

Caring
Always present
Ready to help
Encouraging
Gracious
Incredible
Valuable
Exceptional
Respectable


Symptoms and Treatment Related to GIST bring their own special problems

1. The disease is chronic.
2. Side effects range from mild to severe.
3. Outcomes are uncertain and not always what we hope.



The Role of the Caregiver

Depression or anxiety is a normal part of caregiving for a loved one with cancer

 Between 45% and 60% of caregivers experience depression or anxiety

The present study finds that the prevalence of anxiety and depression in cancer patient caregivers is very high and quality of life of caregivers is low.



No One Should Face Cancer Alone



Our Mission:

Hope Connections helps people with cancer and their loved ones deal with the emotional and physical impacts of cancer. All programs are provided free of charge to anyone affected by cancer.

Support Groups



50 Support Groups per Month

- ▶ Professionally led by licensed therapists
- ▶ Groups provide a chance to talk in a frank manner about what you're going through with people who are sharing your challenges
- ▶ We run caregiver specific groups and groups dealing with specific cancers for patients

What should you look for from a support group?

Best if led by a licensed therapist. Everyone should be respected, allowed to talk, and should feel unburdened and enlightened at the end of a group.

We claim success if a group:

- Provides a safe place to share
- Lessens isolation

And if support group participants:

- Learn coping skills
- Connect with others
- Feel validated





Mind/Body Programs



Hope Connections
for Cancer Support

Mind/Body Offerings

- Gentle Yoga
- Movement for Health
- Pink Ribbon Pilates
- Strength and Balance
- Tai Chi
- Expressive art
- Guided Mindfulness and Meditation
- Hypnosis for symptom reduction
- Inner Peace and Healing
- Katy's Book Club
- Knitting, Stitch, and Chat
- Relaxation and Tranquility
- Massage (Reiki)





Hope Connections
for Cancer Support

Video

But there are no GIST support groups near me!



- ▶ Do your local hospitals or local cancer society's offer All-Cancer support groups?
- ▶ Do they offer GI cancer specific support groups?

If there is nothing suitable in your area, technology can help:

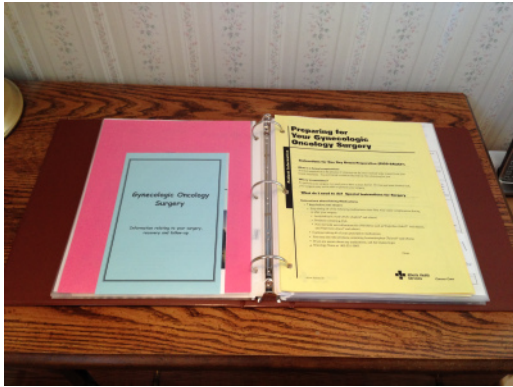
- ▶ **Private Facebook**, or other social media to find caregivers for people with GIST, who may not live near you.
- ▶ **Cancer Cares** (www.cancercare.org), offers face-to-face support groups in the NY and NJ area, also provides online patient and caregiver support groups.
- ▶ **SKYPE**, Skype allows you to host group calling, including conference calling and group chats. You can host a group video chat or conference call for up to 25 people. Adding people who already have Skype is free.
- ▶ **Free Apps**, for stress reduction (Calm, Insight Timer, Head Space)

Metastatic Breast cancer support



- ▶ Began as a private Facebook group “meeting” virtually.
- ▶ Now meeting monthly in our spaces.

What is your role at the beginning of the journey?



You may be the organizer and recorder of information for an overwhelmed patient. Here Are Some TIPS:

- ▶ Know how to get to the appointment. Give yourself enough time.
- ▶ Write down questions you need to ask. Also write down things you want to tell the doctor.
- ▶ Keep a folder of your loved one's health information. Bring this folder to each visit.
- ▶ Bring all medicine bottles with you or keep a list of the names and doses. Bring this list to each visit.

What is your role at the beginning of the journey?



AT THE DOCTOR'S

- ▶ Print your list of questions and give your doctor a copy.
 - ▶ Limited time at the appointment but the doctor can respond to your questions faster if they are written down.
- ▶ If you don't understand an answer, ask the question in a different way.
- ▶ If you need to know more, ask.
- ▶ Let your doctor or nurse know what your worries are.
- ▶ Before you leave the visit, make sure you know what the next steps are for your loved one's care.
- ▶ Take notes. Or ask if you can record the visit.
- ▶ Let the doctor know if your loved one has had changes or new symptoms.

Questions to ask the doctor or health care team

- ▶ What health records should we bring?
- ▶ How can we prepare for treatment?
- ▶ How long will the treatment take?
- ▶ Can he or she go to and from treatment alone?
- ▶ How can I help my loved one feel better during treatment?
- ▶ Can I be there during treatment?
- ▶ What are the side effects of the treatment?
- ▶ After treatment, what do we need to watch for? When should we call you?
- ▶ How do we file for insurance? Who can help us with insurance?
- ▶ Ask about palliative care (getpalliativecare.org)



How do you support yourself? Recognizing your own feelings



- ▶ **Sadness.** It's okay to feel sad. But if it lasts for more than 2 weeks, and it keeps you from doing what you need to do, you may be depressed and need support from a professional.
- ▶ **Anger.** You may be angry at yourself or family members. You may be angry at the person you're caring for. Know that anger often comes from fear, panic, or stress. Try to look at what is beneath the anger.
- ▶ **Grief.** You may be feeling a loss of what you value most. This may be your loved one's health. Or it may be the loss of the day-to-day life you had before the cancer was found. Let yourself grieve these losses.
- ▶ **Guilt.** Feeling guilty is common, too. You may think you aren't helping enough. Or you may feel guilty that you are healthy.
- ▶ **Loneliness.** You can feel lonely even with lots of people around you. You may feel that no one understands your problems. You may also be spending less time with others.



Don't be
AFRAID
To Ask For
HELP

Give yourself permission to ask for help

- ▶ Take a look at how busy you are now. Be honest with yourself about what you can do. Think about tasks you can give to others. And let go of tasks that aren't as important right now.
- ▶ Don't be afraid to ask for help. Remember, if you get help for yourself:
 - ▶ You may stay healthier and have more energy.
 - ▶ Your loved one may feel less guilty about your help.
 - ▶ Friends and family want to help and feel good about contributing. It gives them an opportunity to spend time with the patient or just help with tasks.
 - ▶ How would you feel if the roles were reversed?

How to Support Each Other

- ▶ It may help to remind yourself that everyone handles things in their own way.
- ▶ If possible, talk. It is important and helpful to have open communication.
- ▶ Intimacy may be difficult for many reasons.
 - ▶ Staying close is also about sharing feelings and understanding.
 - ▶ Human touch.
- ▶ Talk about your hopes for the future.
- ▶ Be patient and take things slowly.
- ▶ Be gentle with each other.
- ▶ Be kind.
- ▶ Talk to a counselor or your support group.



What if your partner can't open up?



- ▶ If your partner had a difficult time communicating before the cancer diagnosis, chances are they will not open up now.
- ▶ This does not mean the caregiver should not open up



Deciding how much to share of your own journey

- ▶ When people share, they get more support.
- ▶ Discuss who you are comfortable sharing information with:
 - ▶ Close family members or friends
 - ▶ Support group
 - ▶ Church
- ▶ If you are not comfortable sharing - practice your response if asked:
 - ▶ We are trying to figure that out. I am not comfortable sharing at this time.
 - ▶ It is not a secret, but it is private.

Effective Strategies for joint Decision making



- ▶ Acknowledging this is NEVER easy.
- ▶ There is never a good time.
- ▶ It is helpful to know what each person wants.
- ▶ Depending on the decision, let one person lead.
- ▶ If the patient needs additional treatment, ask them what they want.

Financial Realities: Paying for Treatment and Beyond

- ▶ Some hospitals offer financial counseling and have financial “tumor boards.”
- ▶ *Consumer protection or the attorney general can help if your insurance won't pay.*
- ▶ *Social security has counsellors to talk personally or personnel to talk to a group about your rights and responsibilities.*
- ▶ **Patient Advocacy Foundation**
www.patientadvocate.org

Financial Realities: Paying for Treatment and Beyond



Pharma:

- ▶ Gleevec (Novartis) - Novartis Patient Assistance
- ▶ Novartis offers help to patients who are experiencing financial hardship or who have limited or no third-party insurance coverage for their medicines. [Patient Assistance Now](#) is a website designed for patients to find financial assistance programs for their Novartis Medications. [Patient Assistance Foundation Enrollment](#) offers help to patients who are experiencing financial hardship or who have limited or no third-party insurance coverage for their medicines.
- ▶ To access these resources, visit <https://www.pharma.us.novartis.com/our-products/patient-assistance/> or call 1-800-282-7630 for information on Novartis Patient Assistance or other resources available for eligible patients.
- ▶ Gleevec Co-Pay Card
- ▶ To understand your out-of-pocket costs for Gleevec and to see if you are eligible to pay \$10 for a 30-day supply with the Gleevec \$10 Co-Pay Card, call 1-866-GLEEVEC (1-866-453-3832) or visit <http://www.gleevec.com/index.jsp/>

Caregiver Questions