



Effects of Treatment

SSAs (Somatostatin Analogues)

SSAs may be used to help control the secretion of hormones if abnormal levels are being produced. SSAs may also be used to slow down growth rate in low to moderate grade 'well-differentiated' Neuroendocrine Tumours (NETs)

As a SSA starts to be absorbed by the body, it can temporarily upset your usual hormone balance - whether you already have symptoms or not but things can and do settle and improve.

When you first start treatment with either Octreotide (Sandostatin LAR or Olutatol) or Lanreotide (Somatuline Autogel) - you will be talked through how it works and what you might expect to happen - including any potential side-effects.

Whether you have already had symptoms before starting this treatment or none at all - developing or worsening symptoms can be alarming.

This is normal - if you are going to experience a change to your 'normal'- it usually starts within 24 - 48 hours - if you get to about 10 - 14 days without a day or two of these symptoms, then it may not happen. If it does occur - it usually only lasts for 24 - 72 hours - and your specialist team will have advised you on simple steps you can take to manage these symptoms - such as simple pain relief and / or Imodium.

What is not normal is for symptoms to flare up and become constant beyond 3 - 4 days and / or beyond 4 - 5 injections - if this happens let your specialist nurse/team know.

Many people, especially those with Carcinoid Syndrome, find that not only does this temporary reaction stop occurring - but the symptoms they had beforehand also start to improve.

Severe abdominal pain is not a usual occurrence - if this happens - seek medical attention at your nearest hospital- let them know your diagnosis and how and where it's been treated. It can also be helpful to have your specialist nurse/team contact details with you - if your specialist team is not at the hospital you attend, so that the admitting team can contact them for further information and advice.

The pharmaceutical companies that manufacture somatostatin analogues (which include lanreotide and octreotide) list potential side effects as:

- Loss of appetite - may be further reduced by not eating.
- Feeling and/or being sick - this may be made worse by avoiding food.
- Feeling bloated - often associated with steatorrhoea*, 'wind' and / or constipation.
- Stomach pain and/or cramping.
- Diarrhoea - bowel motions may become more frequent and / or fluid.
- Steatorrhoea* - pale, smelly, oily diarrhoea, that doesn't flush away easily, tending to float in the toilet bowl.
- Soreness or a lump at the injection site.
- Fatigue.
- Blood glucose changes** - this is not the same as developing diabetes. Though if you are diabetic - you may find you need to make some alterations to maintain your usual 'normal' blood sugar levels. Ensure your specialist team, dietician and GP are talking to each other as well as you to help maintain diabetic control.

- Gall bladder infection related to thickened bile, bile sludge and / or stones - the function of the gall bladder as a hold and release vessel for bile flow can be affected by SSA, this leads to thickened bile - which can cause irritation and grit or stones to form.
- Reduced thyroid function - just as the pancreas may be affected in its ability to produce hormones, so too, can the thyroid gland be affected.
- Headache and / or dizziness.
- Bradycardia - slowing of the heart rate. Some of the hormones released by Neuroendocrine Cancers can narrow or widen blood vessels and airways - which can lead to flushing, palpitations (rapid heart rate) and wheezing in Carcinoid Syndrome. Altering the levels of these kind of hormones, by SSAs, may result in slowing the heart rate - rather than increasing it.

SSAs can alter the pancreas' normal response to eating - which is to release certain gut hormones and enzymes to help the body break down and utilise food.

*A lack of pancreatic enzymes (Pancreatic Enzyme Insufficiency - PEI) can result in steatorrhoea occurring.

**An alteration in normal pancreatic based gut hormones being released - can lead to a rise (most common) or fall (less common) in normal blood sugar levels* - especially after eating.

Other changes patients have mentioned include:

- Increased joint discomfort or pain
- Hair thinning or loss (though rarely complete alopecia)
- Vitamin deficiencies - particularly Vitamin A, B (B3 and 12 in particular), D, E & K
- Weight loss or gain.