

Living with Uncertainty

Many survivors feel uncertain about their future after completing cancer treatment. Understanding the reasons why you are feeling this way, and knowing where to look for support, can help you feel more confident in your survivorship.

Living with Uncertainty: Detailed Information

This information is meant to be a general introduction to this topic. The purpose is to provide a starting point for you to become more informed about important matters that may be affecting your life as a survivor and to provide ideas about steps you can take to learn more. This information is not intended nor should it be interpreted as providing professional medical, legal and financial advice. You should consult a trained professional for more information. Please read the Suggestions (<http://www.livestrong.org/Get-Help/Learn-About-Cancer/Cancer-Support-Topics/Emotional-Effects-of-Cancer/Living-With-Uncertainty#s#s>) and Additional Resources (<http://www.livestrong.org/Get-Help/Learn-About-Cancer/Cancer-Support-Topics/Emotional-Effects-of-Cancer/Living-With-Uncertainty#a#a>) documents for questions to ask and for more resources

The uncertainties that cancer can cause do not always end with treatment. While the immediate illness may be in remission, you may find that your life has changed in unexpected ways. You may feel uncertain about the changes cancer caused and worry about what your life is going to be like after cancer. Many cancer survivors find that they feel unsure about many aspects of their lives. This is called living with uncertainty.

You may be able to live with uncertainty in your life and remain positive. However, living with uncertainty can also be very difficult and upsetting. Some survivors think that if they aren't certain about most things in their life, then bad things are likely to happen. It is important to realize that there are some things, like how long you are going to live, that no one can know for certain. It is possible to learn to live with uncertainty and not feel so overwhelmed by the things that you do not know and cannot control.

Do all survivors live with uncertainty?

All cancer survivors live with some uncertainty about their future, but it affects different people in different ways. How you deal with uncertainty could be related more to your personality and coping style than the type of cancer or treatment you received. It could also be related to how much you think about cancer.

Survivors may be uncertain about issues such as:

- Their health status
- The quality of their medical care
- How long they will live after treatment
- Their careers

Some survivors may put the cancer experience in the past and choose to hardly ever think about it. The uncertainties that cancer causes may not bother them very much. Others might think about cancer often and find those thoughts are overwhelming. They may live with a lot of fears about whether the cancer will come back or how cancer will affect the future. Still other survivors might think about the positive changes cancer has brought such as a new purpose and strength in life. They may be able to more easily accept and adapt to the changes and challenges.

All of these responses are normal. However, if the fear of uncertainty begins to prevent you from enjoying life and doing things that are important to you, it may be time to talk with a licensed counselor or therapist about finding ways to live with uncertainty. Uncertainty may be a part of your life now, but it does not have to affect your quality of life.

What effect does living with uncertainty have on survivors?

Living with uncertainty can affect survivors in many different ways. Some may find that it causes them to feel upset or overwhelmed. Others may be motivated to change or improve their lives. There is no right or wrong way to feel about living with uncertainty. However, there are ways to manage better manage this challenge.

Research has shown that some survivors struggle with depression, distress and anxiety, and that these struggles may be related to living with uncertainty. Some people may tell you that you should just be happy that you survived, and advise that you should not worry about the unknown that you see as part of your life now. It is important to understand that living with uncertainty can be very difficult at times. It is also okay to talk about how that makes you feel.

While uncertainty about your health may lead you to worry, it may also motivate you to include more healthy behaviors in your lifestyle. You may chose to eat better, become more physically active to whatever extent possible, and pay closer attention to changes in your body. Feeling like you are doing something to take charge and promote good health may make you feel less uncertain about your future.

In addition, some survivors may find motivation to strengthen relationships with loved ones and friends. Some have described how fighting and overcoming cancer gave them the self-confidence and emotional strength to create positive changes in their lives. If you live with uncertainty about the future, it can motivate you to make the most of every day.

When might survivors notice uncertainty in their lives?

Uncertainty may or may not be part of your daily life. However, at certain times, you may find that you are suddenly faced with a lot of uncertainty. For example, when going in for a check-up, you may wonder if the cancer has spread. There may be concerns about future relationships and whether you will be able to have children. When trying to find a job, you may have concerns about your employer finding out about your cancer diagnosis and whether you can get health insurance. When treatment is done, you may wonder if the cancer will return.

It is also possible to live with a general feeling of uncertainty about what tomorrow is going to bring. Many survivors think that before cancer, they had fewer doubts or unknowns in their lives. Having cancer can make you more aware of uncertainties, because you never expected to get cancer in the first place. You may find yourself thinking, "If I can get cancer, then what else can happen?" This general feeling of uncertainty in your daily life is a common experience for cancer survivors.

If living with uncertainty overwhelms you, talk with your health care team. You can ask for a referral to a mental health professional to find ways to deal with your concerns. It may also be helpful to talk with other survivors about whether they feel like they are living with uncertainty and what they are doing to make it easier. If you are worried about whether your cancer will come back, talk to your health care team about risk factors, cancer prevention and screening, and other healthy behaviors.

This document was produced in collaboration with:

Brad J. Zebrack, PhD, MSW

Assistant Professor, University of Southern California School of Social Work

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Living with Uncertainty: Suggestions

The suggestions that follow are based on the information presented in the Detailed Information (<http://www.livestrong.org/Get-Help/Learn-About-Cancer/Cancer-Support-Topics/Emotional-Effects-of-Cancer/Living-With-Uncertainty#d#d>) document. They are meant to help you take what you learn and apply the information to your own needs. This information is not intended nor should it be interpreted as providing professional medical, legal and financial advice. You should consult a trained professional for more information.

Please read the Additional Resources (<http://www.livestrong.org/Get-Help/Learn-About-Cancer/Cancer-Support-Topics/Emotional-Effects-of-Cancer/Living-With-Uncertainty#a#a>) document for links to more resources.

- If living with uncertainty overwhelms you, talk to a mental health professional:

Ask your health care team for a referral to a therapist who works with other cancer survivors. Most cancer centers employ oncology social workers who are specially trained to work with cancer survivors and their families. Even if you are not a patient at a cancer center, the oncology social worker may meet with you or refer you to someone else in the community. The Association of Oncology Social Work is also a good resource. Visit them online at <http://www.aosw.org> or call 1-215-599-6093.

- It is important to interview the therapist to find out if he or she is the right professional for you.

Speak honestly with the therapist and let him or her know your reasons for wanting to work with a therapist.

Examples of questions to ask include:

- What type of education background do you have?
 - What professional license do you have?
 - What is your experience working with people with cancer?
 - What do you understand about the emotional response to this illness?
 - Will costs be covered, and do you take my insurance?
 - Do you work with people who are anxious? Depressed?
 - Do you know community resources for people with cancer?
- Talk to other survivors about how they are living with uncertainty.

Support groups provide a safe environment to share experiences with other survivors, learn new ways to handle difficult situations and talk about the emotions. You will see different styles of coping with stress and adjusting to life as a cancer survivor. If you are uncomfortable talking about certain subjects with your family or friends, a support group offers you a place to talk freely about what is important to you.

Ways to find out more about support groups in your area:

- Ask a member of your health care team for suggestions. Most cancer programs offer support groups for cancer survivors and their family members right in the clinic or hospital.
- Call a nearby cancer center or university hospital and ask about support groups.
- Visit **LIVESTRONG** Navigation Services at LIVESTRONG.org/Get-Help, or call 1.855.220.7777 for information on support groups.

Share your concerns and feelings with people you trust. Talking with another person about your feelings and what is causing them can help you understand more clearly what you are feeling and help you find ways to manage your feelings.

- If you are worried about a recurrence of cancer, talk to your health care team about cancer prevention and healthy behaviors.
 - Communicating openly with your health care team may help you feel less uncertain your health or medical care. Provide information about your cancer history to all of your health care providers including the primary care physician, OB/GYN, and dentist.
 - Ask about cancer prevention screening guidelines such as:
 - Regularly scheduled mammography and pap smear for women
 - PSA testing for prostate cancer
 - Colonoscopy for colorectal cancer
- Talk to your health care team about what healthy behaviors you should include in your daily lifestyle:
 - You must discuss any changes in your diet or exercise plan with a member of your health care team before you start. Start by reading about healthy behaviors and bringing a list of questions and healthy behaviors you are considering to your health care appointment. Discuss what you have learned from these resources, find out if they are accurate, and ask whether the information applies to your situation.
 - Write down what you eat and drink for a week including any nutritional supplements and herbal products. Ask your doctor for a referral to talk with a dietician or nutritionist—they can often be found through a local hospital. Many cancer centers now have nutritionists who can discuss your food choices with you as a free service through your care center or local hospital. Ask about costs to you before the meeting.
 - Before developing an exercise plan, talk with your health care team about what exercises, if any, would be good for you. After you understand what exercises are good for your recovery needs, you may want to also consult with a physical therapist or a fitness expert through a local fitness center.

Living with Uncertainty: Additional Resources

LIVESTRONG Navigation Services

[LIVESTRONG.org/Get-Help](https://www.livestrong.org/Get-Help)

Online: Complete an intake form through the LIVESTRONG website.

Phone: 1.855.220.7777 (English and Spanish)

Navigators are available for calls Monday through Friday, 9 a.m. to 5 p.m. (Central Time). Voicemail is available after hours.

LIVESTRONG offers assistance to anyone affected by cancer, including the person diagnosed, loved ones, caregivers and friends. The program provides information about fertility risks and preservation options, treatment choices, health literacy and matching to clinical trials. Emotional support services, peer-to-peer matching and assistance with financial, employment and insurance issues are also available. To provide these services, **LIVESTRONG** has partnered with several organizations including Imerman Angels, Navigate Cancer Foundation, Patient Advocate Foundation and EmergingMed.

American Cancer Society (ACS)

www.cancer.org

Email: Submit questions in English or Spanish from the "Contact Us" page.

Phone: 1-800-227-2345

TTY for deaf or hard of hearing callers: 1-866-228-4327

The American Cancer Society (ACS) offers information about many of the challenges of cancer and survivorship. You can search for information by cancer type or by topic. ACS provides a list of support groups in your area. You can join online groups and message boards. Some information on the website is available in Spanish, Chinese, Korean and Vietnamese. ACS specialists can answer questions 24 hours a day by phone or email.

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