

MY TESTICULAR CANCER SURVIVORSHIP PLAN

NAME: _____

DATE OF BIRTH: _____

DATE OF FIRST SYMPTOMS (approximately):

DATE OF DIAGNOSIS:

TYPE OF TESTICULAR CANCER:

Seminoma

Non-Seminoma

Choriocarcinoma

Embryonal

Teratoma

Yolk Sac

Stromal Tumor: Leydig Cell, Sertoli Cell, or Granulosa Cell

TREATMENTS (Check all that apply):

Orchiectomy (Left / Right)

Testicular Prosthesis

Active Surveillance

Chemotherapy

Retroperitoneal Lymph Node Dissection

Radiation Therapy

Last Follow-up Date:

PERSONAL HISTORY

Undescended Testicle Yes /No / Unsure

Hernia Repair Yes /No / Unsure

Family History of TC Yes /No / Unsure

Family History of Other Cancer Yes /No / Unsure

Family Member	Type of Cancer	Date of Diagnosis & Treatment

ORCHIECTOMY DETAILS

Date of Orchiectomy:

Location of Orchiectomy:

Surgeon:

Pathology Report:

Pre-Orchiectomy Tumor Markers:

AFP

bHCG

LDH

Post-Orchiectomy Tumor Markers:

AFP

bHCG

LDH

Final Clinical Stage:

Testicular Prosthesis: Yes / No

Testicular Prosthesis Offered: Yes / No

Testis-sparing Operation: Yes / No

Testicular Sperm Extraction: Yes / No

Sperm Banking: Yes / No

CHEMOTHERAPY DETAILS:

Date of Chemotherapy Start:

Date of Chemotherapy Stop:

Type of Chemotherapy:

BEP

EP

VIP

TIP

High Dose / Stem Cell Transplant

Other

Location of Chemotherapy:

Cycles of Chemotherapy:

Medical Oncologist(s):

Port Placed: Yes / No

Hospital where port was placed:

Date Port was placed:

Area of body:

Problems with port: Yes / No

Complications from Chemotherapy: (resolved yes/no)

RETROPERITONEAL LYMPH NODE DISSECTION:

Date of Surgery:

Location of Surgery:

Surgeon:

Pathology Report: (paste)

Pathological Stage:

Recovery of Ejaculation Post-operatively: Yes / No

Side Effects:

RADIATION DETAILS

Date of Radiation Start:

Date of Radiation Stop:

Location of Radiation Therapy:

Radiation Oncologist:

Radiation Plan and Dose:

Side Effects:

ACTIVE SURVEILLANCE LOG:

Date of Diagnosis:

Date	Labs	Abdominal Imaging	Chest Imaging

MY CANCER SURVEILLANCE PROGRAM (after chemotherapy, surgery or radiation)

Recommended Follow-up	Date of Follow-up	Results

FERTILITY STATUS AND EXPECTATIONS:

I have children. Yes /No

Name	Sex	Date of Birth
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Name:	Sex	Date of Birth
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I desire (more) children: Yes /No/Unsure

Semen Analysis:

Cryopreservation Date:

Cryopreservation Location:

Fertility Specialist:

HYPOGONADISM AND HORMONE EVALUATIONS:

I had bilateral testicular cancer. Yes /No

I am on testosterone replacement. Yes /No

I have low energy. Yes /No

I have low libido (sex drive). Yes /No

I have trouble with erections. Yes /No

Date of Hormone (Testosterone/Estradiol/LH/FSH) Tests:

Hormone Lab Value Results:

Endocrinologist or Hormone Specialist:

Current Testosterone Replacement Strategy:

Androgel

Testosterone Injections

Testopels (implants)

Prior Testosterone Replacement Strategies:

Androgel

Testosterone Injections

Testopels (implants)

OTHER CONCERNS:

TESTICULAR CANCER SURVIVORSHIP KNOWLEDGE...

FOR ALL TESTICULAR CANCER SURVIVORS

Testicular cancer (TC) is a disease of the testicle (testes). In the United States, approximately 9,000 men are diagnosed each year and the estimated survival rate is 95%. That means that there are hundreds of thousands of TC survivors at any given moment! Just because most men are “cured” of cancer, does not mean there are not lasting effects from treatment. These documents are to inform you about the long-term effects of your treatments and help you plan for future well-being throughout your life.

- Testicular cancer surveillance involves tumor markers, imaging tests, physical examination and interaction with a medical professional.
- Timing and frequency of testing depends on your specific cancer and treatments. Guidelines like the NCCN should guide cancer follow-up.
- Self-exam of the unaffected testicle should be performed monthly and the unaffected testicle should be examined annually by a healthcare professional.
- Laboratory and imaging tests may stop at 5 years, but you should see a healthcare professional annually forever!

TESTICULAR CANCER SURVEILLANCE AND SURVIVORSHIP

TC cancer surveillance typically involves routine tumor marker checks, imaging tests, physical examination and updated medical histories. The frequency of testing is determined by the type of testicular cancer (seminoma, non-seminoma, etc.), stage (or spread) of TC at diagnosis, any additional treatments after orchiectomy like chemotherapy, radiation, chest or abdominal surgery and the results of additional tests like pathology reports and CT scans.

In general, follow-up should follow guidelines, like those given by the National Comprehensive Cancer Network (NCCN, <https://www.nccn.org>). Your TC provider may change or alter those guidelines, but you should understand why these changes are being made. In addition, the risk of developing a second TC in the other testicle is less than 2%, but every TC survivor should perform self-exam on a monthly basis and have a health professional perform a testicular exam annually.

Testing should continue for at least five years and a medical professional should follow you on an annual basis. Even after completing your cancer follow up, survivorship is life long and thus we recommend you see your medical professional once a year even after this initial five-year period.

MALE REPRODUCTIVE HEALTH

- Testicular cancer can affect a man's ability to produce testosterone and sperm. The risk of low testosterone (hypogonadism) and infertility (low sperm counts) are influenced by the number of treatments a man has gone through.
- Survivorship regarding male reproductive health includes knowing the symptoms of hypogonadism, consideration of regular blood work for testosterone levels, and early referrals to endocrine and fertility specialists if having symptoms of hypogonadism or trouble conceiving a pregnancy respectively.

The effect of testicular cancer therapy on male reproductive function depends on many factors, including the person's age at the time of cancer therapy, the specific type and location of the cancer, and the treatment that was given. It is important to understand how the male reproductive organs function and how they may be affected by therapy given to treat TC.

Male reproductive organs. The male reproductive system is made up of the scrotum, testicles, vas deferens, epididymis, seminal vesicles, prostate gland, penis, and urethra. The reproductive system is controlled by the pituitary gland in the brain. The testicles are located in the scrotum. The testicles are made up of Leydig cells (cells that produce the male hormone - testosterone) and germ cells (cells that produce sperm). Germ Cell Tumors, the most common type of TC arises from the germ cells that produce sperm.

When a young man enters puberty, the pituitary gland releases two hormones (FSH and LH) that signal the testicles to begin producing sperm and testosterone. As puberty progresses, testosterone causes deepening of the voice, enlargement of the penis and testicles, growth of facial and body hair, and muscular development of the body. Sperm produced by the testicles mature in the epididymis (a network of tubules where sperm mature and "learn to swim") and then travel through the vas deferens (tube that connects the testicle to the prostate, seminal vesicles, and urethra). The seminal vesicles and prostate gland produce fluids that mix with the sperm to create semen. When a man ejaculates, sperm are pumped out through the vas deferens, mixed with fluids from the prostate and seminal vesicles, and exit the body through the urethra (tube that carries fluids out of the penis).

Testicular cancer therapies' effect on the male reproductive system. At a minimum, all men with TC have a testicle removed. While one testicle should produce all the sperm and testosterone a man needs to function "normally" throughout life, there can be lasting effects from orchiectomy (surgical removal of the testicle). The most common effects on the male reproductive system include hypogonadism (low testosterone levels) and infertility (the inability to initiate pregnancy). Additional therapies including radiation, chemotherapy and retroperitoneal lymph node dissection can increase the likelihood of these issues.

Protecting your testicle. Although fertility and testosterone production are not usually affected if only one testicle was surgically removed, you should take precautions to protect the remaining testicle from injury by always wearing an athletic supporter with a protective cup when participating in any activities that may potentially cause injury to the groin area (such as contact sports, baseball, hockey, etc.).

Hypogonadism or low testosterone. Hypogonadism is also known as “Leydig cell failure.” Hypogonadism affects about 5% of the general population, 10% of TC survivors and up to 15% of TC survivors who receive chemotherapy or radiation treatment. This is the inability to produce enough of the male hormone, testosterone, and can result from damage to the Leydig cells or pituitary gland caused by radiation to the testicles or brain. If this occurs in a young boy, he will not be able to go into puberty without the help of hormones prescribed by a doctor. Men who develop testosterone deficiency after puberty will need hormonal therapy in order to maintain their muscular development, bone and muscle strength, proper distribution of body fat, sperm production, sex drive, and potency.

Blood may be tested for hormone levels (FSH, LH, and testosterone). The typical hormone evaluation includes:

- Testosterone Panel
 - Total Testosterone
 - Free Testosterone
 - Bioavailable Testosterone
 - Sex Hormone Binding Globulin
 - Albumin
- FSH (Follicle Stimulating Hormone)
- LH (Luteinizing Hormone)
- Estradiol

Hormone evaluation should be considered at the time of diagnosis (when a man feels most “normal”), annually thereafter or if any symptoms of hypogonadism are present. Symptoms of hypogonadism include:

- Fatigue (Low Energy)
- Decreased sex drive
- Difficulty concentrating
- Hot flashes
- Rare symptoms of hypogonadism include:
 - Erectile dysfunction
 - Infertility
 - Decrease in beard and body hair growth
 - Decrease in muscle mass

- Development of breast tissue (gynecomastia)
- Loss of bone mass (osteoporosis)

If any problems are detected, a referral to an endocrinologist (hormone specialist), urologist (occasionally known as an andrologist or specialist in the male reproductive organs) and/or fertility specialist may be recommended.

Males with low testosterone levels should receive testosterone replacement therapy. Testosterone is available in several forms, including gels, skin patches, and injections. Your endocrinologist or urologist (andrologist) will determine which form of therapy is best for you.

Infertility. About 5% of the general population has infertility and about 10% of TC survivors have difficulty initiating a pregnancy. After chemotherapy, radiation and/or surgery up to 25% of TC survivors can have fertility issues. Infertility is not at all related to sexual function. Most men have normal erections, perform normally in sexual situations but can have difficulty initiating a pregnancy after treatment for TC. In some men with infertility, there may be a decrease in the size or firmness of the testicles, but in others, there are no physical indications of infertility.

TC survivors who had surgical removal of both testicles (<2% of survivors) will not be able to make sperm, and infertility will be permanent. In other males, the only sure way to check for sperm production is to have a semen analysis performed, which checks the appearance, movement and concentration of sperm in the semen. A semen analysis that shows azoospermia (no sperm in the semen sample) on more than one sample is a likely indicator of infertility.

In men who have azoospermia as a result of radiation, return of sperm production is unlikely. However, in men who have azoospermia as a result of chemotherapy, the effect on male fertility is highly variable. Recovery of sperm production may occur months or years after the completion of chemotherapy. For others, the damage may be permanent. It may be impossible to determine if sperm production will resume at some time in the future, especially if chemotherapy ended only a few years prior to the semen analysis. For this reason, males who have azoospermia from chemotherapy should always assume they can make a woman pregnant.

Some men who undergo RPLND may not be able to ejaculate due to nerve damage from the surgery. In these patients, semen must be directly sampled or retrieved from the testicle. Men with anejaculation after RPLND should seek the expertise of an urologist with expertise in male infertility.

When to Have a Semen Analysis. Any sexually mature male who is concerned about fertility should have a semen analysis performed. Most hospitals or clinics with an adult urology or obstetric/gynecology department have the facilities to perform a semen analysis. If the results are within normal limits, there is no need to do anything further.

In addition, couples that include a TC survivor that are having difficulty achieving pregnancy for greater than six months should seek evaluation with a fertility specialist.

Low Sperm Count. If the results show no sperm (azoospermia) or very low sperm counts, the test should be repeated several times. Sperm recovery following chemotherapy may take as long as 10 years, so if you have had chemotherapy that may cause low sperm counts, it may be important to check periodically over several years. Also, men's sperm counts vary considerably from day to day, so sub-normal test results may improve if additional samples are checked after waiting for a month or two. Sperm production and quality may continue to improve as more time passes from the chemotherapy treatment. Men who have low sperm counts cannot rely on this to prevent pregnancy. Pregnancy can occur with low sperm counts therefore, some method of birth control must be used if pregnancy is not desired. If pregnancy is desired, men with low sperm counts may benefit from various assisted reproductive techniques such as artificial insemination or in-vitro fertilization (IVF).

Options for Men with No Sperm. If semen analysis shows no sperm, and fertility is desired, consult with a doctor who specializes in male infertility. Medical advancements dealing with male infertility are being made. Recently, surgeons have been able to locate areas of active sperm production in the testes of men who were thought to be azoospermic. Surgical harvesting of the sperm has allowed conception with techniques devised for men with absent or very low sperm counts. Occasionally, azoospermia may be unrelated to chemotherapy altogether, and treatment for another disorder may be indicated.

Options for using banked sperm depend on the amount and quality of material saved. Men who banked sperm prior to cancer treatment will need to work with a doctor specializing in reproductive medicine, so that the cryo-preserved (frozen) sperm can be used in an optimal manner.

Another option for TC survivors who produce no sperm may be donor insemination. This results in pregnancy with a child that is biologically related only to the mother. Additional options include adoption of a biologically unrelated child or child-free living.

SECONDARY CANCERS

- TC survivors should be aware of a slightly higher risk of a second cancer in their lifetime when compared to the general population.
- Chemotherapy, radiation therapy and family history increase the risk of a second cancer.
- TC survivors should be screened for common cancers (colon cancer, prostate cancer, etc.) by current screening guidelines and see a healthcare provider on an annual basis for routine health evaluations.
- A healthy lifestyle will promote longevity and may reduce the risk of developing another cancer.

All TC survivors are at a slightly higher risk than the general population of developing a secondary cancer of another organ – about 4% of TC survivors will develop another cancer in their lifetime. This can be frustrating and anxiety provoking but is not meant to scare you, only to improve your healthcare follow-up and overall health. Most of these cancers can be detected early and cured. Factors that can contribute to this risk are the person’s age during therapy, their specific treatment, and their genetic and family history. Specifically, men who receive chemotherapy or radiation have higher rates of secondary cancers than men who do not require these treatments (approximately 6-7%). Men who received both chemotherapy and radiation have the highest rates of secondary cancers (up to 10%).

Monitoring for secondary cancers. TC survivors should see a healthcare provider on an annual basis and undergo routine cancer screening (PSA for prostate cancer, colonoscopy for colon cancer, etc.) per the most current guidelines. Occasionally, the healthcare provider may recommend more aggressive testing given an individual’s personal or family history. In addition, knowing your own personal medical history, being aware of problematic signs or symptoms, and bringing those to the attention of your healthcare provider are of vital importance. Signs and symptoms to be aware of include:

- Blood in the stools
- Blood in the urine
- Bloody sputum (spit)
- Bone pain
- Changes in bowel habits
- Changes in moles
- Difficulty swallowing
- Discolored areas or sores in the mouth that do not heal
- Easy bruising or bleeding
- Excessive fatigue
- Lumps
- Painful urination or defecation
- Paleness of the skin
- Persistent abdominal pain
- Persistent cough or hoarseness
- Persistent early morning vomiting
- Persistent headaches
- Shortness of breath
- Sores that do not heal
- Vision changes

Lowering the risk of secondary cancers. To minimize the risk of developing a secondary cancer, TC survivors should avoid cancer-promoting habits. These include:

- Avoiding high-fat diets
- Avoiding smoke, chew tobacco, and second-hand smoke
- Drink alcohol in moderation

Each lifestyle modification described above is linked to the risk of developing at least one adult cancer. Living a healthy lifestyle will promote longevity and can reduce the risk of developing a secondary cancer. A couple habits that will help minimize future cancer risk are:

- Routine exercise and healthy weight monitoring
- Routinely wearing sunscreen, avoiding tanning salons and sunburn

EMOTIONAL DIFFICULTIES

- Emotional difficulties are extremely common for men surviving TC.
- Difficulties that interfere with the ability to complete daily activities (like interactions with loved ones or employment) warrant evaluation by a mental health professional.
- Avoid self-medicating with alcohol or illicit drugs.
- Involvement in TC communities can help some TC survivors with emotional difficulties.

Cancer survivors often experience various positive and negative emotions, including:

- A sense of gratitude to be alive
- Anger
- Anxiety
- Depression
- Fear of recurrence
- Feeling alone
- Guilt
- Relief

These emotions can be extremely strong at the time of diagnosis, around the time of any surveillance testing, and if a recurrence should occur. Cancer survivors, caregivers, family, and friends may have experiences similar to post-traumatic stress disorder, an anxiety disorder that may develop after living through an extremely frightening or life-threatening event, such as cancer diagnosis and treatment.

Each person's post-treatment experience is different. For example, some survivors struggle with negative emotional effects of the cancer. Others say that they have a renewed, positive outlook on life because of the cancer. Just because TC is highly "curable" does not mean it makes it easier on you emotionally. Talking about your feelings about the diagnosis can help alleviate the anxiety and potential depression. If any of these symptoms affect your ability to function in daily activities, you should seek professional consultation from a psychologist or psychiatrist, and even consider taking medications. For instance, it is very common to feel depressed around the new diagnosis of TC. However, a man who is so depressed that he cannot get out of bed, go to work, or enjoy time with family or friends should consider seeing a healthcare professional for consideration of counseling and/or a short course of anti-depressant medications. Medications should be taken under the supervision of a physician and starting an antidepressant or anti-anxiety medication does not mean you will require this medication for life. In fact, routine holidays should be taken to see if medications can be discontinued. TC survivors should avoid self-medicating with alcohol or illicit drugs as these can exacerbate emotional distress and create adverse life situations.

For some TC survivors, being involved in awareness organization, small and large group meetings, communities, and social events can provide emotional support.

*FOR TESTICULAR CANCER SURVIVORS UNDERGOING CHEMOTHERAPY, RADIATION THERAPY or
RETROPERITONEAL LYMPH NODE DISSECTION (RPLND)*

Digestion problems. Chemotherapy, radiation therapy, and surgery may affect how well a person digests food. Surgery or radiation therapy to the abdominal area can cause tissue scarring, long-term pain, and intestinal problems affecting digestion. Moreover, some survivors may have chronic diarrhea that reduces the body's ability to absorb nutrients. A registered dietitian can help make sure people with digestion problems are getting enough nutrients. Consultation with a GI specialist is recommended for problematic symptoms that persist for more than a month.

Hearing Problems. A number of treatments used to in men with TC can affect hearing including chemotherapy, radiation to the head (or brain), antibiotics (aminoglycosides), and diuretics (furosemide). Hearing loss that occurs in the outer or middle ear is called a conductive hearing loss as there is a problem in transmission of sound from the air to the inner ear. This is common after infection or injury. Sensorineural hearing loss refers to damage to the sensory hair cells in the inner ear, most typically from chemotherapy. Sound waves can travel through the inner ear fluid but are not able to be changed into nerve impulses, so the sound does not reach the brain. Sensory hair cells that process high-pitched sounds are usually damaged first, followed by damage to the sensory hair cells that process lower pitched sounds.

Approximately 20% of men receiving chemotherapy will experience permanent deficits in hearing ability or have tinnitus (ringing in the ears). In general, men receiving high-doses of platinum-based chemotherapy are at the highest risk of hearing loss; however hearing loss can occur with any exposure to chemotherapy.

Symptoms of Hearing Loss include:

- Difficulty hearing in the presence of background noises
- Not paying attention to sounds (such as voices, environmental noises)
- Ringing or tinkling sounds in the ear
- Some people may have no symptoms at all

An experienced audiologist (a professional trained in hearing disorders) will perform an audiogram to test for hearing loss. An audiogram is done in a soundproof room. The person being tested wears earphones and listens for sounds of different pitches and different volumes. People who are not able to have an audiogram (such as those who are unable to understand the test instructions) can have their hearing tested using Brainstem Auditory Evoked Response (BAER). During a BAER, brainwaves are recorded while sounds are delivered to the sleeping person through earphones.

TC survivors who received cisplatin or carboplatin chemotherapy should have an auditory evaluation at least two years after completion of TC therapy. If hearing loss is noted, audiograms should be performed annually until stable and more frequently if needed. A variety of hearing aids and assistive devices are available to help with problematic hearing loss.

To prevent further hearing loss, TC survivors should:

- Avoid medications that can affect hearing loss (aminoglycoside antibiotics, some diuretics, salicylates (aspirin), and chelating agents),
- Avoid, limit and/or wear protection around loud noises like:
 - Airplanes, airports
 - Construction work
 - Headphones
 - Lawn mowers, leaf blowers
 - Motorcycles and other recreational machines
 - Music concerts
- Seek prompt evaluation if any suspicion of ear infection (for example, swimmer's ear)

Heart problems. TC survivors are at higher risk of cardiovascular disease at a young age than the general population. This is related to TC treatments like chemotherapy and radiation, as well as changes in testosterone that can predispose men to early heart disease. This is especially important in men who have a strong family history of cardiovascular disease (heart attack, stroke, arrhythmia, etc.). Heart problems following treatment can include:

- Arrhythmias. The electrical pathways that conduct impulses to control heart rhythm may be scarred or damaged resulting in an abnormally fast, slow, or irregular heart beat.
- Cardiomyopathy. The muscle cells of the heart are damaged so that the heart doesn't pump normally.
- Coronary artery disease. The blood vessels of the heart may become scarred or blocked, preventing delivery of oxygen and nutrients to the heart and other tissues. This can lead to heart attacks or myocardial infarction.
- Pericarditis or pericardial fibrosis. The protective covering of the heart may become inflamed or scarred.
- Valvular stenosis or insufficiency. The valves and blood vessels of the heart may be damaged, causing them to be stiff or to leak.
- In severe cases, these problems may result in the death of heart tissue (heart attack or myocardial infarction) or an inability of the heart to pump blood properly (congestive heart failure).

TC treatments also predispose men to metabolic syndrome. Metabolic syndrome refers to a combination of (1) increased blood pressure, (2) high blood sugar, (3) excess body fat around the waist, and (4) abnormal cholesterol or (5) triglyceride levels. Metabolic syndrome increases the risk of heart disease, stroke and diabetes. Metabolic syndrome refers to having multiple of these conditions, however having even one of them can increase the risk of heart or other cardiovascular issues.

TC survivors who have received chemotherapy, radiotherapy or who have signs and symptoms of metabolic syndrome should see a cardiologist at an early age (around 40 years old or sooner if a strong family history) for annual evaluation and prevention strategies.

The risk of heart disease (such as heart attacks and hardening of the arteries) and metabolic syndrome also increases with age in general. Factors that may increase the risk of heart problems include smoking, being overweight, eating a high-fat diet, and not exercising. Medical conditions that increase the risk include diabetes, high blood pressure, and high blood cholesterol. Individuals can reduce their risk of heart problems by:

- Exercising moderately for at least 30 minutes on most days of the week.
- Limiting the fat in the diet to no more than 30% of calories.
- Maintaining a healthy body weight.
- Not smoking (or quitting if currently smoking).

If conditions are present, TC survivors should strive to keep diabetes, high blood pressure, or high blood cholesterol, under good control with diet or medication as recommended by their healthcare provider. Any symptoms of heart problems should be promptly reported to a healthcare provider.

Kidney Health. The kidneys filter waste products from the blood, control blood pressure, and stimulate red blood cell production. TC treatments, especially platin-containing chemotherapies, can damage the kidneys. Other treatments including antibiotics and nephrectomy (surgical removal of the kidney) can affect kidney function. Some kidney problems occur during therapy and persist, while others can begin years after completion of therapy.

As part of annual surveillance, TC survivors should have yearly check-ups that include tests for kidney function and blood pressure. These may include urine and blood tests to look at kidney function and measure salts and minerals. Rarely imaging is needed to better study kidney function. Healthcare providers may refer patients to a nephrologist or urologist (kidney or bladder specialist) for additional evaluation.

The recommendations for good kidney health are similar to those for good heart health – keeping the small blood vessels to the heart healthy will keep the small blood vessels in the kidney healthy! In addition to healthy routines for exercise, diet, and weight control, TC survivors with kidney damage should drink lots of water, avoid non-steroidal anti-inflammatory drugs at high doses or for extended periods of time (Tylenol or acetaminophen is safe), and see a nephrologist on an annual basis.

Lung health. The lungs are responsible for supplying oxygen to the body and removing carbon dioxide. In order for oxygen to reach the blood, it must move through tiny air sacs (alveoli) in the lungs and into tiny blood vessels (capillaries) that surround each air sac. When the air sacs become damaged or scarred, there is less area for oxygen to enter the bloodstream, causing less oxygen to reach the blood. This may cause a person to breathe fast in order to get enough oxygen, which can make someone feel short of breath. Other lung problems can be caused by inflammation (swelling) of the air passages in the lungs or increased mucous production because of irritation or infection. Symptoms can include cough, wheezing, chest pain, and shortness of breath.

Risk factors for lung problems in TC survivors include bleomycin chemotherapy and lung surgery. Patients who have multiple courses of bleomycin chemotherapy and lung surgery are at the highest risk of developing lung issues. Problems can include scarring of the lungs (pulmonary fibrosis), repeated lung infections (such as chronic bronchitis or recurrent pneumonia), rupture of the tiny air sacs in the lungs, or thickening and blockage of air passages within the lungs (restrictive/obstructive lung disease). Symptoms may include shortness of breath, frequent coughing and/or wheezing, chest pain, and frequent lung infections, such as bronchitis or pneumonia. Becoming easily fatigued or short of breath during mild exercise (exercise intolerance) is sometimes an early symptom of lung damage.

The lungs should be evaluated in a yearly examination with a healthcare provider – typically by physical examination. If any suspected issues or symptoms, referral to a pulmonologist is recommended. These doctors may order chest x-rays or pulmonary function tests to evaluate for lung disease.

Patients who have received bleomycin and/or lung surgery should consider annual vaccinations for influenza (flu) and pneumonia (pneumococcal infection), and should be cleared by a physician prior to scuba diving. Most importantly, avoid smoking – especially tobacco, second hand smoke, toxic fumes from chemicals, solvents, and paints; and get regular physical exercise. If work requires regular exposure to smoke or chemicals, make sure you use personal protective ventilators.

If you need help quitting smoking, seek the advice of a healthcare provider or seek additional resources from the:

- American Cancer Society 1-800-ACS-2345
- American Heart Association 1-800-AHA-USA1
- American Lung Association 1-800-LUNG-USA
- www.smokefree.gov Provides support, tips, tools, and expert advice to help you or someone you love quit smoking.
- www.cdc.gov/tobacco The Center for Disease Control's Tobacco Information and Prevention Source (TIPS) includes guides for quitting the tobacco habit.
- www.lungsusa.org/stop-smoking The American Lung Association's free online "Freedom From Smoking" program.

Peripheral neuropathy and Raynaud's Phenomenon. Peripheral neuropathy, or damage to the peripheral nerves (nerves outside the brain or spinal cord), is a potential side effect of chemotherapy drugs and may cause the hands or feet to hurt, tingle, and feel numb or weak. This may be felt as discomfort in a muscle or joint, but the real damage is to the nerves that control the muscles.

Symptoms of peripheral neuropathy include:

- Burning, tingling, or prickling sensation usually in the hands or feet
- Extreme sensitivity to touch
- Loss of reflexes
- Muscle weakness
- Noticeable changes in the way you walk
- Numbness or sensitivity to pain or temperature
- Poor balance or coordination
- Sharp shooting pain

People at highest risk for peripheral neuropathy are those who have received higher doses of platin-containing chemotherapy. Other risk factors include surgery, severe weight loss, diabetes or a pre-existing nerve disease.

If a significant problem is suspected, a referral to a neurologist (doctor who specializes in problems of the nervous system) may be needed for further testing. Medications, elastic stockings, warm packs, and/or exercise may help with the symptoms of peripheral neuropathy. Proper fitting shoes are often helpful for TC survivors with peripheral neuropathy in the feet. Being aware of temperature and its affect on your symptoms may help avoid exacerbation of symptoms. People with peripheral neuropathy may also benefit from physical and/or occupational therapy.

Raynaud's phenomenon is a condition that may cause some areas of your body to feel numb and cool in response to cold temperatures or stress. This is not peripheral neuropathy but can have similar symptoms and management recommendations.

Raynaud's is caused by occasional narrowing of blood vessels, limiting blood flow for brief periods of time called vasospasm. During periods of vasospasm, the skin is deprived of oxygen, and may become pale and then turn a bluish color. As the blood vessels relax and blood flow resumes, the skin may become red. The hands and feet are most commonly affected, but Raynaud's may also involve the nose, lips, cheeks, and earlobes.

Raynaud's is usually a chronic condition that needs lifelong management. Some survivors may see improvement slowly over several years but prevention of attacks is key:

- Avoid drafts such as when opening the refrigerator or freezer.

- Avoid putting unprotected hands in cold water.
- Control stress, which is often a trigger for Raynaud's attacks.
- Do not use tobacco. Nicotine constricts blood vessels and causes the skin temperature to drop, which may lead to an attack.
- Dress warmly when outdoors.
- Exercise regularly to enhance circulation and help control stress.
- Take precautions indoors.
- Use insulated drinking glasses.
- Use the air conditioner sparingly.
- Wear mittens when handling cold items.
- Wear socks.

Treatment for Raynaud's is most often directed at reducing the number and severity of attacks. Patients with severe symptoms can be prescribed medications to help with vasospasm. These are typically prescribed by a rheumatologist. Additionally biofeedback, or using your mind to control stress and body temperature, have decrease the severity and frequency of symptoms for some patients.

This survivorship guide was created and modified from the following resources:

The American Cancer Society

<https://www.cancer.gov/about-cancer/coping/survivorship>

Cancer.Net, The American Society of Clinical Oncology

<https://www.cancer.net/survivorship/what-survivorship>

<https://www.cancer.net/cancer-types/testicular-cancer/survivorship>

The Children's Oncology Group

<https://childrensoncologygroup.org/index.php/survivorshipguidelines>

The National Comprehensive Cancer Network

<https://www.nccn.org/>