypower for goals." Willpower, in this definition is "the driving force to hopeful thinking." It is a sense of mental energy that helps move a person toward a goal. Waypower, the



HOPING IS

COPING.

Avery Weisman

second component in the hope equation, is the mental capacity used to find a way to reach your goals. It reflects the mental plans or road maps that guide hopeful thought.¹³

Hope is a way of thinking, feeling and acting. In fact, hope is a prerequisite for action. Hope is flexible, and it remains open to various possibilities and the necessity to change the desired outcome as the reality changes. These aspects of hope emphasize how important hope is for living with an illness as serious as cancer. Finally, it should be noted that hope is a phenomenologically positive state, and by definition, hope can never be false.



FOR WHEN HOPE

DOES AWAKEN,

AN ENTIRE LIFE

AWAKENS ALONG

WITH IT.

ONE COMES FULLY

TO LIFE.

John S. Dunne

The Changing Mosaic of Hope

Hope has a time aspect and involves a consideration of the future. It is not a static concept. Hope changes as situations and circumstances change.⁹ The phrase “the changing mosaic of hope” is useful for describing the shifting of hope and expectations. For example, when a cancer diagnosis is first determined, the individual almost always hopes for a complete cure. If this is not possible, that hope may be transformed into hope for long-term control of the disease, or for extended periods between recurrences. Even when hope for survival is dim, individuals will find other things to hope for—living to see a grandchild born, control of pain or even a dignified death.

Hope continues, but day by day, and week by week, the mosaic of hope changes as reality changes. When hopes are not realized, “broken hope” may occur.¹¹ Broken hope requires an adjustment of thinking if you are to regain a balance of hope after a setback or major disappointment.

Hope and Denial

A well-functioning hope does repress doubts and fears, but hope does not equate with denial. True hope is always based in reality. One expert notes that the main difference between hope and denial is that hope transcends reality, while denial avoids it.¹⁴

Cancer survivors need and desire accurate and honest information about their disease, treatment, potential side effects and prognosis. If presented with compassion and with assurance for continuing support, even bad news can be accepted, and new, more realistic goals can be assimilated into the hoping process.

Hope and Depression

Nothing ever prepares us for the really bad things in life, and we often are overwhelmed when they occur. Cancer is a negative life event, and it is expected that a person diagnosed with cancer will have feelings of sadness and depression at various times during the disease experience. Yet, research strongly suggests that persons with cancer are no more depressed than persons with other similar serious illnesses.¹⁵

Loss is a cause of much of the sadness and depression that accompany cancer. Just learning your diagnosis—that you have cancer—is depressing; it indicates a loss of good health. Other losses occur and these can accumulate and lead to depression. For example, there is the loss of “normal life” during intensive treatment. Or perhaps there is a loss of a body part due to the need to remove the cancerous tumor, or the loss of a bodily function like the ability to have children. There can be loss of hair, loss of income, loss of relationships and loss of dreams.

This type of depression is called reactive depression because it occurs after a significant and identifiable event (for example, learning about the recurrence of your cancer). These “normal” depressive responses sometimes become severe and they begin to interfere with daily activities, or they can result in very serious symptoms such as thoughts of suicide. Poorly controlled pain also puts you at risk for depression. When prolonged and severe, depressive symptoms usually require treatment that includes counseling and perhaps medication.¹⁶ If you find that you are having trouble with sadness and depression, talk to your physician or other members of your health care team about your concerns.

Depression often is related to bad news and loss of hope. You begin to feel there is no way to remain positive about the future. No matter how serious the situation, it is important to avoid hopelessness.¹⁷

The Threat of Hopelessness

Hopelessness suggests the loss of all hope and the acceptance that a feared and dreaded outcome will occur. An acute loss of hope is very serious because hopelessness is a condition of inaction in the face of threat. Therefore, a hopeless person becomes a helpless person because hopefulness is a necessary condition for action. A hope-lost person appears to be totally separated from, and indifferent to, both the internal and external environment.¹¹

Personal circumstances such as serious illness do not inevitably lead to hopelessness. Even foreshortened life does not in itself create hopeless-



NO MATTER WHAT
BEFALLS ME,
I FEEL COMMANDED TO
CHOOSE LIFE.
YOU CANNOT GIVE IN
TO DESPAIR.
YOU MAY HIT BOTTOM,
BUT EVEN THEN
YOU HAVE A CHOICE.
AND TO CHOOSE LIFE
MEANS AN OBLIGATION
NOT MERELY TO SURVIVE,
BUT TO LIVE.

Nessa Rapoport



THROUGH THE DAYS
AHEAD, MY NEW
SENSE OF HOPE,
NOW NEARLY AN
EXTINGUISHED SPARK,
WILL GROW BRIGHTER
AND LARGER,
AND IT WILL WARM
MY LIFE AS IT HAS
THE LIVES
OF COUNTLESS
OTHER SURVIVORS
BEFORE ME.

Carol Staudacher

ness; in fact, hope has a way of outlasting the facts of the illness.¹⁰ Above all, hope should never be utterly destroyed. Think of the overwhelming impact of the words, “It’s hopeless.”

Maintaining hope is not always easy, and at times of crises, you may need additional support and encouragement from your family, your health care team and other cancer survivors. This is not the time for false reassurances, but instead, it requires helping you to evaluate the situation realistically and to refocus hope. It is clear that hope functions as a protective mechanism, while hopelessness threatens your physical, psychosocial and spiritual health and quality of life.⁷

FAMILY HOPE

As a coping characteristic, hope is individualistic, and persons have various capacities for hoping and different approaches to maintaining hope. Personal hope is embedded in a broad social context. The way you hope develops within a particular family culture and within an historical framework and set of experiences.

Families also have well-established ways of hoping. The way your family of origin views hope and the strategies they use to maintain it have had an impact on how you currently hope. The people with whom you now live also influence how and for what you hope. These patterns are called “family hope constellations,”² and it is important to realize family differences with regard to hope.

For example, if you come from a religious family, your family may use religion as its primary hoping mechanism. As a result, statistics and medical facts may not be as important to this family because they know that “it is all in the hands of God,” or that “only God can know what will happen.” Prayer might be their (and your) major hoping strategy. You might draw great strength from the support of your pastor or priest or rabbi.

On the other hand, if religion and religious activities are not major focal points in your family of origin or in your current life, another hope constellation will predominate. If you come from a family with a strong emphasis on education and academics, you may find that the family relies more on a “research” basis for hope. Their hoping strategies may consist of obtaining and reading as much information as possible about your disease and about possible treatments and positive outcomes. They may use cancer information telephone and computer services, encourage you to get second, third and even more opinions, and to contact various cancer specialists and professionals around the country for their input

and support.

Another family may be less driven to get volumes of information about cancer, or may find it anxiety producing to have so many facts to sort through or to try to understand various theories and research studies. Instead, they put all of their faith in their own doctor or health care team and rely on these professionals as their main source of information and support. This family may find patient and community support groups especially helpful.

SUMMARY POINTS ABOUT HOW PEOPLE HOPE

- People hope differently. While hope is individualistic, your own hope strategies are impacted by how your family of origin and your present family use and maintain hope.
- Families tend to have similarities in the ways they hope, but family hope constellations are not mutually exclusive. For example, you may be religious and academic at the same time.
- Different types of hope constellations may lead to conflict between the person with cancer and family members or friends. It also can lead to conflict between the patient/family and the health care professionals who care for them, because health care professionals also hope in individual ways.
- Most people have never thought about “how” they hope. They just assume everyone hopes in the same manner that they themselves do. This does not refer simply to optimism or pessimism, but to the strategies people use to look forward and for maintaining a positive future outlook.
- Most health care professionals are not trained to do “hope assessments” or to recognize different hoping styles. They often think only in terms of “therapeutic” hope, and equate other hope with denial. This can have a negative impact on your interactions with them and can make you vulnerable to broken hope.
- It is important to think about your own hoping strategies and to be



HOPE AND
HOPELESSNESS
ARE BOTH CHOICES.
WHY NOT
CHOOSE HOPE?

Greg Anderson



EITHER WE HAVE
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Vaclav Havel

direct with family, friends and professional caregivers about what is most helpful to you with regard to using and maintaining hope. Never let anyone tell you that there is nothing further to hope for or that there is no hope. There is always something to hope for, and you, as an individual, have the right to determine for what, when and how you hope.

A NOTE ABOUT HOPING FOR HEALTH CARE PROFESSIONALS

An ongoing goal of National Coalition for Cancer Survivorship is to provide consumer input for health care professionals about how they communicate with their patients, and how they discuss cancer, treatment options, and outlook with patients and their family members. To help with this educational process, NCCS conducted a survey entitled “Words that Heal, Words that Harm.”¹⁸

Cancer survivors were asked to submit the most helpful and the least helpful statements made to them by members of their health care team. A few of their statements are reprinted below:

Surgeon to man with prostate cancer who asked if he shouldn't receive radiation therapy—

Your pathology was terrible. There's nothing you can do or we can do that will extend your life one hour.

Nurse to patient receiving chemotherapy for Hodgkin's disease—

Well, at least you don't have AIDS.

Internist to patient newly diagnosed with cancer—

I don't want you to feel guilty. It's not your fault you got cancer.

Radiation oncologist to patient beginning therapy—

I don't know why we're doing this radiation protocol; there isn't that much hope.

General practitioner telling patient initial diagnosis—

It's only Hodgkin's. It's no big deal. There's no reason you should be upset about this.

Male nurse to patient newly diagnosed with breast cancer—

Ask questions and tell people what you want and what you are concerned about.

Medical oncologist to cancer patient diagnosed with advanced disease—
Someone has to be in the 15% survival figure and it might as well be you.

Oncologist to woman when first diagnosed with gynecological cancer, now a seven-year survivor—
We will treat this cancer and then you will get on with your life.

Oncologist to newly diagnosed patient—
Something good will come of this.

In this list, it is quite easy to identify the helpful—and the harmful—statements. As health care professionals, it may not be as easy to recognize the power that our words can have. They may be uplifting or they may create word wounds. A decade from now, a cancer survivor may still use your words as an example of a negative communication exchange, or your words may still have positive meaning for the individual.



THERE IS

NO SUCH THING

AS FALSE HOPE.

Hope and Confidentiality

An individual's hope for the future is intensely personal and unique. For many persons faced with serious illness, a sense of future outlook that is positive and productive can be hard to maintain. Sharing hope is seen as a sign of confidence and close human relationship, and it implies great trust in the other person's understanding and thoughtfulness. It also deserves the same level of confidentiality as other therapeutic issues.

As a health care professional, think how you respond when someone, a person with advanced cancer for example, in confidence, discloses her hopes to you. Can you share in this hope? Or do you relate to a colleague, "She's in total denial, she's hoping for _____?"

It is extremely important not to be biased against hope in general, not to think only in terms of therapeutic hope, and not to favor solutions simply because they are reality-based. You need to understand the importance of hope for your patients, and to help them use their hope to enhance their quality of life.¹⁹

Maintaining Professional Hope

Sometimes, as caregivers, it is difficult to maintain professional hope. When you find your own vision of hope slipping, you need to reevalu-



WORDS THAT
CANCER SURVIVORS
FOUND MOST
HELPFUL



WERE PROACTIVE
AND EMPOWERING



REFRAMED THE
PROBLEM MORE CLEARLY
AND POSITIVELY



NORMALIZED THE
CANCER EXPERIENCE



ACKNOWLEDGED
INDIVIDUAL DIFFERENCES



SHOWED GENUINENESS
AND COMPASSION



ASSURED
CONTINUING SUPPORT



CONVEYED HOPE

ate your measures of success. This may require moving beyond disease outcome measures to focus more on quality of life issues and psychosocial successes.

Psychosocial successes are those identifiable and significant events, facilitated by the caregiver, that contribute to the emotional well-being of the patient and family.²⁰ Helping a patient meet a goal, returning to work for example, should be hope-reinforcing for the professional. Take note of and comfort from these events and use them to rediscover your vast capacity for professional and personal hope.

Maintaining a Community of Hope

Perhaps the most important thing we can do in our treatment centers is to provide a “community of hope” for our patients, to give the message that we are hopeful about cancer survivorship and hopeful for the individual patients treated there.

A community of hope fosters trust and openness and teamwork. It provides support and continuity of care. It allows for individual differences in coping with cancer and accepts all visions of hope that patients and their family members bring to the treatment process. No matter what the disease stage, every patient has the right to be hopeful, and every health care professional has an obligation to support their patients in their visions of hope.

REFERENCES

1. Leigh, S. and Logan, C. The cancer survivorship movement. *Cancer Investigation*, 9:571-579, 1991.
2. Clark, E. Family Challenges: Communication and Teamwork. In B. Hoffman (ed.). *A Cancer Survivor's Almanac: Charting Your Journey*. Hoboken, NJ: John Wiley & Sons, 2004.
3. Lazarus, B. In Mullan, F. and Hoffman B. *Charting the Journey. An Almanac of Practical Resources for Cancer Survivors*. Mount Vernon, NY: Consumers Union, 1990.
4. Harpham, W. *Happiness in a Storm: Facing Illness and Embracing Life as a Survivor*. New York: W W Norton & Co., 2005.
5. Leigh, S. and Clark, E. Psychosocial aspects of cancer survivorship. In Berger, A., Shuster, and Van Roenn, J. (eds.), *Principles and Practice of Palliative Care and Supportive Oncology*. Philadelphia: Lippincott, Williams & Wilkins, 2007.
6. Nuland, S. *How We Die*. New York: Alfred A. Knopf, 1994.
7. Farran, C., Herth, K., and Popovich, J. *Hope and Hopelessness. Critical Clinical Constructs*. Thousand Oaks: Sage Publications, 1995.
8. Porter, E. *Pollyanna*. Boston: Page, 1913.
9. Groopman, J. *Anatomy of Hope: How People Prevail in the Face of Illness*. New York: Random House, 2004.
10. Weisman, A. *On Dying and Denying. A Psychiatric Study of Terminality*. New York: Behavioral Publications, 1972.
11. Korner, L. Hope as a method of coping. *Journal of Consulting and Clinical Psychology*, 34(2):134-139, 1970.
12. Staats, S. and Stassen, M. Hope: An affective cognition. *Social Indicators Research*, 17:235-242, 1985.
13. Snyder, C. *The Psychology of Hope*. New York: The Free Press, 1994.
14. Callan, D. Hope as a clinical issue in oncology social work, *Journal of Psychosocial Oncology*, 7(3):31-46, 1989.
15. Massie, M. Depression. In Holland, J. and Rowland, J. (eds.), *Handbook of Psychooncology*. New York: Oxford University Press, 1990.
16. Fiore, N. Mind and body: Harnessing your inner resources. In Hoffman, B. (ed.), *A Cancer Survivor's Almanac: Charting Your Journey*. Hoboken, NJ: John Wiley & Sons, 2004.
17. Gil, S. and Gilbar, O. Hopelessness among cancer patients. *Journal of Psychosocial Oncology*, 19:21-33, 2001.
18. Clark, E. *Words that Heal, Words that Harm*. Silver Spring: National Coalition for Cancer Survivorship, 1995.
19. Hearth, K. A. Development and implementation of a hope intervention program. *Oncology Nursing Forum*, 28(6):1009-1017, 2001.
20. Clark, E. in Wessells, D., et al. (eds.), *Professional Burnout in Medicine and the Helping Professions*. New York: The Haworth Press, 1989.



WITH COMMUNICATION
COMES UNDERSTANDING
AND CLARITY;
WITH UNDERSTANDING,
FEAR DIMINISHES;
IN THE ABSENCE OF FEAR,
HOPE EMERGES;
AND IN THE PRESENCE
OF HOPE,
ANYTHING IS POSSIBLE.

Ellen Stovall

PUBLICATIONS ON OTHER SURVIVORSHIP ISSUES

A Cancer Survivor's Almanac: Charting Your Journey, edited by Barbara Hoffman, J.D., John Wiley & Sons (Hoboken, NJ). 2004 Edition. Available from the National Coalition for Cancer Survivorship and bookstores nationwide.

Cancer Survival Toolbox[®] developed by NCCS in collaboration with the Oncology Nursing Society, the Association of Oncology Social Work and the National Association of Social Workers, with support from the Amgen Foundation, Bayer Healthcare, the Eli Lilly and Company Foundation, Novartis Oncology, and sanofi-aventis. Available free of charge 877-TOOLS-4-U (877-866-5748) in English and Spanish. Chinese transcript also available. May be downloaded from www.canceradvocacy.org/toolbox.

Self-Advocacy: A Cancer Survivor's Handbook, Published by the National Coalition for Cancer Survivorship (2003). Available from NCCS.

Teamwork: The Cancer Patient's Guide to Talking with Your Doctor, by Elizabeth J. Clark, Ph.D., Editor. Published by the National Coalition for Cancer Survivorship. Third Edition (2003), 58 pp. Available from NCCS in English and Spanish.

What Cancer Survivors Need to Know About Health Insurance, by Kimberly Calder, M.P.S. and Karen Pollitz, M.P.P., National Coalition for Cancer Survivorship. Sixth Edition (2006), 34pp. Available from NCCS in English and Spanish.

Working It Out: Your Employment Rights As a Cancer Survivor, by Barbara Hoffman, JD. Published by the National Coalition for Cancer Survivorship. Eighth Edition (2008), 19 pp. Available in English and Spanish.

HOPE WORKSHEET 1

Understanding the Significance of Hope in Your Life

How do you personally define hope? What meaning do you give it?

How do you hope? What hope strategies do you use?

What kind of family hope did you grow up with—how did your family of origin hope?

Significance of Hope (continued)

What hope strategies do your significant others use?

Name:

Main hoping strategy:

Name:

Main hoping strategy:

Name:

Main hoping strategy:

Identify any conflicts in your hoping style with those of your significant others.

HOPE WORKSHEET 2

Hoping is Coping

This page is to help you maintain perspective. It is a space for you to chronicle your personal hopes during your cancer experience.

Date:

My hopes:

Date:

My hopes:

Date:

My hopes:

Date:

My hopes:

Date:

My hopes:

Hoping is Coping (continued)

Date:

My hopes:

Date:

My hopes:

Date:

My hopes:

Date:

My hopes:

Date:

My hopes:

HOPE WORKSHEET 3

A Journal of Hope

These pages are for recording the most hopeful and helpful things others have said to you since your cancer diagnosis. REVIEW THEM OFTEN!

Date:

Person Making Statement:

Statement:

Why this statement was helpful:

Date:

Person Making Statement:

Statement:

Why this statement was helpful:

Date:

Person Making Statement:

Statement:

Why this statement was helpful:

HOPE WORKSHEET 4

Random Thoughts on Hope

Use this page to record any of your own random thoughts on hope or any meaningful sayings about hope that you find elsewhere. You might wish to share these sayings with others experiencing similar crises.

THERE IS NO SUCH THING AS FALSE HOPE.



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