

# Quality of Diagnosis, Treatment and Care

IN PURSUIT OF YOUR CURE.™

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Virtual NEW HORIZONS GIST

Patient Advocacy Roundtable

September 12, 2020



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# GIST Episode 9: Objectives

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- Adherence: The importance of professional therapy and side effect management: Getting the best of the treatments
- Discussion:
  - Living with the disease
  - Influencing factors
    - Nutrition
    - Complementary Therapies
    - Coping
  - Challenges for patients
  - Challenges for carers



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# Adherence: The importance of Professional Therapy and Side Effect Management

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- GIST Facts
  - Prior to 2000 survival rates were dismal
  - Discovery of *kit* gene CAUSING the overexpression and constitutively activated KIT protein resulting in cell cycle progression (growth) and metastases (spread)
    - This means that a mutation in the gene causes the receptor always be turned on which causes the cancer to grow and spread
    - Tyrosine kinase inhibitors (TKIs) inactive the receptor (shut it down)
  - Current state of affairs: 5 FDA approved drugs, multiple other treatments (TKIs) shown to be effective
  - Multiple studies showing prolonged survival with continuous treatment with TKI
  - Placebo data showing GIST will grow rapidly if off treatment
  - **BOTTOM LINE:** receptor (KIT, PDGFR, NF-1, etc) that is activating the cancer cell **MUST** be **TURN-OFF** at all times!



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# Adherence: The importance of Professional Therapy

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- GIST experts
  - Know the data
    - Importance of mutation status to determine the dose and proper TKI
  - Understand the importance of plan and “back up” plan
  - Work in a multidisciplinary group to ensure best outcomes
    - Sarcoma medical oncologist
    - Expert soft tissue pathologist
    - Expert/experienced surgical oncologist, radiation oncologist, interventional radiologist
  - If you are unable to be under the direct care of a GIST expert then you need to ensure that a GIST expert is at least indirectly involved
    - 1-2 visits/year with the expert
    - Telemedicine (game changer thank you COVID19)
    - Your oncologist is in direct contact with the expert (make sure you get the name)
    - Contact your GIST support group for options
      - Sarcoma Alliance grants for second opinion



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# Side Effects of GIST Treatment

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## GIST

- Nausea/vomiting
- Diarrhea
- Constipation
- Edema
- Fatigue
- Pain
- Mental effects

## GIST Treatment

- Rash
- Hand Foot Skin Reaction
- Low white blood counts
- Alterations in Thyroid Function
- Altered Taste
- Elevated Blood Pressure
- Muscle Cramping



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# Side Effect Management: Nausea

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## 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
- Look and smell your urine
- “home remedies”
  - Ginger tea

### Antiemetics

- Ondansetron (Zofran)
- Ativan (Lorazepam)
- Prochlorperazine (Compazine)
- Promethazine (Phenergan)
- Metoclopramide (Reglan)
- Granisetron Transdermal (Sancuso Patch)



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# Additional Tips for Coping with Nausea/Vomiting

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- Take your anti-nausea medications as instructed!
- Eat 5-6 small meals a day instead of 3 large meals
- Drink clear liquids as often as possible after vomiting to prevent dehydration
  - Talk to your doctor about IV fluids if you are unable to get proper hydration
- 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
- Talk to your doctor about reflux medications and the timing around your GIST medication



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# Tips for Coping with Decreased Appetite/Early Satiety

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- 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



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# 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.



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# Diarrhea

## Causes

- Certain foods
- Medications
- Tumor/previous surgeries
- infection

## Treatment

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

## Tips for Coping with Diarrhea

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- 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

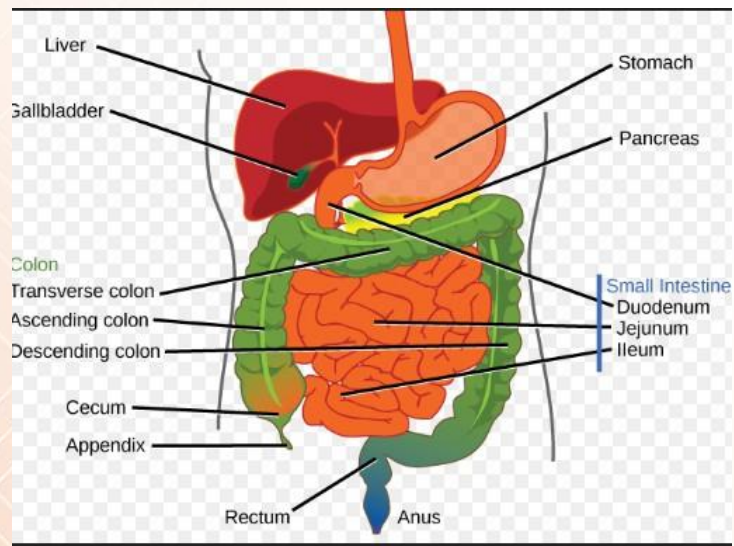


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# Constipation

## Causes

- Dehydration
- Certain foods
- Medications
- Tumor



## Treatment

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



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# 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.



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# Swelling/Edema

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## 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

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– 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



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# Causes of Fatigue

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## 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








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# What is your FATIGUE level?

**FATIGUE SCALE**

Select the number that best describes how you feel today.

 NO FATIGUE	 MILD FATIGUE	 MODERATE FATIGUE	 EXTREME FATIGUE	 THE WORST FATIGUE
0	1 2 3	4 5 6	7 8 9	10

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# Energy Conservation

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## What is Energy Conservation?

- The practice of decreasing the amount of energy used during a task or 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

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- Pacing
- Prioritizing
- Changing positions



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# Strategy: Pacing

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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



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# Strategy: Prioritizing

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- 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



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# Strategy: Changing Position

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- 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



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# Why Exercise?

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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



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# Exercise Recommendations

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

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- **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



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# Aerobic Activities

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



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# Resistance Activities Lower Body



# Resistance Activities -Upper Body

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3  
3

# Flexibility

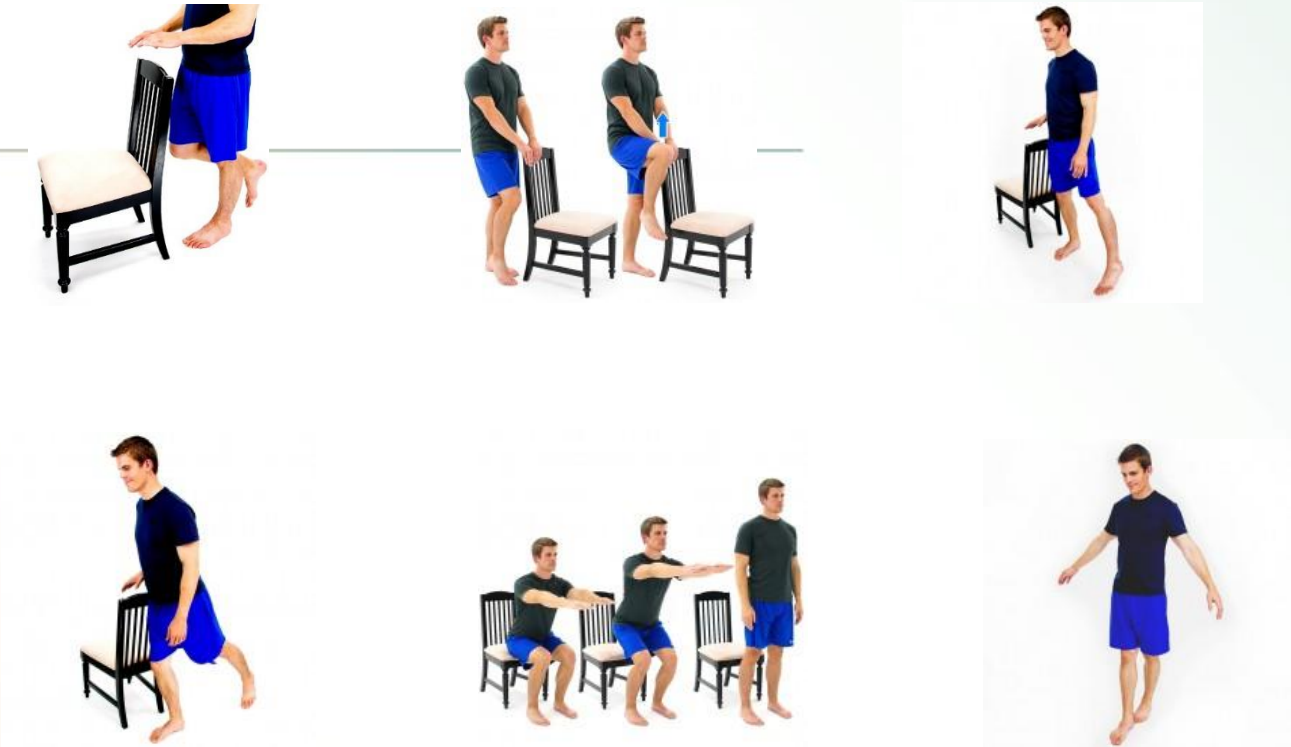
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# Balance

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3  
5

# What to Watch Out for While Exercising

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- 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, stop immediately and contact your doctor!!**



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# Pain Management

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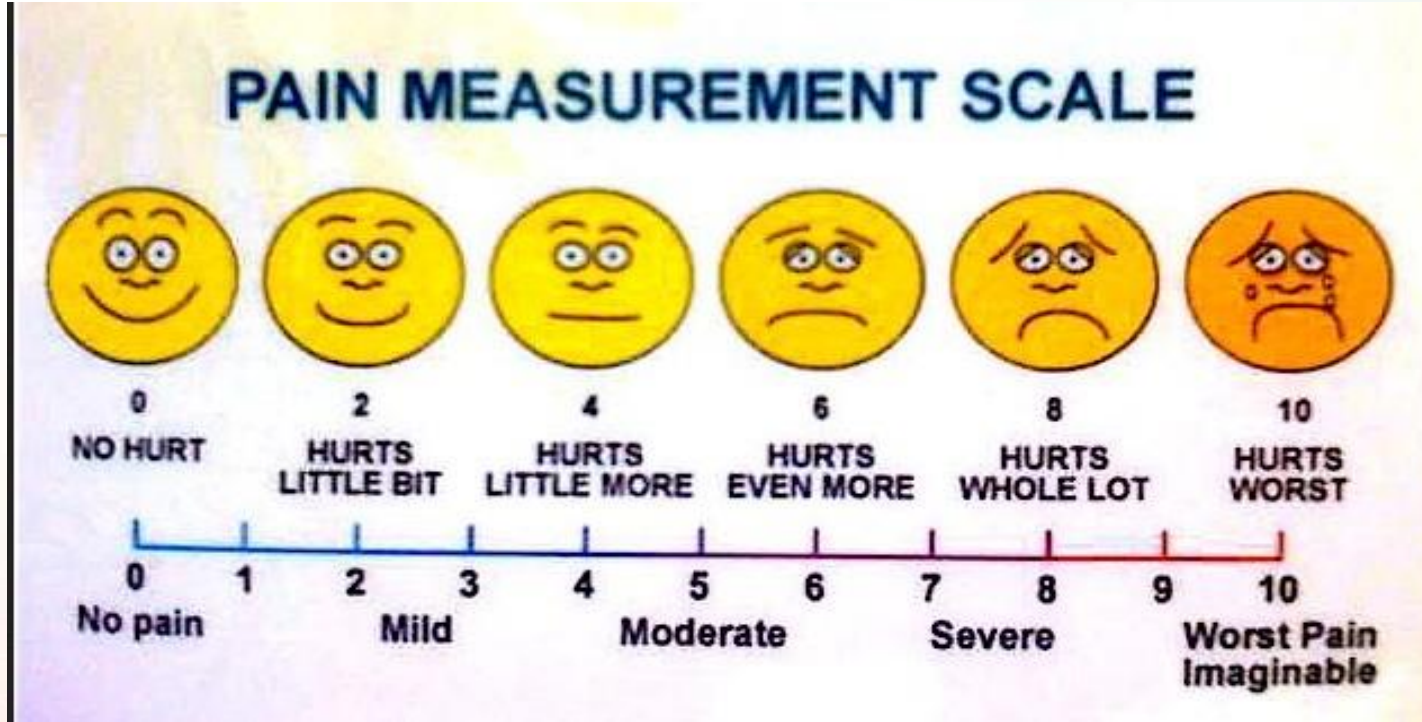
- Pain is subjective
- Pain can cause fatigue, irritability, decreased appetite, nausea, vomiting, problems sleeping, depression, and is a reminder that you have a medical condition
- Need to find out what is causing the pain in order to treat properly
- Causes of pain in GIST patients include
  - Gas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



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# Pain Level Assessment

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# Pain Management

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- 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



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# Mental effects

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- Memory issues
- Anxiety
- Depression
- Stress

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# Anxiety/Stress

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## 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



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# Depression

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## 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



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# Other Side Effects of Treatment

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- Low white blood counts (very rare but possible)
  - Short acting growth factors can be given if ANC (absolute neutrophil count) less than 1000
- Possible dose reduction
- Make sure you are up-to-date on vaccines
  - Flu, pneumonia, hepatitis A, B, shingles– Speak with your doctor about safety, no live vaccines
- Alterations in Thyroid Function
  - Thyroid function should be checked regularly if on a TKI that can affect it and can be treated if abnormal and symptomatic
- Elevated Blood Pressure
  - Needs to be monitored closely and antihypertensive (BP meds) added frequently. Your oncologist often can manage the BP but sometimes a cardiologist needs to be involved
- Muscle Cramping
  - Make sure you are hydrating well (at least ½ of your body weight in pounds= number of ounces of water
  - Too much water alone can cause it so make sure you supplement with electrolytes
  - Speak with your doctor about checking for ca, k, mag, and phos
  - Learn from patient antidotes: pickle juice, ivory soap in bed, electrolyte supplements, Stretching exercises, IV fluids



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# Carers: Loved Ones Who Either Live with or are in Close Contact with the Patient

- LESSON 1: you must take of yourself, otherwise you will not be able to help your loved one!
- CARER: Review slides on proper nutrition, hydration, mental health, exercise these are for YOU also!!
- Feelings of helplessness is normal
  - Remember just being THERE is to CARE
  - Patients just want to know you CARE, they can tell with words and small actions: hug, reinforcing how proud you are, saying “I’m here for you”, asking how you can help
- Ok to ask for help from family, friends, social worker, religious group, counselor, neighbor
  - Despite what the news and social media wants you to think MOST PEOPLE ARE GOOD
  - It is GOOD to ask for help because others also feel helpless and want to help so ok to “put on others assignment”
- Don’t be offended if you cooked and they didn’t like it or finish the dish
  - Remember the taste bud changes and decreased appetite
- Try not to get aggravated if patient doesn’t eat enough
  - Have snacks available (see nutrition slides)
- Take notes at Dr. visits (or ask if ok to record visit)
- Have list of questions available for you and patient to write down anytime you think of something and bring to the doctor’s visit

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# In Conclusion

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- There is so much hope for all GISTers!
- Focus on this hope
- Take your medicine
- 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!!



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# THANK YOU!!



The NEW HORIZONS GIST Patient Advocacy Roundtable:

Improving access to treatment and quality of care through global exchange.

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  - Elizabeth Montgomery
  - Daniel Cassidy
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  - Jean Jose
- **Nurse Practitioner**
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