

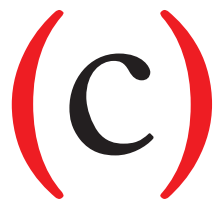


never feel alone

young (cancer) spouses

Helping spouses cope with cancer.

Quick
Guide



About this guide and YoungCancerSpouses

About this guide.

Newly Diagnosed – A Quick Guide is written for you by people who have been right where you are today. It is designed to give you the important information you need now without going into tremendous detail. We hope it will help stop your head from spinning as you begin to navigate all of the complications and implications of your loved one's cancer diagnosis. For more information on any of the topics included in this guide, or to join our forum and talk with other young cancer spouses, please visit our Web site: www.youngcancerspouses.org.

About YoungCancerSpouses

Mission Statement

Our Mission is to bring together young spouses of adults with cancer to share information, support, and experiences.

Vision Statement

The needs of young spouses of cancer patients often go unrecognized and unappreciated. The emotional and logistical issues a young spouse of a cancer patient faces are vastly different from spouses of older cancer patients that dominate oncology units and support groups. General family support groups are likewise inadequate at addressing the needs of a young cancer spouses. At YoungCancerSpouses we seek to provide a source of practical information gained from our experience as a young cancer spouse. We also strive to bring together other young cancer spouses to share ideas, lend support, and validate their wide range of feelings and emotions so young cancer spouses will find comfort in an understanding community.

1 *Immediate Emotional Impact*

The unbelievable has just happened. Your young spouse has just been diagnosed with cancer. You're probably reeling from the impact and your emotions are running wild. They may not make any sense to you right now, but this emotional rollercoaster – and all of the feelings expressed below – are very normal. Be patient with yourself.

Shock/Denial/Disbelief:

How could this be?! Old people get cancer! The doctors must have made a mistake; my wife is too young to have cancer. You may find yourself in a kind of haze – the fog of disbelief – where you just can't process what is happening.

Anger: Why did this happen! Whose fault is this?! Is it all those chemicals she worked with? Too much time on the computer? Not eating right or exercising? Is it the water we drink? There must be something, someone, to blame for this!

Terror: How are we going to get through this? How can we afford this?

Fear of losing your spouse: My wife is going to die. How will I survive if I lose him? How will the kids survive if he dies? How can I be a single parent? If he dies, I'll never have children of my own! I can't support myself (and the kids) if she dies.

Feeling alone: I am young and dealing with this crap – everyone else who has cancer is old. No one knows what I am going through, it's not the same as when you're old!

Are we being punished?: Why me, why him, why us? What did we do to deserve this? Is this my punishment for something I did? Can I somehow make it all right?

Vowing perfectionism: I will be the best caregiver possible. I will go to every appointment and never leave her side. Somehow, that will make her better.

HELP! What do I do? I don't know how to care for a cancer patient! How will we cope?

Why not me?: It would be easier to have the disease instead of watching my wife suffer.

Guilt: I am healthy and my spouse is the one with cancer. I am glad it is not me. This is my wife/husband who is sick, how can I be glad it's not me?

There will also be other feelings too – but realize that all of these confusing feelings are normal!

2 *Why and how to take care of yourself*

Why you need to take care of yourself.

Most young cancer spouses feel that they cannot take breaks for themselves. You may feel that with all your spouse is going through, you don't deserve a break. Everything you have to deal with pales in comparison to cancer, and if he or she can't take a break, why should you? You may fear that the doctors or nurses will make a mistake if you are not there to check their every move, or that if you leave the house for even a minute something terrible will happen.

These feelings are very common, but in order to be the best caregiver you can be, you must learn to take care of yourself. You are a person in your own right, and you deserve care and compassion – both from others and from yourself.

You know it in your head, but you need to know it in your heart, too. By running yourself down, you cannot make your spouse better. In fact, it may make the situation even worse. If you are physically or emotionally sick, no one can care for your spouse as well as you can. So take measures to reduce the chance that you will get so run down that you cannot care for your spouse. If you have children or other dependents, you need to be able to care for them too.

How to care for yourself so you can care for your husband/wife.

Here are a few simple suggestions for taking care of yourself:

Take a walk, preferably outside.

Get some exercise – running, biking or the gym. Commit to it a couple of times per week.

Eat well – get quality takeout if you can't cook (such as salads or healthy soups), or enlist the help of friends or family to help you stock up with healthy meals.

Take a nap whenever possible – a great time for a nap is when your spouse has visitors.

Go out for coffee with a good friend who will let you talk truthfully about how YOU feel and what YOU are going through. You need to get your feelings out as well.

If you can find an appropriate one, try a support group for families of cancer patients.

Individual therapy – Often, this can be the only place that feels truly safe to let out how caregiving and watching what your spouse is going through is affecting you.

3 *Practical things to know now – research and second opinions*

Research.

You have probably had at least one meeting with the oncologists (and various doctors). They may have reassured you that they know exactly how to treat your spouse's cancer. However – it is VITAL that you do your own research! Even the best, most well-meaning doctors can make mistakes or overlook other options. Do your own research, or have a trusted, detail-oriented friend help you to do it.

You will be a better advocate if you are well informed and have a list of questions, concerns, information on clinical trials, etc. Here are some tips:

Make the doctors explain (in terms you can understand) why they want to do a particular treatment instead of the other one you read about.

Don't be afraid to ask questions, get more information, request that your spouse's case be presented to the tumor board, etc.

Ask the oncologist how they get additional perspectives on tough cases. If they don't consult with their colleagues, that is a huge warning sign!

Second opinions.

Second opinions are always a good idea, even if the first doctor seems like a smart, competent person. If possible, get that second opinion before treatment starts. Sometimes the options change once treatment begins.

You won't know for sure if there is a better option out there unless you do the research and do your best to get a second opinion. Don't worry about hurting anyone's feelings, or in questioning what the doctors say. This is your spouse's life. So ASK – it is your right and duty to advocate for you and your spouse!

4 *Fertility – don't take no for an answer*

While preserving fertility is an important concern for many young couples, preserving a patient's fertility is neither the oncologist's main concern nor their specialty. If the desire to have children is in your future, you need to preserve your spouse's fertility before treatment begins. If the doctors don't listen, grab

a nurse and ask her for help. It is all too easy to get sped right into treatment, leaving fertility by the wayside. You might feel selfish, superficial, or like you're focusing on the wrong thing, but you have the right to ask for assistance.

5 *Where to get treatment*

When considering where your spouse should get treatment, there are a lot of factors to consider. You probably have many people telling you what to do, "go to the local hospital because it's close and that will be less stressful than traveling"; "only the closest Brand Name Cancer Center will be able to successfully treat her"; "only a specific doctor will do." Most of us who have walked this path will agree that there is some truth in all these things that you are probably hearing.

Making the very important decision of where your spouse should be treated comes down to what we have already said - research, research, research! It

will seem like there is no time to waste and you need to go with the first option that looks good. However, making the best choice for your spouse's cancer and personal situation is the most important thing. The Brand Name Cancer Center may do the same protocol as your local hospital with the same odds of success, or a lesser-known hospital in your area may have more experience than the Cancer Center with a particular type of cancer. Consider a doctor who will listen to your concerns about individualized care for your spouse as a whole person in addition to delivering a first-rate treatment protocol. Talk with lots of people, and do your own research before deciding where to be treated.

6 *Getting 'stuck' – your spouse has options*

If chemotherapy becomes part of your spouse's treatment, it typically requires intravenous access (IV) for every session. There are several different types of IVs available; here we briefly review your options so you can discuss them with your doctor.

Peripheral IV. – The most basic form of iv and the one that will come to mind when you think of hospital IVs. A nurse will insert a small catheter into a vein in the arm or hand and it will be removed before the patient leaves the hospital.

PICC line – This catheter is typically inserted into the large vein in the arm and has about 6 inches of tube and 1-3 ports outside of the arm. It should last between 2 and 6 months and requires a minor procedure to be put in. The ports do not require a needle to access it, so anyone can be taught to use it. It requires daily saline and heparin flushes and weekly dressing changes.

Port-a-cath – This requires minor surgery to be placed and leaves one or two small nickel sized bumps (the access ports) under the skin. Nothing is exposed to the outside so it requires a needle and certification to access it. This catheter is expected to last several years.

Each type of catheter comes with advantages and disadvantages. For example, a PICC line requires more care, but can be accessed at home if your spouse needs hydration. In contrast, a Port-a-cath cannot be accessed at home, but does not require daily care. A peripheral IV leaves nothing in the patient, but he or she must be 'stuck' every time a procedure is done. Your spouse will receive one or more of these catheters.

At YoungCancerSpouses we do not advocate any particular type of catheter, but we do urge you to discuss the options with your doctor.

7 *Sorting through and sharing information*

Sorting through information, and taking notes

At a doctor's appointment, you will get lots of information that can easily be overwhelming. Here are a few ways to cope:

Have a trusted friend or family member come with you to the appointments to listen and help you take notes.

Bring a tape recorder so you don't miss anything.

Get a sturdy notebook that you can carry with you for questions, research notes, etc. The information needs to be organized and scraps of paper easily get lost. The downloadable forms at www.youngcancerspouses.org are a good place to start.

Sharing information

Lots of people will want to know how your spouse is doing, what is the diagnosis, how he or she is feeling, etc. You probably won't have anyone asking you how you're handling it, or how stressful it is for you to repeat the same story over and over. At first, the easiest thing might be to designate a friend or family member as the contact person to relay the updates through e-mails or phone calls. That will take some of the pressure off of you, both in terms of time spent and the stress of having to constantly repeat the story.

In time, you will probably want to set up some kind of regular, consistent way for people to get basic updates (a website, YahooGroup, etc.). Also, it is okay if you don't answer your phone or emails.

8 *Employment and Insurance Issues*

Employment Issues

Even though these are the last things you want to think about, you will have to deal with these issues. Among the first things you will need to find out is how much time you (and your spouse) will be able to take off from work, whether it will be paid or unpaid, vacation or sick days, how long they will hold your job, if your co-workers can donate sick or vacation time to you, etc. Consider the following:

The Family and Medical Leave Act allows you take 12 weeks per year (if you have been with the company for 12 months and the company has over 50 employees) without losing your job. Whether the leave is paid or unpaid is up to the company.

Ask about flex time – if you need to take an afternoon off, can you make up the time by working at home or on a weekend?

If you can afford it, you might see if your employer will allow you to reduce your job down to half time and at flexible times, giving you more time with your spouse.

Discuss whether your spouse will be able to work at all. For some cancers, he or she will be in the hospital for the treatments, or just too sick to work. Can they do some work from home?

Look into disability insurance, long-term disability insurance, and other such insurances and assistance that might help while you or your spouse is unable to work.

Insurance Issues

Insurance coverage is often very confusing, but it is very important that you thoroughly understand your coverage. When you talk with the insurance company, ask that your spouse be assigned a case worker with oncology experience. Case workers are often more knowledgeable about cancer than the average insurance representative, and can help you navigate the maze of coverage, appeals, and so on. Also, have someone walk you through what is covered under your insurance, what is not, and how your particular insurance works for cancer treatment. It could be an excellent case worker at the insurance company, a Human Resources representative at your company, or even a friend who reads your policy and gives you a basic idea of how things work.

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Disclaimer:

The information provided through this document is not intended nor recommended as a substitute for professional medical advice. The information provided in this document should not be used for diagnosing or treating a health problems or disease. If you have or suspect you may have a health problem, you should consult your health care provider.

Always seek the advice of your health care team regarding any medical condition or treatment. Further, none of the information herein should be construed as a substitute for professional legal or financial advice. Please consult professionals with expertise in your state's laws and regulations to assist you with said issues.