

Eye and Vision Concerns During Cancer Treatment

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Cancer treatments can cause changes in eyes and vision. Your health care team can help you manage these side effects.

Introduction: Common Eye and Vision Changes

Radiation, chemotherapy, immunotherapy, targeted therapy and hormone therapy can cause eye and vision changes, including:

- Sensitivity to light
- Eye pain
- Blurry vision
- Loss of peripheral vision
- Dry eyes
- Watery eyes
- Red and swollen eyelids
- Changes in the way colors are seen
- Small dark shapes (floaters) and flashes of light in the field of vision
- Accelerated development of cataracts

The stress associated with cancer and its treatment can also cause eye and vision changes.

A more serious side effect of certain treatments, especially chemotherapy and radiation, is increased pressure within the eye (glaucoma), which can lead to vision loss.

It's important to remember that not all people experience all of these side effects, and people may experience eye and vision side effects not listed here.

Before or shortly after starting treatment, it is helpful to ask a member of your health care team the following questions:

- Are there any common eye and vision changes for my treatment?
- Should I be tested for glaucoma and/or cataracts on a regular basis during my treatment?
- What are some options to reduce the impact of eye and vision changes?
- Should I wear glasses instead of contact lenses during my treatment?
- How long can eye and vision issues last? Will they go away after my treatment ends?
- How often should I see an ophthalmologist during my treatment?



Tips to Manage Eye and Vision Concerns

It's important that you report any eye and vision changes you experience to your health care team so they can help you manage them. Report them right away—especially those that involve any pain or loss of vision. Doing so will improve your quality of life and allow you to stick with your treatment plan. You can use a health care journal to track the timing and severity of any eye and vision changes you experience (see “Communicating With Your Health Care Team”).

Following is guidance for the most common eye and vision side effects:

- **Sensitivity to light.** Avoid bright lights. If you wear glasses, use tinted lenses.
- **Dry eyes.** Ask your health care team if over-the-counter, preservative-free artificial tears or prescription eyedrops may be right for you. For severe cases, your doctor may recommend punctal plugs—tiny medical devices placed in the tear ducts to help prevent the draining away of tears, helping to keep eyes moist.
- **Watery eyes.** The blockage of passages that allow for the drainage of tears can cause watery eyes. Warm, wet compresses can help. In more extreme cases, the blockage can be removed by a minor surgical procedure, helping the eyes to drain more efficiently.
- **Red, swollen eyelids.** This occurs when fluid collects in the tissues around the eyes. To ease symptoms, put a clean, wet cloth on your eyes for 15 minutes twice a day. Avoid wearing contact lenses or eye makeup while symptoms last.

- **Floaters and flashes of light.** Although in most cases these side effects don't require treatment, let your health care team know if you experience them, especially if you find your vision is affected (blurriness for example). Flashes of light may be a warning sign of retinal detachment.

Additionally:

- **Speak to your health care team about getting support accessories for your home.** These can include stabilizer bars for the bathtub or shower and devices to assist with balance. Your health care team may also be able to provide information about home-based services that help with home navigation and the completion of tasks and activities.
- **Inquire about at-home eye activities.** Blinking exercises and eyelid massages can help with dry eyes. Ask a member of your health care team if these may be right for you, and if they have any specific guidance.
- **Ask for help.** Your family members and friends will likely be a strong source of support at this time. For example, if you're sensitive to light and are not comfortable driving, ask friends and family members to take turns driving you to appointments. You can also ask for help in preparing meals and grocery shopping.



Guidelines for Eye Examinations

If possible, visit an ophthalmologist prior to beginning treatment, so they can perform a detailed examination of your eyes and take baseline measurements of the function of your retina and optic nerve. Specialized tests, such as visual field and optical coherence tomography, may also be performed. If you do not routinely see an ophthalmologist, ask your health care team for a recommendation.

You should visit an ophthalmologist regularly during treatment. Ask your health care team for their recommendation on the frequency, as it will depend on the type of treatment you are receiving and if you are experiencing any eye or vision side effects. Be prepared to tell the ophthalmologist about your type and stage of cancer and the specifics of the treatment you are receiving.





The Multi-disciplinary Team

A multi-disciplinary approach is essential in the management of eye and vision changes during cancer treatment. Depending on the type of treatment being given, the team can include your primary care physician, medical oncologist, radiation oncologist and ophthalmologist. Points to remember:

- Your primary care physician should be kept updated about your cancer treatment and any test results.
- Your local pharmacist is a great source of knowledge about the medications you are taking. Have all of your prescriptions filled at the same pharmacy to avoid the possibility of harmful drug interactions.
- Make sure your medical oncologist knows of any other medical conditions you have or any pain you are experiencing so they can consult with your primary care physician, radiation oncologist, ophthalmologist or other specialists as needed.

The Importance of Clinical Trials

Clinical trials are the standard by which we measure the worth of new treatments and the quality of life of patients as they receive those treatments. For this reason, doctors and researchers urge people with cancer to take part in clinical trials.

Your doctor can guide you in making a decision about whether a clinical trial is right for you. Here are a few things that you should know:

- Often, people who take part in clinical trials gain access to and benefit from new treatments.
- Before you participate in a clinical trial, you will be fully informed as to the risks and benefits of the trial, including any possible side effects.
- Most clinical trials are designed to test a new treatment against a standard treatment to find out whether the new treatment has any added benefit.
- You can stop taking part in a clinical trial at any time for any reason.



The Role of Telehealth

Telehealth, also called telemedicine, refers to the remote delivery of health care services. Through video-conferencing technology, you can communicate with your doctors and other members of your health care team from the comfort of your home.

Telehealth can save time, offer more flexible scheduling and make you feel more connected with your health care team. Information gathered during these appointments will be added to your record, just as with an in-person visit. Although the focus in this booklet is on telehealth appointments conducted through a video conference, the communication can also be via a traditional “voice only” phone call.

Contact your health care team about whether telehealth appointments are available and if they are the right choice for you. Your insurance carrier can advise you about your coverage for telehealth appointments.

Through telehealth, your oncologist and other members of your health care team can provide:

- A pre-visit review of your symptoms, personal health and family history
- A review of your treatment plan and expectations
- Guidance for in-person or hospital visits
- Information on relevant clinical trials
- Guidance for medication adherence
- Symptom management (including pain)
- Education on lifestyle modification to improve your quality of life

A telehealth visit may allow your doctor to prescribe oral medications when an in-person office or hospital visit is not possible or is undesirable from a risk perspective (e.g., exposure to common viruses).

Telehealth is not suitable for medical emergencies or visits that require a physical exam or lab work.



Prior to the Day of the Appointment

If you are seeing a health care provider for the first time, there may be forms to complete in advance of your appointment. These forms will be sent by your provider's office via regular mail or email.

Telehealth appointments require an internet or data connection through a computer, tablet or smartphone that has a front-facing camera. A member of your health care team will provide specific instructions on how to join the video call, including any program or application that may have to be downloaded in advance and the required login information. Ask if there is a back-up program in case the preferred program or application doesn't work or if a phone call can be used if as a last option.

Tell a member of your health care team ahead of time if a caregiver, friend or family member will be joining from a different location, so that any necessary technology-related information can be shared.

Gather your medical information, including information about your diagnosis, treatment plans, surgical procedures, any other health conditions you have and your family medical history. Create a list of your prescriptions plus any over-the-counter products or supplements that you are taking. It is also helpful to have your insurance information handy.

When scheduling your appointment, ask if there are any vital signs you should measure on the day of the visit (e.g., temperature, blood pressure). If you are able to, have the measurements ready to share.



The Day of the Appointment

Here are tips to make your appointment as successful as possible:

- Dress in loose, comfortable clothing.
- Find a space that is quiet, private and well-lighted.
- Check your internet connection.
- Plug in your device or make sure it is fully charged.
- Check that your microphone and camera are working.
- Make sure any required program or application is properly downloaded.
- Ask others in your household to avoid streaming video during your appointment, as this can slow your internet connection.
- Close any other programs or applications to maximize the quality of the connection and to reduce distractions.
- If you are using a smartphone or tablet, prop it up on your desk or table so that the camera is steady and facing you.

Once the appointment starts, try not to be too close to the camera. Your head and shoulders should be visible, similar to a driver's license or passport photo.

Communicating With Your Health Care Team

As you manage your cancer and its treatment, it's important to remember that you are a consumer of health care. The best way to make decisions about health care is to educate yourself about your diagnosis and get to know the members of your health care team, including doctors, nurse practitioners, physician assistants, nurses, dietitians, social workers and patient navigators.

Here are some tips for improving communication with your health care team:

Start a health care journal. Having a health care journal or notebook (either on paper or in a digital format) will allow you to keep all of your health information in one place. You may want to write down the names and contact information of the members of your health care team, as well as any questions for your doctor. You can also use the journal to track the timing and severity of any eye and vision changes you experience. This will allow you to accurately report these changes to your health care team. The information you can capture includes:

- The date and time you experience eye or vision changes
- How long the changes last
- How strong the changes are—for example, if you experience pain, how strong is it on a scale from 1 to 10, with 1 being the least amount of pain and 10 the most intense
- How your daily activities are affected—did these changes keep you from sleeping, eating, walking, working or exercising?

Prepare a list of questions. Before your next medical appointment, write down your questions and concerns. Because your doctor may have limited time, ask your most important questions first and be as specific as possible.

Bring someone with you to your appointments or have them be present during telehealth sessions. Even if you have a journal and a prepared list of questions or concerns, it's always helpful to have support when you go to your appointments. The person you bring may also think of questions to ask your doctor or remember details about your symptoms or treatment that you may have forgotten.

Write down your doctor's answers. Taking notes will help you remember your doctor's responses, advice and instructions. You can also ask the person who accompanies you to take notes for you. If you have a mobile device, ask if you can use it to take notes. Keeping notes will help you review the information later.

Record your visit if your doctor allows it. Recording the conversation with your doctor gives you a chance to hear specific information again or share it with family members or friends.

Remember, there is no such thing as over-communication.

CancerCare's Free Support Services and Programs

It can be very difficult to receive a diagnosis of cancer, and adjusting to the necessary changes in your life can be challenging.

CancerCare® can help. We are a national nonprofit organization providing free, professional services to anyone affected by cancer. Our licensed oncology social workers can provide support and education, help in navigating the complicated health care system and offer information on support groups and other resources.

To learn more about how CancerCare helps, call us at 800-813-HOPE (4673) or visit www.cancercares.org.

You will likely also build your own personal support network composed of family and friends. In doing so, it's best to take some time to think about the people in your life and how they are best suited to help. Match the task to their strengths—ask a family member who loves to shop to pick up something for you at the store, or ask a friend who's a good listener to come over for a chat.



MORE ABOUT EYE AND VISION CONCERNS DURING CANCER TREATMENT

Frequently Asked Questions

Q: What is the difference between an optometrist and an ophthalmologist?

A: Optometrists hold a doctor of optometry (OD) degree after finishing three or more years of college and four years of optometry school. They provide primary health care for the eye, including performing eye exams and vision tests, prescribing and fitting eyeglasses and contact lenses, detecting eye abnormalities and prescribing medication that treat eye diseases.

Ophthalmologists are medical doctors who completed an internship and a residency in ophthalmology. They provide complete eye care services—all the services provided by an optometrist plus medical and surgical eye care.

It is recommended that an ophthalmologist be part of your health care team while undergoing treatment for cancer, especially if you are experiencing eye and vision issues.



Q: What is a treatment summary and why is important?

A: There are two types of treatment summaries: those you create yourself and those given to you by your surgical, medical or radiation oncologist when you complete treatment. Keeping your own records up-to-date in the form of a treatment summary can be helpful, as it allows you and your family members to have instant access to the specifics of your cancer diagnosis and treatment.

A treatment summary should include:

- Your name and date of birth
- Date of diagnosis
- Prescribed therapy/therapies, including dates started and stopped and dosages when appropriate
- Dates and types of baseline and post-diagnosis testing and the results of these tests
- Other medications and supplements you are taking
- Blood transfusion dates and results
- Names, affiliations and contact information of all members of your health care team

Ask the members of your health care team what they suggest be included. Take your personal record with you when you visit any doctor—not just your oncologist—and have it handy during telehealth appointments.

Many cancer treatment centers provide a care plan summary (sometimes called a survivorship care plan) as a record of the care you received. This is for your records and for you to share with other members of your health care team, particularly your primary care doctor. This summary is important for your follow-up care, especially if your cancer treatment team and your primary care doctor do not use the same electronic health record system.

Q: In addition to eye and vision side effects, I am also experiencing fatigue. Do you have any guidance for me?

A: Fatigue (extreme tiredness not helped by sleep) is one of the most common side effects of many cancer treatments. If you are taking a medication, your doctor may lower the dose of the drug, as long as it does not make the treatment less effective. If you are experiencing fatigue, talk to your doctor about whether taking a smaller dose is right for you.

There are a number of other tips for reducing fatigue:

- To be able to sleep well at night, avoid excessive sleep during the day.
- Take walks or do some light exercise, if possible.
- Try easier or shorter versions of the activities you enjoy.
- Ask your family or friends to help you with tasks you find difficult or tiring.

Fatigue can be a symptom of other illnesses, such as anemia, diabetes, thyroid problems, heart disease, rheumatoid arthritis and depression. So be sure to ask your doctor if they think any of these conditions may be contributing to your fatigue.



Resources

CancerCare®

800-813-HOPE (800-813-4673)

www.cancercares.org

American Cancer Society

800-227-2345

www.cancer.org

Cancer.Net

Patient information from
the American Society of

Clinical Oncology

888-651-3038

www.cancer.net

National Cancer Institute

800-422-6237

www.cancer.gov

Cancer Support Community

888-793-9355

www.cancersupportcommunity.org

**National Coalition
for Cancer Survivorship**

877-622-7937

www.canceradvocacy.org

EyeCare America

Part of the American Academy
of Ophthalmology

www.aao.org/eyecare-america/resources

Medicine Assistance Tool

www.medicineassistancetool.org

CLINICAL TRIALS WEBSITES**ClinicalTrials.gov**

www.clinicaltrials.gov

EmergingMed

www.emergingmed.com

National Cancer Institute

www.cancer.gov

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