

# Helpful Online Information for Brain Tumor Patients

**Huntsman Cancer Institute**  
**Cancer Types and Topics**  
[www.huntsmancancer.org](http://www.huntsmancancer.org)

**National Cancer Institute**  
[www.cancer.gov](http://www.cancer.gov)

**National Brain Tumor Society**  
[www.abta.org](http://www.abta.org)

**National Comprehensive Cancer Network**  
[www.nccn.org/patients/guidelines/cancers.aspx](http://www.nccn.org/patients/guidelines/cancers.aspx)

**National Brain Tumor Society**  
[www.braintumor.org](http://www.braintumor.org)

**National Institutes of Health Clinical Trials**  
[www.clinicaltrials.gov](http://www.clinicaltrials.gov)

**American Cancer Society**  
[www.cancer.org](http://www.cancer.org)

**National Institutes of Health  
Complementary and Integrative Health**  
[www.nccih.nih.gov](http://www.nccih.nih.gov)

**American Society of Clinical Oncology**  
[www.cancer.net/cancer-types/brain-tumor](http://www.cancer.net/cancer-types/brain-tumor)



## Neuro-Oncology Diagnosis Summary

### Non-Gliomas

- Germinoma
- Lymphoma
- Medulloblastoma
- Meningioma
- Metastatic Tumor
- Pituitary Adenoma,  
Pituitary Tumor

### Gliomas

- Astrocytoma
- Ependymoma
- Glioblastoma
- Oligodendroglioma

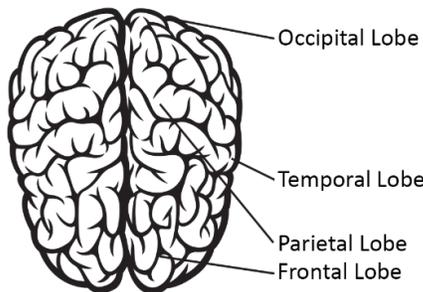
### Grade

- Grade 1
- Grade 2
- Grade 3
- Grade 4

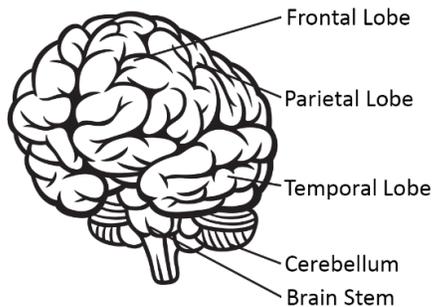
### Mutations

1p19q \_\_\_\_\_  
 IDH \_\_\_\_\_  
 MGMT \_\_\_\_\_  
 Other \_\_\_\_\_

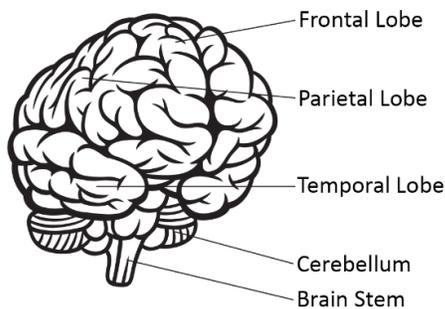
Top View of Brain



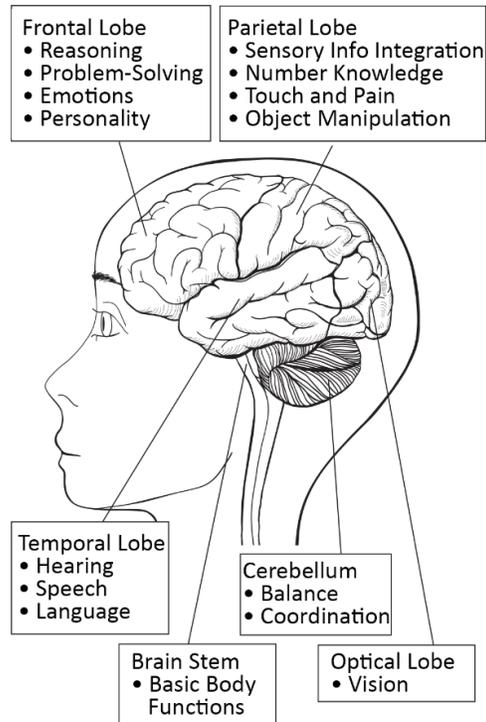
Left Front View of Brain



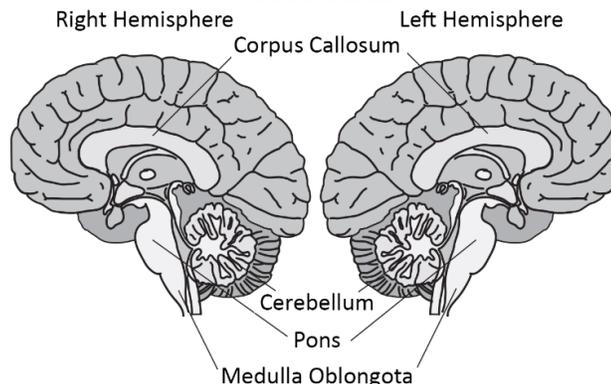
Right Front View of Brain



Functions of Brain Areas



Inside the Brain





## Caregiver Burnout

### What is caregiver burnout?

Caregiver burnout is a normal response to caring for a loved one who is sick. The effects of burnout are similar to feeling depressed.

Taking care of a person who has cancer takes time, work, and effort. Caregivers often forget to take care of their own physical and emotional health. In fact, studies show more than 50% of caregivers experience burnout.

### What are signs of caregiver burnout?

People feel burnout differently, but it often has physical, emotional, and spiritual aspects:

- A feeling that something bad is going to happen
- Anger
- Anxiety
- Fatigue
- Hard time concentrating
- Hard time making decisions or problem solving
- Headaches
- Feeling tense
- Sleep problems
- Shaking or trembling
- Feelings of sadness or grief

It is important to know about caregiver burnout so you can recognize any signs. The more you know, the better you will be able to care for yourself and your loved one with cancer.

### What can I do?

You can take steps to relieve stress related to caregiver burnout. Here are some tips:

- Ask for help. Family members, friends, and neighbors may be able to step in.
- Let someone else take over duties when they offer so you get a break.
- Talk it out. Consider meeting with a social worker or support group.
- Let yourself grieve—to cry, to feel numb, to be angry, or to feel however you are feeling.
- Pay attention to your health. Eat well, exercise, and get enough rest.
- Take things one day at a time. Understand you will have good days and bad days.
- Educate yourself. Knowing all you can about your loved one's cancer may help you feel more in control and help you set realistic expectations.

Huntsman Cancer Institute's Patient and Family Support social workers can help people experiencing caregiver burnout. To learn more or make an appointment, call 801-213-5699.

The Linda B. and Robert B. Wiggins Wellness and Integrative Health Center offers classes and services for caregivers, including art, acupuncture, cooking, massage, group fitness classes, and meditation. For more information, call 801-587-4585.



# 8 *Care for the Caregiver*

A **caregiver** is anybody who provides unpaid help, or arranges for help, to a relative or friend because they have an illness or disability. Help can be physical, emotional, spiritual, financial, or logistical.



## THINGS TO REMEMBER

- You can be a tremendous resource to help your loved one think through treatment options, goals and priorities during this difficult period.
- Reach out to others who are also caring for someone with a brain tumor. These individuals are often helpful.
- Say YES! Remember that it's vital to ask for and accept help.
- Be mindful of your own needs and feelings. There are many ways to support your loved one without neglecting your own physical, economic, spiritual and emotional well-being.
- Talk with the doctors about what to expect and how to plan. Recovery after treatment can take a long time, it helps to feel prepared.
- End-of-life care plans can be helpful. Make sure that all family members are on the same page, and that the doctor is aware of your loved one's preferences.
- Enjoying life is about how you and your loved one focus on the things that really matter.
- If you are grieving the loss of the life you knew, give yourself time to grieve.

## CARE FOR YOURSELF

People who are forced to adopt a new role as “caregiver” have shared that as they gain information about the disease, options for treatment, expectations for recovery, and resources for support, they begin to feel more confident about managing the task before them, and their fear, anger, and frustration begin to dissipate.

### When a Loved One’s Personality Changes

Depression, anger, confusion and mood swings are common symptoms for individuals with brain tumors. These symptoms can be caused by the tumor, the treatment, or may have been present before. Regardless of the source, personality changes in someone you care for can be very challenging. These changes can be subtle or drastic. Speak with your doctor if you notice these types of changes. The symptoms may be treatable.

People who care for someone with a serious illness can forget to take care of themselves and can neglect their own needs. It becomes hard to focus on work, household responsibilities and other demands, yet those pressures continue. There are many ways to build-in time for your own care, and this is essential for your physical and mental wellbeing. Take time for yourself – this is not selfish.

Aim to find a balance between caring for your loved one, caring for yourself, and caring for others in your life. The patient will benefit most from being with you when your own life is in balance—and you will be less likely to feel exhausted or resentful about caregiving.



### TIPS TO MANAGE DIFFICULT MOMENTS

- Recognize feelings such as guilt, resentment and anger. Admit them if it will help you address the problem rather than ignore it or let anger grow.
- Be compassionate with yourself. There’s no one way a caregiver should feel. Give yourself permission to separate your feelings from your actions.
- Reach out to your own support network for some coping ideas. Call a family meeting and say, “Let’s figure out how we can help each other.”
- Create a digital network of friends and family and set up a helping calendar to support you and your loved one on Cancer Support Community’s [www.MyLifeLine.org](http://www.MyLifeLine.org)
- Set limits. Take time on a regular basis to care for yourself. Your batteries must be recharged so you can be a better caregiver over the long haul.
- Remember that you do not need to have all the answers or fix all the problems.
- Often, just “being there” and quietly listening is all that’s needed.

# Making important decisions

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Many people with a brain tumor diagnosis experience changes in their ability to think clearly and process information. This may be due to the tumor, treatment or simply feeling overwhelmed by the diagnosis. Whatever the cause, a loved one is often responsible for setting the course for a patient's care as their advocate. If you must be the treatment decision-maker, know that you can take some time to ask questions, research options, and find support.

Before you can know what's needed and what you can do to help, you must understand the situation.

1. **Learn about the brain tumor** including its location, grade, treatment options, anticipated treatment side effects, and expectations for recovery.
2. **Try to identify the top medical centers and experts** in your loved one's (or your) area for a second opinion or additional services, as needed.
3. **Research information** on credible websites, like through the National Cancer Institute, and the National Brain Tumor Society.
4. **Weigh the pros and cons** of each treatment option with your loved one, including elements like time, where treatment will be given and cost.
5. **Create a "to do" list** with your loved one of immediate versus long-term needs. Decide what your loved one can address independently, what you or someone else can address from a distance (via phone or internet) and what requires hands-on support.
6. **Recognize and respect** the unique capabilities of your loved one and their wishes and desires, in addition to the roles played by others involved.
7. **Set limits.** Define what you can and can't reasonably do for your loved one.
8. **Organize a care-plan** featuring coordination and open communication among all participants (who is doing what, when?). This plan will help reduce family stress and bring needed relief.
9. **Remember that each stage of care requires different levels of support**, and everyone's roles will change along the way. Brain tumors are not the same as other major life events; they can be ongoing and often unpredictable. Try to think through reasonable short- and long-term expectations.
10. **Secure proper authorization** that allows you to gather copies of medical and treatment records (including operation reports and x-rays). By obtaining legal "Power of Attorney" you will be granted this authorization. This will help with follow-up care plans and future medical needs.
11. **Utilize an oncology social worker** at the cancer center or affiliated with the oncologist. They offer a wealth of information and can answer many logistical and financial questions.
12. **Enjoy your relationship.** Try to value the time you spend with your loved one, because every moment is special.

## FINDING SUPPORT AND HELP

Above and beyond the specific advice that the doctor, nurse, and social worker can give you, there are several organizations and websites designed to help family caregivers and volunteers get help and get organized. Look through the resources at the end of the book, and consider:

- **National Brain Tumor Society**  
[braintumor.org](http://braintumor.org)  
Offers information, connection, and advocacy for people affected by brain tumors. NBTS has excellent resources listed throughout their webpages.
- **American Brain Tumor Association's Connections Online Support Community**  
[www.inspire.com/groups/american-brain-tumor-association/](http://www.inspire.com/groups/american-brain-tumor-association/)  
ABTA connects patients, families, friends, and caregivers for support and inspiration.

- **Cancer Support Community**  
[www.CancerSupportCommunity.org](http://www.CancerSupportCommunity.org)  
Provides education, free online support groups, and discussion boards for people affected by cancer and their caregivers.
- **My Lifeline**  
[www.MyLifeline.org](http://www.MyLifeline.org)  
Those with cancer can create their own personal webpage to communicate with family and friends. Pages include online calendar tools, scheduling timelines, and information about ways friends and family can offer support.
- **Musella Foundation for Brain Tumor Research & Information**  
[www.virtualtrials.com](http://www.virtualtrials.com)  
Offers education, support (emotional and financial), advocacy and guidance to brain tumor patients. Online support groups and opportunities to participate in fundraisers for brain tumor research are also available.

## Evaluating your Needs

If your loved one is not receiving the help you hoped for or need, it may be time to regroup. Are your expectations realistic? If you're not sure, have an honest conversation with the medical team. If your expectations are realistic but not being met, you may need to secure a different type of support. Try to brainstorm creative ways to address each issue by breaking problems into smaller parts and tapping into additional resources.

## Respite Care and Palliative Care

**Respite care** is short-term, temporary relief to caregivers who are providing full-time support to an ill loved one. Respite offers intensive care for the patient in their home so a caregiver can take a break. It often provides a positive experience for everyone involved. You can contact a respite care organization when you need time away.

**Palliative care** is a service used at any point in a patient’s experience to help a caregiver with the management of pain and other symptoms. Palliative care has the goal of achieving comfort, managing symptoms, and improving a patient’s quality of life. Palliative care professionals may come to a person’s home to deliver care and to teach caregivers how to manage problems. Check with your insurance, and you can ask your hospital or doctor for a referral.



TO ACCESS RESPITE CARE SERVICES IN YOUR AREA FOR YOU OR ANOTHER CAREGIVER, TRY:

- **Arch National Respite Organization**  
<https://archrespite.org/arch-membership>
- **Caregiver Action Network**  
202-454-3970  
[www.caregiveraction.org](http://www.caregiveraction.org)
- **Family Caregiver Alliance**  
1-800-445-8106  
[www.caregiver.org](http://www.caregiver.org)

## MOVING FORWARD

A diagnosis of advanced brain cancer can make you wonder how long your loved one has to live. It’s frightening to envision a different future than you originally planned for yourself. It can also be difficult to talk about such painful topics.

Finding ways to talk about what is happening makes most people feel relieved. The conversation often leads to hopes about living the life you have together now. Often, people want to make the most of their time together with family, as they make peace with the circumstances. Perhaps these can be uplifting conversations that give you both a sense of peace.



*One day Gary turned to me and said, “will you marry me?” and I said, “we’re already married.” And he said, “no, the first time I asked you was for who I thought you’d be, now it’s for who I know you are.”*

— Candice, caregiver

## BEREAVEMENT

If you try to discuss the subject but your loved one isn't ready, know that we all have our own timing. Finding someone else you can talk to about your concerns when you're ready is important. Research shows that caring for someone with a brain tumor is just as stressful (but in a different way) as having the diagnosis.

As with other difficult emotional issues, you can contact a social worker or counselor skilled in working with people with a brain tumor, or talk to a spiritual leader that you trust.

Losing someone you love to cancer is one of the most difficult and profound experiences in life.

In the weeks and months after a death, people feel an enormous mixture of emotions. It is important to know that practically any emotion you experience is normal. Sadness can also involve physical symptoms, such as sleeplessness, muscle tension, and decreased energy.

Be assured that you will feel a sense of calm eventually. You must give yourself time to grieve.

Some people move quickly through grief; others move slowly. No matter how you grieve, it is important to become aware of the normal aspects of grief, feel it, then be okay to move on.



*My dad was diagnosed when I was eleven and he passed when I was 14. When my dad worked, he was on the road a lot. So when he got sick, we joked that we were really lucky to have a stay-at-home dad for three years. We got to know him really well those years – and if he died any other way, that would not have been the case.*

— Natalie, caregiver



Cancer Support Community and the National Brain Tumor Society together with our partners provide this information as a service. This publication is not intended to take the place of medical care or the advice of your doctor. We strongly suggest consulting your doctor or another health care professional to answer questions and learn more.



**National  
Brain Tumor  
Society**

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## Fatigue

It is very common to feel tired and weak during treatment for cancer. Feeling fatigue can lead to distress, as it may lower your ability to do the things you are used to in daily life. If you have fatigue, you may feel you need to rest more than seems normal or reasonable.

### Symptoms of Fatigue

- General weakness or limb heaviness
- Lower concentration or attention
- Problems with memory and thinking clearly
- Less interest in usual activities
- Hard time doing daily tasks
- Sleep problems such as unable to sleep or still feeling tired after waking up

Cancer-related fatigue is different than other types of fatigue. It can be overwhelming. Resting doesn't always help it go away, and it can take a while for fatigue to get better, even after treatment ends.

### **FEELING WEAK AND TIRED IS A COMMON SIDE EFFECT OF CANCER TREATMENT. TALK TO YOUR HEALTH CARE TEAM IF IT IS TOO MUCH.**

If you feel overwhelmed, it may help to remember

- Fatigue is normal during cancer treatment.
- Fatigue does not mean the cancer is getting worse.
- Fatigue does not mean the treatment is not working.
- Fatigue is not caused by a lack of willpower. It is OK to ask for help if you need it, and tell your care team.

### How Your Doctor or Nurse Can Help

Your health care team will review your overall health to find out if other factors are making your fatigue worse:

- Anemia
- Emotional distress or depression
- Infection
- Nutrition problems
- Pain
- Other illnesses
- Sleep problems

Your health care team can recommend medicines to improve your energy level or help you sleep. Be sure to talk to your care team before taking any over-the-counter medicines, and keep them updated about how you feel, especially if you notice any sudden changes.

### Ways to Help Manage Fatigue

Walking and other exercise can help you feel better. Ask your health care team what level of exercise is right for you.

The Linda B. and Robert B. Wiggins Wellness and Integrative Health Center at Huntsman Cancer Institute (HCI) offers many services that can help with fatigue.

These include one-on-one exercise programs with a cancer exercise specialist, group fitness classes, acupuncture, dietitians, and more. Call 801-587-4585 or visit [www.huntsmancancer.org/wellnesscenter](http://www.huntsmancancer.org/wellnesscenter).

### More Tips to Manage Fatigue

#### Save Your Energy

- Set priorities and give tasks to others who offer to help.
- Take short naps and rest often. Avoid sleeping too much during the day, which makes it hard to sleep well at night.
- Use a cane or walker for assistance if you need it.

#### Find Relaxing Activities

- Get together with small groups of friends and family for short periods of time.
- Share your feelings and experiences by keeping a journal or joining a support group.
- Listen to music.
- If it is hard to concentrate, read short stories and articles.
- Stay connected with friends and family through e-mail and social media websites.
- Go outside to bird watch or visit a park.

## Other Ideas

- Meet with a dietitian from the HCI Wellness Center who can suggest dietary changes to help with fatigue.
- Go to bed and wake up at the same time each day.
- Avoid caffeine.
- Exercise early in the day instead of before bed.

## HCI Resources to Help You Feel Better

**The Linda B. and Robert B. Wiggins Wellness and Integrative Health Center:** 801-587-4585 or [www.huntsmancancer.org/wellnesscenter](http://www.huntsmancancer.org/wellnesscenter)

**Patient and Family Support Social Workers:**  
801-213-5699 or [www.huntsmancancer.org/pfs](http://www.huntsmancancer.org/pfs)

**G. Mitchell Morris Cancer Learning Center:**  
1-888-424-2100 or [www.huntsmancancer.org/clc](http://www.huntsmancancer.org/clc)

## Nausea and Vomiting

### How is nausea treated?

Nausea is treated with medicines called antiemetics. Sometimes it takes more than one medicine to get relief. Your health care team will help you find the best medicine for you. There are many types of antiemetics, so tell your doctor if your nausea is not under control within 24 hours.

### What should I do if I have nausea?

- Fill your prescription for antiemetics.
- Take your antiemetics as prescribed.
- Eat five or six small meals during the day instead of one or two large meals.
- Choose foods that are low in fat.
- Choose cool foods rather than hot.
- Take medicine to control pain as prescribed.
- Breathe deeply and slowly to help ease nausea.
- Use distraction techniques such as walking, listening to music, watching a movie, or doing other activities you like.
- Turn lights low.
- Try fanning cool air on your face.
- Drink plenty of fluids.
- Take good care of your mouth. Brush your teeth three times a day and rinse with salt water solution.
  - Salt Water Solution
    - 1 cup warm water
    - 1/8 teaspoon salt
    - 1/8 teaspoon baking soda

**YOUR DOCTOR CAN PRESCRIBE MEDICINE TO HELP EASE YOUR NAUSEA. BE SURE TO TELL YOUR CARE TEAM IF YOU NEED RELIEF.**

### When should I call my doctor or nurse?

Call your doctor if any of these happen:

- You can't keep down fluid for 24 hours.
- You have vomited more than six times in 24 hours.
- You still have nausea and vomiting after you take antiemetics.
- Your symptoms of nausea or vomiting do not follow their usual pattern.

### Helpful Suggestions

- Keep track of when your nausea occurs, what seemed to start it, and what helps make it better.
- Give your health care provider a list of all medications you take. Some medicines can cause nausea.
- Have someone with you the first time you take your antiemetic. Some medicines to control nausea can make you feel sleepy.

The Linda B. and Robert B. Wiggins Wellness and Integrative Health Center at Huntsman Cancer Institute offers acupuncture, massage, and other services that can help control nausea and other cancer-related symptoms. Call 801-587-4585 for more information.



## How to Avoid Being Constipated

### About Constipation

Constipation is when it is difficult to have a bowel movement and stool becomes hard and dry.

### Why Constipation Happens

The normal function of the large intestine, which is also called the large bowel or colon, is to absorb liquid from the digestive tract.

Even when you don't have a bowel movement, the colon keeps doing its usual job of removing liquid. This makes the stool hard and difficult to pass.



*Large intestine, or colon, in the human body*

These are reasons the bowel may slow down:

- Taking narcotics or pain medicines
- Using some anti-nausea medicines
- Being dehydrated
- Eating or drinking less than usual
- Having surgery in the abdomen area

### How to Keep From Getting Constipated

- Stay hydrated. Drink enough water, juice, sports drinks, soups, or other liquids to keep your urine a light yellow color.
- Avoid drinks that have caffeine or alcohol. They can make you more dehydrated.
- Be as active as you can. Ask your health care provider what is safest for you, or make an appointment with our cancer exercise specialists.
- Eat a healthy diet that includes fruits, vegetables, and fiber. Make an appointment with our dietitians to help figure out what's right for you.

The Linda B. and Robert B. Wiggins Wellness and Integrative Health Center at Huntsman Cancer Institute offers one-on-one fitness and activity plans, nutrition counseling, and more. Call 801-587-4585 or visit [www.huntsmancancer.org/wellness](http://www.huntsmancancer.org/wellness).

**Be sure to check with your nurse or doctor before taking any medicines for constipation, especially medicines that go in the rectum.**

### If You Do Get Constipated

Taking a stool softener or laxative and drinking prune juice or warm liquids can help.

- Stool softeners make bowel movements more comfortable. These are not laxatives. The medicine name is docusate sodium. There are many brand names, so check with your nurse or pharmacist to make sure you get what you need.
- Laxatives make the bowel move faster. Senna (sennosides) and/or Miralax® (polyethylene glycol) are commonly recommended.

Take 1 or 2 senna tablets up to 3 times a day

OR

Take ½ to 1 dose of Miralax® (or a generic brand) up to 3 times a day

- Senna-S is a combination of senna laxative and docusate sodium. Some people like the laxative and stool softener in one pill.

Everyone is different. The correct combination of softeners and laxatives is the one that helps you have a comfortable bowel movement every 1 or 2 days.

- Write down what you take.
- Be sure to tell your doctor and nurse what you take.



## Preventing Constipation from Pain Medicines

### Constipation

When your bowel movements are difficult or don't happen often, you have constipation. It is a common side effect of many pain medicines, including the following:

- Hydrocodone – in Lortab®, Norco®, or Vicodin®
- Oxycodone – in Oxycontin or Percocet
- Morphine
- Fentanyl patches

If you take one or more of these for pain, it is a good idea to take medicines that help prevent constipation.

Before you start taking pain medicine, talk to your doctor if you haven't had a bowel movement in more than five days. Also tell your doctor if you have nausea, vomiting, or very hard stool.

### Medicines

There are two kinds of constipation medicines: stool softeners and laxatives. Stool softeners keep water in your colon, creating softer stools. Laxatives help move stool through your body.

**Sennosides and docusate.** Many medicines that help with constipation have ingredients called sennosides, or senna, and docusate in them. Sennosides are laxatives and docusate is a stool softener. Many products combine sennosides and docusate in one pill.

**Polyethylene glycol.** Medicines containing polyethylene glycol are potent stool softeners.

The column at the right has more information about constipation medicines and common brand names.

### Finding the Right Dose

The amount of constipation medicine to take varies from person to person. Keep a record of your bowel movements and dosage of constipation medicine you have taken to learn what works best for you. If your pain medicine dose changes, you will probably also need to adjust your dose of constipation medicine.

Sennosides and Docusate. Start with a dose of 8.6 mg sennosides and between 50 mg and 100 mg of docusate. Take this amount once or twice a day. You may feel the effects after one to four doses. The goal is to have a normal, comfortable bowel movement at least every other day.

If you don't have a bowel movement by the end of the second day, increase your bedtime dose by one pill. If you still don't have a bowel movement, increase the morning dose by one pill the next day. If you don't have a bowel movement in more than five days or have nausea, vomiting, or very hard stool, call your doctor.

**Polyethylene Glycol.** If medicine with sennosides and docusate doesn't work for you, take 17 g (about ¼ level teaspoons) of polyethylene glycol dissolved in a cup of juice or water. The bottle cap may be marked at 17 g so you can use it to measure.

Some people find that polyethylene glycol works better for them than sennosides and docusate.

**At your next appointment, it is important to tell your doctor what constipation medicine you are taking and the dose.**

### Constipation Medicines

These constipation medicines are available at the Huntsman Cancer Institute Outpatient Pharmacy.

- Senna-S (8.6 mg sennosides, 50 mg docusate)
- Senna (8.6 mg sennosides)
- Docusate (100 mg)
- Senna - liquid form (8.8 mg/5 ml)
- Docusate - liquid form (50 mg/5 ml)
- MiraLax® (17 g polyethylene glycol)
- Polyethylene glycol (17 g)

The following brand name constipation medicines may be available at your local drug store.

- Colace® (100 mg docusate)
- Dulcoease® (100 mg docusate)
- Ex-Lax Regular Strength® (15 mg sennosides)
- Fleet Sof-Lax® (100 mg docusate)
- Phillips Liqui-Gels® (100 mg docusate)
- Peri-Colace® (8.6 mg sennosides, 50 mg docusate)

- Senna Lax® (8.6 mg sennosides, 50 mg docusate)
- Senokot-S® (8.6 mg sennosides, 50 mg docusate)

*Note: Before buying a constipation medicine, read the product label. The medicine and dose may vary by brand name. Avoid products with bisacodyl or casanthranol (cascara). They may cause cramping. Some Dulcolax products with senna and docusate also contain bisacodyl.*

## Bleeding Problems

Some types of cancers and cancer treatments can cause you to have too few platelets in your blood. Platelets are cells that clump together to clot blood, which stops bleeding when you are hurt. Not having enough platelet cells gives you a higher risk of bruising or bleeding, even without an injury.

### What should I do if I have low platelets?

- Use a very soft toothbrush.
- Blow your nose gently with soft tissue. Your healthcare provider may ask you to not blow your nose at all.
- Take extra care to prevent cuts or nicks when using needles, knives, scissors, or tools.
- Switch to an electric razor to avoid the risk of shaving cuts.
- Protect your hands with gloves when gardening.
- Use extra caution near heat sources such as irons, stoves, barbecue grills, and heating pads.
- Tell your health care provider if you are constipated. He or she may recommend a stool softener to be taken orally. Avoid straining to have a bowel movement.

### What should I avoid?

- Don't use dental floss or toothpicks.
- Don't pick pimples or scabs.
- Don't play sports that have a risk of getting hurt.
- Don't put anything in your rectum, not even a thermometer or medicine.
- Don't use tampons. Use pads for feminine hygiene.

### Talk with your health care provider

- Ask if it is safe for you to take aspirin or products that contain aspirin. Aspirin interferes with the platelets' ability to stop bleeding. It should generally not be used if your platelet count is low.

- Ask if it is safe for you to use pain relievers such as ibuprofen and naproxen (products such as Aleve®, Advil®, Motrin®). Acetaminophen (Tylenol®) is usually safe if your platelet count is low, but ask first.
- Tell them all the vitamins, herbal supplements, and over-the-counter medicines you take.
- Check with them before drinking alcohol.

**Talk to your doctor or nurse before taking any medicines, vitamins, or herbs.**

### How are bleeding problems managed?

- You may have more frequent blood tests to monitor the amount of platelets in your blood.
- Your chemotherapy treatment may be delayed while your body builds platelets.
- Your health care provider may prescribe a platelet transfusion to build your platelet level.

### When should I call my doctor?

Call if you develop any of these symptoms:

- Black or bloody stools
- Bleeding from your gums
- Blood in the urine, or reddish or pink urine
- Changes in vision
- Easy bruising
- Nosebleeds that do not stop within 15 minutes
- Severe headaches
- Small red spots under the skin
- Vaginal bleeding that is new or lasts longer than your regular period

**Doctor's Number:** \_\_\_\_\_



## Neutropenia

### What is neutropenia?

Neutropenia means that a person has a low amount of neutrophils, a special white blood cell. White blood cells help your body fight infection. Chemotherapy or radiation therapy may cause neutropenia. Your risk of infection is higher if you have a low amount of white blood cells.

### What is febrile neutropenia?

Febrile neutropenia is having a fever when you have a low amount of white blood cells in your body. This is very serious. Febrile neutropenia needs immediate medical attention. Do not take any medicine to treat your fever until you have been directed by your treatment team. This includes over-the-counter pain or fever reducing medicine.

### Important Facts

- You are neutropenic when the amount of white blood cells in your body is low.
- When you have neutropenia, a simple infection is dangerous to your health.

### Preventing Infection During Neutropenia

- Wash your hands often with soap, especially before eating, after using the bathroom, and after sneezing, coughing, or blowing your nose.
- Keep up your daily personal hygiene habits—bathing, showering, brushing teeth—even when you feel tired or sick.
- Do not put anything in the rectum—no enemas or suppositories.
- Women should not use tampons, vaginal suppositories, or douches.
- Avoid constipation. Ask your doctor or nurse if you should use a stool softener.
- Take your temperature if you feel sick.

### Other Ways to Help Prevent Infection:

- Avoid large crowds and sick people.
- Talk with your doctor about getting yearly flu vaccines (avoid nasal spray vaccines).
- Stay away from children who recently had live virus vaccines such as the chickenpox vaccine.
- Wash fresh fruit and vegetables before eating.
- Avoid being near fresh-cut flowers or other sources of standing water that can have bacteria.

### When should I call my doctor or nurse?

- If your fever is greater than 100.3°F, call your doctor or nurse right away.
- Call your health care provider if you have any of these symptoms:
  - Shaking chills or feeling like you have the flu
  - Sore throat or coughing
  - Burning or pain when you pee
  - Red or swollen area on the body

When you are neutropenic, you may get a fever even without an infection. Medical tests can tell if you have an infection or not.

If you do have an infection, your health care provider may give you antibiotics to treat it, and may also give you a medicine to boost blood cell growth.

If you are very sick, you may need to stay at the hospital to receive antibiotics through a vein in your arm.



Planning for life after cancer can be an important part of healing. Some types of cancer and cancer treatments can change your ability to have children. The ability to get or make someone pregnant is called fertility.

Before cancer treatment begins, talk to your health care team about ways to protect your fertility. Knowing what to expect can help you prepare for and manage many issues.

**It is very important to talk with your doctor about fertility BEFORE you start treatment or have surgery for your cancer.**

## Will cancer affect my ability to have children?

It depends on your age and details of your treatment:

- The type and amount of cancer medicines you take
- Radiation to the pelvis or certain areas of the brain
- Surgery that removes all or part of the organs involved in having children (such as the uterus, ovaries, or testicles)

## Will my treatments make me unable to have sex?

Cancer and its treatments sometimes cause side effects that make it hard to have sex.

**Men:** You may have trouble getting or keeping an erection. Having sex could become painful.

**Women:** You may have discomfort from being too dry. Radiation can cause scars that make having sex painful. You may bleed during or after sex. You may have an abnormal flow of fluids from the vagina.

Talk to your health care team if any of these things happen. Your team can find ways to help.

## What questions should I ask my care team?

Here are some helpful questions to ask about fertility:

- What are my options?
- How much time do I have before I start treatment?
- How will I know if I am fertile after my cancer treatment?

- How do I know when it is safe to try having a baby?
- Will there be any health risks to me or my future children?
- What can be done to help protect my fertility?

Huntsman Cancer Institute works with the Utah Center for Reproductive Medicine (UCRM) at the University of Utah to help people with cancer who want to have children after treatment. Here is how the process works.

**Men:** The UCRM collects your semen and freezes it before cancer treatment begins. They can store semen for many years. They use it later to make your partner pregnant.

**Women:** The UCRM collects some of your eggs before cancer treatment begins. The eggs may be frozen right away or first fertilized and then frozen. Fertilized eggs are called embryos. Frozen eggs or embryos can be stored for years. You can use them when you are ready for pregnancy.

For some women, doctors can give medicines that may protect fertility during cancer treatment.

Experts at the UCRM will work with you and your health care team to find the best fertility plan for you.

## For more information

### Utah Center for Reproductive Medicine at the University of Utah

- Call 801-581-3834
- Visit [healthcare.utah.edu/ucrm](http://healthcare.utah.edu/ucrm)

### G. Mitchell Morris Cancer Learning Center

- Call 1-888-424-2100
- Email [cancerinfo@hci.utah.edu](mailto:cancerinfo@hci.utah.edu)
- Drop by the 6th floor of Huntsman Cancer Institute Hospital



## Eating Well During Cancer Treatment

Eating well is important when you are being treated for cancer. Good nutrition helps you feel better, raises your energy level, and can help lower the side effects from your cancer treatment.

**Getting enough fluid is part of eating well. Try to drink at least 64 ounces (8 cups) of liquids without caffeine every day.**

Getting enough liquid is an important part of good nutrition. Try to get at least 64 ounces (8 cups) of liquids without caffeine each day unless your cancer care team gives other directions. These things can count as part of the 64 ounces:

- Juice
- Soup
- Milk
- Sports drinks
- Popsicles
- Other drinks

### Managing Side Effects

Some cancer treatments can make it hard to eat. You may have nausea. Foods may taste different. Your mouth and throat may be sore. You may feel too tired to make meals. Here are some tips that can help.

#### Nausea and Vomiting

- Have several small meals each day. Set timer for every 2-3 hours. Eat slowly.
- Relax after meals to help food digest, but do not lie down. Loosen your clothes. Breathing fresh air can help ease nausea.
- Avoid or limit foods with strong odors. Limit fried or spicy foods.
- Eat foods cold or at room temperature.
- When you have nausea, eat dry, bland foods such as crackers or toast.
- Do not eat your favorite foods when you have nausea. Eat them when you feel well.

### Taste Changes

- Brushing your teeth or rinsing your mouth before eating may help.
- Use different seasonings, herbs, and spices.
  - Try adding basil, onion, garlic, and other flavors.
  - Try different flavors such as sour, bitter, tart, or sweet to see what tastes best. Try adding vinegar, lemon, lime, and orange to meals.
- Some foods may taste bitter or like metal. Sugarfree lemon drops, gum, or mints may help.
- If food tastes like metal, try using plastic or wood utensils.
- See the factsheet *Taste Changes during Cancer Treatment* for more ideas.

### Sore Mouth or Throat

- Drink plenty of liquids. If your mouth is sore, use a straw.
- Choose soft, moist foods. Add extra gravies, cream sauces, or butter to meals. Cook food until it is soft and tender.
- Eat cold foods to help soothe your mouth and throat.
- Avoid citrus fruits and juices, spicy or salty foods, and rough, coarse, or dry foods.
- Rinse your mouth often. Ask your dentist about gentle cleaning products for your teeth and gums.

### Fatigue

- When you have the energy, make and freeze meals to eat later.
- Let friends or family members cook for you.
- Keep snack foods on hand.
- Use plates and dishes you can throw away to save clean-up time.
- Make sure to keep hydrated and drink adequate fluids to help prevent dehydration which can lead to more fatigue.

## Constipation

- Eat plenty of high-fiber foods such as whole grains, fruits, and vegetables.
- Eat at least five servings of fruits and vegetables every day.
- Add fiber to your diet slowly over 8 weeks with a goal of eating 25-38 grams of fiber each day.
- Drink plenty of liquids. Prune juice may help.
- Take walks and do light exercise often. \*Check with your doctor before starting any exercise program.
- Ask your cancer care team before you take any stool softeners or laxatives.

## Diarrhea

- Eat less high-fiber food such as whole grains, fruits, and raw vegetables.
- Eat several small meals each day.  
Eating certain foods can help:
  - Applesauce
  - Potatoes
  - Bananas
  - Rice
  - Pasta
  - Toast
- Limit foods that can give you gas such as gassy vegetables, greasy, fried, or spicy foods.
- Drink plenty of liquids between meals.
- Try eating less milk and milk products such as ice cream, cheese, and yogurt.
- Ask your cancer care team if a soluble fiber supplement such as Metamucil® would help.

## Weight Loss

- Try to eat four to six small meals each day. Set an alarm for every 2-3 hours.
- Plan ahead and keep snacks in your car, purse, or backpack.
- Eat slowly and take breaks during meals.
- If you get full too fast at meals, don't drink at mealtime. Drink liquids between meals instead.
- When you have a good appetite, make the most of it. Appetite is often best in the morning, so try to eat more at breakfast.

- Add protein to your diet with foods such as cheese, yogurt, milk, cottage cheese, nuts, seeds, peanut butter, meats, and beans.
- Put extra calories in food you already eat by adding one or more of these:
  - Butter or margarine
  - Mayonnaise
  - Honey
  - Peanut butter
  - Creamer
  - Powdered milk
- Be creative. Try making milkshakes or smoothies packed with protein and calories. See the factsheet *High-Calorie, High Protein Recipes* for ideas.
- Use a supplement such as Carnation Breakfast Essentials, Boost, or Ensure.

Call your cancer care team or Registered Dietitian if these tips do not help your nausea, constipation, diarrhea, or weight loss.

## For More Information

### Patient Education Resources

[hci-portal.hci.utah.edu/sites/factsheets](http://hci-portal.hci.utah.edu/sites/factsheets)

Click on the Food and Nutrition icon to find the factsheet *High-Calorie, High-Protein Recipes*. The National Cancer Institute booklet "Eating Hints" is also here.

### Linda B. and Robert B. Wiggins Wellness and Integrative Health Center

801-587-4585

The Wellness Center offers free counseling with registered dietitians for patients with all types of cancer. Call for more information or to make an appointment.

### G. Mitchell Morris Cancer Learning Center

Visit the 6th floor of the cancer hospital

Call 1-888-424-2100

Email [cancerinfo@hci.utah.edu](mailto:cancerinfo@hci.utah.edu)

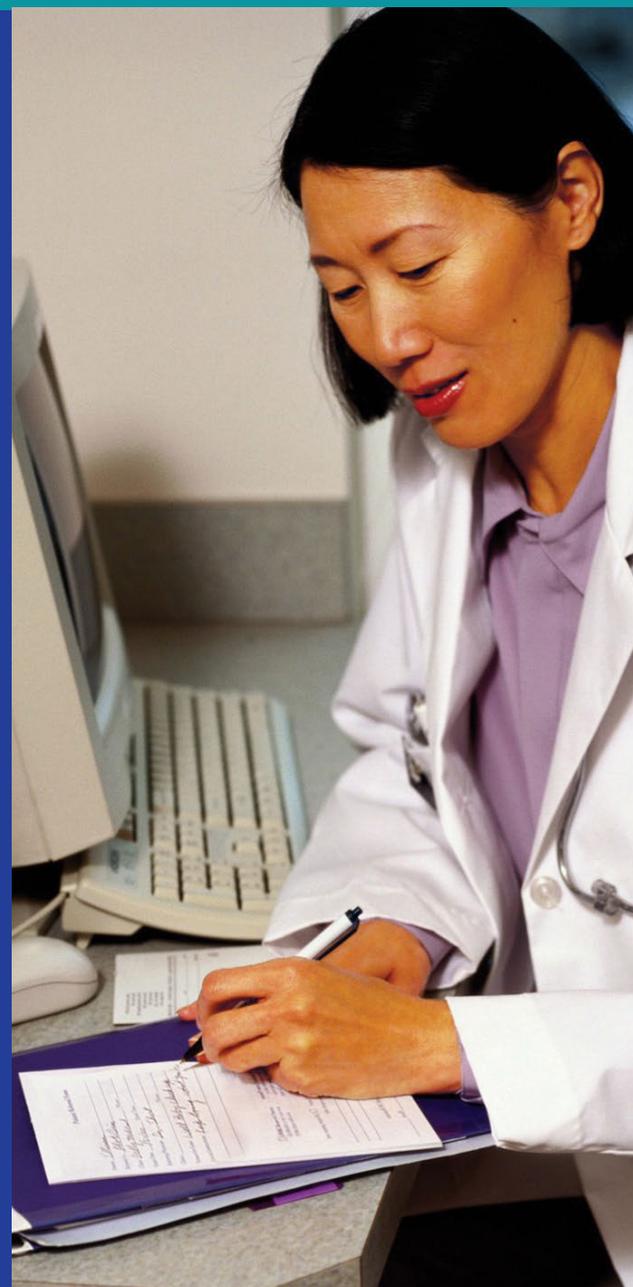
Text 801-528-1112 (text only)

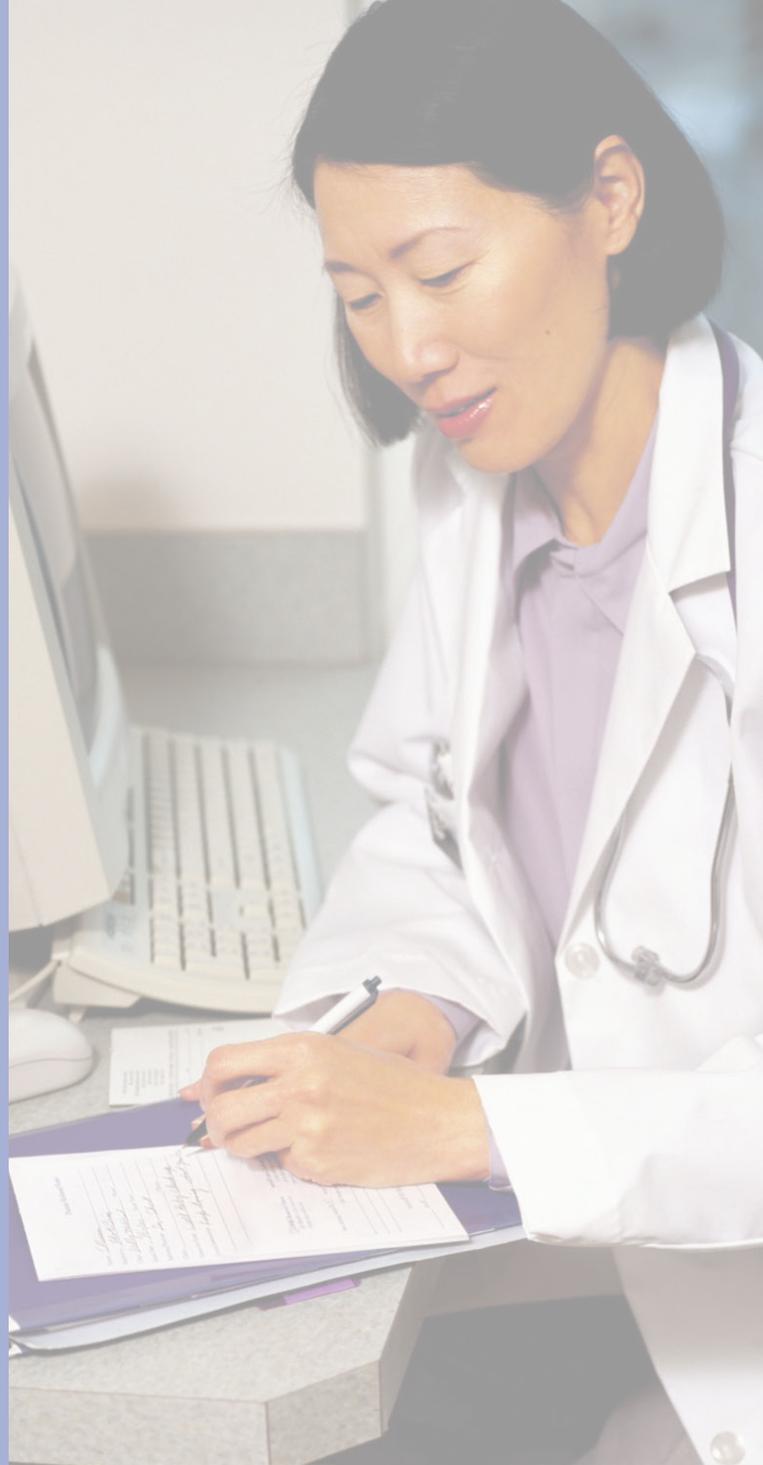
The Cancer Learning Center has free cancer resources in their lending library and cancer information specialists who can help find what you want to know.



NATIONAL CANCER INSTITUTE

# Taking Part in Cancer Treatment Research Studies





# Taking Part in Cancer Treatment Research Studies

If you have cancer, you may want to think about taking part in a clinical trial. Clinical trials are a treatment option for many people with cancer. This book explains cancer treatment clinical trials and gives you some things to think about when deciding whether to take part.

**This booklet is for people with cancer,  
their family, and friends.**

## Inside This Book

What Are Clinical Trials?.....	2
Why Are Clinical Trials Important? .....	2
Clinical Trials Take Place in Phases.....	3
Clinical Trials Follow Strict Guidelines.....	4
Who Can Join a Clinical Trial?.....	4
Randomization.....	5
Patient Safety.....	6
Paying for Clinical Trials .....	10
Deciding to Take Part in Clinical Trials.....	11
Questions to Ask .....	12
How to Join a Clinical Trial .....	13

## What Are Clinical Trials?

Clinical trials are research studies that involve people. Through clinical trials, doctors find new ways to improve treatments and the quality of life for people with disease.

Researchers design cancer clinical trials to test new ways to:

- Treat cancer
- Find and diagnose cancer
- Prevent cancer
- Manage symptoms of cancer and side effects from its treatment

Clinical trials are the final step in a long process that begins with research in a lab. Before any new treatment is used with people in clinical trials, researchers work for many years to understand its effects on cancer cells in the lab and in animals. They also try to figure out the side effects it may cause.

This booklet focuses on cancer treatment studies. These studies are designed to answer questions about new treatments or ways of using existing treatments better. These trials test many types of treatments, such as new:

- Drugs or vaccines
- Ways to do surgery or give radiation therapy
- Combinations of treatments

**Many treatments used today are the results of past clinical trials.**

## Why Are Clinical Trials Important?

Today, people are living longer lives from successful cancer treatments that are the results of past clinical trials. Through clinical trials, doctors determine whether new treatments are safe and effective, and work better than current treatments. When you take part in a clinical trial, you add to our knowledge about cancer and help improve cancer care for future patients. Clinical trials are the key to making progress against cancer.

# Clinical Trials Take Place in Phases

For a treatment to become standard (widely accepted), it must first go through a series of steps, called phases. The early phases make sure the treatment is safe. Later phases show if it works better than the standard treatment. You do not have to take part in all phases.

## Phase 1

### Purpose:

- To find a safe dose
- To decide how the new treatment should be given
- To see how the new treatment affects the human body and fights cancer

**Number of people taking part:** 15–30

## Phase 2

### Purpose:

- To determine if the new treatment has an effect on a certain cancer
- To see how the new treatment affects the human body and fights cancer

**Number of people taking part:** Less than 100

## Phase 3

### Purpose:

- To compare the new treatment (or new use of a treatment) with the current standard treatment

**Number of people taking part:** From 100 to several thousand

Some researchers design trials that combine two phases (phase 1/2 or phase 2/3 trials) in a single trial. In this combined design, there is a seamless transition between trial phases, which may allow research questions to be answered more quickly or with fewer patients.

There are also very early (phase 0) and later (phase 4) phases of clinical trials. These trials are less common. Phase 0 trials are very small trials that help researchers decide if a new drug should be tested in a phase 1 trial. Phase 4 trials look at long-term safety and effectiveness. They take place after a new treatment has been approved and is on the market.

## Clinical Trials Follow Strict Guidelines

The guidelines that clinical trials follow clearly state who will be able to join the study and the treatment plan. Every trial has a person in charge, usually a doctor, who is called the principal investigator. The principal investigator prepares a plan for the study, called a protocol, which is like a recipe for conducting a clinical trial.

The protocol explains what the trial will do, how the study will be carried out, and why each part of the study is necessary. It includes information about:

- The reason for doing the study
- Who can join the study
- How many people are needed for the study
- Any drugs or other treatments that will be given, how they will be given, the dose, and how often
- What medical tests they will have and how often
- What types of information will be collected about the people taking part

## Who Can Join a Clinical Trial?

Based on the questions the research is trying to answer, each clinical trial protocol clearly states who can or cannot join the trial.

### Common criteria for entering a trial include:

- Having a certain type or stage of cancer
- Having received (or not having received) a certain type of therapy in the past
- Having specific genetic changes in your tumor
- Being in a certain age group
- Medical history
- Current health status

Criteria such as these help ensure that people in the trial are as alike as possible. This way, doctors can be sure that the results are due to the treatment being studied and not other factors.

## These criteria also help ensure:

### ■ Safety

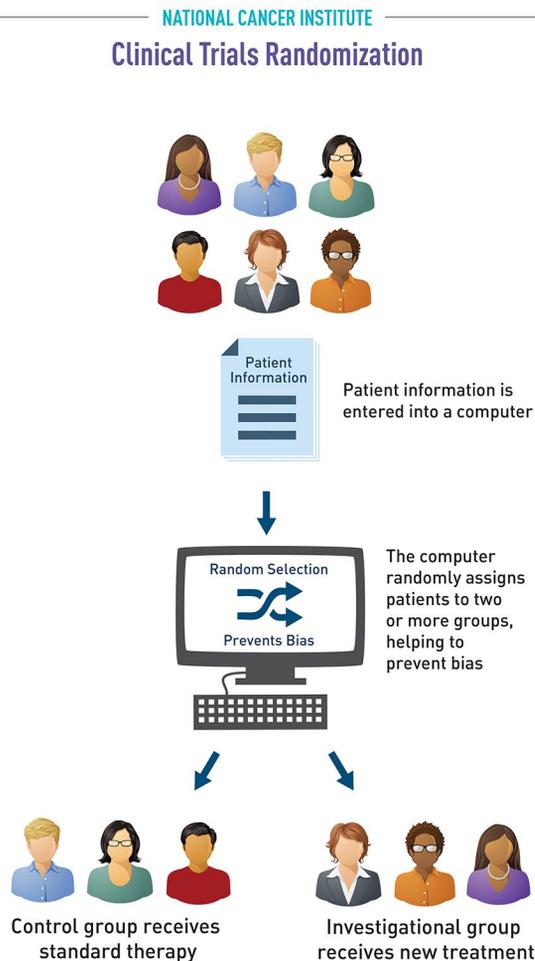
Some people have health problems besides cancer that could be made worse by the treatments in a study. If you are interested in joining a trial, you will receive medical tests to be sure that you are not put at increased risk.

### ■ Accurate and meaningful study results

You may not be able to join some clinical trials if you already have had another kind of treatment for your cancer. Otherwise, doctors could not be sure whether your results were due to the treatment being studied or the earlier treatment.

## Randomization

Randomization is a process used in some clinical trials to prevent bias. Bias occurs when a trial's results are affected by human choices or other factors not related to the treatments being tested. Randomization helps ensure that unknown factors do not affect trial results.



Randomization is used in all phase 3 and some phase 2 trials. These trials are called randomized clinical trials.

If you take part in such a trial, you will be assigned by chance to either an investigational group or a control group. Your assignment will be determined with a computer program or table of random numbers.

- If you are assigned to the control group, you will get the most widely accepted treatment for your cancer.
- If you are assigned to the investigational group, you will get the new treatment being tested.

Comparing these groups to each other often clearly shows which treatment is more effective or has fewer side effects. If you are thinking about joining a randomized clinical trial, you need to understand that there is an equal chance you will be assigned to either group. Neither you nor your doctor chooses which group you will be in.

## Will I get a placebo?

Placebos are rarely used in cancer treatment clinical trials. They may be used when there is no standard treatment. Or, they may be used in a clinical trial that compares standard treatment plus a placebo, with standard treatment plus a new treatment. The placebo is designed to look like the medicine being tested, but it is not active. Using a placebo in this way can help prevent patients and their doctors from figuring out which treatment group they were assigned to.

Placebos are another way to help prevent bias in research. You will always be told if the study uses a placebo.

## Patient Safety

Federal rules help ensure that clinical trials are run in an ethical manner. Your rights and safety are protected through:

- Informed consent
- Careful review and approval of the clinical trial by two review panels, which include:
  - A scientific review panel
  - An institutional review board (IRB)

- Ongoing monitoring during the trial provided by:
  - The IRB
  - Data and Safety Monitoring Boards (DSMBs) for phase 3 trials
  - The organization sponsoring the trial
  - Your research team

## **Informed Consent**

Informed consent is a process through which you learn the purpose, risks, and benefits of a clinical trial before deciding whether to join. It is a critical part of ensuring patient safety in research. During the informed consent process, you learn important information about a clinical trial. This information can help you decide whether to join.

**During the informed consent process, you learn important information about the clinical trial that can help you decide whether to take part.**

**The research team, which is made up of doctors, nurses, and research assistants, first explains the trial to you. The team explains the trial's:**

- Purpose
- Tests and procedures
- Treatment
- Risks and benefits

**The team will also discuss your rights, including your right to:**

- Make a decision about taking part
- Leave the study at any time

**If you decide to leave the study, your doctor will discuss other treatment options with you.**

## Before agreeing to take part in a trial, you have the right to:

- Learn about all of your treatment options
- Learn all that is involved in the trial—including all details about treatment, tests, and possible risks and benefits
- Discuss the trial with the principal investigator and other members of the research team
- Both hear and read the information in language you can understand

After discussing all aspects of the study with you, the team gives you an informed consent form to read. The form includes written details about the information that was discussed and also describes the privacy of your records. If you agree to take part in the study, you sign the form. But even after you sign the consent form, you can leave the study at any time.

## Scientific Review

Most clinical trials have to go through different types of review that are designed to protect all people who take part. These reviews are conducted by scientific review panels, IRBs, and DSMBs.

### Scientific Review Panels

This panel is made up of experts who review a clinical trial protocol before it starts accepting patients to make sure it is based on sound science. All clinical trials that are funded by the government must go through this review. Many other clinical trial sponsors, such as drug companies, also seek expert advice on the scientific merit of their studies.

### Institutional Review Boards (IRBs)

This board also reviews a clinical trial protocol before it starts accepting patients. The board members make sure the risks involved in the trial are reasonable when compared to the possible benefits. They also closely watch the ongoing progress of the trial from beginning to end.

Federal rules require that each IRB be made up of at least five people. One member must be from outside the institution running the trial. IRBs are usually made up of a mix of medical specialists and members of the community where the trial is taking place.

Many include members from diverse careers and backgrounds. In most cases, IRBs are located where the trial is to take place. Many institutions that carry out clinical trials have their own IRBs.

### **Data and Safety Monitoring Boards (DSMBs)**

Some clinical trials—especially phase 3 clinical trials—use DSMBs to monitor the trial to help ensure your safety. They may also be appropriate and necessary for certain phase 1 and phase 2 clinical trials. A DSMB is an independent committee made up of statisticians, physicians, and other experts.

The board must:

- Ensure that any risks that come from being in the study are reduced as much as possible
- Ensure that the data are sound
- Stop a trial if safety concerns come up or as soon as its objectives have been met

### **Office of Human Research Protections (OHRP)**

This office protects people taking part in research and provides leadership for many federal agencies that carry out research involving people.

OHRP enforces important regulations for patient protection in clinical trials, called the Common Rule. These regulations set standards regarding:

- The informed consent process
- IRB formation and function
- The involvement of prisoners, children, and other vulnerable groups in research

### **U.S. Food and Drug Administration (FDA)**

The FDA also plays a role in protecting people taking part in research and ensuring the integrity of data from trials. The FDA can remove researchers from conducting clinical trials when the researcher has repeatedly or purposely not followed the rules intended to protect patients. Or, when the researcher has not ensured data integrity.

The FDA approves new drugs before they can be sold. This helps:

- Prevent quackery
- Ensure that drugs work as they should
- Make sure the drug's health benefits outweigh the risks

## Paying for Clinical Trials

As you think about taking part in a clinical trial, you will face the issue of how to cover the costs of care. There are two types of costs associated with a clinical trial: patient care costs and research costs.

**Patient care costs** are those costs related to treating your cancer, whether you are in a trial or receiving standard therapy. These costs are often covered by health insurance. They include:

- Doctor visits
- Hospital stays
- Standard cancer treatments
- Treatments to reduce or eliminate symptoms of cancer or side effects from treatment
- Lab tests
- X-rays and other imaging tests

**Research costs** are those related to taking part in the trial. Often these costs are not covered by health insurance, but they may be covered by the trial's sponsor. Examples of research costs include:

- The study drug
- Lab tests performed purely for research purposes
- Additional x-rays and imaging tests performed solely for the trial

When you take part in a trial, you may have extra doctor visits that you would not have with standard treatment. During these visits, your doctor carefully watches for side effects and your safety in the study. These extra visits can add costs for transportation and child care.

For more information about insurance coverage and working with your insurance company, see “Paying for Clinical Trials” on the National Cancer Institute’s website at [www.cancer.gov/about-cancer/treatment/clinical-trials/paying](http://www.cancer.gov/about-cancer/treatment/clinical-trials/paying).

# Deciding to Take Part in Clinical Trials

Whenever you need treatment for your cancer, clinical trials may be an option for you. Choosing to join a clinical trial is something only you, those close to you, and your doctors and nurses can decide together. This section has information you can use when thinking about your treatment choices and making your decision.

## Weighing the Pros and Cons

As with any treatment option, a clinical trial has possible benefits, as well as drawbacks. You may want to discuss the following issues with your doctor and the people close to you.

### Possible Benefits

- Clinical trials offer high-quality cancer care. If you are in a randomized study and do not receive the new treatment being tested, you will receive the best known standard treatment. This may be as good as, or better than, the new approach.
- If a new treatment is proven to work and you are receiving it, you may be among the first to benefit.
- By looking at all your treatment choices, including clinical trials, you are taking an active role in a decision that affects your life.
- You have the chance to help others and improve cancer treatment.

### Possible Drawbacks

- New treatments under study are not always better than, or even as good as, standard care.
- If you receive standard care instead of the new treatment being tested, it may not be as effective as the new approach.
- New treatments may have side effects that doctors do not expect or that are worse than those of standard treatment.
- Even if a new treatment has benefits, it may not work for you. Even standard treatments, proven effective for many people, do not help everyone.
- Health insurance and managed care providers may not cover all patient care costs in a study. What they cover varies by plan and by study. To find out in advance what costs are likely to be covered, check with your insurance company and the billing staff at the hospital or doctor's office.

## Questions to Ask

If you are thinking about taking part in a clinical trial, here are some questions that can help you decide.

### About the Trial

- Why is this trial being done?
- Why do the doctors who designed the trial believe that the treatment being studied may be better than the standard treatment? Why may it not be better?
- How long will I be in the trial?
- What kinds of tests and treatments are involved?
- What are the possible side effects or risks of the new treatment?
- What are the possible benefits?
- How will we know if the treatment is working?

### Costs

- Will I have to pay for any of the treatments or tests?
- What costs will my health insurance cover?

### Daily Life

- How could the trial affect my daily life?
- How often will I have to come to the hospital or clinic?
- Will I have to travel long distances to take part?

### Comparing Choices

- What are my other treatment choices, including standard treatments?
- How does the treatment I would receive in this trial compare with the other treatment choices?

## How to Join a Clinical Trial

If you are thinking about joining a clinical trial as a treatment option, the best place to start is to talk with your doctor or another member of your health care team. Often, your doctor may know about a clinical trial that could be a good option for you. He or she may also be able to search for a trial for you, provide information, and answer questions to help you decide about joining a clinical trial.

Some doctors may not be aware of or recommend clinical trials that could be appropriate for you. If so, you may want to get a second opinion about your treatment options, including taking part in a clinical trial.

If you decide to look for trials on your own, the guide “How to Join a Cancer Clinical Trial” may help. This guide is available on the National Cancer Institute’s website at [www.cancer.gov/about-cancer/treatment/clinical-trials/search/trial-guide](http://www.cancer.gov/about-cancer/treatment/clinical-trials/search/trial-guide).

If you need help with your search, you can call, e-mail, or chat with a trained information specialist at the NCI Contact Center.

### Telephone

1-800-4-CANCER  
(1-800-422-6237)  
Mon – Fri  
8 a.m. to 8 p.m. ET

### LiveHelp Online Chat

[livehelp.cancer.gov/app/chat/chat\\_launch](http://livehelp.cancer.gov/app/chat/chat_launch)  
Mon – Fri  
8 a.m. to 11 p.m. ET

### E-mail

[www.cancer.gov/contact/email-us](http://www.cancer.gov/contact/email-us)

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A publication of the NCI Office of Communications and Public Liaison  
[www.cancer.gov/publications/patient-education/cancer-treatment-research-studies](http://www.cancer.gov/publications/patient-education/cancer-treatment-research-studies)



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