

# Finding or Starting a Local Thyroid Support Group: A GUIDE



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# **Finding or Starting a Local Thyroid Support Group**

# **A GUIDE**

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### What is a local thyroid support group?

#### *And why would I want to find or start one?*

Not so long ago, thyroid patients had few places to turn for information and support. Before the internet, educational materials for thyroid patients were practically nonexistent. The main resources were things like journal articles and medical texts – geared toward doctors and often available only at university or medical libraries.

Today, information about thyroid disease is abundant and easily found online. Plus, now there are many online forums where patients can share information and experiences.

But sometimes you just can't beat face-to-face time with other patients facing similar challenges right in your area. Local thyroid support groups provide a valuable opportunity for you to connect in-person with other thyroid patients and to learn from and support each other. And for patients without internet access, a local group can be a real lifeline.

An added bonus is that by standing together over time, well-informed, empowered members of a local support group can influence the quality of care in your area.



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In a nutshell, participating in a local support group can help you:

- Gain a clearer understanding of your condition and what to expect
- Gain practical information about symptoms, testing and medication options
- Compare notes about local resources and practitioners
- Learn about new medical research
- Get familiar with various treatment approaches that can be effective
- Advocate for yourself more effectively
- Promote better thyroid care in your area
- Feel less lonely or isolated
- Gain a sense of empowerment and control
- Improve coping skills
- Talk openly and honestly about feelings

*"..... we've found it really wonderful to get together, share our stories, and sometimes we just laugh and cry about what we've gone through. I keep up with some of the online groups, and those are great to get the latest data, but there are times when nothing beats a real life human being to talk to." ~ Kelly R.*

## Finding a Local Thyroid Support Group

The Local Thyroid Support Group Directory (<http://tinyurl.com/thyroid-support>), a place created by the Coalition for Better Thyroid Care to track thyroid groups, is a great place to start your search.

If you don't see a listing for your area, you might also check with your doctor's office, local hospital, or just Google for thyroid support groups along with your city or state name.

### Starting a Local Thyroid Support Group

If no local groups seem to exist and you are interested in starting one – read on --we can help! As a group founder, you'll be able to shape the group according to your own vision.

If you're wondering if you're equipped to lead a group, relax! The most important qualities a group leader can have are a desire to help people and a willingness to jump in and get started. Other helpful traits include being organized and outgoing.....but don't worry if you're neither! Most support group leaders start small and grow into their role, learning as they go. And you're likely to find some members who can bring complementary skills to the mix.

Keep in mind that the role of a support group leader is to provide support and connect members to information and resources.....not to dispense medical advice or counseling.

You'll want to consider the following steps as you get started:

#### ***Step 1: Pick a name***

The name you pick for your group should be descriptive so that other patients in your city or state will quickly grasp where you're located. It doesn't have to be anything fancy.....maybe something like Key Biscayne Thyroid Support Group or Thyroid Support of Long Island.

#### ***Step 2: Identify potential helpers***

Is there someone you have met on an Internet forum who lives nearby, who might share your interest in thyroid support and information? Do you have a spouse, partner, friend, family member or coworker, with or without thyroid disease, who might be willing to help you get started?

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### *Step 3: Select a Location*

Consider where your group might hold meetings. A central location is ideal but not always possible. Many hospitals, medical centers, places of worship, libraries and community/ senior centers provide rooms for support groups



for little or no charge. Make some calls and see what's available and whether there is any cost. Keep in mind that some smaller groups meet at members' homes or restaurants. It's helpful to have a consistent meeting place, but stay flexible

-- your group's needs may change over time.

### *Step 4: Schedule Your First Meeting & Get the Word Out!*

Once you've decided on the location, get in touch with the contact person there to reserve a meeting time and date. Evenings or weekends may work best for many, and two hours should be a reasonable amount of time to reserve. Be sure to schedule your meeting far enough in advance to leave time to get the word out!

To publicize your first meeting, you'll want to include key facts such as the group's name or purpose, contact information as well as the date, time and location for the meeting. We've included some sample flyers later in this guide.

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Consider creating a dedicated email account (free ones include Gmail, Yahoo, Hotmail, etc) just for your group. That way your personal email addresses or phone number won't need to be displayed all over the internet, or your community!

For your publicity efforts, consider a few of the following:

- Call or email any local thyroid patients you already know
- Take out a small ad in a local paper
- Compose and send out a press release about your new group including details about your first meeting. Call first to find out who to send it to at your local newspaper or to the editors of newsletters at community organizations such as:
  - Hospitals
  - Libraries
  - Places of worship
  - Community Centers
  - Schools
- Submit meeting notices to the local newspaper's calendar of health or community events (usually free and often can be submitted online or via email)
- Submit meeting notices to your community access cable station's listing of community events (usually free and often can be submitted online or via email)
- Post notices to online groups and lists (see examples in Online Thyroid Support, later in this guide)
- Create and post (after asking permission) flyers on bulletin boards at:
  - Healthcare offices, hospitals and wellness centers
  - Town and county offices
  - Community/Senior Centers
  - Places of worship
  - Shopping centers, grocery and health food stores
  - Libraries
  - Schools

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The Coalition for Better Thyroid Care is also creating a directory of local groups – be sure to submit info about your group at <http://tinyurl.com/ltsdirectory> so that patients in search of a group in your area can find you!

The Directory online at <http://tinyurl.com/thyroid-support>

### *Step 5: Plan & Hold Your First Meeting*

Before the day of your first meeting, get a game plan together. Drafting a simple agenda can help you stay on track. Don't worry, it doesn't have to be elaborate – the general agenda for any meeting could be something like this:

1. Greet people as they arrive. Have them:
  - a. Sign-in (have sign-in sheet ready) (A sample sheet is included at the end of this guide)
  - b. Fill out and wear nametags (optional)
2. Introductions
3. Welcome and reading of disclaimer (highly suggested) (A sample disclaimer is included in this guide)
4. Presentation/group discussion of the meeting topic
5. Confirm time/date/place for next meeting
6. Time to visit/socialize

At the first meeting, you'll definitely want to arrive a little early to arrange seats and get your thoughts together. Have the sign-in sheet and some nametags available at the entrance to the meeting room. Try to meet and greet each person as they arrive. Leave a little time to chat and get settled.

To start the actual meeting, introduce yourself to the group and have others do the same. For your introduction, you may want to share a bit of your own thyroid story, including what inspired you to start the support group.

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Sharing your story will help others feel comfortable asking questions and responding with their own stories.

At the first meeting, you might also consider making use of some of the icebreakers featured in the guide. At subsequent meetings, introduce any new members and perhaps quickly introduce yourself and the group.

At this first meeting, you will also want to get input from the group about things like:

### Meetings

- Where will the group meet? Is the current location a good one for most?
- What time and day works well for most for future meetings?
- How often will the group meet? Every month, every other month, quarterly?
- How long should meetings generally last? (1-2 hours is typical)
- Should there be any refreshments? (if yes, ask for volunteers and/or donations)



### Group Communications

- How would members prefer to be contacted for future meeting reminders or other info? (hint: phoning takes the most time)
- Do most people have internet access, emails and/or use Facebook?
- Would it be helpful to create an online place to connect in between meetings? Facebook, Google, and Yahoo Groups are all free. (if yes, ask for volunteers to set up)

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Here are some helpful tips from experienced group leaders:

- Do your best to start and finish the meeting on time, but be gracious about late arrivals.
- Try to introduce yourself to new members as they arrive and encourage them to interact with the others. When the meeting starts, you can then introduce the person yourself, which can help keep the meeting on schedule.
- Inform the group where the nearest restrooms are and give them permission to leave the room at any time. Not only will this ease possible anxieties, it will remind any guest speakers not to be offended if someone leaves the room during their talk.
- If the meeting will include a presentation, decide in advance and announce whether questions are ok during the presentation or should be held until the end.
- If you allow questions during the presentation, try to stick close to the topic being discussed at the time. If questions and comments begin to veer off course, gently guide the conversation back to topic, letting people know you will get back to them after the meeting if needed.
- If you opt to wait until the end for questions, encourage members to jot down their questions along the way.
- Sometimes group members will want to discuss treatment that may be considered controversial by many physicians. If you sense this is happening, remind people of the disclaimer you read at the beginning of the meeting.



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- Don't be surprised if your meetings run longer than planned – people may have a great deal to say.

Patient advocate Leslie Blumenberg described some in-person support group meetings she has attended:

*"It was very empowering to realize that thyroid disease was not just in my imagination, and to feel the realness of this disease by watching people interact and tell their stories. Learning of the struggles others have experienced also validated my own desire to share my story, a story too few people in my personal life knew, let alone understood. You could see the knowing nods as people listened and remembered their own struggles. Truly, the room was electric with hope."*

### Meeting Topics & Speakers

Choosing topics for meetings is an important step in ensuring your group's success.



Having a topic can help frame your meetings as positive experiences for those who attend.

When you choose a topic, it doesn't mean you need to prepare a formal presentation or arrange for a speaker, although those would be good to consider for some meetings.

Support groups can be as individualized as the patients who attend them, so ask your members for suggestions of topics or possible speakers.

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Doctors, pharmacists, holistic practitioners, or experts in areas like health insurance, fitness, nutrition, or stress reduction are often happy to be asked to be guest speakers, often at no charge.

When asking someone to speak, it can be helpful to have an idea of what you'd like them to talk about. Be sure they understand that the meeting is centered on support for your members and is not meant to be commercial or self-promotional in nature. At the same time, if they have a business card or brochure, it's appropriate to allow them to hand these out to participants, or have them available at the end of the meeting.

Here are some topic ideas to get you started:

- Symptoms of hypothyroidism
- The different types of thyroid testing
- Understanding thyroid hormone replacement medication options
- The TSH controversy
- How to lose weight despite thyroid disease (are members having success or frustrations)
- Strategies for hair loss
- How to deal with fatigue
- Dealing with mood and emotional issues that can come with thyroid disease
- Thyroid-related memory issues (aka brain fog!)
- Managing stress
- Helping your family and friends understand your condition
- Finding doctors nearby (you might want to start & maintain a local "Top Docs" list)
- Health insurance issues
- How to be a savvy consumer of internet thyroid/health information
- Thyroid books – a discussion of member favorites, or a swap/book exchange among members
- Thyroid websites – a discussion of member favorites
- New research and findings

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## Handouts

You can often find great handout materials online that relate to your topics. Sometimes you'll find pages that work "as is," or you might find you want to adapt them to your needs by copying and pasting. Often the only cost involved is for printing copies, but if your group grows and printing handouts becomes a burden, get creative. You could consider asking for donations to defray your expense.

Another option might be to email handouts with your meeting announcements/reminders – asking members to print, review and bring to the meeting. When you have speakers, be sure to ask if they'll be bringing any hand-outs.

The sky's the limit for handouts. Here are some URLs to get you started:

- **Hypothyroidism Treatments -**  
<http://thyroid.about.com/od/thyroiddrugstreatments/tp/Thyroid-Hormone-Replacement.htm>
- **Conversion Chart -**  
<http://thyroid.about.com/library/drugs/blconversionchart.htm>
- **Thyroid Tests -**  
<http://www.thyroid-info.com/articles/shames-testsdocs.htm>
- **American Thyroid Association Patient Brochures –**  
<http://thyroid.org/patients/brochures.html>
- **Symptoms of Hypothyroidism from Thyroid.about.com -**  
[http://thyroid.about.com/cs/basics\\_starthere/a/hypochecklist.htm](http://thyroid.about.com/cs/basics_starthere/a/hypochecklist.htm)
- **Signs & Symptoms of Hypothyroidism, from ThyroidUK -**  
<http://www.thyroiduk.org.uk/tuk/pages/conditions/thyroid/hyposymptoms.html>
- **10 Signs That You Need a New Doctor -**  
<http://thyroid.about.com/cs/doctors/a/neednewdoctor.htm>

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- **Practitioners Share Their Approaches to Optimal Treatment-**  
(focus on a few at a time – there are 10)  
<http://thyroid.about.com/od/hypothyroidismhashimotos/tp/Top-Doctors-Share-Best-Ways-Treat-Underactive-Thyroid-Hypothyroidism.htm>
- **Adrenal Fatigue -**  
<http://thyroid.about.com/cs/endocrinology/a/adrenalfatigue.htm>
- **Lose Weight Successfully Despite Thyroid Disease –**  
<http://thyroid.about.com/cs/dietweightloss/a/losingweight.htm>
- **Thyroid Bookshelf –**  
<http://www.thyroid-info.com/bookstore.htm>
- **An Open Letter to Family & Friends of Thyroid Patients -**  
<http://thyroid.about.com/od/bookssupportresources/a/letter-to-family-friends.htm>
- **Study Shows Adding T3 is Superior to T4-Only Treatment for Hypothyroidism -**  
<http://thyroid.about.com/b/2010/05/17/t3-superior-t4-levothyroxine-hypothyroidism-thyroid.htm>
- **Are biochemical tests of thyroid function any value in monitoring patients receiving T4 replacement?**  
<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1341585/pdf/bmjcred00253-0040.pdf>



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## Icebreakers

Taking 10 to 15 minutes for “icebreaking” at the beginning of your first meeting can help set an upbeat, positive tone so that members can relax and start getting to know each other.

Make a handout of the list below, or print it on a board if available, and let members pick the one they want to try. You’ll be surprised how long you might remember some answers! Most of all, it can be fun. Here are some ideas:

- What is the best thing that happened to you this week?
- What is your funniest thyroid moment?
- What three words best describe you?
- What is something about yourself that no one in the group knows?
- What is your secret indulgence (can be food but also massage, manicures, magazines, etc)?
- If you could be on a reality show which one would you want to be on and why?
- Tell the group something on your “Bucket List” that you want to do/accomplish in the next year.
- Share your most effective thyroid coping strategy
- What are you most proud of?
- What is your most unusual hobby?



### Online Thyroid Support

Today there are many places for thyroid support online. They may also be potential places to announce your new local support group, and publicize upcoming meetings and events for your group.

#### Facebook Pages

About.com Thyroid page on Facebook

<https://www.facebook.com/aboutthyroid>

Coalition for Better Thyroid Care

<http://www.facebook.com/BetterThyroidCare>

DearThyroid, Healing Our Thyroids One Letter At A Time

<https://www.facebook.com/dearthyroid>

Mary Shomon: Thyroid Patient Advocate, Author

<http://www.facebook.com/thyroidsupport>

ThyCa – Thyroid Cancer Survivor’s Association

<https://www.facebook.com/pages/THYCA/231492537404>

Thyroid Sexy - With Gena Lee Nolin & Mary Shomon

<http://www.facebook.com/thyroidsexy>

Thyroid UK

<https://www.facebook.com/pages/Thyroid-UK/103981042999801>

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### Forums

About.com Thyroid Disease - Main Forum

<http://forums.about.com/n/pfx/forum.aspx?webtag=ab-thyroid>

Thyca: Thyroid Cancer Survivors' Association Support Community  
Support group for thyroid cancer patients and survivors

<http://www.thyca.org>

Thyroid UK forums

UK-based thyroid support group

<http://thyroiduk.healthunlocked.com>

Thyroid-Disease.org.UK - Support Forum

UK-based thyroid support group

<http://thyroid-disease.org.uk>

### Listservs

The Thyroid Listserv on Yahoo

Covers all facets of thyroid disease, diagnosis, treatment and support

<http://health.groups.yahoo.com/group/thyroid>

Yahoo Thyroid Support Groups USA

Features regional and state-based support groups

[http://groups.yahoo.com/group/Thyroid\\_Support\\_Groups-USA](http://groups.yahoo.com/group/Thyroid_Support_Groups-USA)

### Usenet

Altsupportthyroid.org -- homepage and information about the Usenet thyroid support group

<http://www.altsupportthyroid.org/>

### Sample Disclaimer

We suggest you make time on the agenda at every meeting to read this disclaimer:

*This thyroid support group does not engage in the practice of medicine. The volunteers who lead this group are not trained to provide professional health services. We recommend that you consult your own physician regarding any course of treatment or medication discussed in the group. If your physician does not seem to be able to help you safely and effectively resolve your symptoms, we suggest you search for another, at least for a second opinion. Any discussion of products or therapies here should not be construed as any kind of endorsement.*

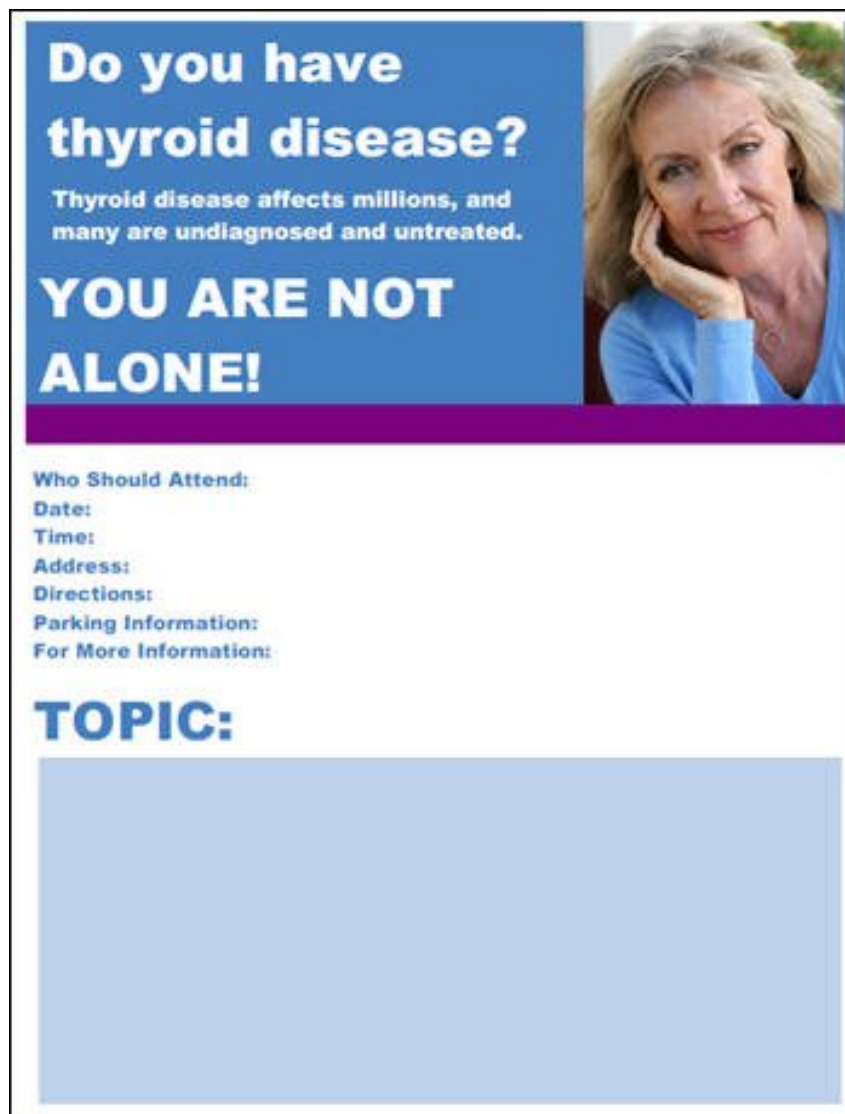
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## Sample Flyers

Sample flyer templates in Word and PDF format are located online at <http://www.betterthyroidcare.org/support/flyers.htm>

The following are examples of the sample flyers:



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