

Coping with GIST

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Coping with GIST

- Physical Effects
- Emotional Effects

Side Effects GIST

- Pain
- Bleeding
- Nausea
- Vomiting
- Diarrhea
- Constipation
- Fatigue
- Edema

Side Effects of GIST Treatment

GIST

- Pain
- Bleeding
- Nausea
- Vomiting
- Diarrhea
- Constipation
- Fatigue
- Edema

GIST Treatment

- Rash
- Hand foot skin reaction
- Low white blood counts
- Elevated blood pressure

Imatinib vs. Placebo in Resected GIST

Table 3A. Common adverse events, n (%).

	Placebo (n=345)				Imatinib (n=337)			
	Grade 1	Grade 2	Grade 3	Grade 4	Grade 1	Grade 2	Grade 3	Grade 4
Neutropenia	11 (3%)	8 (2%)	3 (<1%)	1 (<1%)	23 (6%)	26 (7%)	7 (2%)	5 (1%)
Fatigue	134 (39%)	51 (15%)	4 (1%)	0 (0%)	117 (33%)	20 (5%)	5 (1%)	2 (<1%)
Dermatitis	75 (22%)	32 (9%)	0 (0%)	0 (0%)	54 (15%)	15 (4%)	11 (3%)	0 (0%)
Abdominal pain	64 (18%)	10 (2%)	6 (1%)	0 (0%)	61 (17%)	25 (7%)	12 (3%)	0 (0%)
Nausea	144 (42%)	27 (8%)	4 (1%)	0 (0%)	78 (22%)	14 (4%)	8 (2%)	0 (0%)
Vomiting	60 (17%)	18 (5%)	2 (<1%)	0 (0%)	37 (10%)	9 (2%)	8 (2%)	0 (0%)
Diarrhea	147 (43%)	42 (12%)	5 (1%)	0 (0%)	79 (22%)	17 (4%)	10 (2%)	0 (0%)
ALT	42 (12%)	6 (1%)	0 (0%)	0 (0%)	38 (11%)	9 (2%)	7 (2%)	2 (<1%)
AST	27 (7%)	3 (<1%)	0 (0%)	0 (0%)	31 (9%)	4 (1%)	4 (1%)	3 (<1%)
Edema	96 (28%)	5 (1%)	1 (<1%)	0 (0%)	220 (65%)	32 (9%)	7 (2%)	0 (0%)
Hyperglycemia	34 (9%)	6 (1%)	7 (2%)	0 (0%)	27 (8%)	9 (2%)	2 (<1%)	0 (0%)
Hypokalemia	9 (2%)	1 (<1%)	3 (<1%)	0 (0%)	28 (8%)	0 (0%)	4 (1%)	0 (0%)
Syncope	1 (<1%)	0 (0%)	0 (0%)	0 (0%)	1 (<1%)	0 (0%)	4 (1%)	0 (0%)
Dyspnea	16 (4%)	5 (1%)	2 (<1%)	0 (0%)	13 (3%)	1 (1%)	4 (1%)	0 (0%)

Imatinib vs. Placebo (GIST) in Patients that have previously received Imatinib and Sunitinib

	Imatinib (n=41)		Placebo (n=40)	
	All Grades (%)	Grade 3-4 (%)	All Grades (%)	Grade 3-4 (%)
Edema	18 (44)	0 (0)	5 (13)	0 (0)
Anorexia	14 (34)	1 (2)	8 (20)	1 (3)
Nausea	13 (32)	0 (0)	1 (3)	0 (0)
Vomiting	13 (32)	0 (0)	2 (5)	0 (0)
Diarrhea	5 (12)	0 (0)	4 (10)	0 (0)
Constipation	6 (15)	0 (0)	4 (10)	0 (0)
Stomatitis	0 (0)	0 (0)	2 (5)	0 (0)
Skin rash	2 (5)	0 (0)	2 (5)	0 (0)
Fatigue	15 (37)	4 (10)	5 (13)	0 (0)
Hyperbilirubinemia	10 (24)	3 (7)	6 (15)	1 (3)
Azotemia	8 (20)	0 (0)	4 (10)	0 (0)

Hematologic toxicities

(per patient)

	Imatinib (n=41)		Placebo (n=40)	
	All Grades (%)	Grade 3-4 (%)	All Grades (%)	Grade 3-4 (%)
Leukopenia	14 (34)	0 (0)	9 (23)	0 (0)
Neutropenia	12 (29)	1 (2)	5 (13)	0 (0)
Anemia	27 (66)	12 (29)	18 (45)	3 (8)
Thrombocytopenia	8 (20)	0 (0)	3 (8)	0 (0)
Febrile Neutropenia	- -	0 (0)	- -	0 (0)

Presented by: Yoon-Koo Kang

PRESENTED AT:  Annual '13 Meeting

Sunitinib (Sutent) vs GIST (Placebo)

Table 1. Adverse Reactions Reported in Study 1 in $\geq 10\%$ of GIST Patients Who Received SUTENT in the Double-Blind Treatment Phase and More Commonly Than in Patients Given Placebo*

Adverse Reaction	GIST			
	SUTENT (N=202)		Placebo (N=102)	
	All Grades %	Grade 3-4 %	All Grades %	Grade 3-4 %
Any Adverse Reaction	94	56	97	51
Gastrointestinal				
Diarrhea	40	4	27	0
Mucositis/stomatitis	29	1	18	2
Constipation	20	0	14	2
Cardiac				
Hypertension	15	4	11	0
Dermatology				
Skin discoloration	30	0	23	0
Rash	14	1	9	0
Hand-foot syndrome	14	4	10	3
Neurology				
Altered taste	21	0	12	0
Musculoskeletal				
Myalgia/limb pain	14	1	9	1
Metabolism/Nutrition				
Anorexia†	33	1	29	5
Asthenia	22	5	11	3

Abbreviations: GIST=gastrointestinal stromal tumor; N=number of patients.

* Common Terminology Criteria for Adverse Events (CTCAE), version 3.0.

† Includes decreased appetite.

Regorafenib (Stivarga) vs. GIST (Placebo)

	Regorafenib (N=132 [*])			Placebo (N=66)		
	Any grade	Grade 3	Grade 4	Any grade	Grade 3	Grade 4
Any event	130 (98%)	77 (58%)	2 (2%)	45 (68%)	5 (8%)	1 (2%)
Hand-foot skin reaction	74 (56%)	26 (20%)	0	9 (14%)	0	0
Hypertension	64 (49%)	30 (23%)	1 (1%)	11 (17%)	2 (3%)	0
Diarrhoea	53 (40%)	7 (5%)	0	3 (5%)	0	0
Fatigue	51 (39%)	3 (2%)	0	18 (27%)	0	0
Oral mucositis	50 (38%)	2 (2%)	0	5 (8%)	1 (2%)	0
Alopecia	31 (24%)	2 (2%)	0	1 (2%)	0	0
Hoarseness	29 (22%)	0	0	3 (5%)	0	0
Anorexia	27 (21%)	0	0	5 (8%)	0	0
Rash, maculopapular	24 (18%)	3 (2%)	0	2 (3%)	0	0
Nausea	21 (16%)	1 (1%)	0	6 (9%)	1 (2%)	0
Constipation	20 (15%)	1 (1%)	0	4 (6%)	0	0
Myalgia	18 (14%)	1 (1%)	0	6 (9%)	0	0
Voice alteration	14 (11%)	0	0	2 (3%)	0	0

Data are n (%). ^{*}Excluding one patient who did not receive study treatment.

Table 2: Drug-related adverse events in ≥10% of patients during double-blind treatment period

Nausea

Causes

- Pain
- Anxiety
- Constipation
- Dehydration
- Malnutrition
- Reflux
- Certain foods
- Motion sickness
- Infections
- Tumors
- Medications

Treatment

- keep a log of when nauseated
- Is it associated with other causes besides medications or GIST?
- Try to avoid triggers
 - No texting and driving (even if passenger!)
- Hydrate hydrate hydrate!!
- Keep pain level less than 2
- “home remedies”
 - Ginger tea
- Antiemetics
 - Ondansetron (Zofran)
 - Ativan (Lorazepam)
 - Prochlorperazine (Compazine)
 - Promethazine (Phenergan)
 - Metoclopramide (Reglan)
 - Granisetron Transdermal (Sancuso Patch)

Additional Tips for Coping with Nausea/Vomiting



- Take your anti-nausea medications as instructed!
- Eat 5 - 6 small meals a day instead of three large meals.
- Drink clear liquids as often as possible after vomiting to prevent dehydration
- Freshen your mouth with a homemade mouth rinse of 1 teaspoon of baking soda, 1 teaspoon of salt, in a quart of water. Swish and spit.
- Eat bland foods, instead of foods that are very sweet, fatty, greasy, or spicy.
- Eat dry foods (such as crackers, toast, dry cereal, or bread sticks) when you wake up and every few hours during the day when you are taking medications or when you feel nauseated.

Tips for Coping with Decreased Appetite/Early Satiety

- Eat 5 or 6 small meals instead of 3 large meals. Eat by the clock. Try to eat something every 2-3 hours.
- Keep your pantry and freezer well stocked with foods that make quick and easy meals and snacks, tuna fish, sardines, peanut butter, soups, crackers, cheese, cottage cheese, hard boiled eggs.
- Eat a bedtime snack. This will give you extra calories without affecting your appetite at your next meal.
- Make every bite count by choosing protein rich foods.
- Drink liquids throughout the day even when you do not feel like eating. Choose liquids that add calories and other nutrients.
- Drink only a small amount of liquids when you are eating meals. Many people feel too full if they eat and drink at the same time

Tips For Coping with Altered Taste

- Choose foods with tart flavors, such as lemon wedges, lemonade, citrus fruits, vinegar, and pickled foods. (Caution: avoid these acidic foods if you have a sore mouth or throat.)
- Marinate foods in a balsamic vinaigrette salad dressing.
- Season foods with herbs, spices, and other seasonings, such as onion, garlic, chili powder, basil, oregano, rosemary, tarragon, barbecue sauce, mustard, ketchup, or mint. Try Mrs. Dash seasonings.
- Eat frozen fruits, such as whole grapes and mandarin orange slices, or chopped cantaloupe or watermelon.
- Before eating, rinse your mouth with the homemade mouth rinse, 1 teaspoon salt, and 1 teaspoon baking soda in a quart of water. Rinse and spit.
- If you have a metallic taste, try using plastic flatware and glass cups. Avoid canned vegetables, fruits and soups.

Diarrhea

causes

- Certain foods
- Medications
- Infection

treatment

- Keep a food diary
 - Avoid
 - eat
- Medications
 - Imodium (loperamide)
 - Lomotil (diphenoxylate)
 - Tincture of opium
 - octreotide

Tips for Coping with Diarrhea

- Avoid high fat and spicy foods
- Choose low fiber, bland foods
- Sip on broth, tomato juice, V-8 and electrolyte replacement drinks to help replenish electrolytes
- Add foods with soluble fiber to help thicken stool (banana, applesauce, oats, white rice, white pasta)
- Limit lactose, sugar and sorbitol
- Limit hot, caffeinated beverages
- Watch for medications containing magnesium

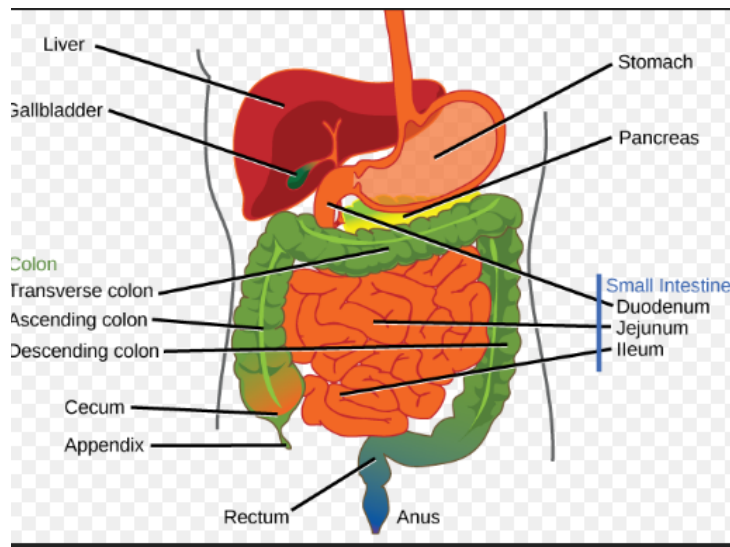
Constipation

Causes

- Dehydration
- Certain foods
- Medications
- Tumor

Treatment

- Hydrate
- Fruits and vegetables
- Stool softeners (docusate)
- Miralax
- Senna
- Enemas
- Mineral oil



Tips for Coping with Constipation



- Eat at about the same times each day
- Drink plenty of liquids (at least 8 cups daily) – 0.5-.66 x your body weight in ounces
 - For variety, drink water, prune juice, warm fruit or vegetable juices, decaffeinated teas, or hot water with added lemon juice and honey.
 - Fluids also include foods that are liquid at room temperature, like frozen ice pops, gelatin, or ice cream.
- Eat foods high in fiber
 - Work up to 25-38 grams of fiber a day. Be sure to increase fiber slowly. Increase the amount of fiber you eat by no more than 5 grams each day.

Swelling/Edema

Causes

- GIST
- Medication
- Blood clots
- Poor nutrition
- Heart dysfunction
- Kidney Dysfunction

Management

- Diuretics (furosemide-Lasix)
- Avoid salty foods
- Hydrate with water
- Keep legs elevated
- Compression stockings
- Lymphedema clinic
- Increase protein intake
- Avoid very hot showers

Skin and Hair Changes

Effects

- Hair
 - Thinning or loss
 - Whitening
- Skin changes

Coping

- Check for lab abnormalities
- OK to dye your hair!
- Avoid HOT water
- Hydrate
- Moisturize with urea-based products
- Call your doctor as soon as you see changes



Fatigue

- Cancer Related Fatigue
 - unusual, persistent sense of physical, emotional and/or cognitive tiredness or exhaustion related to cancer or cancer treatment that interferes with ones' normal activity
- Symptoms
 - Weak feeling all over the body
 - Difficulty concentrating
 - Waking up tired after sleeping
 - Lack of energy or decreased energy
 - Lack of motivation to be physically active
 - Increased irritability, nervousness, anxiety, impatient
 - No relief from fatigue, even with rest or sleep
- Symptoms are present every day or nearly every day for a 2 week period within the last month



Causes of Fatigue

Causes

- Pain
- Dehydration
- Depression/anxiety
- Anemia
- Iron, vit b12, folate deficiency
- Low thyroid
- Not enough sleep
- Not enough exercise
- Infection
- Poor nutrition
- GIST
- medication

treatment

- Hydrate hydrate hydrate
- Keep pain level less 2
- ask MD to do “fatigue workup”
- Get at least 8 hours of sleep
- Exercise
- Prioritize activities

What is your FATIGUE level?

FATIGUE SCALE

Select the number that best describes how you feel today.

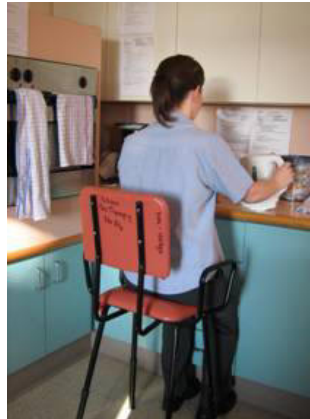


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Energy Conservation

What is Energy Conservation?

- The practice of decreasing the amount of energy used during a task of activity while achieving a similar result



Energy Conservation Techniques

- Sitting to complete daily tasks
- Use cart to push items opposed to carrying
- Avoid bending, use a reacher or other adaptive equipment
- Breaking up components of a task
- Asking for assistance
- Spread energy consuming tasks throughout the week
- Do tasks that require the most energy at the times you have the most energy
- Utilizing recovery breaks, **“Do a little, Rest a little”**
- Implementation of relaxation techniques

Energy Conservation

3 Key Strategies

- Pacing
- Prioritizing
- Changing Positions

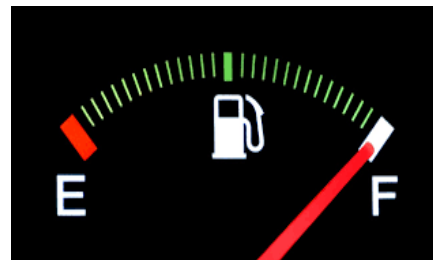
Strategy: Pacing

Understand how to conserve your energy

- Think of your personal energy as being held in an Energy Tank
- The lower the energy in the tank, the longer it takes to build back up
- Before starting a task rate your current energy level
- If your energy level is 5-10 you can use 2 levels of energy before you need to rest
- If your energy level is 1-4 you can use 1 level of energy before you need to rest
- Ask yourself frequently “What is my energy level?”
- Listen to your body and don’t do too much at one time

Empty Tank

Least Energy



Full Tank

Most Energy

Strategy: Prioritizing

- Make a prioritized to do list for the day
 - Spread out activities between the morning, afternoon, and evening
 - Think about the time of day that you have the most energy and complete tasks during this time that require the most energy
 - Spread energy consuming tasks throughout the week
- Save energy for doing what you enjoy and want to do, by adjusting your schedule each day

PRIORITIES

1
2
3



Strategy: Changing Position

Using less energy for an activity allows you to do more

Adaptive equipment can help maintain independence and use less energy

Examples:

- Sitting on the bed or in a chair for getting dressed
- Sit at the table to meal prep
- Sit in a chair for bathing
- Use a rollator for seated break when walking long distances



Why Exercise?

Published research has determined that exercise is safe for cancer survivors and aids in management of cancer related fatigue

Exercise has been shown to have several different benefits for survivors including:

- Better physical functioning
- Improved balance
- Increased strength & flexibility
- Decreased fatigue
- Decreased pain
- Improved heart function
- Increased energy levels
- Improved quality of life



Exercise Recommendations

American College of Sports Medicine (ACSM) Guidelines
for Cancer Survivors

- **Aerobic:**
 - **150 min/week** of moderate intensity, 75 min/week of vigorous intensity or a combination of the two
- **Resistance:**
 - Muscle strengthening activities of at least moderate intensity at least 2 days a week for major muscle groups
- **Flexibility:**
 - Stretch major muscle groups and tendons on days other activities are performed

Aerobic Activities

- Walking
- Jogging
- Biking
- Hiking
- Swimming
- Dancing
- Aerobics
- Gardening
- Tennis
- Sports that require running
- Marching in place
- Jumping Jacks
- Activity Circuits
- Climbing stairs

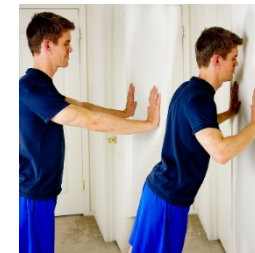
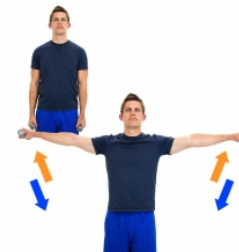


Resistance Activities

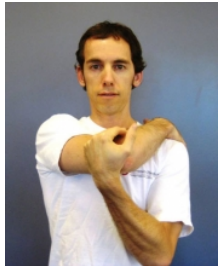
Lower Body



Resistance Activities -Upper Body



Flexibility



Balance



3
5

What to Watch Out for While Exercising

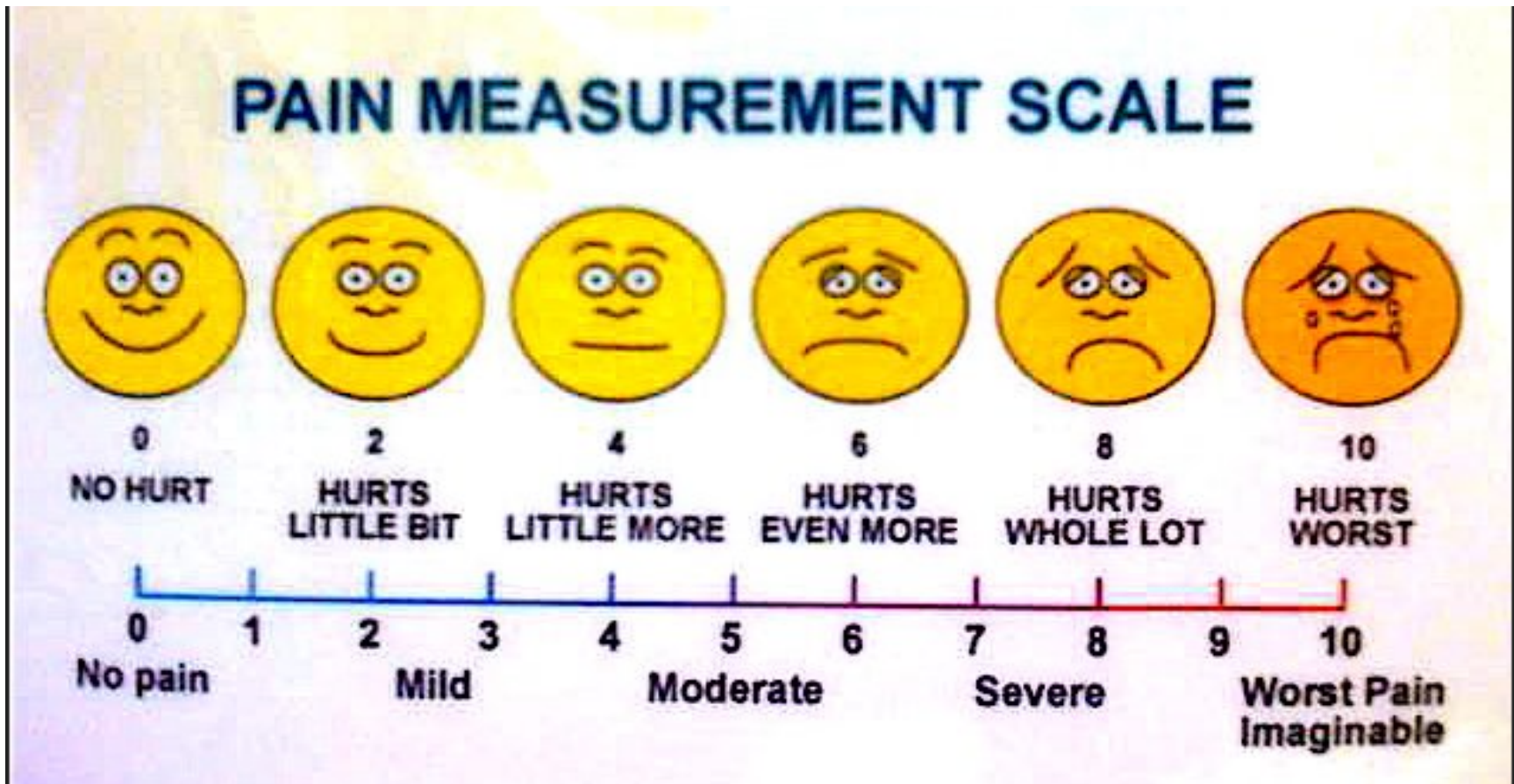
- Unusual Fatigue – more than expected based on the activity level
- Shortness of breath
- Dizziness or light headedness
- Unusual heart palpitations
- Leg cramping
- Headaches
- Visual changes

**If you have any of these symptoms during exercise, stop³
immediately₅**

Pain Management

- Pain is subjective
- Pain can cause fatigue, irritability, decreased appetite, nausea, vomiting, problems sleeping, depression, and is a reminder that you have a medical condition
- Need to find out what is causing the pain in order to treat properly
- Causes of pain in GIST patients include
 - Gas pain, diarrhea cramping, constipation, reflux, muscle cramping/tightness, arthritis
 - Tumor pain

Pain Level Assessment



Pain Management

- Keep a pain diary
 - Is pain related to food, certain positions, time of day etc
 - Assess pain level every few hours
- The best way to treat cancer pain is with narcotics (oxycodone, morphine, hydromorphone (dilaudid))
- Start with short acting pain meds keep a pain log, if requiring more than 4 pills a day your doctor can convert you over to a long acting pain med (MS Contin, Oxycontin, Duragesic Patch (fentanyl), Exalgo (hydromorphone extended release))
- Very very rare that cancer patients get addicted to pain meds

Mental effects

- Memory issues
- Anxiety
- Depression
- Stress

Anxiety/Stress

Causes

- “scanxiety”
- The Internet
- The news
- Family issues
- “Negative Nellies”
- Anxiety/depression disorder

Management

- Schedule MD appointment close to the scan
- Limit the internet
- AVOID the news
- Relinquish control of family/friends issues
- Avoid negative people
- Denial is not a bad thing
- “escape mechanism”
- Deep breathing
- meditation
- Antianxiety meds

Depression

Causes

- Major depression
 - Depressed mood + SICECAPS
 - Problems sleeping, loss of interest, loss of concentration, loss of energy, change in appetite, psychomotor retardation (going in slow motion), suicidal ideations
- Pain
- Fatigue
- “negative” environment
- stress

Management

- Address pain, sleep, eating and fatigue issues
- Avoid “negative Nellies”
- Cut down on the internet and social media
- Don’t watch the news
- Think HOPE and LIVING with cancer
- May need antidepressants

In Conclusion

- There is so much hope for all GISTers!
- Focus on this hope
- Hydrate hydrate hydrate!
- Get your rest!
- Tell your Doctors about how you feel physically and mentally so that they can help you!!
 - Remember they went to school for all those years to HELP people!!
- No watching the news!!

THANK YOU!!!

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NORTHSIDE HOSPITAL CANCER INSTITUTE
SARCOMA PROGRAM
"BUILT TO BEAT CANCER"

SARCOMA AWARENESS sunset stroll

6:30 - 7:00 p.m.
Registration
Food Trucks

Sarcoma Awareness Sunset Stroll
Wednesday, May 9, 2018



SARCOMA EXCHANGE

JULY 20-22, 2018

1st Sarcoma Exchange 147 attendees 21 sarcoma subtypes
29 states represented 48-year sarcoma survivor:
longest since diagnosis



Survey Results Rates All program sections Attendee from
Overall Event received average rating farthest away:
4.53 out of 5 of 4+ out of 5 Oregon!

Testimonials

"Great info! Finally met someone who has a similar projection of the disease. I learned about my treatment options. I feel hopeful for the future."

"Thank you so much for providing me with new info. It gives me a lot more HOPE!"

"I was able to connect with other people that share my disease. I was also able to find out more info about resources and other events."

"Like most that it happened, especially so close to my one year of being diagnosed. The opportunity to hear from leading experts really expanded the range of questions I could ask of my sarcoma care team."

"As a family member I feel a lot more at ease and less stressed if treatments are correct and what I should be doing."

"Thank you for having a great Sarcoma Exchange. This really is going to change my life. Thank you."