North Cheshire and Mersey
NHS Foundation Trust

Information sheet for patients taking carbimazole or propylthiouracil

Endocrinology

Information for patients and carers

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Caring for you

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Introduction to thyroid treatment

You have been given this leaflet because you, or your relative, has an over-active thyroid gland.

The thyroid specialist has recommended starting on a tablet called carbimazole or propylthiouracil (PTU).

Please read this leaflet alongside the information supplied with your medicine.

Why do I need treatment?

The thyroid gland produces hormones that control how quickly your body uses energy.

If your thyroid gland is making too much hormone, treatment can help to bring your levels back to normal.

Without treatment you may get some of the symptoms of hyperthyroidism (over-active thyroid), including:

- weight loss or occasionally weight gain
- agitation
- irritability
- difficulty sleeping
- difficulty concentrating
- palpitations (a fast heart rate, and sometimes atrial fibrillation)
- muscle weakness
- hair loss
- neck swelling (goitre)

If left untreated for a long time, you can:

- collapse
- develop an uncontrolled high temperature
- fast heart rate
- lose bone mass (osteoporosis)

Please tell your specialist or GP if you are pregnant, or you are planning a pregnancy, as this may affect the treatment you are offered. In early pregnancy carbimazole should be avoided if possible. If left untreated, you are less likely to conceive and face a higher risk of miscarriage or a baby that fails to grow normally.

What is anti-thyroid medication?

Standard treatment is with tablets called either carbimazole or propylthiouracil (PTU). The dose of these tablets will be adjusted depending on your response and how quickly your thyroid levels settle.

You may also be given a beta blocker tablet, usually propranolol LA (long acting) to help control symptoms of your condition.

What are the possible side effects?

The most serious is a condition known as agranulocytosis. The risk of this side effect is rare, affecting between 3 and 18 in every 10,000 people.

Agranulocytosis happens when your bone marrow does not make enough white blood cells, which your body needs to fight infection. It may also reduce the number of platelets, which help your blood to clot.

If this happens, stop taking carbimazole or PTU immediately. Your blood count should then return to normal, although in very rare cases the effects may continue.

Warning signs are:

- a very sore throat
- mouth ulcers
- bruising more than usual

If you notice any of these symptoms you should:

1. immediately stop taking the carbimazole or PTU
2. attend either your GP or the Emergency Department (A&E)
3. ask for a blood test (full blood count or FBC)
4. take this information leaflet with you

You should get the result the same day.

If tests show your blood count is normal, your symptoms are not due to the tablet. This means you should continue taking your medication and your doctor can look into other causes of your symptoms.

Sore throats and other symptoms are common and are usually caused by a virus, not the medicine.

Liver problems

These medicines may occasionally affect your liver.

Contact your doctor immediately if:

- you feel itchy
- your skin or eyes have a yellow tinge

Your doctor will arrange blood tests to check your liver.

Serious liver problems are rare. They are most likely in the first few months of treatment.

Risk of pancreatis with carbimazole

Cases of acute pancreatitis have been reported during treatment with carbimazole.

Stop taking carbimazole and seek a medical checkup immediately if you develop a severe pain in the centre of your tummy. This aching pain often gets steadily worse and can travel through to your back

The pain from pancreatitis can make you feel sick or suffer with vomiting. It can be associated with:

- developing a high temperature
- a fast heart rate and breathing
- yellowing of the eyes

Do not use carbimazole if you have a history of acute pancreatitis associated with previous treatment. Re-exposure may lead to life-threatening acute pancreatitis. You need to tell your doctor who will review your medication.

Other possible side effects

Less serious side effects that may occur on their own include:

- skin rash
- itching
- feeling slightly sick
- joint / muscle pains
- headaches
- hair loss
- reduced hearing

They can be related to abnormal thyroid function. These symptoms are common and may not be due to your tablets.

If you do have problems with symptoms, it may be worth speaking to your doctor about another anti-thyroid medication.

If you are pregnant or are planning a pregnancy

Tell your doctor, as it will affect the medication you are offered.

Carbimazole

Taking carbimazole during pregnancy, especially in the first trimester (before week 12) and with more risk at high doses (daily dose of 15 mg or more), increase the risk of the baby being born with medical problems.

Pregnancy and contraception

Use reliable contraception while taking carbimazole.

- If you are pregnant or planning a pregnancy, speak to your doctor.
- Carbimazole should only be used during pregnancy if the benefits outweigh the risks.
- If you need carbimazole, your doctor will prescribe the lowest dose that works and monitor you and your baby closely.

Propylthiouracil (PTU)

PTU is usually used instead of carbimazole during pregnancy. Less of it reaches the baby, but it can still cause problems. Your doctor will prescribe the lowest dose that works.

During pregnancy, thyroid levels need to be monitored frequently by a specialist.

Please remember that, if left untreated, an overactive thyroid can harm you and your baby and medication is usually safer than untreated thyrotoxicosis.

Breastfeeding

PTU is present in breast milk but not at a level that is likely to cause the baby any problems. A paediatrician would need to be told and will monitor baby's progress.

What about my other medication?

These medications do not usually affect other medications you are taking.

- If you are on anticoagulants, such as warfarin, the new anti-thyroid tablets may affect your control. Please speak to your Monitoring Team for an early review at the Anticoagulation Service.
- If you are being started on any new medication, ask the prescriber if this is likely to have any effect on your thyroid medication. As a precaution, it is often worth having your thyroid levels checked a few weeks after any medication change.

When should I take my thyroid tablets?

Take your tablets at the same time every day. If you forget a dose, please take the tablets as soon as you remember.

How will my treatment be monitored?

You should have been given a blood form to have your thyroid level checked when you are being treated so the dose can be adjusted depending on your response to the treatment.

The Specialist Team will then be able to advise you if you need to change your tablet dose. You should be contacted a few weeks after each blood test to advise you of any changes. If you do not hear after 3 weeks, please contact your specialist's secretary.

Blood tests will need to be carried out every few months until your thyroid levels are stable. Treatment with anti-thyroid medication is usually needed for 6 to 18 months, sometimes for longer.

What are the other treatment options?

There are 2 other options for treating an over-active thyroid:

- surgery
- radio iodine treatment

Your thyroid gland needs to be stabilised before these treatments can be considered.

Contacts and further information

- **Endocrinology Service**
  To discuss any concerns about your thyroid care or changes in your condition.
    - Call the trust switchboard on 01925 635911 and then ask for your consultant's secretary.

  In an emergency, please see your GP practice or attend local Emergency Department.
- **British Thyroid Foundation**
  http://www.btf-thyroid.org/