

Name: \_\_\_\_\_

MR#: \_\_\_\_\_

## Your Summary

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Your personalized OncoLife<sup>TM</sup> Survivorship Care Plan gives you information about the health risks you may face as a result of cancer therapies. Your level of risk can vary based on the doses and duration of your treatment and the combination of treatments received.

You should discuss this plan with your oncology team to better understand your personal risks. These results can be concerning, but not every survivor experiences every side effect, and some survivors do not experience any long-term effects. Learning about these risks can help you develop a plan with your healthcare provider to monitor for or reduce your risk for these side effects through screening and a healthy lifestyle.

The information in your plan is broken down by:

- Cancer therapies you received and related risks
- Future screening recommendations
- Healthy living tips
- Psychosocial issues you may face

You may see a particular side effect in more than one section because more than one therapy can cause the same long-term effect.

The information in this plan is based on the available research and literature concerning cancer survivors. This area is continually growing, and as new information becomes available, it will be added to the program. You may want to redo your plan periodically.

### **You received the following treatments for Head & Neck: Tongue, Lip, Oropharynx, Nasopharynx**

- Laryngectomy
- Cisplatin (Platinol®)
- Docetaxel (Taxotere®)
- Radiation treatment for head and neck cancers
- X-ray based radiation- IMRT

### **Information from your oncology office**

## Coordinating Your Care

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As a survivor, it is important that you keep a journal or notebook of your care. Include your doctor's contact information, a list of past and current medications, therapies received, laboratory and radiology studies. (Visit the [OncoPilot](#) section on OncoLink for forms you can use to organize this material). While some survivors continue to see an oncologist, many return to a primary care provider or internist for routine care, many of whom are uncertain how to care for you. Developing the OncoLife<sup>TM</sup> Survivorship Care Plan

can help you and your primary care provider understand what issues to look for, and how to handle them.

If you are being followed only by a primary care practitioner, it is a good idea to maintain a relationship with an oncologist or late effects clinic, should you need any guidance or referrals with regards to late effects. Call the cancer center where you were treated to ask if they have a survivor's clinic, or find one by searching [OncoLink's Survivorship Clinic List](#) (though this list is not exhaustive). A survivorship clinic will review the therapies you received, discuss your risks with you, and act as a consultant to your primary care team. Your OncoLife™ Survivorship Care Plan includes a "Healthcare Provider Summary" (found on the right side of your results), which is an abbreviated summary of recommendations that you can give to healthcare providers for reference.

## What's In Your Care Plan

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## Follow Up Care For Head & Neck Cancers: Tongue, Lip, Oropharynx, Nasopharynx

After receiving treatment for head and neck cancer, it is important for you to adhere to your oncology team's plan for follow-up care, including physical examinations, radiology tests, and dental care. There are several types of cancer that fall into the category of "head and neck cancer," so it is important to talk with your care team about your specific follow-up care needs. The following are general recommendations to discuss with your oncology team:

- Physical exam every 1-3 months for year 1, then every 2-6 months for year 2, then every 4-8 months for years 3-5, then annually thereafter.
- Post-treatment baseline scan of primary tumor site within 6 months of completing treatment. Your provider may order a Chest CT if you have a history of smoking. Further imaging should be conducted when your provider feels there is a concerning symptom but is not needed routinely.
- If your neck was in the radiation treatment field, thyroid stimulating hormone (TSH) levels should be checked every 6-12 months, as radiation can impair thyroid function.
- If you continue to smoke or use alcohol, ask for a referral to a program to help you quit.
- If your mouth was in the treatment field, you should have routine dental evaluations and perform regular oral care, including fluoride and frequent tooth brushing to help prevent and identify any dental problems early. Be sure your primary dentist is aware of your head and neck cancer treatment history. Avoid sugary and acidic foods.
- Follow recommendations to combat dry mouth (xerostomia) to aide in dental health and quality of life.
- Referral for speech, psychological counseling, hearing and swallowing rehabilitation and/or nutritional counseling if needed.
- Any new, unusual and/or persistent symptoms should be brought to the attention of your care team.

## Surgery Side Effects

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### Laryngectomy

Laryngectomy is the surgical removal of the larynx. The person who had the procedure is called a "laryngectomee." The larynx is the "voice box" or vocal cords. The larynx vibrates as air passes over it during exhalation, and this sound is made into our speech by the parts of our mouth. If the larynx is removed, no speech sounds can be made. You may be able to speak after a partial laryngectomy, but your speech will be different than it was before surgery. It may be more difficult for people to understand you. In addition, the trachea (breathing tube) is redirected with the removal of the larynx, resulting in a stoma (hole) in the neck that you breathe through. You may hear people refer to this as a "neck breather." These changes bring about some long-term practical and safety concerns of which you should be aware of.

#### *Safety Concerns*

- Notify your local 911 and EMS service of your condition so that they will respond even if you do not speak when you call.
- Get a medical alert bracelet identifying you as a "neck breather." This is important because CPR breathing or oxygen given through your mouth is ineffective.
- Carry something that can be used as an alarm in an emergency when you would otherwise yell for help. For example, an alarm for a keychain or bell can call attention to you.
- If you cannot speak or speech is difficult to understand, carry paper and pen to write messages.
- Because the air you breathe is not going through your nose, you will not be able to smell well, which

can have safety implications. You may not smell smoke from a fire, natural gas or sour food, for example. Make sure you have working smoke detectors and change the batteries every 6 months.

#### *Practical Concerns*

- **Showering:** You need to avoid getting water in the stoma. Options to keep water out: foam filters, stoma covers, washcloth or baby bib. You may get comfortable with showering over time and not need to cover your stoma.
- **Clean Air:** Remember that the air going into the stoma when you breathe goes directly to your lungs and is not being filtered by your nose. Be cautious about dust, pet hair, aerosol sprays, etc. - anything that can be in the air and inhaled. You may want to use a stoma cover for certain activities where the risk of inhaling something is higher.
- **Humidification:** Prior to surgery, the air you were breathing was humidified by your nose and mouth. After surgery, you no longer have this built in humidifier and this dry air leads to increased mucus production as the lungs try to moisten the air. You will need to learn how to increase the moisture level in the air you breathe and retain this moisture. Tools to do this include using a cool-mist humidifier when sleeping, saline squirts and stoma covers. You can learn much more about humidification from your healthcare team or at the resources listed below.

#### *Speech & Swallowing*

Issues with speech and swallowing are common after laryngectomy, but these issues can arise at any point in your life. If you have difficulty swallowing at any time, notify your oncology team. A speech-language pathologist (SLP) can help manage swallowing difficulties and help with devices and techniques to assist with your speech. SLPs can be accessed at any time in your life for new concerns or to explore newer technologies for speech.

#### *Finding Answers*

As you recover from surgery and get back to life, you are sure to encounter situations for which you weren't prepared. Your healthcare team is there to support you and answer questions. The following resources can provide lots of practical tips from other survivors who have "been there."

- **Web Whispers:** Support for laryngectomee survivors - Offers advice, tips, and education from survivors.
- **Support for People with Oral Head & Neck Cancer (SPOHNC):** Provides support groups, buddy programs, education, and awareness.

### **Key Takeaways**

- Safety is a concern after laryngectomy because your voice and sense of smell will change.
  - It is important to notify your local 911 and EMS that you are unable to talk. You should wear a medical alert bracelet and carry something to use as an alarm to get help in an emergency. Carry a pen and paper to communicate when needed.
  - You should also have working smoke detectors.
- You should use filters and covers to protect your stoma when showering. Ensure you are in a clean air environment and use a humidifier.
- Work with a speech-language pathologist to manage speech and swallowing concerns.

## **Risks Related to Medications**

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## Peripheral Neuropathy

Peripheral neuropathy is caused by irritation or damage to nerves, resulting in feelings of numbness, "pins and needles", tingling, burning, or a generalized weakness/heaviness of the limbs. This can cause difficulties with fine motor skills such as buttoning a shirt, sensation of hot or cold (causing a safety hazard) or difficulty walking. In many people, neuropathy gets better within weeks to months after finishing treatment with the medicine that caused the problem. Unfortunately, for some, the problem becomes chronic. You may require physical and occupational therapy, make changes in your home to ensure safety and take medicines to help with pain.

Pain management is done with medications that are not typically thought of as pain medications. These include tricyclic antidepressants, gabapentin and pregabalin. If your pain is not well managed, referral to a pain specialist may be helpful. This is a side effect that develops during or shortly after treatment and can become chronic. It does not develop as a late effect and if you do develop symptoms of neuropathy after therapy, your healthcare provider should look for other causes.

### Key Takeaways

- Peripheral neuropathy can be a long-lasting side effect that can require physical therapy, changes in your daily life for safety, and managing pain with medication.

## Development of Kidney Problems

Cisplatin, carboplatin and ifosfamide (Ifex) can cause damage to your kidneys. The risk is highest for childhood cancer survivors treated under the age of 5. These medications most often have an effect on your kidney during treatment. The long term risk for adult survivors is not well understood. The chance of kidney damage is higher if the kidneys were in the field of radiation therapy or if you have had one kidney removed. Kidney damage may present with elevated blood pressure or abnormalities in electrolytes (found with a blood test). Other health concerns including diabetes and high blood pressure can also increase risk of kidney problems. If you develop high blood pressure or electrolyte abnormalities, consider being seen by a nephrologist for consultation.

### Key Takeaways

- Have blood pressure checked every year during your physical exam.

## Hearing Changes or Loss

"Ototoxicity" can cause hearing loss, tinnitus (ringing in the ears) or vertigo (sensation of spinning or loss of balance). People who received cisplatin, carboplatin (in high doses), or radiation therapy to the head/neck area have the highest risk of these problems. Hearing loss can worsen over time.

You should report any hearing difficulties or signs of ototoxicity. You should be referred to see an audiologist if you experience any hearing difficulties.

### Key Takeaways

Report the following symptoms to your healthcare provider and request an audiogram and referral to an audiologist:

- Hearing loss:
  - Trouble hearing the TV, or need for increased TV volume.
  - Trouble hearing others in meetings or at large gatherings.
- Ringing in your ears.
- Dizziness/spinning and/or loss of balance.

## Elevated Cholesterol Levels

Survivors who received cisplatin and/or carboplatin may develop high cholesterol levels at earlier than expected ages. You should have your cholesterol levels checked after completing treatment and annually thereafter.

### Key Takeaways

- Have cholesterol checked after completing therapy and annually thereafter.

## Risk of Developing Osteoporosis

Osteoporosis is a decrease in bone density (thinning of the bones) that can lead to fractures (broken bones). While the risk for osteoporosis appears on the medications tab, the risk can be related to a number of things. Risk is increased for:

- People who take corticosteroids for more than 2 months (dexamethasone or prednisone, more than 5mg per day).
- People who receive radiation to weight bearing bones (spine, hips, legs).
- Women who develop premature menopause or have their ovaries removed before menopause.
- Women who take aromatase inhibitors (anastrozole, letrozole and exemestane).
- Pre-menopausal women who take tamoxifen.
- Men who receive hormone therapy for prostate cancer or have a testicle(s) removed (orchiectomy).
- People who have had a gastrectomy (removal of the stomach).
- Several types of chemotherapy have been found to contribute to bone loss, including cytoxan, cisplatin, carboplatin, ifosfamide, doxorubicin, methotrexate, and possibly imatinib.
- General factors that increase the risk of osteoporosis include: being over the age of 50, smoking, drinking too much alcohol, not exercising and some chronic health conditions.

There are things you can do to lower your risk of a fracture and strengthen your bones:

- Get 1000-1200mg a day of calcium.
  - It is best to get calcium in a balanced diet, including 4-8 servings of calcium rich foods a day. Examples of calcium rich foods are low fat milk, yogurt, cheese, green leafy vegetables, nuts, seeds, beans, legumes and calcium fortified foods and juices.
  - A dietician can provide more guidance in choosing calcium rich foods. A good resource is [www.myplate.gov](http://www.myplate.gov).
  - If you cannot get the recommended amount of calcium in foods, take calcium citrate supplements. Your body does not absorb calcium supplements well, so spread the dose out by taking 1 tablet several times a day, instead of all at once. If you take Synthroid / levothyroxine (thyroid hormone), separate it from calcium doses by at least 4 hours.
- Take 800-1000 IU of vitamin D-3 daily.

- Your healthcare provider may check blood levels of vitamin D with the 25-OH Vitamin D blood test.
- Do not take more than 2000 IU of vitamin D3 a day, unless directed by your healthcare provider.
- Weight bearing exercise and strength training can improve your bone strength.
  - Before you start an exercise program, check first with your care team to determine if it is safe.
  - Start with what is comfortable for you and work up to the following recommendations:
  - Get 30-40 minutes of weight bearing exercise 3 times a week. Weight bearing exercises are those in which your feet or legs bear your body's weight while the bones and muscles work against gravity. Examples include: walking, jogging, Tai Chi, yoga and dancing.
  - Strength training 2-3 times per week, with a day of rest in between each session. Complete 8-12 repetitions of the exercises below, and repeat them two times (2 sets). Choose a weight where the tenth repetition is hard for you to complete and you can't complete an 11<sup>th</sup> time. Now remove 1-5 pounds from that "maximum weight," and use that as your training weight. When you can easily do 12 repetitions, try to increase the weight by 3-5lbs.
  - Exercises include: leg extensions, calf raises, leg curls, chest press, latissimus pulldown, overhead press, row machine and curl ups.
  - Your provider can refer you to a physical therapist or a physical medicine and rehabilitation physician for more guidance regarding bone-strengthening exercises.
- Decrease or stop caffeine intake and limit alcohol intake, as these can weaken bones.
- Quit smoking. Learn more about how to get started [on OncoLink](#).
- Your provider may order a DEXA scan, which is a test used to measure the thickness (density) of your bones.

### Key Takeaways

- Avoid smoking, caffeine, and excessive alcohol intake.
- Perform weight-bearing and strength training exercise 2-3 times per week.
- Calcium intake of 1000-1200mg per day plus Vitamin D 800iu to 1000iu per day (ideally from food sources, and supplements when your diet is not sufficient).
- Consider screening with DEXA scan.

## Raynaud's Phenomenon

Raynaud's disease is a condition that causes blood vessels in certain areas of the body to spasm or narrow, leading to numbness and cold feeling in that area.

- It can be triggered by cold temperatures or stress.
- Most often affects fingers or toes, but can involve the nose, earlobes, lips or cheeks.
- Spasm causes limited blood flow to the area, making the area look pale or blue in color.
- Once the spasm subsides, the area may appear red from the rush of blood back into them.

Certain chemotherapies increase the risk for Raynauds, including vinca alkaloids (vincristine, vinblastine or vinorelbine) and platin medications (cisplatin, carboplatin). It can happen during, or months after treatments are finished. For some, the symptoms slowly resolve, but for others they do not.

If you experience Raynaud's disease, suggestions include:

- Avoid exposing the affected area(s) to cold.
- Nicotine can also constrict blood vessels, so smoking should be avoided.

- Some medications, including pseudoephedrine, birth control pills and certain heart and blood pressure medications, can cause constriction of the blood vessels. Talk to your healthcare provider if you are taking any of these medications and are experiencing Raynaud's symptoms.
- Medications that dilate blood vessels may be used to control symptoms in severe cases. However, these medicines have their own side effects.
- Have your blood pressure checked annually.

### Key Takeaways

- Avoid smoking and medications that constrict blood vessels.
- Protect affected areas from cold exposure.
- Have your blood pressure checked every year.

## Understanding Chemo-Brain

Many survivors who have previously received or are currently undergoing chemotherapy or other cancer treatments report experiencing cognitive changes, often referred to as "chemo-brain." This can include difficulty with short term memory, multi-tasking, new learning, reading comprehension, working with numbers and trouble concentrating. Research has found that depression or anxiety over the diagnosis and treatment of cancer may contribute to or worsen these issues. Whether related to the stress of treatment or the treatment itself, cognitive changes after treatment are real. We do not know whether only certain medications are responsible. It does appear that the more treatment a person gets, the more likely they are to have issues. Studies have found that cognitive ability can improve over time in some survivors, but deficits are still present in many long term survivors, years after treatment.

Some medications are being studied as potential treatments, but there is not yet enough evidence to support their use. Some of the agents being studied include: methylphenidate (Ritalin), modafinil (a medication approved to treat narcolepsy), various antidepressants, herbal therapies, such as ginkgo biloba, ginseng and certain amino acids. Cognitive rehabilitation programs use exercise, tasks that use memory and puzzles to "rehabilitate" one's mind. These programs are typically used for people with brain injuries, but therapists have tailored programs for cancer survivors. Bookstores and websites offer memory training, which may be helpful to survivors. Puzzles using numbers, like Sudoku, may help "exercise" your brain. Fatigue can enhance cognitive problems, so avoiding fatigue by getting enough sleep, incorporating exercise into your life and eating a healthy diet may be helpful.

It is important to remember that some very treatable problems can cause cognitive issues, such as thyroid problems, depression and anxiety. If you are experiencing cognitive problems, it is important to be checked for these issues. Hypothyroidism (low thyroid hormone levels) is a common issue for survivors and can make you feel "fuzzy" or "out of it." This is easily treatable with supplemental thyroid hormone. Survivors who are depressed or experiencing anxiety can benefit from working with a therapist experienced in working with cancer patients or survivors.

### Key Takeaways

- There is no proven treatment for chemo brain, but cognitive rehabilitation / brain games, avoiding becoming fatigued, regular exercise, and a healthy diet can be helpful.
- Create reminders by making lists, using to-do apps or alarms on a phone to help you stay on track.
- If you believe you are experiencing chemo brain you should consult your care provider to rule out



other health issues including thyroid problems, depression and anxiety.

## Fertility and Sexuality Concerns for Male Survivors

Fertility after cancer therapy is a very complex topic. Whether or not a man will remain fertile after treatment is related to:

- The doses and types of medications you received (certain medications, higher doses or longer treatments are more likely to cause infertility).
- If you also got radiation to the abdomen, pelvis or brain.
- Surgery to reproductive organs (testes, prostate, seminal vesicles.)
- Your age at the time of treatment.

With all of these variables, there is no way to easily predict a survivor's reproductive health. If you wish to father a child or assess your fertility, consider seeing a reproductive specialist who has experience working with cancer survivors. A fertility specialist can perform tests to evaluate fertility, including certain hormone levels and sperm counts.

[LiveSTRONG](#) and The [OncoFertility Consortium](#) websites can help you find a fertility specialist. LiveSTRONG offers financial assistance to cancer survivors. The OncoFertility Consortium and The National Infertility Association's website, [Resolve](#), offer information on fertility treatments and testing, adoption and deciding to not have children. They also have information on individual state laws about fertility coverage by insurers. If you underwent sperm banking prior to treatment, you will need to work with a fertility specialist to fertilize the egg.

Certain treatments are more strongly tied to infertility, including:

- Certain anti-cancer medications: alkylating agents (Cytosan, busulfan, melphalan, BCNU), procarbazine, bevacizumab, cisplatin and some FOLFOX regimens.
- We do not know how many of the newer treatments will affect long term fertility.
- Total body irradiation and bone marrow transplant are considered high risk for infertility.
- Radiation fields that include a man's pelvis, testicles or brain can affect fertility.
- Surgery that removes both testicles, the pituitary gland or other procedures in the pelvis.

In many cases, azospermia (no sperm) or oligospermia (low sperm count) is temporary, with sperm production recovering in the months to as long as 4 years following cancer therapy. To learn more about fertility related to cancer treatment, please visit [OncoLink's section on sexuality and fertility](#) or the [OncoFertility Consortium website](#).

Sexuality concerns can include erectile dysfunction (ED), dry ejaculation and decreased libido. Many male survivors feel lucky to be alive and don't realize there are solutions available to help with the loss of their sex life. ED after radiation, surgery or chemotherapy can be temporary and can improve up to 2 years after treatment. Remaining sexually active, with the aid of medications or other devices, can improve the likelihood of regaining erectile function. An important first step is acknowledging the problem and seeking the help of an urologist who specializes in erectile dysfunction. Some cancer surgeries can lead to dry ejaculations - this is when the man reaches climax, but no semen is released. This happens because the semen goes into the bladder instead of out the penis. This is not harmful, but can be a concern for men who wish to father a child. A fertility specialist can help as the sperm can be recovered from the man's urine.

It is important to have open communication with your partner about your fears and concerns. Communication can help you both learn new ways to find sexual pleasure when cancer has changed your

routine. You should also feel comfortable asking your healthcare providers for help if concerns arise. The [Us Too Prostate Cancer Education & Support website](#) has many helpful tips for men facing these issues.

### Key Takeaways

- Survivors wishing to become pregnant or father a child should consult with a fertility specialist familiar with cancer survivors.
- Survivors dealing with erectile dysfunction (ED) should seek the help of an urologist who specializes in ED.

## Risk of Cardiac (Heart) Problems Related to Cisplatin

Cisplatin and carboplatin may be present in your blood for decades after treatment. This can lead to vascular disease, which is a condition that affects your blood circulation. Signs of this can include Raynaud's disease (spasms of small arteries in the fingers and toes when exposed to cold temperatures causing cold or numbness), hypertension (high blood pressure), stroke, myocardial infarction (heart attack) and angina (chest pain).

You should be aware of these risks and have cardiac screening (blood pressure, cholesterol) in your annual physical exam. To help reduce your risk of heart problems, you should work hard to not use tobacco, maintain a healthy weight, eat well and get regular exercise.

### Key Takeaways

- Maintain healthy lifestyle:
  - Avoid smoking.
  - Maintain a healthy weight.
  - Exercise regularly.
  - Eat a well-balanced diet.
- Female survivors should consider a cardiac exam by a cardiologist prior to becoming pregnant.
  - Have an annual physical exam that includes a cardiac exam, checking blood pressure and cholesterol levels.
- Report the following symptoms to your healthcare provider:
  - Shortness of breath (with or without exertion).
  - Difficulty breathing when lying down.
  - Chest pain.
  - Palpitations.
  - Dizziness/lightheadedness.
  - Swelling of the arms or legs.

## Risk of Developing a Secondary Cancer

A secondary cancer is one that develops as a result of the treatment for another cancer. This is quite rare, but you should be aware of the risk. In most cases, a secondary cancer related to chemotherapy is a blood cancer (such as leukemia or lymphoma).

- Certain chemotherapy medications can cause damage to the blood cells in the bone marrow. In rare cases, this damage can lead to leukemia or myelodysplasia (MDS) years after treatment.

- Blood cancer caused by chemotherapy or radiation therapy typically occurs 4-10 years after treatment but can occur even later.
- One exception is those cancers caused by etoposide (VP-16) or teniposide (two types of chemotherapy), which tend to occur within 1-3 years after therapy.
- The medication bendamustine has also been associated with secondary blood cancers. This medication has also been associated with secondary lung cancers.

### Key Takeaways

- There is a small risk of developing a blood cancer years after your treatment is completed.
- Report the following symptoms to your healthcare provider promptly:
  - more tired or weaker than usual.
  - shortness of breath.
  - loss of appetite.
  - weight loss.
  - chills, fever, night sweats.
  - painless swelling of a lymph node.
  - easily bruising, nose bleeds, bleeding from the gums.
- Your provider will monitor your labs closely. Consider having a complete blood count with differential checked annually by your healthcare provider if you received high-risk therapies.

## What We Do Not Know

There are many medications that we do not know the long term effects they may cause. Most cancers are treated with a combination of medicines. This can make it difficult to be certain which medication is the cause of a long term effect. Research is continuing and new information may become available. You should periodically talk to your healthcare team about new information or look for new information in reliable journals and/or internet sites.

In addition, there have been many new therapies developed in the last ten years, including many of the biologic therapies, monoclonal antibodies and targeted therapies. We may not know the long term effects of these medications for many years. As a survivor, you should be an active participant in your healthcare and keep an ear out for new information.

### Key Takeaways

- Many cancer treatments today have not been available long enough to determine what effects they may cause in years after treatment.
- Always let your healthcare team know if you notice any new or worsening symptoms. Remember, you know your body best.
- Periodically look for new information about your treatment and talk to your healthcare team to see if they have anything new to report.

## Side Effects of Radiation

Long term effects of radiation therapy vary greatly depending on the areas included in the field of radiation

and the radiation techniques that were used, as these continue to develop and improve. One issue that is consistent across all tissues is the possibility of developing a second cancer in or near the radiation field. Secondary cancers develop as a result of the exposure of healthy tissue to radiation. Newer radiation techniques are designed to limit this exposure, but it is not always possible to prevent all exposure and still achieve the desired outcomes.

## Head & Neck Cancer Radiation

The radiation used to destroy cancer cells can also hurt normal cells in the surrounding area. Most side effects are temporary, going away after therapy is complete. There are some potential long-term side effects that are specific to head & neck cancer treatment. These can occur months to years after cancer treatment and the risks vary depending on the area of treatment and the radiation techniques that were used. Some of the potential long-term side effects of radiation to the head & neck include:

- Swallowing problems: Radiation can cause a build-up of scar tissue months to years after treatment, which can lead to swallowing problems. Report any changes in swallowing to your provider. You may benefit from being seen by a speech and swallowing specialist.
- Radiation fibrosis: This is a scarring of muscles that can make the muscles feel stiff or tough. These muscles can have spasms, stiffness, pain and/or become weak. Scarring of muscles in the neck can cause the head to be rotated and tilted to the side. Physical therapy, cancer rehabilitation, supportive devices, and certain medications can be very helpful in managing these changes.
- Nerve Issues: Nerves in the area that is radiated can be damaged or impinged by scar tissue, resulting in weakness or pain in the area.
- Lymphedema: Swelling of the face, chin and neck area can occur. Notify your provider if you notice swelling. Physical therapy can be used to treat and manage lymphedema.
- Trismus: This is a chronic contraction of the muscle that controls the opening and closing of the mouth (TMJ). Trismus results in an inability to open the mouth normally, which can make it difficult to eat, speak, or perform dental care. Your oncology team can recommend jaw exercises to prevent or help improve trismus. For some patients, jaw manipulation by a dentist or treatment by a cancer rehabilitation provider can be helpful.
- Changes in Saliva Production: You may have either dry mouth or thickened saliva. Dry mouth can lead to cavities. Dry mouth can be managed using a saliva substitute, sipping on fluids and sucking on sugar-free candy. Thickened saliva can be managed by drinking fluids to thin your spit, using a cool or warm air humidifier and warm showers. Some medications can be used to treat thickened saliva.

There are treatments available for many of these issues. Providers who specialize in Cancer Rehabilitation Medicine (called physiatrists) can be very helpful in treating these concerns. You should also see a dentist regularly.

Because the head & neck treatment field can encompass several other structures and organs, the risks to these areas are discussed below.

### Key Takeaways

- Scar tissue caused by radiation can lead to a number of issues including changes in swallowing, muscle strength and movement, swelling or pain in the head, face or neck, or trouble opening your mouth. These can happen even years after treatment. You should call your provider if you have any of these issues.
- Long term side effects are often best managed when treated early.
- Physical therapy, lymphedema (swelling) specialists and cancer rehabilitation specialists can be

helpful in managing these long term and late effects.

- Diligent mouth care and seeing a dentist regularly is important to prevent issues such as cavities.

## Spinal Cord

Radiation to the spinal cord can cause damage to nerves. This can cause a loss of strength, feeling, or coordination of the arms or legs, paralysis, or problems with bowel or bladder control. Sometimes nerve damage can cause a sensation of electric shock spreading down the arms or legs. You may need imaging tests or to be seen by a neurologist for further workup of these symptoms.

Radiation can also cause damage to the bones of the spine. This can result in a reduction in height or change in the curvature of the spine. Radiation to these bones can also put them at risk for fracture. If you have any new back pain you should call your provider right away. You may need x-rays or other imaging tests.

### Key Takeaways

- You should call your provider right away if you are having any new back pain, trouble holding your bowels or bladder, weakness, or suddenly not being able to move your arms or legs. You may need an x-ray to figure out what is causing these symptoms.
- If you are having shock-like pains in the arms or legs, your provider may suggest you see a neurologist.
- If you have any new curvature of the spine, you should be seen by an orthopedist.

## Eyes

If your eyes were in the area that received radiation, you are at long term risk of developing cataracts at an early age. Symptoms of cataracts include: blurry vision, light sensitivity, poor night vision, double vision in one eye, seeing "halos" around objects, needing brighter light to read or fading or yellowing of colors. If you have any of these symptoms you should contact your provider right away.

Damage can be caused to the lacrimal glands (tear ducts). This can cause a loss of or decrease in tear production and chronic dry eyes. You may be given artificial tears or medications to stimulate tear production. Patients with dry eyes from radiation treatment may be at increased risk for infections in the cornea (the front part of the eye).

Other possible effects can include:

- Shrinkage or loss of the eye.
- Corneal abrasions and ulcers.
- Glaucoma.
- Damage to the optic nerve, leading to vision loss or blindness.

Due to the possible side effects to your eyes, you will need to be seen by an eye doctor (ophthalmologist) on a regular basis. If you notice any changes in your vision, you should contact your provider right away.

### Key Takeaways

- Your provider will tell you how often you should be seen by an eye doctor. If you have any changes in your vision you should call your provider right away.

## Ears

Radiation to the head can damage the cochlea, a part of the inner ear. This can lead to hearing loss, dryness of the ear canal and fluid collection in the inner ear. These issues may lead to:

- A full or clogged ear feeling.
- Dizziness.
- Ringing in the ears (tinnitus).
- Vertigo (sensation of spinning or loss of balance).

If you are having any of these issues, you should call your provider. An audiogram (hearing test) or consult with an audiologist can help decide how these side effects can be managed.

### Key Takeaways

- If you have a loss of hearing, pain, or ringing in the ears you should contact your provider. A hearing test may be done by your provider or you may be referred to an audiologist.

## Salivary Glands (Parotid)

The parotid glands are the largest of the salivary glands. They are found behind the jaw, below and in front of the ears, as well as in the floor of the mouth. Their job is to make saliva. Radiation to these areas can affect the parotid glands and decrease saliva production. This can be a short or long term side effect. Loss of saliva can make it hard to eat and speak. Some tips to help provide relief include:

- Saliva substitutes can provide some relief. They come in gels, lozenges and sprays and can be by prescription or over the counter. Talk with your provider for suggestions.
- Chew on sugarless gum or suck on sugarless hard candy to stimulate saliva production.
- Drink plenty of water to stay hydrated. Keep a water bottle on hand.
- Suck on ice chips.
- Avoid soda, caffeinated beverages, alcohol and tobacco, which can all cause more dryness.
- Eat moist foods and sip liquids with your meals.

Saliva is important for killing bacteria in the mouth and on the teeth. It is important to perform good dental hygiene to prevent rapid tooth decay. This includes brushing twice a day and flossing. Avoid sugary foods, candy and drinks. Visit your dentist for cleanings and oral exams every 6 months. Fluoride treatments can help prevent cavities and decay. Your dentist and oncology team will help you decide what method of fluoride treatment is best for you.

If you received radiation to the jaw, you are at risk for osteoradionecrosis (ORN) of the jawbone. ORN is an inability of bone to heal after minor trauma. ORN can happen after a dental procedure (such as pulling a tooth). It may start as jaw pain or not being able to open the jaw. Make sure your dentist knows that you have had radiation to the jaw.

Changes in, or a loss of, taste or smell can occur during treatment, and can become permanent. You also could have a hard time chewing or swallowing. Ask to speak with a dietitian if you are having any of these issues, as nutrition is an important part of health.

### Key Takeaways

- Damage to the parotid (salivary) glands can lead to dry mouth. This lack of saliva can lead to dental issues, so you should brush twice a day and floss daily.
- You should have a dental check-up and cleaning every 6 months.
- You should call your provider if you are having any new or worsening jaw pain.
- Ask to speak to a dietitian if eating is hard due to decreased saliva, decreased taste/ smell, or difficulty chewing or swallowing.

## Sinuses

Radiation to the sinuses can lead to chronic sinusitis (inflammation of the sinus tissues). Symptoms of sinusitis include post nasal drip, nasal discharge, facial pain, and headaches. You may be referred to an otolaryngologist for these issues.

### Key Takeaways

- Talk to your provider if you are having chronic sinus headaches or post-nasal drip. It might be helpful to be seen by an otolaryngologist (ear, nose and throat provider).

## Throat / Upper Airway

Radiation treatment that includes the upper airway and throat (upper esophagus) can lead to scarring or swelling. This scarring and swelling can make breathing, speaking, and/or swallowing difficult. If you have severe trouble breathing you may need a tracheostomy (tube placed in the front of the neck to allow breathing). You may also notice that your voice is hoarse or you may have a chronic cough. Any worsening of these symptoms or coughing up blood should be reported to your provider right away.

Trouble with swallowing can make it hard to eat safely, which can lead to weight loss and malnourishment. You can monitor your weight at home along with having your weight monitored by your care team. If you are losing weight you should contact your care team. You should see a speech and swallowing specialist if you develop any new or worsening swallowing issues. A registered dietitian can work with you if you are having trouble maintaining a proper diet. They may suggest high calorie supplements or particular dietary changes. You should be followed by a registered dietitian until your nutritional status and weight are acceptable.

### Key Takeaways

- If you are having trouble breathing due to upper airway problems, develop a hoarse voice, or a new or worsening cough, you may need to be seen by an otolaryngologist (provider who specializes in issues of the ear, nose and throat).
- You and your provider should make sure that you are eating a proper diet and maintaining a healthy weight.
- You may be seen by a dietitian if you are not able to eat enough because you are having trouble swallowing.

## Thyroid

The thyroid gland is located in the neck, just below the larynx (voice box). Radiation fields that include the thyroid gland can lead to thyroid problems, including hypothyroidism, hyperthyroidism, and thyroid nodules/tumors. Most often, thyroid issues caused by radiation develop 2-5 years after treatment, while thyroid nodules are more often seen 10 years or more after treatment. Risk increases with the amount of radiation received to the area.

Survivors should have a thyroid exam and a history and physical performed each year by their provider to check for thyroid issues. If the thyroid was directly in the radiation field, TSH (thyroid stimulating hormone) levels should be checked every 6-12 months. This is done using a blood test. If you develop thyroid problems, you should be seen by an endocrinologist.

Symptoms of hypothyroidism (the most common complication) include fatigue, weight gain, constipation, dry skin, brittle hair or always feeling cold. Symptoms of hyperthyroidism include weight loss, irregular or fast heart beat, sweating and being irritable. You may also be at risk for hypoparathyroidism, a condition resulting from damage to the parathyroid glands (located in the same area as the thyroid). Signs of hypoparathyroidism are tingling in your fingers, toes and lips, muscle aches, muscle spasms, and fatigue. If you notice any of these symptoms, you should contact your care provider.

### Key Takeaways

- Each year during your annual physical, your provider should feel your thyroid to see if there are any noticeable changes.
- You may have your thyroid levels checked with a blood test each year or if you start to have symptoms of a possible thyroid issue.

## Bone

Damage to the bone from radiation can cause small cracks (fractures) in that bone. As best you can, avoid any trauma such as falling or a car accident. If you do get hurt, you should ask your provider if any imaging tests are needed to check for bone damage. If radiation is given in the area of a joint, permanent stiffness, pain and arthritis can develop in that joint. This can be treated with medications called non-steroidal anti-inflammatories (NSAIDs) and with physical or occupational therapy.

### Key Takeaways

- If you are having pain after any trauma, such as a fall or car accident, you should be evaluated for any damage to your bones.
- If you develop arthritis, you may be given medications to decrease pain and inflammation.
- Working with a physical or occupational therapist may also be helpful.

## Skin

Radiation can lead to permanent changes in the skin. There may be changes in the color or texture of your skin or new scars. It can also change the color and texture of your hair or can cause permanent hair loss in the treated area. The soft tissue and muscles under the skin can develop scarring and/or shrinkage, which can lead to a loss of flexibility and movement or chronic swelling. You may develop chronic or recurring ulcers of the skin in the area treated. Blood vessels of the skin may become dilated and more visible,



although this is not harmful. If the skin feels tight or sore, you can apply vitamin E to the skin.

If your skin is more sensitive after radiation, it is best to use fragrance and dye free soaps and moisturizers in the area. After radiation, the skin in the treated area is more sensitive to sunlight. This sensitivity will last for your lifetime. Make sure to use plenty of sunscreen, wear a hat, and keep the skin covered with clothing. Try to avoid being out in the sun between the hours of 10am-4pm when it is the strongest.

If you notice any new or worsening skin issues anywhere on your body, you should contact your provider for an assessment.

### Key Takeaways

- The area of skin that was affected by radiation may be more sensitive. Care for your skin using mild soaps and moisturizers. Use sunscreen daily to prevent burns.
- Contact your provider if you have any changes to your skin.

## Healthy Living After Cancer

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Survivors often wonder what steps they can take to live healthier after cancer. There is no supplement or specific food you can eat to assure good health, but there are things you can do to live healthier, prevent other diseases, and detect any subsequent cancers early.

In addition to medical problems and screening, cancer survivors also sometimes have issues with insurance, employment, relationships, sexual functioning, fertility, and emotional issues because of their treatment and we will discuss those in this care plan.

No matter what, it is important to have a plan for who will provide your cancer-focused follow up care (an oncologist, survivorship doctor or primary care doctor). You have taken the first step by developing a survivorship plan of care. If you would like to find a survivorship doctor to review your care plan you can contact cancer centers in your area to see if they have a survivor's clinic or search for a clinic on OncoLink's [survivorship clinic list](#).

### General Cancer Screening for Men after Head & Neck Cancer: Tongue, Lip, Oropharynx, Nasopharynx

Cancer screening tests are designed to find cancer or pre-cancerous areas before there are any symptoms and, generally, when treatments are most successful. (Learn more about screening tests) Various organizations have developed guidelines for cancer screening for men. While these guidelines vary slightly between different organizations, they cover the same basic screening tests, including those for prostate and colorectal cancers.

During routine health exams (at any age) your healthcare provider may also evaluate for cancers of the skin, mouth, thyroid and testes. Not all screening tests are right for everyone. Your personal and family cancer history, and/or the presence of a known genetic predisposition, can affect which tests are right for you and at what age you begin them. Therefore, be sure to discuss these with your healthcare provider. Your care plan will also include a section on follow up care for your type of cancer, and these recommendations override the general screening recommendations for that particular cancer in the general population.

### Prostate Cancer Screening

Prostate screening recommendations from the American Cancer Society (ACS) recommend that men discuss the risks and benefits of prostate cancer screening with their provider, and make an informed decision about whether to be screened or not. Men at average risk for prostate cancer should have this discussion starting at age 50. Men with a father or brother who had prostate cancer before age 65, and all African American men, should have this talk starting at age 40 or 45. If you decide to be tested, you should have a PSA blood test with a digital rectal exam. How often you are tested will depend on your PSA result and family history. For more information, please see the document, [Prostate Cancer: Early Detection](#).

### **Testicular Cancer Screening**

The majority of testicular cancers occur between the ages of 15 and 45. All men should examine their testicles regularly, be familiar with their normal look and feel, and report any changes to their healthcare provider for further investigation. Visit the ACS for a [guide to performing a testicular self-exam](#).

*For More Information:*

Visit [the American Cancer Society](#) to learn more about general screening recommendations.

### **Colon and Rectal Cancer Screening**

Most men and women over the age of 45-50 should undergo routine screening for colon and rectal cancer, up until age 75. The American Cancer Society suggests starting screening at age 45, whereas the United States Preventive Services Task Force suggests starting at age 50. Insurance may not cover screening before the age of 50 so you should talk with your provider and insurance company before screening. Testing may be appropriate for younger people with a high-risk personal or family health history.

Options for colon cancer screening can be divided into those that screen for both cancer and polyps, and those that just screen for cancer. Tests that screen for cancer and polyps include flexible sigmoidoscopy, colonoscopy, double-contrast barium enema, or CT colonography (virtual colonoscopy). Tests that screen mainly for cancer include stool testing for blood, or stool DNA testing. [Learn more about colorectal cancer screening options](#).

The “preferred screening” recommended by the American College of Gastroenterologists is a colonoscopy every 10 years. The ACS recommends screening beginning at age 45 (unless you are considered “high risk,” see below), using one of the following testing schedules:

Tests that find polyps and cancer:

*(Preferred over those that find cancer alone. If any of these tests are positive, a colonoscopy should be done.)*

- Flexible sigmoidoscopy every 5 years, or
- Colonoscopy every 10 years, or
- Double-contrast barium enema every 5 years, or
- CT colonography (virtual colonoscopy) every 5 years

Tests that primarily test for cancer:

- Yearly fecal occult blood test (FOBT)\*, or
- Yearly fecal immunochemical test (FIT) \*, or
- Stool DNA test (sDNA), interval uncertain\*

*\* The multiple stool take-home test should be used. One test done by the doctor in the office is not adequate for testing. A colonoscopy should be done if the test is positive.*

Talk with your doctor about your medical history, and what colorectal cancer screening test and schedule is best for you. For more information on colorectal cancer from the ACS, read [Colorectal Cancer: Early Detection](#).

Individuals at higher risk of colon cancer should have screening earlier and potentially more frequently. Individuals at higher risk of colon and rectal cancer include:

- Individuals with a family history of colon or rectal cancer in a relative who was diagnosed before the age of 60.
- Individuals with a history of polyps.
- Individuals with inflammatory bowel disease (Crohn's disease or ulcerative colitis).
- Individuals with a genetic predisposition to colon or rectal cancer, such as hereditary non-polyposis colon cancer (HNPCC) syndrome or familial adenomatous polyposis (FAP) syndrome.

For more detailed information regarding screening for individuals at higher risk for colon cancer, see the [ACS guidelines for screening for high-risk individuals](#).

## Lung Cancer Screening

The American Cancer Society does not recommend tests to check for lung cancer in people who are at average risk. However, they do have screening guidelines for those who are at high risk of lung cancer due to cigarette smoking. Screening might be right for you if you meet the following:

- 50 to 80 years of age and in fairly good health.
- Have at least a 20 pack-year smoking history AND are either still smoking or have quit smoking within the last 15 years (A pack-year is the number of cigarette packs smoked each day multiplied by the number of years a person has smoked. Someone who smoked a pack of cigarettes per day for 20 years has a 20 pack-year smoking history, as does someone who smoked 2 packs a day for 10 years.)

Screening is done with a low-dose CT scan (LDCT) of the chest. If you fit the list above, you and your provider should talk about whether to have screening.

## Sun Exposure and Skin Cancer Risk

Skin cancer is the most commonly diagnosed type of cancer, and rates are on the rise. However, this is one cancer that in most cases can be prevented or detected early. While you may hear that you need the sun to make vitamin D, in reality you only need a few minutes a day to do this. Exposure to ultraviolet (UV) rays, either by natural sunlight or tanning beds, can lead to skin cancer. In addition, UV rays lead to other forms of skin damage, including wrinkles, loss of skin elasticity, dark patches (sometimes called age spots or liver spots), and pre-cancerous skin changes (such as dry, scaly, rough patches). Although dark-skinned people are less likely to develop skin cancer, they can and do develop skin cancers, most often in areas that are not exposed to the sun (on the soles of the feet, under nails, and genitals).

You can do a lot to protect yourself from damaging UV rays and to detect skin cancer early. Start by practicing [sun safety](#), including using a broad-spectrum sunscreen (which protects against UVA & UVB rays) every day, avoiding peak sun times (10 am-4 pm when the rays are strongest) and wearing protective clothing such as hats, sunglasses and long-sleeved shirts.

Examine your skin regularly so you become familiar with any moles or birthmarks. If a mole has changed in any way, you should have a healthcare provider examine the area. This includes a change in size, shape, or color, the development of scaliness, bleeding, oozing, itchiness, or pain, or if you develop a sore that will not heal. If you have a lot of moles, it may be helpful to make note of moles using photographs or a "mole map". The American Academy of Dermatology has a [helpful guide to performing a skin exam](#).

Learn more about the types of skin cancer on [OncoLink](#) and the [Skin Cancer Foundation](#).

## Healthy Lifestyle

For some cancer survivors, the experience is the impetus to making healthy lifestyle changes. It may seem insignificant, but these changes have been shown to reduce the risk of the cancer coming back or a new cancer developing. Below are some tips on adopting a healthier lifestyle.

- Do not use tobacco in any form. If you do, learn more on [OncoLink](#) and talk to your healthcare provider about taking steps to quit.
- Maintain a healthy weight. Many studies have found that excess weight plays an important role in cancer development and recurrence. While maintaining a healthy weight is important in cancer prevention, it cannot easily be separated from the importance of physical activity and eating a healthy diet. Strive to incorporate all three pieces of the puzzle: healthy weight, balanced diet, and regular exercise.
  - Talk to your healthcare team about what a healthy weight is for you, and take steps to reach and maintain that weight.
  - Experts recommend at least 30 minutes of moderate to vigorous activity per day, 5 days a week.
  - Eat healthy, including plenty of fruits and vegetables daily. Strive to have 2/3 of your plate be vegetables, fruits, whole grains, and beans, while 1/3 or less should be an animal product. Choose fish and chicken and limit red meat and processed meats.
  - Learn more about recommendations for diet, activity, and weight in the [AICR's Guidelines for Survivors](#) and the [ACS Eat Healthy and Get Active](#) information on their website.
  - Learn more about the benefits of physical activity from [Macmillan Cancer Support](#).
- Limit how much alcohol you drink (if you drink at all).
- Have regular check-ups by a healthcare professional.
- Keep up-to-date on general health screening tests, including cholesterol, blood pressure, and glucose (blood sugar) levels.
  - Learn about healthy screening tests for [women](#) and [men](#) from the US Department of Health and Human Services.
- Get an annual influenza vaccine (flu shot).
- Get vaccinated with the pneumococcal vaccine, which prevents a type of pneumonia, and re-vaccinated as determined by your healthcare team. Learn more about [adult vaccinations from the CDC](#).
- Don't forget dental and eye health!
  - The American Optometric Association recommends adults have their eyes examined every 2 years until age 60, then annually. People who wear glasses or corrective lenses or are at "high risk" for eye problems (i.e. diabetics, family history of eye disease) should be seen more frequently.
  - The American Dental Association recommends adults see their dentist at least once a year.

## Fatigue

Fatigue is the most common side effect of cancer treatment. What many people do not know is that this feeling of overwhelming physical, mental and emotional exhaustion can last for months to years after therapy ends. Soon after treatment is complete, friends, family and co-workers often expect you to be back to doing the things you did before treatment, with the same energy level. Many survivors have significant fatigue for months or years after completing therapy, which can be extremely frustrating for the survivor and those around them. It is important to remember that fatigue can be caused by many things and,

particularly if fatigue is worsening or new, it should be discussed with your healthcare team to rule out treatable causes.

Research has shown that exercise is the best way to improve fatigue related to cancer treatment. Start where you can – maybe that means a short walk around the block. Add a little more each day. Find a partner to walk with you (or do whatever activity you choose) and encourage you to stick with it. If you are up for more intensive exercise, be sure to talk with your oncology team to be sure you have no restrictions on what you can do.

Most importantly, you should understand that it is normal for fatigue to take time to resolve. You will need to give your body time to slowly return to your former energy levels. The time it takes to get over this fatigue varies greatly depending on the treatment received, the type of cancer, how fatigue affected you during treatment, and how well you can balance the demands on your time. Use some of the tools you may have used during treatment – delegate, prioritize, make lists and group errands to cut down on trips to the store, etc.

Think of your energy as a bowl of candy. You start the morning with a full bowl, and every task takes one or two candies. You will need to continue to balance and prioritize your time and energy. Save a few candies for when you have something special to do in the evening. You will find that your bowl of candy will continue to get bigger every day. Using this metaphor will help you mentally manage your time and energy.

## Life After Cancer

While many patients are told about the long-term health effects of treatment before starting, they often don't recall or didn't concern themselves with them at that time. This is understandable. When you're presented with treatment options to save your life, thinking about what could happen ten or twenty years down the road isn't as much of a priority.

So what to do now? You should learn what your risks are based on the treatment you received, learn what you can do to prevent them, if possible, and learn how to monitor for them. You have taken the first step by developing a survivorship care plan. Some survivors may also benefit from a visit to a survivorship clinic. These clinics review your treatment history and develop recommendations for you and your primary care team based on your personal risks. Contact cancer centers in your area to see if they have a survivor's clinic or search for a clinic on [OncoLink's survivorship clinic list](#) (though this list is not exhaustive).

After active treatment is complete, you will move into follow up mode. This usually means you will see your oncology team less often. For many, this can be a very scary time. The weekly or monthly visits to the oncologist are reassuring; someone is checking on things and giving you the thumbs up. Survivors are often surprised by their emotions at this time. You may anticipate jumping for joy and throwing a party. Instead, you may find yourself crying in the parking lot after your last treatment, feeling vulnerable in unexpected ways.

You may find it distressing that you are no longer getting active treatment. You may miss the much needed daily or weekly support you got from the oncology team. You may experience fear, sadness, anger, isolation, and grief. This is normal! You may also feel a sense of relief, gratitude, and be proud of yourself for getting through treatment – as you should!

The end of therapy is a time when friends and family may say, "Congratulations" and "You must be glad to be done", though you may be feeling uncertain about this milestone. Friends, family and even the oncology team can be surprised by the complicated emotions you are experiencing. They may not realize that these emotions are common and even expected, which may make you feel even more isolated. You aren't alone.

These are common reactions and the information in your care plan will help you transition to survivorship.

For starters, be assured that your oncology team is always there if you have any concerns. Plans for follow-up care have been developed to follow each person in the best way. This plan varies for every type of cancer and may involve periodic blood work, radiology scans and tests, and physical exams. You may only see the oncology team once or twice a year, but they are always a phone call away.

## **Coping with your emotions after cancer**

Any time of transition in your life can be stressful. You must give yourself time to adjust to this new place. You may hear from others, “it must be nice to be getting back to normal.” But as any cancer survivor will tell you, things have changed. So has your definition of “normal”. Many survivors say they look at life differently; they don't take things for granted and don't sweat the small stuff. A cancer diagnosis changes you as a person, something people around you may not fully understand. It may be helpful to join a group of survivors, either formally (in a support group) or informally (gather a few folks you have met along the way). Email and the Internet have created a wonderful support for all sorts of concerns, and survivorship is no different. [CancerCare](#) provides online and telephone support groups and professional counseling. Many cancer centers and cancer service organizations offer support groups for survivors to address their specific concerns after therapy. A “buddy” program can match you with someone who’s been in your shoes and can be a listening ear and support person – or you can become a buddy to someone else. No one understands this time better than someone who has been there, and this support can be very valuable. Buddy programs are offered by [Imerman Angels](#), [Cancer Hope Network](#), and many other disease-specific organizations.

For many, a cancer diagnosis and treatment is a traumatic experience. Recovering from this trauma can be complicated by the late side effects of treatment. These side effects can impact your quality of life long after you have completed your cancer treatment. Some survivors experience symptoms of post-traumatic stress disorder. This can include sleep disturbances, nightmares, flashbacks, avoiding places associated with the experience (like your treatment center), feelings of hopelessness, anger and guilt (including survivor's guilt), loss of interest in things you usually enjoy and substance use.

It is important to find ways to cope with the trauma of cancer and your experiences. If you are having symptoms of post-traumatic stress, ask your care team for a referral for counseling. Your oncology social worker can help navigate your insurance and find an experienced provider who can give you support and therapy. Your team can also refer you for psychiatry support if medication treatment may be helpful in treating your post-traumatic symptoms.

However, out of trauma, comes the possibility of post-traumatic growth. This is the ability to use challenging experiences to change and grow psychologically and emotionally. You may ask yourself, “how has cancer changed me?” Many patients have said, “cancer is the best thing that ever happened to me.” Cancer taught them to live. To appreciate the simple things in life. To love. To give back. To be close to others and show compassion. Even out of the most challenging experiences in our lives, there is room for growth, improvement, and change. After treatment, you may try new things, decide it’s time to take that trip you have always been wanting to do, join a spiritual community, or even find a way to “give back” through volunteer work, advocacy and fundraising for a cancer service organization. All of these activities help you grow after cancer.

Some cancer patients have depression and anxiety during and after treatment. Many patients express “scanxiety” when having their routine scans for follow-up. They worry about what the scans may show - “has my cancer come back?” This is normal after going through such an experience. It’s important to talk to your team if you are having these feelings. They do usually improve with time and with your improved abilities to cope with worry and fear. However, sometimes they don’t go away or even get worse. This is a time for concern. Signs of persistent depression and anxiety include trouble sleeping (insomnia) or sleeping



too much (hypersomnia), hopelessness, inability or unwillingness to participate in normal activities and even thoughts of self-harm or suicide. If you are having these symptoms, talk to your care team immediately.

## **Coping with practical concerns after treatment**

It is essential to maintain your health insurance after you have completed treatment so you can have the necessary follow-up care. Because your health insurance is often related to your job, you may be wondering about returning to work. This can also help to re-establish some normalcy in your life after treatment. However, returning to work can be a challenge as well. For some, disability is the best option. Talk with your care team about your desires for work after treatment. There are also some great resources for navigating work, disability, and insurance.

- Learn about your rights and your employer's responsibilities under the law. You may want to talk with human resources professionals at your job about things like returning to work, FMLA, and reasonable accommodations. [OncoLink's section](#) on legal, insurance, employment, and financial concerns provides great information about these issues.
- The [National Coalition for Cancer Survivorship](#) and the [American Cancer Society](#) websites have financial and insurance information for survivors.
- The [Cancer Legal Resource Center](#) and [Triage Cancer](#) provides information on cancer-related legal issues, including insurance coverage, employment and time off, and healthcare and government benefits.
- [Cancer and Careers](#) is a resource for all things employment-related, from time of diagnosis well into survivorship.

## **Relationships after cancer**

Cancer can have a profound impact on your relationships. This can include our friendships (new and old), our family, our co-workers, or even a dating/intimate relationship. As cancer survivors, you may ask yourself: when what and how do I tell someone that I am a cancer survivor? Or perhaps maybe, do I even need to tell them?

Disclosure of your cancer history can be particularly challenging if you are thinking about dating and new intimate relationships after cancer. Chances are you have physical scars from your cancer treatment. You may also experience changes to your sexual health and function as a result of your treatment. A new partner may bring up questions about your ability to get pregnant or father a child. This is a lot for a cancer survivor to navigate. It's important that you are comfortable "in your own skin." Think about what you want to share with someone new in your life. Perhaps, give them small pieces of information to start to gauge their comfort level. If they ask questions about your scars, be prepared with what you want to say about them. Practice your talk with a trusted friend. Therapy after treatment can also help you strategize how to talk with a new partner about your cancer history and its long term impact on your life.

## **Sexual health and fertility**

How cancer affects your sexuality is different for every survivor. Some find the support they need through their healthcare team, their partner, friends or fellow survivors. Some cancer advocacy groups host discussion boards where you can "talk" about concerns with someone who has been there. The [American Cancer Society](#) and [LIVESTRONG](#) both offer sexuality information for men and women. Couples and/or sex therapists are extremely helpful for couples who are struggling with intimacy after cancer. Ask your team or social worker for referrals to therapists who are experienced in sexual health issues after illness.

Personal issues related to sexuality or fertility can be emotionally draining and can interfere with personal relationships at a time when you need them most. OncoLink's section on [fertility & sexuality](#) may be helpful. Organizations such as the [Oncofertility Consortium](#), [LIVESTRONG](#) and [Resolve](#) can help with

fertility questions and issues. [Us Too](#) and the [American Cancer Society](#) both provide fertility and sexuality resources.

All of this can be a bit overwhelming, but the fact that there are over 15 million cancer survivors in the United States today is a testament to the fact that you can do this! Take it one day at a time, and seek the support you need to live and love your "new normal" life.

# Tobacco

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## Tobacco Use and Quitting Smoking

Quitting tobacco is the single most important step you can take to extend the length and quality of your life. And the benefits happen almost immediately! Just 20 minutes after quitting, your heart rate and blood pressure drop. In just a few weeks, your lung function increases. One year after quitting, your risk of heart disease is ½ that of a smoker. Don't forget, second hand smoke puts our loved ones at an increased risk of cancer, and lung and heart disease. Lastly, tobacco use is expensive. Quitting will put money back in your pocket right away.

If you are a cancer survivor, quitting is also important. Using tobacco during and after cancer treatment can make it harder for you to get through treatment. Tobacco can also affect how well your treatments work, how wounds heal from surgery and can increase the side effects during and after treatment.

But, quitting tobacco is tough. Tobacco use isn't just a habit, it is an addiction. An addiction to nicotine happens with regular use of products that contain nicotine. This causes you to have a physical and behavioral need for it—a craving. On top of that, as you use more nicotine, your brain develops a tolerance to it. This means over time, you need more and more nicotine to satisfy your cravings. This is what makes quitting so hard.

### How do I quit?

- Decide to quit and commit to that decision. You have to want to quit. Write down all the reasons you want to quit and put it in a place where you can easily be reminded of why you made the decision to stop using tobacco.
- This doesn't mean you have to quit right this minute. Experts suggest setting a quit date within the next two weeks and sticking with it. Taking time to get ready can help you be more successful.
- Let your family, friends, co-workers and other important people in your life know that you are quitting and what your quit date is.
- Think about ways you can engage your support people in helping you quit. Help them understand that you may be more moody, irritable and not acting like yourself for a while. Another friend who has quit or a helpline can be an excellent resource in those moments when you are having a hard time.
- Talk to your healthcare provider. Quitting can cause you to have physical and psychological symptoms of nicotine withdrawal. These include irritability, sadness, depressed mood, headaches, cravings and difficulty concentrating.
- If you smoke more than 10 cigarettes per day, you should use nicotine replacement therapy (NRT) as part of your quitting plan. NRT works by partially replacing the nicotine you were getting through tobacco, reducing withdrawal symptoms and cravings. There are also other medications that can help you quit. Your healthcare provider can help you choose which are best for you.
- Contact your health insurance company to ask if tobacco cessation programs and medications are covered by your plan. Learn more about smoking cessation aids on [OncoLink](#).
- Throw it all away. On quit day, be sure you have gotten rid of all tobacco products—even those in your



secret hiding places. Also get rid of things that go along with smoking like lighters, matches, and ashtrays. Make sure you have gum, mints or candy on hand to keep your mouth occupied. Doodle, draw, write or think of ways to keep your hands busy too.

- Quit lines, online chat rooms, and texting and mobile phone apps can help you connect with others who are trying to quit, as well as give you support “on demand.” It is important to know you are not in this alone. Ask others who have quit for their “tips and tricks” for quitting.
- Many employers are incorporating incentive programs for their employees to quit—including lower health insurance premiums. Ask your manager or human resources department if these programs are available at your job.
- Identify your what makes you want to use tobacco. When do you normally smoke—in the car on the way to work? During breaks at work? Before something that makes you anxious, like giving a presentation or going to a follow-up visit? Or, socially at a bar or after a meal? Successful quitting is paired with changing your routines. This is a lifestyle change. Maybe take public transportation to work, take a walk with a co-worker, or meditate before that presentation or appointment. Trying new things can help you avoid the situations where you are used to using tobacco.
- Remember that you may not be successful with quitting on your first try. Or even your second or third. On average, it takes seven attempts to quit for good. If you happen to smoke or use another product again, get back on the quitting wagon right away. This is called a slip. It can be helpful to think about what led up to you smoking again—was it stress at work? An upcoming medical appointment? An argument with a friend? Boredom? How can you prevent a slip from happening again? Remember, quitting is hard. Celebrate every smoke free day.

## Resources

[The American Cancer Society](#): (800-ACS-2345) offers free education and resources for quitting tobacco, including cigarettes, vaping and smokeless tobacco.

[Centers for Disease Control](#), offers a toll-free telephone number, 1-800-QUIT-NOW (1-800-784-8669), which serves as a single point of access to quit lines available in all 50 states. Also offers free quit coaching, quit planning materials, the quitSTART app, a free texting program and referrals for local support and resources. Offers information and support in Spanish, Mandarin, Cantonese, Korean and Vietnamese.

[Smokefree.gov](#): provides free, accurate, evidence-based information and professional assistance to help support the immediate and long-term needs of people trying to quit smoking.

[Tobacco Free Kids](#): one of the nation's largest non-governmental initiatives, with the goal of protecting children from tobacco addiction and exposure to secondhand smoke. They offer talking points and support for parents

[Freedom from Smoking](#): This online resource for adults is an adaptation of the American Lung Association's gold standard, group clinic that has helped thousands of smokers to quit for good.



OncoLink is designed for educational purposes only and is not engaged in rendering medical advice or professional services. The information provided through OncoLink should not be used for diagnosing or treating a health problem or a disease. It is not a substitute for professional care. If you have or suspect you may have a health problem or have questions or concerns about the medication that you have been prescribed, you should consult your health care provider.