Tips for Managing the Side Effects of NET Treatment

Today we will be discussing some of the common side effects experienced by patients receiving treatment for carcinoid/neuroendocrine cancer. The following therapies are commonly used to treat this specific patient population and many can share some of the same side effects:

- Somatostatin analogues (Sandostatin LAR, Lanreotide)
- Oral chemotherapy medications (Afinitor, Xeloda, Temodar, Sutent)
- PRRT (Peptide Receptor Radionuclide Therapy)
- Embolization (Bland, Chemo)
- Ablation (Radiofrequency, Microwave)
- Surgery (Multiple types)

Due to time constraints and the amount of material that needs to be covered, we will NOT be discussing each of these therapies in depth, only the potential side effects related to that treatment.

Please note that the side effects we will discuss today may not be experienced by all patients receiving that particular type of therapy. Side effects can vary from patient to patient and there are many factors that can contribute to if a patient will experience any side effects and if they do, the type, severity and duration of them.

**Somatostatin Analogues**

Somatostatin analogues such as Octreotide LAR (Sandostatin LAR Depot) and Somatuline Depot (Lanreotide) Common side effects include:

- GI upset (abdominal pain, nausea, vomiting, diarrhea, constipation)
- Injection site reactions (pain, redness, bruising, lumps, drainage)
- Gall bladder issues (sludge, stones)
- Hyperglycemia (elevated blood sugar)
- Pancreatic enzyme deficiency (gas, bloating, light colored/greasy/ floating stool)
- Neurological (headache, dizziness)
- Fatigue

**Oral Chemotherapy Medications**

Oral chemotherapy medications such as Everolimus (Afinitor), Capecitabine (Xeloda), Temozolomide (Temodar), Sunitinib (Sutent) share some common side effects such as:

- Abdominal pain
- Mouth Sores
- Nausea & vomiting
- Diarrhea
- Low red blood cell counts (anemia, fatigue)
- Low white blood cell counts (neutropenia, infection)
- Low platelets (bleeding)
- Require chemotherapy and safe sex precautions

Some oral chemotherapy drugs used to treat NET’s can have some very specific side effects related to that drug. Please be aware of the following:

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- Everolimus (Afinitor) may cause upper respiratory infections or pneumonitis
- Capecitabine (Xeloda) may cause hand foot syndrome
- Sunitinib (Sutent) may cause alopecia (hair loss), taste changes, high blood pressure

**PRRT**

PRRT therapy may cause the following side effects:

- Abdominal pain
- Nausea & vomiting
- Decreased blood cell counts
- Alopecia (hair loss)
- Requires radiation therapy precautions

**Embolization**

Embolization (all types) may cause the following side effects:

- Abdominal pain
- Nausea & vomiting
- Fever & infection
- Blood clots
- Fatigue

**Surgery**

- Abdominal pain
- Nausea & vomiting
- Diarrhea or constipation
- Fever & infection
- Weight loss
- Bowel obstruction
- Adhesions

*How do we manage some of the most common side effects of NET treatment?*

**Abdominal Pain**

In order to treat abdominal pain, we need to determine the cause. Abdominal pain related to bowel obstruction is treated differently than abdominal cramping and gas pains related to pancreatic enzyme deficiency.

Tips for managing:

- Keep a symptom diary and **bring it with you to your follow-up appointment!** The more we know the easier it is to help you. When we assess you for pain we want to know the date, time, location, severity, type (descriptive words), what makes the pain worse, what makes the pain better and anything else you think might be important for us to know

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- Take your medications as instructed. Pain medications should be taken at the first sign of pain, not when the pain is so bad that you can’t stand it anymore.

- Know the signs & symptoms of trouble in advance. If you are not sure what these signs and symptoms of trouble are, discuss them with your health care team (small bowel obstruction, pancreatitis, gallstones).

### Mouth Sores

Usually caused by the effects of chemotherapy on the mucous membranes lining the mouth, throat and the rest of the GI tract.

**Tips for managing:**

- See your dentist for a check-up prior to starting therapy and keep him informed of the types of therapy that you are on.
- Hydrate! Hydrate! Hydrate!
- Keep mouth moist. Suck on ice chips or sugar free gum or hard candy.
- Avoid mouth washes with alcohol or peroxide which can dry the mouth further.
- Rinse mouth at least 4 times a day with a mixture of ¼ teaspoon salt and ½ teaspoon baking soda.
- Avoid foods that have sharp edges, citrus, very spicy…

### Nausea & Vomiting

Nausea & vomiting is a common side effect related to treatment for NET patients.

**Tips for managing:**

- Stop it before it starts! Nausea meds, like pain meds, should be taken at the first sign of nausea.
- Take all medications as instructed.
- Plan mealtimes based on the type of therapy you are receiving.
- Avoid hot, steaming foods and other strong odors such as hairspray, perfume…
- Eat bland, easily digested foods.
- Eat small meals and frequent snacks.
- Breathe deeply and keep your eyes open.
- Notify your health care team within 24 hours if you have nausea that is unrelieved by your antinausea medications or more than 4-5 episodes of vomiting within a 24 hour period.

### Diarrhea

May be related to treatment or your disease process. It is best treated by determining the cause.

**Tips for managing:**

- Keep a symptom diary. Are there certain foods that seem to trigger episodes of diarrhea?
- Take all medications as instructed.
- Staying hydrated is extremely important!
- BRAT diet (bananas, rice applesauce, toast).
- Pat gently with baby wipes instead of toilet paper.
- Use a squirt bottle filled with warm water to rinse rectal area after each episode.
- Sitz bath or soak your bum in the tub for a few minutes several times a day.

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- If diarrhea you have more than 4-6 episodes over your usual daily baseline or if the diarrhea is bright or dark red in color, has a coffee ground consistency or is yellow-green with an extremely foul odor, notify your care team immediately.

**Constipation**

Can be due to disease process, treatment or pain medications. Constipation is best treated in the following ways:

- Hydrate! Hydrate! Hydrate! A minimum of 64 oz of “good” fluid per day
- Avoid “bad” beverages that contain caffeine, alcohol or carbonation
- Take fiber supplements and stool softeners as directed
- Engage in moderate activity daily

**Pancreatic Enzyme Deficiency**

A common side effect of somatostatin analogue therapy and many NET surgical procedures is a decrease in the production of pancreatic enzymes used to digest your food. Signs and symptoms of pancreatic enzyme deficiency are:

- Abdominal pain and cramping after eating
- Abdominal bloating and flatus (gas) after eating
- Feeling of fullness or that the “food is just sitting there”
- Diarrhea immediately after eating
- Greasy, oily, light colored stools that float

Tips for managing:

- CREON!!!
- Ignore pharmacy or other instructions. Creon should be taken immediately before the first bite of food
- Standard dose is 24,000 unit capsules, Take 2 capsules before meals and one with snacks
- Per NET dietician 4000 units of Lipase is required to digest each 5 grams of fat
- Do not lie flat or recline for at least one hour after eating

**Low Blood Cell Counts**

Low blood cell counts are a common side effect of chemotherapy and PRRT. Systemic therapies (those therapies which enter the blood stream and travel throughout the body to fight cancer) can sometimes cause damage not just to the cancer cells but to other nearby cells as well. When you are on chemotherapy, blood samples are a quick way for us to monitor your progress and make sure that you are safe to continue your treatment. We will frequently draw a small purple topped tube for a CBC (Complete Blood Cell Count). There are three main types of cells in the CBC that we are paying very close attention to:

1. White blood cells which fight infection (Neutropenia & Fever)
2. Red blood cells which carry hemoglobin and oxygen (Anemia & Fatigue)
3. Platelets which help your blood to clot (Bleeding)

Let’s view this side effects in greater detail:

**Neutropenia & Infection**

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Neutropenia is when the ANC (Absolute Neutrophil Count) is 1.5 or less. This means that there are only about 1,500 fully functioning and ready to fight Infantry on the front lines to fight infection. Normal range is 1.8-8.0. When ANC is < 1.5 you are at an extreme risk of infection.

Tips for managing:

- Wash your hands before & after everything you do! Soap & water for a minimum of 30 seconds or use an alcohol based hand sanitizer until dry
- Avoid crowds & people with infection. Wear a mask if you must be in a crowd
- Do not eat raw or undercooked meats, seafood, eggs or food from a salad bar or buffet that everyone can touch
- Wash all fruits and vegetables well.
- Protect your skin - it’s your biggest barrier against infection
- Do not pick up dog poop or empty cat litter boxes without wearing gloves

Trouble Alert:

*Call your health care team (or go to the closest emergency room) if you have a fever of 100.4 F or 38 C. DO NOT take Tylenol and go back to bed! A fever in a neutropenic cancer patient is considered an oncologic emergency and MUST BE TREATED IMMEDIATELY!*

**Anemia & Fatigue**

Anemia related to chemotherapy is usually caused by decreased low red blood cells. Red blood cells carry hemoglobin and oxygen to all of the organs and tissues of the body. Fatigue or tiredness can be caused by many things, but it frequently goes hand in hand with anemia. If the anemia is severe enough, a transfusion of packed red blood cells may be required (PRBC’s).

Tips for managing fatigue:

- Hydrate! Hydrate! Hydrate!
- Get plenty of rest
- Plan activities so that the most demanding are done during periods with the most energy
- Accept help & realize that although they may not do the task exactly like you would, as long as the end result is the same, IT DOESN’T REALLY MATTER!
- Eat a well-balanced diet
- Change position slowly. Remember- The bigger they are the harder they fall

**Bleeding**

Can be due to low platelet count or disease process.

Tips for managing:

- Brush your teeth using a very soft toothbrush
- Blow your nose gently
- Wear comfortable, low-heeled, well-fitting shoes at all times. Do not go barefoot
- Wear loose fitting clothes and jewelry
- Avoid contact sport or activities with a risk of falls or injury
- Avoid tampons, enemas, suppositories, rectal thermometers and do not strain to have a bowel movement
- Avoid medications, vitamins, aspirin or other blood-thinning products

Trouble Alert

Notify your health care team if you notice any of the following:

- Bruising or small red or purple dots on your skin
- Red or pink colored urine
- Bloody or black stool
- Bleeding from gums or nose
- Heavy bleeding or bleeding longer during your period
- Sudden headache, vision changes, confusion or decreased alertness

Injection Site Reactions

Injection site reaction reactions can include pain, redness, bruising, drainage, lumps. Some slight muscle soreness is a common complaint but normal for an intramuscular injection.

Tips for managing:

- Do NOT rub the injection site!
- If you have pain at the injection site- DO NOT apply heat or soak in hot water for at least 24 hours. Instead, apply an ice pack to the area for 10-15 minutes at a time several times a day
- Notify your health care team if you notice redness, warmth, drainage or a large amount of bruising around the injection site

Sex

Depending upon the type of treatment and the specific side effects and precautions required, sexual contact during NET treatment is allowed.

Tips for enhancing sex during treatment:

- Make sure you are well rested before hand
- Pre-medicate with pain and anti-nausea meds as needed at least 30 minutes prior to sexual activity
- Use lots of lube! You can’t be “too” wet!
- Set the scene. Non-scented candles, favorite music, adjust temperature and other lighting
- Kissing, cuddling and other intimate but non-sexual contact prior to actual intercourse may help both partners to relax and make intercourse easier

Precautions:

Chemotherapy- Moderate to considerable amounts of chemotherapy can be found in blood, urine, feces, semen and vaginal secretions. Minimal amounts have been found in saliva. While receiving chemotherapy and for up to 72 hours after, barrier methods (condoms, dental dams…) should always be used to protect your partner. If you are female and of child bearing age, you should use at least two methods of contraception (one method being barrier) to prevent pregnancy and the possibility of birth defects.

Radiation therapy- Follow the specific guidelines for your type of therapy.
Low blood cell counts- (bleeding & injury) Try gentle instead of vigorous thrusting and use lots of lubrication to prevent injury

When is doubt- ASK!

Resources