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 (%).

<table>
<thead>
<tr>
<th>Event</th>
<th>Grade 1 (n=345)</th>
<th>Grade 2</th>
<th>Grade 3 (&lt;1%)</th>
<th>Grade 4 (&lt;1%)</th>
<th>Grade 1 (n=337)</th>
<th>Grade 2</th>
<th>Grade 3</th>
<th>Grade 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Neutropenia</td>
<td>11 (3%)</td>
<td>8 (2%)</td>
<td>3 (&lt;1%)</td>
<td>1 (&lt;1%)</td>
<td>23 (6%)</td>
<td>26 (7%)</td>
<td>7 (2%)</td>
<td>5 (1%)</td>
</tr>
<tr>
<td>Fatigue</td>
<td>134 (39%)</td>
<td>51 (15%)</td>
<td>4 (1%)</td>
<td>0 (0%)</td>
<td>117 (33%)</td>
<td>20 (5%)</td>
<td>5 (1%)</td>
<td>2 (&lt;1%)</td>
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<tr>
<td>Dermatitis</td>
<td>75 (22%)</td>
<td>32 (9%)</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
<td>54 (15%)</td>
<td>15 (4%)</td>
<td>11 (3%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Abdominal pain</td>
<td>64 (18%)</td>
<td>10 (2%)</td>
<td>6 (1%)</td>
<td>0 (0%)</td>
<td>61 (17%)</td>
<td>25 (7%)</td>
<td>12 (3%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Nausea</td>
<td>144 (42%)</td>
<td>27 (8%)</td>
<td>4 (1%)</td>
<td>0 (0%)</td>
<td>78 (22%)</td>
<td>14 (4%)</td>
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<tr>
<td>Vomiting</td>
<td>60 (17%)</td>
<td>18 (5%)</td>
<td>2 (&lt;1%)</td>
<td>0 (0%)</td>
<td>37 (10%)</td>
<td>9 (2%)</td>
<td>8 (2%)</td>
<td>0 (0%)</td>
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<tr>
<td>Diarrhea</td>
<td>147 (43%)</td>
<td>42 (12%)</td>
<td>5 (1%)</td>
<td>0 (0%)</td>
<td>79 (22%)</td>
<td>17 (4%)</td>
<td>10 (2%)</td>
<td>0 (0%)</td>
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<tr>
<td>ALT</td>
<td>42 (12%)</td>
<td>6 (1%)</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
<td>38 (11%)</td>
<td>9 (2%)</td>
<td>7 (2%)</td>
<td>2 (&lt;1%)</td>
</tr>
<tr>
<td>AST</td>
<td>27 (7%)</td>
<td>3 (&lt;1%)</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
<td>31 (9%)</td>
<td>4 (1%)</td>
<td>4 (1%)</td>
<td>3 (&lt;1%)</td>
</tr>
<tr>
<td>Edema</td>
<td>96 (28%)</td>
<td>5 (1%)</td>
<td>1 (&lt;1%)</td>
<td>0 (0%)</td>
<td>220 (65%)</td>
<td>32 (9%)</td>
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<tr>
<td>Hyperglycemia</td>
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<td>7 (2%)</td>
<td>0 (0%)</td>
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<td>9 (2%)</td>
<td>2 (&lt;1%)</td>
<td>0 (0%)</td>
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<tr>
<td>Hypokalemia</td>
<td>9 (2%)</td>
<td>1 (&lt;1%)</td>
<td>3 (&lt;1%)</td>
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<td>28 (8%)</td>
<td>0 (0%)</td>
<td>4 (1%)</td>
<td>0 (0%)</td>
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<tr>
<td>Syncope</td>
<td>1 (&lt;1%)</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
<td>1 (&lt;1%)</td>
<td>0 (0%)</td>
<td>4 (1%)</td>
<td>0 (0%)</td>
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<tr>
<td>Dyspnea</td>
<td>16 (4%)</td>
<td>5 (1%)</td>
<td>2 (&lt;1%)</td>
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<td>13 (3%)</td>
<td>1 (1%)</td>
<td>4 (1%)</td>
<td>0 (0%)</td>
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### Imatinib vs. Placebo (GIST) in Patients that have previously received Imatinib and Sunitinib

<table>
<thead>
<tr>
<th>Side Effect</th>
<th>Imatinib (n=41)</th>
<th>Placebo (n=40)</th>
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<tbody>
<tr>
<td></td>
<td>All Grades (%)</td>
<td>Grade 3-4 (%)</td>
</tr>
<tr>
<td>Edema</td>
<td>18 (44)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Anorexia</td>
<td>14 (34)</td>
<td>1 (2)</td>
</tr>
<tr>
<td>Nausea</td>
<td>13 (32)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Vomiting</td>
<td>13 (32)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Diarrhea</td>
<td>5 (12)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Constipation</td>
<td>6 (15)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Stomatitis</td>
<td>0 (0)</td>
<td>0 (0)</td>
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<tr>
<td>Skin rash</td>
<td>2 (5)</td>
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<td>Fatigue</td>
<td>15 (37)</td>
<td>4 (10)</td>
</tr>
<tr>
<td>Hyperbilirubinemia</td>
<td>10 (24)</td>
<td>3 (7)</td>
</tr>
<tr>
<td>Azotemia</td>
<td>8 (20)</td>
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</tr>
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</table>
### Hematologic toxicities
(per patient)

<table>
<thead>
<tr>
<th></th>
<th>Imatinib (n=41)</th>
<th>Placebo (n=40)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>All Grades (%)</td>
<td>Grade 3-4 (%)</td>
</tr>
<tr>
<td>Leukopenia</td>
<td>14 (34)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Neutropenia</td>
<td>12 (29)</td>
<td>1 (2)</td>
</tr>
<tr>
<td>Anemia</td>
<td>27 (66)</td>
<td>12 (29)</td>
</tr>
<tr>
<td>Thrombocytopenia</td>
<td>8 (20)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Febrile Neutropenia</td>
<td>- -</td>
<td>0 (0)</td>
</tr>
</tbody>
</table>
Sunitinib (Sutent) vs GIST (Placebo)

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

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

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)

<table>
<thead>
<tr>
<th>Event</th>
<th>Regorafenib (N=132*)</th>
<th>Placebo (N=66)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Any grade</td>
<td>Grade 3</td>
</tr>
<tr>
<td>Any event</td>
<td>130 (98%)</td>
<td>77 (58%)</td>
</tr>
<tr>
<td>Hand-foot skin reaction</td>
<td>74 (56%)</td>
<td>26 (20%)</td>
</tr>
<tr>
<td>Hypertension</td>
<td>64 (49%)</td>
<td>30 (23%)</td>
</tr>
<tr>
<td>Diarrhoea</td>
<td>53 (40%)</td>
<td>7 (5%)</td>
</tr>
<tr>
<td>Fatigue</td>
<td>51 (39%)</td>
<td>3 (2%)</td>
</tr>
<tr>
<td>Oral mucositis</td>
<td>50 (38%)</td>
<td>2 (2%)</td>
</tr>
<tr>
<td>Alopecia</td>
<td>31 (24%)</td>
<td>2 (2%)</td>
</tr>
<tr>
<td>Hoarseness</td>
<td>29 (22%)</td>
<td>0</td>
</tr>
<tr>
<td>Anorexia</td>
<td>27 (21%)</td>
<td>0</td>
</tr>
<tr>
<td>Rash, maculopapular</td>
<td>24 (18%)</td>
<td>3 (2%)</td>
</tr>
<tr>
<td>Nausea</td>
<td>21 (16%)</td>
<td>1 (1%)</td>
</tr>
<tr>
<td>Constipation</td>
<td>20 (15%)</td>
<td>1 (1%)</td>
</tr>
<tr>
<td>Myalgia</td>
<td>18 (14%)</td>
<td>1 (1%)</td>
</tr>
<tr>
<td>Voice alteration</td>
<td>14 (11%)</td>
<td>0</td>
</tr>
</tbody>
</table>

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 seen 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?
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
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
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
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, stop immediately
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 MEASUREMENT SCALE

- **0**: NO HURT
- **2**: HURTS LITTLE BIT
- **4**: HURTS LITTLE MORE
- **6**: HURTS EVEN MORE
- **8**: HURTS WHOLE LOT
- **10**: HURTS WORST

No pain | Mild | Moderate | Severe | Worst Pain Imaginable
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 (diluadid)
• 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!!