

# Illoprost Information



## Raynaud's & Scleroderma

*Published by*

Raynaud's & Scleroderma Association

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## Support for sufferers

The Raynaud's & Scleroderma Association offer emotional support and practical advice to sufferers on the problems of day-to-day living. By joining the Association, members will receive quarterly newsletters giving up-to-date information on research and treatments.

Our aims are to promote a greater awareness of Raynaud's & scleroderma, to raise funds for research and for the welfare of patients. As with all self help groups, members usually find great comfort in contacting others who understand their problems.

We have the full support of a group of doctors who act as medical and scientific advisors to the Association.

The Association would like to thank Professor Athol Wells, Dr Chris Denton and Ailsa Stewart, for their assistance with this publication.

*Health Professional booklets and patient literature, listed on inside back cover are available from:*

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# A Guide for Patients

## ***What is iloprost?***

Iloprost acts in the same way as a natural chemical in your body called prostacyclin.

## ***How does it work?***

- Prostacyclin relaxes blood vessels, which helps to stop them becoming narrowed or blocked. This means that they can carry more blood to all areas of your body.
- Prostacyclin also makes blood less sticky so clots are a little less likely to develop. Prostacyclin also helps to dissolve clots.
- Prostacyclin reduces the number of destructive cells collecting in damaged blood vessels.

## ***How is iloprost given?***

Iloprost is administered intravenously for PAH (pulmonary arterial hypertension), ulcers, Raynaud's, scleroderma and ischaemia. It can also be administered by inhalation for PAH.

Ventavis is a liquid which contains iloprost, it is inhaled as a fine spray or mist by a device called a nebuliser. Different people need different amounts of Ventavis. Your doctor will tell you how much is right for you. Most people will have six to nine inhalation sessions spread through a day. One session will last about four to ten minutes, depending on how much you take.

Iloprost is also available for intravenous delivery. It is given via a cannula using a device called an infusion pump, this process is called an infusion. Each infusion will last between 6 and 24 hours and you will have one infusion every day. The decision on how long you will receive iloprost for will be made on an individual basis in consultation with your doctor. You will probably not notice any improvement for the first 2 weeks of treatment.

## ***How can Ventavis/iloprost help patients with pulmonary arterial hypertension (PAH) secondary to scleroderma?***

Because iloprost relaxes the blood vessels and makes the blood less sticky, Ventavis can help your heart to pump a little more effectively. This means that you should feel less breathless and able to do more without becoming breathless.

### ***How can iloprost help patients with circulatory problems (Raynaud's)?***

By opening up (dilating) the blood vessels, iloprost will increase blood flow through these vessels and around the body.

### ***Does Ventavis/iloprost have any side effects?***

Like all medicines, iloprost can have side effects though it has been given to a large number of patients and has not been found to have any long lasting ill effects. In general, iloprost is a well-tolerated drug.

#### **The most common side effects are:**

- Flushing, or reddening of the face
- Headaches
- Low blood pressure (hypotension), though this will be monitored during treatment
- More coughing than usual (Ventavis only)

#### **Less common are:**

- Fainting (syncope)
- Nausea
- Vomiting
- Abdominal cramps

If you have any questions about iloprost your doctor will be happy to answer them.

Tell your doctor if:

- You are allergic to iloprost, trometamol, ethanol (alcohol), sodium chloride (salt), hydrochloric acid, or water. These are all ingredients of iloprost.
- You are at risk of bleeding, for example if you have a stomach ulcer or any existing injury.
- You have pulmonary congestion.
- You have any heart problem. This may include a heart attack in the last six months, chest pain, severe changes in heart rate, coronary heart disease (poor blood flow to the heart muscle), faulty valves in your heart, or congestive heart failure.
- You have had a stroke or something similar in the last three months.
- You are pregnant, breastfeeding, or are trying to get pregnant.
- You are using contraception. You may need to change the type of contraception you use.
- You are taking any other medicines.
- You are worried or confused about anything you have read here, or would like more information.

These things do not all mean that you cannot take iloprost but it is important to make your doctor aware of them.

## Information for Nurses

It is important that once the decision has been made to treat someone with iloprost that the nurse discusses the nature of the drug, its potential side-effects, the length of time they can expect to stay in hospital, or if attending on a daily basis, the importance of having someone to drive them home after treatment has finished for the day.

### **Administration of Ventavis**

Two compressed air nebuliser systems, HaloLite and Prodose, have been shown to be suitable nebulisers for the administration of Ventavis. For each inhalation session the contents of one 2ml ampoule of Ventavis will be transferred into the nebuliser medication chamber immediately before use. Both the recommended nebulisers are designed to stop automatically after the desired dose, which is pre-set, has been administered. The time taken for inhalation depends on the patient's breathing pattern.

The recommended dose per inhalation session is 2.5mcg or 5.0mcg of inhaled iloprost (as delivered from the mouthpiece of the nebuliser).

Device	Dose of iloprost at mouthpiece	Estimated inhalation time (frequency of 15 breaths per minute)
HaloLite	2.5mcg 5 mcg	4 to 5 min 8 to 10 min
Prodose	2.5mcg 5mcg	4 to 5 min 8 to 10 min

For a 5mcg dose of iloprost at mouthpiece it is recommended to complete two inhalation cycles with 2.5mcg pre-set dose program with a filling of one 2ml ampoule.

Each patient should have 6 – 9 inhalation sessions per day according to individual need and tolerability.

The duration of treatment will depend on the patient's clinical status and is decided by the doctor.



## Administration of intravenous iloprost

On the first day of treatment the patient should be given an opportunity to discuss any concerns that they have. The nurse will then weigh the patient and check their blood pressure, temperature, pulse and urinalysis. A doctor will then see the patient to make sure that they are ready for treatment.

Prophylactic analgesia and an antiemetic may be advised before treatment to minimise the risk of headache and nausea during therapy. The patient's blood pressure and heart rate must be measured at the start of the infusion and after every increase in dose. Blood pressure and pulse rate should be checked immediately if the patient complains of dizziness or light-headedness. Refer to local guidelines for the point at which raised blood pressure should be discussed with the doctor.

If administering the iloprost as an IV infusion, before use, the contents of either a 0.5ml or 1.0ml ampoule of iloprost should be diluted, as required and according to the manufacturer's guidelines, with sterile saline or a 5% glucose solution. The contents of the ampoule and the diluent should be mixed thoroughly.

The diluted iloprost solution should be infused daily by means of an accurate rate controlling delivery system such as an infusion pump or syringe driver. This is normally done via a peripheral vein or central venous catheter. For rates of administration and dose, refer to the manufacturer's guidelines and local protocols. If side effects occur, the infusion rate should be dropped until the tolerable dose is found. If the side effects are severe the infusion should be interrupted.

Please note that dosages will vary on an individual basis.

For the duration of the treatment period, therapy should be continued at the tolerable dose established in the first 2-3 days of treatment, provided observations remain stable.

During infusions the cannulated site will be observed for pain, swelling or redness. If this occurs, in consultation with the doctor, the infusion may be stopped and a fresh cannula may need to be inserted. The patient should be encouraged to inform the nurse of any pain or swelling at the cannulated site or of any other side effects.

More information for Health Professionals  
can be obtained from the manufacturers,  
Schering Health Care Ltd  
Tel: 01444 232323



# Publications

## Health Professional Booklets

- Booklet for GP's
- The Role of the Nurse
- The Role of the Podiatrist (Chiropodist)
- Oral and Dental Aspects of Scleroderma
- The Role of the Physiotherapist
- The Role of the Occupational Therapist
- The Lungs in Scleroderma

## Patient Information Leaflets

- Invitation to Membership
- Raynaud's Phenomenon
- Raynaud's in Teenagers and Youngsters
- Scleroderma (Systemic Sclerosis)
- Limited Cutaneous Systemic Sclerosis (CREST)
- Localised Scleroderma (Morphea and Linear)
- The Lungs in Scleroderma
- Kidney Involvement in Scleroderma
- The Gut in Scleroderma
- Sexuality in Scleroderma
- Scleroderma in Children
- Mixed Connective Tissue Disease
- Chilblains
- Erythromelalgia
- Sjögren's Syndrome
- Vibration White Finger
- Systemic Lupus Erythematosus
- Skin Care
- Hot Tips for Keeping Warm
- Mail Order Leaflet

Posters are also available for displaying in hospitals, health centres etc.

**See our website for a full list of publications [www.raynauds.org.uk](http://www.raynauds.org.uk)**

The earlier lung disease is detected, the more likely there is to be a good response to treatment. The World Health Organisation therefore recommends that all patients with scleroderma should be screened annually for lung complications, even if they possess no symptoms.



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