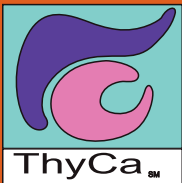
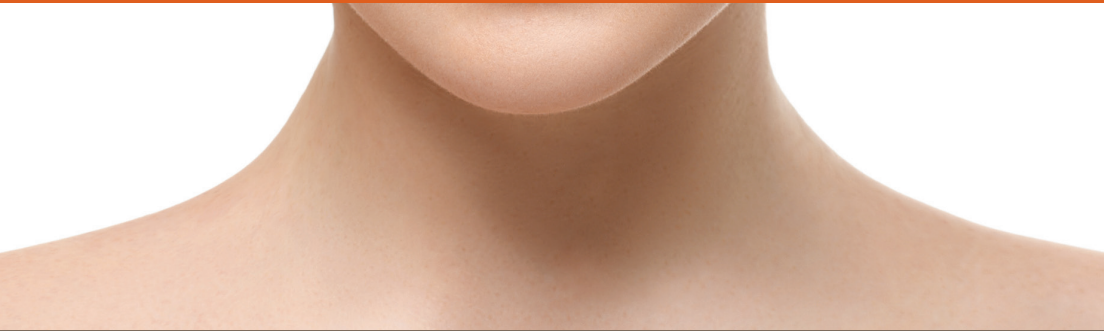


# Anaplastic Thyroid Cancer



**ThyCa: Thyroid Cancer  
Survivors' Association, Inc.**

[www.thyca.org](http://www.thyca.org)

# Anaplastic Thyroid Cancer

*This handbook provides an overview of basic facts about anaplastic thyroid cancer, its diagnosis, treatment options, and free support services and other resources to help both patients and caregivers cope with the emotional and practical impacts of this disease.*

*While this handbook contains important information about anaplastic thyroid cancer, your individual course of testing, treatment, and follow-up may vary for many reasons.*

## ***Thank you to our physician reviewers, our donors, and our publications volunteers***

*Thank you to the physicians on our Medical Advisory Council and to the many other thyroid cancer specialist physicians who reviewed and provided content and input for this publication.*

*Thank you to our generous donors and to the volunteers who contribute your time. We greatly appreciate all your efforts.*

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***Please note:*** *The information in this handbook is intended for educational purposes and is for general orientation. It is not intended, nor should it be interpreted, as medical advice or medical instructions or to replace your doctor's advice. You are advised to consult your own medical doctor(s) for all matters involving your health and medical care.*

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E-mail to [publications@thyca.org](mailto:publications@thyca.org)

# **Introduction — You Are Not Alone**

A diagnosis of anaplastic thyroid cancer is difficult for both patients and caregivers. Please be reassured that you are not alone.

Our goal is to offer help, hope, and support to:

- Strengthen your knowledge about treatment options and research
- Give you suggestions for coping, from others coping with this disease
- Help you feel part of a community of anaplastic thyroid cancer patients and caregivers as you cope with the emotional and practical concerns that come with this disease
- Introduce you to free services and information resources that can help you

**This handbook is for patients and caregivers coping with an anaplastic thyroid cancer diagnosis.**

**This handbook gives you:**

- Basic facts about **anaplastic thyroid cancer**
- Information about treatment and follow-up, plus information on recent research and current clinical trials
- Helpful tips and practical suggestions for coping, from patients and families who have experienced anaplastic thyroid cancer

**More About this Handbook**

This material was developed by thyroid cancer specialist physicians and by anaplastic thyroid cancer survivors and caregivers who participate in the [Anaplastic Thyroid Cancer E-Mail Support Group](#) sponsored by ThyCa: Thyroid Cancer Survivors' Association, Inc., in cooperation with other ThyCa volunteers and ThyCa medical advisors.

As you read through this handbook, it is important to remember that people respond differently to the same treatments. What works for one person might not work for another. Conversely, what doesn't work for one person might work for someone else. Unfortunately, this makes the road a little less predictable than we might wish. However, as time marches on, we hope that there will be more predictability and consistency in finding what works.

We will also share strategies that have helped when it comes to maintaining our emotional energy, whether we are the patients or the families who are dealing with anaplastic thyroid cancer.

We want to provide a place not only for information, but also for emotional support.

So, make sure you see the Anaplastic Thyroid Cancer E-Mail Support Group section for further information and instructions for joining this free group.

# 1. About Anaplastic Thyroid Cancer: Basic Facts

- Anaplastic thyroid carcinoma (ATC) is the rarest type of cancer of the thyroid gland.
- ATC is the most aggressive form of thyroid cancer. ATC is one of the fastest growing and aggressive of all cancers in humans.
- ATC is also referred to as *undifferentiated* thyroid cancer. This means that the cells do not look or behave the way that thyroid cells usually do.
- Only about 1% of approximately 60,220 people expected to be diagnosed with thyroid cancer in the United States in 2013 will have anaplastic thyroid cancer.
- ATC occurs most often in people over age 60. It rarely occurs in younger people.
- Overall survival rates for patients with ATC are very low. However, a small group of patients do well, and there are some long-term survivors.
- The prognosis for a person with ATC depends on several factors, including the patient's age and whether and where the disease has spread outside the thyroid gland at the time of diagnosis.

## **2. More About Anaplastic Thyroid Cancer**

- The cause of ATC is unknown. There are not any known links between ATC and any behavioral factors or lifestyle factors.
- In some people, the ATC is seen together with, or arising from, another form of thyroid cancer, particularly differentiated thyroid cancer (papillary and follicular).
- ATC is difficult to control and treat because it is very aggressive and can spread rapidly within the neck, grow locally into other critical structures, and spread to other parts of the body.
- In about half of patients with ATC, the cancer has already spread to other organs at the time of diagnosis, usually to the lungs and/or bones.
- ATC does not respond to radioactive iodine therapy or TSH (thyroid stimulating hormone) suppression with levothyroxine used for some of the other types of thyroid cancer.
- In addition to this handbook, visit [www.thyca.org](http://www.thyca.org) for more detailed information, a free webinar with ATC experts, plus stories written by survivors and caregivers, and connections to one-to-one support and the ATC online support group.

### **3. Prognosis for Anaplastic Thyroid Cancer**

- Anaplastic is the most aggressive form of thyroid cancer. It has the most severe effects on patient health and overall survival.
- A small group of patients with anaplastic thyroid cancer will do very well, and this is based on several factors:
  - How big the tumor was when diagnosed
  - Whether all of the tumor can be removed by the first surgery
  - Whether or not it has spread to surrounding structures or to lymph nodes in the neck
  - Whether it has spread outside the neck to other organs such as lungs, bones, brain, or liver
  - How well the patient responds to additional therapies, which may include chemotherapy and/or radiation therapy
- Overall survival rates for patients with anaplastic thyroid cancer are low.
  - Overall, about one in five people with anaplastic thyroid cancer live at least 1 year after being diagnosed.
  - A few patients live at least 10 years or more after being diagnosed.
- It is important to remember that each patient experience is unique.



- Some patients respond very well to treatment for reasons not yet understood.
- The survival statistics are discouraging, but there are long-term survivors of ATC. The problem with statistics is that while they are valid for a group, they say nothing about what will actually happen to any one person. Be sure to read the ATC Journey Stories on [www.thyca.org](http://www.thyca.org) and communicate with others in ThyCa's ATC E-Mail Support Group (described in this handbook and on the web site) before getting too discouraged.
- Many believe that the survival statistics can become a self-fulfilling prophecy, and that if doctors and patients aggressively pursue treatment despite the statistics, the survival statistics will improve.
- In all people with ATC, speed and a sense of urgency in getting evaluations done and treatment started are important because of the extremely fast tumor growth rate.
- The patient's care team will discuss options and help guide the patient and caregivers through this process. In ATC, it is important to have a multidisciplinary team (endocrinologist, medical oncologist, surgeon, radiation oncologist, etc.) working together in a timely fashion to complete workup and provide treatment.
- Regarding treatment urgency, one of the leading experts in thyroid cancer said, "Treat ATC like you would treat a heart attack, immediately. Make a decision based on the recommendation of physicians who have treated ATC, not anyone else! And do it quickly!"

## **4. Why Is ATC Often Diagnosed at a Late Stage?**

- The first question in a patient's mind is usually "Will I survive this?" The next question is often "Why did this happen to me?"
- There is usually a feeling among patients with ATC and their families of "if only the ATC was diagnosed earlier, things might be OK now."

While in hindsight this may seem obvious, the fact is that ATC is hard to detect early and progresses rapidly. We need to recognize that early diagnosis of ATC may have been difficult or impossible for our doctors, too. Among the reasons:

- ATC can be difficult to diagnose, even with a biopsy. ATC tumors can grow very rapidly. The time period between developing ATC and having clinical symptoms is very short.
- Symptoms of hoarseness or neck swelling are later-presenting symptoms of thyroid cancer. These symptoms are far more likely to be due to much simpler and less deadly causes.
- Many doctors have never seen a case of ATC.
- Most thyroid growths are not cancerous. Most cancerous thyroid tumors are not ATC. Most non-ATC tumors are treatable.
- ATC can be difficult to diagnose, even with a biopsy. ATC tumors can grow very rapidly.

## **5. ATC Critical Decision Checklist**

### **From the Experiences of ATC Survivors and Caregivers**

Here is a checklist of critical decisions and actions that are typically encountered in the progression of ATC.

Reminder: Appropriate medical care by specialists with expertise in treating ATC is critical. You may have very limited time to start treatment.

- Initial diagnosis. Make sure that the diagnosis is correct.
- Second opinion from source experienced in diagnosing/treating ATC. NOTE: A confirming second opinion may arrive after treatment is started.
- Assemble a medical team experienced in treating ATC. The key person is the oncologist (cancer specialist) who will help guide you to the right experts for ATC treatment. Do not hesitate to ask the oncologist how many ATC patients he or she has treated or whom he or she recommends you see. In some settings, the key person may be the surgeon, endocrinologist, or radiation oncologist, depending on the availability of specialists.
- Because of the time and expense of travel, ask your local doctors whether they have consulted with experts in the field. Doctor-to-doctor collaboration to facilitate consultation and treatment planning is helpful on many levels.
- Determine the Course of Treatment based upon the patient's needs. Factors include: age, general health, speed of tumor growth, occurrence of cancer at other sites, patient personality, and patient choice of options.

- This is the time for a serious discussion about the patient's wishes. What does the patient want? Discuss each treatment's pros and cons. Treatment options to consider:
  - Surgery
  - Radiation
  - Chemotherapy
  - Palliative care to manage symptoms of disease and side effects of treatment, in order to maintain quality of life from the time of diagnosis. Care is individualized. Among the possibilities are:
    - Airway, including tracheostomy and stenting
    - Feeding tube placement
    - Pain control
    - Additional approaches for comfort and emotional support
  - Clinical Trials (Research Studies)
- What people want to know about their diagnosis and care varies with each person. It is important for patients to tell their doctor about what they want to know, how much information they want, and when they want to receive information.
- Start the course of treatment as soon as possible.
- Find out about palliative care, which aims to maintain quality of life from the time of diagnosis.
- Ensure that all legal documents are in place. If these documents are not already in place, now is the time to do so, no matter how difficult the discussions will be.

- Ensure that the following documents are signed and that copies are provided to the appropriate medical personnel, legal counsel, and family members. Consult your personal legal counsel for guidance.
  - Medical Surrogate (to make decisions if you are unable to do so)
  - Power of Attorney
  - Medical Advance Directives / Living Will. Note: Some versions are more detailed than others, identifying, for instance, decisions about nutrition, hydration, antibiotics, pain medication, and so on. A more detailed version is helpful to family members responsible for the patient's care.
  - Will and trusts for disposition of assets.
  - Optional: A joint bank account so that a caregiver can pay the patient's monthly household expenses.
- Residence. Determine where the patient will live during treatment. Each patient's needs are different. Some patients remain at home. Others will require housing near a specialized cancer treatment center. Some patients are admitted to a skilled-nursing facility. Make the right choice for the patient, family, and caregivers.
- Assemble the care team. No one person can provide all the necessary emotional and physical support. A team is needed. Consider including family members, friends, community, health care manager, nursing aides, housekeepers, spiritual representative, and so on.
- When appropriate, contact Hospice. This is different for each patient. Hospice offers a variety of support services and becomes a valuable member of the Care Team.

## **6. Diagnosis of Anaplastic Thyroid Cancer**

- Patients with anaplastic thyroid cancer may first seek medical care because of a growing nodule or mass on their neck, or else a physician may have found a nodule during a neck examination. A nodule that is ATC can grow very rapidly, sometimes over just a few weeks. The nodule is usually noticeable to both patients and doctors.
- **Symptoms May Include:**
  - Neck mass, often noted to be enlarging
  - Hoarseness or changing voice
  - Cough
  - Coughing up blood
  - Difficulty swallowing
  - Loud breathing

Also, something called “stridor” can occur. Stridor is harsh-sounding breathing caused by a restricted airway.

- Thyroid function tests are usually normal.
- Many times, patients who have ATC have previously had a goiter or some other nodule in their neck. It may have been benign (not cancerous) for years, but if it becomes anaplastic cancer it can grow suddenly and rapidly.
- Testing of a thyroid nodule that is not suspected of being ATC is usually done using a fine needle aspiration (FNA) followed by cell analysis. If ATC is suspected, a core biopsy (similar to an FNA with a larger bore needle) may be done.
- The diagnosis of ATC needs to be certain. It is not usually possible to make a definitive diagnosis of ATC on a FNA. Sometimes a FNA or a core biopsy gives uncertain results. If ATC is suspected, an open biopsy may be needed to confirm. This is performed by a surgeon who removes a piece of the tumor for further analysis of the tissue by a pathologist.

## **7. Assessments and Staging**

Treatment usually needs to begin immediately, at the same time or very shortly after a variety of additional tests are being done and while the stage of the ATC is determined.

- Assessments include blood testing to determine the patient's overall health status and needs, as well as radiological studies (imaging such as MRI, CT, PET/CT scans) to determine whether the cancer has spread and, if so, where it has spread.
- All patients with anaplastic thyroid cancer are diagnosed as stage IV (stage 4) because of the likelihood of rapid progression and its severe prognosis. This is different from other thyroid cancers, in which stage I and II are considered low risk and stages III and IV are considered high risk.
- There are 3 sub-classifications of Stage IV for ATC:
  - Stage IVA: ATC is present only in the thyroid
  - Stage IVB: ATC is present in the thyroid and in the neck, but not in other parts of the body
  - Stage IVC: ATC is present in the thyroid as well as other parts of the body, such as the bones, liver, or lungs

The Guidelines published by the American Thyroid Association in 2012 give extensive details on the assessments that should be done, as well as the purposes of the assessments, and staging.

## 8. Deciding About Treatment

Treatment for anaplastic thyroid cancer involves very important decisions that need to be made quickly. These decisions are ultimately yours to make. It helps many patients to remember that they are in charge of their own treatment decisions.

This process can be intimidating for many new patients and should be done with the help of a team of ATC experts. Your team will explore all treatment options with you and with any family members involved with your treatment decisions.

People who may be involved in your treatment may include pathologists, endocrinologists, medical oncologists, radiation oncologists, and/or surgeons. Remember that **these professionals are here to help you in your own process**. Their role is to be informative and supportive of your decisions.

When starting treatment, it helps to set realistic expectations. Your team should be able to explain to you the risks and benefits involved with different treatments, and what side effects to expect.

As a result, some patients choose to be very aggressive in getting treatment, while others choose less aggressive treatments or a palliative care approach that focuses on symptom control and pain control without aggressive therapies.

Note: ATC is highly individualistic in both progression and appropriate treatment. Different doctors will have different opinions on what is appropriate. Also, some patients will have different criteria for what kind of treatment is "acceptable" in light of the benefits in terms of increased longevity and possible cure and the costs in terms of discomfort and the impact of treatment on their quality of life.



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It can be very difficult to predict how well a patient will respond to treatment. Anaplastic thyroid cancer is difficult to study because it is so rare.

If you would like another individual to be involved with your treatment decisions (friend, family member, or other loved one), it is best to decide this early on. Discuss with your lead physician or team if you decide that someone else will be helping you make these decisions and coordinate your care. This will help streamline communications regarding your treatment.

## **9. Anaplastic Thyroid Cancer Management**

Treatment and management decisions will depend on your individual circumstances. Treatment can include a combination of:

- Surgery
- Chemotherapy
- Radiation Therapy
- Clinical Trials
- Palliative care/pain control for symptom control and quality of life

When possible, surgery is generally the first step in treatment of localized anaplastic thyroid cancer. Localized means that the disease is localized to the thyroid gland and possibly the lymph nodes in the neck, and all disease can be removed. If the disease has invaded the trachea (airway), esophagus, or great vessels of the neck (or spread to distant sites), surgery is not recommended.

The American Thyroid Association recommends surgery for all patients with anaplastic thyroid cancer that can be removed, unless the patient has other medical conditions that would make surgery too risky.

Anaplastic thyroid tumors are challenging to operate on, and far more difficult than routine thyroid surgery. Because of this, it is difficult to predict the outcome of surgery.

Treatment may be most effective when a combination of methods is used. The American Thyroid Association recommends multimodality treatment (more than one treatment approach) using a coordinated team, and with the medical professionals on the team in close communication. Developing a treatment plan guides the treatment process.

## **Surgery To Remove ATC**

Surgery is done when it is considered safe and effective in removing the entire tumor from the neck. The decision about whether to do surgery is based on the particular patient's circumstances.

About 10% of patients have ATC that is only inside the thyroid gland. About 40% of ATC patients also have disease in the neck, lymph nodes, or both. The remaining patients have ATC that has spread to other parts of the body.

Oncologically sound surgery requires complete removal of all of the visible disease within the thyroid and the removal of the regional lymph nodes. However, reducing or debulking of the thyroid or neck lymph nodes is not recommended.

Surgery usually consists of total or near-total thyroidectomy, plus removal of lymph nodes in the central and lateral lymph node regions in the neck.

If the ATC is only a small area within a papillary or follicular thyroid cancer (differentiated thyroid cancer), then the ATA recommends surgical removal either of one lobe of the thyroid, or else the entire thyroid. In this situation, further treatment will be done for the differentiated thyroid cancer, as described in the *Thyroid Cancer Basics*, another handbook that is free and downloadable from [www.thyca.org](http://www.thyca.org), or available by mail from ThyCa, or from your doctor.

The surgeon will give instructions to you and your caregiver to follow before your surgery and during your recovery from surgery.

### **Airway Assessment and Possible Tracheostomy**

Often, an ATC tumor grows to the point that it physically compresses the trachea, or airway, causing the patient difficulty in breathing. In some circumstances, a tracheostomy is needed to ensure safe breathing.

**If you are experiencing symptoms such as shortness of breath, hoarseness, cough, or stridor, it is important to address this with your doctor. A first priority of treatment will be to ensure the safety of your airway so you can breathe easily.**

When a tracheostomy is performed, a cut is made in the neck just above the sternum and below the voice box and a plastic pipe ("trach tube") is inserted into the windpipe. The patient then breathes through this tube. The patient can usually talk by placing his or her finger over the air hole (or tracheostomy) to force the breath through the vocal cords.

Sometimes the vocal cords are affected by the tumor via nerve compression, so this may impair vocal quality.

The tracheostomy tube needs to be removed and cleaned several times a day to avoid blockage and infection.

There are many different sizes and styles of trach tubes. Several re-fits may be needed as the tumor grows and shrinks during treatment. Trachs are done by endocrine surgeons, ENT surgeons, or general surgeons experienced in these procedures. These surgeons are the experts in insertion and fitting of the tracheostomy tube for optimal comfort.

## **Chemotherapy**

People with ATC often receive chemotherapy, particularly if their ATC has not metastasized. Chemotherapy drugs used in thyroid cancer include taxane (paclitaxel or docetaxel), anthacyclines (doxorubicin), and platin (cisplatin or carboplatin). These drugs are used either alone or in some combination.

If you will receive chemotherapy, ask your physician about potential side effects, what can be done to help prevent or reduce them, and what to do if they occur.

## **Radiotherapy**

Radiotherapy is radiation directed at the ATC tumor cells to reduce the size of the tumor or destroy it.

Sometimes this is done before surgery in an attempt to make an otherwise inoperable tumor smaller so that it may then be removed.

Sometimes radiotherapy is done after surgery to "clean up" any residual tumor.

Sometimes radiotherapy is done as a palliative approach, to aid the patient's comfort (to improve breathing and swallowing, or for pain).

## **General Guidelines**

A combination of surgery, radiotherapy, and chemotherapy may improve outcomes in ATC, as reported in the American Thyroid Association Guidelines.

These guidelines are written for physicians and are based on expert review of all the available research and treatment literature.

The guidelines go into extensive detail regarding varied situations with ATC, and approaches for addressing each situation.

### **After Going Into Remission**

If your testing after treatment indicates that you have no evidence of disease, then you are in remission.

In this case, your treatment team will develop a plan for follow-up monitoring and testing, based on your individual circumstances.

You will probably have imaging of much of your body, as often as every month to every three months for the first year, and then at intervals of four to six months for at least another year.

This follow-up is likely to continue for many years. If there is a recurrence of disease, you will receive further treatment in accordance with the knowledge available at the time.

## 10. Palliative Care

Palliative care is care and treatment that aims to aid comfort and quality of life—physically, mentally, emotionally, socially, and spiritually.

Palliative care focuses on relieving symptoms, including pain and treatment-related symptoms that are reducing your quality of life. Many hospitals have a palliative care service.

Palliative care is also called *comfort care*, *supportive care*, and *symptom management*.

Palliative care should start at the time your treatment begins and can be used at the same time as treatment. Making use of palliative care services does not mean that you are terminally ill. Palliative care is also helpful if treatment does not work.

### More about Palliative Care

*(From the National Cancer Institute and additional sources)*

- Palliative care is comfort care given to any patient who has cancer or any other a serious or life-threatening disease, from the time of diagnosis and throughout the course of illness.
- Palliative care is given in addition to cancer treatment.
- The goal of palliative care is to prevent or treat, as early as possible, the symptoms and side effects of the disease and its treatment, in addition to the related psychological, social, and spiritual concerns.
- Palliative care is different from hospice care. Although they both focus comfort and support, palliative care begins at diagnosis and continues during cancer treatment and follow-up care, as well as at the end of life. Thus, palliative care is given throughout a patient's experience with cancer, regardless of the prognosis.

- Hospitals, cancer centers, and long-term care facilities provide palliative care. Patients may also receive it at home. Physicians and local hospitals can provide the names of palliative care or symptom management specialists. Cancer centers may also have programs or clinics that address specific palliative care issues, such as lymphedema, pain management, sexual functioning, or psychosocial issues.
- Palliative care addresses the emotional, physical, practical, and spiritual issues of cancer. Approaches for emotional and coping support may include support groups and referrals to mental health professionals.
- Family members may also receive palliative care. Palliative care can help families and friends cope with their own worry, stress, feelings of being overwhelmed with their responsibilities, and other changing needs, and give them the support they need.
- The National Cancer Institute at the U.S. National Institutes of Health, reports that research shows that palliative care improves the quality of life of patients and family members, as well as the physical and emotional symptoms of cancer and its treatment.
- People do not give up their primary care physician to receive palliative care. A palliative care specialist is a health professional who specializes in treating the symptoms, side effects, and emotional problems experienced by patients.
- Cancer centers and hospitals often have palliative care specialists on staff. They may also have a palliative care team that monitors and attends to patient and family needs.
- A patient may also receive palliative care at home, either under a physician's care or through hospice, or at a facility that offers long-term care.



- The physical and emotional effects of cancer and its treatment may be very different from person to person. For example, differences in age, cultural background, or support systems may result in very different palliative care needs.
- Making the transition from curative treatment to end-of-life care is a part of palliative care. A palliative care team can help patients and their loved ones prepare for physical changes that may occur near the end of life and address appropriate symptom management for this stage of care. The team can also help patients cope with the different thoughts and emotional issues that arise, such as worries about leaving loved ones behind, reflections about their legacy and relationships, or reaching closure with their life. In addition, palliative care can support family members and loved ones emotionally and with issues such as when to withdraw cancer therapy, grief counseling, and transition to hospice.
- Patients and their loved ones should ask their doctor about palliative care. In addition to discussing their needs for symptom relief and emotional support, patients and their families should consider the amount of communication they need. As noted earlier, what people want to know about their diagnosis and care varies with each person. It is important for patients to tell their doctor about what they want to know, how much information they want, and when they want to receive it.
- Palliative care services are usually covered by health insurance. Medicare and Medicaid also pay for palliative care, depending on the situation. If patients do not have health insurance or are unsure about their coverage, they should check with a social worker or their hospital's financial counselor.
- More information about palliative care is available through the U.S. National Cancer Institute web site, at [www.cancer.gov/cancertopics/factsheet/Support/palliative-care](http://www.cancer.gov/cancertopics/factsheet/Support/palliative-care)

## **11. Research on New Treatments Offers Hope**

Because of inconclusive data with current treatments for anaplastic thyroid cancer, researchers continue to look for new treatments, or new treatment combinations. The goal is to give patients the most benefit from these treatments while minimizing drug side effects.

Before new treatments or treatment combinations can be approved for patients with anaplastic thyroid cancer, these new or experimental drugs are researched through clinical trials. These clinical trials consist of large, organized testing of treatments on patients with anaplastic thyroid cancer.

There are currently several drugs that offer hope for patients with anaplastic thyroid cancer. One class of drugs is called Vascular Disrupting Agents (VDAs). These drugs destroy tumor vessels but do not damage healthy blood vessels.

Combretastatin A4-Phosphate (CA4P), also called fosbretabulin, is a VDA under investigation in clinical trials. In a clinical trial that has been completed, CA4P produced a nonsignificant trend towards improving patient survival after one year of treatment, with very few bad side effects. This is promising, and CA4P is now moving into a larger clinical trial for more testing.

Other drugs are also being explored. These include sorafenib, crolibulin, gefitinib, and imatinib.

It is important to maintain hope and continue to search for effective treatments for patients with anaplastic thyroid cancer. If you think you may be interested in participating in a clinical trial, more information can be found in section 12 of this handbook.

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See also the web site [www.clinicaltrials.gov](http://www.clinicaltrials.gov). In addition, the Clinical Trials page of ThyCa's web site [www.thyca.org](http://www.thyca.org) has suggestions from ThyCa volunteers who have taken part in clinical trials, and additional information about clinical trials.

## **12. Anaplastic Thyroid Cancer Clinical Trials**

Clinical trials can be considered either as initial treatment options, or as treatment options if conventional options are unsuccessful.

Some patients choose a clinical trial instead of conventional treatments. In other cases, if conventional treatments for ATC are not successful, you might consider participating in a clinical trial. Some upcoming clinical trials are enrolling patients with ATC.

- A clinical trial is a research study where physicians try treatment that has theoretical promise, but has not been proven to work. During clinical trials physicians systematically collect information to find out whether the treatment works.
- Making the decision about participation is not easy. On the one hand, it offers hope of increased longevity or a cure. Clinical trials also result in knowledge that might help others. On the other hand, clinical trials often involve drug side effects, and travel and expense. These can reduce a person's quality of life.
- This is a very personal decision best reached by careful consideration and discussion with your doctors, other professionals whom you feel would be helpful, your family, and friends.
- Clinical trials take place in many different locations—in cancer centers, other major medical centers, community hospitals and clinics, physicians' offices and veterans' and military hospitals.

- Clinical trials usually involve travel to one or more research centers funded for the trial. The cost of the study drug or the study treatment itself is usually free, but physician care fees, medical tests, travel, and lodging are not usually covered. However, there are often hotels with special patient/caregiver rates. Some areas have special residences that are supported by charitable donations and that may ask for a small fee from the patient.
- **More Information:** You will find more information about clinical trials in the Clinical Trials section of ThyCa's web site [www.thyca.org](http://www.thyca.org). Included are links to the National Cancer Institute Clinical Trials Web page, plus helpful tips from ThyCa volunteers who have participated in clinical trials.

## **Some Questions To Ask Before Entering a Clinical Trial**

### **The Study**

- What is the purpose of the study?
- Why do researchers think the approach may be effective?
- Who will sponsor the study?
- Who has reviewed and approved the study?
- How are study results and safety of participants being checked?
- How long will the study last?
- What will be my responsibilities if I participate?

### **Possible Benefits and Risks**

- What are my possible short-term benefits?
- What are my possible long-term benefits?
- What are my short-term risks, such as side effects?
- What are my possible long-term risks?
- What other (treatment) options do people with my risk level or type of cancer have?
- How do the possible risks and benefits of this trial compare with those options?

### **Participation and Care**

- What kinds of therapies, procedures and/or tests will I have during the trial?
- Will they hurt, and if so, for how long?
- How do the tests in the study compare with those I would have outside of the trial?
- Will I be able to take my regular medications while in the clinical trial?
- Where will I have my medical care?
- Who will be in charge of my care?

### **Personal Issues**

- How could being in this study affect my daily life?
- Can I talk to other people in the study?

### **Cost Issues**

- Will I have to pay for any part of the trial such as tests or the study drug?
- If so, what will the charges likely be?
- What is my health insurance likely to cover?
- Who can help answer any questions from my insurance company or health plan?
- Will there be any travel or child care costs that I need to consider while I am in the trial?

## **13. Finding the Right Care Team For You**

ATC is a very rare type of thyroid cancer. Because of this, many physicians who treat other thyroid cancers are not familiar with ATC.

ATC patients need prompt treatment based on current knowledge about ATC. This section gives general comments about physician selection, together with some specific points to consider, plus lists of sources for finding physicians.

Because of the urgency of treatment, it is important for you and your physician to assemble a team as quickly as possible. Treating ATC requires a team of physicians, with one physician as the team leader. You will likely see several doctors in addition to your family doctor.

Some large treatment centers may have specialists there in person (pathologists, endocrinologist, medical oncologists, radiation oncologists, and/or surgeons and others). If you do not live near one of those centers, your team may communicate through phone calls, e-mails, or other means with ATC medical experts.

### **Selecting Physicians for ATC Treatment**

It is important that physicians treating ATC are willing to quickly consult other physicians with known experience in dealing with ATC, in order to develop rapid and useful treatment plans.

It is also important that the physician be willing to answer, with honesty and compassion, patients' and caregivers' questions about their experience with ATC. The physician team should not remove the patient's hope.

We do not believe that patient length of life is the only measure of success for ATC treatment. Quality of life in treatment is also important.

We must remember how alone the newly ATC diagnosed patients feel. We all know that there isn't time to make a lot of telephone calls to find a physician capable of dealing with ATC.

### **Points To Consider**

- Patients and caregivers need to know which physicians are knowledgeable and experienced in treating ATC, as a starting point for those newly diagnosed. A sense of urgency is so critical in ATC treatment that families need to reach those with expertise as quickly as possible.
- Each patient is an individual. Additionally, ATC presents differently for each patient.
- A doctor who has seen many ATC patients might be a better candidate than one who has seen few ATC patients. Remember, very few doctors have seen many ATC patients.
- A doctor treating ATC must be open to reviewing the latest research literature and discussing treatment options with both ATC researchers and experienced ATC clinicians, including (if needed) those involved in clinical trials of new treatment.
- Patient length of life is only one of the important outcome indicators for ATC treatment. Quality of life is another important factor.
- Sources to consult regarding your potential specialists include ThyCa's medical advisors, the members of the ATA Guidelines Taskforce, and speakers in ThyCa's Webinars and Conferences. Participants in ThyCa's ATC E-Mail Support Group also share the names of the specialists involved in their care.



## 14. Tips For Preparing For Appointments

*(Adapted from material from Washington Hospital Center in DC)*

- Bring a picture ID, your health insurance card if you have one, and your referral, if required by your insurance.
- Bring a summary of your health history, including reports from all thyroid cancer doctors. Examples: pathology report from core biopsy (or open biopsy), scan/imaging results, surgical report, with related pathology report.
- Bring a list of medications you are taking, including traditional or alternative medications. This includes prescription medications, over-the-counter medications, and nutritional supplements, including dose (strength) and frequency (number of times you take it each day).
- ATC treatment can be a very stressful process. It is helpful to write down your questions so that you do not forget to ask about anything that is important to you. You may also find it helpful to make notes of the doctors' answers and instructions.
- Keep your notes and records in a loose-leaf 3-ring binder, or in file folders, to help organize them.
- Plan to arrive 15-30 minutes before your appointment. You may have to wait for your appointment because doctors cannot predict how much time they need to spend with each patient.
- Bring something to keep you busy and calm while you wait.

## **15. Tips For Communicating and Remembering What Your Doctor Says**

- Having good communication with your doctors is one of the keys to getting good medical care.
- You want the best care. You are coming to the doctor for your medical care.
- Take a family member or friend to the appointment. Two sets of ears are better than one. A lot of information will be shared, and it can be difficult to absorb it all, particularly during this emotional and scary time.
- Take notes.
- Ask for an explanation of unfamiliar terms and definitions.
- Ask for a visual aid. Seeing what your doctor is talking about on a chart or visual aid will help you remember.
- Ask if the doctor has any printed information to give you.
- Ask questions. Be your own advocate. Let your doctor know what is most helpful.

*(Adapted from tips at ThyCa support group meetings and from Teamwork: The Cancer Patient's Guide to Talking With Your Doctor by L.R. Brusky and others.)*

## 16. Questions You May Want To Ask

*For more questions to ask during your appointments, go to [www.thyca.org](http://www.thyca.org) and put “questions to ask” in the Search box.*

Remember also, every patient’s treatment is different. The answers will depend on your individual situation.

### **About the Cancer**

- What is the stage of my anaplastic thyroid cancer?

### **About Any Treatment Being Discussed**

- What are my treatment options? What are the advantages and disadvantages of the treatment recommended?
- How will I know if the treatment is working?
- What are possible short-term side effects? What can help prevent side effects? What will help me cope with them if they occur?
- What happens when my treatment is over?
- How will the treatment change my day-to-day life?
- About my prognosis
- Points to keep in mind:
  - Ask questions. The medical visits are for you. Also, you do not have to find all answers immediately.
  - Some answers may change over time, based on changes in your personal medical situation and research advances.

## **17. Hospice**

Unfortunately, despite heroic efforts by patients, their doctors, and their families, ATC may progress to the point that patients may have to face a choice between continued treatment, to sustain life with low quality of life, or discontinuing treatment and trying to maximize the remaining quality of life.

The timing and choices are different for everyone. These decisions can be made only after patients carefully consult with their physicians and their families.

Hospice is an option available to those patients who wish to discontinue treatments such as chemotherapy, radiation, or surgery, and who wish to focus on making their remaining life as comfortable as possible. All treatment meant to sustain life must cease, including chemotherapy and radiation, unless the purpose of the treatment is for comfort (known as "palliative care"). Hospice provides palliative care through pain medications, emotional support, and other support.

It is important to know that any patient with incurable cancer (who is no longer getting active treatment for the cancer) can enroll in hospice and take advantage of the services provided. Hospice is not reserved for those expected to have only days or weeks to live.

Most areas have hospice organizations. Many provide hospice care in the home or in a hospice facility or in a hospital.

Hospice doctors and nurses visit the patient as needed and provide comfort care and medicine for pain management. Often, the patient's families can administer medications as needed, which ensures that patients receive immediate attention.

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Hospice nurses are on call 24 hours a day. They can make middle-of- the-night visits if necessary. Hospice is generally covered in full by Medicare and many other insurance plans.

Hospice also provides many other services as needed and desired for patients and their families. These include psychological and spiritual counseling, respite services for family members so they can take breaks from care, and bereavement services for family members.

## **18. Coping with the Emotional and Practical Impacts of Anaplastic Thyroid Cancer**

Please remember, you are not alone. ThyCa is here to help you cope with the challenges of all the aspects of this disease.

### **ThyCa's Anaplastic Thyroid Cancer E-Mail Support Group**

This E-mail (listserv) Support Group, for ATC patients and their families, is available through the web site [www.thyca.org](http://www.thyca.org) of ThyCa: Thyroid Cancer Survivors' Association.

Here is some information about this list from the founders and moderators.

“We are glad you have found your way to the Anaplastic Thyroid Cancer (ATC) listserv. We hope that you will find answers to your questions. We know you will find support.”

“You will find, as you use this mailing list, that others have a wealth of knowledge, from treatment options, strategies for coping with side effects, to experiences and resources. It is a great place to ask questions, seek support, and share your concerns as well as successes.”

“Understand the diagnosis; defy the prognosis! Knowledge shared will help us beat this thing!”

“Welcome and please do not hesitate to post any of your concerns or questions, if any one of us can help or provide perspective we will do it in a heartbeat!”

“Hugs to you and yours! Cheri and Rose, Listserv Moderators”

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## **Instructions for Joining the Free Anaplastic Thyroid Cancer E-Mail Support Group:**

Go to this page on the ThyCa web site:  
[www.thyca.org/email.htm#anaplastic](http://www.thyca.org/email.htm#anaplastic).

Subscribe at [www.groups.yahoo.com/group/anaplastic/join](http://www.groups.yahoo.com/group/anaplastic/join).

Note--If you are not yet registered with Yahoo, you will need to do this before subscribing; click on "I'm a New Member--Sign Me Up" at the above web site.

Registration is a simple and quick process, as well as free; you will set up a Yahoo password.

After you are registered, go back to <http://groups.yahoo.com/group/anaplastic/join> and subscribe to the list. You will receive a confirmation email that you **MUST** respond to, then you will be on the list to get and send email.

If for any reason you cannot complete the Yahoo registration process, you can automatically subscribe to the list by sending a **BLANK** email to [Anaplastic-subscribe@yahogroups.com](mailto:Anaplastic-subscribe@yahogroups.com). This avoids acceptance of cookies but gets you basic list membership only; you will not have access to Yahoo's handy web sites unless you register.

## 19. Support for Caregivers

Family and friends of ATC patients experience many emotional ups and downs and a whirlwind of activity and emotions.

No one person can be the patient's sole support. Caregivers must care for themselves so that they can support the patient.

Often, services are available for respite care, in which a volunteer can stay with a patient for a period of time to give the caregivers a break.

Caregivers are welcome to join the ThyCa ATC E-Mail Support Group.

In the article *Care of the Caregiver* (available on [www.thyca.org](http://www.thyca.org)), ATC caregiver Patricia Scott, R.N., B.S., M.B.A., writes:

The word "**extraordinary**" comes to my mind, to say the least, whenever I think of a caregiver.

For the most part you inherit this position. It shows up at your doorstep, sometimes unannounced due to a series of circumstances. Or you may freely volunteer for this position.

No matter how you acquire this position, it will partially or totally change your life forever.

You sometimes, without even knowing it, become part of that loved one....You eat, sleep, breathe, and feel every physical and emotional change with that person....You become that person's advocate and put your personal needs aside.



You feel their hope and joy.

You laugh with them.

You hurt with them.

You cry with them.

You feel their fear, as you transpose it in to your own fear.

You feel their hopelessness.

You feel their painful solitude, as they helplessly wait for the results of a scan, test, or other procedures.

You rejoice and feel the merriment when outcomes are positive.

Each day, long after the loved one's physical and emotional needs have been met, the caregiver goes on: by working on household chores, by caring for other family members, by keeping up with the financial side, and by making the next doctor's appointments, and more.

So how can we take care of ourselves as caregiver?

As caregivers in this situation, it is very hard to accept the things we cannot change. But nobody can take our HOPE away! Hope Is Huge!

So ... you need to take time to recharge your battery, so you can be strong for yourself, as well as for your loved one.

Examples of things that can help reduce the stress and help clear your mind, so you can function more effectively:

1. Periods of Rest
2. Time for Relaxation, even briefly, through activities such as listening to music, reading, gardening, or hobbies
3. "Stress Busters" such as walking, aerobics, journaling, support groups, or group therapy sessions

## **20. For More Information:**

- **Visit our web site [www.thyca.org](http://www.thyca.org), including our Anaplastic Thyroid Cancer site that's part of the same site.** Our web site receives review and input from more than 50 experts. It has more than 700 pages of information, support, plus a Calendar of Events and links to free support services and numerous helpful organizations and additional resources. The Anaplastic Thyroid Cancer site on [www.thyca.org](http://www.thyca.org) also includes ATC journey stories written by ATC patients and caregivers.
- Read the ATC Guidelines for Physicians, published in 2012 by the American Thyroid Association, for a more technical discussion of options and recommendations on the care of Anaplastic Thyroid Cancer. Remember, this document is written for medical professionals, so may not be completely understandable to patients and their caregivers.
- Join ThyCa's free Anaplastic Thyroid Cancer E-Mail Support Group for ongoing communication, information, and support from other ATC patients and caregivers. This group's members include long-term survivors of ATC, as well as numerous caregivers. Participants share experiences, strength, and hope, offering encouragement and understanding to each other. Instructions for joining this free group are in this handbook and on [www.thyca.org](http://www.thyca.org).

## 21. Thyroid Cancer? ThyCa can help.

We are an internationally recognized, medically advised organization providing **free** support services to people with thyroid cancer.

- **For patients and caregivers** — We offer information and understanding to patients and their families when they need it most.
- **For the public** — We promote awareness for early detection, and provide outreach and education year-round. We sponsor Thyroid Cancer Awareness Month each September.
- **For professionals** — We provide this free handbook, patient brochures and wallet cards, free downloadable Low-Iodine Cookbook, and other materials to give to patients. Plus research funding, with grant recipients selected by an expert panel of the American Thyroid Association.

**Free Services & Resources:** Award-winning web site • Person-to-person support • Local support groups • E-mail support groups • Awareness brochures • Handbooks \* Webinars • Seminars • Regional workshops • Annual International Conference • Online newsletter • Downloadable Low-Iodine Cookbook • and much more

*Please contact us for more information and free materials:*

**ThyCa: Thyroid Cancer Survivors' Association, Inc.**

**www.thyca.org** • thyca@thyca.org

Toll-free 877-588-7904 • Fax 630-604-6078

P.O. Box 1102, Olney, MD 20830-1102

ThyCa: Thyroid Cancer Survivors' Association, Inc., is a nonprofit 501(c)(3) organization of thyroid cancer survivors, family members, and health care professionals, advised by distinguished thyroid cancer specialists and dedicated to support, education, communication, awareness for early detection, and thyroid cancer research fundraising and research grants.

## Anaplastic Thyroid Cancer

Visit [www.thyca.org](http://www.thyca.org) to download this handbook, which is available in English, Chinese, or Spanish.

Visit iTunes or GooglePlay to download this handbook in ePub format.

Our materials are provided free of charge to anyone who needs them. E-mail us at [thyca@thyca.org](mailto:thyca@thyca.org) and we will be happy to mail you individual copies or bulk quantities.

*Courtesy of*



**ThyCa: Thyroid Cancer Survivors'  
Association, Inc.**

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