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## Fact Sheet No.1

# About your medicines

## Preventative medicines for people with CGD

CGD is a disorder of the immune system affecting special white blood cells which are responsible for fighting off infection.

Infections caused by viruses, such as the common cold, or flu, do not pose a particular risk for people with CGD as their immune system is able to cope with these types of infection in the normal way. However, certain types of bacteria and fungi can cause serious infections in people with CGD. For this reason children and adults with CGD take medications every day to help prevent bacterial and fungal infection. This leaflet aims to tell you a little more about the two medicines that most people with CGD take.

Every medication has some side effect ranging from the most common to the very rare, the very mild to the more serious. Each person reacts differently to medication so you/your child will not necessarily suffer any of the side effects mentioned. **If you have any concerns about the side effects of medications please discuss these with your nurse or doctor.**

## Co-trimoxazole (Septrin)

Co-trimoxazole is an anti-biotic which is used to prevent serious bacterial infection. In higher doses it is also used to treat particular infections.

It is taken by mouth as a tablet or liquid medicine. Co-trimoxazole tablets are round white tablets. Most people use the 480mg tablets but 960mg tablets are also available. Adult and Paediatric liquid suspensions are available containing 480mg (adult) or 240mg of Co-trimoxazole (paediatric) in every 5ml.

The most common side effects are symptoms such as nausea and vomiting, skin rashes or headache.

Please read the product information leaflet supplied with your medicine / tablets for more information.

## Less common side effects

Some patients are sensitive to Co-trimoxazole and this can show itself in how well the bone marrow is working. Affects on the bone marrow can result in anaemia, bruising or bleeding more easily than usual. You should tell your doctor if you or your child feel





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more tired than usual, have bruising or bleeding. Your/your child's bone marrow can be checked easily by a simple blood test which is carried out regularly in people with CGD (every 6 months - 1 year if you are well). **Please tell your doctor/nurse if you experience any of the above symptoms.**

## Sensitivity to sunlight

Taking Co-trimoxazole can make people more sensitive to the sun. Therefore any child or adult on Co-trimoxazole should use a high factor sun protection cream (SPF 25 or higher) when out in the sun.

## How to take your medication

Co-trimoxazole is best taken with or after food with plenty of water (but if you are trying to persuade a small child to take it – any drink will do!). However you should not worry if you/your child are not always able to take it with or after food. What is important is that you/your child take it! It is important to drink plenty during the day to ensure the drug is well flushed through the kidneys.

If you/ your child are currently taking any other anti-biotic, such as Ciprofloxacin or Flucloxacillin, it is not usually necessary to carry on taking the Septrin as well. However you must make sure to re-start the Septrin as soon as the other course of anti-biotics is finished. Always check with your doctor or nurse before stopping Septrin.

The dose you are prescribed can be taken all in one go once a day or divided into morning and evening doses, whichever is more convenient.

For instance – if you are prescribed one tablet twice a day and you take 480mg tablets you are taking 960mg each day. So if you want to you can take both tablets together just once each day.

## Itraconazole (Sporonox)

Itraconazole is an anti-fungal medicine which is used to prevent serious fungal infection. In higher doses it is also used to treat particular infections.

It is taken by mouth as a capsule or liquid medicine. Capsules contain 100mg of Itraconazole and the liquid contains 100mg in every 10ml.

## Side effects

The most common side effects are symptoms such as nausea, indigestion, diarrhoea, abdominal pain and constipation.



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Less common side effects include headache, dizziness and menstrual disorders.

**Please read the product information leaflet supplied with your medicine / tablets for more information.**

## Side effects common to both Septrin and Itraconazole

### Liver function

Both Itraconazole and rarely Co-trimoxazole can cause certain enzymes in the liver to be increased. These effects are rare and reversible and can easily be monitored by a simple blood tests call 'liver function tests'. These are carried out routinely in patients with CGD (every 6 months to one year in well patients). The frequency of tests varies from patient to patient as there are a number of factors that affect the liver function.

### Diarrhoea

Please tell your doctor if you/your child has diarrhoea which does not go away. Both Co-trimoxazole and Sporonox can cause diarrhoea, although Sporonox, especially the liquid form, is the most likely culprit. (However diarrhoea or loose bowel motions are not uncommon in CGD and are only sometimes related to medication.)

### Allergic reactions

Although it is rare, some people do experience an allergic reaction to their medications. Reactions can range from the mild to severe. Signs of a mild reaction can include skin rashes, itching, high temperature, shivering, facial flushing, dizziness or headache. If you experience any of these symptoms please report them to your doctor or nurse.

Signs of a severe allergic reaction include any of the above **in addition to** difficulty in breathing or chest pain. If you/your child experience any of these symptoms you should call for an ambulance straightaway.

## How to take your medication

Itraconazole, particularly in capsule form can be poorly absorbed from the gut in some patients. This means that blood levels are low and the patients may need to take a higher dose. If there is any concern about how well the drug is being absorbed your doctor may suggest a blood test to check the level of Itraconazole in you/your child's blood.

The liquid form of Itraconazole can be more easily absorbed but also is more likely to cause diarrhoea and/or abdominal pain in susceptible patients. The liquid form also has a very bitter taste!





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Itraconazole capsules should be taken with food as this can help absorption. Taking it with a drink of something acidic, such as fruit juice, squash, or a fizzy drink (don't forget to clean your teeth well afterwards!) can also help.

Itraconazole liquid should be taken on an empty stomach. Ideally this is an hour after and an hour before food – so bedtime can often be a good time to take it. It is best to take it with water or weak squash (not milk as this counts as food!). However getting young children to take medicines, particularly bitter-tasting Itraconazole, can be difficult. What is most important is that they take their medicine – so making some adjustments to fit in with your routine is fine!

Itraconazole capsules should not be split and administered as granules as this prevents the drug being absorbed properly.

## Important information

**Keep all medicines in a safe place where children cannot reach them.**

Tablets and liquid should be stored at room temperature. If you/your child vomits shortly after taking a dose of medicines, do not repeat the dose unless advised to by your doctor. If you/your child are vomiting medication on a regular basis you should tell your doctor or nurse. If you forget to take a dose, do not take a double dose next time. Simply carry on with your normal dosing schedule.

**Never alter the dosage of your medicines – always consult your doctor. Similarly, if you are uncertain of the correct dosage, contact your doctor or nurse.**

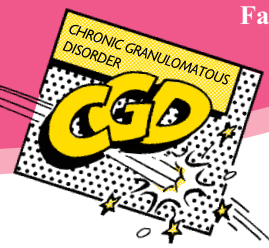
Both Itraconazole and Co-trimoxazole can interact with other medicines if taken together, which can interfere with the action of one or other medicine.

**You should tell your doctor if you are taking any of the following drugs:**

- Heart drugs
- Drugs which suppress the immune system
- Anticonvulsants (taken to prevent fits)
- Anticoagulants (drugs which thin the blood)
- Diuretics (water pills)
- Sedatives / antidepressants
- Other anti-biotics



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### Pregnancy

If you are planning to become pregnant or become pregnant whilst on Co-trimoxazole and Itraconazole please contact your doctor or nurse as soon as possible to discuss treatment during your pregnancy. It is very important that you do not simply stop taking anti-biotics.

### And finally...

**It is very important that you should never stop taking your preventative medicines accept on the specific advice of your doctor. Failure to take appropriate preventative anti-biotic and anti-fungal medication can lead to very serious infections in people with CGD.**

**Important Note:** The information contained in this document is intended only as a guideline, not as a substitute for medical advice. Always consult your doctor if you or your child has any CGD symptoms or concerns.

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