Support Group Leader Training Guide

Laugh. Listen. Learn.
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**Disclaimer:** A support group is a good source of both information and fellowship. However, changes in your medication(s) or treatment plan(s) should be discussed with your physician.
The IETF

Established in 1988, International Essential Tremor Foundation (IETF) is a charitable 501(c)3 not-for-profit, membership-based organization headquartered in Overland Park, KS, a suburb of Kansas City, MO/KS. The IETF is not funded by federal or state grants and therefore depends on the donations of the membership and the public to continue its mission. The IETF increases public awareness about essential tremor through:

Hope. IETF empowers individuals to regain control of their lives by providing educational information, treatment options and coping skills.

Awareness. IETF actively advocates for greater ET awareness and educates at every level--from health care providers to government officials.

Research. IETF funds scientific research to find more effective treatments and a cure for ET.

Support. IETF has support groups across the globe to provide inspiration and fellowship among those living with ET.

Dedication

This guide is dedicated to IETF essential tremor support group leaders who have the courage and vision to embrace the challenge of helping others who are affected by ET.

Mission

To provide global educational information, services and support to those affected by essential tremor (ET), as well as to health care providers, while promoting and funding ET research.
The purpose of this guide

“The Support Group Leaders Guide” along with its companion DVD is a road map for the establishment, development and long-range maintenance of a support group. In addition, it facilitates the understanding of the values and benefits of a support group.

After viewing the DVD and reading this guide, please call us toll-free at 1-888-387-3667 for help in getting started. We look forward to working with you in creating a successful support group!

Meet the panel

Our thanks to the following support group leaders who shared their experiences and insights with us before and during the filming of the DVD.

Shari Finsilver: Founder and leader of the Michigan Tremor Support Group in the metropolitan Detroit area and past-president of the IETF.

Diane Breslow: MSW, LCSW; program coordinator and clinical social worker of the Northwestern University Parkinson’s Disease and Movement Disorders Center; Leader of Northwestern’s IETF support group.

Linda Hope: Support group leader from Loveland, CO. She is one of the most active community outreach IETF support group leaders.

Facilitating the panel discussion was Catherine Rice, IETF Executive Director.
Part One

Starting an essential tremor support group

The idea of starting an essential tremor support group can be intimidating. Most people have no idea where to begin. This guide will:

• Help you understand the role of a support group and the support group leader.
• Tell you how to begin the process of starting a group.
• Provide suggestions about what to do during meetings.
• Inform you of resources available to you as a support group leader.

What is an ET support group?

An informal, self-managed, self-help group. It is run by and for people who have essential tremor or who have a family member or friend who has ET. It is not a therapy group or 12-step program. It is not a substitute for qualified medical care.

A place to be you. Everyone is welcome and accepted at IETF Support Group meetings. The group is a place where people talk openly about the challenges of living with ET and exchange ideas in a comfortable and safe environment. It is a place where privacy and confidentially are respected.

A source of information. With so much information available it’s hard to know what to believe. The IETF offers timely and accurate information about every aspect of essential tremor from cutting-edge research to emerging medications.

A circle of friends. It is a place to talk, laugh and be inspired. At an IETF support group, members never have to worry that someone will ask if they’re cold or nervous. They will find support and fellowship among others who are just like them.

As unique as its membership. The interests and capabilities of support group members vary greatly, and change over time. It is not uniformity that counts or meeting a standard. Rather, it is making the most of what each group has to offer its members at any given time.

What skills and traits are needed to start and lead a support group?

Time
Energy
Organizational skills
Continuing commitment
Ability to work with others
Compassion for others
What are the benefits of being a support group leader?

- Support from others
- Information and education exchange
- Added circle of friends
- Knowledge to help you better participate with your physician in your own treatment plan
- Higher self-esteem

What does the IETF expect of support groups and support group leaders?

Many people become bogged down imagining that too much will be expected of them. In reality, the IETF has very few firm expectations of support groups and support group leaders. The IETF expects:

- Meet a minimum of three times a year.
- Make the meetings open to everyone, not just a select few.
- Have a working email address.
- Possess a knowledge of essential tremor or a willingness to learn.

How does the IETF assist support groups and their leaders?

- Provides training.
- Markets the group to people in the IETF database who live in that community through mailings, website listings and public education events.
- Maintains a physician list for communities.
- Provides a library of literature on essential tremor for each group’s use.
- Provides brochures on essential tremor and the IETF to each group for distribution.
- Lists support groups on the IETF website along with contact information.
- Provides a support group leader forum on the IETF website.
- Distributes a quarterly email newsletter for support group leaders.
- Provides a contact person at the IETF office.
- Provides updates on research and treatment.
- Refers new members, and others, to support groups.
Part Two

The first meeting

When do we meet? Where do we meet? What do we do once we get together? How do I let everyone know about this meeting? These are important questions for the first meeting and following meetings.

When to have the first meeting: When planning the first meeting, or any future meetings, consider your availability as well as the availability of others. The IETF requires that a group meet a minimum of three times a year, but monthly meetings are very popular. Some groups have smaller, weekly gatherings for individuals seeking extra support or who want an additional chance to socialize. With these thoughts in mind, let’s look at the considerations.

• Do you work or go to school? If not, don’t forget that others might.

• At what time during the day do you have the most energy?

• Do you require a caregiver? You will need to find the time for both of you to eat, dress and drive to the meeting location.

• If you are a health care professional, is there time during your workday?

• Do you have trouble driving at night? Meeting during the day might be preferable, and some might need to travel a long distance.

Types of meeting schedules

Alternate times according to the season: For example, some groups hold evening meetings in the spring and summer months when there is more daylight and hold daytime meetings in the winter.

Take the winter off if it is cold: Your climate will probably determine this.

Take the summer off: Many people travel this time of year.

Schedule the meeting for the same day and time each month: People will get into the habit of attending.

Consider weekend meetings: Sunday afternoons are popular. When looking at weekends it is important to consider the religious differences within the group.

Schedule night meetings sometimes: This can be helpful for people who work and can’t get away from their jobs.

Try mid-day gatherings: Have everyone bring a sack lunch.

Where to hold the meeting

The meeting place can often determine when the group meets because some facilities are available only
at certain times. Find a meeting place that offers emotional comfort and promotes friendship, laughter and a positive environment for members. The meeting facility must be able to accommodate members with disabilities so be sure wheelchair access is available. For people who cannot climb stairs, having a meeting on the first floor or having an elevator available is important.

**Some common meeting locations:**

- Community centers
- Hospitals
- YMCA or YWCA
- Senior centers
- Public libraries
- Churches and synagogues
- Rehabilitation centers
- Senior housing communities
- Community rooms at local malls
- Apartment complex clubhouses
- Colleges

**Questions to ask the facility manager**

- Is there a cost?
- When is the room available?
- Are tables and chairs provided? Will they be set up for us?
- How many people will the room hold if some are in wheelchairs?
- How many steps are involved – inside and outside? Is there an elevator?
- Is parking safe and convenient? Is there a good drop-off place at the door nearest to the meeting room?
- Is the entire building, including bathrooms, accessible to walkers and wheelchairs?
- Are bathrooms located near the meeting room and on the same floor?
- Is the room adequately heated and/or air-conditioned?
- How will we gain access to the building especially on nights and weekends? Will there be staff around?
- Is there a telephone accessible at all times?
- Who is the contact person and how can he or she be reached during off hours?
• Is liability insurance required (facilities usually have their own)?
• Can refreshments and beverages be taken into the meeting room?
• Is water easily accessible?

**What to do at the first meeting**

Now that several people have arrived for the first meeting, what do you do? We have suggestions.

• **Make name tags for everyone.** Most of us have trouble remembering names. Name tags will lessen the embarrassment of having to ask someone’s name several times.

• **Arrange the chairs,** preferably in a circle, so that people can make eye contact.

• **Introduce yourself** and welcome everyone. Share why you started the support group.

• **Put people at ease** by stating that confidentiality is a requirement of all members. The identity of anyone attending and the information they share is not to leave the room for any reason. Repeat this at the beginning of each meeting for new people.

• **Set the rules** of the support group with feedback from members at the first meeting. Put the rules into writing and make sure every member gets a copy.

• **Ask everyone to introduce themselves** and tell why they decided to attend. Encourage everyone to share, but remember that not everyone opens up at first. Some people need more time to feel comfortable. Also remember that everyone deals with things differently - there is no correct way to cope with ET.

• **Allow plenty of time for introductions.** Persons with voice tremor find it difficult to speak, so be sure to give plenty of time. It is okay for you to assist, however, do not speak for that person. It helps if the leader repeats each name as you go around with a statement such as, “We’re glad you’re here, Pat!”

• **Set future meeting** times and locations after discussing preferences with members. If the specifics have not yet been determined, the group decides on how everyone will be informed of the next meeting. For instance, a round robin calling system could be established with each person calling the next person on the calling list.

• **Make a list of topics** for future meetings and discuss possible speakers for each topic. For instance, the topic “The Diagnosis and Treatment of ET” is usually presented by a physician or nurse specialist. Encourage a member to volunteer to contact possible speakers, and obtain a commitment for the time and day of the talk. This volunteer can then report back to you so you can arrange for publicity. Schedule speakers six weeks in advance, and be sure to provide the IETF office with this information a minimum of four weeks in advance if you wish the office to mail meeting notices to database...
members living in your area.

• **Discuss the feasibility of serving refreshments** at future meetings. The decision is usually based on the degree of the members’ disabilities and the facilities available. If the group decides in favor of serving refreshments, the job can be rotated among the members. A small donation can be taken each meeting to cover the cost of refreshments.

• **Complete a roster** before everyone leaves. This list includes everyone’s name, mailing address, e-mail address and telephone number. Once the list is developed, it is up to the group as to whether the list is distributed to group members. Please note that each individual must give written permission to be listed, and the list cannot be shared outside the group regardless of circumstances.

• **Discuss how you feel about the first meeting with other organizers** immediately after the meeting. What went well? What did not? Don’t be hard on yourself about the things that do not go well, but use the experience to plan things differently for next time. Take pride in all that worked and look forward to more success in the future.

**How to market the meeting and the support group**

Getting people to come to your first meeting is not as difficult as it might appear. Some people will respond to your personal invitation. Some will respond to local newspaper advertisements. Some will see your name on the IETF website. It’s important not to rely solely upon one method of publicizing your meeting.

Most groups start out with a small number, five to six people, and gradually add members as the group receives more publicity. Some begin with a large meeting and develop a core of members who attend every meeting while other people attend less regularly, as their schedule and interests allow.

**Begin publicizing your meeting through:**

Local newspapers and radio stations. Most newspapers and radio stations accept public service announcements (PSAs) of community events and meetings free of charge. Many local newspapers may also be interested in doing an article about the support group once the group is established. However, you need to submit a press release at least four weeks in advance. A sample release is available in the Support Group Leader section of the IETF website. Follow the step-by-step instructions and submit your release via email. Most media outlets no longer accept releases by fax or mail. Send it to the *Community Editor* or *Calendar Editor*. Unless you have a personal relationship with a specific anchor or disk jockey, it is always best to send releases to the editors. They make the decisions on what will and will not be covered. Also, be sure to ask about their policy about publicity and articles.

**Do not** make follow-up phone calls to the media regarding your release. However, learn who covers health issues in your community and call to schedule a meeting, if possible, and begin to cultivate a professional relationship. Be courteous and brief. Remember that you are helping them become aware of the most common neurological condition that affects approximately 10 million Americans. It could be difficult getting your press release in the paper.
Physicians’ offices, libraries, colleges, community centers, places of worship and senior centers usually allow meeting flyers to be posted on their community bulletin boards, but require permission before posting.

Flyers should have the following information:

- Name of the event (i.e.: Daytona Beach IETF Essential Tremor Support Group)
- Name of a contact person (yourself or another member)
- Contact phone number and email address
- Days/evenings and hours to call
- Brief meeting description
- Meeting time and location

Make sure every flyer and other piece of publicity displays the IETF logo clearly and includes a brief description of ET. You never know where that piece will wind up – nor how much (or how little) the recipient knows about ET.

Also, make sure your flyer indicates that ALL people interested in ET are welcome – patients, friends, family, health care professionals, etc.

Contact the public relations department of your local hospital. This is particularly important if you meet in their facility. However, even if your meetings are held elsewhere, public relations staff members are usually more than willing to assist in advertising community events. Post flyers in the same places that you would post your support group meeting notices.

The IETF office can assist by mailing notices to IETF members in your geographical area.

**Phone Contact**

That first impression made when taking a call for information could be the deciding factor as to whether someone attends the meeting or not. Remember to:

- Project a friendly and helpful attitude and tone of voice. Callers can hear if you are smiling.
- Inform about time, date, location and directions of meeting.
- Maintain a list of people who call and their phone number.
- Refer them to the IETF website (essentialtremor.org) to provide your group with legitimacy.

Some persons call and want to attend; some persons call and choose not to attend now but would like to be notified of future meetings. Others may not want to attend at all. That is just the law of statistics and you needn’t take this personally. Encourage membership in the IETF as they are more likely to become members of the support group at a later date.
Part Three

The meeting agenda

Dividing the responsibilities

It might seem easier to do everything yourself, but this can soon lead to leader burn-out. It is easy to forget that you, as an IETF support group leader, experience the same challenges as other members. As the leader you must preserve energy and the life of the group by delegating jobs. This needs to happen by the second or third meeting, otherwise an unstated expectation will develop that you will do it all while other members only have to attend meetings. Leading and establishing sound expectations and responsibilities of other group members in the beginning prevent having to change expectations of members later.

Some members may hesitate to take on a task because of the severity of their tremor or other circumstances. No one should be pressured into taking on responsibility. However, those who hesitate might accept if each job has a one-year limit and a back-up person assigned to it. Health care professionals who start IETF support groups, or become involved with them, might find it difficult to avoid or resist the leadership role. The sooner delegation happens, the sooner the professional takes an advisory or consultant role that empowers members to self-help.

Below, we have listed some suggested job titles with their associated responsibilities. We highly recommend that you implement these roles as soon as possible.

Small groups (2-25 members)

- Co-leader(s): Plans and leads meetings during leader absence and sometimes assists in leading the group.
- Correspondence Secretary: Maintains membership roster, including updating addresses, phone numbers, e-mail addresses; mails meeting notices, writes guest speaker thank-you notes and other correspondence; and keeps name tags.
- Notes Secretary: Takes meeting notes and shares with people who miss the meeting. These notes can also be used to begin a small newsletter for the group. It is suggested that there be a backup person in this position.
- Reception Committee: Arranges for refreshments including coffee, tea and water as well as cups, straws, lids and plates. Manages the refreshment sign-up sheet.
- Welcoming Committee: Welcomes new members and current members who have missed a meeting or two. It’s nice to know that you have been missed.
- Telephone Contact(s): Serves as contact person(s) for meeting notices and public announcements. Develops a telephone tree or round robin calling system when members need to be contacted by phone.
• Marketing and Publicity Committee: Sends meeting announcements to the local newspapers. Explores ways to market the group through physician’s offices, hospitals, place of worship, community centers, senior centers, etc. Also, maintains a complete list of media and public contacts.

**Large groups (26 and more members)**

The following additional or modified roles can be added as the group grows.

• Welcome/Outreach Committee: Visits or calls to housebound or hospitalized members. Delivers or mails meeting materials. Aligns with newcomers so they feel more comfortable at meetings.

• Treasurer: Keeps member contributions and memorials. Manages treasury to pay for postage, photocopying, sending flowers, etc.

• Librarian: Maintains library of ET books, videos, newsletters and other materials to bring to meetings for members use. Maintains a sign-out list for items that are borrowed.

• Historian: Keeps scrapbook of the group’s activities, including photographs, clippings and other souvenirs. It helps if this person is good with a camera.

• Planning Committee: Meets two or three times a year to plan the year’s agenda. Key members of this committee are Co-Leaders, Secretary, Treasurer, Publicity persons, and of course, any other interested persons.

**Working with speakers**

Speakers are usually available at no charge, and it is important to thank speakers by sending a “thank-you” card within a week of their visit. All speakers have something to offer. However, the difference between a well-prepared presentation and a presentation that misses the mark is often due to the communication between the speaker and the person who invited the speaker. The following checklist has been developed to assist you in communicating your expectations to a speaker.

Confirm the time, date, location and topic in writing as soon as the speaker agrees to make the presentation.

**Two weeks before the meeting**

• Send the speaker a reminder note (“We’re looking forward to seeing you on…” ) along with a copy of the meeting announcement and/or press release.

• Reconfirm the time and format (e.g., a 30-minute talk with 15 minutes for questions and answers).

• Provide information about your group - size, age range.

• Ask the speaker if they will need video equipment, a slide projector or flip chart.
• Provide a list of five to ten questions the group would like to have addressed.
• Ask permission to take photos and/or tape record the presentation.
• Make sure the speaker has good directions and a telephone number to call in case of any last minute problems.
• Provide your best ET booklet or one that pertains to the topic. Use any relevant newspaper clippings to which you would like the speaker to respond.
• Request some background information on the speaker to use for publicity purposes and for introduction. Determine in advance who will introduce the speaker at the meeting. Be prepared with the speaker’s background information. If a blackboard or flip chart is available, it is helpful to write the speaker’s name on it in large letters. Encourage the speaker to use the microphone, if available and necessary, so everyone can hear.

Keep track of the time and provide a warm thank you on behalf of the group at the end of the presentation.

Assisting speakers during question and answer periods

• If time has been allotted for questions and answers, let everyone know what the time limit is and stick to it.
• Ensure that each person gets a chance to ask a question (you may need to set a limit of one question per person depending on the number of persons attending).
• Add helpful background to the question, such as, “This came up at our last meeting, because….”
• Offer to ask questions for group members for whom voice clarity is a problem.
• If the speaker needs to leave at a certain time, someone should escort him or her to the door promptly. After all, you may want that speaker to come back again!
• Finally, it is customary to place your speakers on your mailing list, thus keeping them informed of your activities. They could know persons with ET to refer to your group or they may want to attend a future meeting for their own benefit.

Suggested speakers

Here is list of potential professional speakers. Do not be afraid to ask these individuals to recommend other professionals as potential future speakers.

Neurologist
Nurse specialist
Social worker
Psychologist
Physical therapist
Occupational therapist
Speech therapist
Pharmacist
Dietician
Exercise physiologist or recreation therapist
Health educator
Owner of a local medical equipment company
Travel agent – disabilities specialist
Speaker from local museum or historical site
Local artist
Member of a neighboring ET support group
One of your own members – who has had a recent publication, art show or travel adventure
Computer teacher who is willing to donate some “training” time

**Keeping the faith when group attendance is down**

Even the most upbeat ET support group can have its down times. This may be due to any number of factors: a sudden illness or death of a regular member, absence of the support group leader due to family or work demands, the loss of the support group leader due to a new job, relocation or burnout, the gradual loss of membership due to relocation, general health, personal mobility, etc. or a lapse in meetings due to weather, availability of meeting space or turnover in leadership.

What can you do?

Please understand that it is quite acceptable for the group to take a rest or break. Many ET support groups have taken time out or rested for months at a time only to come back stronger and with renewed membership. Whether you choose to take a break or not, the following ideas may help your group to rejuvenate:

• Ask each member to volunteer to call a missing member and invite him or her back. If he or she cannot attend, offer to visit. Ask if the member would like to send a tape-recorded message or photo back to the group.

• Renew your publicity efforts via the local newspapers and local hospitals. You may have gotten lost among all the other news so let them know you are still around.

• Perhaps the group needs some additional social time. Organize a lunch outing to a favorite local
restaurant. Ask for a large quiet table or private room where you can enjoy one another’s company and hear each other talk. Ask everyone to bring recent family or vacation photos.

• Visit a neighboring ET support group. You will probably find that they have similar difficulties and you may get a few good ideas.

• Try to build contacts with other support group leaders through the use of the IETF Support Group leader Forum, email, letters or phone calls. This is an invaluable way to get new ideas and keep your morale boosted. It can even be helpful to visit other types of support groups to get new ideas and perspectives that may be workable in your group.

• If the group has not met for a few months, contact 2 to 3 members who are still interested and together plan your strategy to start the group again. With other people the work that needs doing can be spread around, minimizing burden on any one person.

Of course, none of these suggestions can make everything right. Change is a reality in the life of every support group, just as it is in the lives of individuals. Allow your group to change, along with the changing energies and experiences of its members. Acknowledge the “down” times and encourage the group to talk about them. Out of these challenges your group will probably see new opportunities and ways to expand and strengthen attendance. Short periods of rest are healthy and can help to renew the energy of the members.

Part Four

Meeting activities and suggested meeting plans

Don’t have a speaker lined up for the next meeting? Not to worry. Most groups have speakers only half the time or even less often. It is important to have a meeting plan or topic for discussion the rest of the time. Here are some meeting suggestions to get you started.

• Genetics of ET: Who in my family has ET?

• Diagnosis of ET: What are the signs and symptoms?

• Medications: What are current and forthcoming medications?

• Research Update: Are we moving toward better treatment options and a cure?

• Living and Coping with ET: How can I do more with ET?

• Progression of ET: What can I expect of my ET in the future?

• Exercise and ET: What are the possible positive and negative effects of exercise for me?
• Nutrition and ET: How does what I eat and drink affect my ET?
• Adaptive Equipment and ET: How can I make getting around safer?
• The Locations of ET: What difficulties are presented by voice, head and hand tremor?
• Computer and Communication Skills: How do I learn how to use a computer?
• ET in the Work Environment: What are my rights by law in the workplace?
• ET and Children: How can ET affect my children and grandchildren?
• Stress Management and ET: How will relaxation affect my tremor?
• ET in Public: What are my dining, recreation and travel options?
• Adaptive Devices and ET: How can adaptive devices make my life easier?

Topic 1 — How do I feel about my ET?

Introduction

One of the most important things the support group can do is try to arrive at a common understanding of what ET is, allowing for the fact that each member experiences it differently.

Discussion questions

• What does essential tremor mean to me?
• How did I feel when I first heard about the diagnosis or heard someone else had ET?
• Am I embarrassed about my ET? If so, why?
• Am I depressed or feel I might be depressed?
• Do I avoid social outings?
• What can I do to feel better?
• How is ET most likely to affect my daily life and activities?
• Are changes unavoidable?
• What is the best way to describe ET to a friend, co-worker or family member?

Suggested speakers

Neurologist, nurse, or health educator, therapist, psychologist who works with ET; an information panel of patients.
Topic 2 — Diagnosis and treatment of ET

Introduction

Each support group member has his or her own story of how they and their doctors made the diagnosis of ET. For some, the diagnosis was made almost immediately. For others, it took much longer. Those with ET may vary in their symptoms and severity, and doctors may differ in their approaches to treatment. Likewise, each person is probably on a different treatment plan.

Discussion questions

• Is there a test for ET? If not, how does the doctor diagnose ET?
• About how many Americans have ET?
• At what age is ET most likely to develop?
• What are the symptoms of ET?
• Do we know the cause of ET?
• What are some of the current theories?
• Can drugs, toxins or germs cause ET-like symptoms?
• Is it important to start treating ET right away? Why do some doctors wait to start ET medication?
• What types of medication are available for ET?
• What should I look for when I take ET medications? What are the good and bad side effects of these medications?
• Is it important to take ET medications every day? Can I skip doses?
• What role does physical, occupational or speech therapy have in the treatment of ET?
• What are the surgical alternatives for ET and who is most likely to benefit from them?
• How can I make the most of my own ET treatment and become more involved in my plan?

Suggested speakers

Neurologist, nurse, and other health professional who works with ET.
**Topic 3 — Nutrition and ET**

**Introduction**

Nutrition plays a role — positive or negative — in every condition, including ET. A healthy, well-balanced diet supports our general well-being and gives us the strength to keep going.

**Discussion questions**

- What is a normal, healthy diet for adults? Is it possible to control fat, sodium and calories (if necessary) and still enjoy eating?
- How much protein do I need? What is the best and tastiest protein source for me?
- What are carbohydrates? Which foods are they in? Are some carbohydrates better for me than others?
- How much water should I drink during the day?
- Should I take vitamins and minerals? If so, what kind and how many?
- Can herbs help my condition? If so, what kind and how many?
- Can you recommend any homemade remedies that may help me?

**Suggested speakers**

Nurse, social worker, nutritionist or health educator who works with ET.

**Topic 4 — You and your doctor**

**Introduction**

The doctor-patient relationship is key in the management of any chronic illness, including ET. Through changing symptoms and medication trials, the doctor-patient relationship can and should be a constant. This is not to say that the doctor and patient will always agree, or that it is easy to find the right doctor. But the search is well worth it.

**Discussion questions**

- Can my family doctor treat my ET? How will I know if I need a movement disorder specialist (a neurologist who specializes in movement disorders)?
- What can I expect from a neurologist? What questions should I ask?
- What is the best way to get my questions answered? Should I write them down?
- What does the doctor need to hear from me? How can I give the most accurate picture of my symptoms?
- Should family members be present in the exam room and/or doctor’s office? Why or why not?
• How should I handle questions or difficulties between visits?
• How do I keep my family doctor up to date on my ET?
• What do I look for in a doctor? How do I know when I have found it?

Suggested speakers

Movement Disorder Specialist (a neurologist who specializes in movement disorders), ET patient and/or family member

Topic 5 — Coping with ET

Introduction

Coping with ET is a matter of using personal resources within the framework of your experience and style. While no two persons cope the same way, there is some common wisdom to be found among all those who live and cope with ET.

Discussion questions

• What does coping mean?
• What are my strengths?
• What has changed since my diagnosis of ET and what has changed because of it?
• What do I tell myself about my condition? What do I tell others?
• What is the most difficult thing for me to cope with? What is the easiest?
• What do I worry about most? How and with whom do I share my worries?
• Who helps me to cope and how do they do it?
• What thoughts or actions help me cope and why do they work for me?
• What practical advice would I give someone who is newly diagnosed with ET? What advice would I give to the spouse and/or family members?
• How do I handle difficulties in my life?

Suggested speakers

ET patients, social worker, nurse or psychologist who works with ET.
**Topic 6 — The value of occupational therapy**

**Introduction**

Occupational therapy is invaluable for people with ET, but so few people know about it! Essentially, occupational therapy teaches people coping skills, new ways of doing things.

**Discussion questions**

• What is occupational therapy?
• How does occupational therapy benefit the ET patient?
• Where do occupational therapists work?
• What kind of training do occupational therapists receive and what are they qualified to do?
• How does one arrange to see an occupational therapist?
• What are assistive technology devices and which ones are effective when dealing with ET?
• How do I purchase the devices?
• Is there a source in the community for used devices that are donated or are sold at a discount rate?

**Suggested speakers**

Occupational therapists, persons with ET who have experience with occupational therapy.

**Topic 7 — Working with your pharmacist**

**Introduction**

Most people don’t know that the neighborhood pharmacist can be a valuable source of information on medications. Do you?

**Discussion questions**

• What exactly is the job of a pharmacist?
• What kind of training do pharmacists receive?
• Is it important to use the same pharmacy all of the time? Is so, why?
• Can a person develop a consultative relationship with a pharmacy?
• What is the difference between a pharmacist and a pharmacy assistant?
• What are generic drugs?
• Does it make a difference if I take a generic or a name-brand drug?
• What is a formulary?
• What are drug interactions? Do over-the-counter medications cause drug interactions?
• What can the pharmacist tell me about mixing my prescription medications with over-the-counter medications?
• Can the pharmacist answer questions about my insurance?

**Suggested speakers**

Pharmacist

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**Topic 8 — Relaxation techniques**

**Introduction**

Stress greatly affects ET, and while there are no ways of eliminating stress from our lives, we can minimize its affects through relaxation techniques.

**Discussion questions**

• How can learning relaxation techniques assist in coping with ET?
• Why does stress make tremor worse?
• How do relaxation techniques reduce stress?
• What are several different forms of relaxation?
• Is there a “best” or “better” form of relaxation?
• How do I learn these techniques?

**Suggested speakers**

Yoga instructor or participant, meditation instructor or participant, Tai-Chi instructor or participant, biofeedback technician, etc. There are many options in this category.